

Socializing Medical Practice: A Normative Model of Medical Decision-Making

by

Thomas Vandiver Cunningham

B.A. Philosophy, University of California at San Diego, 2003

B.S. Biology, University of California at San Diego, 2003

M.S. Biology, University of California at San Diego, 2004

M.A. Bioethics, University of Pittsburgh, 2013

Submitted to the Graduate Faculty of the

Kenneth P. Dietrich School of Arts and Sciences in partial fulfillment

of the requirements for the degree of

DOCTOR OF PHILOSOPHY

University of Pittsburgh

2013

UNIVERSITY OF PITTSBURGH

Kenneth P. Dietrich School of Arts and Sciences

This dissertation was presented

by

THOMAS VANDIVER CUNNINGHAM, MS

It was defended on

December 5, 2013

and approved by

PETER K. MACHAMER, PhD (Dissertation Director)
Professor of History & Philosophy of Science

KENNETH F. SCHAFFNER, PhD, MD (Dissertation Director)
Distinguished University Professor of History & Philosophy of Science

SANDRA MITCHELL, PhD
Professor of History & Philosophy of Science

EDOUARD MACHERY, PhD
Professor of History & Philosophy of Science

ROBERT M. ARNOLD, MD
Professor of Medicine and Chief, Section of Palliative Care & Medical Ethics

All faculty are appointed at the University of Pittsburgh.

Copyright © by Thomas V. Cunningham

2013

Socializing Medical Practice: A Normative Model of Medical Decision-Making

Thomas Vandiver Cunningham, Ph.D.

University of Pittsburgh, 2013

This dissertation is about the way people *should* and *do* make medical choices. It defends the claim that medical decisions should be made by groups of persons acting together, not by individuals acting alone. I begin by arguing that prominent models of medical decision-making are problematic, because they fail to be both *descriptively* and *normatively adequate*, which I argue any account of choice in medicine should be. The remainder of the work articulates a model that meets these two criteria. First, I justify an account of the uniquely medical context my model is designed to apply to by distinguishing *two basic aims of medicine*: (i) to fully understand patients in personal and scientific terms; and, (ii) to intervene upon patients' health states in ways that are consistent with this understanding. Then, I take two chapters to develop a descriptive account of medical decision-making. In them, I introduce a close study of the case of hereditary breast and ovarian cancer decision-making, which I argue shows choices are made by groups of interacting persons over extended spatiotemporal and social dimensions. So, I appeal to the theory of *distributed cognition* to describe this collection of persons processing information together when making choices. Having defended a descriptive account of medical choice, I then take two more chapters to propose a normative account, based on a modified version of Rawlsian reflective equilibrium that I call *medical reflective equilibrium*. On my account, medical choices should be made by searching for, selecting, and integrating the right kind and amount of information, which requires considering sufficient information to meet the basic aims of medicine. Given that the basic aims are defined in terms of an epistemic distinction between *subjective* and *objective knowledge*, I argue that performing the medical reflective equilibrium procedure adequately requires multiple participants in decision-making. Consequently, I conclude that medical choices are and should be social.

TABLE OF CONTENTS

| | |
|--|------------|
| PREFACE..... | IX |
| 1.0 SOCIALIZING MEDICAL PRACTICE: AN INTRODUCTION..... | 1 |
| 1.1 Setting the Stage..... | 5 |
| 1.2 Describing Medical Choice..... | 9 |
| 1.3 Making it Normative | 13 |
| 1.4 Open Questions | 18 |
| 2.0 STANDARDS OF ADEQUACY AND MODELS OF MEDICAL DECISION-MAKING..... | 20 |
| 2.1 Paternalism: Making Good Decisions for Patients | 23 |
| 2.2 Informed Consent: Decisions Should Respect Autonomy | 25 |
| 2.3 Paternalism, Informed Consent, and Descriptive Adequacy | 29 |
| 2.4 Shared Decision-Making: Medical Choice From a Clinical Point of View..... | 39 |
| 2.5 From One “Process Model” to Another | 44 |
| 3.0 THE BASIC AIMS OF MEDICINE | 49 |
| 3.1 The Basic Aims of Medicine..... | 50 |
| 3.2 Health and Disease..... | 55 |
| 3.3 Medicine: Art or Science?..... | 78 |
| 3.4 Subjectivity, Objectivity, and Medicine..... | 85 |
| 3.5 Medical Decision-Making and the Epistemology of Medicine | 90 |
| 3.6 Measuring Objective and Subjective Claims in Medical Practice | 106 |
| 3.7 Normativity, Empathy, and the Practice/Theory Distinction..... | 113 |
| 3.8 Medicine as Dialogue..... | 134 |
| 4.0 THE SOCIAL CONTEXT OF DECISION-MAKING IN HEREDITARY BREAST AND OVARIAN CANCER | 136 |
| 4.1 Hereditary Breast and Ovarian Cancer | 139 |

| | | |
|--------------------------|--|------------|
| 4.2 | Genetic Testing for BRCA1 and BRCA2 | 144 |
| 4.3 | The Case of Ellen Macke | 152 |
| 4.4 | Decision-Making in Hereditary Breast and Ovarian Cancer | 166 |
| 4.5 | The Physician as Captain of the Ship..... | 171 |
| 4.6 | Distributed Cognition and the Nautical Metaphor | 177 |
| 5.0 | DISTRIBUTED COGNITION, COMMUNICATION, AND MEDICAL DECISION-MAKING | 183 |
| 5.1 | Distributed Cognition in Navigation..... | 186 |
| 5.2 | Basic Concepts of Distributed Cognition..... | 194 |
| 5.3 | From Navigation to Decision-Making | 205 |
| 5.4 | Distributed Cognition and Ellen’s Choice | 209 |
| 5.5 | The Emergence of Distributed Cognitive Systems | 217 |
| 5.6 | Distributed Medical Decision-Making..... | 240 |
| 5.7 | Descriptive Adequacy | 255 |
| 6.0 | REFLECTIVE EQUILIBRIUM, COHERENCE, AND DECISION ANALYSIS | 259 |
| 6.1 | Reflective Equilibrium: Interpretations and Limitations..... | 262 |
| 6.2 | Coherence and the “No Guarantees” Objection..... | 279 |
| 6.3 | Decision Analysis and the Logic of Medical Choice..... | 290 |
| 6.4 | Basic Concepts of Decision Analysis | 299 |
| 6.5 | A Generic Decision Tree..... | 310 |
| 6.6 | Decision Analysis and Reflective Equilibrium in Medicine..... | 313 |
| 7.0 | SKEPTICISM AND MEDICAL REFLECTIVE EQUILIBRIUM..... | 317 |
| 7.1 | Skepticism, Reflection, and Practical Identity | 320 |
| 7.2 | Information, Identity, and a Poor Medical Choice..... | 329 |
| 7.3 | Medical Reflection: From the Ideal to the Good | 340 |
| 7.4 | Medical Reflective Equilibrium | 363 |
| 7.5 | Medical Decision-Making as a Social Activity | 381 |
| 7.6 | Normative Adequacy | 396 |
| 8.0 | CONCLUSION: A NORMATIVE MODEL OF MEDICAL DECISION-MAKING | 401 |
| 8.1 | Summary | 401 |
| 8.2 | Open Questions | 405 |
| BIBLIOGRAPHY..... | | 413 |

LIST OF TABLES

| | |
|---|-----|
| Table 4.1: National Comprehensive Cancer Network (NCCN) testing criteria for hereditary breast and ovarian cancer syndrome (National Cancer Institute 2011)..... | 143 |
| Table 4.2: The types of agents Macke interacted with during her decision-making and token members of each type | 169 |
| Table 5.1: A list of factors for discussion in HBOC decision-making | 251 |
| Table 6.1: Calculating expected utility values for comparing strategies by “averaging out and folding back” | 309 |

LIST OF FIGURES

| | |
|---|-----|
| Figure 4.1: Example of a positive HBOC test result | 147 |
| Figure 4.2: Genetic testing algorithm for cancer susceptibility.. | 148 |
| Figure 5.1: Basic network diagram.. | 199 |
| Figure 5.2: A network representation of the navigational system performing the fix cycle | 200 |
| Figure 5.3: The architecture of communication in Macke's choice..... | 215 |
| Figure 6.1: A decision tree for a patient with suspected appendicitis | 295 |
| Figure 6.2: A more foliated decision tree for suspected appendicitis | 305 |
| Figure 6.3: A generic decision tree | 312 |
| Figure 7.1: Alicia's decision tree. | 333 |
| Figure 7.2: Alicia's decision tree and related factors. | 337 |
| Figure 7.3: A generic decision tree for hereditary breast and ovarian cancer..... | 346 |
| Figure 7.4: Initial foliation of the generic HBOC decision tree. | 348 |
| Figure 7.5: Further foliation of reference node [3] of the generic HBOC decision tree. | 350 |
| Figure 7.6: A fully foliated generic HBOC decision tree..... | 353 |
| Figure 7.7: Partially foliated roots of a generic decision tree for HBOC, with an emphasis on the factors related to prophylactic oophorectomy decisions. | 357 |
| Figure 7.8: An HBOC decision tree pruned to represent Ellen Macke's choice..... | 361 |

PREFACE

This dissertation would not have been possible without the ongoing and persistent love, affection, education, nurturance, guidance, criticism, consternation, and support of a number of individuals and institutions. First things first: thank you, mom and dad, for your love and wisdom. Thank you also for cultivating my inquisitiveness and mischievousness, and for valuing my education in a way that taught me not only some book smarts but also the value of working hard for them.

A good friend, Jim Tabery, once made an analogy between writing a dissertation and riding a roller coaster. During both activities one is constantly shifting between the “ups” and the “downs” and sometimes it is so intense one does not know which way he is oriented. My family has kept me grounded and focused on what is important over the three years of my life this project has consumed. Thank you, Stephanie, for your belief in me and your constant support when my ideas seemed puerile and my pen would not flow. You have helped me see which way is up and which way is not. I am better oriented because of you. Also, thank you Charlotte and Vivian. Caring for you has compelled me to see an aspect of being human that I doubt I would have otherwise been exposed to. Your humor and vibrancy are a constant source of inspiration. Because of you, I will always remember to be dexterous and deft, and to never mix up my right foot with my left.

I am lucky to have good friends in and outside the academy who have informed my thinking in general and in this project in particular. Thank you, Steve Francis, Dawn-Marie and Jim Tabery, Tracy and Cause Hanna, Jessica and Keith Bemer, Katie Tabb, and Rich Purcell. I am also lucky to have had the good fortune to learn from a number of brilliant individuals. Thank you, Peter Machamer, Ken Schaffner, Sandy Mitchell, Edouard Machery, Bob Arnold, Doug White, Mark Wicclair, Jim Lennox, Lisa Parker, David Barnard, Randy Hampton, and Paul and Pat Churchland. I have learned many things from each of you in the classroom, in conversation, and by reading your work. You inspire me.

My work has been supported by a number of institutions. The University of Pittsburgh Department of History and Philosophy of Science was been my academic home while writing this. I am grateful for the funding I have received from the department. And I am more grateful for the awesome scholarly environment the stewards of the department provide. “Pitt HPS” is an amazing community of faculty, graduate students, postdocs, and visitors; I have grown as a person and a scholar because of my experiences there. I have also received support from the

Center for Bioethics and Health Law, for which I am very thankful. And I have been supported by the University of Pittsburgh Graduate and Professional Student Government for travel to present my work, as well as to remain a scholar for the last two years I was in residence in Pittsburgh. Portions of this work have been presented at the University of Virginia, University of South Carolina, Northeastern University, Cleveland Clinic, American Society for Bioethics and Humanities, and University of Arkansas for Medical Sciences (UAMS). I thank those who invited me to speak or accepted my applications and those who administered the proceedings. I also thank D. Micah Hester, from UAMS for generous financial support, patience, and encouragement during the final months of this project's completion.

Over the past four years I have had the privilege of observing and speaking with clinicians, patients, and family members about their involvement in health care. You are too many to name, however, I thank you nevertheless. Witnessing how people engage with one another when making medical decisions originally motivated me to perform this research, and it remains a source of motivation today. As I have performed this research, a group of scholars in the Research Seminar on Ethics and Decision-Making, housed out of the CRISMA Center and Department of Clinical Care Medicine at the University of Pittsburgh, have been a source of inspiration. Thank you, Doug White and Leslie Scheunemann, in particular, for including me in this group and for providing me with new opportunities to learn.

Recently, a number of my friends and family members have become ill or been hospitalized. Some have permitted me to take a scholarly interest in their lives in addition to the friendly interest that preceded it. Thank you for sharing your life with me. Your personal experiences have taught me much. In particular, thank you Terri Oakley. This work is dedicated to you.

1.0 SOCIALIZING MEDICAL PRACTICE: AN INTRODUCTION

We are ill, or at least many of us are. In their annual analysis of the health of U.S. adults, the Centers for Disease Control and Prevention reports that right now we suffer in a variety of ways. In America, more than one in three of us reported suffering from lower back pain in the past 3 months and more than one in six of us reported having had a migraine in the same time period. In the last 30 days, roughly one in five of us reported having felt nervous during all or most of those days; and, more than one in eight reported having feelings of sadness during all or most of the same time. More than one in ten of us has been told she has heart disease by a health care professional at some time in her life. One in eleven has been told she has diabetes. And one in twelve has been told she has cancer (Schiller et al. 2012, 5-9).

Our responses to feeling ill vary. However, most of us take our pain to a physician or another health care professional. Roughly five out of every six of us has somewhere that we usually go when we are ill, such as a clinic or a doctor's office. In other words, one in six of us is without a usual place for health care. One in five of us has not visited a health professional in the last year. Out of the rest of us, a bit more than two in five have visited a health care professional 1-3 times in the past year; and, a bit less than two in five have visited one more than 4 times over the last year (*ibid.*, 12). This dissertation is about what we do, and what we should do, during some of those visits.

In particular, I am interested in how we should make medical decisions. I approach this issue from a philosophical perspective. I am interested in people's actions. I want understand how people act when they seek and provide medical care. And I endeavor to make claims about what they should do when performing these activities.

Scholarship concerning good communication, reflection, and intervention in healing extends from the time of the earliest works of Ancient philosophy (Lloyd 1984) to contemporary work on medical choice. As will be discussed below, contemporary research on medical decision-making is dominated by one position, which can be summed up in one word, *autonomy*. Since some time in the middle of the twentieth century – exactly 1957 by some estimates (Faden and Beauchamp 1986, 59) – Western accounts of medical decision-making have focused largely on upholding or empowering a patient's right to make her own choices about what is done to her body. Patients have come to be viewed as rational agents to whom all information should be disclosed, and who should then reflect on their circumstances and select the best of the available options for themselves (Schneider 1998).

Yet, this position can be taken to the extreme. And of course, if it is to be taken there, trust philosophers to usher it along. A recent commentary by David Velleman puts the point well. Velleman reports the experience of being an invited speaker among a group of fellow philosophers. During the socializing after his presentation, Velleman relates having the awkward experience of being a newly diagnosed cancer patient undergoing treatment and engaging in conversation with his peers while they engaged in a bit of smoking. One of the smokers entered into a disquisition on his “right to choose whether to live and die smoking, or to quite and merely survive” (Velleman 1999, 606), and listening to his peer's claims, Velleman

was provoked to outrage at the hubris of his premises. An objection came to Velleman, prompted by his own experience with cancer:

A few months with cancer had taught me that a tumor rarely invades a region smaller than an extended family. Physically, the cancer was confined to my body, but even in that respect it was difficult to regard as mine. The tumor cells were growing in my bone marrow, which...I discovered, was as foreign to me as the far side of the moon...Of course, this fertile gunk in my pelvis and skull was also my sole source of blood cells, and my life depended upon it. But so did the life of my sons' father, my wife's husband, my parents' son, my brothers' brother, and I was never sure who among us would suffer the greater harm if that life ran out of gunk. (*ibid.*)

Velleman's narrative puts the point elegantly and bluntly: the price of our autonomy is an unwarranted emphasis on ourselves. At its extreme, autonomy implies our own alienation. It suggests that we make choices about our bodies but without the help of others. Indeed, in the most extreme, it suggests other's concerns are irrelevant for our choices. All that matters is what we prefer, in light of our unique understanding of the circumstances. We may choose to smoke ourselves to death, since we are all that matters.

Of course, proponents of the autonomy paradigm for understanding medical choice would dispute the assertion that empowering persons to make choices entails their alienation from the concerns of others (e.g. Berg et al. 2001). And they would argue this is especially the case if we reflect sufficiently on the influence our choices have upon those who are important to us, like spouses, friends, parents, siblings, and children (Hardwig 1990; Kukla 2005). Other accounts of autonomy are available, they will say.

Proponents of autonomy-based informed consent are right to make this move. They are right, that is, to emphasize that we are embedded in a social context, and that our choices have implications for ourselves and others to whom we are close to. They can recognize that illness

“rarely invades a region smaller than an extended family,” and then respond that autonomy is up to the task of accounting for such circumstances.

I am skeptical of this maneuver. Rather than bastardize a perfectly sound concept, autonomy, I suggest that we develop an alternative account of choice. I propose we characterize choice in more diverse terms than merely autonomy and the derivatives we imagine it is capable of. I suggest that we consider what is known about people who make decisions, both in terms of how they make decisions and what, if any, cognitive or behavioral limits there are to persons’ abilities to engage in decision-making and related activities. Then I propose we develop an account of choice that guides them to make good decisions, given their circumstances and what is known about them. I agree with a basic point Velleman captures: illness happens to persons, but it affects social groups. When one is ill, this affects others. Others often participate in your healing, just as they participate in your illness. And, this participation includes the choices of which healing practices to engage in. Thus, I believe medical decision-making is a social practice. Furthermore, I believe it should be. Defending this view is the task of this thesis. In this dissertation, I will defend the claim that medical decisions should be made by groups of persons acting together, not by individuals acting alone.

My argument proceeds in three major steps. The first step is to pose the problem within a certain analytic framework (Chapters 2-3). Among other things, my argument requires understanding the problem as being distinguishable into two distinct problems, a descriptive problem and a problem requiring a normative account. The second step is to propose a solution to the first part of the problem, namely, a descriptive account of choice (Chapters 4-5). The third step is to develop a solution to the second part of the problem, to propose a normative

account of choice (Chapters 6-7). Before beginning this argument, let me foreshadow it in some detail.

1.1 Setting the Stage

My first task is to introduce the problem within a particular analytic framework. In Chapter 2, I complete one part of this task by introducing popular accounts of medical decision-making and justifying my view that none of them is sufficient. Chapter 3 then continues to clear important ground by arguing for an account of the unique context that medical decisions are made in.

I begin by demonstrating that there are three popular models of medical decision-making. One is beneficence-based *paternalism*, the view that physicians should decide what is best for their patients and what information to disclose to them. Physicians should then ask patients to consent to the procedures they recommend, irrespective of whether patients might have made a different decision with different information. Thus, paternalism tacitly assumes that patients are capable of making their own decisions, but that if they were more informed about their predicament they might make decisions that would ultimately be against their best interests. Or, paternalism tacitly assumes that the action of disclosure may have harmful effects, and thus that suppressing some pertinent information is beneficial to the patient (§ 2.1).

Another model I consider is autonomy-based *informed consent*, which is the most popular way of characterizing medical decision-making. On this view, the legal informed consent doctrine provides guidance for what information physicians and patients should communicate about before a patient undergoes medical treatment. Informed consent is open to a number of interpretations. Some argue that it is a doctrine for characterizing legal rules that define health care professionals' obligations and penalties for deviation from them, rather than

an account of choice (Faden and Beauchamp 1986). Others, however, argue that informed consent should be understood as simultaneously a legal doctrine, philosophical conception, and model of decision-making (Berg et al. 2001). Given the widespread adoption of informed consent in hospitals and for human subjects research, I consider this model in some detail (§§ 2.2-2.5). Ultimately, I contend it is best understood as admitting of two interpretations, an “event” model of choice and a “process” model. The former can be understood as describing decisions as “punctate” or, “a decision made in response to a discrete choice that can be understood in isolation from the rest of a patient’s health care” (Kukla 2005, 35). The latter focuses on how decisions should be made over time, in relation to patients’ broader health concerns and life narratives.

Despite its popularity, a number of scholars have begun to object forcefully to informed consent on empirical grounds. Thus I also consider empirical research, which suggests patients exhibit significant heterogeneity with regards to their decision-making preferences (§ 2.4). Some desire to be significantly involved in making their own decisions and to seek medical information about their health states, while others desire to have little involvement and to seek minimal information (Levinson et al. 2005). Furthermore, the diversity of patients’ preferences is multiplied considerably, to the point of paradox, when researchers consider specific illnesses. For example, studies of participation in decision-making and patient satisfaction with care in diabetic patients suggests that patients both prefer to participate less in decision-making and that they are more satisfied with care if they are encouraged to participate (Golin et al. 2002). Because of the observed diversity of patients’ decision-making preferences and its paradoxical implications, scholars have argued that a more nuanced account of decision-making and communication is required. Those who heed this call for more nuance have put forward a third

model of medical choice, called the *shared decision-making* model. On this account, satisfactory medical decision-making occurs when patients and providers share information about the medical problem at hand and then consider how the treatment options and consequences best fit with the patient's preferences and values (Frosh and Kaplan 1999).

In addition to introducing paternalism, informed consent, and shared decision-making, I argue in Chapter 2 that each of these models is flawed in a particular way. To develop this argument, I first distinguish between two criteria that I contend any model of medical choice should meet, which I call *standards of adequacy* (§ 2.3.1). One criterion is descriptive adequacy. To meet it, a model of medical choice must be consistent with empirically supported descriptive claims about the agents it is designed to apply to. Another criterion is that it must be normatively adequate: it must generate action-guiding claims, at least for ideal agents the model is designed to apply to.

Having distinguished between these two standards of adequacy, I then argue that none of the three prominent models of choice satisfies them both. I show that paternalism and informed consent both satisfy the standard of normative adequacy; however, neither satisfies the standard of descriptive adequacy (§ 2.3.2). Both of these models conceive of decision-making as an individual activity. Agents are guided to collect a significant amount of medical information about a patient's health and information about that patient's preferences and values. Then, both models suggest the agent (whether physician or patient) reflect upon this information and calculate what is best in light of it. Yet, I discuss empirical research that suggests neither patients nor physicians are capable of performing this cognitive task.

Where paternalism and informed consent fail, I suggest shared decision-making succeeds. This model aims at inductively describing choice in medicine. Thus, insofar as it does

anything well, it is describing how patients and physicians actually make choices. But the shared decision-making model does not fair well as a normative account. It is evident that the model currently lacks clear conceptual boundaries and fails to make normative claims (§ 2.4.2).

Thus, the analysis of Chapter 2 concludes that there are three prominent models of medical choice and that none of them meets the two criteria I put forward for evaluating models of medical decision-making. In the rest of the dissertation, I aim to develop a model that will meet those standards.

One of the problems I identify with the received view of informed consent is that it does not sufficiently describe the uniquely medical context of medical decision-making (§ 2.5). For example, Berg et al. (2005) describe a process model of informed consent, where participants in choice monitor one another's thinking while sharing information. However, I argue it is unclear just what this would amount to in practice because it is not clear what the metaphor of "mutual monitoring" amounts to. In response, I endeavor to make clear that my model of choice makes certain assumptions about the medical context, and that those assumptions are justifiable. The task of Chapter 3 is to flesh these out and justify them against other available assumptions.

To identify available assumptions one might make about medicine, I survey important topics in the philosophy of medicine. I begin by considering whether medicine might be said to have some basic goals (§ 3.1), as some have argued (e.g. Pellegrino 1999). I propose that the conceptual foundations of medicine may be understood in terms of two basic aims: to fully understand a patient's latent or pronounced illness, and to intervene to alter its course in ways that are consistent with that understanding.

A number of standard distinctions have been put forward to describe the "essence" of medicine. It has been suggested that "health" and "disease" are basic concepts in medicine, and

that adequately defining them philosophically will yield an understanding of the foundations of medicine. Others have suggested that medicine should be understood in terms of a different duality, between medicine-as-art and medicine-as-science. After introducing these and other standard distinctions for characterizing the epistemology of medicine (§§ 3.2-3.3), I argue that they rest on a mistaken account of science as pure objective inquiry. I draw on research by Heather Douglas and Peter Machamer to distinguish between different ways in which scientific inquiry can be objective and the different roles that values may play in science (§ 3.4). With this alternative account of science, I argue for an epistemic distinction incorporated into my account of the basic aims of medicine. On my view, medicine aims to understand a patient's illness objectively and subjectively, or in both personal and scientific terms (§ 3.5). I conclude the chapter by considering how we might measure the activities of making objective and subjective claims in practice (§ 3.6), responding to objections that arise from similar approaches to understanding medicine (§ 3.7), and restating my position (§ 3.8).

1.2 Describing Medical Choice

The first step of my argument that medical decision-making is and should be a social activity sets the stage. It reviews the literature on medical decision-making and philosophical conceptions of the nature of medicine. And it defends a view of medicine that rests upon a basic epistemic distinction and two basic aims. Building on this, the second step develops a descriptive account of choice. In this step, I argue that medical choices *are* social.

My argument that medical choices are social begins by focusing on a prototypical example of choice in medicine. I focus on decision-making in hereditary breast and ovarian

cancer (HBOC) for a number of reasons.¹ One is that it is a sub-type of breast cancer, which is a prevalent disease. It is also a disease for which genetic testing is possible; thus, it provides an opportunity to consider additional choices regarding procuring information about one's genetic status. This cancer also has a known hereditary basis, so thinking about it underscores issues of disclosure among family members that may appear unimportant in the context of other illnesses.

I describe hereditary breast and ovarian cancer in considerable detail. I first describe its clinical and pathological features (§ 4.1) and then the history and current application of genetic testing (§ 4.2). In doing this, I show that there are a number of major treatment decisions that a woman who is a candidate for genetic testing may face. These include choosing whether to undergo testing, and subsequent to that choice, whether to medically manage her risk or whether to adopt an alternative surveillance regimen. Yet, I argue that although this much is clear from empirical studies of HBOC, it is also important to consider what it is like to make decisions related to HBOC from a patient's personal point of view.

In order to convey what it seems like to face decisions related to HBOC, I consider a detailed case study, in the form of a first-person autobiographical narrative, by Ellen Macke (§ 4.3.2). Macke's narrative tells the story of a woman who had considerable personal experience with cancer. She begins her story by noting many women in her family had suffered and died from breast or ovarian cancer, and her sister and cousin were both in the process of undergoing or recovering from cancer treatment. Over a three year period, Macke describes her initial attempts to learn more information about her chances of getting cancer, her initial responses to her sister's illness, her attempts to enroll in research on the genetic basis of breast cancer, and

¹ I thank Ken Schaffner for suggesting I consider this case, and Bob Arnold for suggesting that I focus on decision-making in a case other than one arising in end-of-life care.

eventually, her own diagnosis of ductal carcinoma in situ (Macke 1996). I argue that the conclusion to draw from Macke's narrative is that medical decision-making is a complex activity that takes place across spatiotemporal and social dimensions (§ 4.4). Macke says she discussed her circumstances with over twenty different individuals over the time that she formulated and made her decisions (Table 4.2). Thus, even in her autobiographical reconstruction of events after the fact, Macke highlights that her decision-making included conversations with many individuals about a wide range of information. I argue that these conversations are not merely supervenient upon her choices; rather, they are constitutive of them. Thus, I conclude that medical choices are social: information sharing among persons is constitutive of the process.

I conclude Chapter 4 by considering how we might describe medical choices, *qua* social activities. I propose to describe medical decision-making by way of an analogy with the practice of navigating. After reflecting on some thinkers who anticipate this analogy (*e.g.* Barnard 1986; Kraybill 1986), I suggest that a nautical metaphor is useful because it draws attention to the social contexts of complex practices.

To fully understand the practice of navigation, I follow the landmark work of Edwin Hutchins. Hutchins (1995) performs an ethnography of navigation on a large navy ship, which he draws on in putting forward the theory of *distributed cognition*. On this view, persons may be described as thinking together by using the concepts of cognitive science. When solving problems, persons search for information from the environment, select information from it, share it with one another, and integrate that information sufficiently to characterize the problems they face and their solutions. Thus, persons working together can be understood as performing cognitive activities together, if they are doing specific sorts of work (Magnus 2007).

After describing this theory in detail (§§ 5.1-5.3), I argue that medical decision-making may be described well in terms of it.

Describing medical choice in terms of distributed cognitive systems leads me to represent Macke's decision-making in terms of the information processing of a network of interconnected persons and cognitive tools (Figure 5.3). This makes the analogy explicit between the navigational system, which can also be represented using a network diagram (Figure 5.2), and the decision-making system. Yet, I recognize that a very important difference exists between them. Hutchins account of the navigation system draws on years of observational data, which is absent in the case of medical decision-making. Hutchins' data is also prospective, whereas even if Macke's narrative is viewed charitably as data, it is retrospective. Thus, I acknowledge that there is an important contrast between the detail and scope with which Hutchins characterizes his system and the fact that this is missing in my case (§§ 5.4-5.5).

In order to overcome this weakness in my analogy between medical decision-making and navigation, understood as distributed cognitive systems, I consider many of the few microanalyses of communication in medicine (Mishler 1984; Atkinson 1995; Berg. 1996). I argue that these show it is possible to collect the sort of data that Hutchins basis his analysis of navigation on in the medical context. Although the data I appeal to is problematic because it is non-longitudinal and taken from a number of disconnected analyses, I conclude, nevertheless, that there are good reasons to think that the same sorts of communicative activities that Hutchins identifies as present in the navigation system are also present in medical decision-making systems. Thus, I propose to describe medical decision-making as a distributed cognitive activity (§ 5.6). Then I conclude by arguing that describing medical choice in this way suffices for meeting the criterion of descriptive adequacy introduced in Chapter 2 (§ 5.7).

1.3 Making it Normative

After I argue that medical choices are social, I still face the task of arguing that they *should be*. Making my model normative as well as descriptive requires a different, yet complementary, mode of analysis. I begin by introducing a procedural approach to ethical justification known as “reflective equilibrium,” which takes up the whole of Chapter 6. Then I turn to apply that account to the medical decision-making, which I do in Chapter 7.

Reflective equilibrium is well known in philosophy, as it has been discussed in metaethics, normative ethics, and applied ethics. The procedure means many things to many people, including its proponents and opponents (Walden 2013). I begin developing a normative component to my model of medical choice by introducing the most prominent ways to understand reflective equilibrium, which are due to John Rawls and later development of his work by Norman Daniels. I argue that Rawls’ account of reflective equilibrium differs in important ways from Daniels’ and others’ accounts, because it emphasizes the social, deliberative nature of reflection (§ 6.1). I propose that Rawls’ account of justification rests on an understanding of argument as being between reasonable persons, as opposed to argument as individual reflection in the absence of communication with others. Understanding reflective equilibrium in this way makes it a more promising account for characterizing a procedure for incorporating normative concerns into medical decision-making. However, I recognize that a number of pressing objections must be considered if reflective equilibrium is to do the work of producing action-guidance for persons making medical choices.

I suggest that the major issue reflective equilibrium faces is that it rests upon the notion of coherence, which many have argued is an inadequate foundation for ethical justification (§ 6.2). Coherence, many claim, is likely to enshrine the idiosyncratic views one starts with rather

than lead those who perform the procedure to *prima facie* laudable normative beliefs (e.g., Brandt 1979; Beauchamp and Childress 2009). One way to respond to this is to argue that those who perform the procedure and reach *prima facie* blameworthy or shameful sets of beliefs simply have not successfully performed the procedure. They should try harder. However, counterexamples to this response suggest that this requires a level of reflection and consideration that mere mortals seem unlikely to be capable of performing. Thus, this leads to another objection than the worry about *idiosyncrasy*; it suggests a worry about what I call *supercomprehensiveness*, namely, that reflective equilibrium requires agents to be more than simply extremely comprehensive in their search for information that bears on their normative beliefs. It requires them to be super-comprehensive.

I take these objections to reflective equilibrium very seriously. I am attracted to the view because it offers an anti-foundationalist, anti-essentialist account of ethical justification, which rests upon an abstract procedure. I believe that these features would make it particularly compelling for medical decision-making, because when persons communicate while making choices they do not share the same starting points or the same background beliefs. Thus, I hope that a procedural account can provide a means for generating agreement on what is right when information is pooled under the circumstances, despite the unshared starting points from whence that information is derived. But I recognize this will not be the case unless the view is articulated in such a way that it can respond to major objections against it.

My strategy for responding to these objections is to expand the notion of coherence upon which reflective equilibrium rests and to do so specifically in light of my characterization of the medical context within which medical decisions arise and are made. I conclude Chapter 6 by performing the first step of this strategy. I introduce decision analysis as a means for

characterizing the logic of medical decisions (§ 6.3). A number of authors have appealed to decision analysis to abstractly represent medical choice (e.g. Weinstein and Fineberg 1980). Drawing on their work and others, I argue that medical decisions can be understood using a few basic concepts from decision analysis, including *choices*, *outcomes*, and *utilities* (§ 6.4). I borrow the concept of a *generic decision tree* from work in decision theory (Von Winterfeldt and Edwards 1986), which provides a significant formal apparatus for characterizing ordinary choices. In the case of medical choices, I suggest that the formal apparatus need not be used, however. I argue that decision trees can be used heuristically, and that doing so provides a means for articulating a defensible account of reflective equilibrium in medicine (§ 6.6).

The purpose of Chapter 7 is to articulate this account. I begin by suggesting that a difficulty arises in any attempt to discuss ethical justification, when one is pulled toward engaging with the skeptic. I draw on the work of others, including Christine Korsgaard and Bernard Williams, to distinguish between two types of skepticism. I argue that my account of how normative claims may be justifiably generated in the context of medical decision-making only needs to satisfy the demands of *reasonable skepticism* (§ 7.1). Like Velleman and others, I argue that the idea of *valuing* implies *agents who value*. Moreover, I also believe that persons regularly communicate about their values when thinking about their actions. I defend the claim that part of being human is being able to reflect on one's options and to act subsequent to such reflection. Given the commitments that a reasonable skeptic makes, as I conceive of her, I contend that she must accept this too, on pain of practical irrationality.

Understanding normativity in this way positions me well to justify a threshold of reflection that I argue is required for ethical medical decision-making. The first step in this justification is to introduce another case study of HBOC decision-making, Alicia's case. I

suggest that Alicia's is an instance of poor medical decision-making, which I substantiate by considering her first-person autobiographical account in considerable detail and then representing it using the tools of decision-analysis (§ 7.2). I argue that Alicia's choice is deficient because it fails to consider the right amount and kind of information, and because it fails to adequately organize the information it does consider logically. I then move to introduce an abstract, idealized choice to compare Alicia's with. I introduce what I call a *generic HBOC decision tree*, which is constructed by considering what information would be important for a generic individual who was a candidate for HBOC. Given what I have discussed in earlier chapters, I propose to represent all of the information that might be required for a generic agent to reflect upon her circumstances using a complex decision tree (Figure 7.6).

After introducing the generic HBOC decision tree, I then consider whether, in light of it, Macke's choice appears to be a good one. And I argue that it does. Macke's choice can also be represented in decision analytic terms (Figure 7.8). Once it is so rendered, it can then be juxtaposed with Alicia's choice and the ideal decision of a generic agent. Doing so, I argue, shows why Macke's choice is a good one: it considers the right kind of information, and the right amount of it (§ 7.3). From this, I argue it is possible to generalize about the kind and amount of information that should be required for good medical decisions.

I propose the concept of *medical reflective equilibrium* as a means of characterizing good medical decisions (§ 7.4). Just as reflective equilibrium emphasizes the search, selection, and integration of ample information, so too does medical reflective equilibrium. However, unlike reflective equilibrium in general, I argue that when the procedure is applied to particularly medical contexts it begins with certain presumptions. In medical reflective equilibrium, that is, an agent must meet the basic aims of medicine defined and defended in

Chapter 3 in order to adequately substantiate the set of *health judgments* that I propose as part of the procedure. Thus, in order to make a good decision, an agent must adequately consider enough information to fully describe a patient's circumstances in both personal and scientific terms. If an agent fails to consider a threshold of information sufficient to meet these basic aims, then I argue ethical medical choices will not result.

I believe that there are a number of virtues to this account. One is that it makes it possible to describe how people should make medical choices in terms of meeting certain informational constraints, yet without requiring that they consider a super-comprehensive amount of information. The threshold of information that must be considered may be defined as a *satisficing* threshold (Simon 1997), rather than an optimizing one. Thus, agents need only consider enough of the right kind of information. Adequate reflection does not require the consideration of all possible information in a sense that can be defined using decision analytic concepts.

Another virtue of the account is that it highlights the assumptions that are entailed by worrying about idiosyncrasy. I argue that the skeptic faces a dilemma if she aims to reiterate this worry in the case of medical reflective equilibrium (§ 7.5). She may contend that my model of how agents should choose has no empirical support; that is, she may doubt that it is instantiable in practice and that it will actually produce action-guidance for particular persons who face particular choices. I acknowledge this worry and accept it. However, I respond that to meet this worry requires an empirical investigation, which is a different sort of inquiry than we are engaged in in Chapter 7. Yet, the skeptic may also contend that in principle it is not possible to meaningfully deliberate about a patient's circumstances in both objective and subjective terms. As I portray the skeptic, she may say that one may deliberate about how we describe a

person's illness objectively, from an observer's perspective. But, she will continue to say that we cannot deliberate meaningfully about subjective claims persons make about the experiences of being ill and participating in medical care or choice. Rather, such subjective claims are irreducibly subjective and incorrigible. To the skeptic, they are not the sorts of claims about which we can forge agreement.

I believe that the skeptical intuition here is mistaken. To rebut it, I draw on work by Cheryl Misak (2005, 2008) and others to demonstrate that first-person autobiographical narratives are reason-structured. When we describe the way things are and what we think is right in light of them, we are in a sense opening ourselves to criticism. Others may disagree with our assessments. They may disagree with our reasons. Or they may agree with our assessments and our reasons, and thus they may endorse our normative claims. That this is the case, I argue, is reason to reject reasonable skepticism about my account. Thus, I conclude that medical decisions should proceed according to a certain sort of reflection and deliberation. Given how I define these activities, medical decisions should be social because it takes more than one person to perform the information processing tasks that are required for making ethical medical choices.

1.4 Open Questions

As can be gathered from this introduction, the following analysis will be extremely interdisciplinary, although it is fundamentally philosophical. This is in part indicative of my approach to scholarship. However, it is also a reflection of the topic. Medical decision-making overlaps with many fields, from rational choice theory to philosophical ethics, and clinical research to legal theory. We will consider research and themes from bioethics, clinical

medicine, philosophy of science, medical anthropology, biology, sociology, cognitive science, sociology of science, political philosophy, ethics, decision theory, and metaethics in detail in the analysis that follows. My aim is to keep the discussion focused on only what is needed to defend my view that medical decisions are and should be made by groups of persons acting together, not by individuals acting alone. I apologize in advance for moments where the prose becomes digressive.

Despite the many topics we will consider, a number of important issues will be ignored. I do not adequately discuss rational choice theory, behavioral economics, social or individual psychology, some recent work on practical rationality, or philosophical accounts of group agency. And my discussion of some topics may appear insufficiently cogent or consistent. In Chapter 8, I summarize the work and discuss some of the open questions entailed by these inconsistencies and future research that might remedy them.

2.0 STANDARDS OF ADEQUACY AND MODELS OF MEDICAL DECISION-MAKING

The phenomenon of medical choice has been studied from a variety of perspectives and with various methods for centuries. In the courts and legal scholarship medical choices have been analyzed in terms of citizens' rights. In academia they have been analyzed in terms of the history of medicine and ethical theory. In the clinic they have been analyzed in terms of doctors' prerogatives and patients' preferences. Across these approaches, one finds a broad literature concerned with the question, How should persons make treatment decisions? Between the 1950s and 1970s, roughly, a consensus emerged among scholars that there are two basic models for how patients should make medical decisions.²

On one account, attributed to the Hippocratic corpus at the very beginnings of modern medicine, physicians should make decisions for their patients in accordance with the dictum, "To help or at least to do no harm" (Pellegrino and Thomasma 1981, 184). Interpreted as

² The locutions 'treatment decision-making' and 'medical decision-making' and related turns of phrase are used here interchangeably. The intention is to draw attention to decisions concerning treatment, which necessitate choices both on the part of health care providers as well as consumers of health care. It is assumed that this type of decision-making can be distinguished from medical decision-making more broadly in that the latter may refer to diagnosis, hypothesis testing, interpretation of diagnostic tests, and so forth whereas the former refers only to the choice of therapy (or not) that is made both by providers and consumers. Though medical decision-making in the broad sense is not the target of my analysis, it will figure into the discussion below and I take my conclusions to be germane to it.

paternalism, this dictum has given rise to a model for medical decision-making where physicians are guided to learn all that is pertinent about their patients and to make prudent decisions about their treatment, trying at all time to do what is most likely to benefit them without causing harm.

The faults of paternalism prompted the development of an alternative model, which has become the dominant view of treatment decision-making, known as *informed consent*. This model is based on a commitment to the competent patient's right to autonomously authorize his or her treatment plan, which includes a right to reject any and all medical care.

Decades of debate about the structure, content, and implications of these approaches to medical decision-making have recently produced a stalemate of sorts. While informed consent is widely accepted as the standard model of how patients should choose treatments, it is well known that this model has its flaws and that paternalism is not only appropriate in some instances, but is also preferable or inevitable in others (emergency situations or triage). Thus, some have come to hold that neither autonomy-based informed consent nor beneficence-based paternalism is an ideal, uniquely wholly applicable, model of treatment decision-making.

Many of those who espouse this position are clinicians who have argued that these two prominent models of decision-making are too abstract, too much a product of academic and legal discourses, and insufficiently grounded in everyday clinical experience. Non-clinicians have also argued for this view, with a group lead by Kathy Charles spearheading work on what is known as the *shared decision-making* model, or "SDM" (Charles et al. 1997). On this view, claims about decision-making are based primarily upon empirical studies of patient and physician interactions during treatment decision-making, and only secondarily in ethical or legal theories of choice.

The aim of this chapter is to consider each of these three models in detail, and to examine whether any of them meets two criteria of adequacy that I argue must be met by any satisfactory model of medical decision-making. My thesis is that none of them does. On my analysis, beneficence-based paternalism and autonomy-based information consent are descriptively *inadequate*, while the shared decision-making model is normatively *inadequate*. I support this position by first describing paternalism and informed consent, in Sections 2.1 and 2.2, then articulating these two standards of adequacy and relating them to those two models (§ 2.3). Next I describe SDM and argue it fails to be normatively adequate (§ 2.4). I conclude by explaining how this setup relates to an alternative “process” model of informed consent and by forecasting the analysis to come in the next chapter (§ 2.5).

Before beginning my argument, I will provisionally define the two standards of adequacy that are central to it. The terms “normative” and “descriptive” are common in the social sciences and philosophy. Roughly, normative claims are ones that imply norms or are derived from them, where norms are standards such as standards of behaving, reasoning, feeling, and acting. Descriptive claims are ones that describe events and states of affairs, such as behaviors, patterns of reasoning, feelings, and actions; ideally, they do so irrespective of any extent to which said descriptions imply or are derived from norms. Thus, put simply, the distinction between normative and descriptive claims rests upon a difference between claims about what “ought” to be done and claims about what “is” done. I will argue below that models of medical decision-making may be evaluated with regard to the extent to which they *produce* normative claims and *are consistent with* descriptive ones. The former I will call *normative* adequacy, and the latter, *descriptive* adequacy, each of which is clarified below.

2.1 Paternalism: Making Good Decisions for Patients

In the paternalistic model, physicians use discretion in deciding what information to provide to patients and to what extent patients are incorporated into decision-making processes. Following Emanuel and Emanuel, in its modern form this may be defined as a model of decision-making where “physicians use their skills to determine the patient’s medical condition,” stage in the disease process, relevant tests, and then “the physician presents the patient with selected information that will encourage the patient to consent to the intervention the physician considers best” (Emanuel and Emanuel 1992; cf. Pellegrino and Thomasma 1981). The core feature of the paternalistic relationship is that the physician procures consent based on the information he or she provides the patient. Then the physician performs the intervention that is in the patient’s best interests as defined by the physician.

There are also additional features of the paternalistic model that are not captured solely by focusing upon disclosure and beneficence. Another aspect of a paternalistic approach is that it entails the assumption that the intervention under consideration is one that requires some type of moral justification (Gert et al. 1997, 196). That is, if the action to be performed by the physician was not one that required moral reflection and subsequent moral justification, then there would be no need for him or her to act paternalistically, or to encourage the patient to consent to the physician’s chosen option. Part of the controversy surrounding the moral and professional permissibility of the paternalistic model is exactly this assumption, because it confers significant responsibilities and obligations upon the physician, as it implicitly requires the physician to accept responsibility for the moral reasoning and practical consequences of performing an intervention.

Another important feature of the paternalistic model is that it tacitly assumes patients believe they are capable of making their own decisions on the matter at hand. A physician is motivated to behave paternalistically because he or she is aware of his or her patients' convictions that they can make, and perhaps have made, the correct decision regarding treatment. But importantly, the physician feels that the patients' choices are incorrect in some sense. Here paternalistic ethics is the result of a physician's obligation to act beneficently despite the fact that the patient may not agree that the intervention under consideration is the correct action.

Some have argued that while a paternalistic approach to making treatment decisions is permissible in the case of emergency interventions, this is perhaps the *only* circumstance under which the model is acceptable (Emanuel and Emanuel 1992). This recognizes that in emergency circumstances an intention to benefit the patient may be obvious; consequently, so is the moral justification of the act. Often in an emergency, consent is unattainable due to a patient's circumstances. Thus, intervention is justified to stabilize the patient, whose considerations regarding medical care may then be accounted for, once his or her health has been restored. However, even this justification of the paternalistic model underscores that in specific circumstances sufficient knowledge and consideration of patients' beliefs, desires, or treatment goals may be lacking. And this is the overarching problem most opponents of paternalism have had with the model: in some instances it justifies ignoring, suppressing, or even flouting the convictions of patients.

If what justifies paternalism in an emergency is that the circumstances preclude sufficiently ascertaining the patient's perspective, then this line of reasoning entails that in non-emergency situations patients' beliefs and values must be taken into account. To many it seems

unlikely that paternalism can do so sufficiently well. As noted by Emanuel and Emanuel, “it is no longer tenable to assume that the physician and patient espouse similar values and views of what constitutes a benefit. Consequently, even physicians rarely advocate the paternalistic model as an ideal for routine physician-patient interactions” (Emanuel and Emanuel 1992). What makes paternalism suspect is that it presumes to ignore patients’ assessments of the value of medical treatment. Moreover, awareness of a patient’s assessment of an intervention and its consequences is necessary before a patient can be treated without violating his right to refuse medical treatment and without failing to respect his autonomy.

With its appeal to the principle of autonomy, this response to paternalism leads directly to its alternative, autonomy-based informed consent. As we consider that position, we will find that the primary difference between the two is that while paternalism is based on beneficence, and hence making decisions that are good for patients (and do not harm them), informed consent is based on respecting patients’ rights to choose their treatments, without emphasis on its benefit or potential for harm, *per se*. However, though they differ in this way, these two models of decision-making are actually more similar in important ways than is often appreciated, which will be explained below.

2.2 Informed Consent: Decisions Should Respect Autonomy

Within recent literature on the topic, one may distinguish four standard approaches for describing treatment decision-making in the clinical encounter, one of which takes treatment decision-making to be an interaction between physicians and patients that is governed by legal rules and ethical principles. On this approach, to describe treatment decision-making is to subsume it under the rubric of the *informed consent doctrine*. This account sees parameters

such as patient's rights, regulatory policy, and the enforcement of legislation as the salient parameters for representing how medical decision-making should ideally occur. A recent account by Berg and coauthors is indicative of this approach:

Informed consent refers [i] to legal rules that prescribe behaviors for physicians and other healthcare professionals in their interactions with patients and provide for penalties, under given circumstances, if physicians deviate from those expectations; [ii] to an ethical doctrine rooted in our society's cherished value of autonomy, that promotes patients' right of self-determination regarding medical treatment; and [iii] to an interpersonal process whereby these parties interact with each other to select an appropriate course of medical care. Informed consent is each of these things, yet none of them alone. (Berg et al. 2001, 3)

Here, informed consent is distinguished into three inseparable senses, a “policy-oriented conception” a “philosophical conception” and “shared decision-making” (*ibid.*, 15), where the senses must be taken together and cannot be taken alone.

Yet, though the concept of informed consent may not stand without each of these components, this does not entail that each component cannot stand without informed consent. It might be that the projects of providing legal rules for governing the behaviors of health care consumers and providers, constructing ethical doctrines that serve as a basis for patients' right to self-determination, and developing models for how medical practitioners and patients make decisions about medical care are all projects that could be better carried out without having to fit them within the constraints of the informed consent doctrine.

Indeed, since the mid-1980s, the standard view of informed consent within bioethics has been one that explicitly rejects Berg and colleagues' tripartite view of informed consent, which takes medical decision-making to be a proper component of valid consent. For instance, in their landmark work, *A History and Theory of Informed Consent*, Ruth Faden and Tom Beauchamp

contend that although decision-making and valid consent share an historical relationship, they ought to be considered as independent concepts, each with their own domains of application.

The emergence of the legal doctrine of informed consent was instrumental in drawing attention to issues of decisionmaking as well as authority in the doctor-patient relationship. Nevertheless, it is a confusion to treat informed consent and shared decisionmaking as anything like *synonymous*. For one thing, informed consent is not restricted to clinical medicine... Even in clinical contexts, the social and psychological dynamics involved in selecting medical interventions should be distinguished from the patient's *authorization*. (Faden and Beauchamp 1986, 279)

Following Faden and Beauchamp, informed consent and medical decision-making can be distinguished conceptually precisely because, as they say, informed consent finds application in contexts far broader than the clinical medical context; and, treatment decision-making involves the consideration of factors not conceptualized in some renditions of the informed consent doctrine. But as they also note, in practice informed consent and decision-making have been historically intertwined. Even in legal rulings, it has been necessary to presume a certain depiction of the clinical encounter in order to characterize the meaning of the doctrine (Meisal 1991). Thus, within legal, ethical, and as will be noted below, clinical, depictions of decision-making, informed consent has been inextricably tied with treatment decision-making despite the fact that they may be distinguished conceptually.

Unsurprisingly, although the view of informed consent advocated for by Faden and Beauchamp has become standard, it has never resolved this tension over whether informed consent and decision-making are *practically* distinguishable. In fact, the remarks by Berg and coauthors indicate that the standard view of consent is presently being augmented to include decision-making rather than to eschew it. Thus, though informed consent may be interpreted as

other than a model of medical decision-making, it is at least consistent with the standard view of informed consent to also see it as a model of medical decision-making.

As a model of how treatment decisions should be made, informed consent holds that when choosing, patients should do so in way that accords with the “cherished value of autonomy” promoting their right to authorize medical interventions. In this model physicians and other providers are guided by legal rules governing their interactions with patients: they must provide information and procure consent without coercion or manipulation. But they need not get involved in the decision-making process, as would be required on the paternalistic model. In fact, informed consent implies that physicians and other caregivers should not participate in the activities of patients making choices. Rather, patients make choices based on information made available by physicians and other providers. Physicians and providers are thus information sources, not participants in decision-making. Insofar as they share in decision-making it is in providing information, such as a description of the patient’s problems and prognosis, not in giving their opinion or recommendation, and certainly not in making a decision for a patient. To do so would be to flout the guidance to act in accordance with respect for autonomy.

This emphasis on autonomy has led proponents of informed consent to argue that individuals faced with a treatment decision should be in a position to understand not only the medical risks and consequences of a proposed treatment, but also what implications these have for those individuals’ conceptions of the good life (Faden and Beauchamp 1986; Buchanan and Brock 1989). As patients must make decisions to authorize treatment in a way that indicates their understanding of the risks and potential benefits, as well as the impact these potential outcomes would have on their own lived experience, this model asks a lot of patients. In effect,

it requires persons faced with treatment decisions to have an understanding of medical facts approaching that of a physician, as well as knowledge of their own moral beliefs similar to that of the trained ethicist. It is this strong requirement of patients that has made informed consent seem inappropriate to many.

2.3 Paternalism, Informed Consent, and Descriptive Adequacy

The two most prominent models of treatment decision-making, informed consent and paternalism, each have their detractors. As noted above, critics argue that paternalism fails to take into account patients' evaluations of proposed treatments when prescribing how treatment decisions ought to be made. A related objection has been given in the case of informed consent, that informed consent fails to accommodate descriptive knowledge of patients' preferences, specifically their preferences for and against being involved in decision-making and receiving information. I contend that each of these criticisms – the most common and persistent ones against these two models – rests on the same foundation. Critics contend that paternalism and informed consent fail to be descriptively adequate models of treatment decision-making. To elaborate this claim, I will define the concept of descriptive adequacy and its contrast, normative adequacy. Then I will show how these concepts unify the common criticisms against received views of treatment decision-making.

2.3.1 *Normative and Descriptive Adequacy*

In many areas of inquiry, including decision theory and philosophy a distinction between normative and descriptive claims has been made in terms of “prescriptive” and “descriptive” claims. For instance, Michael Resnik notes that there are two main branches in decision theory,

...normative (or prescriptive) decision theory and descriptive decision theory. Descriptive decision theorists seek to find out how decisions *are* made – they investigate us ordinary mortals; their colleagues in normative decision theory are supposed to prescribe how decisions *ought* to be made – they study ideally rational agents (Resnik 1987, 3)

Yet, familiarity with decision theory suggests that this distinction is only so useful. On the one hand, as Resnik notes, it “is somewhat artificial, since information about our actual decision-making behavior may be relevant to prescriptions about how decisions should be made” (*ibid.*). And on the other hand, in decision theory most work is normative rather than descriptive, so one of the “main branches” is far less developed than the other

This is not the context for examining why scant attention is traditionally paid to descriptive analyses in decision theory. But recognizing this does motivate skepticism toward an overly strict distinction between normative and descriptive domains of inquiry. And it serves as a cause for sounding some caution: the distinction between normative and descriptive claims and modes of investigation may itself serve as an unintended barrier to sustained reflection about actual decision-making in practice, where actions are guided by norms of one sort or another. Thus, it may not only be the case that the distinction is somewhat conceptually artificial, but also that it is practically limiting, by holding apart two domains of inquiry where perhaps only one should be.

In light of these considerations, it is possible to say more explicitly, though still to some extent roughly, how the notions of normative and descriptive adequacy will be defined and deployed here in a more cautious tone than may be heard elsewhere.

In this work normative claims are (roughly still) ones that imply norms or are derived from them. Norms are *standards*, such as standards of behaving, reasoning, feeling, and acting. Norms may be moral, in which case they relate to a moral theory, or perhaps a moral sense,

with regards to their derivation or origination. Or norms may be based on such things as consensus or common practice, in which case they may stem from various social institutions and mores, irrespective of whether these are rooted in a moral or ethical theory or sense. Depending upon one's view of moral theory, of course, moral and non-moral norms may or may not be collapsible; they may also be exhaustive, or the broader class of norms may admit of further distinctions.

Descriptive claims are (also, roughly still) ones that serve to describe states of affairs and events in terms of how they *are*, ideally without appealing to how they ought to be; that is, such claims are not derived from how one feels things ought to be, but rather simply how one describes how things are.

As just discussed, the distinction between these two types of claims is tenuous and perhaps also obfuscatory. My intention in invoking it is to capture a basic feature of the way we use language: to describe how the world seems to be on the one hand, and to express how we think it ought to be on the other. I recognize that how we see the world may be influenced by the way we want, or think, it should be; likewise, the way we think the world should be, or want it to be, is presumably dependent in some way on our descriptive vocabulary, on our ways of conceiving of the many experiences we have or could have in the world. Thus, again, there are limitations to the distinction that must be noted, and in this exposition cannot be avoided, but the distinction will be useful nonetheless.³

Drawing on the distinction between normative and descriptive claims allows for a related distinction, between normative and descriptive adequacy, which are two standards we

³ Some of these limitations will be revisited in the discussion of objectivity and subjectivity in medicine that is central to Chapter 3.

will use for evaluating models of medical decision-making. For a model to be normatively adequate it must generate normative claims, at least for ideal agents captured by the model. For a model to be descriptively adequate, it must accord with descriptive claims about how actual agents make decisions. Thus, these standards together impose a sensitivity to both theories of decision-making (normative adequacy) and empirical studies of decision-making (descriptive adequacy). The best model of treatment decision-making will be adequate in both senses: it will be responsive to descriptive work on how patients, physicians, and other parties interact when medical decisions are made; and will generate action-guiding claims from theoretical considerations, at least for ideal agents. Notably, this formulation of normative adequacy only requires that the theory generate action-guiding claims for ideal agents, which is in accord with the distinction between normative and descriptive approaches in decision theory. So to be normatively adequate a model must only do this; however, if a model is *both* descriptively and normatively adequate, then it will be sensitive to descriptions of actual decision-makers to such an extent that it will be capable of generating action-guiding claims for these actual agents, not merely for ideal agents.⁴

2.3.2 Descriptive Inadequacy of Paternalism and Informed Consent

With normative and descriptive adequacy suitably defined, we may revisit criticisms of paternalism and informed consent. To see what it means to say that paternalism and informed consent are descriptively inadequate we may first look to a well known criticism of the latter model, given most fully and forcefully in 1998 by Carl Schneider, in *The Practice of Autonomy*.

⁴ The inspiration for conceiving of these two standards as “standards of adequacy” comes from Bas van Fraassen’s (1980) work on empirical adequacy and the superempirical virtues (see also Churchland and Hooker 1985), although exploring and articulating the relationship(s) between those concepts and the two standards used here is beyond the scope of the present inquiry.

Schneider's principle argument against informed consent, which he calls "autonomism," is that because it takes the preferences of patients as sacrosanct, the autonomy-based model of decision-making mandates that patients must make their own treatment decisions, *even if they prefer not too*. Consequently, he points out that the model is self-defeating because it simultaneously makes patient preferences the sole criterion for guiding decisions, yet it does not consider the possibility that patients might have preferences regarding decision making that run counter to having this as the sole criterion. Schneider argues that autonomy-based informed consent makes assumes that for patients to facilitate their own rights (to privacy, self determination, and bodily integrity), they must personally and singularly select treatment pathways, yet it leaves no room for patients whose choice is to *not choose* and to have someone else choose for them despite their decisional competency. Schneider shows that many patients prefer to have other persons take on at least some decision-making responsibility and some prefer to have others take on ample responsibility. Thus, he demonstrates informed consent adopts a crucial assumption about patients' desires and willingness to be involved in treatment that empirical evidence shows many do not have (Schneider 1998, 35ff.).

Schneider's view, which has become the standard criticism of informed consent, finds support in the results of a recent emerging literature on patients' actual preferences regarding medical treatment. For instance, one study suggests that stroke patients are grossly uninformed about whether they are engaging in the process of making a medical decision about treatment (Mangset et al. 2008). Another study of rheumatoid arthritis patients suggests that patients perceive themselves to be in a decision-making environment, although they see decision-making as a temporally extended process with multiple opportunities for feedback and multiple shifts of decision-making roles and responsibilities (Schildmann et al. 2008). A series of other

studies have argued that patients' projected preferences concerning future health states are often flawed, as compared to the actual preferences of patients who have adapted to those states after becoming chronically ill (Ubel et al. 2005, 2003). Also, studies have cast doubts on the idea that patients have sufficient medical knowledge to process medical information to make informed autonomous choices about their health care. For instance, a study of 185 Swiss subjects revealed that *none of them* had what experts defined as 'minimum medical knowledge' for common illnesses and diseases, irrespective of whether they had a background in medicine or experience with particular diseases (Bachmann et al. 2007).

These studies and others like them indicate that decision-making in the clinical environment is a complex activity. They also suggest that some patients do not even understand that they face a decision or, if they do, when they discuss their preferences for future outcomes in a certain number of cases those preferences will be very different from the actual preferences they will have when those outcomes occur. Furthermore many patients may be ignorant of all but the most common medical knowledge, and consequently they will likely be unable to sufficiently process information about treatment alternatives after health care professionals describe them.

Thus, informed consent may be said to be descriptively inadequate for a number of reasons. First, patients exhibit a range of preferences regarding their role(s) in the activity of making decisions: some want to make autonomous choices, while others do not; likewise, some want information about their condition, while others do not. This means that if a commitment to an informed consent model of choice entails that patients must make their own decisions, while only procuring information (and perhaps recommendations) from providers, then it

ascribes a desire or preference to all patients that many simply do not have.⁵ Second, informed consent is descriptively inadequate because it requires patients to reason in ways that they have been shown not to. While everyone might, in some sense of the term, be capable of learning minimal medical knowledge, refining their predictions of their future preferences, and cultivating their ability to recognize they are in decision-making contexts, empirical studies indicate that patients do not have that knowledge, perform that reasoning, or utilize that perceptual skill. Hence, patients are not, in the main, capable of performing the Herculean task of assimilating medical information, reflecting on their personal values, and synthesizing these two sets of information in ways that an informed consent model guides them to.

The same reasoning undergirds objections against paternalism. Though most accept that paternalistic decision-making is appropriate in emergency contexts and triage, this is only because in these circumstances the patient's values are either inaccessible or irrelevant to the treatment in question. So long as it is assumed that the patient values continued living and hence being stabilized, then in emergency situations whatever is necessary to stabilize them should be done.⁶ In triage, the limited medical resources require higher-order reasoning about how to manage a population needing treatment, which entails that patient's values are immaterial to their treatment in such circumstances; what matters is simply whether, in light of the available

⁵ However, appealing to the tripartite interpretation of informed consent by Berg and coauthors, which is inclusive of shared decision-making, might overcome the model's descriptive inadequacy. This approach will be considered in the last section of this chapter (§ 2.5).

⁶ Yet, when a patient's values are accessible and relevant to treatment options in an emergent situation, then paternalism is justified only if it takes them into account. Thus, religious exemptions to blood transfusion – such as for Jehovah's Witnesses – are commonly understood to be justified in emergency circumstances (see Muramoto 1998a, 1998b, 1999 for an explanation of and rebuttal to this position, and Gohel et al. 2005 for a defense of it). Another example is refusal of CPR or carrying out Do-Not-Resuscitate (DNR) orders for patients with advance illness (Burns et al. 2003).

resources, it is medically possible to save them and doing so is a prudent use of resources in the circumstances.

Outside of emergency and triage situations, paternalism guides physicians to make medical decisions for their patients by first identifying what courses of treatment are likely to confer the most benefit to them and then, out of those options, which is also least likely to harm them. Thus, this approach rests squarely on physicians' competencies in discerning and balancing benefits and harms for patients requiring treatment. If physicians are capable of performing these discerning and balancing activities, which is an empirical question, then paternalism is descriptively adequate. However, if physicians are generally incapable of performing these activities, then paternalism must be altered to take this into account.

While this empirical question is one that remains open, there is some research that provides reason to believe physicians perform poorly on the activities of discerning and balancing benefits and harms for patients requiring treatment, when this is understood as doing so in a way that is specifically anchored to the values of a specific patient facing a treatment decision or evaluating a set of specific health outcomes related to their current health (*e.g.* Zulman et al. 2010). A recent meta-analysis of how accurate physicians and surrogate decision-makers are in predicting patients' evaluation of health states or treatment decisions noted that physicians are much worse than surrogates at making accurate predictions (Shalowitz et al. 2006). One study, for example, found that physicians paired with patients predicted their treatment preferences at just about a chance frequency, and moreover, that physicians themselves anticipated this response, with 59% ($n = 69$) doubting their ability to predict patients' treatment preferences accurately (Seckler et al. 1991).

Relatedly, many studies have examined the extent to which surrogate decision-makers make accurate predictions about patients' treatment preferences. Although surrogates differ from physicians in important respects and they have been shown to make more accurate predictions than physicians, we may nevertheless use their data as a proxy for physicians in order to further inquire about the descriptive adequacy of the paternalistic model of decision-making. These studies show that in some circumstances surrogates are quite good at predicting patient preferences. For example, in one study surrogates performed well when making predictions about patients' evaluation of relatively mild health states that were likely to follow from their current state, in a population of older patients, many of whom perceived themselves to be in poor health. Here, mild health states included limited memory impairment, pain, the current state of health, and miscellaneous mild symptoms. However, when surrogates were asked to predict patients' assessments of more severe states like being bed bound, having severe memory impairment, severe pain, or miscellaneous severe symptoms, their accuracy diminished significantly to a range of between 7-51% agreement with patients' reports (Fried et al. 2003). The meta-analysis summarizing this literature measured surrogates' predictive accuracy across 19 studies to be 68% and highly dependent upon the clinical context, and especially the temporal proximity of treatment options relative to current health states (Shalowitz et al. 2006).

Although there are a number of reasons to be cautious in response to this research, it provides a sufficient empirical foundation for assessing the descriptive adequacy of the paternalistic model of medical decision-making.⁷ As it relies on assumptions about physicians'

⁷ The reasons for caution are both empirical and conceptual. From an empirical point of view, there are important issues with study design and methods in much of the literature on surrogates' predictive accuracy (see, e.g., Johansson and Broström 2008). One that I take particular issue with is the fact that all of the studies examine subjects' responses to hypothetical cases, which is a far cry from measuring

abilities to discern and balance the benefits and harms of treatments, which I take to require anchoring these items in the specific values and preference of individual patients, and given that this seems to be a task that is at least not something physicians have not generally been shown to be capable of doing well, I conclude the model fails to be descriptively adequate until shown otherwise.

On this analysis, then, paternalism and informed consent may each be shown to be descriptively inadequate. On our formulation of normative adequacy, however, they fair just fine. Each model entails claims about how physicians and patients, as idealized agents, should make choices about medical treatment. Again, where they fail, however, is in accommodating certain important facts about patients captured in empirical studies. This has led a number of clinicians to argue for patient-centered approaches to medical decision-making (*e.g.*, Stewart et al. 2003; Charon 2001), the most well established of which is the shared decision-making model. The next section introduces this model of medical decision-making.

responses of physicians, patients, and surrogates in real time in an actual clinical reasoning context (such as in Cunningham et al., in preparation). Conceptually, the construct of “predictive accuracy” as a measure of surrogate and physician performance seems orthogonal to the real issue, which is whether decision makers are making good decisions for (incapacitated) patients. To get at this issue one must first define what “good” means, which is usually lacking in the current literature. It is not clear, for example, whether “good” should be measured against patients’ expectations of surrogates and physicians, patients’ expectations of their own abilities to predict their own preferences and values over time, or some other means of justifying one laudable value for establishing ‘accuracy’. As there is no *a priori* reason to think that some level of agreement between subjects is an adequate threshold for establishing “the good” it is simply unclear what to make of the reported values in this research. However, as on the paternalistic model of decision-making one might expect physicians behaviors to be quite high, this literature does suffice for inquiring about the descriptive adequacy of that model.

2.4 Shared Decision-Making: Medical Choice From a Clinical Point of

View

Many clinicians endorse these criticisms of the informed consent and paternalism models of medical choice. In response they have performed empirical studies of choice in the clinical context, leading them to argue for alternative models. The most well developed of these is the *shared decision-making* model of medical choice (SDM). This third model of treatment decision-making purports to suppress the assumption that decision-making in the clinical encounter should be seen as either a component of the informed consent doctrine or an instance of the paternalistic model. On this account, treatment decision-making is an empirical phenomenon that may be understood using scientific methods common to clinical research, and although *some* theoretical premises are required to construct hypotheses about the factors involved in the phenomenon of treatment decision-making, all of these premises are fallible and warrant empirical validation. Thus, this approach, characterized by what may be called *clinical decision science*, strives to test a number of hypotheses about physicians, patients, and their beliefs, behaviors, and interactions in the clinical setting.

2.4.1 *Shared Decision-Making as a Response to Informed Consent*

One of the central projects of clinical decision science has been to challenge the informed consent model of treatment decision-making, with empirical studies aiming to describe patients' preferences to see if they accord with the assumptions of that model. As previously discussed, the studies suggest that they do not; instead, empirical results suggest that a diverse range of patient preferences exists regarding whether patients prefer to seek information about their illness and whether they prefer to participate in treatment decision-making (Ende et al. 1987;

Deber et al. 1996; Stiggelbout et al 1997; Arora 2000; Levinson et al 2005). Early studies suggested that a majority of patients *do not want to be involved in decision-making*, though a majority of patients *do seek information* about their medical status and treatment options. One might think that this is a factor associated with the medical education of the patients in question, however, when physicians are patients, they too exhibit similar diversity in such preferences (Ende et al. 1990; cf. Klitzman 2007). More recent work has indicated that these two findings may be decomposed. A number of factors correlate with whether preferences for or against involvement in decision-making or seeking information are exhibited, such as: the severity of the illness, age of subjects, and socioeconomic status; (Gibson et al 1995; Puchalski et al. 2000; McKinstry 2000); whether mental illness is present (Hamann et al. 2003); and, whether patients exhibit trust in their physicians (Thom et al. 1999; Joffe et al. 2003; Kraetschmer et al. 2004). Thus, results from clinical decision science further affirm the view that irrespective of the theoretical soundness of the informed consent doctrine its fundamental descriptive assumptions are unsound.

One might argue that despite this, the informed consent model is still a useful model of how *ethical* treatment decisions ought to be made in practice, whether those assumptions are borne out or not. This hypothesis has also been tested by inquiring whether informed consent, as it is ideally explicated, is or can be employed in clinical practice. Studies indicate that as ideally explicated, the informed consent model does not appear to be instantiated in practice because clinicians do not follow the model (Joffe et al. 2001), or because there are systematic factors that serve as barriers to the model's instantiation (Rimer et al. 2004). Then, it seems that as a model of decision-making informed consent neither adopts empirically validated premises nor does it appear to be used in practice.

A strident defender of the usefulness (if not the validity) of the informed consent doctrine might contend that despite the conclusions of empirical studies, the doctrine would produce better treatment outcomes such as patient health or satisfaction, were it to be instantiated in practice and regardless of whether it ever is instantiated. Yet, this too has been studied by proponents of SDM. It seems that no matter which model of decision-making is first adopted, intervening to change the communication styles between physicians and patients has no effect on patient outcomes, which suggests that whether one opts for following an informed consent model of decision-making or another model does not impact patient outcomes (Edwards et al. 2004).

In light of results from this literature, it then seems difficult to accept the position that the informed consent doctrine is a satisfactory framework for characterizing treatment decision-making, because the doctrine makes false assumptions about decision-making, is not employed in practice, and its instantiation appears to be without effect. For those who would wish to work toward a better understanding of treatment decision-making, and ultimately toward interventions to improve the activity of making a decision in the clinical context, a dilemma becomes apparent. One must choose between redefining informed consent to fit medical practice or rejecting informed consent as a model of decision-making and constructing a new model for practice. In the main, those who argue for SDM choose the latter option. For example:

Shared decision-making must not be confused with obtaining informed consent from a patient. While ethical guidelines mandate informed consent, especially when a recommendation involves a potentially harmful intervention, shared decision-making goes several steps further. Beyond presenting the patient with facts about a procedure, shared decision-making is a process by which doctor and patient consider available information about the medical problem in question, including treatment options and consequences, and then consider how

these fit with the patient's preferences for health states and outcomes. After considering the options, a treatment decision is made based on mutual agreement. (Frosch and Kaplan 1999, 285)

There is significant consensus in clinical decision science that the SDM is an alternative to an informed consent model of treatment decision-making. Moreover, some hold that SDM is the only tenable model of treatment decision-making because informed consent has been shown to be an invalid description of decision-making in actual clinical encounters. If informed consent is the endpoint of a spectrum describing the decision-making process, then shared decision-making is a midpoint on that spectrum, and only processes that are described by the midpoint are actually observed in practice. As Elwyn and colleagues (1999) say, "Models of clinical decision-making in the consultation can be represented as a spectrum from a paternalistic model at one end, to the informed choice model at the other end. In between these is the model of shared decision-making." However, I believe that this view is not as sound as it appears because proponents of SDM have not sufficiently elaborated the normative foundations of their position.

2.4.2 Theory, Normativity, and the Shared Decision-Making Model

If the shared decision-making model lies on a spectrum between paternalism and informed consent, then it may be distinguished from them. Thus, it too may be analyzed with regard to its normative and descriptive adequacy. What makes the SDM descriptively adequate is its commitment to modeling the way patients and physicians make decisions by describing their actual behaviors, emotions, preferences, and reasoning. However, it is not clear that the SDM is normatively adequate. This depends on the extent to which the model entails normative claims for particular individuals who face particular medical decisions.

Given how proponents have described SDM, whether it satisfies the criterion of normative adequacy is unclear. The model appears to prescribe that treatment decisions should be made by persons who interact meaningfully during a “shared” process of making a choice. That is, patients and physicians should share information about the medical problems at issue, which includes patients’ evaluations of the problem and options for treatment and physicians’ recommendations. Yet, the most prominent proponents of SDM argue that this fails to be a *normative* model of decision-making, which presumably means that there are cases where the model will have no prescriptive force. And given the diversity of patients described by the empirical research cited above, there may be many such cases. This is why Charles and colleagues argue in a pioneering study of SDM that, “any attempt to define a single normative model of treatment decision-making which both physicians and patients ‘ought’ to follow might not fit with empirical reality” (Charles et al. 1997), which presumably holds for their model as well.

Yet proponents of SDM disagree about its normative force. This state of disagreement may simply be because the shared decision-making model has yet to coalesce into a single model accepted by discussants in the literature, as informed consent and paternalism have. This interpretation finds support from reflections by researchers working on SDM:

Shared decision-making is increasingly advocated as an ideal model of treatment decision-making in the medical encounter. Yet, it is by no means clear what shared decision-making really means or the criteria by which to judge what falls within or outside the boundaries of this model. (Charles et al. 1997)

The patient’s participation in clinical decisions is fostered by the legal doctrines of consent and informed consent and by the ethical process of shared decision-making. (Whitney et al. 2003)

The first quote acknowledges that SDM is an ideal model lacking clear boundaries, criteria, and definition. The second quote suggests that SDM is an “ethical process” that, when coupled with informed consent, fosters patient participation. These quotes indicate that what one commits to when invoking the SDM model is unclear. One may commit to a family of information procurement processes tied to informed consent. Or one may instead commit to a rejection of informed consent and an embracing of an empirically grounded model of treatment choice. Or one may commit to an underspecified ideal because it lacks theoretical boundaries, if it is a theory at all.

Most researchers working on the model accept that the SDM lacks precise specification (Makoul and Clyman 2006). To acknowledge this to recognize the need for articulating what would be required for SDM to be said to be a normatively (and descriptively) adequate account of treatment decision-making, and thus a fully satisfactory account on my analysis. The analysis performed here may be read, in part, as an attempt to provide a normatively adequate model of medical decision-making consistent with the SDM; however, SDM plays only a motivating role in what follows.

2.5 From One “Process Model” to Another

The aim of this work is to develop a model of medical choice that takes the context of medicine seriously. To explicate what this means, let us return to considering information consent. Despite recent theoretical and empirical challenges to the informed consent model of medical decision-making, it remains the received view. As we have seen, proponents of informed consent have traditionally emphasized its foundation in moral theory and legal precedent, rather than in decision-making in medical practice. Faden and Beauchamp, for example, are explicit

about this: “this book is not about the proper role of informed consent in medical care and reaserch [sic]. We do not provide an analysis of the desirability of participation by patients or subjects in decisionmaking, nor do we identify the conditions under which health care professionals and research investigators should obtain informed consents” (1986, vii). Thus a classic model of informed consent emphasizes the universal aspects of informed consent rarefied in moral-legal analyses of rights and obligations and conceptual analysis of autonomy, rather than decision-making in a uniquely *medical* context. Consequently, it is no surprise that on the classic model, *informed consent is not really about medical practice*, nor is it about medical choice in any direct sense. It is only indirectly about choice, and directly about the articulation, enshrining, and promotion of basic values of personal freedom and liberty (Berg et al. 2001, 22-24).

Nonetheless, informed consent remains prominent because of its ubiquitous clinical applications, a phenomenon that has itself been caused by physicians and hospitals adapting to evolving legal requirements for disclosure. But, though the informed consent model has remained the received view of medical choice, it has done so only by evolving too, by moving away from the abstract analysis of informed consent as “autonomous authorization” and toward a conceptualization of decision-making that better accords with what we know about the clinical environment. For example, in *Informed Consent: Legal Theory and Clinical Practice*, Berg and coauthors argue against what they call an “event model” of informed consent. Instead, they describe informed consent as a collaborative activity between physicians and patients, or a “process model” of medical choice, of which informed consent is an integral component. Both why they reject the event model and what they take it to be are telling.

Berg and colleagues see the event model of informed consent as “a relatively simple paradigm” where a patient seeking medical care is seen by a physician; after assessing the patient and formulating a diagnosis and treatment plan, the physician communicates this information to the patient along with information about other treatment options and the risks and benefits of considered actions. “Weighing the available data, the patient reflects on the relative risks and benefits of each course of action and then selects the medically acceptable alternative that most closely fits the patient’s particular values” (*ibid.*, 168). The main problem with the event model, they say, is that it artificially represents choice as a temporally circumscribed phenomenon. The event model assumes that choices are made when, and only when, diagnostic efforts have been concluded and treatment options crystallized. Moreover, it suggests that educating patients about their options – that is, *informing them* – is a “one shot” activity, to happen right before decisions are made and after all information has been procured and processed by clinicians. But, as Berg and colleagues recognize, empirical studies of medical choice suggest this is overly simplistic: decision-making is a temporally extended activity where patients and physicians routinely exchange information, shift roles, and trade responsibilities, all while making provisional decisions along the way that are revisited and revised up until treatment is finally selected and provided. Thus they contend, “a model of decision-making is needed in medical encounters that recognizes both the temporal complexity of medical decisions and the complexity of patients’ decisionmaking processes” (*ibid.*, 171).

I am sympathetic to the Berg analysis and its objections to the event model of medical decision-making (cf. Kukla 2005). I also agree that a process model is required: medical choice should be understood in a way that captures the complexities of modern physician-patient relationships with higher fidelity, including their temporally extended character and their

foundation in interpersonal communication. But I fear that the Berg view does not go far enough in its attempts to refashion informed consent. Consequently, I believe its sketch of the process model of medical decision-making is a move in the right direction, but a move that falls short.

The problem with the process model is that, although it states what would be required for decision-making to be understood as a process, it is silent as to *how* such an understanding of decision-making might be constructed. This is a problem because without specifying what it means to regard decision-making as a process, the model risks being as simplistic as the event model. Consider the following description of the process model's implications for information sharing and the physician-patient relationship. On the process model, information should be exchanged between physicians and patients "throughout the course of the physician-patient relationship," in a fashion called "mutual monitoring," where each party "monitor[s] the factors that are entering into the other's thinking at any given time" (Berg et al. 2001, 171-172). Doing this permits patients "to participate in decision-making in every phase of patient care," which is "a continual facet of all interactions and ought to be woven into the very fabric of the doctor-patient relationship" (*ibid.*, 174). The problem here is that it is entirely unclear how to interpret these statements in a literal sense. That is, it is unclear what the literal meaning of "mutual monitoring" might be, as the notion of being able to "monitor" the factors that are entering into another persons thinking is entirely opaque. Sure, metaphorically we may understand what it means to have a sense of what others are thinking, but in terms of providing concrete action-guidance to monitor the substance of others' thoughts, this approach to describing decision-making is insufficient. It does not make explicit what it would take to perceive the thinking of others in the suggested way, and hence, it must be silent as to how a patient or physician might

follow the model and monitor the thinking of their collaborator in choice. Likewise, though the Berg view does provide a simple taxonomy of the phases of patient care, it is similarly unclear what it means to claim that patient participation in decision-making ought to be “woven into the very fabric of the doctor-patient relationship.”⁸

It is not that the metaphors of “mutual monitoring” and the “fabric of” the doctor-patient relationship are without meaning, nor are they inapt; rather, it is that more is required in order for a process model of medical decision-making to truly compete with the event model of informed consent. In this work I endeavor to say more, to develop a model of decision-making that abstractly explicates processes that ought to occur when choices are made and that are consistent with what we know about patients and physicians.

In the next chapter I begin developing this model by defending a particular account of the conceptual foundations of medicine. In directly linking my normative model of choice to this foundation, I thus adopt a different strategy than theorists of informed consent traditionally do. I begin by explaining and justifying the understanding of medicine assumed by the model. Afterwards, I will then develop a model of choice for this uniquely medical context.

⁸ Mark Siegler (1979, 1981) offers a four-stage process model of physician-patient relationships that will be discussed in the next chapter, which is informative when thinking about how to develop a process model of decision-making.

3.0 THE BASIC AIMS OF MEDICINE

This thesis argues for an alternative process model of decision-making that does not exclude informed consent as *one* way to make decisions and includes many other possible processes of choice as well. To develop this model, in this chapter we begin by elaborating preliminary conceptual foundations for medicine (§ 3.1) and exploring their justification. In justifying those particular conceptual foundations for medicine, we will consider conceptual analyses of health and disease (§ 3.2), which others have taken to be the conceptual basis of medicine, and whether medicine should be understood as both art and science (§ 3.3). It will be argued that standard distinctions used to characterize the conceptual foundations are insufficient. Instead, the goals of fully understanding patients and intervening in the progression of states of ill health are better foundations for medicine (§ 3.4). Along the way, I will take pains to clarify the novelty of this proposal by defending the terms with which it is constructed and drawing attention to those with which it has affinity and those with which it does not. This includes arguing for a particular epistemic distinction between subjective and objective knowledge (§§ 3.5-3.6) and distinguishing my characterization of medicine in terms of its basic aims from other accounts of the epistemology of medicine (§ 3.7).

For instance, similar to the Berg view discussed in the previous chapter, the model proposed here takes seriously the claim that medical choices are temporally extended phenomena that emerge from interpersonal interactions. However, unlike Berg and coauthors,

and *pace* Faden and Beauchamp, my approach to elaborating this model will be to begin by considering the uniquely medical context within which these decisions occur. Thus, I take the fact that medical decisions are made *within medicine* as primary, and the fact that they have moral and legal features as secondary. This reversal of emphasis, I contend, draws attention to aspects of the phenomenon that are largely assumed among theorists of medical choice, but that have been left implicit. Because of this, an advantage of my account is that it makes these assumptions explicit, which opens them to criticism and analysis, rendering them corrigible.

3.1 The Basic Aims of Medicine

Over a four-year period in the early 1990s, the Hastings Center undertook an interdisciplinary international project to study the goals of medicine and create a consensus document summarizing its conclusions. The results of this project, which was motivated in part by a recognition that “there is no literature to speak of on the goals and ends of medicine, either new or old” (Hanson and Callahan 1999, ix-x), represent an important advance on our understanding of the conceptual foundations of medicine. A reprint of the project report and additional essays, *The Goals of Medicine: The Forgotten Issue in Health Care Reform*, contains a thorough consideration of the many goals and ends one might imagine being constitutive of medicine, various justifications for them, and arguments against them. It serves as a comprehensive starting point for our discussion of the basic aims of medicine, which will lead us to provisionally state two basic aims that will constitute the conceptual foundations of the model of medical decision-making under development.

The Goals of Medicine Report provisionally states four goals for medicine: “[1] the prevention of disease and the promotion of health, [2] the relief of pain and suffering, [3] the

treatment of disease and the care of those who cannot be cured, and [4] the avoidance of a premature death and the promotion of a peaceful death” (Hastings Center Report 1999, 19). In justifying these goals, the report considers the nature of foundational concepts in medicine (including health, malady, disease, illness, and sickness), medicine’s commitment to relieving pain and suffering, and the appropriateness of non-restorative interventions at the end of life. In its analysis, the report describes medicine as being both humanistic and scientific – as ideally being concerned with both understanding the causes of disease and the experience of illness.

By describing medicine as being fundamentally dualistic, as both technical and humanistic, the Goals of Medicine report captures an intuition often espoused by philosophers and other scholars of medicine, that medicine is at root dualistic, and in a sense that requires explication. Here and elsewhere one often finds scholars taking positions with regard to whether medicine is value-free *or* value-laden, whether medicine is science *or* art, whether medicine is concerned with promotion of health *or* treatment of disease, whether medicine aims to treat patients’ subjective feelings of illness *or* the causes of disease. The concern with these distinctions indicates agreement that medicine is fundamentally of two minds, so to speak. However, it reveals disagreement regarding what language best captures this basic duality. By stating the basic aims of medicine I attempt to capture this duality and to do so while justifying the language I adopt against alternative turns of phrase.

Suppose that the basic aim of medicine is *to understand and intervene upon a patient’s latent or pronounced illness*. This accords well with Edmund Pellegrino’s account in the *Goals Report*, that medicine aims at healing but healing requires understanding the patient as a person as well as understanding the causal structure of disease localized in a particular time and place, in a particular human being. As he says, “in its everyday clinical practice, the ends of medicine

are technically right and morally good decisions and actions made by, and with, the person who is ill...On this view, physicians do not determine the ends of medicine; it is their task to realize these ends in a specific clinical encounter with a particular patient;" moreover, "for this healing, technical knowledge is essential, but not sufficient. That knowledge must also be applied within the context of the patient's notion of health and well-being" (Pellegrino 1999, 63).

As stated, this basic aim of medicine is complex in at least two ways: it expresses an obligation to both *understand* and *intervene*, and to do so with regard to *latent* or *pronounced* illness. The first source of complexity captures the intuition that medicine is not merely about intervention; it is also about understanding illness, both as a means to the end of intervention and as an end itself. That is, one cannot intervene reliably without understanding; however, as medicine aims at healing, and healing often requires humanity, medicine also requires understanding as an end apart from a means of generating thoughtful interventions. The second source of complexity captures the intuition that medical practice is concerned not only with persons who are currently ill, but also those who are not ill, but for various reasons might be expected to be in the future. Thus there are preventative aspects of medicine aimed at latent illnesses and there are practices aimed at currently felt, or pronounced, illnesses.

Our supposition may, then, be decomposed into two parts, or two aims of medicine. One aim is then to *understand* a patient's latent illness. The other aim is to *intervene upon* a patient's latent or pronounced illness. These may be stated as:

Aim I: To fully describe the patient's condition objectively (in scientific terms) and subjectively (in personal terms).

Aim II: To treat the patient via means that are consistent with the patient's state of health, as defined in Aim I.⁹

So stated, Aim I captures two ways of *understanding* a patient by appealing to alternative ways of “fully” describing them, in objective, scientific terms and in subjective, personal terms.¹⁰ Including both ways of understanding in one aim captures the intuition that reducing medicine to mere scientific inquiry is insufficient, as it strips the practice of its emphasis on humanity and healing, which requires knowing the patient in personal terms. Yet it also captures the intuition that medicine without a scientific foundation is mere pseudoscience. As Pellegrino notes, technical knowledge is a necessary conceptual component of medicine, but it is not a sufficient one. Thus, both ways of understanding are required for medicine to meet the basic aim of fully understanding the patient’s illness (cf. Nordin 2000).

Similarly, reiterating this sense of understanding defined in Aim I in Aim II captures the intuition that while medicine is interventionist at its foundations, it is not merely interventionist, without context. Rather, medicine aims at interventions insofar as they are consistent with what is known about the patient. And to know the patient sufficiently well to warrant intervention

⁹ As stated, these aims might appear overly egocentric, with their emphasis on single patients, and by implication, single physicians. There are many instances in medical practice where this construction is evidently inappropriate, for example: the physician working in virology concerned with the impact and spread of viruses throughout a population of persons at risk of exposure; the obstetrician providing care for a pregnant woman and an unborn fetus; or, the family practice physician caring for husband, wife, and children while perhaps balancing different individual’s interests (such as in cases of confidentiality). One of the motivations for carefully unpacking and justifying the basic aims of medicine is to be clear about the non-dyadic nature of medical practice, and to ensure that the aims of medicine are sensitive to this. Thus, for the moment the tilt toward egocentrism should only be seen as provisional, to be revised as the meanings of the basic aims of medicine are fully developed and justified throughout this chapter.

¹⁰ The notion of “full” description will remain unspecified in this chapter, however, the aim of subsequent chapters will be to articulate what it means to satisfy this threshold, provided that the other components of the basic aims – defended here – have been accepted.

requires satisfying the demands of Aim I. Intervention is appropriate only when the patient's circumstances are fully understood, in both scientific and personal terms.

Notice that where the Goals of Medicine report came up with four aims I have instead articulated only two. The reason for this is that where it emphasizes concepts like disease and health, pain and suffering, care and cure, and concerns appropriate forms of end of life care, I have instead tried to use broader notions, including a patient's "objectively described condition" and "subjectively described condition," which I further summarize as the "patient's state of health." This chapter aims to justify my perspicacity while defending the language of the Basic Aims used here. To do so, we will consider a variety of *standard distinctions* that scholars have used in conceptual analyses of medicine. I will argue that while the move to understand medicine in fundamentally dualistic terms is not mistaken, the distinctions commonly employed to do so are mistaken, in that they fail to capture the conceptual foundations of medicine in a way that is consistent. In surveying this work and making this argument, I will defend my characterization of medicine as resting conceptually on two basic aims.

The plan of the chapter can now be described in more detail. The next section surveys a prominent area of inquiry in philosophy of medicine, on the concepts of health and disease and their usefulness as conceptual foundations of medicine. In this literature, we will find consensus that medical knowledge is *value-laden* in some sense. However we will also find a diversity of interpretations of this claim and a reliance on a number of other standard distinctions in arguments justifying them. Section 3.3 continues to examine how these distinctions appear in another prominent area of inquiry in philosophy of medicine, debates over whether medicine is science or art. In this debate, we see that those who question the scientificity of medicine make assumptions about its value-ladenness and objectivity. Yet, these

assumptions are often implicit and go unanalyzed. To critically examine them, we consider work in history and philosophy of science that provides a better understanding of objectivity, subjectivity, and appropriate roles for values in science (§ 3.4). This leads to a more nuanced account of how sciences produce claims that are objective in varying degrees and the ways such claims relate to values. Having developed this account, we then use it to justify the position that a distinction between objectivity and subjectivity suffices for capturing the conceptual foundations of medicine, whereas other standard distinctions do not (§3.5). We conclude by considering how objective and subjective claims appear in two examples of clinical practice (§ 3.6) by further clarifying the position argued for against a number of apparently similar accounts on the concepts of narrative and empathy in medicine (§ 3.7), and by looking forward to how the Basic Aims of medicine can be used as conceptual foundations for a new normative model of medical decision-making (§ 3.8).

3.2 Health and Disease

We begin our discussion of philosophical analyses of health and disease with a 1954 essay by pathologist and historian, Lester S. King. Like others who have worked on the topic since him, King analyzes the concepts of health and disease in terms of standard philosophical distinctions. He recognizes that in one sense the problem of how to define health and disease is an easy one: it is the problem of finding the right reference class. If only we had reliable perceptual capacities for identifying healthy persons in one respect or another, it would be easy to define the concepts. All that would be necessary would be to sample enough healthy persons, plot the appropriate values to identify statistical deviations from the normal range, and disease could be defined in terms of those deviations. Yet there are obvious problems with this approach. For

one, we have no such reliable perceptual capacity. Also, though bodies, brains, behaviors, and so forth may be measured and deviations from the norm discovered, there are no *a priori* reasons to select one area under a curve as abnormal and another as normal. Consequently, even if we could reliably identify health in terms of some value or set of values, we would lack grounds for a precise inductive measure of health. Given that biological phenomena arise in nature as particulars, and those particulars deviate from a statistically defined norm, we will lack a means for deciding which individuals are healthy merely by appeal to such a data set.

Lacking such an easy route for defining health and disease, King considers how these concepts are used in language. He finds that, “when we speak of health or disease, we use certain implicit values” (1954, 195). That is, for King, health and disease have evaluative aspects; they are “good” and “bad,” respectively. And this evaluative element is an ineliminable aspect of both concepts.

At its most basic, the evaluative aspects of health and disease can be found in the feeling of being well on the one hand, and feeling pain, suffering, disability, or illness on the other. These *feelings*, says King, can be captured most immediately through a patient’s subjective reports. He states that positive and negative states of awareness are “subjectively recognized although indescribable;” yet, although “these subjective impressions are essential...they are not entirely reliable” (*ibid.*, 195). To King, this is the moment where understanding health and disease requires appeal to yet another standard distinction, between *appearance* and *reality*. While patients may be aware of healthy or ill states, he says, this awareness is in-and-of-itself unreliable. Instead, another perspective is required in order to confirm a patient’s complaints or assessment of well being. That is, “to understand health or disease we must have some objective measurements in addition to the introspective account” (*ibid.*).

For King, then, to understand health and disease requires distinguishing between “factual” and “evaluative” bases, acknowledging a distinction between apparent health and disease and real health and disease, and accepting that subjective reports and objective measures are required to appropriately deploy both concepts.

In later work, other scholars have found similar complexity in the concepts of health and disease. Christopher Boorse’s examination of the concepts and response to critics is of particular importance. In a number of essays (especially 1975, 1977, 1997, and 2011), Boorse has argued for a “biostatistical theory” of health and disease, or BST. The target of Boorse’s criticisms are those who, like King, argue that there is an essential evaluative or normative component to health and disease. In this literature, the terms “naturalism” and “normativism” about health and disease have been used to refer to the Boorsian position and its opposite. Examining these views demonstrates the sorts of commitments that have been taken on the nature of health and disease, which provides insights on how to reconstruct the conceptual foundations of medicine.

3.2.1 *Naturalism About Health and Disease*

Over almost forty years, Boorse has described and defended the biostatistical theory of disease, which holds that health and disease are value-free concepts as they are found in medical theory. Medical theory, in turn, is defined in terms of *pathology*, “the scientific study of disease...based on anatomy, physiology, biochemistry, genetics, and other biological sciences” (Boorse 1997, 52). Health and disease can be defined through their inter-relation, where health is defined negatively in terms of the absence of disease according to the follow schema:

1. The *reference class* is a natural class of organisms of uniform functional design; specifically, an age group of a sex of a species.

2. A *normal function* of a part or process within members of the reference class is a statistically typical contribution by it to their individual survival and reproduction.
3. A *disease* is a type of internal state which is either an impairment of normal functional ability, i.e. a reduction of one or more functional abilities below typical efficiency, or a limitation on functional ability caused by environmental agents.
4. *Health* is the absence of disease. (*ibid.*, 7-8)

Important assumptions ground Boorse's analysis. One is that medical theory may be exclusively demarcated by reference to the science of pathology, which overlaps with various biological disciplines, yet is distinctly and uniquely focused on disease. Pathology "comprises whatever general principles about disease can be stated, plus descriptions of basic manifestations and recurrent types of pathologic reaction with whatever generality is possible, plus specific disease entities" (*ibid.*, 52). There is a certain patent circularity about defining disease in terms of pathology, and then pathology as whatever general things are known about diseases, pathological reactions and manifestations, and the entities that relate to them. Yet, to merely attack BST on the grounds of circularity would be to miss its usefulness, to ignore what it gets right in its analysis of health and disease (cf. Schaffner 1999).¹¹ As Boorse says, "any process causing cellular dysfunction, no matter how local, is pathological" (Boorse 1997, 46). The pathologist's conception of disease, or "the theoretical level where pathologists operate" (*ibid.*, 45), is one concerned with the breakdown of organs and organ systems, which can be characterized in exquisite resolution at the levels of cells and macromolecular structures. Thus,

¹¹ Moreover, Boorse recognizes and defends the circularity of his analysis as it has been demonstrated by various critics (1997, 16-23). His response is to move away from an analysis of "health and disease" and to one of "normal and pathological." Yet, if this move is accompanied by a move to smuggle "disease" in as a means for defining pathology, then the circularity recurs in a way that he does not appear to appreciate.

Boorse should be understood not as saying that pathology is the study of various aspects of diseases, but rather that it is the study of ways that organs and organ systems can malfunction, where malfunctioning is defined by decomposing organs or organ systems into their component parts and where those parts are expected to perform certain ways and in certain arrangements under various conditions.¹²

In addition to assuming that medical theory is exclusively defined by appeal to pathology, BST assumes that pathology is *value-free*. As Boorse notes, critics of BST have argued vigorously against this view.¹³ We will touch on some of these criticisms below, in discussing how some have defined health and disease as *value-laden* concepts. At the moment it is important just to be clear about the sense in which Boorse takes BST to be value-free.

In his reconstruction of the BST position and response to critics, Boorse makes an important concession on this front. At times he refers to his *analysis* as value free as in, ‘the BST is value free.’ In other moments he refers to the *concept of disease* as value free, as it is defined by BST. And at other moments he refers to *science* as value free, in the sense that the science of pathology is value free. Distinguishing these is important because one may agree

¹² My characterization of Boorse here suggests that his position might be rendered in a more favorable light if it was reinterpreted using terminology and concepts defended by neo-mechanistic philosophers of science (e.g., Machamer et al. 2000; Bechtel and Richardson 1993). As such, pathology could be described as concerned with discovering and explaining certain types of biological mechanisms and their characteristic ways of failing to function. Doing so might permit BST to be described such that functions are defined less in terms of species typicality in the statistical sense that Boorse uses and more in terms of mechanism typicality based on startup conditions, termination conditions, and the entities and activities that bring the former state to the latter, irrespective of the type of organism that is instantiating the mechanism or the typicality with which a mechanism type occurs in species or other evolutionary unit. Similarly, an internal state could be defined as any entity or activity residing within an organism’s external boundary (e.g., epidermis for humans) that engages in a mechanism. Developing this insight, such as it is, lies beyond the scope of the present work.

¹³ This is such a common criticism against BST that it has produced its own wide-ranging literature. For example, see essays in a number of anthologies, including Caplan et al. 1981, 2004; Humber and Almeder 1997; Hanson and Callahan 1999.

with Boorse that pathology is value-free but disagree that the concept of disease is. Or one may think the BST analysis is value-free and hold nevertheless that pathology or the concept of disease is value free (or both). Other combinations are also possible. The point is that depending upon how one interprets Boorse's claim of value-freedom, one may be disposed to argue for or against BST from different points of attack.

In light of Boorse's overarching analysis, it seems fair to say that he takes the concept of disease to be value free, insofar as it is defined in terms of the concept "pathological," which he takes to be value free in that it is defined in terms of the basic science of medicine, pathology. However, Boorse does not adopt the strongest possible view with regard to what it means to be value-free. In his subtler moments he interprets the property of being value-free in a relative sense, as merely being *as value-free as* certain paradigmatic sciences. Thus when he contends that pathology is value-free, he means only that pathology is as value-free as sciences like "astrophysics" (*ibid.*, 56-58, 75). Boorse clearly states his belief that physics is completely value-free, though he does not elaborate on just what this means. Rather, he explicitly leaves open the possibility that if a cogent analysis in philosophy of science renders physics value-laden in some way, he will accept that the result spreads to pathology. What is important is that pathology does not require appeal to human values, desires, preferences, etc. in order to fashion its results. What makes a condition pathological "has nothing to do with how an individual patient views it or how it affects his life activities" (*ibid.*, 46).

Many have criticized BST for its failure to apply to *clinical* medicine as opposed to medical theory. Yet it is clear why this is the case. Unlike the Goals of Medicine report, which described people who "turn to medicine" and patients who bring their injuries and subjective experiences to doctors (Hastings Center Report 1999, 26), Boorse's analysis is focused on the

allied sciences that make up medical theory. BST does not cover the personal sentiments and relationships that are the foundation of medical practice. The BST is about theory, not practice.

Yet Boorse is upfront about this potential weakness of BST, though he contends it is actually a strength. Boorse agrees that clinical medicine is more than just applied biology or more than just applied pathology. But that does not mean that the correct conceptual analysis of health and disease should hold that those concepts are clinical concepts rather than theoretical ones. Indeed, Boorse argues that “treatment of a condition is neither necessary nor sufficient for it to be a disease” (1997, 92). Doctors treat fertility, pregnancy, normal aging, and so forth, yet these are normal human conditions, not diseases. That they are not diseases does not preclude them from being appropriate for medical treatment. Likewise, that they are often treated does not make any of them an appropriate candidate for being called a “disease.” That BST makes this distinction possible is one of its major strengths:

BST...provides a theoretical, value-free concept of disease or pathological condition. But on this foundation one can build value-laden disease concepts, by adding evaluative criteria to taste. Starting from the basic disease concept, one can define clinically evident disease, or harmful disease, or serious disease, or treatable disease, or disabling disease, or disease that should be covered by insurance, or disease that should remove civil or criminal responsibility, and so on...[O]ne can use different “disease-plus” concepts for different purposes (*ibid.*, 100).

In order to make the BST a clinical concept, one must provide an additional analysis; one must argue for appropriate evaluative criteria that are consistent with the clinical context.

Boorse’s biostatistical theory of disease is useful because it comprehensively describes one of the three available positions on offer for characterizing the conceptual foundations of medicine in terms of health and disease. As will be discussed at length below, I am suspicious of BST’s reliance on a “value-free” conceptualization of both pathology and the concepts of

health and disease, because work in history and philosophy of science suggests that the concept of “value-free” science is a red herring. Values play many different roles in science, some of which are more appropriate and some of which are less. But there is no such thing as literally value-free science.

Despite my suspicions, however, I agree with Boorse that there is a certain usefulness to demarcating the concepts of health and disease as they appear in “medical theory” from their uses in clinical practice. However, I believe that restricting medical theory to the domain of pathology is unjustifiable. Other scientific domains of inquiry are important for medicine, especially clinical medicine. For the moment I leave open the question of whether medical theory can be so defined. Later, in § 3.7.3, I will conclude that it cannot be. But I will also adopt a broader view of “medicine” that necessarily includes medical practice, so my thoughts on this will not be formulated as a direct response to Boorse’s account.

In order to ground my account, it is also important to consider the other two available positions for characterizing health and disease, *normativism* about health and disease and a *hybrid view* that takes these concepts to have both objective and subjective elements and hence to be inextricably and simultaneously value-neutral and value-laden. Afterwards we will analyze the meaning of value-ladenness and related distinctions, including science and art, subjectivity and objectivity.

3.2.2 Normativism About Health and Disease

Analyzing health and disease has become a cottage industry of sorts. Boorse has steadfastly defended the view that health and disease are value-free concepts, appropriately analyzed in terms of normality and pathology, with specific reference to medical theory and the science of pathology. But despite being a touchstone for discussants in the field, few if any scholars agree

with him. By far, the received view is that health and disease are value-laden concepts. Yet just what this means differs considerably between authors and threads of the debate. Some, like Joseph Margolis (1976, 1971) analyze those concepts in terms of formal distinctions about the properties of value propositions compared with factual propositions. Many others challenge Boorse's emphasis on the scientific aspects of medicine and concomitant de-emphasis of its humanistic aspects, a challenge which takes on many different forms (e.g., Engelhardt 1975; Kass 1975; Siegler 1981; Whitbeck 1981; Clouser et al. 1981; Fulford 1989; Reznik 1987; Nordenfelt 1987, 2007; Sade 1995; Cooper 2002). Others find fault with the BST's reliance on and characterization of an evolutionary account of functions (Engelhardt 1976; van der Steen and Thung 1988; Lennox 1995; Ereshefsky 2009), which has lead some to argue for other means of providing an objective foundation for the concepts of health and disease (Lennox 1995; Sade 1995; Schaffner 1999). More recently, Boorse's assumption that pathology is value-free in the sense required for his analysis has been questioned (DeVito 2000; Ereshefsky 2009).

Respondents to Boorse's analysis agree it is flawed, yet they locate its flaws in different places. Consequently, work on the concepts of health and disease has splintered into a variety of subsidiary questions, including whether the work is even worth doing at all (Hesslow 1993; Nordenfelt 1993). Among the many offshoots that can be distinguished, however, one question has received the most attention, often with different scholars interpreting it differently depending upon how it relates to the subsidiary question of the moment: given that an *evaluative consensus* has emerged, almost everyone thinking about health and disease wonders how to make sense of the view that these concepts are value-laden. Three routes have been popular for answering this question. One is Boorse's, to deny it. Another purports to ground health and disease in subjective evaluative experience, where personal values and norms are

necessary (but not sufficient) components of these concepts. A third route argues that objective values or norms are necessary components of health and disease concepts.

Having considered Boorse's account in detail, we now consider the latter two accounts. Afterwards, I identify consensus between them in the claim that if medicine is viewed as fundamentally practical as well as theoretical, then its conceptual foundations must be value-laden.

3.2.2.1 Subjective normativism

So called “normativist” accounts of health and disease contend these concepts must be understood in terms of subjective evaluations, meaning personal assessments of the value or disvalue of states of illness and wellbeing. In its purest form, subjective normativism is the view that the concepts of health and disease are defined solely in value-laden terms, that is, in terms of subjective assessments of value or disvalue. In order to make sense of this position it would be necessary to unpack the meaning of difficult terms like “subjective assessments” and “value-laden.” For the moment we will delay that analysis and instead simply canvas some instances of how those and related terms are used in health and disease debates. In Sections 3.3 and 3.4, we will directly take on the task of examining objectivity, subjectivity, and value-ladenness.

H. Tristram Engelhardt is often interpreted as articulating a pure form of (subjective) normativism in his many writings on health and disease (cf. Boorse 1997; Ereshefsky 2009). Yet his view is more complex than that. Rather than see disease and health as purely evaluative notions, he argues they are multifaceted, having both descriptive and normative content. In early work on the subject, for example, Engelhardt states, “the concept of disease acts not only to describe and explain, but also to enjoin to action. It indicates states of affairs as undesirable and to be overcome. It is a normative concept; it says what ought to be done” (1975, 127). The

concept of disease, then, has both descriptive and normative aspects, in that it performs both explanatory and action-guiding roles. Later in this piece, Engelhardt elaborates, claiming that diseases are multifactorial, meaning that they are psychological and sociological as well as biological and pathological. They are also moral: “the concept of disease has fuzzy borders with moral concepts” (*ibid.*, 137). So Engelhardt claims that disease has both normative and descriptive aspects; “disease” is not a purely evaluative concept.

Others come closer to a pure (subjective) normativist account. Fulford argues that disease and health are ‘value terms’ and provides an analysis of disease where all medical terms are based on evaluative assessments in some sense. His analysis of the term “kidney” is illustrative. A kidney, says Fulford, has the function of removing waste products from the body, which might be taken as a purely descriptive definition of the organ’s function. However, that would be mistaken, he says, “for how is the term ‘waste’ to be defined without introducing a value judgment?” Fulford concludes that “the value judgment, ‘bad kidney functioning’ has then not been defined descriptively, but in terms of another value judgment, ‘waste’” (Fulford 1989, 51).

Fulford’s account appears to be a pure normativist account, in that it locates the foundations of concepts of health and disease in value judgments. But it is incomplete because Fulford does not provide a theory of value (Schaffner 1999). He does not make clear whether the value judgments on which definitions of concepts and terms like “kidney” rest are judgments of individuals, societies, or Laplacean demons. Thus, though Fulford offers a normativism of a sort, because he does not describe the source of evaluation it is not clear his view amounts to subjective normativism.

More recently, Sade (1995) and Cooper (2002) have argued for positions that at times appear to move even closer to a pure form of subjective normativism. Cooper's account takes the strongest position, as she argues that whether something is a disease depends necessarily upon whether a specific individual disvalues it. Thus, whether something is a disease depends on an evaluation by the bearer of the state of illness. Consequently, a disease or pathological state in one person may not be a disease or pathological state in another:

I am suggesting we should think about diseases in a way analogous to the way in which we think about weeds. A plant is only a weed if it is not wanted. Thus a daisy can be a weed in one garden but a flower in another, depending on whether or not it is a good thing in a particular garden. This claim, that one and the same condition can be pathological for one person but not for another, may initially seem counter-intuitive. (Cooper 2002, 274-275)

We need not explore how Cooper justifies this counter-intuitive claim because she argues that three criteria must be met for something to be a disease. Since one of them is that “for a condition to be a disease it must be such that it could potentially be treated by medical science” (*ibid.*, 277), Cooper requires that for something to be a disease it must be describable in medical-scientific terms, insofar as it must at least “potentially” be the sort of thing a practitioner of “medical science” would treat. Just how Cooper intends to integrate what appears to be a radical relativist criterion on the one hand and a reference to scientific understanding on the other hand remains unclear, as it pertains to a *definition of disease*. It is doubtful her third criterion of a disease state being viewed as “unlucky” will help. Yet she is in good company in holding that the concept of disease has both subjective, evaluative aspects and scientific aspects, as this is a common result from normativist accounts of health and disease.

Many cite Joseph Margolis as espousing a paradigmatic version of normativism about health and disease in his 1976 article in the *Journal of Medicine and Philosophy*. Yet I see his

position very differently. I believe it too is another impure form of normativism, in that it sees medicine as resting on fundamentally dualistic conceptual foundations rather than solely on subjective evaluations. Like those who have come after him, Margolis argues that the conceptual foundations of medicine contain both evaluative and descriptive aspects, that both are necessary, and that neither is sufficient to capture the foundations of medicine.

For Margolis, understanding the concepts of health and disease depends upon “how we understand the nature of factual and value judgments, norms and normality, and the functioning of organs, organisms, and human persons” (1976, 239). Basing his analysis on his own account of the formal and substantive differences between evaluative and descriptive propositions (Margolis 1971), Margolis holds that ascribing states of health and disease requires both types of language. Moreover, he contends that descriptive language – namely, factual ascriptions – are supported by vast networks of norms, norms that are generally uncontentious and agreed upon, regarding what states are worthy of rigorous inquiry and explanation. Thus, “the concept of disease...makes no sense without reference to appropriate norms” (Margolis 1976, 243). And those norms arise from the difficult and complex human work of producing functional ascriptions in the biological and related sciences. Making functional ascriptions requires some appeal to human interests, even if only very distally for codified concepts in pathology that are often based on universally accepted dysfunctional states, such as the state of cardiac arrest. Other functional ascriptions are more contested. In such cases, Margolis suggests a procedural approach grounded by reference to decision-theoretic concepts echoing a Rawlsian account of fairness:

[A] fair way of proceeding [in ascribing function] is to confine ourselves to what may be called rational minima, that is, constraints regarding normative matters, including norms of health and disease, that are *least controversial or*

objectionable to agents endowed with a minimal measure of rationality more or less presupposed by every significant human society” (*ibid.*, 251; italics added).

On Margolis’ view, then, the normative scaffolding for disease ascriptions is laid bare; and, moreover, an alternative norm for ascribing functions (and therefore dysfunctions) is suggested.

Margolis articulates a normativist account that, like others, does not succumb to a purely subjectivist account; but unlike others, his nevertheless makes clear disease and health are based on values. Some of the values, however, are entailed by the activity of ascribing functions, and are in this sense epistemically far prior to the personal context of ascribing a particular disease state in a particular patient. Rather, they are operative at moments far removed, when researchers and the institutions they work within privilege a project and thereby select activities resulting in contributions to the scientific activities that result in ascribing functions to parts of human bodies, brains, and behaviors.¹⁴

It is in this sense that Margolis’ account should be understood as normative. We should be mindful of his conclusion that medicine is thoroughly dualistic, but do so without ascribing to him the view that medicine is founded on a thoroughly subjective normativism. To Margolis, “medicine is ideology restricted by our sense of the minimal requirements of the functional integrity of the body and mind (health) enabling (prudentially) the characteristic activities and interest of the race to be pursued. And disease is whatever is judged to disorder or to cause disorder, in the relevant way, the minimal integrity of body and mind relative to prudential functions” (*ibid.*, 252). We can agree with him that “medicine is a doubly normative discipline”

¹⁴ Understanding Margolis in this way better captures his sympathies with contemporaneous philosophers of science working on the legitimacy of values in science (see McMullin 1982) than the common interpretation of his position as being pure subjective normativism about health and disease.

(*ibid.*, 242), in that it rests on appeals to putatively universal, abstract, and idealized functional ascriptions *and* functional ascriptions for which their universality, abstractions, and idealizations remain open questions of varying degrees of contention and controversy. We can agree that the descriptive aspects of medicine rest on distant evaluations. And we can also accept his proposal to ferret these out and only permit them if they are grounded in a “prudential” process of the sort he gestures at when appealing to rational minima and least controversy. If we accept this interpretation of Margolis’ view, then we understand medicine to rest on descriptive and normative foundations. However, we also accept that it is possible, though controversial, to thus consider medicine to be thoroughly normative but not *subjectively* normative. Not all norms are personal, subjective evaluations. Norms may also be the result of objective processes or objective means of inquiry. Thus there may be objective norms and these may be integral to the conceptual foundations of medicine, whether or not subjective evaluations are too.

This consideration of so-called “subjective” normativism reveals that no one adopts the view in its pure form. All who have made an effort to carefully analyze health and disease concepts and have espoused some form of normativism agree the concepts rest on both descriptive and evaluative elements. Some, like Engelhardt (1975) and Cooper (2002), appear to claim that subjective, personal, and moral evaluations are necessary but insufficient components of health and disease concepts. Others, like Margolis (1976), Fulford (1989), and Sade (1995), hold that there is a sense in which the descriptive foundations are also based in (perhaps distant) evaluations, which may or may not be the direct result of individuals’ evaluative assessments. Thus, in considering this line of inquiry, we have returned to King’s view with which we began, that to speak of health and disease is to marshal implicit values, and that some of these values

are subjective assessments while others are based on the privileging of some objective measures over others.

Another line of reasoning about concepts of health and disease is tenable. In the 1990s, James Lennox (1995) and Kenneth Schaffner (1999) both argued for what have been called “hybrid” (Ereshefsky 2009) or “objectivist” (Sade 1995) accounts of health and disease. Since both authors contend that these concepts are inextricably value-ladden, we will continue to refer to them as arguing for a type of normativism, however, it is one that reconceives of norms as the results of objective processes. Hence, they provide an objective normativist account. Considering it will conclude our discussion of health and disease, having learned from it that there is considerable agreement to be found in this debate on the conceptual foundations of medicine, which is informative for our aim of justifying the Basic Aims of medicine introduced above.

3.2.2.2 Objective normativism

Responding to Boorse’s account, Lennox argues that Boorse erroneously assumes his position results in a value-free analysis of health and disease. Rather, noting that terms like “health” and “disease” require reference to “successful functioning,” which itself is a normative judgment “requiring standards of value,” Lennox argues Boorse “supposes that this apparent appeal to values is actually only an appeal to a concept of 'statistically normal functioning for a class'. This is reductionist in the sense that it reduces the apparently evaluative basis of medical judgments to statistical judgments - sick people are merely statistical outliers” (Lennox 1995, 500). Against Boorse, Lennox argues in a similar vein to Margolis, holding that in some sense evaluations underlie biological claims about health and disease. So he contends that Boorse’s reductionist move is untenable because it fails to appreciate the values at the foundation of

biological assessments of function and dysfunction. Yet taking a different tack than Margolis, Lennox contends biological values are objective, in the sense that they have discoverable empirical bases. Going into some detail, Lennox gives the following argument.

Lennox first rejects the view that values are based on subjective evaluations or, in his words, “a commonly held view of value concepts as modes of expressing human emotional attitudes toward various states of affairs” (*ibid.*, 502). Defining his biologically informed account of value, Lennox continues:

Certain differentiating features of life form the empirical basis for a certain class of value concepts, and thus provide them with objective validation. Specifically, the continued existence of a living thing is dependent upon its continuous performance of a species-specific and determinable set of functions within a certain determinable range. Unlike other changes, such functions are distinguished by reference to their goals. But it is of the essence of life that these functions may or may not be successful in achieving their goals. The most fundamental value concepts are based on that simple fact: any living function may, judged by the standard of their agent's life as its goal, be a success or a failure. 'Health' is, I am claiming, one of this class of value concepts. It refers to that state of affairs in which the biological activities of a specific kind of living thing are operating within the ranges which contribute to continued, uncompromised living (*ibid.*).

Ultimately, Lennox argues that the basis of a biologically informed standard of value lies in the “fundamental alternative faced by living things,” which is life or death; “the standard by which one judges whether biological function is appropriate is, therefore, life” (*ibid.*, 506). Attribution of health is objective insofar as it is the attribution of a state or function’s contribution to continued unencumbered life.

Consider an example given by Lennox, the case of the relationship between elevated cholesterol levels and cardiac arrest. Here, he says, we are interested in cholesterol levels not because they are typical of the species, as BST would require, but specifically because they are

predictive of malfunction, of arrest, and of death. Lennox's account thus redirects our attention to the role of positive definitions of function in concepts of health and disease. Knowing how the circulatory system contributes to a person's persistence is integral for understanding why measuring cholesterol levels is important for providing care. Regardless of whether a specific range of measurements is statistically normal or not for certain people, certain values within the range are predictive of poor functioning.

Lennox's view elaborates upon an important weakness of the BST that others have noticed but have not challenged in quite the same way. By emphasizing that biological notions like "life" are value-laden, he demonstrates that the BST errs if it presumes that claims about pathophysiology (of the circulatory system for example) are completely value-free. Rather, such claims require appeal to standards of value, by which different systems' success or failure is evaluated, and hence, abstract models of various degrees of well- and poorly-functioning systems are elucidated.

Lennox's view has provoked a number of responses. Some argue it too errs by requiring that for a value to be "objective" in the necessary sense, it must be "true that one must always have that value" (DeVito 2000, 547; cf. Sade 1995). They note that there are many reasons to think that values are context sensitive, and thus, that values will not be sufficiently universal to be objective; consequently, they say accounts like Lennox's fail. For example, kin selection suggests that at times organisms will die to protect kin from harm, especially if the kin are numerous or intimately genetically related (DeVito 2000).

While this is true, it is a poor response to Lennox's view because Lennox does not hold that for values to be objective they must be universal in this sense. For Lennox, an objective value is merely one that has universal *significance*. However, one may choose to disvalue it or

to value it, and consequently one may choose to perform actions that are contrary to objective values. Thus the universality of such values is unrelated to whether they apply always and everywhere, such that choices to act contrary to them cannot be made. Rather they are universal in the sense that if one chooses to disvalue them, then any actions following from that choice will have empirically measurable consequences, namely death (Lennox 1995, 506).

Yet something is amiss in Lennox's account: it does privilege one fundamental value over all others, the value of "life." Presumably, this means that life should be understood in evolutionary biological terms, such that what fundamentally matters to all organisms is survival and reproduction. However, like other organisms, humans have various interests and goals; thus, although from an evolutionary biological point of view these may be reduced merely to their effect on biological fitness, from a point of view that includes additional perspectives than simply that of evolutionary biology there is more to life than fitness (Ereshefsky 2009). Thus despite his aim to counter Boorse, Lennox's seems to make one of the same mistakes he does, which is to assume an unwarranted reduction from the many goals and interests humans may legitimately have – and which may legitimately be analyzed from a number of empirical standpoints – to a very circumscribed set of goals, survival and reproduction.

Ken Schaffner proposes another approach for crafting an objective normativism that purports to skirt the issue of unwarranted reduction. Unlike Lennox, Schaffner is explicit in adopting Boorse's BST, which he says has a "certain elegance and plausibility" (1999, 367). But he aims to add "a 'minimalist' value theory" to it, which adds the missing normative aspect others argue is needed (*ibid.*, 368).

Schaffner locates the missing value theory in a confluence of biological and ethical theses. From Hume, Schaffner adopts the view that human sociality provides a foundation for

moral theory, in that reflecting upon our sociability provides a means for understanding how reason and emotion relate in moral matters. "The relations among reason and emotions or sentiments in Hume are multifaceted. Though morals appear dependent on empathy and sympathy with one's fellow beings, socialization within the family plays a significant role. Reason both can correct sentiment...as well as be integral to the matter of moral justice" (*ibid.*). Schaffner also draws on a common core found in proposals by subjectivists such as J. L. Mackie and contemporary emotivists like Allan Gibbard in crafting his theory of value. This common core amounts to a sociobiological claim, about the extent to which evolutionary forces could result in selection for individual- and community-level values. Starting from some innocuous assumptions common to game-theoretic models of human evolution, Schaffner concludes that cooperative behavior is likely to have been selected for. Moreover, "the cooperative behavior will be grounded in dispositions to behave cooperatively with other humans, that *from a subjective, motivational point of view*, will be seen as *sentiments*, including those of sympathy, empathy, and benevolence" (*ibid.*, 370).

The normative element Schaffner adds to BST is that a collection of dispositions may have been selected for to feel sentiments like sympathy and empathy, and to behave in ways that follow from them. Thus, we might say that a moral sense (a collection of these sentiments) may itself have been selected for by evolutionary pressures for social beings such as ours (see Joyce 2006 for a thorough exploration of this possibility). If we assume that individuals with such dispositions are more evolutionarily fit than competitors, then those dispositions can be seen as consistent with the BST. Normal functional abilities, so defined, include sentiments. But, as Schaffner notes, "these sentiments are also moral or evaluative notions, and thus can be

the basis of a prescriptive or valuational element in a now modified and extended Boorsean account” (*ibid.*, 371).

Without going into detail about the plausibility of the “just-so story” Schaffner tells, which he recognizes is too sketchy for the weight he places upon it, we may draw an important lesson from his account: though Boorse purportedly argues for a value-free account of health and disease, there is yet another route to recovering value within it. One may adopt a strictly “scientific” account of medicine-as-pathology and yet still examine the pathological ways in which humans may behave socially and morally.¹⁵ At a certain point, these “dysfunctions” may be so well described scientifically that they are consistent with the BST account of disease; hence, one may be diseased in ways that are perfectly suited to moral discourse, to description in emotive, social, ethical, and moral terms. If so, then it is not at all inconsistent to place moral considerations *within* the biostatistical theory.

However, just *how* this is accomplished remains an open question. Although Schaffner (1993) has written at length about the multi-level nature of biomedical explanations, providing case studies to show how knowledge is integrated across levels of scientific inquiry, he has not provided as much detail in developing an account of how explanations of human sentiments might be integrated with such information. We will also not attempt to develop such an account here. But we will seek to put forward a cogent and reasonable account of how to integrate

¹⁵ This reasoning suggests the importance of the concepts of health and disease in the specific contexts of *mental* health and illness. Just as with the concepts of health and disease more generally, this topic has been covered in a wide-ranging literature (e.g., Szasz 1974; Kendell 1975; Wakefield 1992a, 1992b; Radden 1994; Zachar 2000; Murphy 2006; Thornton 2007). The present aim is to consider conceptual analyses of health and disease as a means of arguing for certain conceptual foundations for medicine, rather than to argue for a novel account of those concepts. Thus, I set aside the important issues that arise when considering health and disease in psychiatric or psychological contexts and hope that they are adequately covered by the Basic Aims of medicine I set forth, regardless of the extent to which the Basic Aims are illuminated by, or illuminating for, debates about the cogency of mental health and illness.

moral, ethical, and evaluative discourse on the one hand with scientific discourse on the other hand, as this is a common feature of decision-making in medicine. That is, given the evaluative consensus that the conceptual foundations of medicine – in notions of health and disease – are in some sense “value-laden,” this suggests that decision-making too will be value-laden in some sense. It behooves us to endeavor for more clarity regarding what this sense of “value-ladenness” might amount to.

3.2.3 *From Health and Disease to Theory and Practice*

Conceptual analyses of health and disease have resulted in a consensus, namely that there is a certain *duality* in medicine. Medicine can be understood narrowly in terms of pathology or broadly as encompassing all scientific inquiry including, say, a science of the sentiments. Medical theory is defined by appeal to scientific terms, models, and theories. However, medical practice is defined, at least in part, by appeal to personal terms, the shared language that patients and providers must use when discussing illness before it has been rarefied in the clinical language of disease. It may be, as Margolis suggests, that “the clinician operates with the pathologist’s categories” (1976, 244), but she does not do so to the exclusion of other ways of understanding. Rather, medical practice requires understanding patients by listening to the ways that they speak, to the terms they use and are comfortable with. In this sense, medicine is fundamentally dualistic: it requires adopting a scientific mode of understanding and a type of understanding that is grounded in colloquial, personal ways of speaking. Medicine requires *both* theory *and* practice; thus it requires both of these ways of understanding.

Like Schaffner, I agree that something like the BST account of disease is required to characterize one aspect of medical epistemology. A rich scientific language grounded in empirical investigation is a necessary component of medicine. Yet I also agree with him that an

account of the personal, social relationships that occur when humans experience illness and share those experiences via verbal and extra-verbal means is a necessary component too. Indeed, the right conclusion to draw from our survey of work on the concepts of health and disease is that everyone else agrees with this claim too, in the abstract. Participants in these debates agree that when medicine is taken to include both theory and practice it must be analyzed in terms of descriptive and normative aspects. But disagreement persists regarding how to do this. One option appears to be to adopt Schaffner's approach, to look for an objective basis for normativity in a scientific account. Another option is to look instead at the "art" of medicine, the clinical encounter, and to hold that it is primary to medicine's scientific aspects and the proper location of the personal conversations that are the foundation of medicine. Doing so would be to follow Margolis, who argues that "medicine is primarily an art and, dependently, a science: it is primarily an *institutionalized service concerned with the care and cure of the ill and the control of disease*, in facilitating which certain purely descriptive and causal inquiries are pursued" (*ibid.*, 241-242; italics in original).

Adopting a dichotomous distinction between medicine-as-art and medicine-as-science is a perennial move in philosophy of medicine, which cleaves across debates such as those about health and disease. However, it is also a distinction that is appealed to exactly when such debates appear to have reached their deepest moments of collective intransigence. For this reason, we will look at this common epistemic distinction in some detail. In doing so, we will see how some of the standard distinctions that are common in work on the concepts of health and disease are also actively used in debates about the scientificity of medicine. We will find that discussions of issues of the value-ladenness of medicine, medicine's concern with subjective experience, and the extent to which medical theory is about particular persons are

more pronounced in this debate. Because of this, looking to this debate provides an opportunity to consider what these issues are about and which, if any, of these distinctions suffices for characterizing the basic aims of medicine.

3.3 Medicine: Art or Science?

Clinical medicine is often said to have a dualistic nature, to be both science and art. How this claim is interpreted is important because the extent to which we view medicine as science rather than art affects our epistemological expectations of medicine, expectations which bear on the meaning and plausibility of the conceptual foundations of medicine given here. On a common interpretation of this claim, for example, if we hold that medicine is a science, it follows that we should thus only expect it to meet scientific standards of inquiry, where the sole standard is the acquisition of objective knowledge. However, a problem arises upon accepting this view: on it medicine need not meet additional moral standards of inquiry, such as being sensitive to patients' health care needs and how they are met (Munson 1981). Thus, there would be no need to place emphasis on patients' knowledge at the conceptual foundations of medicine (Aim I), nor would it be necessary to recognize a congruency between understanding patients in their own terms and performing treatment interventions consistent with that understanding (Aim II). But characterizing medicine as being without such moral sensitivity would be deeply flawed, because doing so would remove any commitment to benefitting the patient through restoration and healing. This leads many to claim that medicine cannot be merely a science; it must be *both science and art*, consequently many adopt a *dualist epistemology of medicine*, which recognizes a distinction between two equally fundamental ways of medical knowing: in terms of objective

scientific knowledge of biology and physiology, and subjective personal knowledge of understanding the patient through the craft of patient care.

I am sympathetic to this view but I believe it is mistaken because it is too simple. It conceptualizes medical practice as a mysterious activity that cannot be understood in objective terms, and must solely be understood as an “art” without further specification of what that means. In this section, I challenge the distinction between medicine-as-art and medicine-as-science, ultimately concluding that it obscures the issue. The issue is whether it is possible to measure certain aspects of patient care, and if so, whether such measures are “scientific,” which relates directly to whether such measures are “objective” or not. If so, then medicine is a science through and through, even though the day-to-day practices of most clinicians differ dramatically from the practices of a pathologist or – to go even farther afield – Boorse’s astrophysicist.

3.3.1 *Being a Science Versus Being Scientific*

To challenge the common distinction between medicine-as-art and medicine as science, it is important to give some context for it. To do so, we begin with a debate between Lee Forstrom and Ronald Munson.

Over thirty years ago Forstrom argued clinical medicine is not only scientific, but also is an autonomous science. Following Braithwhite, Forstrom defined a science in terms of two criteria, whether it has its own natural domain of inquiry and whether it aims at establishing general laws explaining the phenomena of that domain (Forstrom 1977, 8-9). Rendered in light of contemporary concepts in philosophy of science, we may interpret Forstrom as arguing that medicine has both a unique domain of inquiry and that it aims at robust generalizations.

According to Forstrom, the domain of clinical medicine is the living human being, which is both its object of inquiry and “its usual experimental context” (*ibid.*, 15). Yet, as

human illness manifests across levels of analysis, from molecules and organs to organ systems and social systems, the clinician “must interpret and evaluate the effects on the organism of social and economic as well as physical and biologic factors” (*ibid.*, 9). Thus, medicine’s unique domain is the sum total of levels of analysis required to understand health and disease in a living, embodied person. It is not simply an aggregate of the other sciences that explain phenomena in these domains, because medical science synthesizes the results of these domains for the purpose of developing knowledge designed for individual patient care.¹⁶ Medicine is thus directed at knowledge about patient care rather than about biopsychosocial phenomena isolated from the context of human well being and suffering.

Against Forstrom, Munson argues medicine is not, and will never be, a science, even though it is *scientific*. Using Forstrom’s criteria, Munson argues that despite the fact that the notion of a unique domain of inquiry is vague, medicine nevertheless fails to have one. Because, he says, simply identifying a concern with the health and disease of living humans, and a requirement that this concern be expressed in considerations of many levels of analysis, fails to demarcate medicine from other fields, such as “medical sociology, epidemiology, bacteriology, biochemistry, and social work” (Munson 1981, 186). Moreover, distinguishing medicine from these fields by appealing to medical intervention as the defining aspect of clinical medicine will not do, because that would be patently circular.

What is at issue here is the type of generalizations clinical medicine aims at and how robust they are. To see this, notice that Munson’s main objection is that not only is medicine not a science, but also, it can *never* be a science. While Munson recognizes that medicine is

¹⁶ This depiction accords well with Engel’s “biopsychosocial model of medicine” (Engel 1977) and the more recent model of “patient-centered medicine” (Bardes 2012).

scientific, he rejects the claim that it is a science because of how he defines science. Munson holds something is a science if and only if it aims to generate robust generalizations; thus, the basic aim of science “is the acquisition of knowledge and understanding of the world and things that are in it,” (*ibid.*, 190), no more and no less. For a scientist to justify her work, she “need only demonstrate that it is likely to increase our knowledge” (*ibid.*, 191). For a physician, however, solely appealing to increasing knowledge is insufficient and actually negligent. Since the aim of medicine is “to promote the health of people through prevention or treatment of disease,” to justify her work, “the medical researcher must, in effect, present a dual justification: (1) the work will increase our knowledge; (2) the knowledge will be relevant to the aim of medicine” (*ibid.*).

Munson’s response is perhaps the clearest of many attempts to justify the common view that medicine is both science and art. He argues it is fundamentally dualistic since, on the one hand it aims at robust generalizations and on the other hand it aims at idiosyncratic inferences concerning the treatment of particular persons. Because of this duality, medicine is bound to be concerned with patients’ assessments of health, which entails a consideration of patients’ values. Consequently, Munson concludes medicine has an inherently subjective, moral component that makes it unscientific because, given that it aims only to generate objective knowledge, science lacks such a component.

3.3.2 *Values, Scientificity, and Objectivity*

Assumptions about what characteristics must be present in order for science to aim at robust generalizations lie beneath Munson’s and Forstrom’s debate. As with the debates over health and disease, this debate shows that what justifies construing medicine in terms of a dualism between science and art is another assumed standard distinction, between inquiries that are

“value-free” and those that are “value-laden,” where the former pertain to the science of medicine and the latter to its art. For Munson, understanding what it means to aim at robust generalizations requires conceiving them in terms of objective, value-free knowledge of the world. This is the target of science, whereas medicine aims *also* at a subjective understanding of the patient. By questioning this distinction we can show that there are better ways to understand “science,” and thus, better ways to describe the sense in which science and medicine both aim at robust generalizations of various sorts.

Consider the approach adopted by Gorovitz and MacIntyre in a classic paper from the same era. Science, they say, does not only aim at universal knowledge of properties, kinds, and generalizations linking one to the other; it also aims at generalizations about particulars. And, medicine is a science, so understood. For the clinician, understanding what makes a particular individual distinctive is paramount, even if this understanding comports poorly with medical theory. Whereas a scientist aims to yield abstract generalizations from his or her experiments rather than fuller knowledge of the specific features of samples being studied, for the clinician working with particular patients, “how such particulars differ from one another in their diversity thus becomes as important as the characteristics they commonly share” (Gorovitz and MacIntyre 1976, 59). Gorovitz and MacIntyre’s claim that medicine is a science hinges on their rejection of the fact-value dichotomy, which they say gives a false impression of the epistemology of science. It is the familiar thesis that sciences generate statements of fact, which cannot entail statements of value, that they contend leads to the erroneous view that natural sciences are not concerned with particulars, and as medicine is clearly so concerned, that

medicine is not a science.¹⁷ For Gorovitz and MacIntyre, then, medicine is a science, and that it is so is entailed by an account of scientificity that differs from Forstrom's and Munson's. Sciences *are* concerned with understanding particular phenomena, such as particular hurricanes, tsunamis, aneurysms, election results, and cardiac arrests. Hence, the fact that medical theory and practice are focused on understanding particular patients does not imply medicine is not a science.

Taken together, the claims made in these classic papers indicate that there are at least three different concerns at issue in debates about the scientificity of medicine, each of which rests on a different distinction. One concern is with apparent differences between subjective and objective knowledge in medicine. Another is with value-free versus value-laden types of inquiry and their relation to the production of knowledge in medicine. A third concern is captured in the distinction between general explanations in medical theory and explanations of particulars in medical practice.

When understood in terms of objectivity and subjectivity, the debate over whether medicine is a science comes down to whether medicine is “purely objective” and aims at the accumulation of objective knowledge, or whether it includes an inherently “subjective” component. This “subjective” component has been rendered in terms of personal values in the debate over the scientificity of medicine. In this way, we see the interplay between the value-free/value-laden distinction and the distinction between objectivity and subjectivity, in that medicine is an art if it aims at understanding patients’ subjective knowledge of illness in terms

¹⁷ This claim warrants comment. It is not clear that ethical non-naturalists will be troubled by Gorovitz and MacIntyre's assertion here. They need only deny that factual information is sufficient for informing claims about what is good, not that it can play a (non-sufficient) warranted role in justifying inferences about what is good for a patient or other agent in the health care system.

that are patently laden with the patient's values. Likewise, medicine is understood as a science in as much as it aims to understand diseases in objective terms, meaning those that are independent of the values of particular patients and clinicians. Distinguishing between general explanations and explanations of particulars also relates to the other two distinctions. If understood as a science, medicine is taken to aim at knowledge that holds of patients in general, indeed *because* it aims at objective knowledge, free from the values of particular patients and clinicians. And, medicine is art insofar as clinicians aim to skillfully bring these generalizations to bear on subjectively understood, value-laden illness in particular instantiations; that is, in particular patients.

Eric Cassell provides a paradigmatic example of how these distinctions interrelate in philosophical explorations of medicine. Cassell argues that in practice physicians adopt a narrow understanding of the concept of objectivity and a multifaceted understanding of subjectivity. Imagine you feel feverish, he says. You are achy and have cold sweats. You feel ill. If you go to a physician and she takes your temperature, then, "the reading on the clinical thermometer is an objective measurement of an elevation of body temperature. The feeling of feverishness is subjective because a feeling can only be experienced by the subject" (Cassell 2004, 171). This is one sense of what it means to be subjective; it is to feel a certain way, which can only be felt by you, the subject. There is also another sense, which is associated with your ideas *about* the way you feel. You may think that your feelings of achiness warrant the belief that you have a fever. According to Cassell, that idea is subjective in a second sense. Thus, on this view, how you feel and what you reason about your state of affairs in light of your feelings are both subjective. But, there is also a third sense of 'subjective' in medicine: "your *statement*

that you feel feverish is also considered subjective...What the words *mean* is not something outside observers can hold in common," hence, they are subjective too (*ibid.*; italics in original).

Notice here that for Cassell, being subjective connotes being specific, local, and particular. Individual persons have particular feelings, ideas, or understandings of meaning. However, being objective is associated with generality: a thermometer reading is taken to be objective by contrast to being felt solely by the subject – it is valid everywhere, no matter who wields the apparatus, as long as it is used correctly.¹⁸ Also, being objective is associated with being general in the sense that there is general agreement about objective features of the world, in contrast to the particular meaning of statements as understood by specific persons.

Thus, underlying debates about the scientificity of medicine are assumptions about the meaning of objectivity, which is intimately related to the role of values in, and generality of, the target knowledge of interest. It is assumed that the clinician is tasked with acquiring two types of knowledge about the patient, objective (scientific) knowledge, for which there are general, measurable facts of the matter, and subjective knowledge, for which there are particular, incorrigible idiosyncrasies and thus, no facts of the matter.

3.4 Subjectivity, Objectivity, and Medicine

I believe we should resist the conclusion that because clinicians are tasked with acquiring two different types of knowledge medicine cannot be a science. If we adopt this view, then such

¹⁸ In contrast to Cassell's assertion, Hasok Chang's (2004) work on the science of thermometry shows that the standardization of the activity of measuring "temperature" over hundreds of years is what makes this example appear as an innocuous instance of the elucidation of a objective fact about a patient. However, Chang's account of the evolution of the concept of temperature shows that such facts require literally centuries of research and debate in order for the idiosyncrasies of experimentation to be codified into a broadly accepted physical theory of temperature measurement.

common activities as a clinician inquiring about a patient's symptoms, beliefs about the genesis of his complaint, or way of speaking about his illness, become activities that cannot be objectively characterized. That is, if medicine is *both* science *and* art, then we must agree with Cassell that "establishing a scientific basis for dealing with values and human qualities" is "doomed...Instead, each physician must solve the problem internally" (2004, 19-20). If we adopt this view, as many do in philosophy of medicine (e.g., Waymack 2009; Saunders 2000; Cassell 1995; Malterud 1995; and Battista et al. 1994), then we cannot identify ways of participating in decision-making that are better or worse for others, because we will be unable to qualitatively or quantitatively compare aspects of decision-making that fall under a subjective understanding of illness, the balancing of values and human qualities that Cassell contends must be internal to each practitioner. To challenge this view, then, we will develop an account of understanding as both objective and subjective, which moves beyond the simplistic epistemological position favored in past debates over the scientificity of medicine

3.4.1 *The Irreducible Complexity of Objectivity*

One way to challenge views like Cassell's is to challenge their conceptualization of scientific objectivity. In light of recent work in history and philosophy of science, objectivity may be seen as far more complex than discussants in the art/science debate suppose.¹⁹ Consequently, the notion of "value-free" aspects of clinical medicine is a nonstarter. Therefore, clinical medicine should be understood as an integrative science that draws on various methods, which are objective by varying degrees.

¹⁹ This argument could be expanded to draw on additional philosophical and historical literatures on objectivity and science (e.g. Nagel 1979; Longino 1990; Proctor 1991), but doing so is outside the scope of the present discussion.

In its contemporary usage, the concept of objectivity is, as historians of the notion have put it, “hopelessly but interestingly confused” (Daston and Galison 1992, 82). Following Heather Douglas (2004, 2009), we may distinguish between different senses of objectivity implicit in the concept by attending to the different ways objective claims are *produced*. Douglas distinguishes three categories of processes that result in objective claims: interactions with the world (such as experimentation or observation), individual thought processes (particularly reasoning leading to certain claims), and social processes for generating claims (such as polling, voting, or collaboration).

As illustrated by Cassell above, from the clinician’s perspective, interacting with patients may be seen as an instance of an interaction with worldly phenomena. Though a patient is a person, he is also a phenomenon to be studied, to be poked and prodded, in order to generate evidence for knowledge claims. To make such claims, physicians procure evidence through multiple avenues, such as different types of diagnostic tests (e.g., genetic, blood, and imaging), and inquire whether the evidence supports inferences about the patient’s illness. On Douglas’ typology, this is *convergent* objectivity, where convergence of sufficiently independent lines of inquiry yields “increasing confidence in the reliability of the result” (2009, 119-120).

Interacting with patients may also be understood as a social process, for instance, of eliciting information about the patient’s illness, of healing, or of deliberating about treatment options. These processes may also be understood as generating objective claims. *Concordant* objectivity occurs when “some set of competent observers all concur on [a] particular observation” (*ibid.*, 126). *Interactive* objectivity denotes moments where persons deliberate “to ferret out the sources of their disagreements” before certifying a claim (*ibid.*, 127). In the

clinical context, concordant objectivity may be exemplified by physician consultations or second opinions. In each case, the question is whether multiple observers will agree on a patient's diagnosis, prognosis, and treatment options; if so, then in this sense the agreement conveys that these are objective claims about the patient. Interactive objectivity is exemplified by treatment decision-making and team-based approaches to clinical care, where in both instances persons deliberate over whether a choice is correct in light of what is known about a patient. Douglas notes that the more diverse the deliberators and the more robust the disagreement and deliberation, the more objective this type of objectivity will be.

According to Douglas, individual thought processes may also be described as objective. In this sense, to be objective is to think about phenomena while keeping personal ‘distance’ from it. That is, *detached* objectivity follows from a “prohibition against using values in place of evidence” (*ibid.*, 120); the investigator is prohibited from appealing to her values in making inferences about the happenings of the world. This seems to be the kind of objectivity intended by Munson in his characterization of science, where scientists aim at producing general knowledge and nothing more. Yet, Munson’s characterization of science is ambiguous in that it also implies *value-free* objectivity, which is more restrictive than detached objectivity, because it denotes a process where all values are prohibited from entering into reasoning. If science is characterized as lacking an inherent moral principle, as Munson holds, then this suggests values are banned from scientific reasoning, which is a stronger prohibition than that they cannot serve as components of inferences (detached objectivity) or that one must adopt a neutral position with regard to the values at play in inquiry (*value-neutral* objectivity).

3.4.2 Scientificity and the Epistemology of Medicine

Whether clinical medicine is both art and science depends on how one defines “science.” In the art/science debate, to be a science is to be “value-free,” “objective,” and to aim at (robust) generalizations. Yet, since the meaning of “objectivity” is irreducibly complex, the extent to which being value-free is a hallmark of science is an open question that depends for its answer on the extent to which science exhibits various *types of objectivity*. Thus, if science is not value-free in the requisite sense (value-free objectivity) then the claim that medicine is not a science becomes unsupportable. Just as other sciences exhibit types, and hence degrees of objectivity, so too does medicine. Accordingly, just like other sciences, medicine may be a science despite the fact that it is not “value-free.”

There are good reasons to think that value-free objectivity is not and should not be a hallmark of scientific inquiry. As Douglas and others argue, scientists routinely make decisions about research based on various methodological and ethical values. Scientists also dispute the relative importance of different epistemic values and their implications for hypothesis acceptance. Furthermore, the distinction between epistemic and non-epistemic values is untenable. Finally, scientists have a responsibility to consider the consequences of errors in their reasoning (Machamer and Douglas 1998). What follows from this is that the role values play in science indicates that the value-free ideal of objectivity is also a nonstarter. Values are ever-present in science; understanding the roles they play in inquiry and the extent to which they are justified is what is important.

Values play many roles in medical reasoning. Hence, a satisfactory epistemology of medicine should not be dualistic, but should be both unified and multifaceted. It should be possible to describe the moments where, for example, detached objectivity is warranted or inapt,

or where convergent objectivity justifies a claim that is nonetheless challenged through processes described by concordant objectivity. To put it another way, if we shift from a dualistic epistemology of medicine to a unified and multifaceted one, we may leverage rich philosophical accounts of the multi-level nature of explanation in medicine (Schaffner 1993) in order to justify the types and degrees of objectivity operative at each level and the extent to which they interact in the making of justified medical claims.

On such an account, clinical medicine is a science through and through, only to be a science is no longer to be “objective” in a simple sense of being value-free; rather, to be objective is to be produced by a process one can rely on, a process that is likely to be trustworthy. To understand science in this way – and to understand medicine as this kind of science – is to meet Boorse’s challenge head on: it is to articulate an alternative view of the complexity of values in scientific inquiry, and thereby to conclude that medicine, like other sciences, is value-laden in various degrees. Likewise, medicine is also objective, yet too, in various degrees.

3.5 Medical Decision-Making and the Epistemology of Medicine

Crafting a unified and multifaceted epistemology of medicine is consistent with recognizing that there *is* an important sense in which medicine appears to be fundamentally dualistic. In this chapter we have encountered standard philosophical distinctions for capturing this duality, including appearance/reality, health/disease, practical/theoretical, general/particular, value-free/value-ladden, art/science, and objective/subjective. We have also seen that debates over definitions of health and disease rest upon presumptions about how scientific medicine is,

including whether medicine is primarily a theoretical science and secondarily a practice or whether it is essentially both theoretical and practical.

Distinguishing between theory and practice often leads to other standard distinctions, particularly between art and science. As we just discussed, this distinction in turn rests upon assumptions about what it means for a science to be value-free and to aim at the ideal of objectivity. Also, talk about the role of values in science appears to be closely related to talk about objectivity: once different senses of objectivity are themselves distinguished, it becomes clear that science is suffused with values, whether in the sense of what research topics are chosen, what criteria are used to judge arguments, how we assess the relative merits of fields of inquiry, whether the solution to a particular problem seems sufficient, and so forth. In whatever senses values play roles in science, these roles relate to assessments of which practices produce objective claims.

Standard distinctions in philosophical analyses of medicine, then, rest predominantly on assumptions about the appropriateness of values in medicine and relatedly on objectivity in medicine. Recognizing this supports the intuition that the conceptual foundations of medicine can be adequately described in dualistic terms, yet ones that are fundamentally related and also admit of further distinctions. The epistemology of medicine can be cast in terms of two different ways of knowing, two alternatives for understanding patients but yet remains unified in the sense that it rests ultimately on epistemic foundations, and also multifaceted in that those foundations admit of diverse subsidiary distinctions. If we describe medicine in this way, we may say that on the one hand there is a way that aims to achieve objectivity in all the degrees in which it is attainable and on the other there is a way that aims to forego any commitment to objectivity and neutrality in favor of accessing subjective knowledge of illness.

Although it is often only implicit, contributions to the debates covered in this chapter have sought to demarcate different practices as sufficiently objective to warrant inclusion in the category of the “objective” aspects of medicine, and similarly practices that warrant exclusion. Except for Schaffner (1999), few authors in this literature have seriously considered the legitimacy of subjective knowledge and those that have (*e.g.*, King 1954; Cassell 2004; Cooper 2002) recognize it only in passing, without developing a positive account of *how* subjective knowledge can play a legitimate role in medical practice.

In this section, I will distinguish different senses in which subjective knowledge can play a legitimate role in medicine. I begin by defining what I call “subjective knowledge” by contrast to a sense of objective knowledge that follows from the analysis of objectivity above. I then show how subjective knowledge can be used as information in clinical encounters. But I go on to say that subjective knowledge also has a legitimate, constitutive role in practice in a sense sometimes described by those who have studied the importance of narrative and empathy in medicine, that is, as more than merely a datum in clinical reasoning.

By doing this, I show how a multifaceted epistemology of medicine based on a distinction between objective and subjective types of knowledge and nuanced accounts of each type may be useful for describing the conceptual foundations of medicine identified in this chapter, which can in turn be used for modeling decision-making. In short, having justified the Basic Aims as generally agreed upon foundations for medicine that incorporate a distinction between the patient as a feeling subject and as a studied object, which pervades medical theory and practice, they may now be used as basic constraints for our model of decision-making. Given that the Basic Aims describe substantive assumptions about the aims of medicine, we will seek to define a model of choice in medicine such that goals of choice are consistent with the aims of

medicine. What this means for particular choices, rather than for an abstract model, will be explained in the following chapters.

3.5.1 Objective Knowledge and Objective Claims

A number of standard distinctions have been used to capture medicine's inherent duality. Each of them has been shown to have its limitations above. Thus, we are left to accept that medicine is inherently dualistic in some sense, but that finding acceptable language to capture this duality is difficult. I believe that this situation can be overcome by distinguishing objective and subjective knowledge, and by casting the basic duality of medicine in terms of the ways we communicate about these two related but different ways of knowing. If I am right, then the perspicacious description of the Basic Aims of medicine we began with readily emerges.

Following Douglas, I have suggested that objectivity is not a binary quality; rather, it comes in degrees. Furthermore, distinguishing between different ways of being objective allows for distinctions between different types of objectivity. Douglas' typology does not purport to be exhaustive. Instead, it purports only to be sufficiently thorough to prove the point that there are different ways of producing objective claims. Thus claims about the objectivity of knowledge claims – and thus the extent to which they are value-free – cannot be understood as simply demarcating one type of claim (objective ones) from another type (non-objective ones). Since knowledge claims can be objective to varying degrees, the extent to which they relate to the roles of values in their production will be multifaceted, and cannot be determined simply by establishing that they are objective. Additional analyses will be required to describe what sorts of objective claims are evident in a given moment, which will determine the extent to which values played any of many possible roles in their production.

With this concept of objectivity in mind, it is important to be clear about what types of things it applies to. I have described objectivity as being a quality of knowledge claims. I take such claims to be pieces of language: they are verbal, written, or otherwise depicted communicative acts that persons exchange during the activities of thinking and reasoning. The picture I have in mind is of agents who aim to describe a state of affairs to which they both are attending. Yet, one may also think and reason in ones own mind, without sharing ones thoughts with another person. Here I believe that one is not making objective claims *per se* (and in this regard I differ from Douglas). Rather, one is making claims *as-if* one is going to share them, which makes them putatively objective. They become objective when shared and when shared in a way that conforms to the sorts of processes described by Douglas.

I thus make a basic epistemological assumption, which is that objective knowledge is something one has only in the context of sharing reasons or other types of information with others. One cannot have objective knowledge “in ones own mind,” so to speak. In the sense that I am using it, objective knowledge can only arise by certain types of social processes. One can directly perceive states of affairs and thus have a perceptual experience that would serve as testimony to be shared with another person, which would then become an objective knowledge claim. However, one’s perception is not knowledge until it is shared via a communicative act.

Many problems can arise with this way of speaking but I am pressed by the subject matter to say these few things about objective knowledge, as it directly relates to medicine and thus medical choice. It is worth recognizing that I am not the only one to be so pressed. For example, in his critical assessment of debates about the concepts of health and disease, Mark Ereshefsky concludes that we should stop talking about definitions of these concepts altogether. Instead, “we should explicitly talk about the considerations that are central in medical

discussions, namely *state descriptions* (descriptions of physiological or psychological states) and *normative claims* (claims about what states we value or disvalue)" (Ereshefsky 2009, 221). This suggestion echoes Margolis' original position discussed above. I interpret it as suggesting that it is important to attend to how claims are made that affect reasoning in medicine: sometimes claims are made about the state of affairs; other times claims are made about our personal assessments of those states of affairs.

Yet unlike Ereshefsky, I believe that it is more important to distinguish between claim making and experiences that prefigure the claims we make but that are not captured by our claims. It is for this reason that I distinguish between objective and subjective knowledge. As I describe them, objective claims are those that are made about states of affairs, whether these states of affairs include the putative existence of physiological or psychological states or the putative existence of values or disvalues of those states (or other states, such as whether a discussion of psychophysical phenomena will be covered by health insurance, for example). Thus, where Ereshefsky distinguishes between state descriptions and normative claims, I urge a different distinction, between objective knowledge, which comes in degrees and is the product of various strategies for securing objectivity that Douglas describes, and subjective knowledge, which I describe just below. Thus, although I agree with Ereshefsky and others that it is important to move from aiming at definitions of health and disease to aiming at a better characterization of the sorts of claims made in medicine, I disagree that distinguishing between state descriptions and normative claims is the right way to capture this. Some additional comments on norms are on order to justify my intuition and are important for characterizing the sense of subjective knowledge I deploy (see also § 2.3.1).

The emphasis Ereshefsky explicitly places on norms by distinguishing them from state descriptions is common among those who worry about the legitimacy of values in medicine and scientific inquiry, which we have already discussed at length. Just as Boorse and Munson each in their way expresses the worry that scientific inquiry will be sullied if values are permitted to play a role in it, Ereshefsky also captures this worry, albeit inflected into the realm of medicine in particular. The problem appears to be that if we do not distinguish between facts – state descriptions, as he puts it – and normative claims or values then medical reasoning could appear flawed by moving from opinions about states of affairs to conclusions about what is indeed the matter (that is, to the states of affairs themselves).

But as we have seen in detail above, this worry is overly simplified. There are legitimate roles for values in scientific inquiry. Likewise there are legitimate roles for values in clinical inquiry. Thus the issue of how to understand the role of values in medicine need not be put in terms of normative claims on the one hand and state descriptions on the other. Rather, we can accept the legitimate role of values in inquiry, seek to identify values and deliberate about their legitimacy, and then recognize them as pertaining to descriptions of the state of affairs. We can, as it were, use the concept of state descriptions that Ereshefsky usefully suggests for speaking of psychophysical phenomena and use it also for describing different evaluations of those phenomena. And when we do so, we will be performing communicative acts that produce objective claims. We will be relating information about our beliefs about the states of affairs, including not only what putatively is the case, but also what putatively are our evaluations of it. As we investigate the state of affairs and deliberate about it, we will come to conclusions about the appropriateness of the putative state of affairs and our putative evaluations. Consequently, we can see these ways of speaking as on a par, as both leading to knowledge claims of various

sorts, and ultimately as in this sense both objective. Yet we may also note that because objectivity comes in degrees this is not to claim that these claims are *equally* objective if that is taken to mean that they are produced by the same means. Rather, we can distinguish between making claims that are convergently objective, as might be the case for claims about the pathophysiology of a given illness, and making claims that are interactively objective, as might be the case when two persons agree that it is true that a given illness is disvalued in any number of specific ways.

Thus, I recognize the usefulness of speaking of state descriptions without assuming that evaluative speech cannot be described as part of the state of affairs. Doing so motivates additional clarification on the nature of normative claims. Normative claims are claims about *how* evaluative claims are generated, not (*contra* Ereshefsky) about *which* evaluative claims are present in response to a given state of affairs. Following Machamer and Wolters (2004, 9), then:

Norms are like rules or the principles that guide regulated activities. They are embodied in performance skills; they are constitutive of knowing how to do something, be it intellectual, practical, or productive. They apply to individuals or groups. They apply in specific social locations. And they are public: they can be learned and observed and have the possibility of being used to correct actions or practices that do not accord with them. A norm is *constitutive* of a practice's being the kind of practice it is (the kind of game it is, the kind of form of life it is). It is by doing things "in this way," and only this way (though there is often some latitude), that a practice is exhibited or defined. Practices, of course, can change, be revised, be ignored, or be discarded. They exist only in specific locations at specific times. They are historical "objects." Norms specify for individuals or groups when practices are being carried out correctly or properly.

Following this view of norms, claims about norms, like claims about values, will be objective to various degrees in they are made via communicative acts as described just above. It is thus not only possible, but also quite common to encounter objective knowledge about norms,

just as it is common to encounter objective claims about evaluations of states of affairs. Claims about norms serve as justifications for claims about evaluations: that a state of affairs, φ , is disvalued may be justified by appealing to a norm ψ , that φ -ing is bad. Such claims may be objective because of the ways they are produced, just like claims about state descriptions that are uncontroversially considered to be “objective.” Yet again, however, this does not mean they will be objective in exactly the same way, and as such equally objective. Rather, their objectivity will come in different degrees, if at all. And if claims are not objective, then they will be subjective in the following sense.

3.5.2 Subjective Knowledge and Subjective Claims

The expansive view of objectivity I have just described follows naturally from adopting Douglas’ account. This view entails that various claims about states of affairs should be seen as on a par, as being ways of describing states that are more or less objective. It also makes it possible to describe subjective knowledge by contrast to objective knowledge.

Whereas objective knowledge arises in the process of making claims that are proffered between persons while describing states of affairs, subjective knowledge arises from personal assessments of experience that are not communicated in language. Subjective knowledge is produced in response to personal experience. For example, proprioceptive knowledge of how to balance while riding a bicycle is personal knowledge about how you – one who is a subject – need to be positioned to successfully ride a bicycle. A hallmark of subjective knowledge is that it correlates to feeling of some sort: it is knowledge of oneself in the world, which may be powerful and intense or may be measured and banal. That is, subjectivity in this folk sense is marked particularly by an association with intensity of feeling (Sytsma and Machery 2010; though see Sytsma forthcoming). However, subjective knowledge may also be distinguished as

referring to one's thoughts about one's feelings, the meanings of those thoughts, and so on, as discussed above (§ 3.3.2).

Discussing subjective knowledge in this way threatens to bring us to various thickets – for example about consciousness and phenomenal experience – that I seek to avoid. My aim is not to partake in open debates about subjectivity and phenomenological experience (cf. Zahavi 2005). Rather, I aim to make plausible assumptions about a difference between knowledge of the world of objects that is codified in language – when persons give reasons to one another – and knowledge of a world that is deeply and inextricably personal. I do not claim that the latter, which I am calling subjective knowledge, is unrelated to the world of objects or independent to it. I claim that there is experiential knowledge of oneself as a subject in the world of objects that exists apart from the additional move to communicate that knowledge. This is also not to say that such knowledge is alingual – that it is thought without propositional form, without words (Bermúdez 2003). My assumption that subjective knowledge exists is agnostic with regards to what approaches are best or even legitimate for characterizing the “internal” aspects of subjectivity. I only mean to say that *subjective knowledge of ones feelings may be distinguished from objective knowledge insofar as it arises in personal terms apart from whatever terms one uses to describe that experience to another agent.*

Taking these thoughts a step further, we may distinguish subjective claims as *initial communicative acts* intended to convey subjective knowledge in public terms, terms that another agent can contest or agree to. On this picture, when someone reports his or her personal experiences, which will often be verbal, the activity of reporting produces subjective claims, communicated information about the experiences of the person. Once those claims have been produced, they may then be discussed by other persons. The practices that ensue, of

deliberating, giving reasons, and so on, are means of producing objective claims. As discussed above, there are many ways to produce objective claims. On this view, some of them will arise from subjective claims, if and only if an individual communicates about his or her personal experiences in a way that is accessible to another agent.

Understanding the distinction between subjective and objective knowledge in this way has important consequences, especially for thinking about medicine. For one, it describes *how* claims about personal experience are given meaning in the clinical encounter by emphasizing the continuity between objective and subjective claims, both being ways of speaking about important aspects of the world, though the former being the world about which we can forge agreement and the latter being the personal world, a world in which the concept of agreement does not properly apply.

This epistemic distinction also provides a way of understanding how subjective and objective knowledge serve as constraints on claim making. If we understand objects as simply things that are part of the causal structure of the world, then objects are conceptualized entities and activities; they are things that are already understood in part by the roles we expect them to play in the world (Machamer and Wolters 2004, 10). One's subjective experience serves as a check against the roles one expects objects to play, and in this way, the categories one perceives with. One's willingness to see states of affairs as one way or another serves as a check on the types of objects that exist and the relationships they are able to exhibit. Likewise, the objects in the world constrain the sorts of categories one forms through untold feedback loops and learning events. “Humans cannot do with objects what they will or wish, for the objects constrain our very actions, including the activity of thinking” (*ibid.*, 12). Thus, subjective experience is constrained by objects in the world; yet, the experience of being a subject also

constrains the way one interprets the world and thus the ways in which one is willing to describe experience, and ultimately to participate in the production of objective claims.

3.5.3 Knowledge Claims and the Basic Aims of Medicine

Distinguishing between objective and subjective knowledge and objective and subjective claims is useful for characterizing the conceptual foundations of medicine, which is in turn useful for modeling medical choice. If we accept this basic distinction then disputes over the appropriateness of standard philosophical distinctions for medicine fade away. What we are left with is a presumably contentious vocabulary for capturing an uncontroversial epistemological distinction. Yet, I hope to have shown that other standard distinctions do not suffice for taking the place of the conceptual foundations of medicine in my considerations of them above. Distinguishing between subjective and objective knowledge is sufficient, however, because it provides a means of capturing the two different perspectives that scholars agree are integral to medicine, the perspective of the earnest, thoughtful healing practitioner and the perspective of the ill, though engaged, patient. Yet a bare distinction between subjective and objective knowledge is especially helpful because it can be used to capture myriad ways of describing the patient as “objective” in various senses; and it can also provide conceptual space for respecting the singular importance of patients’ perspectives in medicine. Furthermore, it can do this without reifying simple conceptions such as disease as a value-free notion, medicine as an art, or science as pure inquiry unsullied by values, which we have seen are common stock of standard philosophical distinctions in medicine.

Consequently, if we permit a distinction between subjective knowledge and objective knowledge and couple that to a distinction between intervention and understanding that is assumed here, then the Basic Aims result. One aim is to understand the patient objectively and

subjectively, while the other aim is to intervene by treating the patient via means that are consistent with their state of health, which is defined in terms of the understanding gained if the first aim is met.

In Section 3.1, the notion of objectively understanding a patient is equated with understanding them “in scientific terms.” Having discussed the scientificity of medicine in some detail, this terminology may now be defended. By scientific terms, I mean something like a Quinean conception of observation statements, though without the radical behaviorism he infuses into the concept. For Quine, observation sentences are those that garner assent from observers partaking in inquiry. Importantly, observation sentences serve “as vehicles of evidence for our knowledge of the external world” precisely because they motivate agreement between persons, and despite the fact that assenting to them “may be more or less delayed or hesitant” and may be corrigible, or open to “self-correction” (Quine 1993, 108-109). According to Quine, such sentences provide an ideal basis for scientific inquiry because they relate both to what he calls “the subjective or solipsistic half” of the story and the “intersubjective” half, which he captures with typical eloquence: “The observation sentence is Janus-faced. It faces outward to the corroborating witness and inward to the speaker. It faces outward to its subject matter and inward to the range of neural intake that is keyed to trigger it” (*ibid.*, 109).

Dropping Quine’s specific emphasis on “neural intake,” observation sentences in this sense are those that garner assent from persons who share in the perception of states of affairs. And it is precisely because of this that they are ideal vehicles for capturing intersubjective agreement. To capture the nature of objective understanding that is a hallmark of medicine, we need not do any better than this: to understand a patient objectively is to depict that patient in scientific terms, meaning terms that are designed for corroboration, terms that *invite* agreement

or disagreement, and in doing so, contestation and inquiry as to their appropriateness. Yet unlike Quine, I am interested in scientific ways of describing patients as opposed to observation “sentences.” Thus I adopt the familiar locution, “scientific terms,” in order to demarcate a way of expressing oneself or a piece of language, rather than specifically a sentence.

We may extend this reasoning to subjectively understanding patients, which is equated with understanding a patient’s condition in personal terms in the first of the Basic Aims of medicine. The notion “personal terms” is intended to capture personal responses to engaging with another person in a social interaction, including the feelings of empathy, sympathy, and benevolence remarked on by Schaffner (1999). Yet merely *feeling* empathy for a patient’s condition does not suffice, which is why I use the locution “personal terms” rather than merely the adverbial phrase, “understanding personally.” That is, on this view, understanding a patient in personal *terms* happens if and only if there is an attempt to describe that patient’s experience in language. The picture I have in mind is one where the patient herself gives voice to her own experience, making some attempt to describe her situation by conveying her experiences of her state of health. Yet it is clear that this will not be possible in many cases, such as where the patient is incapable of reasoning or communicating precisely because of her illness (Misak 2005), or where the patient has never developed the ability to use language. In such instances, describing the patient’s condition in personal terms will require that someone takes responsibility for ensuring that the patient’s lived experience has been captured in language. This person may often be a physician, and may also be the physician who is responsible for providing the patient’s care. Or it may not. It need not be any single person at all. Demarcating which person or persons fill this role is not necessary in order to demarcate the role that is required to be consistent with the first of the Basic Aims.

The first of the Basic Aims thus conveys a continuum of understanding: on one end medicine aims to understand the patient in personal terms while on the other it aims to understand the patient in scientific terms. Characterizing these modes of understanding thusly depends upon the cogency of an epistemic distinction between two different types of knowledge, objective and subjective knowledge. At the interface between subjective and objective knowledge one finds persons engaged in giving reasons, in communicating about states of affairs. In medicine in particular, one finds persons communicating about state descriptions regarding health and the ways in which persons lack it. Thus reason-giving is a social activity that requires the proffering of evidence and consideration of the appropriateness of judgment (Machamer and Douglas 1999). At times, the activity of giving reasons is merely the activity of making claims; and at times making claims is merely the activity of describing ones personal experience using whatever language one has at his or her disposal. In such cases, an important moment can be discerned where subjective claims are made but without an invitation to agreement or dissent. They may be accepted as mere opinion, and thus incorrigible. If so, they remain subjective claims, facts of a sort, but facts only about how that person at that time, and in that moment, felt about the state of affairs. However, subjective claims may also be contested or assented to. One's interlocutor may agree that they are apt for the circumstances, that they are a reasonable report of the circumstances. At this moment, the move from subjective claims to objective claims has been made, and in this fashion intersubjective agreement serves as a minimal procedure by which objective claims are produced

The second of the Basic Aims captures the common interventionist goals of medical practice. Yet it does so in a way that anchors intervention to *full* understanding, as captured in the first aim. It captures the intuition that intervention is always a means to a certain end, and

that end is to help the patient without doing harm. Here, harm is captured in both subjective and objective terms. Harm would be done if an intervention is performed that is inconsistent with how the patient is understood scientifically: if the patient was experiencing an asymptomatic inguinal hernia, for example then surgical repair would be inconsistent with how the patient is understood because it has a much higher risk of increased pain than the dysfunction itself and because it also has attending low risks of far more severe outcomes than closely watching the dysfunction over time (Simons et al. 2009). Likewise, harm would be done if an intervention were performed that is inconsistent with the patient's subjective claims about his or her state of health. For example, take the fictional case of a motorcyclist who presents in the emergency department after a devastating accident (Aulizio 2003, 8). Her right leg is in danger of requiring amputation due to decreased blood flow, so the surgeon recommends removing a vein from her wrist and moving it to her leg, which would likely save it. It would seem natural to go forward with surgery rather than to amputate the leg, because if the treatment is successful it will result in only moderate loss of function in the patient's wrist. However, unbeknownst to the surgeon, the patient is also a concert pianist who has built her self-identity and earned her livelihood as a musician. Consequently, in her case we might assume that her personal assessment is that losing the leg is preferable to altering her wrist. As such, even if the operation were successfully performed, it would harm her because it resulted in circumstances that were markedly inconsistent with an adequate subjective understanding of her experience of this particular health state.

In this way, the two basic aims of medicine defined at the beginning of this chapter serve as conceptual foundations of medicine, in that they describe the two basic goals of medicine in both its practical and theoretical aspects. Medicine aims at understanding patients

subjectively and objectively, and it aims at intervening to alter the progression of ill health, where this state – of ill health – is defined in terms captured in the first aim.

This conceptualization of the aims of medicine provides a foundation upon which we will develop a model of decision-making: because it identifies the two foundational goals of medicine, this conceptualization allows us to identify some basic constraints that any decision must meet. All medical choices must be made such that patients are *fully* understood and that treatments are performed that are consistent with that understanding. But this leaves open what it means to reach the threshold of full understanding and how that might be accomplished. Describing this threshold precisely and providing a normative theory for how it should be met will take up the ensuing chapters. Before doing this, however, we will take up the important issue of how subjective and objective claims may be identified in practice.

3.6 Measuring Objective and Subjective Claims in Medical Practice: Two Examples

There are a number of ways to “get at” medical practice, so to speak. For instance, we might examine the first person accounts of patients who have undergone, or are undergoing, care. Or we might look to empirical studies of patients’ experiences of care and/or clinicians’ experiences of providing care. Or we could look at clinicians’ reports of care giving, whether these are brief reports about specific moments of care (*e.g.*, Garber 1999) or lengthy reflections on the practice of giving care. Each of these ways of describing medical practice is partial, only depicting part of the phenomenon. In this section we will consider empirical research on patients and clinicians’ experiences briefly and then turn to consider clinicians and patients’ reflections on practice. By doing so, we will see how distinguishing between objectivity and

subjectivity fits with practice, allowing for us to track the moments where subjective claims are contested and rarefied, and in the process, objective claims are produced. As we begin the detailed work of building our model of decision-making in the next chapter, we will return to this theme as we consider an expanded case study of decision-making in breast cancer.

3.6.1 Pathophysiology, Psychology, and Social Science in Hereditary Breast and Ovarian Cancer

Hereditary breast and ovarian cancer (HBOC) is defined in terms of a known genetic predisposition to breast and ovarian cancer. Many factors must be considered in its diagnosis, but the determining one is returning a positive result for mutations in the *BRCA1* or *BRCA2* genes (Rubenstein 2001). In order to qualify for a genetic test, a patient must meet certain criteria, including having a first degree relative with a known mutation, being of Ashkenazi Jewish descent, or receiving a diagnosis of breast cancer before age 45 (National Cancer Institute 2011). If a patient is diagnosed with HBOC, this licenses a number of inferences about processes that are occurring in her cells, depending upon the mutation she harbors (Turner et al. 2004). While much is known about the genetics and physiology of this syndrome, the study of HBOC is still in its infancy, so it is known with varying degrees of uncertainty. Despite this uncertainty, knowledge of HBOC would surely fall under the notion of objective knowledge on any account.

However, we know much more about HBOC than simply its pathophysiology. We also know how the ways in which clinicians communicate with patients may affect their decision-making. And, we know what patients' typical emotional reactions will be when faced with the prospects of having HBOC. Appreciating research described briefly here on various phenomena arising from typical clinical encounters in HBOC underscores the sense in which

what is often understood as the “art” of medicine is also a science, though in the psychological and social sciences. It aims to measure qualities of particular social beings and social relations. And it studies agents who seek care, their loved ones, the professionals who provide care, and the relationships among them. Through increasing success at such measurement, increasing development and application of statistical techniques, increasing conceptual progress, and increasing innovation in experimental design, we are learning about these relationships in ways that support interventions upon them. Thus, the art and craft of medicine is constituted by diverse studies of social relations in medical practice and their application to particular moments of patient care. Consequently, using the terms defined here ways of broadening the domain of objective knowledge to include what heretofore was thought of as mysteriously personal and subjective are being developed.

Empirical studies of the psychosocial aspects of HBOC have resulted in a rich portrait of what it means to face an HBOC diagnosis, how patients and family members make treatment decisions, and what the consequences of their choices commonly are. For example, we know that genetic counselors are far more disposed to choose genetic testing and prophylactic surgery than their patients (Matloff et al. 2000). And we know that what is most important to patients who face decisions about testing and surgery is information about their test results and their family history. Yet, also of importance are concerns about the risks of surgery, the timing of interventions in their lives, and the impact treatment will have on sexuality (Ray et al. 2005). Finally, for those who choose testing, we know that irrespective of the results, patients will feel a mixture of sadness, anger, guilt, and relief; and many will worry about insurance discrimination in light of their results (Lynch et al. 1997).

Though this description of HBOC is abstract and simplified²⁰, it suffices to illustrate both how the nuanced characterization of objective and subjective knowledge described above is useful for characterizing the scientificity of medicine and why it is better to understand medical knowledge as scientific, rather than as both science and art. That is, on this account we can characterize empirical studies of clinicians' dispositions toward treatment options and patients emotional responses as means of taking subjective claims about illness experience and objectifying them – of codifying them using language that fosters intersubjective agreement subsequent to contestation.

This approach can be contrasted with those discussed throughout this chapter. For example, Cassell holds that there are certain aspects of the craft of medicine that are inherently subjective and particular, meaning they are value-laden, and hence, inaccessible to scientific methods of inquiry. These include the values of the patient, the idiosyncrasies of clinical judgment, and emotional influences on patient and physician cognition during all aspects of clinical interactions. The position argued for here is that these features may also be understood as being objective, once a simplistic account of objectivity is identified, challenged, and replaced with a more nuanced account. On this view, empirical studies of phenomena like clinicians' biases and patients' emotional responses to various moments in treatment provide knowledge that is objective, and in an important way, in the same sense as knowledge of the molecular processes that cause cancer. Both types of knowledge are the result of many processes of data collection and inference. These processes will be objective to varying degrees, if modeled in terms of the types of objectivity above. Whereas our knowledge of the molecular pathophysiology of HBOC may be a product of processes where concordant,

²⁰ This research will be discussed at length in the following chapter.

convergent, and detached objectivity are more salient than other types, it is also true that our knowledge of the psychosocial aspects of HBOC are produced by processes where concordant, interactive, and value-neutral objectivity play prominent roles. Hence, it is not the case that what has been characterized as the art of medicine is incorrigible by appeal to scientific inquiry; rather, it is, and this entails that there may be a science of the art of medicine. Furthermore, just as making objective claims about pathophysiology and etiology is necessary for the optimal delivery of patient care, making objective claims about psychosocial aspects of medicine is also instrumental to optimal care.

3.6.2 End-of-Life Care in the Intensive Care Unit and the Scientificity of Medicine

Research on decision-making in end-of-life care is another case where important recent progress has been made in scientifically studying aspects of care that would traditionally be confined to the “art” of medicine because of their subjectivity and value-ladenness. For many people, life will end in an institutional setting; indeed, recent studies showed that for over 65% of subjects life ended in an institutional setting, including a hospital or nursing home; and, for those who died at home, over 60% received some type of nursing or hospice care at home before death (Teno et al. 2004). In recent years, clinicians, social scientists, and applied ethicists have endeavored to describe how people die in institutional settings and to suggest ways for optimizing these most common ways of ending life (e.g., Kaufman 2005). What considering a tiny but representative portion of this literature indicates is that, like in the case of HBOC, studies have developed significant, empirically justified knowledge describing end-of-life care from the perspectives of providers, patients, caregivers, and other stakeholders and decision makers. In doing so, this research demonstrates how empirical inquiry can capture information about the subjective experience of illness, providing insight into what others would simply

distinguish as the art of medicine, intractable to empirical inquiry. If we drop a simple distinction between medicine-as-art and medicine-as-science and instead speak of objective claims and subjective claims, then we can better capture how these studies result in knowledge that relates to other knowledge that is useful for providing care under such circumstances. But if we maintain a simple art/science distinction in medicine, then there will be no coherent way to describe how to take into account knowledge about both (a) how patients understand dying in institutional settings or what it means to provide quality end-of-life care, and (b) how to provide quality medical interventions at the end of life. And this result would be deeply problematic because integrating these different types of knowledge is required in end-of-life care, as it is in all medical practice.

In a recent review, physician J. R. Curtis argues that “[Intensive Care Unit] clinicians should approach the family conference with the same care and planning that they approach other ICU procedures” (Curtis et al. 2001). That is, he believes it is just as important to understand how to communicate well about end-of-life decisions as it is to understand how to perform a procedure such as a tracheostomy. Moreover, knowledge of how to do both well is not just equally important, it also may require the same types of reasoning.

As Curtis has shown in many subsequent studies, to be a better communicator requires developing an expertise in understanding how physicians communicate poorly and how they communicate well. For instance, in a recent paper, he and his colleagues show that there are four distinct roles that physicians take on when discussing surrogate decision-making regarding life support decisions. Most physicians adopt a collaborative role, defined in terms of communicative acts such as providing medical information, eliciting patient’s values, and making treatment recommendations. However, others adopt what they describe as “directive,”

“facilitative,” or “informative” communicative roles in the decision-making process (White et al. 2010).

In another recent study of decision-making in the ICU, researchers show that physicians’ beliefs about the appropriateness of withdrawing life support strongly correlate with whether patients in the ICU receive the option to withdraw treatment (Shenker et al. 2012). This research suggests that by better understanding the mental mechanisms by which physicians form beliefs it may be possible in the future to create interventions to increase the quality of end-of-life care, in terms of increasing the goodness of fit between presented treatment options and patients’ intuitions about quality of life. Consequently, the logic of this research presupposes that by empirically studying the “art” of medical practice – and in particular postulating explanations about what it is like to be a clinician – using common scientific methodologies, it will be possible to both better understand clinical practice and create empirically derived interventions for bettering patient care.

As in the case of HBOC, briefly considering research studying various aspects of clinical practice and decision-making in end-of-life care indicates that there are many instances where scientific methods are fruitfully applied to patient care. What results are reliable measures of various aspects of patient care that relate to patients’ and physicians’ subjective experiences. These are not *measures of* that experience; rather, they are measures of persons’ subjective claims, which have then been codified and reflected on. In other words, these subjective experiences have been “put through a conceptual grinder” (Suppes 1967, 62) in order to produce objective claims about the experience of being ill and receiving care from both doctors’ and patients’ perspectives. Such measures are out of place if one joins scholars like Cassell in assuming that there is an art to medicine that cannot be studied scientifically, and for

which no progress can be made other than by the apprenticeship model of accruing individual knowledge. Given the value of these measures, and their patent centrality to medical theory and practice, it is only reasonable to conclude that the time has come to move past a simple dualist epistemology of medicine and to begin the process of crafting a new, coherent epistemology that is multifaceted while also remaining unified in recognizing the persistent scientificity of medical theory and practice.

3.7 Normativity, Empathy, and the Practice/Theory Distinction

My argument that to adequately characterize medicine requires explicitly stating that it rests on two different types of knowledge is not novel when put in this way. Many have recognized that medical practice is founded on a relationship between physicians and patients, which has been cast in terms of a basic sense of empathy (Cassell and Siegler 1979; Pellegrino and Thomasma 1981; Zaner 1990; Halpern 2001) and a consequent need for narrative as a means of eliciting patients' stories (Brody 1987; Hunter 1991; Charon 2001, 2006). Some have also considered the extent to which narrative and empathy may be cast as eliciting information about patients that is in some sense "scientific," much like the move to objectivity I demonstrate in end-of-life care and HBOC. In this literature there is widespread agreement that recognizing the need for narrative and empathy further indicates the sense in which medicine is not purely scientific, and the sense in which it requires subjective understandings of patients in order to be successful. Because scholars working on these issues exhibit considerable overlap with the problems I have discussed in this chapter, and because they draw conclusions that run counter to my own, considering how they envision narrative and empathy figuring in medical theory and practice serves as an illustrative contrast to my account.

3.7.1 *Narrative, Empathy, and the Practice/Theory Distinction*

Recently, the concept of *narrative medicine* has garnered considerable interest, even to such an extent that Columbia University supports a Program in Narrative Medicine that awards a Master of Science degree in narrative medicine. Proponents of narrative medicine conceptualize it as resting on a distinction between different types of medical knowledge, which entail distinct competencies that a skillful physician should have. Rita Charon, who coined the phrase “narrative medicine,” describes *narrative knowledge* as necessary for medicine, where “narrative knowledge provides one person with a rich, resonant grasp of another person’s situation” (2006, 9). Narrative knowledge is distinguished from scientific knowledge because the latter “tries to discover things about the natural world that are universally true or at least appear true to any observer,” whereas “narrative knowledge enables one individual to understand particular events befalling another individual not as an instance of something that is universally true but as a singular and meaningful situation” (*ibid.*). A fully competent physician is thus one who has narrative and scientific competence, understood as an ability to procure and utilize both types of knowledge in the case of a single patient (Charon 2001).

There are a number of points of affinity between my account of the conceptual foundations of medicine and narrative medicine’s emphasis on storytelling and communication as features of ideal medical practice. Like those who are interested in narrative, I believe that good communication is necessary for good medical practice, which is why I fashion the Basic Aims of medicine as problems of description and consistency. As I describe the conceptual foundations of medicine, they are goals for adequately understanding patients – in terms of communicating about their health states – and intervening upon their illnesses in ways that are consistent with the terms used. This way of putting the goals of medicine can be seen in an early

work on storytelling in medicine, which paved the way for newfound interest in narrative. Howard Brody argues that for a successful healing act to take place in a medical encounter three components must arise. One is that a patient’s “illness experience must be given an explanation of the sort that will be viewed as acceptable, given the patient’s existing belief system and worldview.” Another is that the patient must believe she is “surrounded by and may rely upon a group of caring individuals.” Finally, the patient must feel confident that the illness can be controlled, “either by feeling personally powerful enough to affect the course of events for the better or by feeling that his or her individual powerlessness can be compensated for by the power of some member or members of the caring group (such as the physician)” (Brody 1987, 6ff.). Brody thus distinguishes three components of storytelling in medical practice that he contends are integral for successful practice. A type of story is the *explanation* of illness that is given in terms that the patient can understand but that also appeal to an etiologic conception of the patient’s state of health. Another type of story is one that instills confidence and delineates the roles of the care giving team such that intervention seems possible, perhaps even likely.

Brody provides a taxonomy of story types and argues that the concept of a story is less vague than might be supposed. Thus, he holds that stories are well-organized pieces of language, which may be analyzed on a par with other bits of language. Furthermore, in medicine it is crucial to recognize the importance of storytelling because it is in an important sense “inherently democratic,” in that the standards of storytelling are those that are “widely shared by lay persons” (*ibid.*, 15). This provides grounds for assessing explanation and information sharing that are not exclusive to experts, the health care providers. Instead it characterizes the success of explanation and information sharing in terms of features of

storytelling perceivable by all who are familiar with exchanging stories, including the story's coherence and its likely fidelity, in light of one's knowledge and familiarity with stories.

Yet, though the emphasis on communication and commitment to understanding patients' illness experience in personal (as opposed to technical) terms found in scholarship on narrative aspects of medical practice is consistent with my approach to understanding the conceptual foundations of medicine, there are problems with the theory of narrative medicine that make it a less compelling frame for understanding medicine than the frame of medicine's two Basic Aims.

One of these problems is that the distinction between narrative knowledge and scientific knowledge may only be apparent. That is, depending upon what narrative knowledge is, which is ambiguous, it may simply be an alternative means of securing a degree of objective knowledge about patients. If narrative knowledge is simply knowledge gained by both listening to another person describe their subjective experience using what I have called subjective claims and then further deliberating about the aptness of those claims, then producing narrative knowledge is a means of producing claims that are to some degree objective insofar as they are corrigible.

It is not clear whether narrative knowledge is gained just by listening to another person describe their subjective experience or it also requires reflecting upon the appropriateness of that description – the subjective claims – in order to determine whether the narrative meets some standards before acquiring legitimacy. Charon's view is that narrative knowledge and scientific knowledge are distinct because the former aims at understanding particular persons while the latter aims at universal truths. Yet, this way of distinguishing between the two fails just as other attempts to distinguish between scientific knowledge and other knowledge in

medicine fail, discussed at length above. As discussed in § 3.3, Gorovitz and MacIntyre argue science can be applied to particular circumstances, or that sciences can be used to make claims about specific events that have features that can be categorized in terms of the categories of various sciences. Charon does not make clear what she means when claiming that science aims at universal truth, but she seems to be adopting an antiquated view of science much like Munson's, which has been shown to be misleading when applied to medicine. Contemporary accounts of the ways in which values are involved in scientific inquiry and claim making, and the consequent degrees of objectivity that can be associated with scientific claims suggest that the vision of science used to distinguish “scientific knowledge” from “narrative knowledge” is overly simplistic and too impoverished to perform the distinguishing work.

This insight becomes more pronounced if we look to ambiguous ways that narrative medicine has been described. In another article Charon contends, “with narrative competence, multiple sources of local – and possibly contradicting – authority replace master authorities; instead of being monolithic and hierarchically given, meaning is apprehended collaboratively,” which is contrasted to “logoscientific knowledge [that] attempts to illuminate the universally true by transcending the particular” (Charon 2001, 1898). Thus, by implication, Charon appears to hold that scientific knowledge *is* monolithic and hierarchical in a sense that precludes it from integrating multiple sources of local and possibly contradicting sources of knowledge. Yet, this runs afoul of decades of progress in history and philosophy of science to understand the nature of scientific inquiry in exactly this fashion, including biomedical sciences in particular (*e.g.* Longino 1990, 2002; Schaffner 1993; Mitchell 2003, 2009; Dupré 1993; Cartwright 1999; Kellert et al. 2006). I have only touched on few components of this large literature in my defense of the multifaceted account of objectivity and consequent adoption of a distinction

between objective and subjective knowledge above. Yet even my relatively brief discussion suffices to show that the notion of science assumed to demarcate narrative knowledge from scientific knowledge is impoverished.

Furthermore, even momentarily granting for the sake of argument that science aims at universal laws from which deductions about phenomena are made, the common account of narrative is still ambiguous regarding whether narrative knowledge is objective or subjective. In this sense, it is also internally inconsistent. For example, Charon argues that engaging with a narrative “enlist[s] the listener’s interior resources – memories, associations, curiosities, creativity,” and so on (Charon 2001, 1899). Such claims appear to be ontological claims about the sorts of cognitive states that listeners to narratives may be in, which in turn serve as evidential support for the view that narrative medicine provides an important addition to mere scientific or technical medicine – precisely because it produces certain cognitive states in persons who incorporate narrative techniques in their practices. One might respond that Charon here is merely talking about cognitive or affective states of in a vernacular sense and there is no implication that there is a ‘science of narrative’ that undergirds her theory of narrative. This is not only a response that is inappropriate given Charon’s care as a scholar and her pedigree in both literary theory and basic sciences, but it is also mistaken. Charon implies there are biopsychosocial mechanisms undergirding narrative medicine, which is important because this entails we can examine narrative practices and make objective claims about their causes and their positive effects:

Adding to early evidence of the usefulness of narrative practices, rigorous ethnographic and outcomes studies using sample sizes of adequate size and control have been undertaken to ascertain the influences on students, physicians, and patients of narrative practices. Along with such outcomes research are scholarly efforts to uncover the basic mechanisms pathways, intermediaries, and consequences of narrative practices, supplying the “basic science” of theoretical

foundations and conceptual frameworks for these new understandings (*ibid.*, 1901).

Charon thus writes as though understanding the 'narrative' aspect of narrative medicine entails empirical study regarding the processes by which narrative practices improve care and the processes that constitute adequate narrative practices. And this account of narrative as empirical inquiry *about narrative practices* is not uncommon (cf. Greenhalgh and Hurwitz 1998; Elwyn and Gwyn 1999; Haidet and Paterniti 2003).²¹ If the theory of narrative medicine entails an empirical approach to understanding medical practice informed by narrative, then it too entails making objective claims about narrative, and thus, the distinction between narrative and science is misplaced.

In addition to resting on seemingly inconsistent epistemic distinctions, the theory of narrative medicine is problematic because it fails to delineate the proper scope of narrative practices. Some authors appear to claim that all medical practice requires narrative to be successful (Brody 1987; Hunter 1991; Charon 2006). Yet others appear to hold that narrative is important only as a means to the end of increasing quality outcomes in certain health care settings, which suggests that in some settings narrative practices need not be deployed if they are not necessary for causing better outcomes (itself an empirical question). As an example of those who contend narrative is essential to practice, Hunter states:

Medicine is an interpretive activity, a learned inquiry that begins with the understanding of the patient and ends in therapeutic action on the patient's behalf. Far from being objective, a matter of hard facts, medicine is grounded in subjective knowledge—not of the generalized body in textbooks, which is

²¹ Likewise, witness interest in studying scientific practices in much the same way, as practices with cognitive, affective, and social aspects that can be elucidated by the tools of modern cognitive and social sciences (Carruthers et al. 2002).

scientific enough—but the physician's understanding of the particular patient (1991, xx).

While Hunter's emphasis on distinguishing between objective facts and subjective knowledge appears similar to the account argued for here, and is actually similar in many ways, it differs importantly because it appears to hold that the essence of medicine is subjective knowledge of a particular patient, and *is not objective knowledge of that patient*. Thus for Hunter and other theorists of narrative medicine, narrative practices seem necessary and sufficient for medicine, which means the proper domain of narrative practices includes any and all instances of medical practice.

Other theorists of narrative medicine suggest otherwise, however. Haidet and Paterniti justify narrative practices not based on their being essential to all medical practice, but rather on their positive effects on particular aspects of practices. They contend that "greater expression of patient perspectives" contributes to a variety of positive health outcomes, including adherence to treatment regimens, decrease in blood pressure and glycohemoglobin levels, expedited symptom resolution, and increases in patient trust and satisfaction (Haidet and Paterniti 2003, 1135). On this view, since what justifies narrative practices is their contribution to the end of increased benefit to the patient, it is an open question if they are always appropriate for practice, and the answer will depend on whether they have been demonstrated to be an effective means to that end. This differs considerably from the claim that narrative practices are constitutive of good practices, which would make them an end in and of themselves.

I draw attention to this problem of scope because it highlights a feature of my conceptual analysis of the foundations of medicine. My analysis purports to capture something about the conceptual essence of medicine. Thus it should not be ambiguous: my view is that the Basic Aims of medicine are essential goals of medical practice. They are not mere means, but

rather they capture the ends of medicine in the form of two complex aims. They thus are applicable to all instances of medical practice.

Characterizing the Basic Aims as having the domain of all instances of medical practice might appear *prima facie* too strong to be defensible. However, considering the way the aims are defined mutes this worry. Unlike Hunter's view quoted above, the Basic Aims are clear in holding that *both objective and subjective knowledge lay at the conceptual foundations of medicine*. It is not as though the one takes precedent over the other, as a basic goal of medicine. Rather, they are of equal fundamental import. Thus I agree with the spirit of Hunter's view, which is shared by other theorists of narrative medicine, that understanding patients' subjective experience is essential to medical practice. However, I disagree that it is necessary and sufficient. It is necessary but it is not sufficient. Moreover, recognizing that it is necessary does not entail any of the mistaken claims about the nature of scientific knowledge that are common on the narrative account of medicine. Instead, I only hold that medicine requires fully understanding patients in personal and scientific terms. And I have resisted the move to articulate what I mean by "fully," which will remain a job for subsequent chapters. Thus I place both subjective and objective knowledge (claims) at the conceptual foundations of medicine but, unlike narrative theorists, I do not then make the further step of holding that one type of knowledge (claim) takes precedent over the other as a general principle.

3.7.2 *Empathy in Medical Practice*

Discussing narrative is useful for drawing attention to virtues of my view of the foundations of medicine and distinguishing it from similar accounts in the literature on medical decision-making and the physician-patient relationship. The same strategy can be applied to work on empathy in medical practice.

If understood in terms of being sensitive to the emotional experiences of patients, empathy has long been thought to be integral to medical practice (Zaner 1990) and decision-making (Pellegrino and Thomasma 1981). Physicians intent on modeling the patient-physician relationship abstractly have argued that understanding the subjective experience of the patient is necessary, which entails understanding their emotional predicaments from their own perspectives via activities like extended listening (Cassell 1979; Brody 1987) and forming an accommodation between physician and patient (Siegler 1979, 1981; Pellegrino and Thomasma 1981, 217). More recently, scholars have deployed the concept of empathy in order to analyze the many different activities that relate to good listening and adequate accommodation. Drawing on richer philosophical and empirical resources, the language of patients “subjective experience” has since given way to descriptions of mechanisms of empathetic responses and the cognitive and social dimensions of empathy described in fine detail. Thus my view might be seen as antiquated in its reliance on a relatively simple epistemic distinction rather than in terms of a taxonomy of empathetic responses and other emotional states that purportedly explicate the features of subjective experience. Explaining why I believe this would be mistaken helps further describe the implications of understanding medicine in terms of the Basic Aims.

Empathy is a rich topic, on which work is done in many different disciplines. It has become particularly interesting to philosophers because it promises to provide a means for bridging the gap between understanding the world from a first person phenomenal perspective and empirically measuring that understanding in a rigorous, defensible way (see Goldman 1992; Gallese and Goldman 1998; and for a summary of empirical work, Bernhardt and Singer 2012). Thus by discussing empathy, there is a threat of inviting considerations of such issues as mental-state attribution and debates between simulationist- and theory-theorists in philosophy of

mind (Goldie 1999). While these interests are germane to the topic of empathy in medicine, I will forestall discussion of them by narrowly considering how empathy has been examined in a uniquely medical context and then justify the move to pass over these important issues in the remainder of this work.

According to Jodi Halpern, physician, philosopher, and author of *From Detached Concern to Empathy*, recent interest on empathy is motivated by a collective response to a longstanding emphasis on detachment within the medical profession. Historically, she says, “medical effectiveness has depended upon pursuing correct diagnoses, and this aim has been equated with an interest in objective truth, as in science;” however, she argues that detached concern – a stance where the physician is concerned about her patient but in an emotionally detached way (Fox and Lief 1963) – is insufficient for good practice because, “the pursuit of a correct diagnosis requires a *full*, as well as accurate, understanding of a patient’s problems” (Halpern 2001, 94). And a full understanding requires empathy, says Halpern, which is a type of knowledge that is necessary for adequate medical practice. Thus, as it has been applied to medicine, empathic knowledge is demarcated from scientific knowledge in much the same way as narrative and “art” have been.

This conception of empathy defines it in terms of emotional engagement. As Halpern describes it, emotional engagement is a process whereby physicians can gain “subjective information” as opposed to scientific data, which conforms “to the standard of objectivity.” Emotional engagement is a complex activity that produces empathic knowledge. On this view, emotion is not merely a perceptual phenomenon like “feeling.” Having an emotion is not “like an itch. It also involves judging, or imbuing the world with certain qualities that may not be warranted by external circumstances” (*ibid.*, 26-27ff.). Emotions are thus cognitive and

affective states that individuals have some control over but that also have some type of inevitability. For Halpern, an individual can work on being more or less empathic, and can tailor their emotions to fit the circumstances in ways that are more apt than they would be without such effort. Yet there is a certain irreducible subjectivity to emotions – a certain “givenness” – that emotions have that cannot be captured by modeling emotions objectively, such as in terms of sense perceptions.

So understood, empathy is thus both irreducible and corrigible inner perception of the emotional states of another (human) being. There is a certain tension in this way of understanding empathy that makes it difficult to apply to medical practice, although this has not stopped its proliferation as a theoretical construct in empirical studies of physician-patient interaction (*e.g.* Lelorain et al. 2012). The tension arises from two contradictory claims that are implicit in accounts like Halpern’s. Halpern states that empathic knowledge is distinct from objective, scientific knowledge precisely because it is knowledge of a sort of information that is inaccessible to scientific inquiry and irreducible to empirical categories. Yet she also appears to hold that empathy is a cognitive and affective state, which presumably could be measured using social scientific methods. This tension is captured well, for example, when she says, “by distinguishing emotional from detached reasoning, I do not mean to imply that the two are truly independent” but rather that this distinction is “a heuristic device” (Halpern 2001, 34). As a heuristic device, then, the distinction may not be secure, and rather, is useful only insofar as it facilitates problem solving. In this sense, distinguishing empathic from scientific knowledge is useful in that it draws attention to the differences between these knowledge types, rather than because it demarcates two alternative and mutually exclusive types.

Viewing Halpern's distinction as a heuristic device makes sense of another tension in her work, between seeing empathic engagement as a cognitive-affective activity and as a communicative activity. Often, Halpern and others describe work on empathy in medicine as having close affinity to work on narrative medicine, because they each draw attention to the importance of fully understanding the patient's perspective by communicating about it (Hunter 1991, 13ff.; Charon 2006). That Halpern's characterization is consistent with this view is apparent, for example, when she describes emotional linking as constitutive of empathic engagement:

This kind of linking is characteristic of empathy. Rather than looking into the patient's mind from a detached perspective, the empathetic physician relies on her capacity to associate in order to link to the patient's images and ideas...empathic communication is a two-way street in which the distinct affective associations of individuals interact and mutually shape each other to yield new thought (Halpern 2001, 41).

As in the case of Berg et al. discussed at the end of Chapter 2, I can agree with Halpern's metaphorical depiction of patient-physician communication, however I find its reliance on metaphor insufficient for the task of specifying clearly what empathy is and thus how one knows whether and to what extent it is present in clinical encounters. Is it a cognitive perceptual capacity, a mind-reading of sorts, which is implied by her dismissal of the view that it is "looking into the patient's mind?" Or is empathy an affective response whereby non-cognitive emotional states constitute the forming of shared emotional states in physician and patient? Or is it a form of communication, listening, and so forth, such that it is defined in terms of gathering certain subjective information about the patient's predicament?

Halpern's account suggests that to her empathy is a complex phenomenon constituted at least by each of these three activities. She emphasizes that in empathically engaging with the

patient, the physician and patient will settle on shared terminology for understanding the patient's illness yet, "the two will also find distinct words, phrases, sounds, pauses, and looks meaningful or not, according to their distinct individual histories of communication regarding serious matters" (*ibid.*, 42). Here and elsewhere Halpern discusses empathy in terms of communication, yet she appears to be focused on the *meanings* of verbal and non-verbal communication rather than the *signs* used to communicate. Thus, while attending to communication is clearly a part of empathy for Halpern, her emphasis suggests that cognitive and affective states – states of agents, rather than forms of communication between agents – is paramount for understanding empathy in medicine.

This view of empathy is shared by many (see Decety and Ickes 2009) including those working particularly on the concept of empathy in medicine (e.g., Decety 2012; Marcum 2013). Having described it, the account may now be used to distinguish my own. My view makes no commitments regarding the inner states of agents, except for that they are assumed to have them. I make no claims about accounts of cognition, consciousness, emotional states, or affect in characterizing the conceptual foundations of medicine. Thus I do not claim that empathy is a necessary feature of practice, *per se*. My reason for remaining agnostic regarding such matters is because discussions of them are needlessly obfuscating. I believe that, although it would likely be very useful to have a robust account of cognitive and affective phenomena to illuminate the cognitive and affective dimensions of clinical encounters, having such an account is not *necessary* for understanding the medical encounter. In order to understand medicine, which I take to be both a theoretical and a practical domain, it is only necessary to convey that in the medical encounter the patient's subjective experience must be *considered*. Whether such consideration *requires* empathy, narrative, or some other theoretical construct I remain agnostic

about. At root, medicine merely requires procuring subjective information from patients and/or their proxies. Subjective claims are what are conceptually basic to the goals of medicine, not particular emotional or cognitive states. We should expect those to vary to considerable degrees and to be beholden to a wide variety of modeling practices constrained by various disciplinary norms of inquiry. Yet we can capture such variance broadly by focusing on the terms that are used in practice, irrespective of the states that caused those terms to be used and the many different ways that will be used to model those states.

Thus, I rest my conceptualization of medicine on an epistemic distinction between subjective and objective knowledge, and consequent types of claims, rather than on any of the many other standard distinctions, including between empathic knowledge and objective knowledge or narrative knowledge and scientific knowledge. On my view, what matters is who uses what terms and whether there is agreement on their usage. By attending to the communicative aspects of medicine, it is possible to move past the many false and misleading dichotomies discussed above. Instead, medicine may be understood as requiring a full understanding of patients – which includes objective and subjective knowledge – and performing interventions that are consistent with that understanding. Whether “full” understanding requires art or science, empathy or narrative, value-laden claims or value-neutral claims, and so on is not basic to the conceptual foundations of medicine. What is basic is simply that both objective and subjective information are required to fully understand patients’ health states.

3.7.3 An Epistemology for Theory and Practice

In subsequent chapters it will become clear why I eschew ontological claims about the specific sorts of cognitive and emotional states or communicative practices that are necessary for

medical practice. For now, though, I conclude this chapter by conveying a final clarification of yet another common distinction in medicine, between theory and practice, as it pertains to the ongoing discussion.

Scholars concerned with epistemic aspects of medicine frequently, though often implicitly, distinguish between medical theory and medical practice. We have seen Boorse (1997) do this explicitly, as well as Munson (1981), and many participants in debates about health and disease concepts. However, the literature on narrative and empathy in medicine is less clear with regard to whether it respects this distinction or whether claims about these constructs are orthogonal to it. Thus Charon claims that narrative knowledge is necessary for medicine and demarcates a basic science of “narratology” for studying such knowledge. Evidently, then, narrative is a part of the theory and practice of medicine, at least insofar as it is a part of the *theory of practice* as well as being a part of practice itself, insofar as such a distinction can be maintained. It might rather be that for Charon the distinction between theory and practice dissolves and other epistemic distinctions replace it. Halpern, however, appears to hold that there is something irreducible in practice that cannot be captured in medical theory. She states that while we can certainly model practice theoretically, this will always fail to capture certain aspects of practice. Halpern distinguishes “theoretical reasoning” from “experiential reasoning” and holds that for logical reasons empathy requires both: if empathy only required the former, then it would aim only at predication or hypotheses about the feelings of other agents, rather than achieving states of emotional “resonance” with them.

This hypothetical stance would lend itself to *scientific inquiry* – one could apply...social scientific research and estimate the likelihood that people expressing themselves in this way are feeling one emotion or another...this form of hypothesizing and data gathering does not yield an understanding of the particular terrain of an individual’s emotional state of mind...Applying concepts

and making predictions constitute an inadequate mode for gaining a *first-person sense* of emotional experience (Halpern 20001, 73; italics added).

Although I have been critical of aspects of Halpern's account, I agree with her intuition here, though not her explication of it.²² There is an important distinction to be made between theory and practice in medicine.

Distinguishing between theory and practice allows for a distinction between abstract consideration of medical entities without consideration of how they impact a particular patient and the different epistemic activity of bringing general, abstract knowledge to bear on the care of a particular patient. However, where others might cast this distinction in terms of scientific knowledge and something else, whether art, narrative, or empathy, here distinguishing between theory and practice should be understood in terms of different ways of integrating knowledge and information. The distinction is in terms of different *processes* for bringing knowledge together for different *purposes*, not between different types of knowledge. Thus it is not as thought there is theoretical knowledge and practical knowledge, and the two never meet. Rather, there are problems of how to make theoretical claims – to produce abstract models – and problems of how to understand a concrete phenomenon, a particular ill patient. Thus, to reintroduce an issue discussed in § 3.3.2, the issue lies with producing abstract, general knowledge and particular, specific knowledge. This is literally an Ancient problem,²³ so it is not

²² Part of the reason I disagree with Halpern's language is that, as she does elsewhere, here she invites consideration of different accounts of mental-state attribution as a means of distinguishing between the two ways of empathizing she describes, in terms of a theory-theory account of empathy (as hypothesis generation and testing) and in terms of a simulation-theory account of empathy (as being in another's shoes, so to speak). As I explained, I think such considerations *are* relevant and *potentially* worth pursuing, but I also think they are not necessary in order to characterize the basic aims of medicine.

²³ Ancient Greek thinkers distinguished between different ways of knowing, including *episteme* and *techne*, a distinction based in part on the claim that the best explanations are those that are timeless and apply with broad generality (Parry 2009). However, different interpretations of these terms were

one that we will expect to solve in any generic sense here. However, it is possible to be clear about the distinction between theory and practice, how it relates to the Basic Aims defined here, and what use the distinction is for modeling medical decision-making.

In recognizing a distinction between medical theory and medical practice, I aim to accept a different distinction than, for example, that used by Boorse when distinguishing between pathological science and clinical practice. Rather, I envision pathology as being clinical and theoretical, rather than only the latter. My understanding of medicine is informed by some of Pellegrino's views on the essential nature of medicine, which were mentioned at the beginning of the chapter. With his co-author, Pellegrino argues that the essence of medicine is “the clinical event, which demands that scientific and other knowledge be particularized in the lived reality of a particular human, for the purpose of attaining health or curing illness, through the direct manipulation of the body, and in a value-laden decision-matrix” (Pellegrino and Thomasma 1981, 26). On this view, pathology is a science, just like the social scientific study of empathy in practice is a science – in the senses defined above. And objective knowledge is brought to bear on the particular patient’s lived experience during the clinical event. Yet, pathology does not exist independently from this particularization; rather, what justifies pathology as a field of inquiry, at least in part, is its aim of abstractly characterizing biological

common. For example, in the *Nicomachean Ethics* (especially *Book VI*), Aristotle describes these two types of knowledge as more general, in contrast to a third type of knowledge of how to act rightly in particular contexts, known as practical wisdom or *phronesis*. It is fascinating that Ancient Greek thinkers took medicine, along with navigation, as an exemplar of practices where all types of knowledge were required (Jaeger 1957). Although these discussions are clearly relevant to modern debates about the epistemology of medicine, contemporary scholars are in agreement that the Ancient Greek conceptions of knowledge do not mirror the standard distinction between medicine as art or craft and medicine as science, or the accumulation of objective facts (Hofmann 2003, Evans 2007).

mechanisms that have a certain likelihood of being instantiated in particular human beings. When those mechanisms function sufficiently poorly, those human beings may present to the clinic, in which cases, they become patients and objective knowledge from pathology and other sciences may be invoked in order to conceptualize their predicaments.

Yet as has been stressed above, invoking objective knowledge is not sufficient for a full understanding of patients. Put simply, the threshold for full understanding is knowledge sufficient to assist the patient in describing her lived experience and to explain the particular patient's illness. As the essence of medicine rests with meeting this threshold and then intervening in illness only in ways that are consistent with the information gleaned subsequent to doing so, the theory/practice distinction is subordinate to the distinction between the two types of knowledge that are conceptually basic in medicine.

Medical theory presupposes a patient who is ill and for whom action is called for. Medical theory must thus presume a patient within which pathological entities and activities are presumed to reside (King 1954; Forstrum 1977; Pellegrino and Thomasma 1981). And medical practice is oriented toward making judgments regarding the right action for a specific patient. Pellegrino calls such judgments experiential judgments, of which "clinical judgment" is a particular type. Patients make experiential judgments, as do clinicians. When clinician's make them, they take into account information about the subjective experience of the patient, including his or her values. But they also take into account objective knowledge about the patient's likely illness, given his or her symptoms, which are communicated in personal terms as well as via the clinical exam and various diagnostic procedures. Thus Pellegrino notes two important aspects of clinical judgment and concludes that it is a complex reasoning activity rife with uncertainty.

First is the overriding fact that the whole process is ordained to a specific practical end – a decision for a particular patient – and that this end must modulate each step leading to it in important ways. A value screen is thus, in a way, cast over the entire sequence. Second is the fact that no unitary explanation or logical method can encompass the several different reasoning modes and several kinds of evidence acceptable in responding to the different kinds of questions the clinician must answer...The complete process is a multistep, end-oriented concatenation of decisions demanding different types of reasons and reasonings which will justify a particular course of action for a particular patient, given that patient's existential situation at the time of the decision. Each step is shot through with uncertainties, some eradicable, some not. Selection of the 'right' action requires optimization of these uncertainty states" (Pellegrino 1977, 170).

I agree with Pellegrino that medicine is decision oriented and that to make good decisions requires having adequate information. And I further add that adequate information is merely that which is required by the first Basic Aim, which is full objective and subjective knowledge about the particular patient and her particular circumstances.

By casting the aims of medicine in terms of a basic epistemic distinction and the two types of knowledge claims it entails, I can agree with Pellegrino here, yet avoid some of the implications of his view that he also strives hard to explain away. Pellegrino characterizes clinical judgment as something a physician does, yet later takes pains to characterize the sorts of obligations his characterization of medicine enjoins the patient to, including being truthful, not manipulating the physician, educating himself, and so on (Pellegrino and Thomasma 1981, 217). This way of describing the patient's role in the clinical moment furthers suggests that the patient is a mere reporter to the physician, rather than a participant in the medical process. This implies not only that the physician has the cognitive ability to synthesize subjective claims and objective claims, but also that she is the *only* person capable of doing so. By consequence, the patient appears inferior to the physician, a mere information source in an infirmed state, rather

than a person to partner with in making pressing decisions. The physician, *qua professional* is the decision-maker, rather than the physician and patient together as partners (as in Veatch [1981, 1991], who Pellegrino and Thomasma distinguish themselves from [1981, 231-231]).

As the last chapter concluded, a new model of medical decision-making is needed that is both normatively and descriptively adequate. Descriptive adequacy requires modeling decision-making such that it is consistent with what is known about patients, physicians, and other participants in medical choices. In the next chapter, I argue that medical choices are made by groups of persons, not by singular individuals. Thus, granting for the moment that my argument is correct,²⁴ a weakness of Pellegrino's depiction is that it implies decisions are made solely by physicians in light of information gained from patients. A strength of my account of the conceptual foundations of medicine is that it is not committed to this view. By describing the conceptual foundations in terms of understanding (Aim I) – defined as fully describing patients in subjective and objective terms – and intervention consistent with understanding (Aim II), I remain agnostic about *who* must understand and intervene. My characterization of medicine as resting on two basic aims does not preclude a view like Pellegrino's, where the clinician is responsible for making a choice. Nor does it preclude the opposing view, where a patient is responsible for making a choice. My description of the basic aims describes them in more generic terms of the information that must be gathered as a precondition for intervention, without stating who is responsible for gathering and integrating that information. Thus my account remains open regarding who is responsible for integrating objective claims from

²⁴ I am not the first person to have *claimed* that medical choices are in some sense social. This is a familiar view in philosophy of medicine and bioethics (e.g., Pellegrino and Thomasma 1981, 244ff.; Brody 1987, 15; Barnard 1986, 92ff. Halpern 2001, 9; Anspach 1993; Berg et al. 2001). However, I will give a detailed argument for this view and adopt some representational conventions for modeling such social decisions, both of which are novel approaches for articulating and substantiating this position.

medical theory and other domains with subjective claims about the particular patient and his particular state of health.

3.8 Medicine as Dialogue

This chapter has argued for a particular approach to understanding the “essence” of medicine. I have articulated two basic goals of medicine, which I contend constitute medicine’s goals. To justify this view I have surveyed issues in philosophy of medicine widely. We have considered an analysis of the goals of medicine, conceptual analyses of health and disease, whether medicine is best understood as both art and science, what it means to say that medicine is value-laden, and the centrality of narrative and empathy to medicine. In considering these themes I have endeavored to highlight standard distinctions in philosophy of medicine that purportedly tell us something integral about medicine in theory or in practice. And I have provided reasons to doubt the usefulness or the validity of most of these distinctions. What remains, I contend, are distinctions between objective knowledge and subjective knowledge, understanding and intervention, and theory and practice. It is upon these distinctions – and especially the first two – that the model of medical decision-making defended here will be elaborated upon.

The conception argued for in this chapter might be summarized as ‘medicine as dialogue,’ to repurpose a title from Zaner (1990). As Zaner argues, “what Pellegrino identifies as ‘the healing relationship’...can be conceived of as a special form of dialogue” (320). To Zaner, clinical encounters rest essentially upon *conversations*: if a patient asks for help and a doctor responds, then a medical encounter thus commences. At the foundation of medicine, on this view, are thus communicative acts. Understanding medicine in terms of communicative acts does not thereby preclude us from also understanding medicine in terms of any number of

other theoretical constructs, including all of the standard distinctions discussed above as well as others. But understanding medicine as dialogue does provide a sufficiently abstract means of describing what is shared across the many different contexts to which the noun “medicine” refers without begging questions about what types of objective and subjective knowledge are most appropriate for them.

In Chapter 2 I argued that a model of medical decision-making must meet two criteria of adequacy, normative and descriptive adequacy. This chapter has taken a first step in that direction by arguing for a conception of the foundations of medicine that includes understanding, and in a sense that is inclusive of subjective and objective knowledge. Thus I have described the foundations of medicine in a way that is inherently inclusive and pluralistic, yet that is also consistent with a wide range of philosophical explorations of medicine. In this way, I have articulated foundations for medicine that reflect rarified assumptions of medical theory and practice that should be agreeable to all of the many authors surveyed here. The next steps will be to move forward from this cleared ground and to build upon it. Now that I have conceived of medicine as necessitating communication about the patient as experiencing subject and the patient as object of inquiry, the next step is to show how, given this foundation, a model of decision-making can be elaborated that is both descriptively and empirically adequate, and results in the selection of interventions that are consistent with full knowledge of patients health states.

4.0 THE SOCIAL CONTEXT OF DECISION-MAKING IN HEREDITARY BREAST AND OVARIAN CANCER

In the previous two chapters I described three models of medical decision-making, each of which, I argued, failed to meet the two standards of adequacy I contend any model must meet. I also analyzed the conceptual foundations of medicine in terms of the two basic aims of (I) full understanding and (II) intervention consistent with it. Whereas the first two chapters were largely about setting the stage, this one and those that follow focus on directly developing a new model of medical choice in medicine. One could of course dispute the way the stage has now been set, such as my characterization of the models of medical choice, whether the story told was entirely historically accurate, or whether the conceptual analysis of medicine stands on its own or even as a backdrop for the arguments to come. However, in what follows we will put these issues aside and assume the cogency of what has been said before.

As the goal of my model is to succeed where I contend the other three models fail, this means it should place demands on patients and physicians that they are capable of meeting. That is, the model should be consistent with the description of decision-making that serves as a foundation for patient-centered models, like shared decision-making. The model should also justify the normative framework it assumes on more than simply descriptive grounds.

Providing this framework is necessary for putting the model on philosophical grounds that are as firm as those enjoyed by the paternalism and autonomy-based models.

In this chapter and the next, we will tackle the jobs of articulating reasonable demands for the model to place on physicians and patients and conceptualizing those demands such that they may be met by the sorts of agents we believe physicians and patients to be. Chapters Six and Seven will articulate the normative framework grounding the model and defend it from anticipated objections.

The plan of this chapter is to begin the task of constructing a descriptively adequate model by examining a case of decision-making in significant detail, the case of hereditary breast and ovarian cancer (HBOC). I begin by describing the biological understanding of breast cancer in general and HBOC in particular in Section 4.1. Then I describe the origins of genetic tests for HBOC and the major treatment decisions that a woman who is candidate for such genetic tests would face (§ 4.2). Yet focusing only on so-called “major” decisions leaves out a considerable amount of decision-making that goes on in such cases, so I also relate a specific extended case study of HBOC decision-making in Section 4.3, the case of Ellen Macke (Macke 1996). I draw some lessons about the spatiotemporal and social distribution of medical decision-making from this case (§ 4.4). These lessons are then considered against the backdrop of some prior work on the social nature of medical choice (§ 4.5), which leads me to conclude that the distributed cognition framework is a good one for describing medical decision-making (§ 4.6). The next chapter takes up the challenge of modeling group interactions in medical choice as a distributed cognitive system in considerable detail.

Hereditary breast and ovarian cancer has been chosen as the paradigmatic case for capturing the details of medical decision-making for a number of reasons. One reason is that

HBOC is a sub-type of breast cancer, which is the most prevalent cancer affecting American women, and the second most lethal female cancer (U.S. Cancer Statistics Working Group 2010). Thus, presumably physicians can be expected to see patients presenting with signs and symptoms indicative of breast cancer and many women can be expected to have this illness. Many women who suffer the symptoms of breast cancer will also either fit the profile of those who are at increased risk for breast and ovarian cancer, as measured by familial history, or will wonder whether they fit the profile. Women who appear to fall into this breast cancer sub-category will face decisions about whether to undergo genetic screening to determine if they have, or are at risk for, HBOC. These decisions will also entail considerations of how putative results should be interpreted and with whom they should be shared. Hereditary breast and ovarian cancer is thus a good case because it is a clinically prevalent sub-type of breast cancer and because of its complexity, in that a number of important factors are typically considered when HBOC decisions are made.

In addition to its clinical relevance, another reason for taking hereditary breast and ovarian cancer as representative of medical decision-making is that it is a cancer that has a known genetic basis, which means that considering the basis and import of genetic information will be a component of the decision-making process. The currently accepted taxonomy of breast cancers sorts cancer types based on assumptions about their etiology based on incomplete knowledge of the complex etiological mechanisms that generate breast cancers. As our knowledge of this etiological complexity increases it is likely that we will discover commonalities between the three basic types of breast cancer.²⁵ It is reasonable to assume that

²⁵ For example, researchers have discovered that the tumor pathology of cancer cells caused by *BRCA1* and *BRCA2* mutations is shared by a significant percentage of sporadic cancers. They have termed this

when this happens the percentage of cancers classified as “hereditary” (10%) will only increase. That is, as knowledge about the genetic etiologies of breast cancer increases, the percentages of hereditary cancers will increase while the percentage of sporadic and familial cancers will decrease concomitantly. Therefore, HBOC is a good case for studying medical choice not only because it is a subset of a serious and very common illness, but also because it is a subset that will only get larger over time relative to the total number of breast cancers. So clinicians can be expected to encounter increasingly more of the sorts of decisions implied by suspicion of HBOC in the upcoming years. As such, an analysis of these decisions will only increase in relevance as the number of HBOC cancers increases too.²⁶

4.1 Hereditary Breast and Ovarian Cancer

Among American women, breast cancer is the most prevalent of all cancers. During the years for which the most recent statistics are available (2002-2006) there were more than two times as many new breast cancer cases as there were lung and bronchial cancer, which is the second most prevalent cancer affecting women, ranked by incidence. In the same time frame, breast cancer was the second most lethal female cancer when ordered by lethality (U.S. Cancer Statistics Working Group 2010). In 2009, estimates projected approximately 192,000 new breast cancer cases and 40,000 deaths from breast cancer (Jemal et. al. 2009).

property, “BRCAness”, which is hypothesized to be caused by breakdown in a common cellular pathway, in which BRCA proteins are thought to play an important role (see Turner et al. 2004).

²⁶ It is worth noting that in many cases the decisions faced by a patient with HBOC will bear many similarities with those faced by a patient with familial or hereditary breast cancer. Though HBOC adds additional complexity to the decision, many factors stay the same, especially if the patient has both an increased risk of breast and ovarian cancer and has active breast cancer, which is not an uncommon occurrence amongst HBOC patients. So the HBOC case is also in this sense more representative of the general breast cancer category than the 10% statistic suggests.

Our current scientific understanding is that breast cancer, like other cancers, has a complex etiology marked by genetic and environmental interactions. Contemporary epidemiological models of breast cancer hold that clinically detectable disease is caused by the serial occurrence of five key factors. First, one undergoes an initial exposure to a carcinogen, which modifies DNA in breast tissue. Second, this provokes a cellular response, which proceeds through biological mechanisms that are sensitive to the type of exposure as well as differences in an individual's age, genetics, and metabolism. Third, this results in a neoplasm, which becomes a clinically detectable mass in a manner dependent upon hormone levels and hormone metabolism, specifically estrogens. Fourth, the activities of additional genetic factors related to host susceptibility further differentially effect an individual's risk of developing clinically detectable disease. Finally, additional developmental or exposure events increase the probability of metastatic disease as the cancer develops (Kuller 2001). Though stated simply, this *five-factor model* nonetheless illustrates the complexity of our understanding of breast cancer development as a biomedical phenomenon.

Clinically, an individual's diagnosis, prognosis, and subsequent treatment options will be initially determined by the type of breast cancer she has. There are three basic categories for grouping cancer subtypes, which are determined by the family history of the individual patient. *Sporadic* cancers are those that develop in individuals who lack a family history indicative of breast cancer, which account for between 70-80% of all breast cancer patients. The remaining 20-30% of patients exhibit family histories of breast cancer (Rubenstein 2001). For many of these patients, who are said to have *familial* breast cancer, all that is known is that some form or forms of cancer is or are seen in abnormally high numbers of their relatives, usually first and second-degree relatives. Breast cancer patients with abnormally high levels of cancer in their

families, and who meet additional diagnostic criteria stated in the NCCN guidelines below, are thought of as at risk for having genetic mutations that are predisposing for the third category, which is *hereditary* breast (and ovarian) cancer, or HBOC.

Hereditary breast cancer, which covers 5-10% of annual breast cancer diagnoses, is determined by a positive genetic test for one of a number of mutations, the most well studied of which are *BRCA1*, *BRCA2*, *PTEN*, *TP53*, and *CHEK2* (Schwartz et. al. 2008; Wooster and Weber 2003). Of these four genes, *BRCA1* and *BRCA2* currently account for approximately 85% of all hereditary breast cancers. If a mutation occurs in either gene, it results in a significantly increased risk of developing breast cancer over the course of a person's lifetime.²⁷ Although estimates vary widely, and the variance in these estimates is the subject of ongoing controversy (e.g., Easton et al. 2003; Wacholder et al. 2003; King 2003), no matter which estimates are selected, the lifetime statistical risk of HBOC conferred by a BRCA mutation is staggering. The lifetime risks of developing breast or ovarian cancer in the general population are estimated to be 12% and 1.4%, respectively. In women with cancer-predisposing mutations in *BRCA1* or *BRCA2*, the lifetime risks of developing breast or ovarian cancer are roughly 60% and 15-40%, respectively (National Cancer Institute 2011). Estimates put the prevalence of *BRCA1* and *BRCA2* mutations in the general United States population at 1 per 345 individuals (Rubenstein 2001). In Ashkenazi Jews, a founder effect has led to increased prevalence of three particular *BRCA1/2* mutations. It is estimated that 1 member in every forty of this population carry either the 185delAG, 5382insC or 617delT mutations (Struewing et al. 1997), which is

²⁷ BRCA mutations confer an increased risk of breast cancer on both men and women who inherit them, and additionally an increased risk of prostate cancer in men and ovarian cancer in women. Henceforth I will only refer to women in speaking of individuals who face medical decisions following from being identified as a candidate for HBOC; however, it is noted that these findings also apply to men.

considerably higher than the carrier rate of the U.S. population. Understanding the clinical features of hereditary breast cancer is necessary for understanding the types of medical decisions faced by individuals who have, or are at increased risk of, HBOC.²⁸

Before an individual can receive testing for, and hence confirmation of, increased risk for hereditary breast and ovarian cancer, she must meet a number of clinical criteria. These are determined by the National Comprehensive Cancer Network (NCCN) guidelines (Table 4.1). One way to meet these criteria is to present with clinically detectable breast cancer and a certain family history. However, having breast cancer is neither necessary nor sufficient for being a candidate for HBOC genetic testing.²⁹ One can also be a candidate if one has a first or second degree relative who meets the guidelines for genetic testing, which means that in many cases candidates for testing do not yet have breast or ovarian cancer, nor are they suspected of currently having it. Instead, they are viewed as potential carriers of a genetic mutation, a status which is conferred by their family pedigree. Thus, candidates for HBOC genetic testing are

²⁸ Because the genetic mechanisms that cause hereditary breast cancers are poorly understood, mutations in BRCA genes are routinely interpreted as ‘causing increased risk for’ breast and ovarian cancer, a locution that is unsatisfactory because it implies that a mutation causes a change in an individual’s likelihood for developing breast or ovarian cancer over her lifetime. Strictly speaking, a mutation correlates with a range of statistically expressible outcomes, but it does not cause such things; rather, a mutation causes a change of (or loss of) function for whatever the proximate gene product is for that gene. In the present case, the etiological mechanisms describing the BRCA genes’ products are sketches of mechanisms only. For example, evidence suggests that *BRCA1* encodes a protein that functions as a transcription factor involved in a DNA repair mechanism in what has come to be known as the BRCA-pathway (Foulkes 2010). Breakdowns in this pathway are also implicated in Fanconi’s Anemia, another hereditary disease that can cause breast cancer (Couzin 2003). Given the role BRCA genes play in both hereditary cancer and sporadic cancers that show a “BRCAness” in their clinical pathological features (Turner et al. 2004), contemporary research focuses on describing the phenotype of cells with aberrant BRCA genes and therapies that take advantage of the unique genetics of BRCA deficient cancer cells (see Tutt et al. 2005).

²⁹ Absent any relatives who meet NCCN criteria, a patient with diagnosed breast cancer must have received her diagnosis before age 45 in order to meet the NCCN criteria for BRCA testing.

often patients whose breast cancer has been diagnosed as familial, sometimes patients with what appears to be sporadic breast cancer, and sometimes individuals who do not have cancer at all.

Table 4.1: National Comprehensive Cancer Network (NCCN) testing criteria for hereditary breast and ovarian cancer syndrome (National Cancer Institute 2011).

| HEREDITARY BREAST AND/OR OVARIAN CANCER SYNDROME TESTING CRITERIA ^{a,b} | |
|---|---|
| • Individual from a family with a known BRCA1/BRCA2 mutation | |
| • Personal history of breast cancer ^c + one or more of the following: | |
| ► Diagnosed age ≤ 45 y | |
| ► Diagnosed age ≤ 50 y ^b with ≥ 1 close blood relative ^d with breast cancer ≤ 50 y and/or ≥ 1 close blood relative ^d with epithelial ovarian/fallopian tube/primary peritoneal cancer at any age | |
| ► Two breast primaries ^e when first breast cancer diagnosis occurred prior to age 50 | |
| ► Diagnosed at any age, with ≥ 2 close blood relatives ^d with breast and/or epithelial ovarian/fallopian tube/primary peritoneal cancer at any age | |
| ► Close male blood relative ^d with breast cancer | |
| ► Personal history of epithelial ovarian/fallopian tube/primary peritoneal cancer | |
| ► For an individual of ethnicity associated with higher mutation frequency (eg, Ashkenazi Jewish) no additional family history may be required ^g | |
| • Personal history of epithelial ovarian ^f /fallopian tube/primary peritoneal cancer | |
| • Personal history of male breast cancer | |
| • Family history only: | |
| ► First- or second-degree blood relative meeting any of the above criteria | |
| ► Third-degree blood relative with ≥ 2 close blood relatives ^d with breast and/or ovarian cancer (at least one close blood relative ^d with breast cancer ≤ 50 y) | |
| | HBOC criteria met → See Follow-up (HBOC-2) |
| | HBOC criteria not met → See NCCN Breast Cancer Screening and Diagnosis Guidelines |

Although the decision of whether to undergo genetic testing for increased risk of HBOC is often made within a broader context of decisions related to having a breast cancer diagnosis, this is not always the case. This is because there are no initiatives to perform population-wide genetic screening for known HBOC genes; consequently, the only way to become a candidate for testing is to have an appropriate cancer diagnosis or family pedigree. To receive a test, one must either have cancer or have had close relatives who have had it. Because of this, most women who consider testing have had personal experiences with cancer: either they have it or they have seen someone very close to them experience the process of undergoing medical treatment for it. In order to better understand the meaning of this claim, we must better understand the history, purpose, and activity of HBOC genetic testing. Then we will consider a detailed case study of decision-making within the context of this health state.

4.2 Genetic Testing for BRCA1 and BRCA2

4.2.1 *From Discovery to Myriad Genetics*

Discovery of *BRCA1* and *BRCA2* (Hall et. al. 1990; Miki et. al. 1994; Wooster et. al. 1995; Tavtigian et. al. 1996) led to the development of a much publicized genetic test for deleterious mutations that correlate with an increased susceptibility for breast cancer. Motivated by then-recent discoveries of chromosomal regions correlating with increased risk of breast cancer, in the early 1990s four different initiatives were begun to develop a genetic test for mutations in these regions, which came to be known as the *BRCA1* and *BRCA2* genes. By 1999, Myriad Genetics had leveraged its collaboration with Eli Lilly, and its position as holder of significant intellectual property related to BRCA testing, to force its competitors out of the breast cancer genetic testing market. Myriad's patents included "various aspects of the sequences, mutations, and methods of testing for the *BRCA1* and *BRCA2* genes" (Parthasarathy 2005, 22; see also esp. 19-24). However, recently the U. S. Supreme Court struck down some of these patents in a landmark case against Myriad, on the legality of patenting naturally occurring phenomena. While this ruling is of considerable interest for many reasons – not least of which being the impact it might have on innovation in biomedical technologies – for the moment it is unclear what effect it will have on HBOC genetic testing. Currently, a candidate for BRCA1/2 testing must use one of Myriad's services in order to receive genetic testing. However, many companies have announced plans to bring HBOC genetic tests to the market since the Supreme Court ruling. Whether they will be successful will depend on their abilities to overcome not only technological, but also legal barriers (Kesselheim et al. 2013).

Historically, Myriad has offered four different means of testing an individual's BRCA status, each of which has been tailored to fit the needs of specific subpopulations.³⁰ Commonly, Ashkenazim elect to receive analysis of only the three mutations common among the Ashkenazi Jewish population, which costs \$450 USD. For the same price, individuals who have a relative identified as a carrier of a BRCA mutation may elect for single mutation analysis, in which one's genome is searched for a single previously identified mutation in one of the BRCA genes only, rather than for all of the more than 300 possible mutations in both genes (Kahn 1996, 496). Individuals who are neither Ashkenazi, nor have a family member with an identified genetic mutation, can choose between two tests that differ only in the speed with which results are returned. Full sequence analysis of *BRCA1* and *BRCA2* cost \$3,340, with the results being returned in up to three weeks. Those who need faster results can pay around \$4,500 for Rapid BRACAnalysis™, with results being returned to physicians in less than two weeks (Parthasarathy 2005).³¹

³⁰ As the genetic testing marketplace is in flux following the *Association for Molecular Pathologists v. Myriad Genetics* decision, in what follows I will refer to historical pricing and policies in the present tense in order to describe this aspect of HBOC medical decision-making. However, I note that this data will most likely change, and perhaps significantly, in the near future.

³¹ It is worth noting that the costs listed here for HBOC genetic testing are the full costs of testing, which many clients do not pay. Myriad Genetics promises to work with all health insurers to help clients cover the cost of testing, and to notify their clients if out of pocket costs exceed \$350 USD, which provides clients an opportunity to cancel testing before incurring significant expenses. According to a Myriad representative, in most cases testing expenses are reimbursed by medical insurers. For example, for the \$3,340 BRACAnalysis™ reimbursement rates are around 90% (Chambers, personal communication). Of course, such a high reimbursement rate could simply be a product of discrimination against the uninsured. While considering this possibility is beyond the scope of this discussion, it is notable that for those who are uninsured, Myriad offers a Financial Assistant Program that supports testing for individuals who meet their financial criterion, which is a household income of less than the US Department of Health and Human Services poverty guidelines, multiplied by 2. For example, in 2011, an individual in a four person household who lived in one of the contiguous 48 states would have to have a household income of less than \$44,700 to qualify (see: <http://www.bracnow.com/considering-testing/Brac-analysis-payment-insurance.php>).

In order to undergo Myriad's genetic testing, an individual's physician must order the test for her. Scholars, physicians, and various medical societies are in agreement that this 'gatekeeper model' of genetic information is, at least at the moment, best for patients and the health care system (see Hogarth et al. 2008). The primary benefit of this system is that it entails that genetic information can only be given to those who need it and have been informed about its implications. This model is also endorsed by many professional organizations and institutions, which contend genetic testing should be done only in concert with pre- and post-test counseling by an appropriate professional, such as a genetic counselor or physician (National Cancer Institute 2011).³²

4.2.2 Genetic and Clinical Interpretation of HBOC Test Results

After HBOC tests are ordered, Myriad has received the sample, and they have analyzed it according to one of the types of testing described above, physicians receive the results, becoming responsible for communicating them with their patients. The results return in the form of a simple, one-page document. The important information contained in the document can be found in a section marked, "Test Results and Interpretation." Under this section are two boxes, one that conveys the results of the analysis in large, bold-faced, all-caps, type; and another where a table describes the type of test performed, the result, and the interpretation for each test performed. For example, in the three site BRCA analysis for an individual of Ashkenazi decent, a positive result conveyed to the physician who ordered the test is depicted in Figure 4.1.

³² The following organizations in support this position: American College of Medical Genetics American Society of Clinical Oncology, American Society of Human Genetics, International Society of Nurses in Genetics, National Society of Genetic Counselors, National Comprehensive Cancer Network, Oncology Nursing Society, and Society of Gynecologic Oncologists. (See <http://www.cancer.gov>.)

| Test Results and Interpretation | | |
|---|--|--|
| POSITIVE FOR A DELETERIOUS MUTATION | | |
| <u>Test Performed:</u> 187delAG <i>BRCA1</i> 5385insC <i>BRCA1</i> 6174delT <i>BRCA2</i> | <u>Result:</u> No Mutation Detected No Mutation Detected 6174delT | <u>Interpretation:</u> No Mutation Detected No Mutation Detected Deleterious |

Figure 4.1: Example of a positive HBOC test result.

After receiving test results, a physician must contact the patient and communicate them.

Positive results are often given in person, although it is not uncommon to give negative results over the telephone. The activity of giving results often occurs in the context of post-test counseling, sometimes by a genetic counselor and sometimes by a physician. In this interaction, counselors must convey the results of the test, as well as provide a *clinical* interpretation of the results. Providing an interpretation requires more than a recapitulation of the ‘interpretation’ given in Myriad’s results. It also includes assessing the risk of hereditary breast and ovarian cancer conveyed by the individual’s test results as well as how that information influences treatment options. Although Myriad does supply a brochure to educate patients on how to interpret their results, this information serves as a guide for clinicians in constructing their conversations with clients, not as a substitute for a discussion between patients and health care providers. Part of the reason for requiring post-test counseling is that genetic tests in general are often difficult to interpret clinically, and the HBOC test is in particular (Verp et. al. 2001). The following diagram from the National Institute of Cancer captures this point well.

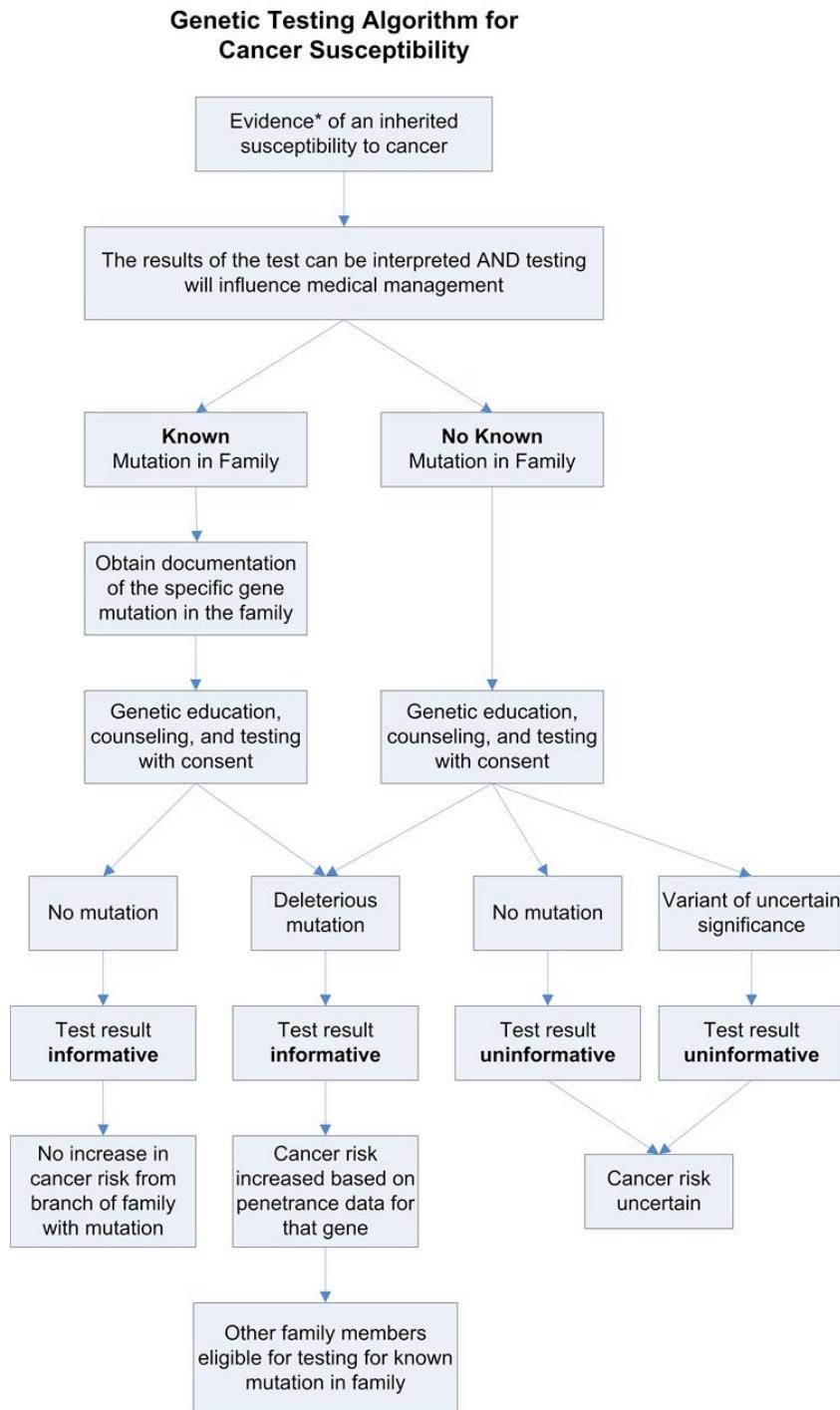


Figure 4.2: Genetic testing algorithm for cancer susceptibility, from the National Cancer Institute, with permission.

Although one might expect a negative test result to be extremely uplifting news, the case is often much less straightforward than that. While studies report that learning of true negative results causes anxiety (Lynch et al. 1997), which is a psychological description of the

complexities of receiving such news, we will put such reactions to one side for the moment. Instead, looking at test results from an epistemological rather than a psychological point of view, we find that negative results are difficult to interpret because of the difficulty in distinguishing between true and false negatives (Rubenstein 2001). A false negative is one where the tested individual carries a BRCA mutation but it was not found by testing. In order to determine if this is the case, an individual must have a family member who has a BRCA mutation that has been identified by genetic testing (the scenario on the far left-hand side of Figure 4.2). Unfortunately, for many women who undergo testing, as they have no access to the tissue sample required for discovering whether a candidate family member is or was a carrier, they fall into the group on the right-hand side of Figure 4.2, those who have no known mutation in their family. For these women, a negative test is clinically uninformative, as the NCI diagram notes.

Distinguishing between these two possibilities has important consequences. If a patient's result is a true negative, then despite the high risk statistically conferred by her family pedigree, her risk of breast cancer is that of the general population. However, if it cannot be determined that the result is a true negative, then the patient's risk is calculated only by reference to her individual and family medical history. Although it is common in such cases to predict risk using one of a number of risk assessment models, the most popular of which is the Gail model, these models will over- or underpredict risk when an underlying, and unknown, genetic mutation is present (*ibid.*). Thus, depending upon the richness of the family history and access to samples from potential carriers, significant epistemic uncertainty often hampers efforts to draw certain conclusions from negative BRCA test results.

Positive test results may also be difficult to interpret because they will sometimes signify mutations in chromosomal regions whose medical significance is unknown. These so-called “variants of unknown significance” (VUS) occur in approximately 15% of all individuals with positive test results. While in such cases it is clear that such individuals carry a mutation in one of the *BRCA* genes, at present this knowledge has no straightforward implications for the patient’s medical treatment (Ponder 1997; Schwartz 2001).³³ The therapeutic options for patients with VUS follow from their family history and other factors, irrespective of the knowledge that they carry a mutation.

In a recent consensus conference on breast cancer genetics and risk management, experts stated that “two major choices” follow in the wake of HBOC genetic testing (Schwartz 2008). Individuals must decide what type of surveillance regimen to begin, which may include breast self examinations, mammography, ultrasound, and in some cases, MRI imaging (Harris 2001). They must also decide whether to undergo risk reduction surgery, such as prophylactic mastectomy or oophorectomy, or whether to undergo pharmacological intervention, such as tamoxifen or raloxifene. Each of these decisions is complex, as it requires the balancing of options, such as oophorectomy versus mastectomy, as well as the balancing of timing. Considering prophylactic surgery requires women thinking about their life plans, and the impact losing their breasts will have on child bearing, child rearing, and their sexuality (Oktay 2005; Green 2008). Studies suggest that women who consider prophylactic surgery begin with heterogeneous perspectives on the idea. Some think of getting HBOC genetic testing as a

³³ The interpretive difficulties following a VUS result are not confined only to HBOC, but are common with genetic tests for any cancer. For instance, the Mayo Clinic, which is developing a test for the 18 genes associated with colon cancer risk, has decided that solving this interpretive problem will be a necessary component of their test development (Heger 2011).

means of gathering more information, some choose not to have testing and elect for surgery nonetheless, and yet others receive a positive genetic test result but decide not to undergo surgery (Ray et al. 2005; Lynch et al. 1997). For those who elect for prophylactic surgery, still more decisions will follow, such as which type of mastectomy to perform, whether to undergo breast reconstruction, or in the case of oophorectomy, whether to use hormone replacement therapy.

In addition to the “major” choices of prophylactic surgery and surveillance strategy, because genetic information has implications for an individual’s relatives, those who undergo genetic testing must also decide whether to inform others of the results, and if so, whom to inform. This is frequently known as an ethical problem regarding the “duty to warn,” where one must choose whether to inform implicated individuals of their potential for carrying a deleterious mutation. Presently, physicians are not obligated to warn family members and can even be held liable for doing so. The received view is that the patient alone should choose who to inform and when (Parker et al. 2001; Schwartz et al. 2008).

As this discussion has made clear, hereditary breast and ovarian cancer is a complex disease and decisions about how to treat it are similarly complex. What has been said thus far in this section could be said with far more detail; yet, at even this grain of analysis it is clear that there are many factors that must be accounted for when an individual considers whether to decide to take a genetic test to estimate her risk of HBOC. Moreover, this is not the only medical decision that such a person will be facing at the time she becomes a candidate for testing. In some instances she will also face decisions concerning the medical management of her cancer – for which the information from the test may be useful. At other times, an individual receiving testing will have to consider whether to elect for an aggressive surveillance

regimen, with its own psychosomatic risks, and she may also consider whether to undergo prophylactic surgery to prevent breast or ovarian cancer. Finally, a candidate for testing will face the question of who to inform of her decision to undergo testing and her results.

In order to convey what it seems like to face, and make, such decisions *from the patient's point of view*, the following section introduces the major case study that guides the development of a model of medical decision-making here.

4.3 The Case of Ellen Macke

In medicine, perhaps more so than in philosophy, it is common to explain phenomena of interest by appeal to case studies. Because understanding and explaining illness requires attention to a number of different factors, each contributing in different ways to the complex cause of an illness, using case studies has become prominent in medicine. Moreover, because these factors operate at different levels of organization, from the levels of molecules and cells to minds and nations, capturing this diversity has led clinical explanations to be predominately, if not always, *interlevel* explanations, which are captured by appeal to complex case studies, or *prototypes* (Schaffner 1993, esp. 97-99). I adopt this approach here to capture the interplay between these factors, *as understood by a particular patient* as she reconstructs her experiences. Before doing so, however, a word of caution is warranted regarding the case study approach more broadly.

4.3.1 *Limitations of Case Studies in HBOC*

A major limitation to the cases one frequently encounters in bioethics is that they are compressed: the information contained within them is frequently biased towards only what is

necessary to support the theoretical analysis under discussion.³⁴ This has prompted two authors to devote an entire casebook to producing cases that capture more of the case details that will interest both clinicians and scholars alike. As Ackerman and Strong note in the preface to their casebook:

Case histories available in the literature of medical ethics typically suffer from two major defects. First, the rich complexity of the factual dimension of most cases is rarely depicted. This shortcoming is reflected in rather superficial examination of the medical aspects of cases. Ubiquitous uncertainties related to prognosis, effectiveness of alternative treatments, risks of harm to the patient, and similar matters are rarely explored...Second, failure to adequately depict the medical and psychosocial aspects of clinical situations impairs the quality of the ethical analysis in crucial ways. Important values or obligations relevant to formulations of the ethical problems may not be acknowledged. The full range of options for resolving the issue may not be identified and explored... (Ackerman and Strong 1989, vii).

Unfortunately, few have heeded Ackerman and Strong's proposal to compose richer case studies.³⁵ And, this is especially true in case studies on hereditary breast and ovarian cancer, which are covered only in discussions of the broader topics of cancer and genetic testing.³⁶ For instance, in his medical ethics textbook, Raymond Devettere includes a short case on the topic of medical decision-making in HBOC, which takes up a single paragraph, followed by a three page discussion of the ethics of decision-making in genetic testing (Devettere 2010,

³⁴ An interesting exception can be found in the many authors' contributions to a recent edited volume where bioethicists share their personal experiences with cancer (Dresser 2012). However, though these essays are often more expansive, inclusive, and detailed than most case studies, they nevertheless remain topic-oriented, rather than oriented to the purpose of thoroughly explicating a particular individual's illness experience in and of itself (cf. Frank 1995).

³⁵ For example, Horn 2003 is a recent example of a thematically organized casebook, where the cases are have been composed precisely in order to reflect a specific theoretical issue, and the given facts are relevant primarily only for the consideration of that topic.

³⁶ As their book was published in 1989, Ackerman and Strong do not include any cases on the topic of genetic testing, nor do they provide cases on the topic of breast cancer.

425-429). Similarly, Judy Garber's seven-page *JAMA* article presents a case study of the decision-making of a young woman with HBOC, but it spends only three paragraphs developing the case, while the rest of the work is focused on reflecting upon the ethical and clinical issues that the case illustrates (Garber 1999).³⁷

Unlike the approach found in medicine and bioethics, a number of works in both sociology and anthropology contain detailed discussions of women's experiences when facing decisions following a breast cancer diagnosis or becoming candidates for HBOC testing. For example, in her study of how women responded to becoming diagnosed with breast cancer, Julia Ericksen (2008) compiled testimonies from ninety-six women regarding their style of information processing and coping, as well as the effects the diagnoses had on their relationships with family, friends, and health care providers. Yet, although Ericksen's research provides rich detail on the cases she analyzes, her work does not cover the particular experiences of women who have hereditary breast cancer, due to the fact that her selection criteria for participants was admittedly idiosyncratic (Ericksen, 2008, 6-11). Thus, while valuable for understanding the rich experiences of patients with breast cancer in general, Ericksen's study will not assist in understanding the experiences of individuals with HBOC in particular.

There are additional examples from the sociology and anthropology literatures that are particularly useful for capturing the experiences of women with, or at increased risk for, HBOC. In their book, *Breast Cancer: Daughters Tell Their Stories*, Julianne Oktay and Dianne Garner use an ethnographic method to capture to narratives of daughters of breast cancer victims. Amongst this population, thinking about genetic testing is common, so Oktay spends

³⁷ Aronwitz (2005) is another example of this style of case study.

considerable time relating the testimony of women who have faced the decision of whether to undergo testing for increased breast and ovarian cancer risk.³⁸ In each of these narratives we find that the women quoted have had personal experiences with hereditary breast cancer, either because they have had it themselves or because they were once caretakers for others who had or were believed to have it. These women often discover later in their lives that they are candidates for genetic testing and for having a predisposition for hereditary breast and ovarian cancer.

Though they often provide richer detail than case studies in bioethics, the approaches common in anthropology and sociology also suffer from some of the same limitations as are seen in bioethical case studies of HBOC. The primary limitation is that they fail to describe any single narrative in significant detail. Rather, they argue for their own thematic account of coping with the breast cancer of a loved one, to which these narratives are put to service.³⁹ For our purposes, what is desired is a case study that conveys the entirety of the experience of making decisions that follow from having, or being a candidate for, HBOC. Although Oktay's work does convey a pattern of experiences among the surveyed HBOC candidates by providing selected first-person responses from many women, it does not provide a continuous narrative in conveying that pattern. Thus, it can be read when taken as a whole, as being suggestive of a

³⁸ There are two additional example of how case studies on HBOC are composed in this literature, Greene (ms) and d'Agincourt-Canning (2003; 2005). Greene's (ms) ethnographic study of women deciding whether to undergo HBOC genetic testing is similar to the chapter on this topic by Oktay in both its content, style, and the conclusions it draws. D'Agincourt-Canning's work will be discussed in detail below.

³⁹ This is also a common limitation to journalistic coverage of cancer. Recent coverage of Angelina Jolie's decision to undergo HBOC genetic testing, prophylactic, and public disclosure of her results (positive for a VUS) is a case in point (Kluger and Park 2013). However, Jolie's unusual first-person editorial in the *New York Times* means that in this case there is some access to the individual's perspective that is typically lacking in health journalism (Jolie 2013).

number of characteristics that emerge when a woman confronts the choice of undergoing genetic testing. But, it does not portray one woman's narrative of that confrontation.

There is one exception to the rule that HBOC case studies are lack sufficient detail for portraying the decision-making activities of HBOC candidates, which is a narrative by Ellen Macke (1996). It is a first-person rational reconstruction of her decision-making about genetic testing and prophylactic mastectomy. It will be drawn on it throughout this dissertation as a means of providing a point of departure for theorizing about medical decision-making from a patient's perspective.

4.3.2 *Macke's Choice*

Ellen Macke begins her reflection as “a 41-year-old female in a family where four other women first had breast cancer in their mid-thirties to mid-forties” (Macke 1996, 31).⁴⁰ Knowing her family members’ experiences of courageousness, coping, care giving, and illness, Macke called the Dana-Farber Cancer Institute in Boston, in 1991, to ask whether it provided any programs for women like her. She was interested in a lecture series or support group, which, as she says, “could put me in contact with other women who shared similar family histories so that I could learn from their experiences.”

Macke was also motivated to reach out for institutional support by her cousin’s recent diagnosis of breast cancer, which was the first diagnosis of someone in family in her generation. According to Macke, that diagnosis “made me feel more vulnerable to the disease than I had

⁴⁰ Due to copyright restrictions, the following section is written in both the first- and the third-person to reduce the total number of words quoted, which is awkward at times. All citations in this section are to this essay so page numbers will be suppressed. Readers are encouraged to read the original article: “A Family History of Breast and Ovarian Cancer,” by Ellen Macke in *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*, edited by Theresa Marteau and Martin Richards, pp. 31-37. Copyright © 1996 Cambridge University Press. Reprinted with permission.

ever before.” The response she received from the Dana-Farber Institute was that physicians there were in the process of establishing a high risk clinic for breast cancer, but that it was not operational at that time. Before she could continue her discussion with representatives from the institute, Macke left Boston for a year.

Upon her return in 1992, two events led Macke to reconnect with the institute: the retirement of the surgeon she had been regularly seeing for mammograms, manual examinations, and medical information, and the fact that her younger sister had called with news that she had “discovered a lump in her right breast and was scheduled for a biopsy.” As Macke reconstructs her thinking, this event in particular led her to pay increasingly more attention to her own health and to think of herself in new terms, as someone who may have a specific risk for hereditary breast cancer, and may need to consider medical treatment for managing that risk:

The biopsy indicated that my sister had invasive ductal carcinoma. The panel of doctors that she consulted first surprised both of us by suggesting that she have both breasts removed and her ovaries as well (with a hysterectomy). This was the first time that doctors had recommended prophylactic mastectomy directly to either of us and the first suggestion that either of us consider prophylactic oophorectomy and hysterectomy. For the panel, my sister’s diagnosis in the context of our family history set off alarm bells. I wondered whether I also needed to pay attention to them.

Macke’s immediate response to learning about her sister’s diagnosis was to reach out to the cancer institute she had contacted almost a year ago. She learned that the high-risk clinic was functioning, and her description of her family history “quickly led to an appointment with the oncologist directing it.” Macke notes that the oncologist “listened to me reciting my family history again. Solemnly, she sketched my family tree with her own notations and began an explanation of the suspected role of a gene named *BRCA1* in family histories like mine.”

Macke had always suspected that her family history placed her at increased risk for breast cancer, yet in her mind, “the source of risk was a nebulous ‘genetic predisposition’”, which was all the more opaque because of her mother’s description of the impact of heredity on breast cancer victims in her family. Growing up, Macke’s mother explained the appearance of breast cancer in many family members in terms of birth order and other vague hereditary factors:

When I was young, my mother attributed her own breast cancer to birth order. She talked about being the first-born daughter of an affected first-born daughter. She told me that as a first-born daughter in this line, I should expect to encounter the disease as well. With the diagnosis of one of my mother’s younger sisters when I was 25, my mother stopped talking about the disease as a problem for first-born daughters. Instead, she dwelt on the personality traits that her affected sister shared with their mother—a certain intensity and vulnerability to stress looming large among them. Her focus implied that if family history increased risk, it operated through some common temperament, either environmentally or genetically shaped.

According to her, Macke had learned her earliest way of thinking about heredity from her mother, and that nebulous understanding of genetics had persisted until this moment when she was given a different explanation by an oncologist. As she puts it, “as the oncologist at the Dana-Farber spoke to me, a vague ‘genetic predisposition’ became a dominant pattern mutation of a gene with a name, even though scientists had not yet identified it.” What Macke found at the institute was not a series of seminars and support groups. Instead, she found herself becoming a patient of a high risk breast cancer clinic that studied the genetic causes of increased predisposition of breast and ovarian cancer.

At this point in her story, Macke has only begun the process of identifying herself as someone who faces a medical decision. She has done so by empathizing with her sister and cousin, and more distally, with her mother and aunt. In addition, she has begun to see herself as

a person with a medical problem – a hereditary predisposition to breast cancer – that can be both diagnosed and treated medically, via medical genetics and such interventions as increased surveillance, prophylactic surgery, and chemotherapy. Making the move of identifying herself as someone with a potential medical problem required Macke to communicate with many people about her health, including health care providers at the Dana Farber Institute and her family members. As we will see, the number of individuals Macke interacts with increases as she actively constructs the health care decisions she faces.

After learning about how *BRCA1* could influence one's predisposition to breast cancer, Macke sought to learn more about the genetics of breast cancer. She learned "that inheritance of this 'genetic predisposition' was not inevitable, but a 50:50 chance for any family member." But, she says, "even more exciting was the possibility that my unaffected cousins and I might learn through linkage analysis whether we were likely to carry *BRCA1* before we made decisions about prophylactic surgery—and perhaps contribute to progress in identifying the elusive gene as well." However, this excitement was also tinged with a realization of the risks conveyed by a BRCA test.⁴¹ Macke had not appreciated that her grandmother's and aunt's cancers conferred an increased risk of genetic abnormality for herself, her sister and cousin, and for future generations. Nor had she realized that genetic mutations could be passed through unaffected males to their children and that men in her family might be at increased risk for breast and other cancers.

⁴¹ As noted in § 4.2, in 1992 there were a number of ways to learn whether one harbored a mutation in the regions that would later be identified as the *BRCA1* (and to a lesser extent) *BRCA2* genes. At this time, "genetic testing" for breast cancer meant to be part of a research study where linkage analysis was performed to discern whether a subject had such mutation. In Macke's case this is how she and her family members participated in research and learned their own BRCA mutation status. They did not receive a 'genetic test' in the sense of contemporary genetic testing for breast cancer; they did not undergo Myriad Genetic's proprietary diagnostic testing service.

As Macke received more information about the genetic basis of breast cancer and the likelihood that she and her relatives were at increased risk, the first of many medical decisions became apparent to her: she had to choose whether to undergo testing for mutations conferring increased risk of HBOC. In her narrative, Macke does not expand on her thinking at this juncture, however, she does make clear that in order to make this important decision she felt it was necessary to include many of her relatives who also had been affected by their shared family experiences with HBOC, and who shared her genetics, and consequently would also be affected by the information contained in the results.

As soon as I left my meeting with the oncologist at the Dana-Farber, I telephoned my father, my sister, and my mother's sisters and brother (all of whom lived 3000 miles away). I told them what I had learned and what participation in the linkage analysis study would require from the family...If the study showed that we were a linked family, we would know that my sister's three daughters were vulnerable to being carriers as well as my cousin's two sons. My mother's youngest sister might still turn out to be at risk even though she had survived to age 55 without a diagnosis. Four unaffected family members remained in my generation, all in their mid-thirties to early forties. If my mother's brother turned out to be an unaffected male carrier, even his daughter could be at risk. The concerns spread to the four unaffected males in my generation as well—for their children as much as themselves.

Macke's family chose to participate in the study, a process which began with several months of collecting samples from many affected and unaffected family members.

Though we do not know how each family member came to the decision to participate in testing because this information is not captured in Macke's narrative, it is clear from what she does say that their choices were made together. Presumably, the family members discussed their own knowledge of breast cancer and the experiences each had with the illness, whether from having had it or from having empathized with a loved one who had. While the substance, tone, and tenor of these discussions is lost, we can estimate this information by attending to

further moments in Macke's story, as she undergoes further medical decisions of whether to undergo prophylactic surgery.

A snapshot of Macke's family as it began participating in the linkage analysis study captures a dynamic that often exists within families where HBOC is prevalent. In April of 1993, Macke's aunt died from complications arising from ovarian cancer while her own daughter, Macke's cousin, was undergoing such an intense program of high-dose chemotherapy that she could not attend her own mother's funeral. To celebrate her aunt's life, her cousin's completion of treatment, her sister's completion of chemotherapy, and their recent marriage, Macke and her husband organized a family reunion. Macke's sister scheduled a prophylactic mastectomy of her left breast immediately following the reunion so that she could have family around to help her through recovery. Thus, we see that in this family, as is often the case in families of HBOC patients, breast cancer was an ever-present component of lived experience. Although this was to be expected at this moment in the life of the family – when many members were undergoing treatment and the family itself was united in participation in research – this was only a moment where the ever-presence of the illness was so marked that Macke found it worth capturing in narrative. In far subtler ways, especially for women in such families, the specter of illness is part of the family narrative that each member constructs in the process of communicating about his or her experiences.⁴²

In Macke's case, her experiences became more aligned with the experiences of her cousin and sister when she discovered that she too had breast cancer. In her own words, "we were still awaiting results from the linkage analysis in August [1993] when microcalcifications appeared on the mammograms of both my right and left breasts. A surgeon performed a biopsy

⁴² See Oktay (2005), pp. 263-282; and, Greene (ms).

to remove a cluster from my right breast. She called with pathologists' report a few days later. Associated with the microcalcifications, they found ductal carcinoma in situ ('DCIS').” Prior to her diagnosis, Macke had become more attentive to her breast health and had identified her own need for medical treatment for HBOC. Now, after diagnosis, she felt as though she unexpectedly faced new treatment decisions, which were uncertain, and which she was unprepared for. “I had not expected a diagnosis before the results of the linkage analysis...Whether or not I was a carrier, however, the DCIS diagnosis began my personal encounter with the disease...my surgeon suggested three options for further treatment of the right breast: (1) close observation alone, (2) radiation therapy, or (3) mastectomy. Scattered microcalcifications remained in my left breast...no one could say for certain what would happen to those remaining microcalcifications; so much about the process of the disease remains a mystery.”

In light of her relatives' experiences, Macke was concerned that surveillance alone would be insufficient to manage her cancer. “I thought about how massive chemotherapy and extensive radiation had disrupted my cousin's life, but failed to arrest her cancer. She had only a one in four chance of surviving the next five years. Then I couldn't help but remember images from the slow, painful deaths that cancer had brought to my grandmother, my mother, and my aunt. The more I thought, the more that bilateral mastectomies began to seem like an opportunity.” Although Macke was motivated to choose surgery because of the relative certainty that intervention conferred (her surgeon estimated a 1-2% chance of cancer post-mastectomy), she remained unsure of her choice and instead decided to carefully weigh her options before making a decision.

At first Macke looked to contemporaneous scientific research for more information about her risk, given her diagnosis. But, she found little useful research on women with HBOC. She “learned that the estimated risk of further breast cancer was 5-8% for women diagnosed with DCIS who receive radiation treatment. For women who had neither radiation nor mastectomy, the estimated risk was 20%,” but these estimates were derived from only one study, which had not followed women who carried mutations in *BRCA1*.

Lacking what she took to be solid scientific information, Macke opted to use “statistical decision analysis” to “evaluate her options.” She “drew a decision tree that began with three branches, one for each of the options among which I had to choose: simple mastectomy, radiation therapy, or close observation.” Each of these branches concluded in a node that then also branched into two options: “recurrence” or “no recurrence”. Although Macke does not specify, it is apparent that each of these final two options was given its own utility value, as were prior nodes in the decision tree. Using this formalization, Macke was able to represent her evaluation of “the impact on my life of traveling along the branches to the end of each path;” however, she could not assess the veracity of her assumptions about those evaluations or of the probabilities that the outcomes at the endpoints of her decision tree would occur. Using decision analysis, she could only estimate “that simple mastectomies were the best choice for me over a considerable range of those probabilities – given the values I had assigned to each path.”

In light of the uncertainty of her evaluative and probabilistic assessments, Macke sought to validate her assumptions against information from her sister and cousin, as both of them performed many of the decision-making activities she was currently engaged in and had later experienced the outcomes whose likelihoods and values she was attempting to estimate. Macke

called both of them frequently with questions about factors, like the impact of treatment side effects and the downstream operations that followed prophylactic surgery.

My sister patiently answered each day's questions. She compared the results of her two surgeries for me: swelling occurred sporadically on her right side where she had the modified radical but not on her left where she had the simple mastectomy. She told me that her self-supporting prosthesis was still comfortable; she had only minor adverse reactions to the adhesive strips that it required. We talked about how she felt without prostheses since the second surgery and how other people reacted, including her husband. We discussed the pros and cons of reconstruction. When my sister thought that I had missed an issue during these conversations, she raised it for me. When I telephoned my cousin for her perspective on the surgery and life without breasts, she did the same. We talked frankly about what choice she would make if she could go back in time far enough to consider prophylactic surgery. Talking to the two of them reinforced my inclination to take advantage of my opportunity. I scheduled my surgery.

Macke refers to surgery as "her opportunity" because in her assessment it was a chance to both manage her current illness and to most significantly decrease her risk of having breast cancer in the future.

Despite her sister's and cousin's validation of her probabilistic and evaluative assessments, Macke's says that she had not decided with certainty whether to undergo prophylactic surgery or not until she received further information, in the form of her BRCA test results. A week before her scheduled surgery, her oncologist gave her "preliminary results from the linkage analysis. Markers believed to be associated with *BRCA1* appeared on chromosome 17q in DNA samples from all of the members of my family diagnosed with breast cancer, including me." With these tests results, Macke now had as much information as she could about her prognosis. In light of her prior diagnosis, she also new with certainty that she had breast cancer. Finally, she also knew, after long and careful discussions with her family

members, how she evaluated the impact various likely options would have on her quality of life. Together, these pieces of information informed her decision.

For the purposes of analyzing her decision-making, it could be useful to know which of these types of information were most compelling for Macke as she chose to undergo genetic testing and have prophylactic mastectomies. But as Macke herself notes, it is impossible to estimate the counterfactual of whether Macke would have chosen genetic testing if other factors were different, such as her sister's and cousin's diagnoses and experiences; likewise, it is impossible to estimate whether she would have chosen another type of medical management in light of her diagnosis alone or the results of her genetic testing alone. For her, “with or without a diagnosis, my evaluation of the choice between ‘close observation’ and simple mastectomies could well have turned out differently if I had feared that the surgery would threaten a career or important relationships...[or] had I been contemplating bearing children or had I lacked adequate medical insurance.” Similarly, “I will also never know for certain whether I would have had prophylactic mastectomies if the results from the linkage analysis had been available before my diagnosis.”

The information Macke had access to in making her decision was of a number of different types, and despite her use of formal decision-making tools, it could not all be assimilated well into that framework. She characterizes her decision-making process as one that took place in three stages, an emotional stage, an analytic stage, and a mixed stage combining both of those elements. As she ultimately elected to undergo surgery, the experiences of her relatives, the information she had received from her physicians, and the probabilities and utilities she had estimated were all assimilated together in order for her to choose that medical intervention amongst the available alternatives. Yet, exactly how this assimilation was

performed – what factors were most important, what factors mattered less than they previously had, and what factors no longer mattered at all – is something that is left out of Macke’s reconstruction. What her story does show is that decision analysis allowed Macke to “test the impact of various assumptions about risk on the outcomes of the various choices available” to her. But as she says, the medical knowledge she received from her physicians that she formally represented “could not give me the same insights and support that I received from my sister and cousin.”

Macke’s decision-making about BRCA testing and treatment for breast cancer ended with her choice to have a double mastectomy, but her medical decision-making about hereditary breast and ovarian cancer did not conclude at that moment. Less than four months after her mastectomies, she chose to have prophylactic oophorectomies and a hysterectomy. As she did not at that point have a diagnosis of ovarian cancer, we can assume that this choice was influenced by her knowledge of her BRCA status as well as her experience with breast cancer diagnosis, prognosis, and treatment.

4.4 Decision-Making in Hereditary Breast and Ovarian Cancer: Social, Temporal, and Physical Dimensions

The central message to take away from Ellen Macke’s narrative of her medical decision-making is that making a medical decision is a complex activity that (i) requires the input of many types of information from many different people, (ii) occurs over a considerable amount of time, and (iii) takes place in a number of different physical spaces. Although, as she tells it, Macke’s narrative is a rational reconstruction of her *individual* decision-making, it still highlights the importance of the *social interactions* she took part in when making her choices. This emphasis

on the influence of other persons underscores that making a medical choice is more complex than would appear on any of the standard models of decision-making discussed in Chapter 2. Macke's decisions were not discrete events that occurred solely within the physical space of a clinical office or waiting room; nor did they occur simply while she was at home thinking calmly, coolly, and carefully about her choices; nor did they occur over a short time interval. Instead, Macke's choices unfolded over days and months, if not years, and they required significant input from her family, friends, and health care providers at a number of different moments.

In making her decisions, Macke explored the social spaces, comprised of her family and providers, in a fashion that permitted her to identify her options and to choose among them satisfactorily. If we begin counting with her initial interaction with the Dana-Farber Institute and stop at her final decision to undergo prophylactic mastectomies, *Macke had at least one significant discussion of her medical care with more than twenty people over three years*. She also recalled past discussions with others who had given her information she felt was relevant to her decision-making, but whom she did not speak with during this time period. An example of the latter case would be her mother's lessons on how their familial breast cancer was inherited. Looking at all of the individuals Macke interacted with while making her medical decisions, we can sort these people into two major groups, her family members and health care providers.

When describing Macke's interactions with her family members, it is useful to draw on a distinction made by Lori d'Agincourt-Canning in her empirical studies of how women's experiences with breast cancer affect how they perceive their personal risk of developing the illness. D'Agincourt-Canning distinguishes between two types of experiential knowledge that women draw upon when conceptualizing risk, *empathetic* and *embodied* knowledge.

Empathetic knowledge is knowledge grounded in the experiences of others, which has been gained either through an individual's participation in another persons illness, such as through care giving or grieving, or through information shared in the form of stories, narratives, and family or cultural lore. Embodied knowledge is knowledge grounded in one's own subjective experience with illness (d'Agincourt-Canning 2005).

In Macke's case, as she initially sought to learn about the medical options available to her, she began with empathetic knowledge of her mother's, aunt's, and cousin's experiences with breast and ovarian cancer. As she notes in the conclusion of her article, her journey of dealing with HBOC began with "the hushed voices of my mother and her sister discussing what happened during my grandmother's stay at the hospital when I was 9" (Macke 1996, 37). These hushed voices carried tones of importance that would later confer increased meaning unto her mother's description of their family's hereditary pattern of illness. Later on in her decision-making process, Macke spoke with her cousin and sister often as she evaluated the impact different medical outcomes would have on her life and estimated the likelihood that they would occur. In these ways, empathetic knowledge was an important component of Macke's decision-making. However, Macke also appealed to embodied knowledge when considering whether to undergo prophylactic surgery or increased surveillance for HBOC. Having experienced for herself the emotions that follow from a breast cancer diagnosis, which she refers to as beginning her "personal encounter with the disease", Macke then gained an additional source of information for her decision, her subjective experience of being diagnosed with the illness.

In addition to the information shared with her by her family members, Macke also learned about her illness from many health care providers under the auspices of a number of private institutions. Even from the beginning of her story, she notes that a surgeon at the breast

cancer clinic recommender by her employer health plan would take the time to deliver “a tutorial on current trends in breast cancer research” (*ibid*, 31). This surgeon was also responsible for giving her regular mammograms, which presumably means he or she helped Macke interpret those current trends in light of Macke’s own particular medical and familial history. Later, as Macke’s sister began treatment for breast cancer, Macke tells the reader that her sister’s panel of physicians “surprised both of us” by recommending that her sister undergo prophylactic mastectomy and oophorectomy. Though it is ambiguous, it is possible that Macke was present for this recommendation, as family members are often present when loved ones learn of cancer diagnoses and prognoses in the clinic. If so, given how salient this information’s was for Macke and its later downstream implications for her treatment decisions, this also be moment where she interacted with health care providers in a way that imparted information, even if the information was not directed at her specifically.

Table 4.2: The types of agents Macke interacted with during her decision-making and token members of each type.

| Types of Agents Interacted With | Token Individuals Within Type |
|---------------------------------|--|
| Family Members | Aunt, Affected cousin, Sister, Unaffected Aunt, Husband, Nieces, Affected Cousin’s Son, Eight Unaffected Relatives and their Children |
| Health Care Providers | Surgeon at ‘Breast Clinic’, Phone Operator at Dana-Farber, Sister’s Panel of Doctors, Oncologist at Dana-Farber, Surgeon at Dana-Farber, Radiologist |
| Institutions | Employer Health Plan, ‘Breast Clinic’, Dana-Farber Cancer Institute |

Shortly after hearing of her sister's prognosis, Macke began a series of interactions with health care providers at the Dana-Farber Institute with the goal of becoming informed about, and then treated for her, her own breast cancer risk and illness. These individuals, of whom Macke mentions an oncologist, a radiologist, and a surgeon, related information to Macke that was necessary for understanding her particular medical status and risk, which she relied upon in estimating the chances of various outcomes' occurrences. In addition, she relied on stories they shared with her about the experiences of their previous patients who had faced decisions that she was confronting. However, according to Macke, these narratives were not as impactful as the ones she heard from her cousin and sister.

In sum, then, Macke interacted with a number of individuals when making her medical decisions, the most prominent of whom are noted in Table 4.2. Notably, as her narrative is a first-person reconstruction of her choices, Macke does not make an effort to describe others' viewpoints about their participation in her decision-making. This is a limitation of her account because in order to describe how medical decisions should be made within groups of interacting individuals, it would be necessary to have a description of other persons' points of view in addition to the patient's (Macke's). However, this information will be gleaned from other cases studies and empirical analyses and added to Macke's as we develop a general model of decision making in the following chapters.

What we learn from Ellen Macke's reconstruction of her decision-making is that her processes of formulating and making choices were distributed across time, space, and individuals. A number of persons helped formulate and make her choices, and they did so in a variety of circumstances over time periods much longer than the momentary depiction of

decision-making than is assumed by the event model of choice favored by autonomy-based informed consent, for example (see § 2.5).

4.5 The Physician as Captain of the Ship

What we find in Ellen's choice is that decision-making is *social*: a number of persons took part in processing information about Ellen's circumstances and providing it to her. In doing so, I contend that they took part in the decision-making process itself in a very important way, which will be elaborated upon in the next section and the next chapter. Before elaborating, though, it is important to note that there is some scholarly precedent for thinking about medical decision-making as a social activity.

In May of 1986 a number of bioethicists, physicians, and other scholars took part in a conference to examine the notion of the physician as the captain of the ship, which they noted had been a guiding metaphor for decades. In her contribution, Nancy M. P. King captures the sense in which the metaphor seems apt for capturing medical decision-making:

Good navigation is a matter of using a lot of information to make a lot of decisions. You need an abundance of technical knowledge about your ship and crew, the stars, the waters you are in and where you are bound. You need experience to line up the pros and cons of each possible route and destination, as well as the probabilities of successfully executing any maneuver you choose. And you need to be able to map your course according to your needs and goals: where you are going, and how – and how fast – you want to get there. Many of the decisions to be made on a given voyage are easy, straightforward, or indisputable; some are difficult and highly technical; at least a few are likely to be risky or controversial. (King 1986, 223)

There is an important analogy to be drawn between medical practice and the nautical metaphor, according to King. Like navigation, medical work often aims at short-term goals that serve to move the entire ship toward its long-term goal of going from one port to another safely and

efficiently. Likewise, moving a ship requires significant technological expertise, the synthesis of various streams of information, and selecting among trade-offs between different short-term goals in the service of higher-order goals. Moreover, experience seems integral to these tasks, and sometimes the tasks will be easy and straightforward. Although at other times they will be difficult and controversial.

King's account appears to suggest that the physician is the locus of decision-making and is uniquely well suited to perform the information synthesis required to "move the ship," so to speak. Such a view would amount to a sort of paternalism, where the physician was fully and uniquely responsible for procuring and integrating information, as well as acting upon it. Yet, others in the conference volume make evident that this would be a misconception.

For our purposes, Ernest Kraybill's contribution is particularly compelling. Kraybill, a neonatologist, examines information processing, decision-making, responsibility, and authority in the Neonatal Intensive Care Unit (NICU), and argues that the nautical metaphor fails to capture it well. According to Kraybill, the metaphor is useful even if inapt, because it draws attention to the many *passengers* that are on the voyage of delivering care to an ill infant over an extended length of time. In addition to the patients and their parents, Kraybill describes a number of individuals who fulfill the many typical roles in the NICU almost thirty years ago. These include various physicians: the attending physician (a certified neonatologist), many consultants from various medical and surgical subspecialties, and physicians in charge of care ("house staff"), including fellows, interns, and residents; nurses, who have their own hierarchy and subspecialties; other health care workers, such as respiratory therapists, clinical nutritionists, and physical therapists; and, social workers (Kraybill 1986, 79-82). While he does not mention pharmacists, chaplains, clinical ethicists, or any of the various administrators

common in the ICU setting, these individuals are also commonly found in the settings of modern NICUs, as doubtless are other individuals.

Given the complexity of the social environment, Kraybill distinguishes between different decision-making activities within it, within which different team members have their roles. Like Pellegrino (see § 3.7.3), Kraybill settles on the notion of a “matrix” to describe decision-making. He then distinguishes between “counseling and advocacy roles [that] are essential to the family’s ability to cope” and what Pellegrino calls clinical judgment. Kraybill sees advocacy and counseling as being “largely outside, but parallel to, the matrix of day-to-day decision making that goes on in the NICU.” Day-to-day decision-making, or clinical judgment, is important but not necessarily paramount. When decisions are particularly complex and significant, these two matrices of decision-making converge, such as during “decision about the care of a terminally ill infant” (*ibid.*, 81).

Thus, for Kraybill, decision-making in medicine cannot be captured well by the nautical metaphor of the captain of the ship. The physician-as-captain has marked implications regarding his or her authority, responsibility, and epistemic abilities that Kraybill seeks to resist. In the NICU decision-making is a social activity that may be led by the physician. But in some cases it may not even be physician-led at all.

“Captain of the ship” seems too restrictive a figure of speech to describe the complexity of relationships that exist in the NICU. In some situations it may well fit... In other situations, e.g., when the diagnosis is not clear, when treatment is controversial, or when no effective treatment is available, and when social concerns or moral issues overshadow medical issues, the metaphor may not apply. Captaincy, when it exists, is based on acknowledged competence and a broad perspective, which is necessary to integrate the team members effectively into a common cause. For this reason, captaincy may be transferred as warranted by the situation. (*ibid.*, 84)

Sometimes, Kraybill concludes, the physician may not be the captain; he or she may have to transfer authority as warranted by the situation, to whomever can integrate team members effectively in order to meet the aim of providing the best care for the patient.

As he believes that the captain metaphor is inadequate for capturing NICU practices, Kraybill considers another nautical metaphor, that of a flotilla, a fleet of ships assembled for naval operations. On this metaphor, the NICU would function without a leader or decision-making authority. Rather, all of the “lifeboats” would function in accordance with the shared aim, “to rescue the same sinking passenger” (*ibid.*, 85). Kraybill rejects this idea on practical grounds: he predicts that different individuals or small groups would end up working at cross-purposes, yet ostensibly toward the same goal. Ultimately, he thus concludes:

The nautical model does not fit the NICU. The recent advances in medical knowledge have been so vast that any one individual’s knowledge is far from comprehensive. Consequently, no one individual’s authority can be absolute. Although a leader is essential, responsibility must be shared. But like a ship’s captain, the NICU leader must have broad knowledge, expansive experience, and acknowledged competence. Like the ship’s captain, he must effectively blend a wide variety of skills to the common goal – the benefit of the patient. (*ibid.*, 86)

According to Kraybill, the captain metaphor fails to capture NICU practices, although it is apt for drawing attention to the social nature of information sharing and decision-making their. Furthermore, another nautical metaphor – the flotilla – is also inadequate because NICU practices are more cohesive and goal directed than it would imply. While knowledge is shared across the many individuals in the NICU social network, Kraybill envisions it as nevertheless requiring leadership. Under normal circumstances that person will be the attending physician, if only because hospital bureaucracy requires that a single individual is responsible for choices. Yet under circumstances of identifying the goals of care and making extremely important treatment decisions, other experts will take on significant roles (such as the social worker), as

will the patient's parents. In such instances of significant complexity, Kraybill contends it is inappropriate to view responsibility as vested in any single person, just as it is inappropriate to see one individual as having sufficient knowledge to perform the decision-making task. He thus believes neither of the nautical metaphors fit.

In response to Kraybill, David Barnard takes issue with the conference's guiding metaphor, because it "is definitely not patient-centered. The image of the physician as the captain of the ship, or of illness and treatment as an ocean voyage requiring the coordination of deck-hands, mates, officers, and nautical machinery, is a bureaucrat's image... It does not reflect the patient's experience of illness" (Barnard 1986, 89). According to Barnard, this approach is all too common. Echoing the themes discussed in the last chapter, he states that for decades modern physicians have exhibited distrust toward "patient's views of their own experience" and have tried "to translate idiosyncratic or culture-bound expressions of discomfort into the supposedly universal categories of biomedicine" (*ibid.*, 90). Barnard aims to counter this trend by arguing that "the experiences of falling ill, being ill, seeking help, and recovering from illness are *social events*" (*ibid.*, 92).

Barnard's argument is rich and stimulating, drawing on literature, philosophy of religion, and psychology (in the form of Bowlby's attachment theory and Winnicott's work on the "holding environment"), so I cannot summarize it here. Rather, I wish only to emphasize that his conclusion bears some similarities to Schaffner's (1999) view discussed in Chapter 3. In this sense, it provides yet another example of how some of the foundational conceptual issues we considered there relate directly to the topic of the social nature of medical choice, and the understanding of human sociality that it presupposes. Barnard concludes, "every aspect of human experience is conditioned by the social nature of human existence" (Barnard 1986, 102).

According to him, we are irreducibly social beings. Consequently, for medical practice to be ethical and patient-centered it must appreciate this. Like Schaffner, Barnard analyses our sociality in terms of a plausible scientific account of its evolution, though he opts for an account of attachment theory whereas Schaffner opted for a few innocuous sociobiological assumptions. Either way, the view they share is that one is justified in the claim that subjective experience may be rendered in scientific terms by appreciating and studying the social context within which it arises, and within which it is communicated about. When we move from this abstract premise to considering its implications for medical practice, we secure a means of re-introducing sociality into practice because it is justified on scientific grounds, just as, presumably, other biomedical knowledge is.⁴³ Therefore, human sociality warrants inclusion into the basic facts of medical knowledge.⁴⁴ Bringing this insight to bear on decision-making in particular, Barnard suggests that recognizing our social nature entails that decision-making must also occur in a social context. Barnard asserts that “the locus of medical decisionmaking...is a fabric of social relationships” (*ibid.*, 106).

Thus, in 1986 a number of thinkers highlighted the social nature of medical practice and decision-making. Less than a decade later, a new area of study in cognitive science was formed called “distributed cognition.” As we will see in the next chapter, its guiding assumption is that

⁴³ It is worth noting that the extent to which biomedical knowledge is evidenced based (and even the meaning of this qualifier) has recently become an open question with the rise of the “Evidence Based Medicine” movement, which proposes a hierarchy for analyzing evidence appealed to in advancing claims in medicine (Sacket et al. 1996, 2000). However, the cogency of this insurgent position is unclear (Worrall 2007). Regardless, it will not be considered in detail in this work, despite its potential relevance.

⁴⁴ This claim could be further substantiated along naturalistic and empiricist lines by appeal to recent work pioneered by Michael Tomasello and colleagues on cooperation (Warneken et al. 2011), cultural intelligence (Herrmann et al. 2007), joint commitment (Gräfenhain et al. 2009), and joint intentionality (Tomasello et al. 2005) in children and primates, though this will not be done here.

interacting groups of persons can form cognitive systems, systems of information processing – and hence thinking – that is distributed across members of the interconnected group. Perhaps serendipitously, the ethnographic work that serves as the empirical foundation for the distributed cognition framework was performed in a nautical context, on the process of navigating a large navy vessel. As I seek to argue that medical decision-making is a distributed cognitive activity, I find the reflections of others on the social nature of decision-making in medicine under the purview of considering the appropriateness of the nautical metaphor for medicine prescient. Let me know turn to substantiating this conviction, which will sustain us through the entirety of the next chapter.

4.6 Distributed Cognition and the Nautical Metaphor

To capture the complexity of medical decision-making processes as they unfold over time, through complex social interactions, and in a number of physical spaces, the next chapter describes this process in terms distributed cognition. The term “distributed cognition” captures an idea that is simple and can be characterized initially without appeal to the specific framework that I will describe in significant detail. The basic idea is that people frequently work together to solve problems, and when they do so, they can be understood as *thinking together* in order to perform *coordinated actions* required to solve those problems.

Having to solve problems together as a member of a team is a familiar phenomenon. Consequently, thinking about it is not a new pastime or domain of inquiry. Consider the task of painting a house.⁴⁵ A house is a very large object. And paint comes in many colors. It is of

⁴⁵ This example has been selected because, for whatever reason, it is a common one within the literature on group intentionality, group cognition, and shared morality; see in-text citations.

course possible to think of painting a house as something that *someone* does and as something that only requires one person's thinking, planning, and acting in order for the task to be completed. We might say that a single individual procures the tools, chooses a color, and then, in the heroic case, performs the entire task of painting the house alone. However, it seems reasonable to assume, as most authors do, that painting a house is a group activity, if for no other reason than it seems reasonable and prudent to distribute labor when so much labor is required (cf. Bratman 2009, 47; Berg et al. 2001, 17).

But even if a painter performs the task of applying paint to a house, this does not mean that the painter has in fact painted the house alone. There are many happenings that must occur in order to paint a house. Reflecting upon them indicates that even to paint a house "alone" actually requires the help of many people. Accordingly, we should conclude that house-painting requires working together to solve a problem.

Consider the following activities that will be performed before a painter can paint a house. Assume that the painter is painting a home in the United States. At some point, the painter has to purchase tools from various sources. In doing so, she interacts with retailers to purchase goods made elsewhere by another person, or more likely, another group of persons. Also, she has to purchase paint, which usually entails eliciting others' opinions about the appropriateness of the color for the house, given such factors as its physical location, the color of the trim and roof, the landscaping, and so forth. The opinions of others may simply mean other retailers conveying their 'expert judgments' or it may mean the opinions of other people who live in the house or have a financial stake in it. Finally, the painter chooses a strategy for how to paint the large object in front of her and chooses what season to paint during and what days to paint on. Though it is conceivable that the painter could not seek any assistance in

choosing a strategy or predicting the optimal weather for her needs, this seems less reasonable than that she would seek help in making these choices. Thus, when painting a house a painter will work with many other people to solve the problem of how to paint the house, even if she paints the object all alone.

The example of painting a house suggests that working together to solve problems is a familiar and quintessential human activity. The purpose of this dissertation is to argue for a way to understand this familiar activity, specifically as it arises in the case of making treatment decisions. The framework of distributed cognition is one way to describe such interactions theoretically, and it is the framework we will adopt here for describing how to work together to solve the problem of making a medical decision.

The central notion that lies at the foundation of the distributed cognition framework is that the *computational metaphor* can be fruitfully applied to persons interacting with one another and with their physical environments just as well as, if not better than, it can be applied to individual human minds interacting with external stimuli. The computational metaphor holds that individual human cognition *is* computation. Applying it to individual persons rather than individual instances of cognition means viewing human interactions in problem-solving groups as computation. The principle concept at work in this metaphor is that of computation, which entails the notion of an *information-processing activity* (Hutchins 1995, 49). Putting this altogether, then, by adopting the framework of distributed cognition, we will endeavor to see persons working together to solve problems as instances of information-processing activities that are directed towards specific goals held by the information processing system, as a whole.

The exact meaning of this description of the distributed cognition framework and its relevance for medical choice will be explicated shortly. Yet, for the moment it can be

provisionally clarified by appeal to the house-painting example. To redescribe the activity of painting a house within the framework of distributed cognition would require attending to the patterns of communication, or *information transfer*, that meet the constraints the system must satisfy in order to achieve the goal of producing a well-painted house. With the paucity of detail with which this example was given above, the system would include the person(s) who owned the house, and consequently held authority and responsibility for the final outcome; it would also include the many persons that (those) individual(s) communicated with in order to decide on the items listed above – the ladders, rollers, color, company to hire, season to perform the work, etc.; and, it would also include the many persons that those persons had to communicate with in order to convey information to the individual(s) holding decisional authority. Clearly, many individuals will be part of the distributed cognitive system that emerges when one “makes a decision” to paint one’s house.

However, the system includes more than just the persons who communicate and thereby convey and process information in the service of moving the system to its final goal of producing a well-painted house. The system also includes the various physical tools, or “artifacts,” that the individuals manipulate in the service of conveying information to one another; for example, the calculator the painter uses to compute how many gallons of paint will be required to paint the entire house; an almanac or network of computers that constitutes the Internet, either of which is required to compute the weather forecast⁴⁶ and consequently the best set of days to perform the physical task of placing paint on the house. As persons interact with these artifacts, they produce information that must be processed in order to meet the constraints

⁴⁶ One might extend this list to such items as satellites, artifacts and persons that constitute government funded surveillance programs, and so forth, but the point is made sufficiently without doing so.

placed on the overall distributed cognitive system as it performs the sub-tasks required to move the system to its goal of a producing a well-painted house.

Adopting the distributed cognition framework thus implies conceptualizing human problem solving activity as activity that can be modeled under a computational metaphor. Such activities are, then, ones where the system is defined in relation to a specific task (Magnus 2007, 300) and where the system performs that task by processing information. For our purposes, thinking of medical decision-making as distributed cognition will motivate us to look to the many sources of information that are required in order to identify the parameters in a medical decision, to provide values for those parameters, and to process the information contained in those parameters taken alone and integrated together. On the distributed cognition framework, to model medical decision-making is to explicate it in terms of information flow between individual persons and between persons and computational artifacts.

At this point the reader may be excused for being offended at the ontology that appears to be implied by viewing medical decisions in the idiom of distributed cognition. One might ask, “Are we really to believe that people are *merely* information sources when they undergo the varieties of illness, pain, angst, anguish, perplexity, surprise, bewilderment, and so forth that commonly occur when medical decisions are made?” No, one is not asked to believe this. The next chapter will address these concerns after describing distributed cognition in detail. For now, the reader is asked to recall that the framework confers a *metaphor* for conceptualizing human interactions – *as* information processing activities. This is a metaphor only, but I aim to prove it is a powerful one that significantly alters our understanding of medical choice. After learning how the activity of navigating a ship can be rigorously and thoroughly modeled as a distributed cognitive system, I will then suggest that the nautical metaphor may be quite

usefully applied to medical choice. However, first we must understand that metaphor in precise detail.

5.0 DISTRIBUTED COGNITION, COMMUNICATION, AND MEDICAL DECISION-MAKING

To model the physical, temporal, and social dimensions of medical decision-making, I will employ the distributed cognition framework. The notion of ‘distributed cognition’ was introduced by Edwin Hutchins in his (1991) contribution to a collection on social psychology and cognition edited by Resnik, Levine, and Teasley, from the Learning Research and Development Center at the University of Pittsburgh.⁴⁷ Hutchins’ introduces distributed cognition in order to describe a familiar phenomenon in everyday life, people working together in small groups to perform tasks more optimally than they could be performed alone. To Hutchins, distributed cognition emerges from even the simplest divisions of labor. As long as labor is divided, cognition will be distributed amongst individuals involved in shared pursuits:

All divisions of labor require some distributed cognition in order to coordinate the activities of the participants. Even a simple system of two men driving a spike with hammers requires some cognition on the part of each to coordinate his own activities with those of the other. When the labor that is distributed is cognitive labor, the system involves the distribution of two kinds of cognitive labor: the cognition that is the task and the cognition that governs the coordination of the elements of the task. In such a case, the group performing the cognitive task may have cognitive properties that differ from the cognitive properties of any individual. (Hutchins 1991, 284)

⁴⁷ For an historical overview of the emergence of the distributed cognition framework see Hutchins 2001.

Stated as such, distributed cognition is a familiar activity that cooperating individuals perform when working together to accomplish shared goals. Distributed cognition describes even the simplest shared cognitive tasks, but it also describes more complex tasks like navigating a ship, the system Hutchins' describes when introducing his view.

Before discussing navigation in detail, let us consider his simple system of men driving a spike. Here the men must work together to complete their task, which requires at least two distinct modes of cognition: cognition necessary to perform the task (what he calls “the cognition that is the task”) and cognition necessary to coordinate the performance of the task with others. In this case, the distributed cognition framework is useful for describing the second type of cognition, where behaviors must be coordinated between agents in order for them to achieve a shared goal.⁴⁸

In his later work, *Cognition in the Wild*, which is known as the *locus classicus* for the contemporary concept of distributed cognition (Magnus 2007, 298), Hutchins develops his theoretical framework in significant detail by performing an ethnography of coordinated work on a navy ship. Section 5.1 introduces this position by summarizing Hutchins’ major claims there. We will learn that the core of Hutchins’ framework is the view that when people work

⁴⁸ It should be noted at the outset that in some moments Hutchins explains distributed cognition in ways that threaten to obscure a distinction between cognition and *distributed* cognition. As is evinced in the above quote, Hutchins appears to hold that his spike-driving dyad exhibits two types of cognition, both of which are properly understood as ‘distributed’. Yet, I think this needlessly overstates the distributed cognition position because his interpretation here blurs the distinction between each agents’ individual cognitive processes, which constitute the cognitive mechanisms causing their individual behaviors, and the cognitive processes that have the specific purpose of coordinating behaviors with another person to perform a task together. It is a basic logical point that in order to maintain a distinction between individual cognition and distributed cognition, there have to be some activities that do not fall into both categories of cognition (Magnus 2007). If every instance of distributed cognition were also an instance of individual cognition, and vice versa, then there would be no distinction between them. Returning to the example, then, this is why I interpret the ‘cognition that is the task’ as individual cognition, and the cognition that is coordinating activities with another individual as distributed cognition.

together to solve problems they should be understood as *coordinating* their perspectives of the tasks to be performed; and, *the successful performance of a task is thus nothing more than the successful coordination of ways of representing a problem such that a solution emerges*. After introducing distributed cognition in detail by considering navigation, it will be important to summarize the conceptual foundations of distributed cognition that will be put to the service of describing medical decision-making here (§ 5.2). The concepts of most importance are information processing, connectionist networks, and computation as constraint satisfaction. After explaining them, they are then applied to the case of medical choice in the remainder of the chapter. Section 5.3 begins this discussion by forestalling anticipated worries about the appropriateness of drawing an analogy between navigation and choice in medicine. Though important differences between these activities and the systems that enact them are recognized, important similarities are also underscored. Consequently, it is argued that by focusing on the social organization of Ellen Macke's decision it can be shown to bear important similarities to the social organization of the navigation system (§ 5.4). However, in the case of navigation, the architecture of the system is discovered in part by close analysis of the communication patterns of its constituents, which is inaccessible in Macke's case. But this information can be estimated by looking at studies of communication between individuals as they contribute to the activity of formulating and making medical decisions in hereditary breast and ovarian cancer and other medical context. This shows exactly how distributed medical decision-making systems might possibly emerge from communications between patients, physicians, family members, and various tools people use to think with, including the paradigmatic medical chart (§ 5.5). Returning to the case of HBOC, it is argued that social scientific studies of individual's experiences as members of the decision-making group can be used to predict the topics that

would be communicated about during a decision-making process like that captured in Macke's case (§ 5.6). Thus, this chapter concludes in Section 5.7 by arguing that by adopting the distributed cognition framework the model of medical decision-making under development meets the criterion of descriptive adequacy articulated in Chapter 2 and briefly succinctly explain what this entails for the remainder of this work.

5.1 Distributed Cognition in Navigation

In the last chapter, the activities of painting a house and driving a spike were given as illustrative examples of persons working together to solve a problem, or persons engaged in activities that exhibit distributed cognition. Such examples are useful for explaining distributed cognition to skeptical readers because they appear to require little higher cognitive activity on first encounter, and yet, this appearance may be shown to be illusory. Like driving a spike, even the seemingly simple task of painting a house requires different types of cognitive effort and at least some of that effort is shared over time and space between different persons in a fashion that may be described as distributed cognition.

Rather than appeal to cognitively simple examples like house painting and spike driving, in his work on human cognition outside of the laboratory environment Hutchins elaborates the distributed cognition framework by explaining ship navigation in extraordinary detail. Specifically, he studies the navigation of a US Navy helicopter transport ship, which he calls the *U.S.S. Palau*. We will begin introducing the distributed cognition framework by describing the navigational system of the Palau as it performs a routine navigational task while the ship is at sea. Once the framework has been introduced in detail, I will abstract some general conceptual principles from it for the purpose of describing medical decision-making.

5.1.1 *Constituents of a Distributed Cognitive System*

In order to understand what is meant by ‘distributed cognition’, it must first be stressed that the notion pertains to *computational systems*: to be cognitive in a distributed fashion is to be a system performing an operation that involves computation. Such systems are composed of *elements*, interactions between which result in the accomplishment of a task that the system has the purpose of performing. Distributed cognitive systems are composed of two types of elements, *persons* and the tools that they use in order to perform subtasks, which we will follow Hutchins in calling *artifacts*.⁴⁹ Together, persons and artifacts serve as the basic building blocks of distributed cognitive systems. So, such systems permit of three different types of organization, in that they can be composed of:

- (i) a person working with other persons,
- (ii) a person working with one or more artifact(s), or
- (iii) a person working with other persons while also working with one or more artifact(s).

The navigational system of the *Palau* is of the latter sort. To describe the distributed cognition framework, I will describe that system in terms of the different elements that work together to

⁴⁹ Artifacts are to be distinguished from the broader category of tools by the fact that they perform some functions that are cognitive in the sense that without the presence of the artifact a person could still perform that task with her own cognitive resources. Consider a calculator versus a hammer. The calculator performs mathematical functions that can, within certain limits of human cognition, be performed by a person. So the calculator can be an artifact if a person uses it to perform tasks that she could do without the calculator, as will be seen in an example later in this section. A hammer might be a part of distributed cognitive system, as for example in the toy example of spike driving above; but, a hammer will not be an artifact because it cannot perform tasks that a human could perform with their cognitive resources in the hammer’s absence. “Artifact” is perhaps an unfortunate term because of its common negative connotations, particularly in the biological sciences and medicine, where an artifact is an effect in an experiment or diagnostic procedure that is attributable to (perhaps ineliminable) errors in the experimental protocol rather to the properties of the specimen under study. In this work, the term “artifact” will be used to denote a specific category of tools, as noted above, as opposed to a spurious effect in a diagnostic or experimental procedure.

produce the functional navigation of the ship. There are many interacting elements in the navigation system that must be described to understand how a ship is successfully navigated. We will focus on the tasks people and artifacts perform together as part of the system (§ 5.1.1.1), the people who are part of the system (§5.1.1.2), and the artifacts they employ when performing those tasks (§ 5.1.1.3).

5.1.1.1 Tasks

The navigational duties of the ship are performed by the Navigation Department, which has the responsibility of fulfilling the needs of the Officer of the Deck (OOD). The primary need of the OOD is that the ship's position is fixed, which requires the performance of two tasks: the ship's actual location must be estimated by being mapped onto a location in the navigation chart (Task 1); and the ship's track must be projected to a future location, given its current location, directional headings, and speed (Task 2). When the ship is underway, its movements are constantly being estimated via the completion of these two tasks, which together are called the *fix cycle*. But, the frequency of the performance of these tasks changes depending upon the ship's location. When the ship is in open waters, *taking the fix* (Task 1) and *projecting the ship's track* (Task 2) can be done once an hour; yet, when the ship is coming into harbor or under potentially hazardous conditions, these tasks must be performed more frequently: once every one, two, three, or six minutes depending upon the needs of the OOD

5.1.1.2 People

Under the most serene of circumstances, the navigational duties can be performed by a single person, while under the most intense they are performed by many more. According to Hutchins, “in order to satisfy the OOD’s need for information about the location and movement of the ship when it is near hazards, the Navigation Departments of Navy ships take on a watch

configuration called Sea and Anchor Piloting Detail” (Hutchins 1995, 41-42). Taking on this configuration requires filling specific roles in the ship’s hierarchy, as defined by specific job titles, which include: Navigator, Assistant to the Navigator, Navigation Plotter, Navigation Bearing Recorder/Timer, Starboard Pelorus Operator, Port Pelorus Operator, Restricted Maneuvering Helmsman, Quartermaster of the Watch, Restricted Maneuvering Helmsman in After Steering, and Fathomer Operator. There are thus ten roles defined in the official Watch Standing Procedures for Sea Anchor Piloting Detail. However, usually an individual takes on more than one of these roles, which is how the members of the *Palau* perform their duties with only eight or fewer men. To get a sense of the workings of the navigation system, we must introduce these individuals and describe their performance.

At the top of the Navigation Department hierarchy lies the *Navigator*, who has supervisory responsibility for the department. However, “navigators seldom do any navigating themselves. The work of the Navigation Department is carried out by enlisted personnel of the quartermaster rating under the direction of the Assistant Navigator (a quartermaster chief)” (*ibid.*, 20). The *Assistant Navigator* is responsible for making decisions about the ship’s motion and communicating them to the *conning officer* in the form recommendations. If the course fails to meet the demands of the OOD, corrections are then made accordingly. When information about the ship’s motion is passed from the assistant navigator to the conning officer, it is given in variations on the following form: “‘Recommend coming right to 0 1 7 at this time.’ The conning officer...will act upon [the recommendation] by giving orders to the *helmsman*, who steers the ship, or to the *leehelmsman*, who controls the engines” (*ibid.*).

Below the assistant navigator in the departmental hierarchy are a number of enlisted personnel who perform the integral duties of taking measurements required to estimate the

ship's location and assisting in the computations required to complete the fix cycle. Each of these individuals is located in a specific area of the ship and has specific artifacts at his disposal that are required to perform his duties. The most important parts of the navigation work are done on the 05 level in the pilothouse and charthouse. In this area are a number of work stations where essential navigational duties are performed, such as the chart table, the two pelorus stations, and the helm. Most of the artifacts used for gathering the information required to complete the fix cycle are also located in this area, including the chart, gyro, magnetic compass, and peloruses. Since these items are located in a space that is roughly 335 square feet in size they can often be operated by only a few people under normal conditions.⁵⁰

5.1.1.3 Artifacts

In order to perform the fix cycle, the assistant navigator must receive properly recorded bearings by the *navigation bearing recorder*, who has the responsibility of communicating with members of the navigation team who are not in the pilothouse. Two such individuals are the *pelorus operators*, who are stationed on the wings of the ship. In order to compute the ship's location by triangulation, the bearing recorder needs to know where the ship is relative to three distinct landmarks. So each pelorus operator is responsible for taking relative measurements of the ship from one or two chosen landmarks. Once they know these landmarks, the pelorus operators use an instrument called an *alidade* to measure the position of each one in relation to the ship. They are then responsible for communicating that measurement to the bearing recorder at the appropriate time via *telephone*. For example, in one moment captured by Hutchins, the bearing recorder looked at his *wristwatch* and said "Stand by to mark. Time 14," after which a pelorus operator responded, "Dive Tower, 0 3 4" (*ibid.*, 45), which communicated that a building

⁵⁰ For a diagram of the pilothouse and charthouse see Figure 1.1 in Hutchins (1995, 27).

named the Dive Tower was measured at 034° from his station at the time of 16:14. In addition to taking the three spatial measurements from the pelorus operators, the bearing recorder is also responsible for taking measurements from the *fathometer operators*, who provide a measure of the depth of water under the ship at the time of the reading. For example, in the moment just discussed the fathometer operator used the *fathometer* to take the depth, which he gave to the bearing recorder as, “Fifteen fathoms” (*ibid.*, 45), a measure both individuals then logged into their respective *log books*.

With the information gathered by the bearing recorder, the assistant navigator can plot the ship’s location and speed, which can then be used to project the ship’s forward motion and hence to estimate its location at the next planned fix cycle. In doing so, the assistant navigator uses a number of devices to plot the given bearings on a *navigation chart*, which allows him to coordinate the location of the ship by triangulation. Here is Hutchins’ description of this activity, as performed by Quartermaster Chief Richards:

Chief Richards held in his hands a one-armed protractor called a *hoey*. The hoey has a circular scale of 180 degrees on it, and a straight-edged arm about 18 inches long that pivots in the center of the scale. It is used to construct lines on the chart that correspond to the lines of sight between the ship and the landmarks [as measured by the pelorus operators]. Richards aligned the straightedge with the fourth tick mark to the right of the large mark labeled 030 on the scale of the hoey and turned the knob at the pivot point of the arm to lock its position with respect to the scale. He then laid the hoey on the chart and found the symbol on the chart that represented the Dive Tower. He put the point of his pencil on the symbol on the chart. Holding it there, he brought the straightedge up against the pencil point. Keeping the straightedge against the tip of the pencil and keeping the protractor scale further away from the charted location of the landmark than the anticipated location of the fix, Richards slid the hoey itself around on the chart until the directional frame of the protractor scale was aligned with the directional frame of the chart. The wedge of the arm now lay on the chart along a line representing the line of sight from the ship to the landmark. Richards held the hoey firmly in place while he removed his pencil from the symbol for the

landmark and drew a line segment along the protractor arm in the vicinity of the expected location of the ship on the chart. (*ibid.*, 46)

Repeating this exercise two more times with two different landmark measurements will give the assistant navigator a triangle on the chart that represents the ship's actual location. If the bearings have been correctly taken, then the result of the calculation is an estimate of where the ship resides: in actual space it is somewhere in the vicinity of the area represented on the chart that is captured by the triangle lying at the intersection of the three lines of position plotted by the assistant navigator on the chart. Thus, the smaller the triangle the more precise the estimate of the ship's location, and consequently the better the navigation duties have been performed. This is why, according to Hutchins, "it is sometimes said that the navigator's level of anxiety is proportional to the size of the fix triangle" (*ibid.*, 30).

5.1.2 *The Navigational System*

Although there are a number of secondary and tertiary duties of the navigation department, the description of which would illustrate the significant complexity of the many tasks required for successful operation of the navigation system, their primary duty is to perform the fix cycle and to communicate its results to the officer of the deck. This requires a number of people to take a number of measurements, perform a number of calculations, and to communicate various information to one another. If more detail were provided, it would be noted that proper navigation requires that the fix cycle be performed continuously, and often repeatedly over extremely short periods of time, so a fuller description would discuss the workings of additional personnel with other measuring instruments and artifacts, as well as many additional moments of communication between these persons. It is not necessary to go into such detail to capture the pith of the distributed cognition framework as it is exemplified by the navigation system.

On the distributed cognition framework, the *distributed cognitive system* that performs the task of navigating the ship is constituted by the individuals who make up the navigation department and the artifacts they use to compute the location of the ship. In the example of performing the fix cycle, the members of the navigation department must work together in order to determine the ship's location relative to three landmarks and the undulated sea floor. This information must be communicated to other members of the navigation team. Then those members must employ additional artifacts in order to compute the ship's actual location using the method of triangulation that is permitted by the temporal and spatial measurements recorded and transposed onto the chart. Altogether this is an example of distributed cognition because, although it is conceivable that a single individual could perform all of these tasks without the aid of artifacts under some circumstance, in practice these tasks are performed by a group of persons working together and with a number of artifacts. Working together, they *perform measurements, share information, and perform computations* to solve the task of estimating the ship's location.

The purpose of this example is to illustrate that the central concepts of the distributed cognition framework are *information* and *computation*, which are communicated between and performed by individuals and artifacts. The next section elaborates on the meaning of these concepts within the framework, again with reference to the navigational system. Sections 5.3 onward apply these concepts to the activity of medical decision making; in so doing they show how medical choice can be understood as a distributed cognitive activity.

5.2 Basic Concepts of Distributed Cognition

In describing the ship’s navigation system as a distributed cognitive system, Hutchins employs *the computational metaphor*, which is the principle metaphor of cognitive science.⁵¹ To understand this metaphor and its application to any system (including the navigational system) requires explaining the concepts of information processing (§ 5.2.1), networks (§ 5.2.2), and computation (§ 5.2.3).

5.2.1 *Information Processing*

The computational metaphor is a way of understanding the workings of the human mind and brain. Just as employing metaphors generally involves describing one object in terms of another, different object, the computational metaphor involves describing human cognition in terms of computing. To understand what this means, we will first describe computing by considering the familiar personal computer (PC).

A PC is composed of hardware and software. Hardware consists of a number of modularly functional components, which are familiar items to those who have ever considered how a computer works. These include such things as processors, hard drives, random access memory modules (RAM), graphics cards, wireless networking cards, Ethernet ports, USB ports, displays, and the many cables and connectors that connect these and other components to the

⁵¹ Compare this with Paul Thagard’s claim, that the “Computational-Representational Understanding of the Mind” is the “central hypothesis of cognitive science,” which holds that “thinking can best be understood in terms of representational structures in the mind and computational procedures that operate on those structures” (Thagard 1996, 10). Although Thagard’s use of the term hypothesis might seem to have a different connotation than the term metaphor, in context it is not. Thagard holds that cognitive scientists understand the mind *as if* it is a computational system, by which he means that this way of understanding the mind “employs a fertile analogy derived from the development of computers” (*ibid.*, 11).

logic board (or motherboard). Altogether, the hardware serves as the basic physical system that is required to produce a functioning PC. It is composed of connected elements in a particular organization.

However, the physical system is necessary but not sufficient for producing a PC. One also needs software in order to bring about the familiar personal computing experience, which consists of an operating system and a number of applications. The operating system manages the hardware resources that a computer contains and serves as an intermediary, controlling access to those resources as they are needed for the operation of applications. Applications perform the functions that constitute the typical end-user experience with a PC, such as word processing, web browsing, data management, and media playback.

Hardware is responsible for reliably storing, transmitting, and transforming information via electrical circuitry. Software is responsible for managing these storing, transmitting, and transforming activities in such a way that they may be controlled by the PC user. For instance, if a user wants to compose a document, then the operating system provides a graphical interface that permits the user to operate assistive devices (peripherals) to select a word processing application, like a mouse and a keyboard. Upon selection, that application then interacts with a number of hardware elements via the operating system, such as the processors, RAM, and hard drive. As one selects a document, the application uses a number of stored templates and temporary files to realize the user's experience. Ultimately, the words on the virtual page (on a screen) are encoded and stored in a particular area on the hard drive. The operating system manages the file system on the drive, which enables the application to direct the file to that location. In most PCs, all information, including the file system and the file itself, is saved on a

hard disk drive in the form of binary digits (0 and 1), or bits, which correspond to the state of magnetization of a specified region of magnetic discs.

The basis of the personal computing experience is, then, the storage, transmission, and transformation of information. In other words, although anyone familiar with their beloved (or despised) PC knows that the machine does a number of things, and some of them well, at root a PC is designed to do one thing that makes all of those other things possible. Personal computers are designed to process information; they are *information processing* machines.

In employing the computational metaphor, cognitive science commits to understanding cognition in terms of information processing. On this account, the mind/brain contains *representational structures* analogous to the structures created by spinning magnetic disks in modern hard disk drives. On this metaphor, the mind/brain also contains patterns of cellular activity akin to software that manage the states of those representational structures, much like a word processing application manages the resources that must be used to realize the user's experience and store compositions she has created.

In invoking the computational metaphor to describe the navigation system aboard the *Palau*, Hutchins explicitly puts the information-processing approach of describing cognition to work in the service of describing navigation. According to him, this is what it means to understand navigation practice in terms of distributed cognition, which is to understand it as *a practice whereby information is processed in order to move the overarching system to a goal state*. For Hutchins, in order to describe the navigation system, we must describe it in terms of computations that are “realized through the creation, transformation, and propagation of representational states” (Hutchins 1995, 49). So, to understand how the navigation team performs the fix cycle, we must describe it as a group of elements (the persons and artifacts)

whose interactions *store, transmit, and transform information* in order to enact the computations necessary for performing the fix cycle. In this case, the elements that interact to perform the information processing tasks required to accomplish the functions of the system are persons and artifacts, rather than parts of brains that bring about cognitive functions in specific persons or parts of personal computers that underpin the realization of the familiar personal computing experience.

5.2.2 Networks and Connections

In cognitive science there are a number of ways to employ the computational metaphor. Perhaps the most popular approach of the last thirty years has been to describe the brain in terms of *networks* of interconnected computational elements, where the elements are various types of cells found in the brain and the interconnections are the many types of stimulatory and inhibitory interactions these cells can have with one another. This approach is often called *connectionist* because of its emphasis on the connections between simple elements (e.g., Thagard 1996, 107).

Artificial connectionist networks provide a useful analogy to the brain because they are composed of multiple hierarchically organized groups of computational elements akin to the hierarchically organized cellular networks found in the brain. Moreover, artificial neural networks have been shown to encode, store, transmit, and transform information along the same principles as neural networks do (Churchland 1986, 458ff.). The ubiquity of such artificial networks has led the term “network” to be applied to both biological and artificial networks equally.

Generically, networks are simply organized elements that receive, respond to, and transmit stimuli. Simple computational networks can be represented mathematically in terms of

elements that are connected to one another via inputs and outputs, as depicted in Figure 5.1. At the bottom most level of the network, the elements receive stimulus from whatever input source(s) are used to train or stimulate the network. If a network is solely a mathematical network, then these inputs could be something like a string of bits, or binary digits, in the form of 0s and 1s (*e.g.*: 00001101000110). Other artificial networks can have bottom layers that are composed of physical elements that receive stimulus and then transmit bits to elements higher up in the network, corresponding to that input.

For example, researchers have constructed an artificial neural network (ANN) that can ‘perceive’ faces. At its bottom level, this network is composed of light-sensitive elements that receive input about the luminosity and color of specific regions on a 64 x 64 grid. Each of the bottom-most elements then transmits information to elements in the next layer up about the region on the grid it is trained to attend to (Churchland 2002, 293-302). The middle layers of a network receive inputs from the lower layers at varying numbers, frequencies, and intensities, which then cause them to transmit information of corresponding variety on to any elements they are connected to. In Figure 5.1, each element in the middle layer (the “hidden layer”)⁵² receives inputs from numerous elements in the input layer. Depending upon the structure of these inputs, each middle-layer element will then transmit a stimulus on to the output layer. In this figure, the output layer is a single element that receives stimuli from all of the middle-layer elements. Just as the middle-layer elements process their respective inputs, so too does the outer-layer element, which will then produce a final stimulus whose content communicates the

⁵² This is called the “hidden layer” because researchers will not know, *a priori*, what computational structure that layer will have. That is because the elements in it will adapt to the inputs they receive and will send stimulus to elements they are connected to in correspondence to those adapted set ups. For a more detailed explanation of ANNs, see Churchland 1989.

processing that was performed by the network as a whole, the specific content of which will depend upon the computational structure of the output element.

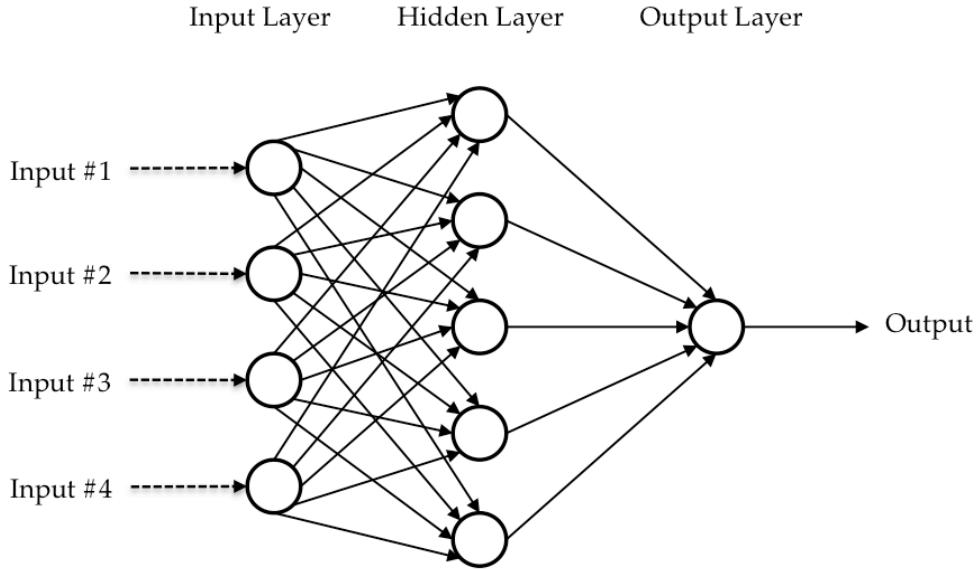


Figure 5.1: Basic network diagram. Adapted from Figure 1.8 in Priddy and Keller (2005, 8).

We can think of the individuals and artifacts that interact together aboard the *Palau* during a performance of the fix cycle as a network of connected elements.⁵³ Returning to that example, some of the individuals who are parts of the network are the assistant navigator, the bearing recorder, the pelorus operators, and the fathometer operator. Some of the artifacts involved are the chart, the hoey, the gyro, the telephone, and the alidade. When, for example, the pelorus operator uses the alidade to measure the location of the ship relative to the Dive Tower, the

⁵³ Indeed, the network representation is common to sciences other than cognitive science and it is useful for other purposes than as a metaphor or analogy for studying the mind/brain. Outside of neurobiology, modeling biological systems in terms of networks is now common, with research programs studying topics such as intra- and intercellular dynamics (Barabási and Oltvai 2004), genetic and metabolic networks (Wagner and Fell 2001), relationships between genetics and organismal behaviors (Anholt 2004), and ecological and evolutionary dynamics (Proulx et. al. 2005). In the case of distributed cognition, thinking about social systems in terms of networks is simply another aspect of adopting the computational metaphor.

pelorus operator is procuring information about the relationship between the ship and that landmark and transmitting that information to the bearing recorder. The pelorus operator employs the alidade to compute the location of the landmark relative to the ship, so the alidade can be said to be performing information processing activities too, in that it coordinates the visual sighting of the landmark with two compass scales that are imprinted upon its sighting device. Because of its design, the alidade allows the pelorus operator to not only see the landmark through its sight, but also to see the landmark immediately as an object located at a certain geometrical orientation to the ship. Expanding this use of the network representation to encompass the entire Navigation Department during the performance of the fix cycle summarized in Section 5.1, the navigational system can be represented as diagramed in Figure 5.2.

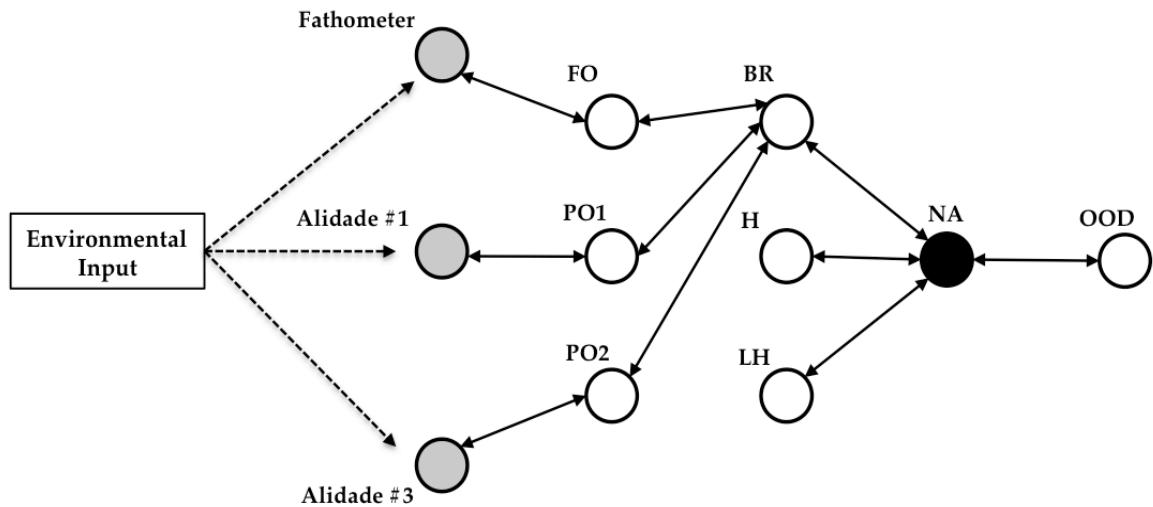


Figure 5.2: A network representation of the navigational system performing the fix cycle. Environmental stimulus is represented with unidirectional dashed arrows. Bidirectional solid arrows represent information flow within the navigation system, between persons and artifacts and persons and persons. A circle represents each element in the system, with artifacts represented in grey shading and persons represented by white shading (except the Navigation Assistant, who is shaded black). The abbreviations for persons correspond to members of the Navigation Department.

In the above figure, the navigational system is represented as a distributed cognitive system by analogy to a computer network. Each element in the network corresponds to an element in the system and each solid line corresponds to an information processing, storage, transfer, or transformation activity. Representing the interactions between members of the navigation department and their equipment in this fashion clarifies the emphasis that the distributed cognition approach puts on information processing. That is, whether information is being processed by a person or an artifact, or whether it is being transmitted between persons, between artifacts, or from person to artifact, what matters is the flow of information and its impact on the functioning of the system. So to model the system's activities we must think of it as a system that is caused to perform its task(s) by changes in the flow of information. One final aspect of this framework must be explained for this way of looking at social groups to fully come into view, the relationship between computation and constraint satisfaction.

5.2.3 Computation as Constraint Satisfaction

When an artificial network is set up such that it performs an information processing activity, the network is said to be performing computations in the face of specifiable constraints. As a functional system, the network executes tasks that together lead to the accomplishment of the goal or goals of the system. These tasks constitute the ways the system can satisfy the constraints upon it, which is why, within cognitive science, such systems are referred to as solving *constraint satisfaction problems*. As a further aspect of the computational metaphor, cognitive scientists commonly characterize minds, qua networked information processing systems, as performing the task of cognition in light of known or presumed constraints. As such, the mind/brain is rendered as one of many systems that must solve constraint satisfaction problems in order to perform their canonical functions.

In adopting the computational metaphor to describe the workings of the navigational system, Hutchins explicitly describes the system in terms of the constraints it must satisfy to perform the function of navigating the *Palau*. He also distinguishes between the basic constraints that the system must satisfy, which are physical constraints, and additional constraints unique to the social aspects of the system. According to Hutchins, the primary constraints on navigation are simply the directional constraints on locating an object in space. That is, when at seas, the answer to the question, “Where am I?” must be given in three-dimensional space, meaning that three one-dimensional values must be given for the answer to have the correct form. Given these values, the ship’s position can be estimated on a three dimensional graph in terms of its depth, longitude, and latitude. Yet, commonly navigators are only interested in the location of a ship on the surface of the sea, irrespective of the depth of the water upon which it is floating. So, the ship can be represented in just the two-dimensional space of longitude and latitude. Consequently, the basic constraints on performing the navigation task are two one-dimensional constraints that take the form of measurements of the ships location on a chart along two dimensions.

Returning to the example of the fix cycle, the way the navigation system performs its function in the face of the basic constraints is complex, in that there is no single element that performs a computation to move the system from a state of not having an estimate of the ship’s location to having an estimate of its location. Rather, all of the elements in the system work together in order to satisfy the basic constraints of estimating the ship’s location in two dimensions. The system does this by forming representational states of pieces of information that are required to perform the computational task of the system and coordinating these different representational states such that a solution to the task emerges. Thus, the navigation

system reaches its goals as information flows through the network such that the function of the system is accomplished.

When describing the many representational states that are formed, propagated, and transformed in the successful operation of the navigation system, it is important to bear in mind that these states are states taken by persons as well as artifacts. Thus, the alidade represents the landmark in its viewfinder in terms of its angular orientation relative to the ship, which is possible because the alidade's representational markings have been calibrated with the ship's compass and gyro, two additional artifacts that are part of the system. When viewing the alidade, the pelorus operator then reads the markings on the artifact in order to obtain a three-digit value that represents the ship's location relative to the landmark. In the case of the Dive Tower, mentioned earlier (§ 5.1.1), this value was 0 3 4. Although what is literally seen in the alidade is a far away landmark and two separate rows of degree values, the pelorus operator conveys this information in a form that differs from what is actually seen. He tells the bearing recorder, "Dive Tower, 0 3 4", an utterance which the bearing recorder then transforms back into a three-digit value entered into the appropriate row and column in his log book. Once in the bearing log, this measurement has then been organized such that it sits alongside two other measures of different landmarks and their angular location relative to the ship. These three values are also paired with a depth and time value. In this processed form, the information now becomes useful for the assistant navigator, who can use the values in the bearing log to estimate the ships' location, at that time. The assistant navigator uses each angular value by entering it into the hoey, which mechanically represents the angle relative to the ship, allowing the navigator to draw a pencil line from the landmark to a sequence of regions on the navigation chart representing the first of three lines of position, which together provide an estimate of the

ship's location. When the navigator has plotted all three lines of position, the fix triangle results, which is yet another way in which the information represented sequentially by the alidade, the pelorus operators, and the bearing recorder, is propagated and transformed onto another medium – the navigational chart. With the lines of position coming together on the chart to form the fix triangle, the first task in the fix cycle has been completed, and the various representations of the ship's relative location to the landmarks at a specific time and depth have been coordinated in order for that task to have been accomplished (Hutchins 1995, 119-146).

As with the above descriptions of the senses of information processing and network organization that are central to the distributed cognition framework, this description of the way constraint satisfaction fits into that framework could be elaborated upon considerably. Hutchins spends hundreds of pages describing how elements in the navigational system coordinate representational states in ways that satisfy the constraints of the system. In this way, he depicts the system as one that performs computations, where to perform computations means that *the system coordinates a number of representational states such that, in the end, a solution to the problem emerges that satisfies the constraints imposed upon the system.*

In a useful term of art, Hutchins says that this way of describing the system is following the “trail of representations” (*ibid.*, 129) through the system such that it is clear where the inputs are, what their content is, and how these informational stimuli are processed by the system to result in an output. In the case of taking the fix, Hutchins says, “what we see here is a set of functional systems, each of which is capable of making the mappings from inputs to outputs but each of which organizes a different set of representational media in relation to one another” (*ibid.*, 150). That is, the elements in the larger navigational system (the artifacts and persons) come together to constitute distinguishable functional subsystems, such as the alidade, the gyro,

and the compass; the pelorus operator and the alidade; the pelorus operator, the telephone, the bearing recorder, and the bearing log; and, the navigator, the bearing recorder, the log, the hoey, and the chart. Each of these functional systems takes in specifiable inputs through certain channels and transforms the inputs via mapping relations into alternative representational states. Altogether, these transformative activities, are constitutive of the computational operations of the navigational system, and are how the system performs the task of navigating the *Palau*.

5.3 From Navigation to Decision-Making

In the case of navigation, following the trail of representations requires attending to the locations on the ship where elements in the system form representations of information latent in the environment, identifying the content of these representations, and tracing their transformation through the system, such that the overarching goal of navigating the ship results. Some of the elements in the navigation system are artifacts. Other elements in the systems are people. Though some of the individuals could, given unlimited time, be capable of performing the task of navigation without the aid of other individuals or artifacts, in practice navigation is a team activity: it is always performed at least with the aid of tools, and often in small groups composed of persons working with each other and with tools. In this section I suggest how small groups of interacting persons making medical decisions over time might be described as a distributed cognitive system like navigation and the limits there are to this analogy.

Thus, the question that now arises is to what extent navigation bears an analogy to medical decision-making. In other words, how does navigation relate to the topic of inquiry? Navigation and medical decision-making exhibit the following similarities. In each activity information is transferred within small groups, over time, in order for the group to achieve some

goal. In navigation the goal is to estimate the ship's location and act to change its speed or direction in a way that satisfies the physical constraints of the system. In medical decision-making, the goal is to estimate a patient's prognosis and act to alter it in a way that is consistent with the norms of medicine and the patient's beliefs and preferences. The norms of medicine – its technical limits and professional ethics – and the patient's values are the constraints that a medical decision-making system must satisfy.

Another similarity between making medical choices and navigating large ships is that in both the information transfer that occurs within the system takes the form of verbal and nonverbal means of communication. Some of these are deliberative, requiring discussion, reasoning, and agreement, while others are imperative, only requiring command and assent. In both navigation and medical decision-making, these communicative acts are performed in *social spaces*, meaning transitory or static arrangements of persons that mediate the flow of information, and hence the rate and types of processing the system can perform. Both the Navy and the Clinic have their own explicit and implicit hierarchical social organizations (recall Kraybill's analysis of the NICU discussed in § 4.5). In each, there is a chain of command of sorts. Thus navigational and medical decision-making systems are also similar in terms of their hierarchical structure.

Of course, the similarities between navigation and medical decision-making only go so far. The time span during which the navigation system typically operates may be very different than the time span during which many medical decision-making systems operate. In hereditary breast and ovarian cancer, for example, many patients have been impacted by a loved one's struggle with the disease, which often means they have thought about HBOC for many years. If communicated, these thoughts may be described as pieces of information that feed into their

own medical decisions as they emerge during routine or acute medical care. Likewise, physicians, care givers, and other health care professionals have also had many experiences with HBOC patients, which moves them to form their own intuitions about the disease and the value of various medical services under various circumstances. If communicated, the terms used to describe the experiences also become part of the information within the system. Thus, medical decisions may occur over longer time spans than the operations of the navigation system.

In addition, there is a stark difference between the fates of the elements in each system with regard to the outcomes of the systems' operations. In the case of navigation, we may assume that the elements of the system *share a fate* that is a direct consequence of the system's actions. If the navigation system performs adequately, the ship changes course successfully, whether it makes a turn or stops at a pier. Presumably, the individuals and artifacts all make the turn or come to a stop with the ship under normal conditions. Yet this is not the case in medical decision-making. There the elements in the system do not have a shared fate. Even if a decision is performed successfully, and the subsequent treatment is performed optimally, given the epistemic uncertainties of prognostication, it remains not only possible but in some cases likely that the patient will nonetheless remain in a poor or worsened health state. Thus, unlike in navigation, the elements in a medical decision-making system do not have a shared fate even subsequent to the system's attainment of its aims.

Finally, there is perhaps a more important and glaring sense in which medical decision-making appears especially dissimilar to navigating a ship. On the face of it, the information processed in the two systems seems markedly different. Consider the case of deciding whether to undergo a prophylactic mastectomy. Studies have shown that when women make such decisions, they are influenced by their anxiety, worry, and risk perception (De Leeuw et al.

2008; Mendick et al. 2010), as well as their perception of the impact the surgery will have on their sexuality, including their relationships with partners and sexual identity (Schneider et al. 1997; Ganz et al. 1999). If the information processed in medical decision-making systems is of this sort, about complex emotions, perceptions, and their bearing on such constructs as identity, then it seems to be simply a different sort of information than what is processed in a navigation system. Worries about sexual identity simply seem markedly different than relative bearings or computations of the fix triangle.

To be sure, there are as many apparent dissimilarities between navigating and making medical choices as there are similarities. And, this is an extremely important point because it would be a mistake to judge the analysis thus far simply on whether navigation appears to be a useful analogy to medical choice. The purpose of this analysis is not to propose that one should make inferences about medical decision-making based on an analogy with navigating a ship. Rather, the analysis has been given to describe a theoretical framework, distributed cognition, which has been most thoroughly and persuasively articulated in terms of an ethnography of navigation practices. Hence, the correct interpretation of our discussion of navigation in this section is not as the basis of an analogy, but as the basis of an exposition, of the distributed cognition framework that serves as a foundation for modeling medical decision-making. Thus, only insofar as describing navigation is useful for characterizing this framework is it useful for understanding medical decision-making.

To represent medical decision-making as a distributed cognitive activity is to represent it as an operation performed by a computational system. The system is composed of persons and artifacts, or elements. Elements process information by performing computations within the constraints of the system; they *form, propagate, transform, and coordinate* representational

states for the purpose of solving a particular task. In this case, the task is to decide upon a course of medical treatment and enact it.

Just as the navigation system is to be understood in terms of *information processing*, *networks*, and *computation* within constraints, so too is medical decision-making to be understood using those same concepts. Just as the navigation system is understood as being extended over *physical space*, *temporal space*, and *social space*, so too is medical decision-making to be understood. With this understanding of cognition distributed across members of a group in mind, we may shed new light on how medical decisions are made and in later chapters, how they should be made.

In the next section, I show *how* medical decision-making can be described *as* distributed cognition. This requires drawing on the descriptions of hereditary breast and ovarian cancer decision-making from Chapter 4 and focusing on the usefulness of information processing and computation for capturing the activity of making an HBOC decision.

5.4 Distributed Cognition and Ellen's Choice

To describe medical decision-making in terms of distributed cognition requires that the activities of the persons involved are represented as forming parts of a computational system, *a medical-decision making system*. Consider the example of a Psychiatric Emergency Department (PED). Representing how decisions are made in the PED requires depicting the activities of its patients and members in terms of information flow through a system of interconnected persons and artifacts. In this example, the persons could be nurses, social workers, residents, psychiatrists, substance abuse counselors, security personnel, and patients. The artifacts would be computers, centrally located whiteboards throughout the floor, diagnostic

devices, clinical notes, and medical charts. To represent how decisions are made in the PED as a distributed cognitive system would be to analyze how these elements were connected, how they shared information, and what activities the system performed.

In the case of the PED, as in all areas of medical practice, errors occur. One of the uses of depicting medical choice as a distributed cognitive activity is that it compels a different perspective on the analysis of errors in practice: to understand the causes of error requires analysis of the flow of information between the various elements in the decision-making system rather than analysis of the reasoning of individual human beings. This may be seen in the following case, where understanding how a patient received an unrecommended dosage of Lamictal requires attending to information flow through the PED.

A patient was assessed by an attending psychiatrist in the PED. One of this patients treatments was the anti-epileptic drug, Lamictal. According to the explanation suggested on the ward round, this psychiatrist allegedly misinterpreted a written note of the dose “Lamictal 200 mg b.i.d.” as “Lamictal 1200 mg b.i.d.”. Further inquiry suggested that this note may have been written on the whiteboard, although we were unable to determine this with certainty. Another clinician who was very familiar with this patient was present in the PED earlier in the evening, but was not contacted for clarification by the attending psychiatrist. The psychiatrist then prescribed the dose of 1200 mg, which is six times higher than the patient’s actual dose and three times higher than the top of the usual reference range for Lamictal. The nurse on duty received the order, and requested this dose from pharmacy as Lamictal is not commonly used in the PED. Pharmacy provided the medication without warning about the unusually high dose. The dose was administered. Once this was detected, the patient was transferred to the medical ER where oral charcoal was administered. Fortunately, the patient suffered no permanent ill effects. While it is tempting to attribute this event to a combination of individual errors, it is the features of the system that contribute to this error that are amenable to intervention. (Cohen et al. 2006, 82)

This account shows how decision-making in the PED may be usefully represented as distributed cognitive activity. However, there is something about the PED that makes it a poor system for the purpose of abstractly modeling medical decision-making, namely, that the

patients in the PED presumably lack decision-making capacity or are at least treated as lacking capacity. Thus, a crucial element in the information flow of medical decision-making systems is left out – the patient. In the quote above, health care professionals were responsible for selecting a treatment and enacting it. This is a case where, for practical purposes, traditional questions of autonomy and choice have dropped out of the equation and all that guides decision-making are the medical facts of the matter and a general commitment to beneficence. Yet although, as this case shows, making decisions without patient or proxy involvement is not a simple activity, it is simpler to model conceptually than cases where patients or proxies and caregivers are part of the decision-making system. These are the harder cases, which are exemplified here by the case of HBOC. Drawing on the resources of our detailed HBOC case study shows in detail how the distributed cognition framework may be applied to medical decision-making.

5.4.1 *On Making the Right Medical Decision*

The first step to understanding medical decision-making *as* distributed cognition is to think of making medical decisions as an activity performed by a computational system. As with any computational system, a medical decision-making system must have an aim or aims in order to be said to be performing a function, or operation. Only relative to some goal or goals can a distributed cognitive system be said to be a system at all (Magnus 2007). The system may have multiple goals or one goal; it may have a primary goal and many subsidiary goals that must be satisfied in service of the primary end; or it may have contradicting goals whose completion are mutually exclusive. What is necessary for medical decision-making to be thought of as a distributed cognitive system is that the system has a goal.

We may suppose that the goal for a medical decision-making system is to make the right decision. But, what does that mean? What is a *right* decision in medicine; and, how ever might we answer this question? This question, though extremely important and crucial for any satisfying account of medical choice, cannot be answered by appeal to the resources of distributed cognition alone, because that framework is useful only for providing a *description* for representing how medical choices are made; it does not provide the *normative* resources for saying why some choices are better or worse than others. The aim of Chapters Six and Seven is to defend a normative framework for the model being developed here. Thus, at the moment we lack a justified goal for medical decision-making system, abstractly conceived. However, we can provisionally characterize the goals of such systems in terms of the two Basic Aims or goals defined in Chapter 2. Thus, at a significant level of abstraction a medical decision-making system has the following goals (from § 3.1):

Aim I: To fully describe the patient's condition objectively (in scientific terms) and subjectively (in personal terms).

Aim II: To treat the patient via means that are consistent with the patient's state of health, as defined in Aim I.

Thus, abstractly, making a good medical choice requires identifying what is wrong with the patient, which requires describing his or her health states objectively and subjectively, and electing a treatment that is consistent with both of these descriptions. If a medical decision-making system meets these two basic criteria, then this results in an actionable decision that is consistent with both the scientific and personal understanding of a patient's illness.

If the Basic Aims provide the goals of a medical decision-making system, then to meet them requires two basic activities, a certain sort of communication and a certain sort of action.

The remainder of this chapter focuses on the former – the sorts of communicative practices that could fulfill Basic Aim I. Having explained this in detail, we will subsequently turn to considering how to generate action-guiding norms from the model under development in the remaining chapters.

5.4.2 *The Architecture of Communication in Macke's Choice*

One way to describe communication is to describe who is communicating with whom. We might think of this as describing the *architecture of communication*, where the relationships between communicating elements in a system take precedence over the information content communicated between them. This is how the navigation system is represented as a network of interconnected and interacting elements in Figure 5.2 above. That representation captures the flow of information in terms of the binary variable of connection or disconnection between elements in the navigation system, rather than capturing what information is shared between them in terms of other variables.

This same approach can be used to describe Ellen Macke's choice (§ 4.3.2). In that case, we learned that Macke communicated with many persons while making her choices. She spoke with her cousin and sister about their experiences having breast cancer, interacting with health care providers, and the physical and emotional consequences of treatments they underwent. She also discussed her circumstances with her more distant relatives, asking for their participation in genetic testing and listening to their fears and concerns as they learned more about the possibility that their family included carriers of genes that increased susceptibility to breast and ovarian cancer. And, she discussed her family history with her oncologist, who represented this information in terms of a family tree diagram, as well as a surgeon, who performed a biopsy of cells in Macke's right breast and informed her that she had breast cancer. Altogether, Ellen

Macke communicated with many family members, health care providers, and representatives of institutions while making her decision (Table 4.2).

To capture the architecture of communication in Macke's case, however, additional elements must be described in addition to the persons whom she communicated with and whom communicated with others. For example, it is important to recall that Macke states her oncologist discussed her circumstances and choices with her surgeon. Macke also reports that her surgeon conveyed the pathology reports on her biopsy to her. Likewise, Macke's radiologist communicated with her regarding the results of her mammogram. And, presumably many of the physicians Macke was in communication with as she chose to undergo genetic testing, surveillance, and prophylactic surgery were communicating with one another via making entries in her medical chart, if not also via direct conversation. Thus, the architecture of communication in Macke's case must include connections between physicians, connections between physicians and artifacts, and between Macke and artifacts. This is captured in Figure 5.3.

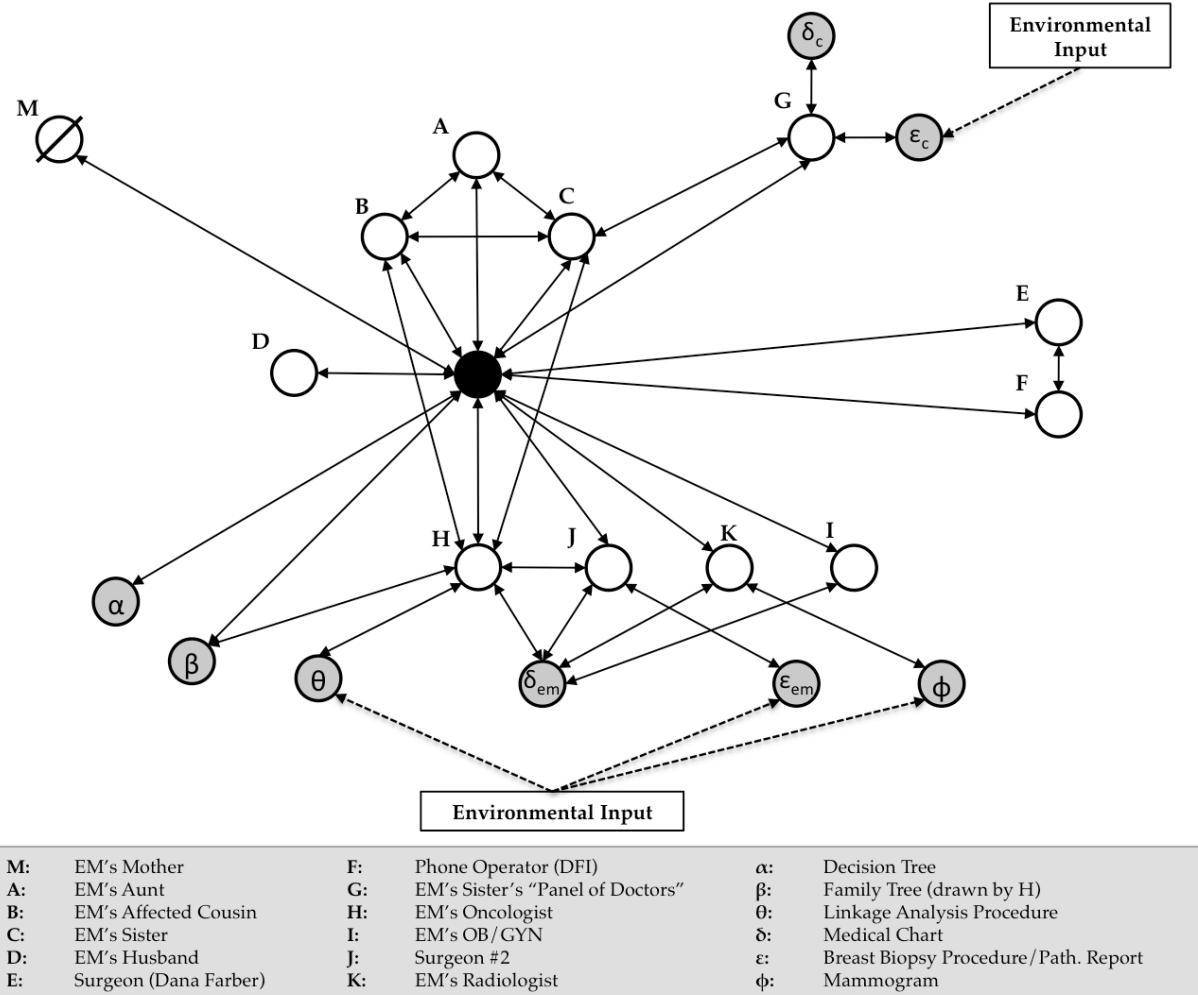


Figure 5.3: The architecture of communication in Macke's choice. Circles represent elements in the system, as labeled: black represents Ellen Macke; white represents other persons; and, shaded represents artifacts. Bidirectional solid lines represent information flow between elements. Unidirectional elements represent environmental stimulus.

Just as the navigation system may be represented using network diagrams, so too can Macke's choice be. Thus, it may be described in terms of the flow of information between elements in the system, each of which processes information, conveying it to connected elements. A virtue of representing medical decision-making and navigation in this way is that it describes these activities in a graphic form that captures the information flow between elements visually, rather than capturing it in narrative form, which in both Macke's case and in the case

of the navigation system required many pages of exposition. Furthermore describing a system’s architecture of communication statically as a network of interconnected elements allows one to appeal to standard terminology for describing network structures, which further summarizes the state of information flow in the system at a given time. Using such terms, the medical decision-making system described by Macke looks like a spoke-and-hub network and the navigation system looks like a chain network. Yet, both networks could be represented differently with more information and neither fits the ideal type of hub-and-spoke or chain, respectively. Thus, in Figure 5.2, the bearing recording acts as a hub for the information processed by the pelorus and fathometer operators; yet, save for that moment, the navigation system looks like a linear hierarchy, with information feeding up the chain, where it is sequentially processed and ultimately given as output. In Figure 5.3, although the hub-and-spoke architecture is immediately apparent, there are also sub-networks within the system. One forms as a “circle” of communication between Macke’s Aunt, Affected Cousin, and Sister. Another forms as an “all-channel” sub-network, when information is shared between various healthcare professionals and artifacts.⁵⁴ Therefore, both distributed cognitive systems are better referred to as mixed networks, as they deviate from the ideal types of hub-and-spoke and chain networks.

Another virtue of describing medical decision-making as a network of interconnected elements with an architecture of communication is that it readily captures what elements *are not included in the system*. For example, presumably many other health care professionals were

⁵⁴ Introducing vocabulary defining different types of networks might be useful at this point; however, I believe this is unnecessary given the illustrative and self-explanatory nature of such terms as hub-and-spoke, chain, circle, and all-channel (where all elements communicate). Clarification may be found in any number of textbooks on network architecture. For example, see Griffin and Moorhead (2011, Chapter 11) on communication in small groups.

involved in Macke's care.⁵⁵ But they are not captured in her reconstruction of her care and decision-making, and thus, are not described in my rendering of that reconstruction as a computational network. If we needed to describe the information flow in Macke's case such that the connections between elements to hospital administration or legal counsel – for example, if an important error occurred in her care – then with more information we could re-describe the system such that Macke's choice would become just one decision-making system within a larger system, changing its appearance from a mixed hub-and-spoke architecture to a hub-and-spoke sub-network within a more complex communication architecture. Likewise, further elaboration of the navigation system's duties beyond taking a single fix would show that it is part of far more elaborate network with a less chain-like structure.

5.5 The Emergence of Distributed Cognitive Systems

Though there are virtues to the network representation I have used here, there is also a glaring limitation to it: as it has been used in Macke's case it is patently *ad hoc*. This representation of Macke's reconstruction is consistent with it; however, we have no means of validating her

⁵⁵ If represented from a less egoistic viewpoint, the network would depict other elements in the system and their connections. These elements might take the form of additional persons, such as: the physicians who treated Macke's sister (represented collectively as Element G); nurses who interacted with Ellen and her physicians (unrepresented, but would be connected to Elements H, J, or I, in addition to Ellen); hematologists or pathologists who reviewed Macke's biopsy (unrepresented, but would connect to the medical chart and perhaps other elements); or additional family members Ellen and her oncologist spoke with when discussing linkage analysis, performing the procedure, and conveying the results (unrepresented, but would be connected to Elements A-C, and H, as well as Ellen). These elements could also take the form of additional artifacts, for example: computers, electronic medical records diagnostic tools and test results, whiteboards located on hospital floors, clinical notes not in the medical chart, or the pocket books common amongst physicians (e.g., Sabatine 2001). Such artifacts would be connected to health care professionals (physician's assistants, social workers, nurses), hospital staff, and perhaps care givers, proxies, or legal professionals. In short, this network could be represented quite differently with more data about the persons in the system and their interactions.

reconstruction of the circumstances from her admittedly first person and partial point of view. Perhaps from another vantage point this representation could be not only incorrect, but also egregiously misleading. Macke's reconstruction of her decision-making could be an attempt to describe her decision-making in a way that purposely obfuscates the actual events that occurred, depending on her interests. Thus given its admitted partiality, her reconstruction tells us little, that is, about how a medical decision-making system *emerges*. It describes the system that emerges over time only after it has formed, by describing past communications between certain participants in the system. However, her reconstruction leaves many unasked and unanswerable questions about the informational dynamics that led to the communication architecture described in Figure 5.3 rather than another possible architecture. To allay the concern that the network I have used to describe Macke's choice is *ad hoc* and thus that any such description would be *ad hoc*, and to further develop my model of medical choice, let us return to Hutchin's description of navigation and look in particular at how the navigation system emerges from communication between elements in the system (§ 5.5.1). Then we will consider what would be required to describe the emergence of a medical decision-making system (§ 5.5.2).

5.5.1 *Communication in a Navigational System*

As Hutchins describes the elements of the navigational system and the flow of information between them, the system's architecture emerges from a microanalysis of discourse between persons, interactions between persons and artifacts, and representational capacities of artifacts. To take the fix requires individuals on the deck of the ship to manipulate tools to measure particular features of the environment. These measurements must then be communicated verbally to other members of the navigation team residing in the pilothouse or charthouse, who then record them in a log or use them as data points to enter into other apparatuses. In this way,

information is processed as it flows through the system; and, in this way a variety of representational states are coordinated such that the system reaches its goal of taking the fix.

Let us consider in more detail how communication between persons in the navigation system leads to the emergence of the communication architecture. In the following example, Hutchins traces and comments upon an interchange between the Bearing Recorder, the CIC talker, and the Plotter. Central to Hutchins' claims is that the interchange requires simultaneous negotiation between Recorder and Plotter because of the need to disambiguate an apparent error in communication, which he captures by transcribing the conversation verbatim and inserting his own commentary in parentheses. For our purposes, though, what is important is only that this is one of untold examples of communications between persons that Hutchins' describes, and from which he justified his representation of the navigation system that Figure 5.2 is based upon.

Recorder: Stand by to mark. Time ... 0 1 2.

CIC Talker: Combat holds 3100 yards to the turn. Holds 50 yards left of track.

Recorder: 26 feet under the keel. Mark it.

(After a 13 second pause, the plotter watches the recorder write down the first bearing, sets the hoey, and aligns it with the chart.)

Plotter: What's at 2 7 7? (plotting)

Recorder: 2 7 1

(The recorder's correction may be based on a re-reading of the log entry or on memory of the actual bearing reported. Notice the properties of the medium in which the bearing is represented—there is a greater potential confusion of 1 and 7 in written form than “one” and “seven” in spoken form.)

Plotter: What is it?

(The plotter uses the positions of landmarks on the chart, the projected position of the ship, and the angle on the hoey in evaluating the bearing. This one does not fit any of the landmarks he expects.)

Recorder: Um, carrier tower.

Plotter: Oh, I don't want that thing. It's OK, go ahead.

(The chief does not want this landmark because its position is not yet established. It is a back-plot. Once they have established several of their positions with

known landmarks, they can back-plot the position of the tower and make it a usable landmark in the future.)

Recorder: The aero beacon is 2 9 2. 10th Avenue Terminal is 1 0 5. (then speaking into the phone circuit) Give me the last bearing you took.

Plotter: 1 0 5. (The plotter is reading this from the bearing record log.)

Plotter: Is that 10th Avenue Terminal that is 1 0 5? Or that little pier?

Recorder: 0 5 9 is that little pier. This one is 0 5 9 (pointing to the depiction of the pier on the chart).

(The reference of “this one” in the recorder’s statement is determined indexically by his orientation to the symbols on the chart.)

Plotter: OK. What’s at 1 0 5?

Recorder: 10th Avenue is at 0 5, 1 0 5.

Plotter: Still outside here.

Recorder: Still outside?

Plotter: What’s the other one?

(The notion of “the other one” relies on the knowledge that three lines of position are required for the fix. The recorder seems to have a problem with the back-plot in the procedure.)

Recorder: 2 7 1.

Plotter: No, no, that’s back-plot.

Recorder: Carrier tower.

Recorder: 2 9 2.

Plotter: yeah, yeah. What’s that?

Recorder: Aero beacon, OK, 1 0 5.

Plotter: What’s that?

Recorder: That’s 10th Avenue.

Plotter: Oh, it is huh ... is he use ... He must be using the tip of it (8 seconds)

Well, it’s almost ... actually nothing. (Hutchins 1995, 237-238)

For some context, what Hutchins’ takes away from this brief communication is that discourse between persons in the navigation system is rich with meaning, and that the meanings of the utterances are established in concert with references to the artifacts in the system, in this case the chart and the hoey. Furthermore, the meanings of the utterances entail presumptions about the shared task these individuals are engaged in and the shared knowledge they have about what is necessary in order to complete the task.

For our purposes, what is important is just to convey the sort of close discourse analysis that is required to substantiate the claim that the navigation system is organized such that the representation in Figure 5.2 is an accurate depiction of the system. That is, although the network diagram of the navigation system I have put together is also *ad hoc* because it was not produced by direct observation of Hutchins' data, but rather from reading his representation of that data, Figure 5.2 is nevertheless *ad hoc* in an importantly different sense than Figure 5.3 is. Unlike Macke's reconstruction of the communication patterns in her decision-making process, Hutchins' description of the navigation system is based on extraordinarily close observational studies of the system. In the above quote he analyzes an exchange between persons while also noting the way those persons interact with computational tools. His account of distributed cognition is grounded in many years worth of similar exchanges, which he conveys throughout *Cognition in the Wild*.

Thus I suggest that what makes the representation of Macke's case as a distributed cognitive system in Figure 5.3 problematically *ad hoc* is that it is based on her first person reconstruction of events, rather than from an observer's perspective. It is not that Macke is wrong. And it is not that representing the system as a network of information flow is inaccurate. Rather, it is that Macke's reconstruction is problematically partial, in that she does not attempt to describe much information flow between persons in the system that she is not privy to. Thus, important elements and connections not described. And, despite my view that her narrative provides an especially rich case study (as I argued in § 4.3.1), her narrative is nevertheless too partial to provide an adequate source for describing medical decision-making systems in the abstract. To do this, I contend it is important to consider additional sources that can show how a medical decision-making system emerges from information flow between persons and other

persons and artifacts. To do this, in the next sub-section we will consider how physicians and patients communicate with each other and interact with artifacts during routine medical care. In the next section (§ 5.6) I use the knowledge gained from this consideration to make claims about factors that are likely to be represented and discussed during decision-making in HBOC.

5.5.2 *Communication in Medical Choice*

As I understand them, medical choices are extended over spatiotemporal and social dimensions. They emerge during conversations between persons and as persons represent their knowledge using computational tools. Thus a basic assumption of my view is that were one to observe conversations between individuals or observe the way individuals represent their knowledge via artifacts, one's observations would be consistent with my account of choice. That is, I predict that such conversations would exhibit the purveying of information, the processing of information, the representing of knowledge via measurement and report, and the transformation of representations. To support this view, I consider work on patient-physician communication during medical interviews (§ 5.5.2.1), conversations between physicians about patients' health states (§ 5.5.2.2), and the activity making entries in and reading the medical chart as a means of exerting influence on medical care across time and space (§ 5.5.2.3). From this, I will make generalizations about medical decision-making and apply them to the case of HBOC.

5.5.2.1 Voices in the medical encounter

In a highly original work in the microanalysis of medical communication, Elliot Mishler studies how patients and physicians communicate during routine medical interviews. Although his research can be faulted for examining only a few minutes of five distinct interviews, it does draw its reported interviews from a much larger data set of 481 interviews so it is possible to

interpret Mishler's findings as an interpolation from examination of more than merely five interviews (Mishler 1984, 28). Regardless of this methodological shortcoming, however, Mishler's work is important because it is one of the earliest to closely examine patient-physician conversation and it also remains one of the few studies of its kind, given the detail with which Mishler examines doctor and patient speech.

One moment in routine practice captured by Mishler has become particularly well known. Using it, he distinguishes between two *voices* present in the medical interview, the *voice of the lifeworld* and the *voice of medicine*: "The voice of the lifeworld refers to the patient's contextually-grounded experiences" of health, illness, and life in general, whereas "the voice of medicine reflects a 'technical' interest and expresses a 'scientific attitude.' The meaning of events is provided through abstract rules that serve to decontextualize events, to remove them from particular personal and social contexts (*ibid.*, 104). Mishler sees the medical interview as being an activity of negotiating fit between these two voices. Yet he leaves open whether the medical interview proceeds such that the voice of the lifeworld is integrated into the voice of medicine or whether the translation goes the other direction. Mishler contends both modes of translation are conceivable and, indeed, one can look at the same stretch of communication between physician and patient and see it as being either an attempt to translate the lifeworld into medicine or translate medicine into the lifeworld. For Mishler, it is not whether one voice does or should take precedence in an ultimate sense that matters, but rather the extent to which we recognize the presence and potential incommensurability of both voices in the medical encounter.

I interpret Mishler's view as consistent with my own distinction between objective knowledge (and claims) and subjective knowledge (and claims), defined and defended in § 3.5.

Thus I see Mishler's close analysis of conversation during the medical encounter as a piece of evidence in support of both the distinction and, further, the claim that it is a useful distinction for describing medical practice. Thus, where Mishler posits two voices, I would instead posit two categories of knowledge and claims. Therefore, I see communications during routine medical encounters as moments where persons make and affirm subjective claims about illness, which are claims that give voice to the lifeworld, the world of experience that has not been made corrigible, for which no one purports objective process have produced them. Likewise, when communicating in routine medical encounters, persons also make objective claims, claims that purport to be produced according to unstated norms and to be corrigible. These are the claims of the voice of medicine.

Witness the conversation quoted below, which I have abbreviated significantly. In Mishler's coding schema, the conversation excerpt covers 195 turns, although I only include 39 turns here. Notice that the doctor (D) greets the patient (P) in a standard way, as "Doctor Gerson." The patient responds but with words that are difficult to understand as caught on tape, which Mishler demarcates by parentheses (see *ibid.*, 91-93 for Mishler's full notational conventions). The doctor relates his understanding of why the patient is here, because of a referral, and the patient responds by clarifying. Next, which I have not quoted, the doctor reviews the patient's past medical history of ulcers, diagnosed at age nine, to which the doctor expresses surprise that Mishler captures using italics. After discussing the patient's symptoms, additional medical problems, additional perceptions of ill health, and diagnostic tests that have been performed, the doctor asks the patient about a recent event that motivated her trip to the clinic. This leads them to discuss "sour stomach," her turn of phrase to capture her experience of illness. Subsequently, the conversation turns to potential causes of her pain, and to her

drinking, which the patient notably conveys without prompting and in moral terms of “cheating,” as seen at lines 153-154: “I’ve cheated and I’ve been drinking which I shouldn’t have done.” The doctor picks up on this and then asks how much the patient drinks. Notice that the initial response by the patient is in terms of the threshold of drink required to help her sleep, but the doctor asks for clarification in objective, measured terms of drinks per day.

001 D I’m Doctor Gerson.

002 P (...) I know (what it is).

003 D Oka:y

004 Now let’s see . you were .. referred here .. actually they sent

005 you up here from medical clinic from the . screening

006 clinic clinic rather

007 P Yea:h. Well I was sent up here from uh-

008 from neurology really because I told them- I

009 told them what my symptoms were and uh they said

010 Okay we’ll get you up here.

[...]

127 P I’m on a diet now

128 and I don’t dare go off it because if I do I end up with a sour

129 stomach.

130 D Hm hm

[

131 D Now what do you mean by a sour stomach?

132 P What’s a sour stomach? A heartburn like a

133 heartburn or something.

[...]

156 D Does drinking make it worse?

[

157 P (...) Ho ho uh ooh Yes.]

158 Especially the carbonation and the alcohol.

159 D Hm hm

160 How much do you drink?

161 P I don’t

162 know.

[

163 P .. Enough to make me go to sleep at night and that’s

164 quite a bit.

[

165 D One or two drinks a day?
 166 P O;h no no no humpf it's
 167 (more like) ten. at night.
 [...]
 174 D How long
 175 have you been drinking that heavily?
 [...]
 176 P Since
 177 I've been married
 [...]
 181 P (giggle) huh Well I started out with before then I was
 182 drinkin beer but u:m I had a job and I was ya know
 183 had more things on my mind and ya know I like- but since I
 184 got married I been in and out of jobs and everything so
 185 I- I have ta have something to go to sleep
 186 D Hm:m

(Mishler 1984, 129-135; bracketed ellipses demarcate my abbreviation)

In Mishler's notation, which I have suppressed, the voice of medicine is used in lines 001-010, 131-162, and 165-175. The voice of the lifeworld is used in 127-130, 163-164, and 176-186. Thus, what we see in this conversation is the emergence of these two voices and their co-expression within the context of the medical encounter.

Through conversation, the two individuals Mishler analyzes strive to understand the patient's predicament together by making claims they can agree upon. Some of these claims are ones that are accepted as unique to the patient and therefore incorrigible. For example, we have the patient's claim that she gets "sour stomach" and her estimate that she drinks "enough to make me go to sleep at night." Other claims are objective and corrigible, such as the doctor's initial estimate that the patient drinks one to two drinks a day, which is updated to ten a day by the patient, and his later request for the patient to clarify how long she has been drinking in terms other than "since I've been married," to which she responds, "(giggle). Four years" (lines 179-180). Numbers of days and years are objective measures of time. They can be accurate to

various degrees. They are thus examples of objective claims, claims that are produced via an estimate of time put forward in an idiom that is consistent with other means of producing objective claims.

By focusing on communicative acts occurring in routine medical practice, such as Mishler and others have done (*e.g.*, Tuckett et al. 1985; Cassell 1985a, 1985b; Clark and Mishler 1992; Fisher and Todd 1993; Elwyn and Gwyn 1998; Mendick et al. 2010), we may describe the medical decision-making systems that emerge during conversations between patients and physicians, much like Hutchins describes the emergence of the navigation system from communications between members of the Navigation Department. Moreover, focusing on communicative acts in the way described in §§ 3.7.2 and 3.8 allows us to describe these acts in terms that underscore their relationship to other types of claims we might make about the system. We can identify the subjective and objective claims made by persons when communicating and demarcate this from other ways we might describe the interaction between doctor and patient. As I discussed in Chapter 3, there are many ways to characterize the doctor-patient relationship. However, as I argued there, I contend that a basic epistemic distinction between subjective and objective knowledge is more useful than others for describing different ways of speaking and conversing found there. And we can do so in a way that captures the negotiations that are hallmarks of such interactions (Roter and Hall 1992) without also introducing assumptions entailed by other ways of describing this relationship. Thus, I agree with Robert Arnold, who recognizes the value in Mishler's work precisely because, "Whatever views one holds about the ideal doctor-patient relationship, those views are reflected and embodied in the structure of the medical interview" (Arnold 1989, 12). By looking at routine

medical encounters, therefore, we can justify claims about that structure, and thus, the architecture of communication in such relationships.

5.5.2.2 Conversation and measurement amongst physicians

However, what we do not gain access to in measuring communication within the doctor-patient relationship is how doctors communicate with one another while delivering care. Looking only at communication between doctors and patients ignores important communication between other elements in the decision-making system, including the health care providers who share information with other providers as well as with patients. It is necessary to look at this flow of information in order to describe medical decision-making in anything approaching the detail with which Hutchins describes the navigation system.

Few studies have measured communication between physicians. Yet, one that does supports the view that when physicians communicate with one another about patients' health their communications are also describable in terms of the basic epistemic distinction between subjective and objective claims. Therefore, it is not, as those who adopt the art/science distinction might suppose, that when communicating about patients health states, physicians merely deduce findings from theory and observation in a manner akin to deductive-nomological explanation (Hempel 1966). Rather, physicians deliberate with one another in order to establish their observations. In doing so, they make subjective claims about their experiences that they then contest verbally or otherwise; that is, they expose their subjective claims to criticism and thus make them corrigible in a sense described by Suppes (1974). In this manner they thus produce objective claims to various degrees. Thus, even when physicians discuss patients' health with one another, we see the same basic types of communication dynamics as we do when physicians and patients communicate in routine medical encounters: individuals make claims

that they contest or accept, and in this way, come to agreement about the state of affairs under consideration at the time.

To see this we may look to research by Paul Atkinson, a sociologist who argues that contemporary accounts of knowledge by sociologists of science are mistaken because they focus narrowly on some practices at the exclusion of others, and therefore fail to sufficiently justify their conclusions. He contends that looking at communications between hematologists demonstrates that knowledge is not constructed in the strong sense that sociologists of science have argued for. Rather, Atkinson says, knowledge is distributed through a complex division of labor in contemporary medicine that requires attending to and modeling its intricate social dynamics. While Atkinson's aims are worth considering on their own, they are orthogonal to the current interests. For the moment, what is important is simply the data that Atkinson reports, namely, conversations between hematologists and physicians working together to determine whether patients are healthy or not.

In the specific conversation quoted below, a hematologist works with another doctor to determine whether a blood sample includes dysfunctional cells, and if so, what type of dysfunctions they exhibit. In this excerpt, the hematologist is also the Attending Physician (At), who is discussing a prepared blood sample with a Fellow (F) as they both look under a microscope that can be viewed by four persons at a time for teaching purposes. In this case, they are trying to determine the severity of the patient's leukemia diagnosis by looking at the behavior of her blood cells.

At: Oh look at that one. Some of them are really nasty looking. Now, is the peripheral smear available here?

F: I haven't actually had in and seen the peripheral smear, we should get that

At: Would be interesting and because...

F: = Make sure she doesn't have any

At: = Make sure she's a plasma cell leukemia

F: Yeah, I'll get that today

...

F: Er we don't see any dividing ones right here but they certainly were around

At: Yeah

F: So what do you estimate, around thirty per cent?

At: Yeah I woulda said greater than thirty per cent, you see I mean it always varies depending

F: Yeah

At: = *ON*

F: We were, we saw

At: Would be nice to see the bone marrow biopsy, it ought to be quite impressive

F: Yeah, I hope that that'll be ready now

At: Um there are quite a lot of megakaryocytes

F: = Yeah

At: = She obviously has adequate of those, and

F: And she's not

At: Still, hard to estimate the ratio, because there are so many

F: Would you call this sheets, though? I guess you

At: *No*

At: = They're pretty close they're not really sheets

F: Well

At: No, sheets you normally talk about like () arrangement

F: Right

At: The way it looks like the cytoplasm are merging into each other

F: Right

At: Um and that is truly pathological but no, this isn't pathological (but)

F: Yeah

At: No, I wouldn't call it sheets. Very nice, very nice indeed.

(Atkinson 1995, 82-82)

What is important at the moment is simply that even here, when performing what might appear to be a simple observation of typical cellular irregularities, we see a mixture of the voice of the lifeworld and the voice of medicine. In other words, we see a mixture of subjective claims and objective claims while these individuals communicate about their observations of the same thing. Thus the attending notes that some of the cells are "really nasty looking" and then moves to talking in increasingly technical terms, from "smear" to "plasma cell,"

“megakaryocytes,” and merging “cytoplasms.” Whereas colloquialisms like “nasty looking” serve to orient the expectations of those looking through the scope, technical terms serve to justify sorting observations into categories nested within dense biological theories of cellular pathology. Despite this, agreement about the presence or absence of pathology is not immediate. It does not follow deductively merely from a direct observation of the sample.⁵⁶ Rather, the fellow and attending question their agreement regarding the presence of “sheets” in the sample. They confer and the fellow assents to the attending’s way of describing what they both see. Thus, the result is that in this excerpt the sample was deemed to be normal, or sufficiently free of pathology in regards to the criteria under consideration.

Though there are clear differences between the conversation reported by Atkinson and the one reported by Mishler, there are also important similarities. In both cases the participants may be described as *negotiating*. In both cases, that is, each participant uses terms provisionally, presumably with the expectation of some degree of disagreement and the ultimate aim of coming to agreement regarding the determinations made in the conversation.

In the discussion between the hematologist and the fellow this is perhaps more striking because both individuals are looking at the same material in their visual fields, both are presumably knowledgeable about the models of cellular pathology that guide their use of technical categories, and presumably the purpose of making observations on a microscope that

⁵⁶ My manner of speaking here might be taken to invoke longstanding issues in philosophy science on the theory-ladenness of observation and related topics (see Bogen 2002 for an introduction). The topics of concern at this moment, and the epistemic distinction between subjective and objective knowledge, certainly do relate to this historic line of inquiry. However, I have aimed to sidestep it and instead marshal alternative vocabulary, rather than engage with those issues, which the field has moved passed in many ways but which nevertheless remain in the background of this and other discussions. See Bogen and Woodward 1988, Woodward 1989, and Hacking 1983 for arguments supportive of my move to avoid these longstanding issues with the relationship between theory, observation, and verbal report.

permits multiple users is to facilitate education by training one or more users to see the material as the teacher does. Thus, both fellow and attending recognize that this is a teaching opportunity and that the purpose of looking together is to aid the fellow build observational skills – to learn to *see as* – while also identifying the presence of pathological features in the sample that will be useful for the clinical management of the patient from whom the sample was taken.

In the conversations between the physician and the patient reported by Mishler we also see participants negotiating over the terms being used. The doctor states that the patient was sent up from the medical clinic, but the patient contests this claim, asserting that she was referred from neurology. In a portion not quoted above, just afterwards the patient states that her ulcers were first diagnosed at age nine. The physician responds incredulously and the patient reiterates the age, continuing to note that she later had another ulcer at thirteen. The patient and physician discuss what health care providers determined she had ulcers, when they did so, what diagnostic tests were used, and what her symptoms were, which takes from line 19 to line 89 in the transcript. Thus, negotiating the appropriateness of the term “ulcer” takes 36% of the excerpted conversation. By this time, both doctor and patient are using the terms “peptic ulcer” and “ulcer” to describe her underlying condition. Yet she continues to describe her symptoms, including their severity and frequency, until she lights upon the term “sour stomach,” which then becomes a term of contention. The doctor queries its meaning and then embraces the term, using it himself. And then the patient confesses she drinks considerably, which as we already noted begins a negotiation over the appropriate terms for describing her behavior – whether in terms of drinking enough to fall asleep ever since her marriage or drinking ten drinks a night for four years.

In the examples of routine conversations during medical encounters between two physicians and between a physician and patient, one finds participants negotiating the terms of agreement, the shared terms they can together endorse to describe what is going on. Though it is more pronounced in the physician-patient exchange above, in both cases we see the “voice of the lifeworld” as well as the “voice of medicine.” That is, in both cases we see individuals making and accepting subjective claims as well as making, contesting, and accepting objective claims too. In looking at these conversations we get a sense of the conversational context from which a medical decision-making system emerges. However, there is still an additional piece missing: we have yet to describe how persons interact with other elements in the systems, the artifacts.

5.5.2.3 Charting as communication through space and time

The medical chart is perhaps the most important artifact in a medical decision-making system. In complex cases requiring an extended hospital stay, it serves as a repository of information about the patient, from which her entire stay can be reconstructed, and through which the orders that determine her activities are made. In more routine practices it serves as the official record of activities, from the patient’s communication with her physician to the physician’s findings and any follow up that is indicated in light of them. Of course, there are other artifacts of importance, such as the microscope that the hematologist and fellow use to observe cellular features or the family tree Ellen Macke and her oncologist construct to represent her family history of cancer and estimate her breast cancer risk. As the findings from these artifacts are typically represented in one way or another in the medical chart, it is in this sense that it is particularly important, because it is ever-present in medical encounters.

Like Atkinson, in his work on the social and epistemic structure of medical practice Marc Berg has argued for a richer and more detailed analysis of the distribution of cognitive labor in medicine, as opposed to traditional accounts of knowledge common in the sociology of scientific knowledge. Furthermore, though he does not develop the idea in the way that has been done here, Berg also suggests that medical practice might be understood in terms of distributed cognition. As with the other scholarship considered in this section, however, although Berg's analysis is worth considering in its own right, here I am concerned with the data he presents more than the theses he supports with it.

Let us specifically consider a routine moment in the practice of one of the physicians Berg follows in his ethnography of medical practice, whom he refers to as Dr. Bear. In the quoted excerpt below Dr. Bear, an oncologist at an academic hospital in the Netherlands, readies himself for a new patient visit. Before standing to get Ms. Roth, the patient, the doctor scans a few papers in the chart, one of which is a letter from the general practitioner who referred her (from Berg 1996, 502):

Re: Ms. Roth 10/02/1928

Having spoken with you by telephone, I refer above-mentioned patient concerning carcinomatous pleuritis.

For 1 week, patient has been nauseated and vomiting.

Investigation: severe weight loss

abdomen: well demarcated lumps

pulm: reduced respiratory sounds Right

Previous history: in 1977 breast amputation because of adenoca.

Thorax X-ray: massive amount of pleural fluid in right hemithorax.

Lab: enclosed

Treatment requested.

Immediately, we see that the chart captures a significant amount of information about the patient with few words, numbers, and abbreviations. It tells Dr. Bear how old she is (in her mid sixties at the time of Berg's research). It also tells him that she has fluid around her lungs that is

caused by underlying cancer. And from it he can learn of her recent symptoms, as well as the referring physician's assessment of them and their causes. He is also directed to laboratory findings, which are enclosed, and his treatment is requested. Thus, in this case we see how the chart organizes information about the circumstances at hand, in that it contains information about the patient's state of affairs that may or may not be available to her, and that serves as a point of origin for Dr. Bear as he begins the consultation.

In his research, Berg notes not only what is said between different participants in medical decisions, but also what they record in the medical chart during their conversations, which he captures with italics. This provides an opportunity to trace the trail of representations from the verbal representations of the circumstances that patients, physicians, and others use to describe the situation verbally to how that information is represented symbolically in the chart with words and other notations. In the case of Dr. Bear, we see that before he even begins conversing with Ms. Roth he "smiles reassuringly, picks up his pen, and looks at the referral letter again. He opens the record at the first page of the case history. At the entry called *Reason for Referral*, he writes *metastasised breast ca*" (*ibid.*). Dr. Bear begins by orienting himself to this patient by simultaneously orienting himself to the chart and beginning discussion with her. As Berg describes their interaction in the following long quote, which I have altered from its original form to emphasize both the dialogue and the charting (captured in parentheses), there is a constant interplay between the spoken words Dr. Bear uses and the notations he deploys to summarize the information he elicits from Ms. Roth in her medical chart.

Bear: "What has your doctor told you?"

(He looks at Ms. Roth),

Roth: "Yeah . . . I could not eat well the last couple of days, but I'm doing a bit better now. It remains inside."

(Bear nods, looks down at his papers again.)

Bear: "But he has taken some pictures, hasn't he? X-rays of the lungs? And he drew some blood?"

Roth: "Yes . . . I don't know . . . they gave me a letter to give to you."

Bear: "So you haven't seen your doctor any more - he called and said . . . eh . . . please be at the hospital next Thursday?"

Roth: "Yes."

(Bear starts writing in the next section, *Previous Diseases and Surgery: 1977. Breast amputation.*)

Bear: "The breast surgery was in 1977, wasn't it?"

Roth: "77, yes."

Bear: "And have you ever had anything else wrong with you?"

Roth: "No, thank goodness."

Bear: "Just a bit of diabetes, right?"

(writes this down)

Roth: "Just diabetes, yes . . ."

Bear: "And the breast surgery, what side was that, left or right?"

Roth: "Right."

(Bear jots *R* after *breast amputation*)

Bear: "Has that received any radiation after the operation?"

Roth: "At the time, yes, but I haven't had that for years."

Bear: "And no drugs for that operation?"

Roth: "No."

Bear: "No,"

(writing *follow up radiation* after the previous entry)

Bear: "No other hospital admissions?"

Roth: "Yeah . . . I have . . . once . . . an inflammation in . . . in my mouth . . . but otherwise . . ."

(Bear ignores this, skips the section *Major Complaint(s)*, and jots down a circled *I* under the next section, *Anamnesis*.)

Bear: "And why did you go to see your doctor this time?"

Roth: "I couldn't eat anything any more, I hadn't eaten for four days at least, and drink came up also."

(Bear writes *appetite i.*)

Bear: "And you have lost weight?"

Roth: "Yeah . . ."

(*weight loss +*)

Bear: "How much?"

Roth: "Well, I don't know, I hardly dared to weigh myself,"
(*how much?*)

Bear: "Do you have any other complaints?"

Roth: "Yes, I've got lumps, here" (She points at her belly.)
Bear . . . "And how long have they been there?"
Roth: "That must be some months already . . . they are getting larger and larger . . . And there is another one here." (She points at a lump.)
(Bear ignores this, and writes 2. *Has lumps in her abdomen, for some months already.*)

[...]

Bear: "Is there anybody in your family who has had breast cancer?"

Roth: "Not that I know of."

(Bear moves back up to the earlier section *Previous Diseases*, and adds *family history negative* beneath *breast amputation.*)

Bear: "Now I would like to take a look at you."

(Adapted from *ibid.*, 503-504; bracketed ellipses demarcate my abbreviation.)

As in the case reported by Mishler, we see the interplay between the voice of the lifeworld and the voice of medicine in the interchanges between Dr. Bear and Ms. Roth. From their initial exchange, Ms. Roth emphasizes her symptoms in subjective terms. She says, she cannot eat well and "It remains inside," which Dr. Bear later uses the notation "*appetite i.*" to capture. Yet when discussing the growths in her abdomen, Ms. Roth employs the term "lumps," which suffices for Dr. Bear, who records exactly that in her chart. Thus, in some moments patient and physician deploy shared terminology that is then codified exactly in the chart, while in other moments their terminology diverges, with Dr. Bear deploying medical terminology to capture aspects of her circumstances irrespective of whether Ms. Roth endorses those terms.

Continuing this narrative, Berg tells us that while Ms. Roth undresses, her physician flips through his notes and considers what he has written. It is as though, not recalling what was just said, Dr. Bear checks his memory by looking again at the symbols he just recorded. He then examines her and asks someone from the pathology lab to take a sample of one of the lumps today. After the examination, he sits back at the office desk and jots down additional notes. Berg captures the conclusion of the consultation: "When Ms. Roth is dressed again, [Bear] tells her that he thinks 'the cancer has returned and has spread.' She reacts calmly, and he proposes

to treat her with hormones to ‘reduce the lumps’ ... He concludes the consultation by writing down: *Concl: metastasised breast ca, followed by RINolvadex 2x20 mg”* (*ibid.*, 504).

While this interaction was likely routine for Dr. Bear, it was undoubtedly anything but routine for his patient. One can only assume that receiving the bad news that her cancer has returned and spread was not a typical experience for Ms. Roth. While she had personal experience with breast cancer many years earlier, nothing that we know from Dr. Bear’s consultation or the general practitioner’s note suggests she has had any major medical problems since then. Given the meaning of the medical terms used in her referral and used by Dr. Bear, it is highly likely that Ms. Roth was just informed she had terminal cancer and, although Dr. Bear could help reduce the size of the tumors in her abdomen and thus the symptoms they caused, that only palliative care was available for her. Yet these are not words that Dr. Bear used. Perhaps he used them at another time when interacting with Ms. Roth. We do not know.

What do know from looking at the exchange above is that information flowed between Dr. Bear and Ms. Roth and Dr. Bear and the chart. The chart was a repository of information about Ms. Roth’s health state that she did not know, and which structured Dr. Bear’s communicative and other interactions with her. Ms. Roth told Dr. Bear about her experiences, but she said little that he recorded that was not already summarized more tersely in the referral. Though Dr. Bear did briefly discuss Ms. Roth’s social history with her and recorded this information in the chart in a portion not quoted above – asking about her children (none) and her husband (healthy) – he does not provide her an opportunity to express her concerns about her situation or to share any sort of emotional reaction upon having learned of her recurrent and terminal cancer. There are many strategies for better engaging with his patient and delivering bad news that Dr. Bear could have used at this moment (cf. Roter and Hall 1991; Buckman

1992). What is important is that we see that he did not use them. By describing in close detail how this patient and this physician communicated, and how the physician rendered their conversation in the medical chart, we see not only the importance of the medical chart, but also how it serves as an element in the decision-making system.

One of the special features of the medical chart is that it allows those who have permission to enter information into it a means of communicating across time and space with others who will view the chart and perform actions with patients in light of information contained therein. Thus, Dr. Bear accesses the information shared by the general practitioner in his referral letter. In considering this information before seeing his new patient, Dr. Bear draws upon it as a means of shaping his interaction with her, of constraining the types of information he elicits from her in their conversation. In this sense, the general practitioner is also an element in the decision-making system that emerges during Dr. Bear's and Ms. Roth's interaction: the general practitioner processed information he received from his examination of Ms. Roth, discussions with her, tests he performed, and perhaps other sources, to arrive at the conclusions accessed by Dr. Bear. In this sense, the general practitioner is an element too, a source of information that is processed and distributed through the system. He represents Ms. Roth's circumstances using the words in the letter. Dr. Bear then coordinates a representation of the information he elicits from Ms. Roth during their conversation and his clinical examination, which is noted in the chart. Thus, in these interactions, we can see how the chart serves as an extension of the voice of medicine and an important element in an emerging decision-making system.

5.6 Distributed Medical Decision-Making

By examining microanalyses of discourse in routine medical encounters, I have shown it is possible to describe communicative aspects of medical practice in much the same detail as Hutchins describes communication in navigation. My analysis differs from Hutchins' in the important respect that it is not an ethnography of a single system, but rather it is a sampling of a few sociological analyses of diverse medical practices. Thus it is not, and does not purport to be, as thoroughly empirically grounded as Hutchins. Nevertheless, it does demonstrate the possibility of measuring communicative acts and, in doing so, tracking the ways that persons represent the circumstances by making claims.

What we find when looking at communication in navigation and medical practice is that there is a rich ground from which the architectures of communication emerge. Information flow between persons and artifacts can be measured, and from this it is possible to create the sorts of network diagrams given in §§ 5.2.2 and 5.4.2. I have not shown how a specific instance of such a network emerges in the case of medical decision-making, but I have shown what it would take to track the communications within the system sufficiently to justify a particular depiction of a particular system using that representational scheme. Thus, I have demonstrated that by tracing the communicative interactions between persons and artifacts it ispossible to capture the foundation from which a medical decision-making system emerges.

In this section I will further substantiate this result by considering work on decision-making in hereditary breast and ovarian cancer by what I have previously termed clinical decision science, a loose confederation of social scientists, humanists, and clinicians performing a variety of research that all bears on decision-making in HBOC. I begin by considering another microanalysis of discourse performed in patients with breast cancer, which is focused

particularly on decision-making (§ 5.6.1). Then I review a number of studies on HBOC decision-making to chart the factors that are important in making such decisions (§ 5.6.2). In the next section I conclude that having identified these factors and performed the above analyses, I have demonstrated how one can describe a medical decision-making system as a distributed cognitive system. As such, I contend that, coupled with the work performed in Chapter 4, I have put forward a description of medical choice for inclusion in the model under development that is sufficient to meet the standard of descriptive adequacy described in Chapter 2.

5.6.1 *Conversations About Breast Cancer Decision-Making*

In a recent study, Nicola Mendick and her coauthors set out to examine medical decision-making in the wild in a population of patients with breast cancer and the surgeons, nurses, and other providers involved in their care. Mendick et al. (2010) were particularly interested in examining the fit between decision-making processes exhibited during consultations and participants' reflections on their roles in decision-making after choices had been made. They hypothesized that traditional models of autonomy and paternalism would not adequately describe their data; rather, newer models of autonomy such as "conscientious autonomy" (Kukla 2005) would be exhibited. They also anticipated a poor fit between patients' and surgeons' observed behaviors and their reconstructions of their participation in decision-making, which Mendick et al. suggested would support the view that received views of shared decision-making require further substantiation in light of the complex dynamics of such decision-making in actual consultations.

While Mendick et al.'s results relate to other aspects of this project, specifically insofar as they are consistent with the argument given in Chapter 2, at the moment I focus on the data they report. That they found diversity in information seeking preferences and desire for

involvement in decision-making is of interest. But what is of particular interest is the microanalysis of discourse they report and what it says about decision-making in breast cancer. In the only extract of a consultation they give at length, Mendick and colleagues capture a surgeon (S3), patient (P6), and nurse (B) discussing treatment options. The patient had already undergone one operation (a wide local excision or “WLE”) to remove ductal carcinoma in situ, however the operation did not successfully remove all of the cancer. Consequently, the patient was a candidate for further surgery. The surgeon offers mastectomy during the consult and also suggests a breast-conserving surgery, which would be another WLE. Central to the conversation is the patient’s worry that if the breast-conserving surgery as chosen and also failed to result in clear margins, then she would face yet another surgery afterwards. Using Mendick et al.’s conventions, speech is italicized, square brackets mark concurrent speech, “< >” during dialogue marks explanatory text from the authors, and bolded speech draws attention to portions of the dialogue supportive of the authors’ claims.

S3 *But as I say, if if you are strongly against it and you don’t feel, you know, you don’t want to lose the breast, if you want to do further more surgery too then we can offer, you know...if you want, even do some reconstruction or something, you can do if you want to.*

P6 **You tell me.**

S3 *Hmm.*

B4 *So, we’ve got all these options now and we are not, you know, we’re not expecting you to make a decision here and now.*

P6 *I mean, I’m not, I would sooner you tell me what’s best for me* <patient upset> **I would sooner you did that, don’t leave it because I don’t know. I don’t know.**

S3 *Now what do you feel about having your, you know, breast removed. You know some people are OK with that. As I say, they kinda ask me to remove the whole thing there and there’s no chance of it coming back and I would be more than happy that way rather than me keeping the breast. Some people are not OK with this and say whatever, I want to keep my breast and you do everything in your possible hands because I want to keep my breast. So, we have two different views people have. It depends upon what you feel, you know.*

P6 *No, I, I would prefer to do what's best for the [health] side.*
S3 *[Hmm].*
P6 *Yeah, I would, I would.*
S3 *You're not more worried about your cosmetic*
(Mendick et al. 2010, 1908)

After this exchange, the patient explains that the idea of using a breast prosthesis does not concern her. The surgeon then recommends mastectomy, which she enthusiastically accepts. Neither of these exchanges is reported by Mendick et al.; instead, they draw attention to a subsequent interaction, where the surgeon further conveys information about the size of the patient's tumor and gives her an opportunity to reconsider the treatment options in light of this information. The surgeon also notes another piece of information, that the patient dislikes anesthesia, as another reason against performing a second WLE, because by implication it would increase the risk of a third surgery and thus more anesthesia. The patient reiterates her preference for construing her circumstances solely in terms of 'the health point of view,' which in context appears to be a move to emphasize survival and fewer states of health that necessitate involvement with health care professionals. That is, the patient appears concerned more with quickly returning to her prior life of baseline health rather than risking prolonged medical treatment by focusing on breast preservation.

S3 *The lesion was you know what we say four and half centimetres size. When it's five centimetres we say you know definitely you need mastectomy. Four and half is not much difference there, and in your case you're already worried about anaesthetics and things.*

P6 *I mean, I hate I [hate] it with a passion.*

S3 *[Yeah] so maybe one operation, try to do the, you know, proper thing then you'll be alright. ...*

P6 *I would go for that and then I'll take it from there. ...*

S3 *Do you, do you want to take your time or discuss, er your preference is mastectomy and if you change your mind we will do something, or what do you want?*

P6 *I, I, I would go for ... I'm looking at it strictly ... from the health point of view ...*

B4 *Well it's not written in tablets of stone, so shall I come out in the week and go through and we can go through everything [again?]*

P6 *[yeah] but I mean ... let's just just let's get it done as quick as possible, that's it.*

(ibid.)

As with the other conversations discussed in the prior section, in this consultation we see persons negotiating over the way to represent problems arising under the circumstances and their solutions. However, in this instance there are three participants rather than two. Regardless, the negotiation is similar. Just as in the other conversations we see an interplay between subjective claims and objective claims and an attempt to forge agreement over the terms being used. Given the opportunity to state a decision, the patient each time uses passive, conditional language, stating she "would prefer," "would sooner," and "would go for." And she reiterates that her preference is to focus on a nebulous "health point of view" or "health side." Her surgeon, however, uses more technical language, such as "reconstruction," "cosmetic," and measurement in "centimetres."

Yet, the surgeon does present two divergent dispositions to the patient in the voice of the lifeworld, which provide alternative ways of conceptualizing the problem and concomitant solutions, when stating that "some people" are OK with one way of proceeding and "some people" are not OK and seek another solution. Thus we see the surgeon alternating between different vernaculars, trying to forge agreement with the patient on the treatment to pursue. In this excerpt the patient does not take up the surgeon's vocabulary, even when the surgeon endorses the voice of the lifeworld, so to speak. However, at the end of the excerpt, when the nurse reiterates that choice of treatment may be delayed, we see the patient respond with her first assertion and most direct speech act. She says to just "get it done as quick as possible."

Considering this interchange lends further support to the view that by attending to communication between participants in the medical decision-making process it may be possible to describe the flow of information constitutive of the system. As with the other interchanges related in this chapter, it is a mere moment in a temporally extended activity that includes other persons and artifacts, which interact in other spaces than merely this doctor's office. Nevertheless, though, considering these discussions supports the conclusion that such conversations are constitutive of decision-making activities in medical practice. Indeed, they comprise much that is integral to medical care. As Cassell has said, "all medical care flows through the relationship between physician and patient; and the spoken language is the most important tool in medicine," which I presume means it is also the paramount feature of that relationship (Cassell 1985, 1). What I have aimed to show by considering discrete instances of that relationship as it is manifested in communication is that a reasonable way of describing the sum total of these communications is by using the tools of distributed cognition as articulated above.

When described in terms of distributed cognition, medical decision-making is an activity that includes a network of information processing elements, which are persons and artifacts. These elements encode information, form representations, transform representations, and then coordinate representations as they share information with connected elements. Using this computational metaphor for describing interactions between the many persons and tools documented in the conversations above, it is possible to imagine how a decision-making process like Ellen Macke's could be justifiably rendered in terms of a network of elements, as rendered in Figure 5.3. Even though we have no access to the data that would be required to show that representing Macke's choice in that way is not an *ad hoc* move, considering the conversations

presented here suggests that doing so is at least possible. Moreover, considering these conversations also indicates that the information processing network representation is consistent with that sort of data, if it was available.

To further substantiate the claim that describing medical decision-making as a distributed cognitive activity is justified, in the next section I argue that considering many social scientific studies of HBOC decision-making provides insights into the sorts of communication that would be anticipated across the many elements in a system like that seen in Macke's case.

5.6.2 *Factors for Discussion in HBOC Decision-Making*

Looking at microanalyses of discourse reveals that conversations between participants in medical decisions may be useful for making generalizations about the types of claims individuals make and the variations with which they make them. And it further supports the view that looking at information flow only between persons will not suffice for describing decision-making systems. Describing such systems necessitates tracking information flow between artifacts and persons too, perhaps none more important than the medical chart.

However, looking at microanalyses of discourse in medicine does not provide a useful means for making generalizations about the architecture of communication because, unlike navigation, no studies report sufficient data to ground such conclusions. Thus, up to this moment this chapter has presented two different perspectives from which to describe medical decision-making. One looks at the phenomenon over a lengthy time interval, aiming to capture all of the important participants in the process and reconstruct the flow of important information between them (Figure 5.3). The other perspective aims to look at the phenomenon as an observer attending to the flow of raw information between components in the system, including between patients, physicians, and other health care providers (§§ 5.5.2.1, 5.5.2.3, and 5.6.1),

between physicians and physicians (§§ 5.5.2.2 and 5.5.2.3), and between physicians and the medical chart (§ 5.5.2.3). Between the “macro” and “micro” perspectives there might appear to be a chasm. In this section I will indicate how this gap might be filled in the particular case of hereditary breast and ovarian cancer.

To fill this “gap,” so to speak, I suggest that what is required is to review what is known about the biopsychosocial dimensions of a patient’s health state (Engel 1977, 1980, 1981), which in this case is the health state of suspected hereditary breast and ovarian cancer. As Roter and Hall note, “social factors precede diagnosis,” as do psychological factors; and moreover, although “many doctors and patients undoubtedly recognize how profoundly social the process of medical care is...few...are aware of how well developed our scientific knowledge of that process is” (Roter and Hall 1992, x). Clinicians, social scientists, and empirically minded humanist scholars have collected an impressive amount of data on the factors that influence decision-making in HBOC, just as they have in other treatment contexts. Here I aim to convey how that data fits into the model of decision-making under development. I contend that reviewing these factors, that is, reviewing what is known about the psychosocial aspects of being ill and making medical decisions in breast and ovarian cancer, provides a means of moving between the micro-perspective of discourse and the macro-perspective of communication architecture. Once these factors are recognized, they then become factors that we may predict to be relevant to various degrees for an HBOC decision. They are the categories and types of information we could anticipate being important to discuss in conversations from which HBOC decisions emerge.

To identify the factors associated with HBOC decision-making, I reviewed a “convenience sample” of 62 publications that I have procured while researching HBOC

decision-making. Unlike a systematic review, I do not purport to systematicity in the sense of performing a defined search through PubMed or another service and then whittling down the set of studies using well defined criteria or interpersonal agreement (for such a review of how the perception of risk influences decision-making by patients in clinical genetics, see Sivell et al. 2008). Rather, over the years I have studied the social basis of decision-making in HBOC I have procured papers on the topic that I review. This set of papers is not exhaustive, but I have reason to believe it is representative.

In reviewing these papers, I began by reading each title and abstract, looking for (i) reports of communication between participants in decision-making related to breast or ovarian cancer and (ii) descriptions of factors purported to influence that decision-making. Next, in cases where the abstract was unclear or where it appeared that the paper included relevant information not discussed in the abstract, the whole paper was quickly read. From this, 6 additional papers were found in references and 9 papers were excluded for not including (i) or (ii) above. For each of the 59 papers⁵⁷ containing the requisite information, all of the factors that were considered as possibly influencing decision-making in breast and ovarian cancer were recorded. Redundant factors were then eliminated and near matches were synthesized and

⁵⁷ The 59 studies included in this review are: Aizer et al. 2013; Armstrong et al. 2005; Berhardt et al. 1997; Borgen et al. 1998; Botkin et al. 2003; Bradbury et al. 2012; Braithwaite et al. 2006; Claes et al. 2003; Collins et al. 2009; Croyle and Lerman 1999; d'Agincourt-Canning 2005, 2006; De Leeuw et al. 2008; Dorval et al. 2000; Douglas et al. 2009; Elmore 2005; Erblich et al. 2000; Escher and Sappino 2000; Ford et al. 1996, 2000; Ganz et al. 1999; Gaston and Mitchell 2005; Geller et al. 1998; Gilbar and Gilbar 2009; Grenn et al. 2010; Hallowell and Lawton 2002; Hallowell et al. 2004; Hughes et al. 1997; Jacobsen et al. 1997; Kavanagh and Broom 1998; Kenen et al. 2003; Klitzman and Chung 2010; Lapham et al. 1996; Lerman et al. 1996, 1997, 2000; Lynch et al. 1997; Matloff et al. 2000; Mendick et al. 2010; Meyer and Ringberg 1986; Miller et al. 1999, 2010; Olaya et al. 2009; Ormondroyd et al. 2012; Prospero et al. 2001; Ray et al. 2005; Sachs et al. 2001; Sagi et al. 1994; Schneider et al. 1997; Schwartz et al. 2000; Shoda et al. 1998; Sivell et al. 2008; Stalmeier et al. 1999; Staton et al. 2008; Tambor et al. 1997; van Dooren et al. 2005; and van Roosmalen et al. 2004.

recorded as discrete factors on a table, grouped by major categories. Then all of the figures in each paper were reread to identify specific socio-demographic variables not recorded prior and to look for factors missed in the initial review (6 of which were found). The review was completed once redundant socio-demographic variables were eliminated and the final list was re-synthesized to again eliminate redundant entries and near matches.

This review process revealed 8 major categories of factors scholars have studied to estimate their influences on decision-making in breast and ovarian cancer (Table 5.1). One category lists some of the possible roles that might be adopted by participants during decision-making. Another category lists factors relating to a patient's health states, such as whether she has a family history of certain cancers, is a carrier of a BRCA mutation, or engages in preventative health behaviors. I have also included socio-demographic factors in one category, such as the influence of race on uptake of testing and other services (Armstrong et al. 2005). And I have also identified a category for types of communication patterns that researchers have documented and studied for their influence on the decision-making process. For example, Ford et al. (1996) studied the extent to which oncologists used open and closed questions or emphasized biomedical rather than psychosocial factors in talking to patients, and whether this influenced the responses given by breast and other cancer patients, including the extent to which patients emoted during conversations. Another study, by Prospero et al. (2001) used a focus group methodology to measure whether individuals who had recently been given positive results had communicated them with their family members and correlated their responses with other factors.

Three other categories are also listed on Table 5.1. Reported knowledge includes assessments of patients', providers', and caregivers' self-reported knowledge about the listed

factors. These include such items as pre-implantation genetics, which might be an option worth considering for *BRCA1/2* carriers (Ormondroyd et al. 2012), and understanding of HBOC testing procedures, which some physicians have been shown to have a poor understanding of (Escher and Sappino 2000). Decision-making factors include such items as patients' or care givers' decision-making preferences (Gilbar and Gilbar 2009), measures of family influence in decision-making (Croyle and Lerman 1999), and participants' usage of heuristics to process information (Kenen et al. 2003). Finally, the psychosocial category, which is the least coherent of them, includes such items as patients' spiritual faith (Schwartz et al. 2000), personality characteristics (Meyer and Ringberg 1986), sexual identity and body image (Ganz et al. 1999), cancer related distress (van Dooren et al. 2005), and various types of feelings (Douglas et al. 2009).

Table 5.1: A list of factors for discussion in HBOC decision-making. See text for description.

| Socio-demographic Information | |
|--------------------------------------|---|
| Role: | <ul style="list-style-type: none"> - Patient - Provider: physician, nurse practitioner, genetic counselor - Care giver: spouse, child, close relative, distant relative, friend, support group member - Institution |
| Health States: | <ul style="list-style-type: none"> - Personal history: comorbidities, body mass index, number of pregnancies and children, previous psychiatric treatment, estimated (empiric) risk, menstrual status, hormone replacement therapy, hot flashes - Cancer status: absent, tumor stage, tumor stage at diagnosis, type of malignancy, site of malignancy - BRCA1/2 carrier status: unknown, true positive, false positive, true negative, false negative, variant of unknown significance - BrCa family history: first-degree relative, second-degree relative, multiple relatives - Sexual health: interest, dysfunction (e.g., vaginal dryness), satisfaction - Preventative health behaviors: diet or exercise changes, stress management, control over risk, self examination, past physician visitation |
| Use of Services: | <ul style="list-style-type: none"> - Prophylactic surgery: oophorectomy, mastectomy - Surveillance: mammography, MRI, breast self-exam, clinical breast exam, transvaginal ultrasound, CA125 screening - Pharmacological intervention: chemotherapy, tamoxifen, contraceptives - Genetic testing - Genetic counseling - Decision aids: education, counseling - Family-planning - Pre-implantation genetic diagnosis (PGD) |
| Communications: | <ul style="list-style-type: none"> - Age - Sex: male, female - Race: White, Black, Hispanic, Asian, Native American, Other - Socioeconomic status (SES) - Education: high school or less, some college, college degree, graduate school - Employment: unemployed, part-time, full-time, profession allied to medicine - Residence: rural, urban - Marital status: single, married, divorced, separated, widowed - Religious heritage: Jewish, Christian, Muslim, Other, None reported - Language spoken: English, Spanish, Other - Member of support group - Insurance coverage: none, health maintenance organization, preferred provider organization, fee for service - Physician specialty: general practice, family practice, internal medicine, obstetrics/gynecology, oncology, general surgery, other - Patient with relatives: offspring, close relatives, distant relatives - Patient with primary care physicians - Referral to testing by HCP - Physician makes recommendation - Initiator of discussions: testing, test results, treatment options - Risk communication: of individual risk, risks of genetic testing, with family - Framing of breast cancer risk statistics - Personal assessment of risk communication during consultation or counseling - Conversation variables in communication of bad news: type of talk, open / closed questions, biomedical / psychosocial content, expressions of emotion, engagement (partnership) - Interaction between doctor and patient during consultation - Communication of probabilistic information: objective risk, risk perception |

- Reported Knowledge:**
- HBOC testing: accuracy, practical details of process, benefits, risks, limitations, costs, counseling
 - HBOC management options
 - Types of risk perception: objective, experiential, empathetic
 - Estimated risk comprehension: individual, population
 - Role of heredity in cancer
 - Prediction of personal actions: genetic testing uptake, emotional reactions to disclosure, treatment decision
 - Post-operative complications of prophylactic surgery: onset of menopausal symptoms, side effects of hormone replacement therapy, negative effects on body image and gender identity
 - Post-operative benefits of prophylactic surgery: risk reduction, enabling one to fulfill family obligations, removing the need for gynecological screening, cessation of menstruation, positive side effects of HRT
 - Preimplantation genetic diagnosis (PGD)

Decision-Making Factors:

- Information seeking preferences
 - Information comprehension
 - Information processing ability
 - Perceptions of: information importance, role in decisions, burdensomeness of decision-making, decisional conflict
 - Interpretation of risk information
 - Preferences for involvement in decisions: provider recommendations, nondirective, inclusive (care givers, HCPs)
 - Preferences for decision-making style: SDM, autonomy, paternalism
 - Preferences for treatment options: personal preferences, utility measures, QALY measures
 - Family influences
 - Calculated "decisional balance" (ratio of perceived pros/cons)
 - Objective measure of decision-making responsibility
 - Use of heuristics in information processing
- Psychosocial Factors:**
- Personal cancer experience: self, as care giver, relative, mother, mother's death
 - Family narratives told about: breast cancer, ovarian cancer, heredity
 - Individual personality characteristics
 - Psychological style: monitoring, blunting
 - Perception of cancer risk: personal, offspring, relatives, general population
 - Perception of testing: risks, benefits, limitations, insurance discrimination, curiosity
 - Perception of medical decision-making responsibility
 - Perception of personal health
 - Body image: concern about appearance, comfort with appearance
 - Sexual identity: concern about libido, concern about sexuality, concern about relationship status
 - Mental health: worry, anxiety, depression, distress, intrusive thoughts, well-being
 - Cancer related mental health: worry, distress, perception of vulnerability
 - Feelings of concern about: surveillance, breast self exam, preventative measures, insurance discrimination
 - Feelings of: uncertainty, control, security
 - Coping: strategies, skills, processes
 - Physical and emotional responses to services used, care received, decisions made
 - Psychological adaptation (short and long term) to use of services: acceptance of surgical results, sexual function (increased) or dysfunction, depression, anxiety, reduced affect
 - Emotional responses to disclosure (patients, offspring): anxiety, informational content
 - Emotional responses to communicating results to family
 - Spiritual faith
 - Identity perception: personal identity, embodied self, familial-relational self, social self
 - Health care related intentions: undergo testing, undergo counseling, reproduce
 - Desire to participate in care
 - Decision uncertainty

The overall result to take away from this review is that there are many factors scholars have studied as being potentially influential when persons participate in decisions related to hereditary breast and ovarian cancers. I have not evaluated the reports for their methodological soundness; indeed I do not even distinguish between reviews of many studies and single research reports. Thus, I do not evaluate particular assertions regarding the influence of any particular factor in such decisions. Some of the methods may leave much to be desired. Other methods may be particularly sound, and they may have shown some of these factors to be influential or not. Regardless, the usefulness of these studies for the present purposes is simply that they provide a sense of the possibilities, of what topics we might anticipate clinicians and patients discussing when conversing about the many different things that arise during the emergence of medical decision-making systems related to hereditary breast and ovarian cancers. That is, the factors documented in Table 5.1 are things that researchers consider to be possibly important in HBOC decision-making; thus, I assume that these are factors that it would be important for patients, care givers, providers, and others to discuss during the many conversations that take place when HBOC decisions emerge.

For example, in describing her decision-making, Ellen Macke described many different roles that different persons played in the process. She also described a number of health states that she embodied over the three-year process she reconstructs. She described the many services she and others used, and she described some of her socio-demographic characteristics as well as those of others. Macke also reconstructed communicative activities she and others performed. And she described her knowledge of certain topics, such as heredity in cancer and of the likely sequelae of prophylactic mastectomies, as well as others' knowledge of these factors. Finally,

Macke described her own decision-making dispositions and numerous psychological and social dimensions of her and others' circumstances and her decision-making process.

While, as I have noted, we do not have access to the communicative experiences that gave rise to Macke's reconstruction of her decision-making process, I submit that it is likely that the topics communicated are well captured by the factors schematized in Table 5.1. That is the sense in which I suggest that this list of factors provides an additional means of describing HBOC decision-making between the micro and macro perspectives.⁵⁸ It provides a means of tracking the language persons are likely to use when conversing about topics in the process of participating in decision-making. I presume that most persons will not use terms that will map directly on to the factors listed above. However, the exact terms they use will be relatable to these factors. And, as the study of these aspects of patient care develops, more factors will be included and the means of correlating between employed terminology and topics will improve in scope and precision.

The list given in Table 5.1 could be expanded in a number of ways. It could be amplified considerably by including more of what is known about the health states that are often observed in HBOC patients, the ways of modeling breast cancer risk, the ways of testing for it and their implications, and other aspects of the biomedical study of HBOC covered in Chapter 4. Different elements in HBOC decision-making systems will be expected to access, process, and

⁵⁸ I recognize that the term "perspectives" here is a fuzzy one. Insofar as it provides some clarity, I believe Bill Wimsatt has analyzed the colloquial usage of "perspective" well, as a "a diverse range of things that nonetheless appear to have at least some of the properties of being 'from a point of view' or to have a subjective or quasi-subjective character. In spite of that, perspectives differ substantially in terms of their other properties, and in terms of their relative objectivity" (Wimsatt 2007, 207ff.). I use the term "perspectives" to capture a way of looking at the world such that one renders aspects of it in terms that are corrigible. To adopt a perspective is to look at things a certain way; this "looking at" may have its own properties, including the degree to which it is objective, which I would cast in terms of the means of producing (objective) claims it incorporates.

convey this information differently. We can anticipate that in some cases information relating to diagnosis and prognosis may be captured in more detail in artifacts and by health care professionals than by care givers and patients, for example. In other cases, however, patients and care givers who take on a significant role in information processing and decision-making, like Ellen Macke, will have considerable access to more of the biomedical information, and thus will be more connected to different elements in the system.

Thus, by attending to the biopsychosocial factors that are likely to be discussed during decision-making, some of which are captured for HBOC in Table 5.1, I contend we can describe the types of information that is likely to be shared between elements in medical decision-making systems that occur in cases of HBOC. In the following section I conclude this chapter by asserting that the approach to describing decision-making I have argued for in the last two chapters suffices for meeting the standard of descriptive adequacy put forward in Chapter 2.

5.7 Descriptive Adequacy

The aim of the last two chapters has been to describe a particular example of a medical decision-making system, to introduce a theoretical framework to capture it, and to argue for some representational conventions for describing the system, so understood.

In Chapter 4, I began by describing a sub-type of breast cancer, HBOC, in considerable detail (§ 4.1). I then covered the historical background and contemporary application of genetic testing for HBOC, including the criteria a person must meet to qualify for testing and the typical clinical relationships that precede testing (§ 4.2). I then introduced Ellen Macke's case in considerable detail (§ 4.3) and argued that it shows how spatiotemporally and socially

distributed her decision-making was (§ 4.4). In light of this, I suggested that her choice could be understood as an instance of distributed cognition (§§ 4.5-4.6).

This chapter has developed that insight considerably. While introducing the distributed cognition framework, I have focused on the way it was initially proposed by Hutchins (§ 5.1) and the basic concepts of distributed cognition that can be distilled from his presentation (§ 5.2). Yet I have been clear that, though I believe distributed cognition is an extremely useful way of describing decision-making in medicine, I recognize there are clear senses in which the analogy between medical choice and navigation break down (§ 5.3). Nevertheless, I have argued that by invoking distributed cognition we gain access to representational conventions from cognitive science and other fields, which follow from adopting the computational metaphor for describing complex systems. By adopting the convention of describing a social system as a network, I argued that we may describe Macke's choice in terms of its communication architecture (§ 5.4). However, I also recognized that doing so is incomplete because there are important perspectives left out of that representation of a medical decision-making system. One of those important perspectives I have called a micro-perspective, in that it aims to characterize communication between participants in decision-making and other systems in terms of raw information flow (§ 5.5). This is contrasted with the macro-perspective of communication architectures, which capture rarefied information flow merely in terms of connections between elements in the system where important information was shared, and importance is defined merely by Macke's recollection. In between these two perspectives I have gestured at another means of describing information flow in the system, by abstracting away from particular communicative behaviors and identifying the types of things we would expect to be discussed, which I call factors, as they identified by empirical work on HBOC decision-making (§ 5.6).

Taken together, these two chapters satisfy the criterion of descriptive adequacy introduced in Chapter 2 as a basic criterion that any model of medical choice should meet. There I said that “descriptive claims are ones that describe events and states of affairs, such as behaviors, patterns of reasoning, feelings, and actions; ideally, they do so irrespective of any extent to which said descriptions imply or are derived from norms.” In describing Macke’s choice in terms of distributed cognition and the representational conventions related to it, I have described the events and states of affairs that exhibited in a particular instance of medical decision-making. I have endeavored to describe the sorts of behaviors, patterns of reasoning, feelings, and actions that took place in Macke’s case, even though her reconstruction of it necessitates that my description must treat her case as an instance of a type, rather than as a collection of data points from which to make inductive inferences, such as about its structure and emergence. And I have described Macke’s case without presupposing that it ought to be a particular way because of specific norms governing choice in medicine. I have not isolated aspects of her decision-making and argued that they are consistent with autonomy-based informed consent, beneficence-based paternalism, or shared decision-making. Rather, I have aimed to describe her decision-making and to introduce a conceptual framework for abstracting some generalizations from it.

My approach in the past two chapters is a major departure from the received normative models of medical choice, autonomy and paternalism, because it carefully reconstructs decision-making and thereby captures a particular decision-making process in a way that indicates how varied and complex the process might be. I do not suppose that those who have put forward autonomy and paternalism as normative models have failed to appreciate this complexity. Yet, I contend that in crafting their normative accounts they have failed to

adequately explicate how they are supposed to be directly applicable to actual decision-making in actual clinical contexts. My intuition has thus been to invert the trajectory of inquiry and to focus on explicating that context by understanding its conceptual structure (Chapter 3) and considering an instance of decision-making in considerable detail. In this way, I contend to be grounding my model of choice in a richer account of the *uniquely medical contexts* in which it occurs. Readers may disagree with my approach or disagree with the conclusions I have drawn about routine medical practices. However, I would argue that by making this approach explicit and by attempting to make explicit how I derive my assumptions about the context of medical decision-making, I have provided a foundation for my model of choice that, in this way, makes it an improvement over the normative models described in Chapter 2.

What remains, however, is to now relate this description of medical decision-making with a sufficiently rich normative framework, and thus, to fashion a model of medical choice that meets both the descriptive and normative standards of adequacy. This is the aim of the following two chapters. In them, I pick up on a contention made in § 5.4.1 above, that the Basic Aims may serve as provisional and defeasible normative foundations for medical decision-making systems. However, in order to articulate this view, I must first convey how appealing to the Basic Aims is justified as a means of providing normative content into the model under development. This necessitates considering a specific model of ethical justification in terms of coherence, or reflective equilibrium, which is the aim of Chapter 6. After I have described how coherence and reflective equilibrium might be used in order to justify particular ethical choices, I then explain how they can be used in a specifically medical context. This concludes the analysis, which is reiterated, summarized, and reconsidered in light of a few likely objections in Chapter 8.

6.0 REFLECTIVE EQUILIBRIUM, COHERENCE, AND DECISION

ANALYSIS

In the previous two chapters I argued for describing medical decision-making in terms of distributed cognition. I hold that this approach is better than traditional accounts of medical choice because it provides tools for representing important details of decision-making in practice that they do not. As proposed thus far, however, the model being developed is insufficient because it lacks normative content. The representational tools discussed in the last chapter make it possible to describe medical decision-making from a number of perspectives, including close analysis of communication between individuals, the factors one can anticipate being discussed by them, and the overarching structure of communication. However, these tools are useful for describing how medical decision-making systems are structured and how they function, not how they *should be* structured or *should* function. The representational tools can describe how a system is organized at a given time, what factors are considered by experts to be important for a system of its type, and what information is processed by it. But these tools cannot say how a system should be organized, what its goals should be, or how it should process information in order to reach the terminal state of making a choice.

Yet, in Chapter 2 I argued that a satisfactory model of medical decision-making should be both normatively and descriptively adequate. Merely achieving one type of adequacy is

insufficient, as this entails that the model can either provide action guidance, but without sensitivity to the actual context of action or it can accurately depict the context of action, but without the ability to guide actions themselves. Both standards should be met. The purpose of this chapter and the next is to address this issue. In them, I complete the social model of medical decision-making under development by arguing for an account of ethical justification that provides it with specific normative content.

The purpose of this chapter is to argue for assimilating the method of *reflective equilibrium* into my account of medical choice and to explain the benefits accrued by doing so. Reflective equilibrium is a popular, procedural account of ethical justification attributed to Rawls. It holds that ethical principles are justified if they are generated through an ideal procedure, whereby persons most laudable convictions and moral judgments are made to cohere with one another, and with certain background assumptions or theories, and this coherent set includes the affirmation of the principles under consideration. Yet, a number of powerful criticisms may be lodged against the reflective equilibrium method of ethical justification, including that it is either circular or it is impracticable. Section 6.1 describes the reflective equilibrium method in all of its complexity, articulates these objections, and accepts that it may not be possible to overcome them, depending upon what our aims are for adopting reflective equilibrium.

My analysis of reflective equilibrium demonstrates that scholars disagree on the aim of the method, and consequently on what activities must be performed in order to justify ethical claims when following it. I take this disagreement to be a problem because it indicates conceptual confusion, particularly regarding whether reflective equilibrium is a method that should be performed by individual agents for the justification of particular ethical claims or

whether it should be performed by groups of individuals for the justification of ethical principles. My aim is to develop a normative framework for groups of individuals for the justification of particular ethical claims pertaining to particular circumstances. Thus, in Section 6.2 I articulate this problem in reflective equilibrium and suggest a way toward a solution. This requires explaining the notion of coherence in detail and considering how, though it is not without its own limitations, it may be used to respond to objections to varieties of reflective equilibrium.

Yet, coherentism is shown to have its weaknesses too. Most importantly for us, it appears to place arbitrary and unjustified selection criteria at the foundations of ethical justification. Recognizing this, Sections 6.3 and 6.4 aim to overcome the issue of arbitrariness by describing and appealing to concepts in decision analysis as a framework for conceptualizing coherence in the specific context of medical choice. I argue that the notational conventions expressed by *decision trees* are particularly useful for providing parameters for schematizing choices. With these parameters on hand, I show that coherence may be understood in terms of both the *search* for information and the *selection* of information. Models of coherence that rely solely on logical consistency (and not on how consistency is reached) assume that only selection is important for generating coherence. However, justified coherence also requires justified search procedures, or so I claim.

While decision trees provide conceptual resources for defining coherence as the sole criterion of reflective equilibrium methods, they also suffer from arbitrariness and normative inadequacy because there is always a sense in which more information might be represented in a tree. Moreover, which information is represented is not a matter of adopting justified norms but is a matter of differences in modeling strategies. However, I believe that decision analytic

concepts may be given normative content by considering how they apply to specific cases of medical decision-making, such as Ellen Macke’s case. I perform this analysis in Chapter 7, but to prepare for that analysis, Section 6.5 describes a “generic decision tree” that can be used to develop decision analytic models of medical choice. Reaching this result concludes this chapter. The next chapter moves from discussing ethical justification in the abstract, as is done here, to discussing ethical justification in particular instances of medical choice and the generalizations that can be made about that activity.

6.1 Reflective Equilibrium: Interpretations and Limitations

Reflective equilibrium originates in the work of John Rawls and Norman Daniels’ extension of it. It has been popularized by others, notably Beauchamp and Childress (2009) and enriched by yet others, especially DePaul (1993) and Richardson (1990, 1994). Though it has been criticized for being a rather simpleminded account, I aim to convince the skeptic that for our purposes the notion suffices, even if it fails for the more grandiose projects for which it has been proposed. Moving toward this goal, this section introduces reflective equilibrium by considering different interpretations of it and their limitations.

I begin with Beauchamp and Childress’ account, which is based on reflective equilibrium but deviates from it, because it is perhaps the most widely accepted method of justification in bioethics; hence, I assume it is the most likely candidate for conceiving of reflective equilibrium for medical contexts (§ 6.1.1). Beauchamp and Childress provide an objection against reflective equilibrium that they and many others take to be fatal. To develop a response to it, in §§ 6.1.2 and 6.1.3 I delve into the nuts and bolts of reflective equilibrium, summarizing its emergence as distinct varieties in the works of Rawls and Daniels. I show that

Rawls' account has two distinctive features when viewed in relation to both Daniels' and Beauchamp and Childress' interpretation. One is that Rawlsian reflective equilibrium aims at the justification of higher-order normative concepts. Though Rawls characterizes reflective equilibrium as a procedure for justifying ethical theories in general, it is important that his motivation is to justify justice as fairness in particular. For this reason, I believe the move to appropriate reflective equilibrium for other purposes must be done with more care than is commonly taken. Recognizing this leads to the second feature of Rawlsian reflective equilibrium, which is that it interprets justification in ethics as a dialogical activity, as something *interlocutors* do in the process of arguing over ethical norms. This is important because I aim to emphasize exactly this aspect of reflective equilibrium. I thus see his account as describing justification as a deliberative process, which I contend accords well with my use of distributed cognition as a descriptive theory (§ 6.1.4). However, I nevertheless recognize that Rawlsian reflective equilibrium aims at justifying ethical principles rather than particular ethical claims. Thus I consider whether and how to retool the Rawlsian approach throughout the rest of the chapter.

6.1.1 *Reflective Equilibrium Justifies Particular Actions and Moral Norms*

In their most recent edition of *Principles of Biomedical Ethics*, Beauchamp and Childress distinguish between three basic models of ethical justification. “Top-down” models privilege normative theories and claims derived therefrom. On them, justified ethical judgments are deduced from normative precepts in combination with a description of the state of affairs. The converse – “bottom-up” models – emphasize practical decision-making and privilege experiences in particular cases, under particular circumstances.

According to Beauchamp and Childress each of these models is flawed, a claim that is commonly accepted in bioethics literatures.⁵⁹ They contend deductive approaches fail to apply to cases because it is unclear how normative precepts apply or attach to particular cases. And, inductive approaches fail because they face the problem of induction, how to infer reliable generalized normative precepts from particular experiences. In light of these problems, Beauchamp and Childress offer a third, “integrated” model of ethical justification, which they refer to as “reflective equilibrium” or “coherence theory.” On this view, justified ethical claims result from “a reflective testing of our moral beliefs, moral principles, theoretical postulates, and the like to make them as coherent as possible” (Beauchamp and Childress 2009, 381-382).

For Beauchamp and Childress, reflective equilibrium is an activity that an individual performs in order to (i) justify a particular course of action (out of a set of possible actions) or (ii) justify a set of moral norms (principles) to guide reasoning about particular cases. Reflective equilibrium can serve these complementary justificatory functions because when an individual engages in it, she must perform two tasks. She must identify her *considered judgments* and her *moral principles*; the former being thoughtful assessments of the state of affairs; the latter being inferences about her moral commitments or convictions. According to Beauchamp and Childress, performing both tasks enables the performance of both actions:

The goal of reflective equilibrium is to match, prune, and adjust considered judgments and their specifications to render them coherent with the premises of our most general moral commitments. We start with considered judgments of moral rightness and wrongness, and then construct both a more general and a more specific account that is consistent with these judgments, rendering the whole as coherent as possible. We then test the resultant guides to action to see if they

⁵⁹ E.g., Daniels (1979, 1996a, 1996b); Richardson (1990); DeGrazia (1992); DePaul (1993); Demarco (1997); Childress (2007); Arras (2007).

yield incoherent results. If so, we must go back and readjust the guides further. (Beauchamp and Childress 2009, 382)

This process of reiterative pruning may be described as a *selection type process*:⁶⁰ out of a pool of moral principles and considered judgments, the set that is the most internally consistent and coheres best with what is known about the circumstances of action is selected. Considered judgments are those that are formed under ideal conditions, are about the morality of particular types of activities, and have a scope that covers “all levels of generality in moral thinking”(*ibid.*), including such disparate ‘generalities’ as particular situations and abstract conditions on moral conceptions. For Beauchamp and Childress reflective equilibrium is the activity of matching, fitting, pruning, and adjusting our considered judgments and moral principles in light of the particular situation.

According to Beauchamp and Childress, however, when understood solely as a selection type process, reflective equilibrium is deeply flawed because it relies only on the criterion of internal coherence in order to select against competing systems of belief. Coherence merely requires logical consistency; it fails to take other qualities of belief systems into account. Beliefs may be incredible, offensive, or any other of many things. Thus, merely invoking coherence as the criterion for selecting beliefs is deeply problematic because it is not clear that we are protected from a very serious worry: what prevents someone from beginning with

⁶⁰ This term is adapted from Darden and Cain’s “selection type theories.” As they say, “selection theories solve adaptation problems by specifying a process through which one thing comes to be adapted to another thing” (1989, 106). That is, selection type theories explicate processes of selection for biological structures that solve adaptation problems. I see the process by which Beauchamp and Childress depict an incoherent set of information becoming a coherent set as being an analogous selection process, in that it is via reiterative pruning that the members of the set are either selected for or against, in accordance with which they ‘solve the problem’ of being internally consistent. The result of reiterative pruning is thus a total set that is adapted in accordance with the extent to which it meets a single criterion, internal coherence.

considered judgments and moral precepts that are arbitrary, or even worse, patently offensive or perverse, and thus ending with a purportedly justified set of beliefs after reflective equilibrium that is nonetheless a patently unjustifiable?

Beauchamp and Childress illustrate this problem by appeal to the “Pirates’ Creed of Ethics or Custom of the Brothers of the Coast,” which they contend makes plain that “bare coherence never provides a sufficient basis for justification, because the body of substantive judgments and principles that cohere could themselves be morally unsatisfactory” (Beauchamp and Childress 2009, 384-385). They describe the Creed and its lesson as follows:

Formed under a democratic confraternity of marauders circa 1640, this creed for pirates is a coherent set of rules governing mutual assistance in emergencies, penalties for prohibited acts, the distribution of spoils, modes of communication, compensation for injury, and "courts of honour" that resolve disputes. This body of substantive rules and principles, although coherent, is a moral outrage. Its appeal to "spoils," the awarding of slaves as compensation for injury, and the like involve immoral activities. (*ibid.*)

Beauchamp and Childress ask, “what justifies us in saying this coherent code is an unacceptable code of ethics?”⁶¹ For the Rawlsian, the reply to this worry is to accept the problem and to put constraints on the reflective equilibrium procedure. To best understand this reply, we must discuss Rawls’ account in some detail.

6.1.2 *Rawlsian Reflective Equilibrium: The Justification of Ethical Principles*

Rawls’ account of reflective equilibrium is most sensible when understood in light of his motivation for developing it. His general aim is to characterize how principles in moral and

⁶¹ Their answer is that a privileged set of considered judgments, which they call “common morality,” that other judgments and principles must cohere with as reflection tends toward equilibrium.

political philosophy may be justified. His specific aim is to justify the principles of justice he argues would be adopted under the hypothetical contractual situation known as the original position, where hypothetical agents under a veil of ignorance deliberate upon and choose the moral and political norms of society.⁶² A constraint Rawls' places on his conception of justice, *justice as fairness*, is that it must accord with a theory of rational choice akin to rational choice theory (1999, 365-372; 116 fn. 9; 124 fn. 14). Describing this leads Rawls to claim that what would justify the principles chosen by individuals in the original position is not only that their choices are rational, but also that they match what he terms our *considered convictions*. Thus, in order to justify his description of the original position, Rawls says we must inquire whether,

...the principles which would be chosen match our considered convictions of justice or extend them in an acceptable way...For example, we are confident that religious intolerance and racial discrimination are unjust. We think we have examined these things with care and have reached what we believe is an impartial judgment not likely to be distorted by an excessive attention to our own interests. These convictions are provisional fixed points which we presume any conception of justice must fit. (*ibid.*, 17-18)

According to Rawls, this sort of inquiry provides a means for checking whether the deliverances of his thought experiment are justified by considering the extent to which they have the capacity “to accommodate our firmest convictions and to provide guidance where guidance is needed” (*ibid.*, 18).

⁶² Rawls initiates the discussion of reflective equilibrium in the following way: “Understood in this way the question of justification is settled by working out a *problem of deliberation*: we have to ascertain which principles it would be rational to adopt given the contractual situation. This connects the theory of justice with the theory of rational choice” (1999, 16; italics added). For Rawls, the notion of reflective equilibrium is a means of describing apt deliberation.

For Rawls, considered judgments are thus fixed points of reference predicated upon an individuals' socially situated norms.⁶³ Considered judgments are important because they provide an initial foundation for justifying the principles an agent would adopt under specified conditions, the original position. According to Rawls, reflective equilibrium serves as a justification for a conception of justice because such a conception cannot be deduced merely from self-evident principles, but rather, must be reasoned to from *broad considerations*. Reflective equilibrium thus “represents the attempt to accommodate within one scheme both reasonable philosophical conditions on principles as well as our considered judgments of justice.” If it succeeds it does so because “its justification is a matter of the mutual support of many considerations, of everything fitting together into one coherent view” (*ibid.*, 18-19). While on this account reflective equilibrium and justification are closely associated, we may consider them apart as well. We will begin with Rawls on reflective equilibrium (§ 6.1.2.1) and then turn to his characterization of justification (§ 6.1.2.2).

6.1.2.1 Rawls on reflective equilibrium

The basis of Rawls’ formulation of reflective equilibrium is the concept of mutual support of many considerations, described as follows:

In searching for the most favored description of this situation we work from both ends. We begin by describing it so that it represents generally shared and preferably weak conditions. We then see if these conditions are strong enough to yield a significant set of principles. If not, we look for further premises equally reasonable. But if so, and these principles match our considered convictions of justice, then so far well and good. But presumably there will be discrepancies. In

⁶³ Critics have rightly pointed out that Rawls’ reliance on such considered convictions as “that religious intolerance and racial discrimination are unjust” shows hubris, because it is unclear that such “convictions” are widespread (e.g. Haslett 1987; Brandt 1990). Indeed, even minimal awareness of the 24-hour news cycle suggests prejudice to be far more common than such convictions. Objections following from this worry will be explored in § 6.2 below.

this case we have a choice. We can either modify the account of the initial situation or we can revise our existing judgments, for even the judgments we take provisionally as fixed points are liable to revision. By going back and forth, sometimes altering the conditions of the contractual circumstances, at others withdrawing our judgments and conforming them to principle, I assume that eventually we shall find a description of the initial situation that both expresses reasonable conditions and yields principles which match our considered judgments duly pruned and adjusted. This state of affairs I refer to as *reflective equilibrium*. It is an equilibrium because at last our principles and judgments coincide; and it is reflective since we know to what principles our judgments conform and the premises of their derivations. At the moment, everything is in order. But this equilibrium is not necessarily stable. It is liable to be upset by further examination of the conditions which should be imposed on the contractual situation and by particular cases which may lead us to revise our judgments. Yet for the time being we have done what we can to render coherent and to justify our convictions of social justice. We have reached a conception of the original position. (1999, 18; italics added)

I interpret Rawls here as providing a conception of justice that is justified by appeal to the *character*, *scope*, and *coherence* of the judgments and principles that give rise to it. Thus, Rawls takes pains to specify that considered judgments are no ordinary judgments; they are our most laudatory judgments about justice, stemming from careful reflection of well-described mores of our society; they are also judgments that follow from the considered convictions we have about justice; and, they are judgments that cohere with one another.

It is important to appreciate not only how Rawls describes what reflective equilibrium is, but also what it is not. Rawls' reflective equilibrium is not a procedure for making particular ethical decisions, nor is it for abstractly describing justified ethical decision-making (cf. Rawls 1951). Rather, it is an idealized procedure for justifying an abstract conception of justice, which we may refer to as a *higher-order principle* because it rests on a semi-stable coherent system of lower-order principles and judgments that follows from iterating the reflective equilibrium procedure.

Rawls anticipates a number of questions and objections regarding reflective equilibrium. A most obvious one is simply, How does it work? That is, as it stands the precise relationship between the constituents of a stable equilibrium and the higher-order principle they justify is entirely opaque. One wants to know more about how equilibrium between such potentially disparate items might arise if the position is to be at all persuasive.

One simple but mistaken is that the higher order principle is identical to the logically coherent set of constituents selected at equilibrium. Rawls rejects this view because he believes there is something about the instability and fallibility of our considered convictions that makes them poor candidates for comprising a higher-order principle like justice, even when they suitably fit with relevant lower-order principles (Rawls 1999, 42-43). For this reason, he contends reflective equilibrium does not result in a justified higher-order principle merely by virtue of identifying it with the set of constituents that result from the termination of the procedure. Thus, the question remains: How does it work?

Rawls does not answer this question directly, though we can pursue an indirect route for getting a sense of how he envisions reflective equilibrium working: we can look at two traditional approaches to justification he negatively contrasted it with. Rawls states that ethical theories have traditionally been justified in one of two ways:

[Some philosophers] attempt to find self evident principles from which a sufficient body of standards and precepts can be derived to account for our considered judgment. A justification of this kind we may think of as Cartesian... A second approach (called naturalism by an abuse of language) is to introduce definitions of moral concepts in terms of presumptively non-moral ones, and then to show by accepted procedures of common sense and the sciences that the statements thus paired with the asserted moral judgments are true." (*ibid.*, 506)

Rawls rejects both of these. He asserts the Cartesian approach fails because "there is no set of conditions or first principles that can be plausibly claimed to be necessary or definitive of

morality and thereby especially suited to carry the burden of justification.” Likewise, Naturalism fails because it “must first distinguish moral from non-moral concepts and then gain acceptance for the definitions laid down. For the justification to succeed, a clear theory of meaning is presupposed and this seems to be lacking” (*ibid.*).

Irrespective of whether one agrees with Rawls’ characterization of these positions and his responses, it is notable that his language is consistent with Beauchamp and Childress’. Rawls contends Cartesians attempt to ground moral theory in deductive inference, but no satisfactory principles are forthcoming. Naturalists attempt to ground moral theory in inductive inference, but the connections between particular data and moral principles require a theory of meaning that is lacking.

However, stating these contrasts is not equivalent to a positive account of how reflective equilibrium is supposed to work. At most, they are constraints on how the procedure might possibly work. But more must be said for a positive sense of the reflective equilibrium procedure to emerge. For a further window into Rawls’ account of the notion, we next consider his discussion of justification in ethics.

6.1.2.2 Rawls on justification

At the end of *A Theory of Justice*, Rawls portrays justification as an essentially *dialogical activity*, as opposed to a logical one.⁶⁴ By his lights, empirical demonstration of truth and deduction from self-evident principles are insufficient for ethical justification by themselves.

⁶⁴ This opposition need not be put very strongly, depending upon whether one views logic as itself being predicated upon an essentially dialogic activity. For example, Catarina Novaes argues that understood in historical context deduction is “primarily (originally) an *argument* (a discourse), not an inner mental process” (Novaes 2012, 154). On this account, argument is primarily a discursive practice; hence, so too is justification. Thus it may be that what distinguishes Rawls’ reflective equilibrium is its emphasis on the *social* character of justification rather than internal cognitive reasoning processes.

Rather, what is necessary is a shared starting point, which may include merely the shared stance of being engaged in argument. Only in the context of proffering, refusing, and accepting reasons does justification have meaning. However, justification is not merely the activity of proffering and rejecting reasons, but the activity of doing so with others, while sharing reasons. Argument, says Rawls, presupposes some basic foundation of agreement, at the very least, to the activity of engaging in argument – to the activity of purveying and considering reasons as a means to the end of reaching a state of justification.⁶⁵

For Rawls, justification entails deliberation in the sense that it entails a “clash of views” between interlocutors. On his view only the participants in dialogue can evaluate the extent to which their judgments cohere with any principles they induce or invoke in order to forge their conclusions. Thus, the vision of justification entailed by Rawls’ account of reflective equilibrium is *justification by deliberation*.

However, as anyone familiar with being engaged in an actual argument with another knows, the intoxicating heat of argument may be very different than the sobering chill of disagreeing with oneself.⁶⁶ For one, in all but the most prolonged arguments, we can presume

⁶⁵ Consider that Rawls says: “Justification is argument addressed to those who disagree with us, or to ourselves when we are of two minds. It presumes a clash of views between persons or within one person, and seeks to convince others, or ourselves, of the reasonableness of the principles upon which our claims and judgments are founded...justification proceeds from what all parties to the discussion hold in common...thus, mere proof is not justification... proofs become justification once the starting points are mutually recognized, or the conclusions so comprehensive and compelling as to persuade us of the soundness of the conception expressed by their premises...[C]onsensus...is the nature of justification” (Rawls 1999, 508-509).

⁶⁶ Some clarification is in order here: I assume individuals will vary widely with regard to whether they find debate more heated when it is with themselves than when it is with others. That is, I wish to be neutral with regard to whether internal conflict is more emotionally salient than conflict with another. What matters only is that a reasonable distinction may be made for any given person between deliberating in the first person sense and deliberating in the second and third person senses. While for some the manifest differences between these types of deliberation may be so small as to be negligible, I

only a small subset of considered judgments and moral principles will be invoked. Likewise, it is simply not clear how often one individual is expected to sample the possibility space of judgments and principles while disagreeing with oneself. Thus, we must wonder whether Rawls takes actual disagreement with others as paradigmatic of justification or whether he emphasizes simulated disagreement with others (i.e., disagreement with oneself) as exemplary. Perhaps surprisingly, it appears to be the former: Rawls takes mere personal reflection⁶⁷ as an insufficient paradigm for justification in ethics.

There are, however, several interpretations of reflective equilibrium. For the notion varies depending upon whether one is to be presented with only those descriptions which more or less match one's existing judgments except for minor discrepancies, or whether one is to be presented with all possible descriptions to which one might plausibly conform one's judgments together with all relevant philosophical arguments for them...Clearly it is the second kind of reflective equilibrium that one is concerned with in moral philosophy. To be sure it is doubtful whether one can ever reach this state. For even if the idea of all possible descriptions and of all philosophically relevant arguments is well-defined (which is questionable), we cannot examine each of them. The most we can do is to study the conceptions of justice known to us through the tradition of moral philosophy and any further ones that occur to us and then to consider these. (Rawls 1999, 43)

I believe Rawls may be interpreted here as being very skeptical of personal reflection alone as a means of justifying ethical theory. Rawls recognizes that whether reflective equilibrium is justificatory depends on the type of judgments the procedure begins with. Earlier, I interpreted

am assuming that such individuals are exceedingly rare. What feels more "hot" or "cold" does not matter, just so long as there are differences between the two types for most people.

⁶⁷ Whether Rawls' words are consistent with this claim will hinge on what one takes "mere personal reflection" to mean. As I think is clear from the current discussion, I take it to mean less than perhaps what philosopher's believe themselves capable of in their most self-aggrandizing moments. Absent these conceits, I assume most will accept the claim that (at least temporally constrained) personal reflection cannot achieve the type of reflection Rawls describes here, which he too seems to accept. Of course, whether deliberation with others can do so is an open question, which will be pursued below.

his account of reflective equilibrium as requiring not just considered convictions, but ones with certain characteristics; namely, they must be our most laudatory, have sufficient scope, and be coherent. If we wonder where these convictions come from, it seems that we cannot get them solely from personal reflection, at least of the garden-variety sort. We need Herculean personal reflection. Thus, I believe Rawls can be interpreted as putting forward an account of reflective equilibrium where justification is predicated upon deliberation with others. I will call this *Rawlsian reflective equilibrium* to distinguish it from other varieties discussed below.

Rawlsian reflective equilibrium (RRE) is an ideal procedure that takes as inputs considered convictions about all sorts of items, including moral principles and reflections on particular cases and gives as output a justification for a specific higher-order concept. RRE requires considered convictions to meet certain criteria, which, though opaque in his account, are at least present: such convictions must be most laudable, of a certain scope, and in some sense coherent.

This characterization of Rawls must be distinguished from other interpretations of reflective equilibrium because all interpretations have problems but it is not clear that they share them, and if they do, if they share them equally.

6.1.3 *Narrow and Wide Reflective Equilibria*

In his work extending and formalizing the notion of reflective equilibrium, Norman Daniels distinguishes between narrow and wide reflective equilibria. Daniels' motivation is to solve what he terms, “the problem of theory acceptance or justification in ethics,” which he contends is “intractable unless, that is, one is willing to grant privileged epistemological status to the moral judgments...or to the moral principles” that are standard on the two-tiered view of moral theories as a set of judgments and principles that account for them or from which they are

derived (Daniels 1979, 256). Because the concept of wide reflective equilibrium is commonplace, it is important to explain Daniel's distinction between narrow (§ 6.1.3.1) and wide (§ 6.1.3.2) reflective equilibria.

6.1.3.1 Narrow reflective equilibrium

According to Daniels, reflective equilibrium is a method of justification that attempts “to produce coherence in an ordered triple of sets of beliefs held by a particular person, namely, (a) a set of considered moral judgments, (b) a set of moral principles, and (c) a set of relevant background theories” (*ibid.*, 258). Notice right away that where Rawls puts forward a social, deliberative account of reflective equilibrium resting upon the conceptualization of justification as argument between persons, Daniels sees the procedure as being performed by a single, isolated individual. The individual performing reflective equilibrium may begin with either set and move in between them in any order she likes, just so long as producing coherence is the activity guiding her reasoning (*ibid.*, 259 fn. 5). Also notice that nothing in Daniels' definition of reflective equilibrium prevents the procedure from generating an ethical code like the Pirates Creed. To counter this, Daniels distinguishes between wide and narrow reflective equilibria.

By Daniels' lights, narrow reflective equilibrium (NRE) is only nominally a method of ethical justification. To reach it, a person would only bring an ordered pair of beliefs into a coherent system $\langle \{a\}, \{b\} \rangle$, but without considering any criticisms of or alternatives to members of $\{a\}$, $\{b\}$, or $\{c\}$. Thus, on NRE, one will “simply settle for the best fit of principles with judgments.” But, Daniels says this would not suffice, for it “would give us only *narrow* equilibrium. Instead, we advance sound philosophical arguments intended to bring out the relative strengths and weaknesses of the alternative sets of principles (or competing moral conceptions). These arguments can be construed as inferences from some set of relevant

background theories” (*ibid.*, 258). Thus, for Daniels, NRE occurs when an individual begins with her initial judgments, culls some from them to make considered judgments {a}, and brings these into coherence with a set of moral principles {b}. The resulting ordered pair is presumably maximally logically consistent, though how this constrains the membership of the sets is left implicit. Irrespective, this procedure is deficient because it fails to take into account all sorts of relevant considerations that a sufficient version of the procedure must consider. Thus Daniels distinguishes wide reflective equilibrium.

6.1.3.2 Wide reflective equilibrium

Daniels describes wide reflective equilibrium (WRE) in terms of an “agent working back and forth, making adjustments to his considered judgments, his moral principles, and his background theories. In this way he arrives at an equilibrium point that consists of the ordered triple (a), (b), (c)” (*ibid.*, 258). The principle difference between narrow and wide reflective equilibrium follows from the latter’s incorporation of background theories that serve to check against the problematic narrowness of the latter. According to Daniels,

The background theories in (c) should show that the moral principles in (b) are more acceptable than alternative principles on grounds to some degree independent of (b)'s match with relevant considered moral judgments in (a). If they are not in this way independently supported, then there seems to be no gain over the support the principles would have had in a corresponding narrow equilibrium, where there never was any appeal to (c) (258-259).

And he defines this sense of independence thusly:

Suppose that some set of considered moral judgments (a') plays a role in constraining the background theories in (c). It is important to note that the acceptability of (c) may thus in part depend on some moral judgments, which means we are not in general assuming that (c) constitutes a reduction of the moral [in (b) and (a)] to the nonmoral. Then, our independence constraint amounts to the requirement that (a') and (a) be to some significant degree disjoint” (259-260; brackets in original).

Daniels' account of WRE thus formalizes and schematizes Rawls'. In so doing, Daniels' types of reflective equilibrium depart from RRE in important ways. Of particular importance, WRE contains constraints not found in the RRE: WRE (i) makes explicit that background conditions ($\{c\}$) are part of the set of items brought into coherence during the procedure, and (ii) adds a constraint captured by the set (a'), which constrains the structure of the background theories such that they purportedly gain some degree of independence for the other types of information under consideration in the procedure.⁶⁸ In addition, as Daniels describes them, NRE and WRE are instantiated by individual cognitive agents, which is also a departure from RRE, where justification is an essentially dialogical activity and hence one that does not pertain solely to individual cognitive processes.

There is a clear similarity that binds all three types of reflective equilibrium though. They each rest upon the notion of coherence as the criterion against which pieces of information are selected: if a piece of information is a member of the coherent set of items included in the total set of equilibrated items, then that piece will remain at equilibrium; if not, then it will not. With this in mind, we can define reflective equilibrium as follows.

6.1.4 *Reflective Equilibrium Defined*

While there is considerable disagreement about what reflective equilibrium is, some things may be said about it with some certainty. First, reflective equilibrium is an idealized procedure for generating justified higher order principles.⁶⁹ Second, the procedure rests solely on the notion

⁶⁸ For doubts about the necessity and utility of Daniels' independence criterion, see DePaul (1993, 20–22).

⁶⁹ Although some authors argue (Richardson 1990) or claim (Arras 2007) that reflective equilibrium is a procedure for justifying something other than higher order principles (e.g., concrete ethical problems or

of coherence; however this concept is defined, it is the only criterion against which the set of judgments and beliefs that justify a higher order principle is selected. Third, it proceeds according to the following steps, which are adapted from DePaul (1993, 16-23).

- (0) An agent (A) begins in the initial state, with a set of *initial moral judgments*, $\{\text{IMJ}\}$.
- (1) In the first step, A filters $\{\text{IMJ}\}$ according to the extent to which individual members of the set meet its logico-epistemic standards. The remaining judgments may be called *considered moral judgments*, forming the set, $\{\text{CMJ}_i\}$.
- (2) In the second step, A formulates a set of moral principles that explicate the members of $\{\text{CMJ}_i\}$, forming the set $\{\text{MT}_i\}$.
- (3) In the third step, A brings $\{\text{CMJ}_i\}$ and $\{\text{MT}_i\}$ into coherence by considering the extent to which members of each set are consistent and selecting for optimal logical consistency. The resulting ordered pair is said to be in narrow reflective equilibrium (N), represented as: $\langle \{\text{CMJ}_N\} , \{\text{MT}_N\} \rangle$.
- (4) In the final step, A considers additional sources of information, represented as the set of *initial background theories*, $\{\text{BT}_i\}$. Once this information is brought into coherence with the previously coherent ordered pair, the resulting ordered triple is said to be in wide reflective equilibrium (W), represented as: $\langle \{\text{CMJ}_W\} , \{\text{MT}_W\} , \{\text{BT}_W\} \rangle$.

This description of reflective equilibrium captures the structure of the procedure and its aim of justifying a moral principle through a wide consideration of information, which are emphasized by Rawls, Daniels, and others. Yet it also captures an important ambiguity between Rawls' and Daniels' interpretations by using the term "an agent (A)," which is ambiguous between a singular individual, as Daniels primarily describes the procedure, or a deliberating collective acting together. Codifying this ambiguity is important because it draws attention to a basic problem with reflective equilibrium, namely, that it is unclear who its target users are. That is, who is supposed to instantiate this procedure remains open. Perhaps a computer is supposed to do it, perhaps a committee of persons, or perhaps a single individual. If it is the

beliefs), and although this account may be widespread, as I have shown above neither of the originators of the view express this position.

latter, then it seems entirely unlikely that individuals could perform the cognitive labor required to instantiate the procedure. Thus, reflective equilibrium does not appear to be action guiding for actual persons with finite cognitive resources. However, it may be possible to resist this conclusion by considering the concept of coherence in more detail.

6.2 Coherence and the “No Guarantees” Objection

Two problems arise when reflective equilibrium is understood as resting solely on the notion of coherence: it is unclear what constraints are to be placed on the sort of agent that is to maximize coherence while carrying out the procedure and it is unclear how maximizing coherence suffices for justifying the results of the procedure, since coherence requires only the production of logical consistency. That is, with coherence at its foundation, the problem with reflective equilibrium is that what one gets out of the procedure depends entirely on what one puts in. Only if one begins with laudable beliefs, judgments, or principles in the beginning is it even possible to end up with a set that includes members with such qualities. Moreover, though it might be possible, it is not at all *guaranteed*.

Suppose that bringing an ordered triple into coherence requires significantly reducing the number of claims in each set. Imagine, that is, that going from disequilibrium to equilibrium solely by maximizing coherence leads one to hold few remaining considered moral judgments and few resulting moral principles that consist with background theories. Perhaps both $\{\text{CMJ}_w\}$ and $\{\text{MT}_w\}$ are an order of magnitude smaller than $\{\text{CMJ}_i\}$ and $\{\text{MT}_i\}$. If so, then while the members may remain laudable, taken as a whole they may be so reduced as to insufficiently apply to the situation at hand. They may be coherent but they may not be coherently about much at all.

I will refer to this objection as the *no guarantees objection*, because it aims at showing that the operation of reflective equilibrium does not guarantee anything valuable at all. With coherence as its criterion for selection, it might generate a laudable ordered triple, but there is no reason to think it will. Furthermore, even if there were such a guarantee, there is no guarantee that persons could appreciate or perceive that equilibrium has been reached. There is no guarantee we can have knowledge of equilibrium, even granting for the sake of argument that it is guaranteed to follow.

Many have suggested this objection, and many have responded to it, though in ways that are generally unsatisfying.⁷⁰ Consider Richard Brandt, who argues that because of its reliance on coherence, what matters in reflective equilibrium is what beliefs the procedure begins with:

There is a problem here quite similar to that which faces the traditional coherence theory of justification of belief: that the theory claims that a more coherent system of beliefs is better justified than a less coherent one, but there is no reason to think that this claim is true unless some of the beliefs are initially credible – and not merely initially believed – for some reason other than their coherence, say, because they state facts of observation. In the case of normative beliefs, no reason has been offered why we should think that initial credence levels, for a person, correspond to credibilities. The fact that a person has a firm normative conviction gives that belief a status no better than a fiction. Is one coherent set of fictions supposed to be better than another? (Brandt 1979, 18-19; quoted in DePaul 1993, 24)

The Rawlsian response to this objection is to focus on how justification follows from judgments and principles with a certain character, scope, content, and coherence, not merely the coherence of *any* judgments and principles. Judgments and principles must follow from our considered convictions, free from distorting influences, not merely our initial responses.

⁷⁰ DePaul (1993) provides an accessible summary of this literature.

Yet, one still wants to know much more. What does it mean to create a set of considered judgments from one's initial response, which is now free of distortion? What does it mean to consider a wide range of perspectives in testing one's system of beliefs? And, perhaps most importantly, what does it mean to be coherent? More recent discussions of the no guarantees objection distinguish two ways in which reflective equilibrium is not guaranteed to result in anything valuable, and furthermore, will likely result in unjustified beliefs (cf., Arras 2007; DePaul 1993; Beauchamp and Childress 2009). I will consider each of these below, which I call *idiosyncrasy* (§ 6.2.1) and *supercomprehensiveness* (§ 6.2.2). Once we have considered the substance of this objection in additional detail, we will be in a good position to understand how *not* to respond to it. That is, we will discover what reflective equilibrium should not mean. Thereafter, we will be able to articulate what it could mean in a uniquely medical context (§ 6.2.3).

6.2.1 *Idiosyncrasy*

We may refer to the first version of the no guarantees objection as *idiosyncrasy*: it states there is no guarantee that someone starting with patently idiosyncratic normative convictions will be led by reflective equilibrium to opt for laudable beliefs. In fact, we will expect those who begin with idiosyncratic normative convictions will end up with the same such convictions once the procedure is completed. Only now their views will be coherent and no better for it.

Consider the following hypothetical cases suggested by John Arras. First, a hypothetical teenager named Rush, "who immerses himself in the world of right-wing politics in order to provide himself with 'an identity'. All day long, he tunes into the rants of right-wing ideologues on talk radio, reads and rereads their screeds in pamphlets and books, and avidly participates in their website chat rooms. Rush emerges from this ideological bath feeling much better about

himself as a committed Republican, free-marketeer, political libertarian, and a sworn enemy of the welfare state, which he decries as a haven for losers and a drain on the energies of virtuous, wealthy entrepreneurs” (Arras 2007, 63).

Assuming that Rush and his critics are both committed to reflective equilibrium, it appears Rush is beyond reproach. He has considered many viewpoints over and above his own initial considered judgments. As Arras puts it, he has taken an ideological bath, and that bath has been sufficiently full, we are to suppose, so that Rush’s reflective equilibrium transcends narrow reflective equilibrium. But of course, the proponent of reflective equilibrium is supposed to respond that Rush has for some reason failed to reach the standard of wide reflective equilibrium. Another counterexample suggests this move fails.

Consider Sophia, an intelligent, educated, thoughtful, progressive, and generally cosmopolitan young woman living in the early twentieth century. Sophia happens to be an “amateur eugenicist who advocates sterilization of the ‘unfit,’” a commitment she adopts because of its consistency with her other beliefs, “including the Bible, as she has learned to interpret it; ‘common sense’; the then-ascendant social Darwinist theory of political economy; and, of course, then-current theories of genetics,” all of which “tell her the same thing: namely, that the white race is superior, that it is under siege, and that sterilizing the ‘unfit’ represents the quintessence of social responsibility” (*ibid.*, 64).

Unlike Rush, the problem with Sophia is that her case is not as easily dismissed as one of narrow reflective equilibrium. Whereas Rush’s beliefs seem insular, Sophia’s, we suppose, are built from a full sampling of the landscape of moral judgments available to her. She has sought out diverse alternatives, lived a cosmopolitan lifestyle, and generally challenged her moral convictions. And this has led her to a fine, and coherent, system of beliefs that includes a

commitment to eugenics. But, we now believe her view is abhorrent and inconsistent with being progressive, intelligent, and thoughtful.

As the Sophia and Rush examples illustrate, idiosyncrasy captures the following worry: unless the number and diversity of considered judgments and moral principles meets a certain threshold of acceptability, even adequately performing wide reflective equilibrium (as in Sophia's case) will be insufficient to guarantee *prima facie* morally appropriate systems of belief. Thus, the no guarantees objection rests on an assumption that applies to any putative method of ethical justification: it assumes that a basic criterion of any method of ethical justification is that it produces systems of belief that are at least *prima facie* morally appropriate. The reason reflective equilibrium appears illicit to proponents of the no guarantees objection is that coherence alone does not meet this criterion. Hence, reflective equilibrium is and unacceptable method of justification for ethical theory.

This worry about idiosyncrasy is amenable to further distinctions. It might be the case that what went wrong in Sophia's iteration of reflective equilibrium is that she failed to converge on a *prima facie* morally appropriate system of belief. We might say that in our pluralistic society tolerance of diverse moral starting points is assumed. This means Sophia, and everyone else, has the right to begin the reflective equilibrium process from his or her own idiosyncratic set of judgments and principles. What matters, then, is that through a sufficient sampling of alternatives and counterintuitions, Sophia and the rest of us will converge upon a tight range of moral systems, all of which fall into the set of *prima facie* morally appropriate systems of belief. Responding to this line of reasoning is what motivates wide reflective equilibrium, with its requirement that judgments and principles cohere with background theories that are themselves constrained by sufficiently independent moral judgments. The problem

arises again, though, that without privileging some particular judgments there seems to be no plausibility to the claim that different individuals will converge upon the set of *prima facie* morally appropriate systems of belief. Rather, nonconvergence seems far more likely. So the problem of idiosyncrasy can be understood as a *problem of nonconvergence*.

Idiosyncrasy may also be understood in terms of pruning rather than convergence. Reflective equilibrium requires that judgments and principles be *pruned* during the process if they fail to cohere, which depends on whether they are consistent with principles and judgments that have higher or lower ‘consistency relations’ with other principles and judgments. As one “goes back and forth” isolating less coherent constituents, one prunes them from the set of constituents that are being brought into equilibrium. But, in and of itself, coherence neither guides nor constrains pruning. It provides no criteria for which constituents to prune and which to leave.

A reasonable response might be that coherence suggests rank ordering constituents from most to least coherent. Then one might prune from the bottom up, or one might choose all the constituents below a threshold of coherence for pruning. However, this is a problem because the removal of a lesser-coherent constituent will affect the coherence of remaining constituents, because the remainders will now appear more or less coherent than they did before pruning simply by virtue of the fact that they are no longer related to the highly-incoherent constituents that have been removed. Thus, whether one prunes from the bottom up or below a threshold, before successive iterations of checking for coherence can occur the remaining constituents will have to be reordered after each pruning. Acknowledging this draws attention to the need to justify the selection of a pruning strategy.

Yet, bare coherence does not justify a pruning strategy; it is as though logical consistency carries its justification on its face. It is here that few good arguments are forthcoming. Understood in terms of idiosyncrasy, the no guarantees objection seems fatal to reflective equilibrium, if the procedure is understood as resting on the notion of coherence. Moreover, the case is made even stronger by considering another interpretation of the objection, against proponents of reflective equilibrium who would try to argue that the width of wide reflective equilibrium suffices for resisting the charge of idiosyncrasy.

6.2.2 *Supercomprehensiveness*

Let us consider a response to the no guarantees objection that emphasizes the width of wide reflective equilibrium. On this view, we suppose that neither Rush nor Sophia had actually adequately performed the procedure sufficiently. We this claim that if only they had sampled the possibility space of judgments, principles, and background theories more adequately, and if only they had also pruned more satisfactorily, then they would each have been led to a more laudable system of beliefs at the conclusion of the procedure. In Sophia's case, for example, one might say that her reflective equilibrium was not wide enough: it failed to account sufficiently for philosophical arguments and alternatives from the broad philosophical tradition. If she had taken these into account, Sophia would have rejected forced sterilization and eugenics, presumably along with many other of her previously held principles and judgments. Moreover, if others in her era adequately performed reflective equilibrium, they too would have rejected these ill-gotten views.

This response evidently devolves into a simpleminded exhortation to merely “try harder.” In effect, it says to search for, sample, and select from knowledge of all philosophical traditions great and small and their points of disagreement. Thus, this response asks ordinary

cognitive agents to consider a very wide range of information to justify their ethical claims. However, pursuing this response to the charge of idiosyncrasy reveals the other glaring objection against coherentism: it asks too much from ordinary cognitive agents. Reflective equilibrium appears to require that agents be *super-comprehensive*, not merely comprehensive in their sampling of the range of judgments, principles, and background theories.

Yet, one might say there is no reason to hold agents to this standard of comprehensiveness when reasoning about moral problems. Consider what it would take in Sophia's case: on Arras's account it would seem to require that she consider every possible item in the vast possibility space of items that may be logically connected to any items in her sets of beliefs. When undergoing the reflective equilibrium procedure, for Sophia this suggests, "were we to use time travel miraculously to inject our contemporary knowledge of genetics into her constellation of beliefs, Sophia would have to prune many of her considered judgments and background theories right down to their stumps" (*ibid.*). Clearly, appeal to knowledge of unknown future scientific theories cannot be required for wide reflective equilibrium to take place. So, how comprehensive must it be?

There is no need to belabor this point. The only answer available to the proponent of reflective equilibrium is that the devil is in the details. The details describing the procedure, such as they are, and such as they have been presented carefully above, state what wide reflective equilibrium is and is not. As Rawls notes, "one is to be presented with all possible descriptions to which one might plausibly conform one's judgment together with all philosophical arguments for them" (*op. cit.*). But as he notes, it is doubtful whether anyone could process such information. So in some sense we are left where we began. We wonder

what level of comprehensiveness is required for the procedure to have said to be adequately carried out. Clarity does not appear forthcoming.

Therefore, coherence, *per se*, fails to provide the necessary resources for specifying what constituents to add to the coherence-maximizing procedure. If insufficient constituents are added, then the procedure will reach an idiosyncratic equilibrium, and there is no guarantee that this will accord with our *prima facie* acceptable moral systems of belief. Absent some criterion for specifying the sufficient constituents of a coherence procedure, one might simply respond that *all possible* constituents must be included. Surely, then, whatever judgments and principles are members of our *prima facie* acceptable moral systems of belief will be included, and then the coherence procedure will entail that they remain after it has been performed. But, this is obviously *impracticable*; it would require far too much expertise and far too much time, neither of which, one presumes, normal humans have.

Thus, considering both ways in which one might object to reflective equilibrium because it does not guarantee laudable results shows that relying solely on coherence as a means of justification in ethics is a problem. Bare coherence lacks the conceptual resources to distinguish between narrow and wide reflective equilibrium. Therefore, it cannot help proponents of reflective equilibrium escape the worry of idiosyncrasy. Yet, in its wider guise, when supplemented with the independence criterion and demand for breadth, coherence invites an objection on the grounds of supercomprehensiveness. The problem then, is one of specifying the meaning of coherence in such a way that neither of these extremes is entailed. That is, if coherence is to serve as a foundation for reflective equilibrium, it must be clear what coherence is. And this requires at least stating *what* sorts of things a coherence based reflective equilibrium justifies out of candidates like higher-order principles (*e.g.*, justice as fairness), lower-order

principles (*e.g.*, respect for autonomy), or particular judgments (*e.g.*, an instance of reproductive cloning is immoral). It is also necessary to explain *how* coherence justifies, including how it constrains the initial constituents of a coherence-engendering procedure such that it is neither idiosyncratic nor impracticable.

6.2.3 Toward a Redefinition of Coherence

There is one straightforward response to both interpretations of the no guarantees objection, which is to shift the burden of proof from proponents of coherence methods of justification to their opponents. For example, one might assert the issues of idiosyncrasy and impracticability are faced by all methods of justification. Thus, merely illustrating that coherence faces them too is insufficient to undermine its utility as one of, perhaps equally deficient, approaches to ethical justification. Indeed, one might argue that a virtue of the reliance on coherence is it makes clear what sort of tradeoffs may be made in order to satisfy worries of idiosyncrasy and supercomprehensiveness. To speak to the former, one must include sufficient constituents in the starting setup of a coherence procedure; to speak to the latter, one must constrain the constituents sufficiently for the procedure to be instantiable by real, as opposed to idealized, human beings. Given the fancies of traditional ethical theories, it is unclear that they do any better at satisfying this tradeoff between idiosyncrasy and impracticability than a coherence-based account.

Of course, shifting the burden of proof is not so simple as pointing at putative weaknesses other ethical theories. One needs more than a red herring to shift a burden. One actually needs to provide evidence that a justificatory procedure grounded in coherence is a workable means for justifying ethical theory. This evidence must be persuasive in speaking to the worries about idiosyncrasy and supercomprehensiveness. The evidence should show that,

while there may not be any *guarantees* that coherence will lead to justified ethical theory, coherence will at least *reliably* result in such theory.

For a number of reasons, I am skeptical of the view that a project explicating and marshaling such evidence for coherence as a *general methodology* in ethics is likely to succeed. As DePaul notes, the richness and diversity of ethical theory alone should make us pause if we wish to claim that reflective equilibrium will be capable, once refurbished and retooled, of generating an ethical theory sufficiently exalted to engender assent from all of those who are disposed toward any of the teachings of, say, Plato, Aristotle, Marx, Mill, or Nietzsche (DePaul 1993, 54). To do so would require a significant amount of evidence on a wide range of topics, and a display of the sense in which coherence operates such as to assimilate it into a coherent picture. This is not likely to be forthcoming.

I am also skeptical too because I am not sure what *coherence* is supposed to mean. It might mean simply logical consistency, but if so, then it will be impotent, because more must be said if the selection procedure envisioned by reflective equilibrium is to be instantiable. Precisely, what at least needs to be said is by what standards one is supposed to prune the constituents upon which the procedure works. Thus, the choice is either to redefine coherence in terms of more than simply logical consistency or to appeal to non-coherence criteria of choice and to justify such appeals. But this choice is really no choice at all. Really, it is just a way of expressing the obvious: strict coherence must be abandoned to save reflective equilibrium. If coherence is to form the foundation of the procedure, then it will only be capable of doing so if redefined.

I recognize that “redefining” coherence *in general* would be a quixotic enterprise. And it will not be on that preoccupies us. Rather, my aim is to extent to notion of coherence as it is

applied in a particular domain. I will argue for a more elaborate and precise definition of coherence as a foundation for reflective equilibrium in a particular arena – in medical decision-making. To do so I will introduce additional conceptual tools that I argue allow for a better representation of the dynamics of bringing about coherence in medical contexts. Doing so will take the remainder of this chapter. In the next chapter I use these tools to explicate the normative framework assumed on my model of choice, a framework which I call *medical reflective equilibrium*.

6.3 Decision Analysis and the Logic of Medical Choice

In the remaining sections of this chapter, the aim will be to define a type of reflective equilibrium for the medical context, rather than the context of metaethics. For clarity, I will explain a common approach for representing medical choices, in terms of *decision trees*. Decision trees are commonly used for representing choice in the social sciences, including medicine (for an early example, see Klein and Pauker 1988; for introductions and textbook accounts, see Weinstein and Fineberg 1980; Hunink and Glasziou 2001; Rao 2007; Schwartz and Bergus 2008). Although this approach to choice is often lauded for its quantitative power, particularly in standard decision theory, I employ decision tree diagrams differently – for their usefulness in explicating the logical structure of decisions. Thus, I begin by explaining decision analysis as it has been applied to medical contexts, specifically by considering a case study of suspected appendicitis (§ 6.3.1). I then show how the deliberations involved in the case may be represented in basic decision analytic terms using the concepts of *choices* and *outcomes* (§ 6.3.2). Yet I recognize that the representational convention does not solve some of the important issues with coherence that were just introduced. However, the convention does introduce new

vocabulary for capturing those issues, in terms of the modeling activities of *pruning* and *foliating* (§ 6.3.3).

I argue that adopting this notational convention makes it possible to defend an interpretation of wide reflective equilibrium at the foundation of my model of medical choice. I contend that particularly widely branching decision trees capture the concept of wide reflection in a way that enables a response to the no guarantees objection, and in a way that relies on qualitative features of decision trees, such as their breadth and depth, rather than quantitative features, such as their precision and amenability to algorithmic computation. Before this argument can be elaborated, however, we must consider some basic concepts of decision analysis.

6.3.1 *A Decision Tree for Suspected Appendicitis*

A decision tree is one of the many graphical tools used in decision analysis,⁷¹ such as flow charts, influence diagrams, and Venn diagrams (cf. Lusted 1968, 70ff.; von Winterfeldt and

⁷¹ In the main I will be describing decision trees as *tools from decision analysis*, which, following von Winterfeldt and Edwards (1986, 560ff.), I take to be a distinct area of inquiry from economics. Although decision analysis originates from centuries-old work on probability and utility, its modern history may be said to begin in the middle of the twentieth century. While between 1920 and 1950, a number of developments in economics laid the groundwork for decision analysis, decision analysis began with von Neumann and Morgenstern's foundational work on game theory, which became influential after the publication of *Theory of Games and Economic Behavior* in 1944. In economics, game theory developed primarily as a theoretical enterprise without significant applied results. But psychologists and statisticians, such as Edwards (1954) and Savage (1954), realized it had significant applied implications. In the 1950s, the concepts of utility and probability were given rigorous mathematical formulation as subjective concepts. Personal probabilities and subjective utilities were seen as values that could be estimated behaviorally, by empirical experimentation with human subjects. In the early 1960s, this insight – coupled with continued interest in the psychology of inference and the validity of subjective expected utility theory as a descriptive model – led researchers to operationalize ways of measuring individuals' preferences, utilities, and personal probabilities. Decision analysis emerged as a field of inquiry with the publication of *Decision Analysis* by Raiffa in 1968, however, it was not until after a

Edwards 1986). I assume that decision trees are familiar to the reader in some sense so I will begin by way of a medical example.

Appendicitis is an infection of the appendix, an organ whose function is unknown. If left untreated the infection will cause intense pain and will rupture, sending the infected contents into the abdominal cavity, which will cause further life-threatening infection. The common intervention for acute appendicitis is surgery, either an open appendectomy (via an incision through the skin and abdominal wall) or a laparoscopic appendectomy, which is less invasive. If treated quickly via surgery, a patient with suspected appendicitis faces the risks of surgery (e.g., side affects of anesthesia, breathing problems, internal bleeding, additional abdominal infection) and the benefits of a markedly decreased chance of infection. If left untreated, a patient with *suspected appendicitis* faces no risk of surgery and increased chance of downstream abdominal infection, yet also, a chance of recovery from abdominal pain without surgery (in the case that the symptoms are caused by nonspecific abdominal pain (NSAP) rather than appendicitis). Thus, in the case of a patient with suspected appendicitis, there is always a risk of unnecessary surgery because its symptoms are frequently caused by mere delocalized abdominal pain.

Assuming that someone who faces the decision to undergo an appendectomy should keep in mind that surgery entails its own risks, a decision tree may be useful for representing the logic of the choice of whether to undergo surgery or not. In the first book length application of

number of subsequent publications in the late 1970s (e.g., Keeney and Raiffa 1976) that the field coalesced around its defining problems, which are to adapt many of the methods and conventions of economic theory for the purposes of solving concrete local dilemmas rather than for explicating economic theory.

decision analysis to medical decision-making,⁷² Weinstein and Fineberg represent this dilemma from the physician's point of view, as follows:

A patient comes to the emergency room of a community hospital with signs and symptoms that the chief resident calls equivocal for appendicitis. He decides to consult with the chief of surgery, who agrees... She knows that patients with such symptoms and signs often have NSAP and, if an operation is performed, will have had unnecessary surgery. Some such patients, however, have an inflamed appendix which may perforate by the time of surgery. She wonders if it might be beneficial to hold this patient for six hours in the emergency room to see whether the symptoms improve or worsen (or remain the same) before deciding whether to operate. (Weinstein and Fineberg 1980, 13)

For the physicians, the primary concern is what action is most likely to result in the patient's survival. The major choice they face is whether to operate or not. However, there is a preliminary choice that occurs before this one: (i) whether to wait and see if the symptoms resolve without operating and then to decide whether to operate or not, or (ii) whether to choose for or against operating right now.

It is important to note that waiting to see if the symptoms resolve provides additional information than what is initially available. That is, if the patient becomes far worse it is likely that the patient has appendicitis; if he gets much better it is likely he doesn't. So there is a benefit to waiting: it decreases the likelihood of unnecessary surgery. Yet there is also a risk: if he actually has appendicitis, waiting changes the odds the patient's appendix will rupture or perforate.

⁷² Lusted's (1968) *Introduction to Medical Decision Making* might be equally deserving of this description, however, as it lacks the emphasis on the tree notation seen in Weinstein and Fineberg, it strikes me as a *precursor* to the application of decision analysis to medical decision making, rather than an initial emphasis. Certainly, Lusted's work is decision theoretic in its assimilation of the probability theory of the 1960s, but it is not yet decision analytic.

With this description of the case constructing a decision tree is quite simple. We know what the major decision is, what preliminary decision must first be made, and whether there is a way to get more information. We also know that the important outcomes are, whether the patient has a perforated appendix, an inflamed (infected) appendix, or whether his appendix is healthy and the pain has another cause (*i.e.*, NSAP).⁷³ Thus, we know what choices must be made and what important outcomes are likely to follow from them.

6.3.2 *Choices and Outcomes*

To represent the above dilemma in decision analytic terms, the first step is to distinguish between choices and outcomes.⁷⁴ *Choices* are moments in time when decision makers can perform one of several alternative courses of actions. By convention, they are represented in decision trees by squares (□), which are called *choice nodes*. *Outcomes* are moments in time that denote the occurrence of events beyond the control of the decision maker. They are represented in decision trees by circles, (○) which are called *chance nodes* because they denote

⁷³ This case may appear too simplistic for various reasons: it is constructed from the physician's point of view and hence is entirely paternalistic; it does not represent any non-biomedical outcomes for consideration; the risks attending unnecessary surgery are not described as being relevant to the choice. Note that the aim here is to begin with a simplified though realistic case.

⁷⁴ Authors differ on terminology here. Choices may also be referred to as *decisions* or *acts*; outcomes may also be called *chances* or *events* (*e.g.*, Weinstein and Fineberg 1980, 14; von Winterfeldt and Edwards 1986, 66-71; Resnik 1986, 6). It is common to restrict "outcomes" to the *tips* or right-most endpoints of a decision tree, and to use "events" for all chance events that happen between the left-most choice and the tips. I believe this falsely suggests a distinction between events and outcomes while they are indeed the same. Thus I will use "outcomes" synonymously with "events," preferring the latter, and use "terminal outcomes" to refer to the *tips* of decision trees, which are commonly simply referred to as "outcomes."

that the occurrence of the symbolized events may be described by a probability distribution or density function (Weinstein and Fineberg 1980; von Winterfeldt and Edwards 1986, p. 79).⁷⁵

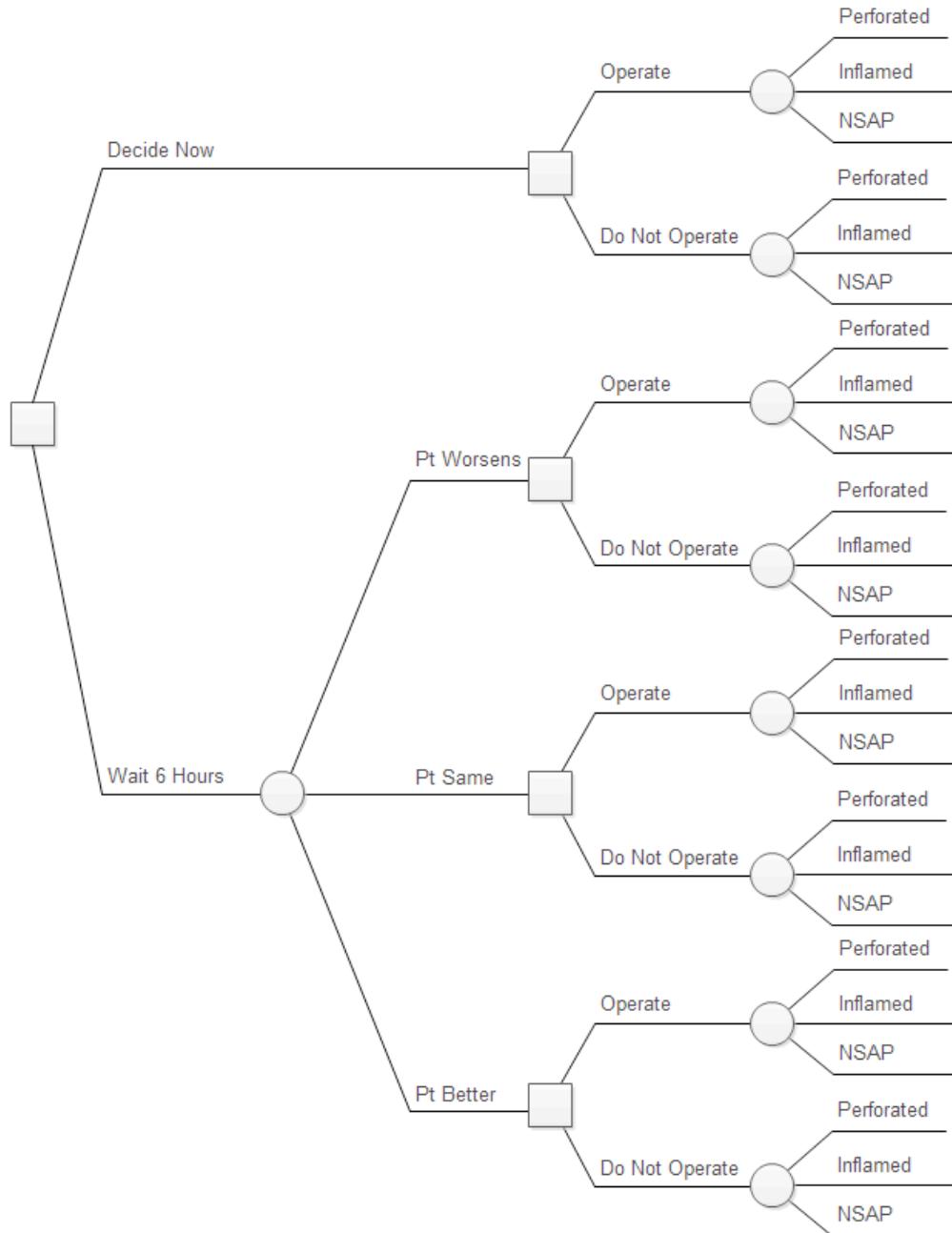


Figure 6.1: A decision tree for a patient with suspected appendicitis (adapted from Weinstein and Feinberg 1980, 18)

⁷⁵ In in-text discussions of choice nodes and chance nodes, I will use brackets in place of squares and double-parentheses in place of circles.

At this level of description, the choices and outcomes in the case of suspected appendicitis may be described as follows. There are two choices: [1] to decide now or wait to decide, and [2] to operate or not. Whether the physicians operate now or wait, the important outcomes are ((1)) whether the patient has a perforated and infected appendix, an infected appendix, or a healthy appendix. If the patient waits, there are additional outcomes to take into account, ((2)) whether the patient worsens, stays the same, or gets better. Figure 6.1 captures this dilemma.

The decision tree above is useful because it facilitates recognition of the logical structure of the represented choice problem. As shown in Figure 6.1, choices and outcomes may be represented in terms of a nested hierarchy, in light of their logical and temporal relationships. For example, deciding now is logically inconsistent with waiting six hours before deciding. Consequently, these options are represented as two distinct branches of the first choice node in the tree. As the case is presented, operating and not operating are likewise inconsistent. However, if waiting to decide is selected, then whether the patient worsens, stays the same, or gets better is an outcome that occurs before the choice of whether to operate; hence, it lies more *upstream* in the hierarchy than choosing whether to operate. Since decision trees are read from left to right, the outcomes describing the patient's status after waiting are *downstream* of the choice nodes representing the choice of whether to operate.

Representing dilemmas using decision trees is also useful because it draws attention to qualitative differences between different aspects of a decision. In the case of suspected appendicitis, for example, we see that the “decide now” branch is less complex than the “wait six hours” branch, as represented in Figure 6.1. If one waits, then the decision tree shows that additional effort will be required to procure more information. Thus, using a decision tree

diagram draws attention to the different informational dynamics entailed by the different branches of the tree.

In its simplest form, decision analysis begins with a problem that is complex and unanalyzed. One then decomposes the problem, resolving it into subsidiary choices and likely outcomes. Those may then be further analyzed as seems necessary. And indeed, in some sense where one chooses to stop representing the downstream implications of strategies for solving a current problem is arbitrary. As von Winterfeldt and Edwards note, “*outcome* is simply a name applied to the end point at which you cut a branch of the tree. Outcomes are essentially fictions, though indispensable ones; the truth is that life goes on after the outcome occurs” (von Winterfeldt and Edwards 1986, 66). However, though selecting outcomes is arbitrary in the sense that decision trees can never completely represent a decision maker’s circumstances, nor all of the “conceivable” choices and outcomes that could be modeled, decision trees may be constructed in more or less justified ways, depending upon how they are “pruned” or “foliated”.

6.3.3 Pruning and Foliating

One may make two basic moves when justifying the construction of a decision tree: one may justify why items are included or why they are excluded. That is, on the one hand, one must justify how the tree is *pruned*, meaning how branches are excluded or eliminated from the representation. For example, it might be that a choice is so repugnant that it certainly will not be selected. Or one may know for certain that an outcome will not occur. In each case, pruning either node would be justified for the reason that it would not be chosen, because of its repugnance or non-occurrence. That is, the nodes may be pruned simply because we know for certain that the events will not happen.

We might call the pruning strategy just described *certain pruning*, in that it follows a sensible principle of pruning any nodes that certainly will not occur. This is perhaps the only pruning strategy that may be justified in principle, as it results in simpler trees, and perspicacity, we may presume, is a universal value. However, all other pruning strategies must be justified *ad hoc*, in light of the circumstances being modeled.

The same reasoning applies to the concept of *foliating*, which is the opposite of pruning. Following the tree metaphor, to foliate is to expand upon the existing structure of a decision tree. Just as pruning may be justified by appeal to the chance of a choice or outcome, so too may foliating. For example, some authors suggest a good rule of thumb is to try to expand high probability branches, thus gaining higher resolution into the logical substructure of high probability outcomes (von Winterfeldt and Edwards 1986, 72). The same reasoning applies to highly valued choices. Thus, one way to justify foliating is by appeal to increased clarity and precision, which permits the decision maker to represent important distinctions (and options) that are masked prior to foliation.

Obviously, the clarity and precision entailed by foliating are opposed to the simplicity gleaned by pruning. Thus, in decision analysis we find the same problem as we saw in reflective equilibrium: namely, there are no in-principle justifications for pruning or foliating strategies. Yet, unlike reflective equilibrium, there are a number of additional constraints for the construction of decision trees than merely that they must be coherent. So there are additional constraints on pruning and foliating that promise to shed light on the problem of justifying them. Reviewing the basic concepts of decision analysis that provide these basic constraints provides a means of thinking about how such constraints may be adapted for enriching the reflective equilibrium framework.

6.4 Basic Concepts of Decision Analysis

Thus far I have described decision trees quite informally by way of an example. I have done so because I think the formal foundations of decision analysis are easier to understand if one first has an intuitive grasp of tree diagrams. Yet in many ways, decision analysis is a rather formal field. So, although we will rarely appeal to its formal resources when using decision trees, it is necessary to cover the basic formalism to fully introduce these representational tools.⁷⁶

Initially, we may decompose the process of performing decision analysis with decision trees into four steps. First, one must *identify and bound the problem*, meaning you must describe the problem in a way that it is stated clearly with limits. Second, one must *describe the logical structure of the problem* in hierarchical terms, which may often be done simply by considering the temporal orderings of choices and outcomes (or events). Third, one must *characterize the information* necessary to give meaning to the logical structure. We will find that this is the most difficult and controversial step, however, it can be described summarily as estimating the values of outcomes and the likelihoods that they will occur. Fourth, one must choose a course of action in light of your preferences (Weinstein and Fineberg, 4-8; cf. von Winterfeldt and Edwards 1986, 4-18).

As described by Weinstein and Fineberg, the case of suspected appendicitis is already formulated such that steps one and two have been taken. We know what the problem is and it has been bounded; moreover, its logical structure is evident. They also tell us that what matters to the physicians is the likelihood that the patient will live. They do not elaborate. For example, they do not provide any details about this patient, such as comorbidities, personal

⁷⁶ This introductory section is indeed introductory; those familiar with decision analysis should skip to § 6.5, though minding the figures along the way.

preferences, demographics, access to social support or health insurance, and so forth. Such information would personalize this depersonalized case, giving it some realistic definition.

Thus, as it stands the logical structure of the decision emphasizes only the health of the patient's appendix (as perforated, inflamed, or NSAP), rather than the overall health of the patient as a person. No other outcomes are represented; likewise, nor are any other means of gathering information than "wait six hours". Perhaps the patient has major depressive disorder that has caused him to sit alone in his apartment for twenty-four hours developing sweats, chills, and nausea, while reasoning that he just has the flu and will be fine in the near future. Such information would suggest that the estimated likelihood of NSAP should be much lower than it would without the knowledge of this psychiatric comorbidity. Similarly, suppose the patient is particularly concerned about the implications of risks of surgery, perhaps particularly the effects of anesthesia. In such a case it would seem prudent to represent this explicitly by adding terminal outcomes (the right-most outcomes) describing negative and positive effects of surgery and their likelihoods, such as the successful treatment of appendicitis without complications, the chance of certain ill effects of anesthesia, or the development of any number of post-surgical infections.

Such considerations show that deciding what information is relevant for filling in the logical structure of a decision tree will often lead one to change the logical structure itself. Thus, there is feedback between steps two and three that must be accommodated in order for decision trees to be justifiably composed. Consequently, though decision analysis may be summarized in terms of a few steps, it is important to recognize that these steps are recursive.

In addition, it is also important to emphasize again that the language used above in describing the third step is the language of *probability* and *evaluation*. That is, in addition to

checking against insufficient representation of the decision structure, in order to give the logical structure some meaning, it is necessary to describe how the decision maker values outcomes and the probabilities that they will occur. This section introduces standard terminology of probability theory as it is used in decision analysis. We will discuss probabilities and chance nodes (§ 6.4.1); the representation of coupled probability estimates to represent chains of events in terms of *strategies* and *paths* (§ 6.4.2); and, the concept of utility as a means of measuring evaluative information (§ 6.4.3). We will also consider how, when taken together, these concepts allow for formal comparisons of choices in terms of expected value (§ 6.4.4).

6.4.1 Probabilities and Chance Nodes

The language of probability has become commonplace. As the above discussion shows, it is natural to speak in terms of the chance an event will occur. We wonder whether it will rain today. When we are told that there is a 30% chance it will, we feel like we know something. But what do we know? Unfortunately, the answer is simple though uninformative: the meaning of probability statements requires interpretation, and hence, what one knows in light of a probability claim depends on how one interprets probabilities. For our present purposes, although we need not delve into interpretations of probability claims in order to understand how they function in decision analysis, we must recognize that how one should interpret probability claims is an open question requiring its own justification (see Resnik 1986, 61-80). Where we need more from probability claims than simply their contribution to decision trees, this issue will reemerge.

It suffices to say simply that how one interprets probability claims may be important because it affects ones beliefs and actions. For example, a study by Gigerenzer and colleagues (2005) showed that a majority of randomly sampled pedestrians in New York City interpreted a

“30% chance of rain tomorrow” to mean that in 3 out of 10 cases where the weather is like today’s there will be at least some trace of rain in the forecasted area on the following day. Yet in Europe this interpretation was judged the least appropriate out of three options. Instead, randomly sampled European pedestrians preferred the other two interpretations, that it will rain tomorrow 30% of the time, or in 30% of the area. Free-responses to the same question varied widely, suggesting that this dichotomy actually hides considerable diversity in the public’s interpretation of probabilistic claims.⁷⁷ Furthermore, when subjects were asked at what probability of rain they would bring an umbrella along on an errand, their answers differed, on average, depending upon which of the forced choice answers they selected. This suggests that how you interpret probability claims may impact how you act upon them, or at least it may impact how you predict you would act in light of them, in such circumstances.

Moreover, this result holds for physicians as well as patients, since they also exhibit considerable variation in their understanding and interpretation of probabilistic representations of information. In a review of research on statistical illiteracy in physicians, for example, Wegsworth and Gigerenzer describe a number of errors in physicians’ use of probabilities and the ways they communicate risk to patients. They report that physicians and hospital managers routinely overestimate the benefits of interventions if these are reported as relative risk reduction (RRR), rather than absolute risk reduction (ARR) or other reports of natural frequencies. Experiments also suggest physicians are confused by sensitivity and specificity

⁷⁷ For example, several in New York said the claim means “30% of meteorologists believe it will rain” tomorrow. A Berliner said, “Thirty percent means that if you look up to the sky and see 100 clouds, then 30 of them are black.” In Athens, a subject responded, “If we had 100 lives, it would rain in 30 of these tomorrow” (Gigerenzer et al. 2005, 626).

measures, which are conditional probabilities (Wegworth and Gigerenzer 2011; see also Gigerenzer and Gray 2011).

Yet, regardless of how one interprets probabilities, their formal representation does not change. Following Resnik's (1986) presentation, the basic formula of probability calculus takes the form

$$P(S) = a \quad (4.1)$$

where S may be atomistic or complex. That is, it may be an assertion, such as “ p ”, a conjunctive, such as “ p or q ”, or a more complex claim, such as “(p and q) or (z and y).” The symbol a represents a number, thus the basic formula may be read as “the probability of S is equal to a .⁷⁸” Tomorrow's rain (R_{t+1}), may be represented as $P(R_{t+1}) = 30\%$, or, “the probability it will rain tomorrow is equal to thirty percent.” So written, a probability is in *absolute* form, meaning that it simply expresses that the probability of rain tomorrow takes on a value of thirty percent, irrespective of any other considerations. One might wonder what the probability of rain tomorrow is, given, for example, that today's temperature is very cold (say 10° F). To express this type of probability is to express a *conditional probability*, written as

$$P(S/W) = a \quad (4.2)$$

or, “the probability of S given W is equal to a .⁷⁸” In the case of rain tomorrow, we may write, $P(R_{t+1}/T_t) = a$, which would be read as, “the probability it will rain tomorrow, given that it is 10° F today, is equal to a .⁷⁸

⁷⁸ This presentation ignores *joint probabilities* and other formalisms common in decision analysis, such as the relationship between absolute, joint, and conditional probabilities or definitions of important concepts such as independence. See Weinstein and Fineberg (1980, 37 ff.).

Probability estimates are commonly used in decision analysis as a means of representing important information in decision trees. They represent the chance that an outcome will occur, either in absolute or conditional terms. Thus, once a decision tree has been drawn, part of completing the third step is to provide a value for any event for which a probability may be estimated.⁷⁹

For example, in the case of suspected appendicitis (Figure 6.1) a more complete decision tree would include variables expressing the probability of all outcomes. Deciding whether to make the choice of operating now or waiting requires estimating the chance that the patient worsens, stays the same, or gets better, given the decision to wait. Likewise, one must also estimate the chance that the patient's appendix is perforated, inflamed, or healthy in light of the probabilities of any upstream variables. Thus, for each chance node there should be an expression of the outcome above the line following the chance node and the estimate below the line. After all of the probabilities have been assigned, a little algebra provides the conditional probability of terminal outcomes, given upstream estimates.

In the case of the suspected appendicitis, we are told that the terminal outcomes of interest are whether the patient lives or dies. Thus, for each terminal node in Figure 6.1, a final chance node should be added denoting the chance of survival or death in light of the upstream

⁷⁹ It is common to describe different types of choices in terms of the extent to which the outcomes in a decision tree may be given (reasonable) probability estimates. On this approach, a decision tree with outcomes that are all given probability values of zero or one is a *decision under certainty*; a decision with outcomes that are all given probability values, and for which some values are greater than zero but less than one, is a *decision under risk*; a decision tree with outcomes for which only a subset may be given probability estimates of greater than zero and less than one, but for which no reasonable estimate may be given for others, is a *decision under partial ignorance*; finally, a decision for which no probability estimates may be given for any outcomes is a *decision under ignorance or uncertainty*; Resnik 1986, 13-14).

estimates. This is captured in Figure 6.2 for one branch of the tree, although the probability values are not represented here.

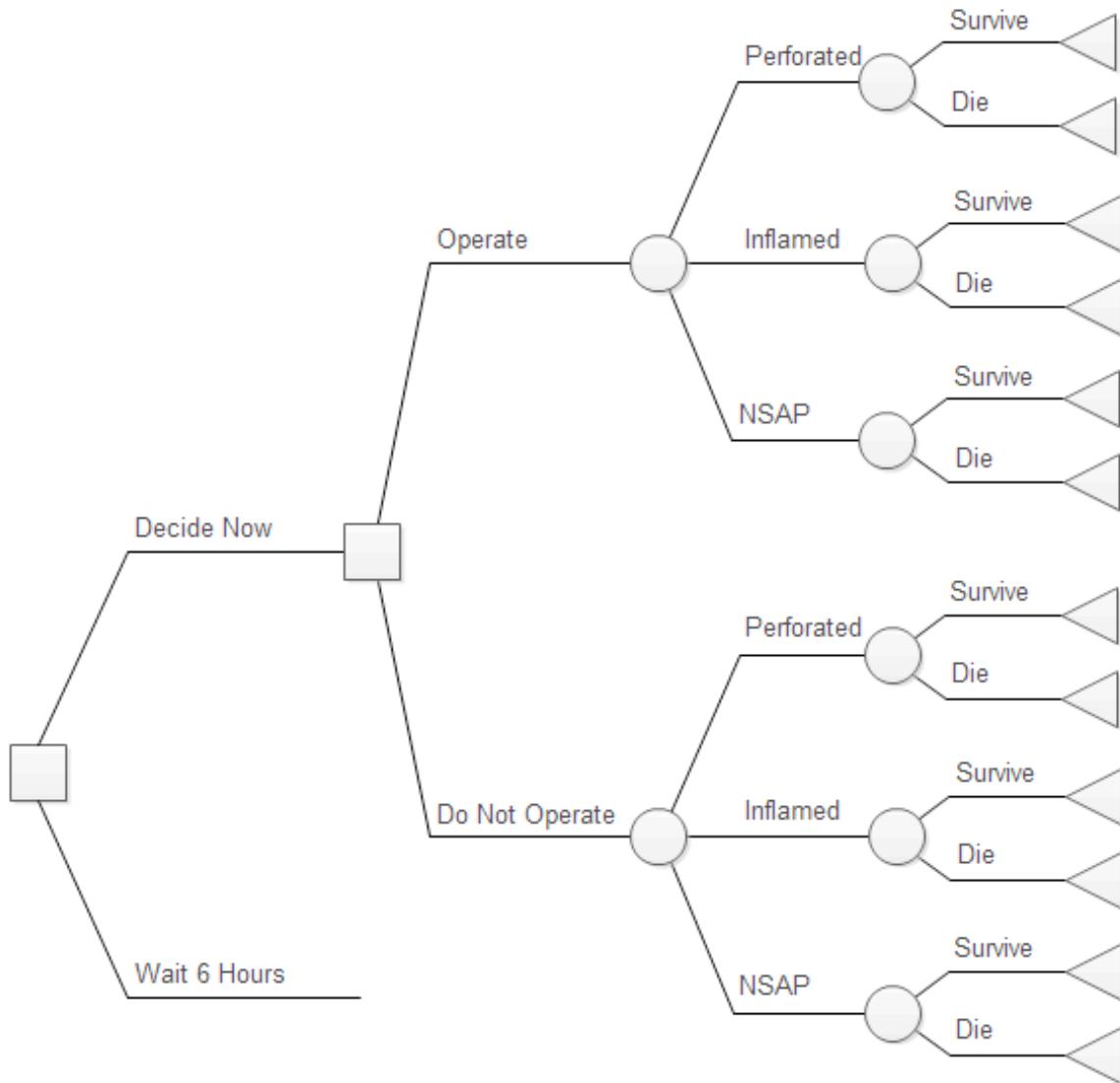


Figure 6.2: A more foliated decision tree for suspected appendicitis, including chance nodes (adapted from Weinstein and Fineberg 1980, 15).

6.4.2 Strategies and Paths

With probability estimates in mind, it is possible to define the concepts of *strategies* and *paths*.

A path is the route from the *point of origin* (the left-most decision node) to a downstream terminal outcome. Paths may be demarcated by reference to the strategies that lead to them, the probabilities they will occur, and their values. Strategies are the sequences of choices made by a decision-maker to lead from the point of origin to a terminal outcome. Probabilities are the conditional probabilities computed from the chance nodes in the path. And, values are given in terms of utility (discussed in the next sub-section). For example, the strategy for deciding now and operating may be represented as “decide now; operate.” The probability that the patient will live on this strategy if he has a perforated appendix may be estimated by multiplying the chance that the patient has a perforated appendix by the chance he survives the appendectomy, given that his appendix has ruptured. Assimilating probabilities into decision trees thusly permits one to formally characterize strategies and paths numerically and algebraically.

6.4.3 Utilities and Terminal Outcomes

In addition to describing the chance that outcomes will occur, to give meaning to a decision tree it is common to describe what outcomes are valuable to decision makers. As it is presented, the suspected appendicitis case indicates that the physicians only explicitly value the patient’s survival. To represent this using decision analytic conventions, we may appeal to the concept of *utility*. Like probability, utility has a rich history, though it is not germane to our concerns.⁸⁰ Yet it is important to note up front a potential confusion between utility, as we will use it, and

⁸⁰ For an introduction, see Driver (2009). For a classic history of the concept of utility, see Stigler (1950).

the ethical theory, utilitarianism, which also draws on a different sense of the notion of utility.⁸¹

For our purposes, utility is simply an arbitrary measure of value; specifically, it is a measure of an agent's evaluation of the value of particular outcomes in a particular context. Here, utility is neither pleasure, nor happiness, nor satisfaction, as these are commonly understood. If we wish for something more intuitive than "an arbitrary measure of value" then we might say utility is an amount of good or goodness (Baron 2000, 224). I try to resist this intuition and instead opt for a more systematic, albeit perhaps less intuitive definition: utility is an arbitrary measure of value.

A utility value has meaning only relative to other utility values measured against the same arbitrary scale (e.g., 0 to 1, -10 to 10, or 0 to 100).⁸² To take the case of suspected appendicitis, utilities would be estimated for the outcomes of survival and death. Utility values only make sense in contrast, so it would be meaningless to simply say survival has a certain

⁸¹ Consider that for J. S. Mill, "utility" was simply, "the greatest happiness principle," or the view that, "actions are right in proportion as they tend to promote happiness; wrong as they tend to produce the reverse of happiness" (Mill [1861] 2001, 7). As an ethical theory, utilitarianism may be developed upon this simple foundation and the many (often competing) interpretations given of it (see Smart and Williams 1973). Given this, there is a simple argument for distinguishing between utility as conceived of in utilitarianism and as used in decision analysis. As it figures into utilitarianism, utility defines a norm for action, which says to act such that one produces the greatest amount of good for the greatest number. However, in decision analysis, utility is an abstract measure of what a particular decision maker evaluates as good, irrespective of the impact his or her choice has on the overall good. Hence, given that in its decision analytic sense utility is a measure of the good of outcomes relative to individual agents, and that utility in the sense of utilitarianism is a norm for ethical action taking the overall good of the many as primary, these two concepts may be treated as distinct, although their historical relation is nevertheless presumed.

⁸² There are many ways to estimate utilities in practice, particularly in healthcare contexts. Measurement tools such as questionnaires may be used to estimate the evaluation of health states by members of the general population, which may in turn be used to develop health indices with numerical values that correspond to proxy utilities – utilities for the general population that may be used to estimate ill persons' actual utilities (Schwartz and Bergus 2008, 24-25). Such utility values are numbers with arbitrary units that map preference orderings of the general population by a positive linear transformation (as described in Resnik 1986, 82). Utility values may also be estimated by asking patients to rank aspects of health to produce a composite rating scale, or by rating and comparing holistic health states directly (see Schwartz and Bergus 2008, 26ff.).

utility value, such as 100, without stating its contrast. Thus, we might say that the value of survival is 100 and the value of death is 0. With these numbers, we may assign a utility value to outcomes in our decision tree. In suspected appendicitis, we would assign any terminal outcome of “survival” a utility value of 100 and any terminal outcome of “death” a utility value of 0.

With numerical estimates of the value of outcomes, it is possible to calculate what is known as the *expected utility* of a given outcome, path, or strategy. The expected utility of an outcome is equal to the utility value of the outcome multiplied by the probability it will occur. The expected utility for a path is equal to the sum of the conditional and joint probabilities of its constituent outcomes multiplied by the utilities of each outcome. The expected utility for a strategy is equal to the sum of the expected utilities of each of its paths.

The basic normative principle underlying an expected utility approach to decision analysis is that choices should be made that maximize expected utility (EU). In the case of suspected appendicitis, let us assume that $P(\text{Survive}/\text{Infected}) = 0.999$ on the strategy “decide now; operate.” Given that “Survival” has a utility of 100, the expected utility of this path is equal to the probability that the patient has an infected appendix multiplied by the conditional probability that he survives an appendectomy, given that he has appendicitis; that is, EU (Survival) on this path is equal to 12.99. Calculating the expected utility for paths is only useful for comparing alternative strategies because strategies are what decision-makers have control over. The technique of “averaging out and folding back” allows one to use EU path estimates to perform such calculations for any decision node with multiple downstream events having differently valued outcomes.

6.4.4 Averaging Out and Folding Back

To compare two different decision options using decision analysis, one compares the expected values (here, utilities) of the consequences of making a choice. In the case of suspected appendicitis, we may compare the expected utilities of the two strategies downstream from “deciding now” by calculating the EU of each strategy. With this information, and using these conventions, we could also compare the strategy, “decide now” with “wait six hours to decide” and hence, complete the decision analysis. However, performing only the first comparison will be sufficient to convey the averaging out and folding back method.

Table 6.1: Calculating expected utility values for comparing strategies by “averaging out and folding back”

| Strategy: | “decide now; operate” (O) | | “decide now; do not operate” ($\sim O$) | | |
|-----------------|---------------------------|------------------|---|-----------------------|-----------|
| Appendix is (x) | P (x) | $P [S (x \& O)]$ | EU (path) | $P [S (x \& \sim O)]$ | EU (path) |
| x = Perforated | .03 | .973 | 2.92 | .5 | 1.5 |
| x = Infected | .13 | .999 | 12.99 | .5 | 6.5 |
| x = Healthy | .84 | .9993 | 83.94 | 1 | 84 |
| EU (strategy) | | | 99.85 | | 92 |

Table 6.1 summarizes what we know about the values of the variables on the two strategies downstream from deciding now, “decide now; operate” and “decide now; do not operate” (adapted from Weinstein and Fineberg 1980, 55). Averaging out and folding back requires calculating the EU for each path on a strategy (Columns 4 and 6) and summing them to get the EU for the strategy. Thus, “deciding now; operate” has a higher EU than deciding now and not operating. Hence, using these estimated utilities and probabilities, deciding now is the correct strategy to choose, given the normative criterion of maximizing expected value, understood here as utility.

6.5 A Generic Decision Tree

In the case of suspected appendicitis, the above calculations might appear to be superfluous. Because of how highly valued survival is relative to death, and given that these are the only two outcomes evaluated, expressing their values in terms of expected utility is quite trivial. One outcome is so greatly preferred to the other that it will always *dominate*. Since death is so negatively valued (at zero), the probability that it will occur does not matter. Every path ending with death will have an expected utility of zero. Hence, as any positive number is greater than zero, all events with a probability greater than zero that lead to survival will dominate all events leading to death. Hence, survival dominates death in this decision analysis in that death is so disvalued that no paths terminating in it will outrank any path ending in survival. Moreover, given that the probability of surviving after appendectomy is so high, irrespective of the health of the appendix, in this case the choice is obvious: do what is most likely to bring about the only positively valued outcome, operate now.

Despite this appearance, decision analysis is not superfluous in this case. So described, we gain considerable clarity into the logic of choice and the implications of assumptions. And this clarity is crucial because it facilitates inquiry into the implications of including or excluding different information from the representations. For example, we may change both the assumptions and the logic and investigate the consequences, which is known as *sensitivity analysis*. Say we learn that the patient positively values death, perhaps because he suffers from a comorbid terminal illness. Then we can change the utility values of death and survival accordingly, such as in the face of pronounced and prolonged suffering. Likewise, if we think that the probability estimates are incorrect, perhaps because we suspect the studies from which they are derived were performed in populations that are dissimilar to the patient at hand, then

we can change those too. Doing so will show whether any strategies dominate under different assumptions, and will permit the calculation of probability and utility *thresholds* for choosing various strategies.⁸³ This is how Ellen Macke described her use of decision trees when making medical decisions (see § 4.3.2).

Stepping away from the case of suspected appendicitis, some general points may be made regarding decision analysis, specifically for the purpose of constructing decision trees. For our purposes, decision analysis may be described as the recursive performance of four steps:

- I. Identify and bound the problem.
- II. Describe the logical structure of the problem.
- III. Characterize the information necessary to fill in the logical structure.
- IV. Choose a course of action in light of stated preferences.

Step (I) requires identifying the choices available and their likely outcomes. Step (II) proceeds by justifying the size and complexity of the resulting decision tree; in other words, it requires balancing, pruning, and foliating in light of an acceptable description of the decision environment. Step (III) requires first providing reasonable estimates of the probabilities for events and the values of outcomes, where possible. It then requires computing the expected utility values of outcomes, paths, and strategies, which can be described as follows using a generic one-stage decision tree.

⁸³ Weinstein and Fineberg do this for suspected appendicitis and conclude that “wait six hours; operate if patient worse or same” is the optimal strategy (1980, 57-61).

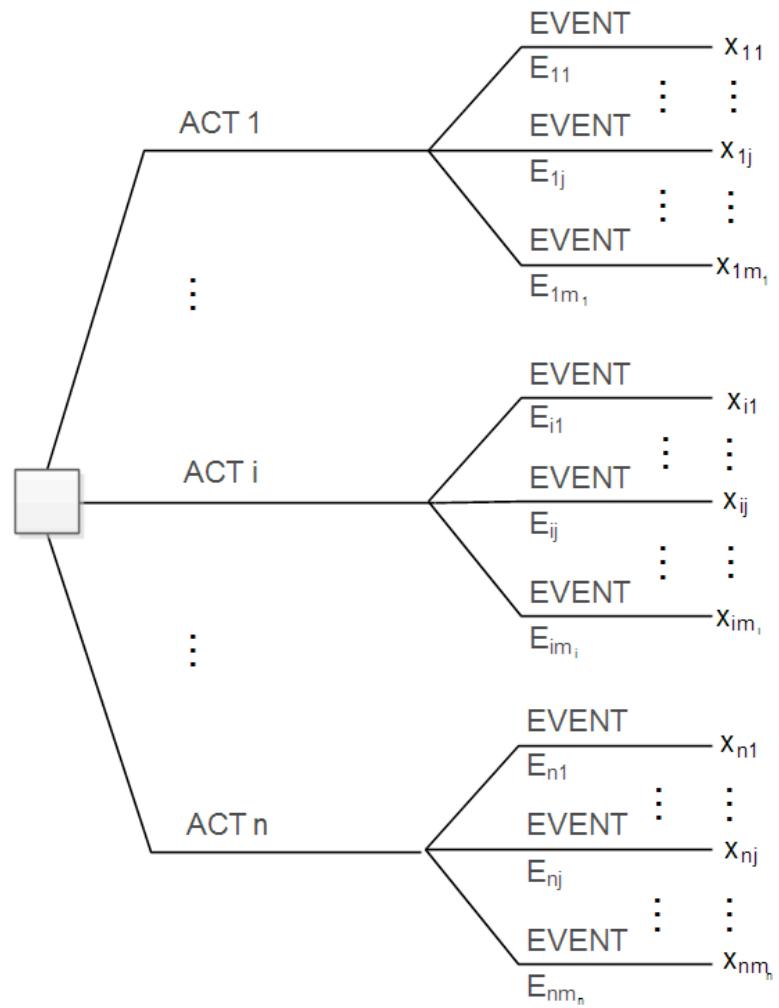


Figure 6.3: A generic decision tree (adapted from von Winterfeldt and Edwards 1986, 75)

Following von Winterfeldt and Edwards (1986, 75), the EU of a generic one-stage choice (a_i) may be defined by the formula,

$$EU(a_i) = \sum_{i=1}^{n^i} P(E_{ii})u(x_{ii}), \quad (4.3)$$

where $u(x_{ij})$ expresses the utility of outcome x_{ij} . Thus, for any generic strategy, this equation expresses the principle that its utility may be calculated as a sum of the expected utilities of its

composite acts.⁸⁴ In order to investigate the meaning of expected utility values relative to the logical structure of a decision, one may perform sensitivity analysis by altering probability and utility estimates in various combinations. Some strategies may dominate, or there may be thresholds of probabilities, utilities, or expected utilities, at which different strategies are more or less favorable. In such cases, if more information is available it can help adjudicate which sets of values are most justified, and hence, which choice should be made if the norm of optimizing EU is adopted.

6.6 Decision Analysis and Reflective Equilibrium in Medicine

This chapter began with a promise, to argue for an assimilation of the reflective equilibrium method into the account of medical decision-making under development. The reason for doing so is that reflective equilibrium is widely understood to be a procedure for making justified ethical claims while making minimal assumptions about the ultimate nature of morality and ethical justification. Hence, it was assumed that invoking such a non-foundationalist and minimally constraining procedure – as compared to other moral theories – would be an excellent match for the project of providing a normative foundation from which to articulate an ethically justified model of decision-making.

However, upon closer examination the notion of reflective equilibrium was found to be open to a number of important criticisms. After their consideration, it subsequently became clear that reflective equilibrium is no monolithic position; rather, it admits of multiple

⁸⁴ The formal power of decision analysis is significant. For example, one can model continuous events in terms of conditional probability distributions and derive formulas for calculating the EU of any act within a multistage decision, which is the formal representation of the averaging and folding back operation. Describing these methods is unnecessary for our purposes; though see von Winterfeldt and Edwards (1986, 78-82).

interpretations (§ 6.1). At the root of all interpretations of reflective equilibrium lies the notion of coherence. When this notion was examined in some detail, it too was shown to be open to criticism as it figures into the reflective equilibrium procedure. Because it may be equated with a mere demand to generate logical consistency, coherence was shown to either enshrine idiosyncratic views as the justified results of reflective equilibrium (§ 6.2.1) or to require a level of reflection, comprehension, and information processing that seems inappropriate for ordinary individuals (§ 6.2.2). Thus, coherence was determined to be an insufficient foundation for supporting a defensible account of reflective equilibrium, which motivated exploration of an alternative definition of coherence for the specific purposes of explicating ethical medical decision-making (§ 6.2.3).

The reason I have appealed to decision analytic representations of choice in order to redefine coherence is that they provide a means of articulating and meeting the no guarantees objection in general, although whether this general method is justified in specific circumstances depends upon what justifications are given for the foliation and pruning of particular decision trees. The methods for constructing decision trees above show that there is a certain inescapable arbitrariness to their construction. While I have given four steps for producing them, I recognize that these are rules for making precise the extent to which arbitrariness is present and, nevertheless, legitimate. They are not explanations of why the representation is completely non-arbitrary. One must make choices when representing phenomena, whether when representing procedures for ethical justification or anything else. This is just the problem of representation in general (Callender and Cohen 2006). However, using decision trees enables one to recognize what would be required, in a particular instance of ethical choice, to meet the no guarantees

objection. It would require that participants in the choice agree that the tree has been sufficiently foliated and pruned, given the state of affairs being represented.

In this way, decision analysis faces and meets its own version of the no guarantees objection. That is, for any given tree it may be objected that it excludes important information or includes unnecessary information. Decision analysts have responded to this inexplicable arbitrariness by both accepting it and defining reasonable pruning and foliating rules that ward against it. The lesson to draw from this is that *we may accept there are no guarantees; nevertheless, the right combination of rules of thumb and ad hoc justifications may suffice for making good decisions*. Just as long as sufficient information has been considered in the production of a decision tree (foliation) and that information has been selected for its salience, quality, and consistency with other information under consideration (pruning), then it will be justified. In this sense, there are echoes of Rawls' account of reflective equilibrium in the ideal account of how to construct decision trees. Just as Rawls requires convictions that are laudable, of a certain scope, and in some sense coherent, likewise construction of a decision tree requires information that has a certain salience, quality, and consistency.

Coming as it does in the wake of the lengthy consideration of the putative strengths and hidden weaknesses of reflective equilibrium above, asserting nevertheless that ethical justification hangs on the sampling and selection of information is likely to be unpersuasive. The key difference with the approach I envision, however, is that it is *domain specific* in a way that reflective equilibrium in general is not. My interpretation of reflective presumes certain defeasible foundations as fixed starting points for an instantiation of the procedure. And it presumes to justify those starting points for a particular purpose, the justification of claims pertaining only to that domain. Thus in the case of medical choice, these starting points will be

germane to medicine and decision-making thereof, and the claims will pertain to medicine and medical decision-making. While this is surely a wide domain, it is certainly a more narrow scope than the whole of ethically theory, covering as it does all of human cognition, action, culture, and so forth.

In the next chapter, I will demonstrate how, when we assume that the Basic Aims of medicine justified in Chapter 3 serve as starting points for reflective equilibrium in medicine, adopting the basic concepts of decision analysis (§ 6.4) and generic decision tree representations (§ 6.5) then serve as a normative foundation for medical choice. I argue that the Basic Aims serve as assumptions for which there is a high initial credence value, and that information search and selection in the reflective equilibrium procedure must be consistent with these aims. I then show how, in the case of hereditary breast and ovarian cancer, this search and selection process would ideally be performed. By using what I call an “HBOC Decision Tree,” I argue that the logic of medical choices may be modeled in general, with particular emphasis on their informational content. From this I argue that we can discriminate between good and bad choices in a way that allows for generalization about the normative features of decisions in medicine. For a choice to be good, it must search both for information in the form of subjective claims about the patient’s experience of the state of affairs and in the form of objective claims about the state of affairs.

7.0 SKEPTICISM AND MEDICAL REFLECTIVE EQUILIBRIUM

The previous chapter introduced a generic framework for justification in ethics, interpretations of it, and objections to it. It also introduced representational conventions for clarifying the normative framework adopted in the model of medical decision-making under development and responding to those objections in a specifically medical context. It did not, however, articulate that clarification or response; that is the aim of the current chapter.

I begin by restating the problem, which I argue should be understood as how to justify particular claims about particular medical decisions, not how to justify ethical theories or claims in general. To do this, Section 7.1 suggests that there are two varieties of skepticism worth distinguishing in order to evaluate whether the model of medical choice under development meets the standard of normative adequacy described in Chapter 2. Once we accept that a lower threshold of skepticism is all that must be met, this suggests a way out of the endless need for justification that higher thresholds of skepticism appear to warrant.

The way out is to persuade the reasonable skeptic that some medical choices appear good while others appear poor, and then to leverage this agreement to generalize features of good choices by contrast with poor ones. This is accomplished in part by introducing a case of poor HBOC decision-making, Alicia's choice (§ 7.2). After considering Alicia's choice in some detail, I propose that her choice is deficient in the amount and type of information it considers. Despite the fact that Alicia does consider a number of factors relevant for hereditary breast and

ovarian cancer decision-making, including her personal history, anxiety, and relationships, her choice is evidently one that does not consider enough of the right information.

To further persuade the skeptic that Alicia's choice is poor because of information deficiencies, I propose to represent her choice using decision analytic concepts and compare it against an ideal choice in HBOC (§ 7.3). This marks a turning point in the analysis because it marks the introduction of a generic HBOC decision tree representing all of the choices, outcomes, and factors associated with HBOC that we have discussed in earlier chapters (Figure 7.6). Using this representation, I then argue it is possible to demonstrate why Ellen Macke's choice was a good one, even though it falls short of an ideal HBOC decision.

If these distinctions in between ideal, good, and poor decisions in terms of information content and organization hold, then I contend it is possible to demarcate different levels of reflection in medical choice. Moreover, it is possible to argue for an account of reflection in medicine that suffices as a threshold for demarcating good choices (§ 7.4). Good choices require consideration of a set of information I call "health judgments" by analogy to "initial moral judgments" in reflective equilibrium. Unlike initial moral judgments, however, health judgments include the Basic Aims of medicine as defeasible initial considerations and other additional information that arises for an agent facing a state of affairs that warrants medical action. Good choices also require consideration of comprehensive biopsychosocial information about a given patient under medical care. Thus, on this account of sufficient reflection, decision makers are guided to adequately consider this information and to explicate its logical structure in the senses defined below. If they do, then the Basic Aims of medicine will be met in a particular case, and thus the choice will be good.

However, the reasonable skeptic is likely to find this argument unpersuasive. One is likely to object that it does nothing to meet traditional objections to reflective equilibrium, which are captured by the no guarantees objection. To respond to this, Section 7.4 also introduces a distinction between satisficing and optimizing choice, arguing that meeting the former threshold is a necessary but not sufficient condition for good medical decisions. I contend this reply meets concerns about supercomprehensiveness in medical choice, although it does not suffice for responding to worries about idiosyncrasy.

The final substantive section (§ 7.5) responds to this aspect of the no guarantees objection by arguing that the reasonable skeptic must accept that deliberation should be required for good medical choices, because she accepts her own fallible capacity for reflection and accepts that her reasons may be swayed by discussions with others. If so, then I contend deliberation ought to be understood as requiring that medical decision-making is a social activity in at least the minimal sense of requiring the doctor-patient dyad. However, in many cases deliberation will require more participants in choice, which will depend upon what information must be searched for, selected, and integrated in order to satisfy the Basic Aims, and the level of participation the patient is able and willing to engage in. So long as enough individuals participate in medical decision-making such that the constraints of medical reflective equilibrium are met, then choices will be good. Thus, medical reflective equilibrium can be understood as guiding those who face medical decisions to work with others as necessary to meet a certain informational threshold.

If my argument is sound, the reasonable skeptic may nevertheless remain unconvinced. However, I contend that these considerations, coupled with those in previous chapters, suffice

for demonstrating the normative adequacy of the model of decision-making under development. A brief summary of the normative framework thus concludes the chapter (§ 7.6).

7.1 Skepticism, Reflection, and Practical Identity

In many ways, the argument given in the previous chapter was directed at a common philosophical foil. The approach there was to look for a generic account of ethical justification serviceable for justifying any range of ethical constructs, from abstract ethical theories to concrete ethical judgments about particular circumstances. Bernard Williams, who is skeptical of the wisdom of this approach, though he recognizes its pervasiveness in moral theory, has described this as directing argument toward the “universal constituency.” Williams claims that from the standpoint of morality the universal constituency is always what matters most; it is the perspective from which moral theories are presumed to be judged. A moral theory succeeds, that is, if it articulates compelling reasons supportive of it that universally command assent (Williams 1985, 11).

Yet Williams believes that ethics cannot ultimately satisfy the demands entailed by targeting the universal constituency. He argues instead that there are limits to philosophy. I take his argument as inspiration for adopting an alternative strategy to provide normative content for my model of ethical medical choice. This strategy is to recognize that behind the pull toward the universal constituency is a felt need to respond to the most intransigent skepticism and then to respond by demarcating this skepticism from a more reasonable variety to target. In this section, I will show how Williams and others have used this strategy in ethical theory, which leads me to demarcate two varieties of skepticism (§ 7.1.1) and to suggest how to respond to the only one of them that matters (§ 7.1.2). Then I draw some implications from this for how to conceive of the

project of finding normative foundations for medical choice, which carry through the rest of the chapter (§ 7.1.3).

7.1.1 *Reasonable Skepticism*

To understand skepticism and its implications for us, let us consider an account given by Christine Korsgaard. According to her, “the moral skeptic is someone who thinks that the explanation of moral concepts will be one that does not support the claim that morality makes on us” (Korsgaard 1996, 13). Yet, it is also someone who recognizes that “morality is a real force in human life, and everything real can be explained” (*ibid.*). But the moral skeptic asserts that any explanations of morality’s force will not be sufficient to justify the *particular* claims morality makes. This person recognizes the existence of morality, insofar as she recognizes the existence of norms. Yet she asserts that these norms are unjustified, regardless of the aptness of their explanations. Hence, she believes they do not properly govern her.

Korsgaard’s response to the moral skeptic motivates her entire project in *The Sources of Normativity*, and it is impressive and compelling in its own regard. For our purposes, though, we will consider it only to the extent that it conveys something about reflection, ethical inquiry, and the influence of moral skepticism. What is important for us about Korsgaard’s response is that it is ultimately a concession of sorts. She concedes she cannot show “that *complete* practical normative skepticism is impossible” (*ibid.*, 163). But in making this concession, Korsgaard also extracts a concession from her interlocutor. She forces a distinction between two varieties of skepticism, *moral skepticism* and *complete practical normative skepticism*. Then she defeats the former while alienating the latter.

At the root of Korsgaard’s view is her definition of *the normative question*, which she states is “a first-person question that arises for the moral agent who must actually do what

morality says” (*ibid.*, 16). The normative question is not appropriately detached from agents. It does not ask how to justify ethical theory in a generic sense; rather, it is a question of what *to do* in light of the moral considerations for the circumstances at hand. Korsgaard describes three conditions that an answer to the normative question must meet. It must take a certain form, namely, being addressed to the agent for whom the deliverances of morality are binding. It must also be transparent, in that the basis of moral motives must be revealed to the agent to whom they are addressed. And, it must appeal deeply to who the moral agent is, to his or her practical identity.

Characterizing the normative question in this way puts Korsgaard in a strong position: it allows her to argue that if an agent accepts his or her own humanity and accepts that reflection is a central component of agency, then that agent is at most a moral skeptic. Moreover, if the agent goes this far with Korsgaard, then she provides a persuasive argument against moral skepticism. Korsgaard’s strategy for defeating the moral skeptic is thus to cut her off at the pass, to thwart her move to a deeper, more complete skepticism.

Korsgaard does this by asking what happens if the skeptic really persists in denying that valuing is a basic fact of life. What happens, that is, if one denies that humans, *qua* members of humanity, partake in the activity of reflectively valuing states of affairs, and that this can be explained both naturalistically and by appeal to the phenomenology of being a first-person agent engaged with one’s surrounds? She concludes this denial is tantamount to denial of one’s own *life*. For, she argues, “it is necessary to have *some* conception of your practical identity, for without it you cannot have reasons to act. We endorse or reject our impulses by determining whether they are consistent with the ways in which we identify ourselves” (*ibid.*, 120ff.). Thus she concludes, “moral obligation and moral value are a condition of all obligation and of all

value. The price of denying that humanity is of value is complete practical normative skepticism" (*ibid.*, 163).

With this result, Korsgaard contends a sharp dilemma arises for what thus appears to be the *mere* moral skeptic: she can either accept the claim that she is a member of humanity, a member of the living and the valuing, or she can deny it. To do so, says Korsgaard, is to assert a deep skepticism; it is to deny ones own practical *identity*. To deny that humanity is of value is to deny the cogency of one's sense of self, to deny oneself. For Korsgaard, it is a form of suicide, a negating of life.

In their replies to her lectures, Korsgaard's critics endorse her strategy of distinguishing between ordinary moral skepticism and complete skepticism. G. A. Cohen, for example, objects to Korsgaard's first requirement for an answer to the normative question because it articulates a threshold for ethical theory that is too high when we take the complete skeptic into account. Cohen does not see why an answer to the normative question "has to sound good when addressed to the radically disaffected;" instead, he urges Korsgaard to reconsider this standard of adequacy: "I do not think that we can show the intransigent why they should be moral. But I do think that I can show the sincere inquirer why *I* must be moral" (Cohen 1996, 180-181). Cohen thus endorses Korsgaard's claims against the moral skeptic who she gives reasons to believe must, on pain of practical irrationality, accept her membership in humanity, her consequent commitment to reflective endorsement of values, and finally, her standing as a creature beholden to obligations.

Though he does not reply in kind to Korsgaard, Williams does cover these themes in his landmark work published a decade earlier. There, he too identifies the skeptic as the target of ethical justification. Williams suggests that for an individual, there is "an alternative to

accepting ethical considerations. It lies in a life that is not an ethical life” (Williams 1985, 24). Yet, Williams believes that this is not a position an individual can continue to endorse over the long run while retaining membership in the ethical community.

In this way, Williams too endorses the strategy of demarcating between reasonable and unreasonable skeptics. According to him, “the ethical involves more” than a limited benevolent or altruistic sentiment, it involves “a whole network of considerations, and the ethical skeptic could have a life that ignored such considerations altogether” (*ibid.*, 25). However, such a person would be unable to share reasons with other persons, and in this sense they would be unreasonable. The complete skeptic, that is, could not “engage himself to use the ethical vocabulary, but with regard to every ethical question, suspend judgment” (*ibid.*). In this manner, Williams paints the complete skeptic as one who cannot be reasonable, who cannot engage in the sharing of reasons with others. In the face of a need to action, he can either act without reason or he can engage in reason. If he reasons using vocabulary with any relation to ethical discourse at all, then he has, in this way, foregone the commitment to complete skepticism.⁸⁵ If he abstains from vocabulary with entailments in ethical discourse, then in this sense he chooses a life that alienates him from those who are reasonable.

⁸⁵ As Williams says (1985, 26): “It is hard, for example, to use the vocabulary of promising and at the same time to sustain the position that there is nothing decisive to be said, for or against, on the question of whether one ought to keep promises. Moreover, the skeptic has to act, and if he includes himself in the world of ethical discourse at all, then what he does must be taken as expressing thoughts he has within the world. If he speaks in terms of actions being ethically all right or not, and he cheerfully does a certain action, then we must take him to regard it as all right. So this is not an option for ethical skepticism. But there is another option, which is to opt out of using ethical discourse altogether, except perhaps to deceive. While it is not an easy thing to do, the skeptic might be able to establish himself as one who is not at all concerned with ethical considerations.”

7.1.2 *Skepticism and Practical Identity*

If we may distinguish reasonable skeptics from those who deny that they must use *some* ethical vocabulary, then we may find a clear route for justifying a normative framework for medical decision-making. The key is to be clear about the role that reflection plays in overcoming reasonable skepticism, which is familiar, legitimate, and also constrained in a way that unreasonable skepticism is not. Reasonable skepticism recognizes the basic importance of agreement, of sharing reasons in the activity of justification. The reasonable skeptic may often or even predominantly disagree on substantive or procedural grounds. But she must recognize the *importance* of agreement. She must recognize, as Korsgaard puts it, that “as long as we go on living, we *have* to engage in rational action” (Korsgaard 1996, 164). Living, as it were, requires having a practical identity, having a conception of oneself as agent acting in the world, for which certain vocabulary is apt and other vocabulary is not.

Practical identity is a key concept for Korsgaard, as it is through the acceptance of this concept that she rebuts moral skepticism. Once the skeptic assents to the view that she has a practical identity, she cannot resist Korsgaard’s primary conclusion that she must recognize moral obligations. (Although she may yet resist the secondary conclusion that those are properly neo-Kantian obligations.) How Korsgaard describes practical identity as a natural implication of the structure of cognition is important for us.

Korsgaard notes that an agent may envision herself from any number of vantage points. She may see herself as a legislator, a steward, a ward, a wanton, or an egoist. And she may see herself as many other things. And she may do so simultaneously, apparently for Korsgaard, without limits. To do so is natural; it is a product of “the reflective structure of the mind...it

forces us to have a *conception* of ourselves.” (*ibid.*, 100). And for Korsgaard it is important that there is something especially practical about this self-conception:

The conception of one’s identity in question here is not a theoretical one, a view about what as a matter of inescapable scientific fact you are. It is better understood as a description under which you value yourself, a description under which you find your life to be worth living and your actions to be worth undertaking. So I will call this a conception of your practical identity. Practical identity is a complex matter and for the average person there will be a jumble of such conceptions. You are a human being, a woman or a man, an adherent of a certain religion, a member of an ethnic group, a member of a certain profession, someone’s lover or friend, and so on. And all of these identities give rise to reasons and obligations. Your reasons express your identity, your nature, your obligations spring from what that identity forbids (*ibid.*, 101).

For Korsgaard, one’s practical identity is one’s subjective experience of selfhood. It is multifaceted, diverse, and likely to be so complex as to be incoherent – it is “a jumble.” Yet one simple quality of having a practical identity unifies this jumble as *your* jumble, even if this unity defies logical coherence: it is a conception of a self under which *you have some value*. Having such value entails that you have some obligations. Doubtless, the value some place on themselves is so minimal as to yield minimal obligations. But so long as there is value, there are obligations.

7.1.3 Practical Identity and Ethical Medical Choice

Practical identity is a useful construct for understanding medical choice, because precisely what is at issue when persons seek medical care or care is sought on their behalf is their integrity, their practically unified identity. One comes to suspect that something is wrong with one’s self or one’s loved one; one comes to worry that something deeply disvalued has emerged from within. Or in more epistemically clear cases, one is certain that an injury has occurred, one

knows that something disvalued has emerged. And in these cases, one aims to remedy the situation.

We can, then, view medical choices as specific types of normative questions. When seeking medical care for themselves or on behalf of others, agents are confronted with circumstances and must act. They, their loved ones, or their patients appear to be in states of ill health; therefore they face questions about *what is right and what to do*. Using Korsgaard's language, we may say that answering these questions requires putting them in the right form, being transparent, and above all appealing deeply to who the persons are for whom these questions arise. Thus, the problem of how to justify normative claims in medicine may be seen as having its source in the experiences of particular persons, some of whom are ill and some of whom are deeply involved in taking care of ill persons. To make ethical medical choices thus requires explicating what Williams calls "a whole network of considerations" that are relevant for discerning what is right in such circumstances.

If medical choices are understood as types of normative questions, then it is easy to describe the normative force of reflection, as a means for protecting and facilitating patients' practical identities. Consider an example shared by Cheryl Misak. After experiencing ICU psychosis subsequent to treatment for acute respiratory distress syndrome (ARDS) and multiple organ failure, Misak drew upon her experiences to argue for an alternative conception of decision-making than the autonomy paradigm discussed in Chapter 2. Central to her argument is Misak's claim that her specific symptoms caused a break with reality. In her case, she experienced violent, vile, and disorienting hallucinations and delusions, a common side effect of her treatments. And these experiences continued to have lasting effects after she had been extubated from the ventilator, returned home, and even during her lengthy recovery over the

following months. According to Misak, the destabilizing effects of her experiences suggest that the autonomy model is problematic because it undermines the strength of the commitment to respecting patients' autonomy and primary roles in decision-making. Rather, Misak suggests, "perhaps we ought to recognize that physicians, if you like, need to keep a double set of books:...they must on the one hand, see the patient as a person, but on the other, as a physical body on which they need to act, often in horrific ways that are in tension with seeing the patient as an individual with desires, needs, family, and friends" (Misak 2005, 421-422). There are cases, that is, says Misak, where once we recognize the complex experiences of critically ill patients, it becomes inappropriate to view the patient as an autonomous agent who is steward of her interests. We should instead recognize that in some cases patients' experiences indicate that they are not well positioned to make autonomous choices because they have experienced such an extreme break with their own practical identities.

Putting Misak's narrative in this way shows its affinity with Korsgaard's account of normativity as a sentiment that ultimately springs from within. She spent days and weeks after extubation and during recovery attempting to simply get her memories in order, to place her memories "in the correct box," as she puts it (*ibid.*, 414). She relied on her husband and others to help her regain her sense of self, her integrity, her ability to see herself in the world intelligibly. That is, she endeavored to see herself as a person of value from a personal perspective that made sense. Thus, her narrative supports the view that the source of normativity is one's own valuing, which begins most readily with a non-pathological sense of self.

To respond to the skepticism implicit in the no guarantees objection considered in the previous chapter, I distinguish between two varieties of that skepticism. Call them reasonable and unreasonable skepticism. Reasonable skeptics are those who recognize that persons have

practical identities, that as we participate in our lives we reflectively value ourselves. Moreover, in doing this we use vocabulary that binds us at least to speaking as though ethical considerations govern our actions. Unreasonable skeptics deny this. They are bound, as Williams puts it, to choose alienation, where they cannot earnestly use ethical discourse or terms entailing it. Reasonable skeptics can, however. And in doing so, they are pulled toward accepting arguments for the existence of morality, if not its particular contours, by works like Korsgaard's.

As Misak's argument shows, practical identity and the capacity for reflection may be disturbed in the context of medical care. Indeed, in critical illnesses such as hers, it is doubtless more often significantly disturbed than not. If the reasonable skeptic can come this far with the argument, then I contend she must recognize there is some normative force to merely recognizing the necessity of reflection in medical care. She may remain skeptical about the cogency of reflective equilibrium in general, and if so, she will surely be skeptical about the concept of medical reflective equilibrium introduced below. But I aim to show in the rest of this chapter that by accepting that the source of normativity is our own capacity to reflectively craft a personal identity, the reasonable skeptic must also conclude that there is a certain normativity in the nature of medicine that suffices for the model of medical decision-making under development.

7.2 Information, Identity, and a Poor Medical Choice

Reasonable skepticism about the normative force of reflection in medical choice accepts that reasons are often given during medical decision-making, yet it questions whether any or all of those reason can be justified sufficiently to guide action. This section aims to persuade the

reasonable skeptic that the reflective consideration of ample information is a precondition for “good” medical choices. The argument begins by introducing a new example of decision-making in hereditary breast and ovarian cancer, Alicia’s case. I then use decision analytic concepts to schematize Alicia’s choice, which draws attention to the paucity of information she considers (§ 7.2.1). Given the richness of Alicia’s account of her choice, I consider whether merely learning more about the existential context of her choice, as she describes it, permits us to further describe information relevant to decision-making in her case (§ 7.2.2). I conclude that while her experiences provide additional important information, her choice nevertheless appears deficient because it lacks enough important relevant information (§ 7.2.3).

7.2.1 *Alicia’s HBOC Choice*

To characterize a poor medical decision, I use the case of a woman named Alicia, which is captured by Julian Oktay in her sociological research on the experiences of daughters of women who have had breast cancer. Alicia characterizes her thoughts about BRCA testing as follows, which I take to be a narrative account of her choice at the moment the conversation takes place.⁸⁶

I was thinking of doing the test. I’m scared to do it. At first, I thought that if it came back positive I would go in and have mastectomies with implants. Then I decided that would be too radical for who I really am. I would just want to know genetically if I’m predisposed to it, for the estrogen purposes, and for my daughter. For my peace of mind. If it turned out yes, then I would just monitor myself even closer. If it was not, I wouldn’t decrease what I was doing, but I might live my life a little freer. I would go on estrogen. And I think I would loosen up with my daughter. I would feel better about her own sexuality. So I’m leaning toward it, but I’m scared. I’m so afraid of medical confidentiality. If I did it, I would pay cash, and use somebody else’s Social Security number. To find

⁸⁶ In-text citations for Alicia’s case will be suppressed through this section for the sake of clarity. All quotes are unaltered (including brackets) from Oktay 2005, 145-153.

out I'm not [genetically predisposed] would be the greatest liberation for me, but I don't know if I can handle finding out that I could be.

From her narrative, we learn Alicia thinks that knowing her objective risk of HBOC would influence her treatment decisions, including prophylactic surgery, hormone treatment for menopause, and continued surveillance measures for breast cancer. She also believes that learning her objective risk would influence her self-conception and personal relationships: it would make her freer, altering her relationship with her daughter and generally easing her fears. But Alicia worries about her genetic information getting into the wrong hands. Even more importantly, she worries about how learning she is predisposed would impact her overall well-being. Thus, for Alicia the decision whether to undergo testing is intimately related with a broad range of factors, including potential medical care, interpersonal relationships, potential relationships with institutions like employers and health care insurers, and her intrapersonal relationship – her relationship with herself – particularly her anxiety, fear, and overall feeling of well-being. To use William's terms, these are constituents of the network of considerations that determines whether Alicia believes genetic testing is right for her.

We can use the tools of decision analysis to characterize the factors that Alicia discusses when describing her disposition regarding genetic testing. The four steps of decision analysis are identifying and bounding the problem, describing the structure of the problem, characterizing the information necessary to fill in that structure, and then choosing in light of all of this information (§ 6.5). If we take Alicia's narrative as a report of her attempt to complete these steps, then we can consider the structure and content of the decision problem that is conveyed by her description.

In her narrative, it is not clear that she views herself as having a choice, although she does say that she is thinking of having the test, which suggests she either could or could not

choose it. Thus, she faces a dilemma even if she does not see it that way. The salient factors Alicia describes are what happens after she chooses to have the test. She notes that if the results were positive she has considered the prospects of prophylactic mastectomies and reconstructive surgery. Yet she appears to think this would be against her personal identity, in that “it would be too radical” for who she “really” is. So Alicia also reports considering what she would do if she receives a negative test result. She states that she “would go on estrogen,” presumably meaning she would undergo hormone replacement therapy. She also suggests she would alter her current surveillance routine, or monitor herself “even closer.” And she also says she would do both of these activities.

We can render Alicia’s discussion in terms of five choices following from undergoing BRCA testing, which each depend on the results of the test. The choices are prophylactic mastectomy, breast reconstruction, hormone replace therapy (HRT), increased surveillance, and increased surveillance and HRT. However, her narrative emphasizes far fewer outcomes of interest to her. For example, Alicia does not mention that she is keen to reduce her objective risk of getting cancer, a very likely outcome of prophylactic surgery. The only two outcomes she mentions, and she mentions them often, are improvements in her own sense of self (including peace of mind, fear, sexuality) and in her relationship with her daughter. Thus, when rendering Alicia’s narrative in decision analytic terms, the resultant decision tree includes five choices and only two outcomes, as represented in Figure 7.1.

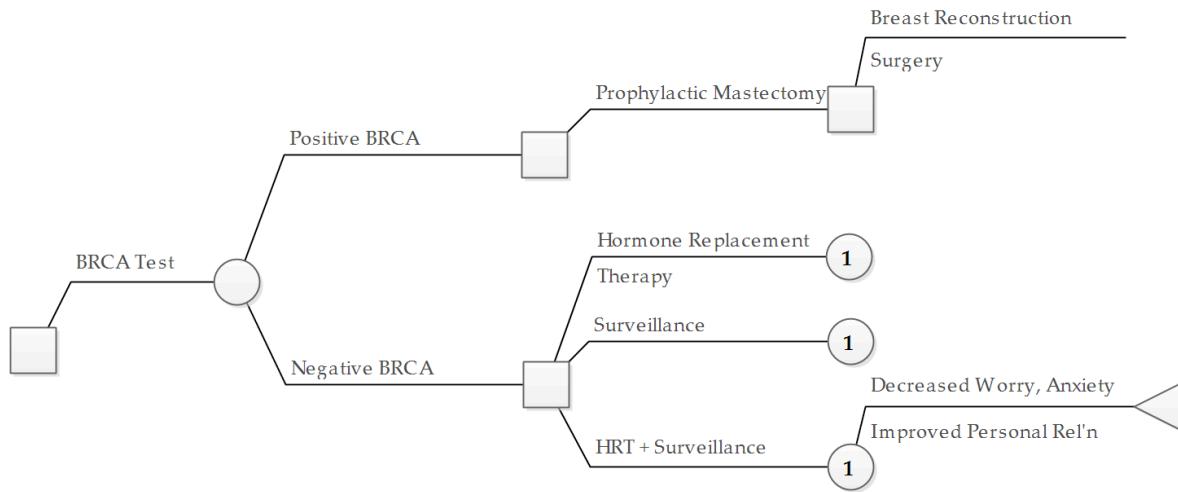


Figure 7.1: Alicia's decision tree. Squares denote choices, circles denote outcomes, and triangles denote terminal outcomes. Numbered nodes denote reference nodes, which reiterate where marked.

By using decision analytic concepts heuristically, we see that Alicia's choice is a poor one because it fails to consider important information. That is, her decision tree is insufficiently foliated. She does not appear to be aware of choices entailed by her considerations. She does not appear to be aware of outcomes that are entailed by the choices she is aware of. And she is unaware of outcomes that are entailed by the choices she is also unaware of. For example, Alicia's decision tree is missing an entire branch stemming from the main decision node: she does not report considering the option of not taking a BRCA test. It is also lacking a branch representing choices that follow once a positive test result is learned, including other medical management strategies or whom to inform about her results. And she is missing numerous likely outcomes of learning about her risk, beyond the important affective outcomes she emphasizes. For example, if she underwent HRT, this would increase her risk of various physical and psychosocial side effects.

7.2.2 *The Existential Context of Alicia's Choice*

It may be possible to understand more about Alicia's choice by considering her reports of personal experiences with breast cancer. At age forty-six, her age at the time of these interviews, she had never experienced breast cancer personally, though she had a breast cancer scare eleven years earlier, at age thirty-five. Of that time, Alicia says, "I just remember shutting down. I could not eat. Could not sleep." Since then, getting her annual mammogram has continued to be very stressful: "Getting ready to go, the whole day before, I have diarrhea, I can't sleep, I can't eat. The minute they just mention my name I burst into tear. I'm a mess!"

Alicia reports emotional responses to thoughts about breast cancer risk that stem from her particular experience as a caregiver for her mother, who died from breast cancer. After her mother's death, Alicia realized that she too was at risk for breast cancer, a realization that causes her great worry and anxiety. "I worry tremendously about my own health. All the time. I've worried about breast cancer since the time she died. I just felt that there was a genetic link and I'm scared."

Alicia's experience with breast cancer is inextricable from her personal identity. As a child, she grew up in a Jewish household with her mother, father, and brother. Her grandmother died of breast cancer at fifty-three, which caused her mother to be overcome with worry thereafter. Alicia says that whenever she and her brother were bad, her mother would say, "You can treat me miserably, but I'm going to die when I'm fifty-three." Alicia did not believe her. But when she was fifteen, Alicia's mother discovered a cancerous lump in her breast. After her radical mastectomy, Alicia's mother continued drinking heavily, a habit she developed after discovering the lump. During this period, Alicia says her mother "became more and more detached from me emotionally. Wanting me to grow up and become independent. She would

go about her chores, you know, the traditional housewife, cooking and having meals ready, but she was no longer my mother...I did a lot of crying those days, and talking to my friends. And I would talk a great deal to my brother. He was a very big support."

At the end of Alicia's freshman year of college her mother's condition deteriorated rapidly. Her father told her that her mother had a virus and needed someone to take care of her while he was at work, so Alicia moved home to help. At the time, she was too naïve to realize her mother's cancer had returned. Alicia spent the rest of her mother's life as her caregiver. These were precious moments for her, as they had "important bonding time," including "the first time ever that we shared even to say 'I love you.'"

Although her condition was terminal, Alicia's mother died abruptly at age fifty-three under dramatic circumstances. Her death left lasting, painful memories that Alicia vividly recalls, beginning with the night before her mother's death:

I just kept praying with my mom all night, *Don't die. Don't leave me. Don't do it.* It was awful. The next morning, the nurse said we needed to go to the drugstore to get some syringes. Mother was going back and forth with her head. Talking incoherently. In just miserable pain. So we went, and when we came back, my brother came outside and he said, "I've got to tell you something." And I said, "No way are you telling me anything." ...They wouldn't let me go upstairs and see her. My father was on the phone in the den crying. My father would never cry. And finally my uncle said, "Let her come upstairs." And they brought me upstairs. She was lying there but her eyes were sort of open, and I said, "She's just sleeping." And they said, "No. She's dead." And they made me touch her, and it was this dank coldness that [stayed in] my hands and arms for weeks. I was afraid to touch anybody. It was just awful. They put her in a bag, and then they came down the stairs. They were, like, bumping her [on the stairs]. It was really bad.

Considering Alicia's narrative in more detail provides additional information about the background experiences that have shaped her understanding and assessment of breast cancer. While we may presume that most women disvalue breast cancer, by considering Alicia's

narrative we learn why she disvalues it so strongly, and the extent to which the activity of disvaluing breast cancer pervades her everyday experience. From her narrative we learn that Alicia's understanding of her own breast cancer risk is deeply influenced by the social circumstances of her mother's death. It reveals that her anxiety about breast cancer is so pervasive that it causes her sleeplessness and diarrhea. And we also learn that hidden in Alicia's emphasis on improving her relationship with her daughter is her own tragic relationship with her mother and the pain she still carries from how her mother died and her own experiences as a caregiver. Further considering Alicia's narrative reveals that her emphasis on the possibility that BRCA testing might improve her relationship with her daughter is not misplaced, given her own life experiences.

Yet, the additional details Alicia reports about her life provide little additional information about her HBOC choices. In the main, we do not know with whom she discusses her dilemmas, nor do we know whether or to what extent she has expressed her evaluation of her options. Alicia only tells us that she has spoken with doctors who recommend estrogen therapy for her menopause and disagree with her claim that it is too risky, given her HBOC risk.

I struggle now with going on estrogen or not going on estrogen. I should be on estrogen. I desperately need it. The doctors want to put me on it. They are very insensitive. [They say] "If you get breast cancer, we'll monitor you closely. We'll get it [early]." But to me, breast cancer still signals a little bit of a death sentence. I don't believe you can get rid of it and be healthy, even though I have seen many women get over it. For me, there's too much [of a] leap of faith in that.

When deciding whether to undergo estrogen therapy, Alicia is torn between her felt need for it, her doctor's urgings, and her belief that it carries too much risk of causing breast cancer, an illness she personally believes is unbeatable in a profound sense. Consequently, Alicia disvalues estrogen therapy in light of her worries about developing breast cancer. Believing it

would increase her risk of an outcome that she so strongly disvalues, and that she believes is a “death sentence,” Alicia sees hormone replace therapy as a treatment to avoid.

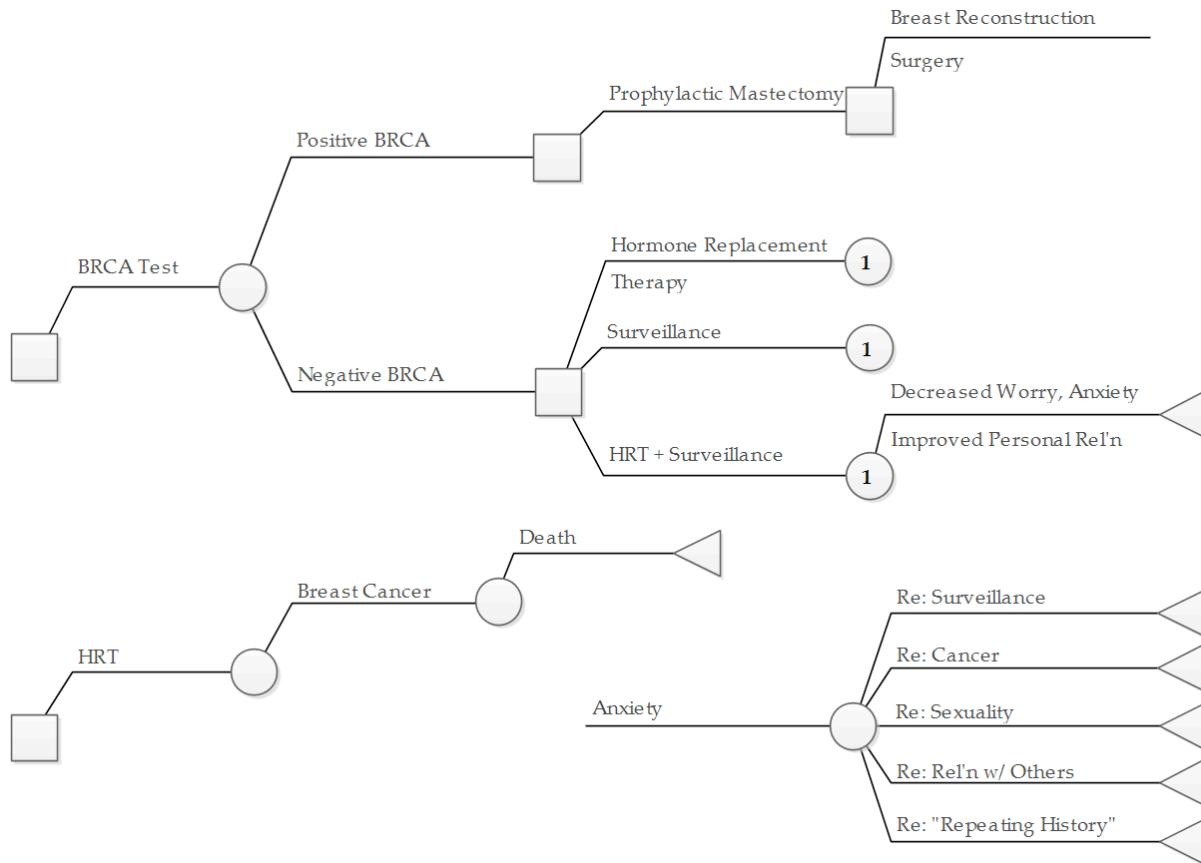


Figure 7.2: Alicia’s decision tree and related factors.

Considering more of the existential context of Alicia’s decision, we learn she is aware of additional factors. She recognizes her physicians want her to undergo hormone replacement therapy now, for a different medical condition than her putative HBOC. She also further specifies the experiential sources and manifestations of her anxiety. However, she gives little indication that her considerations about HRT are related to her choice of whether to undergo BRCA testing. And she does not make clear whether she believes all of her anxiety might be resolved by medical treatment or whether it might require other sorts of intervention. What we

learn can also be represented in decision analytic terms, combined with what was rendered in Figure 7.1.

By representing the additional factors Alicia discusses in her narrative in decision analytic terms, we get a sense of just how disorganized her thoughts are regarding her medical choices. Alicia *feels* the burden of experiencing breast cancer and worrying about her risk. But she does not represent her medical choices coherently. What information she has about HBOC she does not integrate into a reflective whole. And she is also missing important information of the sort covered in detail in Chapters Four and Five. Thus, from what Alicia describes of her thoughts about BRCA testing, her decision-making is poor because it fails to consider important information relevant to her particular circumstances, and what information it does consider not coherently organized.

7.2.3 A Case of Missing Information

The sort of information that is relevant for Alicia’s decision is at minimum information about the choices one is likely to face in circumstances like hers, the outcomes and choices that are likely to follow from these choices, and far downstream choices that we have called terminal outcomes, despite recognizing the ineliminable arbitrariness of the concept “terminal.” An ethical medical choice in Alicia’s case would also need to be made in light of her evaluations of the outcomes that are likely to follow from the choices that are often faced in circumstances like hers, that is, for people who putatively have hereditary breast and ovarian cancer.

Our reconstruction of Alicia’s choice would thus be improved if it included some of this information, which could be inferred from our prior consideration of HBOC. For example, there are a number of choices that are entailed by her consideration of genetic testing that are not present in her story. One is whether to undergo genetic counseling or not, which is normally a

prerequisite for testing. There are also other choices implied by thinking about alternative options for medically managing HBOC, such as prophylactic oophorectomy, chemoprevention, lifestyle changes, and ovarian surveillance. Alicia might also consider non-genetic means of estimating risk, particularly epidemiological models. Finally, for each of these missing choices, proper foliation would require representing their converse; the option of not choosing each of them should also be captured by distinct choice nodes in the tree, including connections to downstream choices and outcomes.

Some of the relevant outcomes that could be added to a more foliated decision tree for Alicia's case include the following. BRCA test results may be positive, negative, or variants of uncertain significance. Since negative test results cannot be distinguished between true or false negatives unless a known BRCA carrier exists in the family, outcomes for interpretable versus un-interpretable results are also relevant. A more foliated tree would include objective estimates of Alicia's breast and ovarian cancer risk, and, because of these interpretive complexities these would need to be more complex than simply, "risk is estimated as greater than the general population" and "risk is estimated as equal to the general population." It is also unclear what impact knowing her objective estimated risk will have on Alicia's anxiety; hence, the additional distinctions regarding types of anxiety in Figure 7.2 would need to be placed in different relationships to outcomes, including risk estimates. Additionally, all medical interventions have risks and benefits, so representing these would certainly be relevant. For example, prophylactic mastectomy and breast reconstruction both entail various risks attending surgery that could be represented in a more foliated decision tree.

As a heuristic device, decision analysis allows us to focus on choices and outcomes while also drawing attention to how terminal outcomes are evaluated. Some of the evaluations

that are relevant to Alicia's decision-making would include her assessment of being at different degrees of risk for breast and ovarian cancer. She clearly strongly disvalues being at a high risk for breast cancer. And she also apparently disvalues her anxiety, aspects of her self-conception, and aspects of her current relationship with her daughter. But it is unclear whether and how she assesses these outcomes relative to one another. We also do not know much of her assessment of beneficial and harmful outcomes from prophylactic surgery and related interventions, each of which has different likelihoods of occurring.

Altogether, then, Alicia's choice is lacking in that it is missing crucial information about the *choices* she faces, including the *outcomes* associated with those choices and subsequent choices entailed by them, and her *evaluations* of some or all of those outcomes. As she renders them, her thoughts about BRCA testing are also disorganized in the ordinary sense that we might imagine. As Korsgaard might put it, her practical identity includes something about her being someone at high risk for breast cancer, and though this much is clear, Alicia's practical identity is evidently a "jumble." Thus, Alicia's case illustrates that poor choices are deficient in information. This suggests the generalization that in poor medical decisions the processes of searching for, selecting, and integrating information are insufficient. Hence, in order to describe good medical decisions we must describe the processes of search, selection, and integration.

7.3 Medical Reflection: From the Ideal to the Good

Another way of describing what is missing in Alicia's case is that it is missing adequate reflection. Presumably, if someone in Alicia's position reflected on her circumstances sufficiently, then she would search for more information about the choices related to her

circumstances. She would also select some of that information as relevant for her. And she would endeavor to make sense of that information in light of information she already knew. She would, that is, strive to understand how the choices she faces impact her sense of self, her practical identity. In this sense, reflection in medicine is tied to the consideration of one's circumstances and, given them, the options that might be possible.

We have already considered a better case of HBOC decision-making in considerable detail, in Chapter 4. In Ellen Macke's case, we find more reflection in this sense. We find more searching for information and more careful selection of information relevant to her circumstances. We also find the integration of information over time until a fuller picture of the circumstances emerges.

One might think that Macke's decision-making appears better than Alicia's because she employed decision theoretic tools to model her choice. Macke mentioned that she used decision analysis to improve her understanding of the logic of her choice. She says, "In the absence of extensive data, statistical decision analysis helped me to evaluate my options. I drew a decision tree that began with three branches, one for each of the options among which I had to choose" (Macke 1996, 35). However, I think that this would be to mistake an effect for a cause. Macke's choice is not better than Alicia's because she uses decision analytic conventions. It is better because she considers far more relevant information than Alicia and carefully considers the possible relationships among those bits of information.

Macke makes clear in her narrative that decision analysis was a representational convention that allowed her to characterize the relationships between the numerous factors she considered. It was also a tool she used to evaluate those outcomes for her, given her life. For example, she considered what likely outcomes of surgery would be. And she asked her sister

and cousin to help her understand what experiencing these outcomes could be like. In doing this, she evaluated those outcomes and did so in a way that was personal, that estimated the meaning those outcomes might have for her.

Consider Macke's discussions with her sister and cousin about their experiences with breast cancer treatments. As they share their experiences, they process information for Macke, by relating to her what mattered – what was meaningful – in their experiences. This provides Macke with pertinent information for her own choices, in that it allows her to estimate how experiences she might have could be meaningful for her. And it relates those possible experiences directly to the different choices she perceives herself to be facing.

For example, Macke's sister tells her she experienced swelling in one breast after a modified radical mastectomy. But she did not experience swelling in the other breast, after a simple mastectomy. She also says her prosthesis is comfortable but that she sometimes reacts to the adhesive used to keep it on. And she discusses her husband's reaction to the surgery and the harms and benefits of reconstructive surgery as opposed to prostheses. Likewise, Macke's cousin discusses her choice to undergo chemotherapy for her own metastatic breast cancer. And when they talk about Macke's options she expresses regret at not having been able to choose prophylactic surgery.

The information Macke gathers from her sister and cousin allows her to better assess the meaningfulness of possible outcomes, which may then be further related to the choices that precede them. Thus, in talking to her family members about her decisions, Macke becomes more informed about them, both with regards to the outcomes that might occur and her assumptions about the value of those outcomes for her. This process may be described as Macke's *searching* for information about the value of outcomes for her.

To make sense of Macke's search, we may describe it in decision analytic terms. Macke, it can be said, is estimating the value of the outcomes for her, under her circumstances. In decision analytic terms, she could be understood as using arbitrary units of value or "utilities" in order to provide a relative ranking of outcomes in order of her preference of them, given their meaning to her.⁸⁷ Understood this way, we find that when talking with her family Macke can be seen as calling on them to provide checks against her evaluations of outcomes, which is like asking for their collaboration in the estimation of utilities for those outcomes. Thus, Macke's family members provide her with information that challenges her existing assumptions or impels her to make assumptions about factors she had not perceived were relevant. In so doing, Macke confirms her belief that what was most important to her was reducing her risk of breast cancer by identifying other relevant factors and comparing their importance to reduction of breast cancer risk. It is because of this recursive searching, comparing and contrasting, and selecting of information that Macke's choice appears to be a better one than Alicia's.

Yet, although Macke's decision-making is evidently better than Alicia's, it may seem inappropriate to say that it was a "good" instance of decision-making. And describing Macke's decision-making as "ideal" certainly seems inapt. The apparent problem with Macke's case is that her decision-making also failed to consider important information. As I discussed in Chapter 5, Macke's reconstruction of her decision-making is incomplete. She explains whom she interacted with over the years during which her choices emerged. Thus she provides a sufficient evidential basis from which we can draw conclusions about the macro-structure of her choice, its communication architecture. Macke also provides some information about

⁸⁷ Note that this does not require reifying such utilities. They can be understood as mere counting devices, as explained in § 6.4.3.

intermediate levels of communication with her family members and providers. She describes the factors that were relevant for her circumstances, the choices she saw as important, and the outcomes that were particularly salient. But more of this information is missing than information about who participated in her decision-making.

In Chapter 5, I suggested two ways to fill this information gap. One would be to perform microanalyses of discourse between candidates for HBOC, family members, and providers. Another would be to approximate the results of such analyses by reviewing social scientific research on the factors that scholars have anticipated being influential in HBOC decision-making. Drawing on this work, I think it is possible to characterize an ideal decision in the case of HBOC. If this is possible, then by working backwards it will then be possible to say what good reflection might look like.

7.3.1 Ideal Reflection in Medical Choice

To characterize an instance of ideal reflection in medical choice I will draw on what we have learned about hereditary breast and ovarian cancer in previous chapters. I will also appeal to concepts from decision analysis.

In Chapter 4, I describe our biomedical knowledge of hereditary breast and ovarian cancer (§ 4.1). I also describe the process of undergoing genetic testing and interpreting results of testing (§ 4.2). And I summarize Ellen Macke's detailed reconstruction of her decision-making (§ 4.3.2). In Chapter 5, I describe instances of communication between patients and providers about breast cancer and breast cancer decision-making (§§ 5.5.2.3 and 5.6.1). I also review a convenience sample of studies on the psychosocial factors associated with HBOC choices (§ 5.6.2). In light of the information contained in those sections, it is possible to enumerate the many different choices, outcomes, and terminal outcomes that a generic

candidate for HBOC would face. It is also possible to identify the factors that would bear on this generic agent's evaluation of outcomes. Thus, it is possible to render this agent's choice in decision analytic terms. This representation then provides a means of describing an ideal medical choice for the context of hereditary breast and ovarian cancer.

To describe this generic, ideal choice let us start by minimally describing the "generic agent." We know nothing about such an agent *a priori*. However, let us presume such an agent is a person, which licenses additional assumptions about his or her cognitive abilities and so forth. Let us also presume that this agent is a woman. And she is a candidate for HBOC. She is thus a person with suspected HBOC. Other than this, we know nothing about her practical identity.

Since we know nothing about this generic agent's health state, we do not know if she currently has cancer of the breast or another organ, body system, or bodily region. We also do not know whether she has breast cancer worry or anxiety. Nor do we know whether she has other psychological symptoms. And we know nothing about her social context, including the persons she communicates with regarding her potential illness or her family history of breast cancer. We know nothing about the medical factors relevant to her circumstances, the demographic factors that describe her, or the psychosocial factors that might influence her choices.

Yet, despite not knowing any of these things, we do know that merely because she is a person with suspected HBOC this woman faces three choices. There are three basic options that any candidate for HBOC faces. She could choose not to engage in the medical management of her risk or symptoms. She could also choose a medical management strategy for her risk or

symptoms without seeking any information than whatever is known at the time. Or she could choose to collect more information than is known at the time.

Thus, it can be said that a generic agent who is suspected of having HBOC faces three basic choices. Furthermore, there are three basic categories of information that describe the generic agent and would be particularly relevant to those choices. These include *medical factors*, *demographic factors*, and *psychosocial factors* that describe her and her health state. Beginning with these factors and choices, we can represent the generic agent's state of affairs heuristically using a modified decision tree (Figure 7.3). Doing so, the generic person constitutes the mid-point or the "stem" of the tree. The factors that are relevant to her choices lie to the left, which are the "roots" of the tree. To the right lie the branches of the tree. In Figure 7.3, the roots and branches are foliated such that they only show the three basic choices and categories of factors just described.⁸⁸

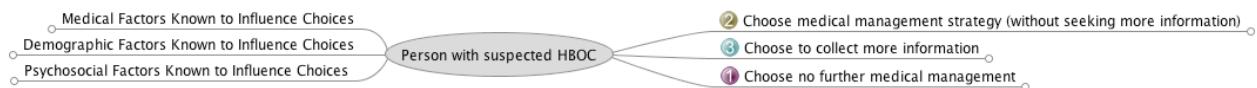


Figure 7.3: A generic decision tree for hereditary breast and ovarian cancer.

⁸⁸ I use FreeMind software to produce this decision tree and those in subsequent figures in this chapter because it is freely available, runs across operating systems (in the Java Runtime Environment), it is easy to use, and it allows for dynamic viewing of trees. That is, once a tree is created and shared, it can be easily manipulated by collapsing, expanding, reorganizing, or altering nodes. Other software packages for rendering decision trees do not allow for such easy manipulation, although they do allow for easier rendering of formal aspects of decision trees. But as I use decision analytic conventions heuristically and non-formally, these are not necessary for my purposes. FreeMind is available at http://freemind.sourceforge.net/wiki/index.php/Main_Page.

If one can agree with the move to abstract away from the details of the lives of particular persons and instead think about a generic agent for whom little is known except that she is a candidate for HBOC, then this conceptual device makes it possible to represent all of the many things that *might* be relevant for an actual person to consider when making an actual HBOC decision. By considering this generic agent, that is, it is possible to model all of the potentially relevant information for HBOC choices, because all information is generically relevant. And this creates a means for explicating all of the factors, choices, and outcomes that may be of interest to persons making HBOC decisions.

Representing all of the potentially relevant information for the generic HBOC decision-maker requires further foliating the roots and branches of the generic decision tree in Figure 7.3. From the description of HBOC decisions in Chapter 4, it is possible to foliate the branches of the generic HBOC decision tree in the following ways. Each of the choice nodes in Figure 7.3 is a reference node, and is therefore marked with a number that could be referred to recursively, downstream from its origin. This demarcates a node in the tree where feedback loops occur, in that an agent can be lead from one node to another and then back upstream, given the logic of the decisions she faces. If we foliate the reference nodes shown in Figure 7.3, then we find that [1] leads to two outcomes (marked with blue arrows), which each also then lead to two additional outcomes. Thus, foliating node [1] can be said to reveal two terminal outcomes and different paths for reaching them. If a generic individual chooses no further medical management of her suspected HBOC, then it is possible that she is not at increased risk for breast and ovarian cancer. It is also possible that she is at increased risk. Either way, it is further possible that she is in need of near term medical attention because of or despite her underlying

risk status. This is captured in Figure 7.4 by the outcomes downstream of “choose no further medical management.”

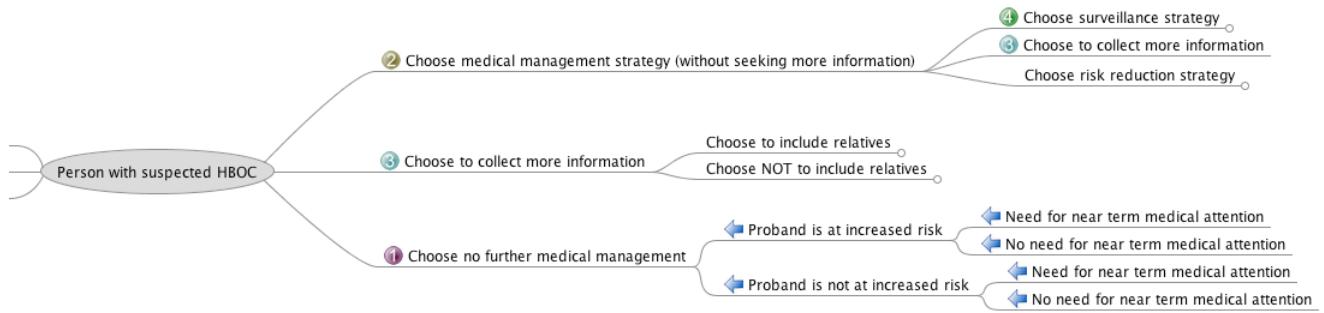


Figure 7.4: Initial foliation of the generic HBOC decision tree.

Just as reference node [1] in the generic HBOC decision tree can be further foliated, the other nodes may also be foliated further. Doing so, we find that choosing a medical management strategy without choosing more information, node [2], leads to three additional choice nodes. One may choose a risk reduction strategy, choose to collect more information, or choose a surveillance strategy. Tiny circles at the end of each line mark two of these choices, signifying that they may also be foliated further. The other choice is a reference node without a tiny circle, signifying that further foliation is achieved upstream on the tree. There, we see that immediately downstream of reference node [3] is another choice node, of whether to include relatives in the process of collecting more information.

Further foliation of node [3] is also possible. If we foliate both branches downstream from [3], then we see either one leads to another choice. This choice is of whether to use either computational models or genetic testing to assess one’s risk. Each of these can then be foliated further. In Figure 7.5, one of the branches downstream from “choose not to include relatives; choose to assess risk using computational models” is marked by red and white flags, signifying that each of these branches warrants further foliation but that this foliation is not represented by

this generic tree.⁸⁹ More is known about the choices and outcomes related to each computational model, but this tree does not represent that knowledge.

By attending to both of the branches that represent the choice of assessing risk using genetic testing, we may see why the upstream choice of whether to include relatives in the genetic testing process is relevant to later choices and outcomes. The path “choose to include relatives; choose to assess risk using genetic testing” leads to two outcomes. These are that a known mutation in the family may be found or that no known mutation may be found. The path “choose NOT to include relatives; choose to assess risk using genetic testing” also leads to the same outcomes. However, one of them has a probability of zero for epistemic reasons. Since, on this path one has not included relatives in the process of collecting information about genetic risk, then one cannot know whether one of those relatives has a mutation. Thus one cannot determine whether there is a known mutation in the family. Consequently, this outcome cannot occur. Thus, comparing these two branches underscores that some outcomes have a zero probability of occurring under some paths (signified by a red circle with a white dash in the middle) while having different probabilities of occurring under another path.

⁸⁹ These diagrams are best shown by using FreeMind and do not reproduce well on an 8.5" x 11" sheet of paper. The file is freely available from the author via email at: tvc.hps@gmail.com, or at: https://dl.dropboxusercontent.com/u/25699874/HBOC%20MDM_generic%20decision_FM_0.1.0_publi_c.mm

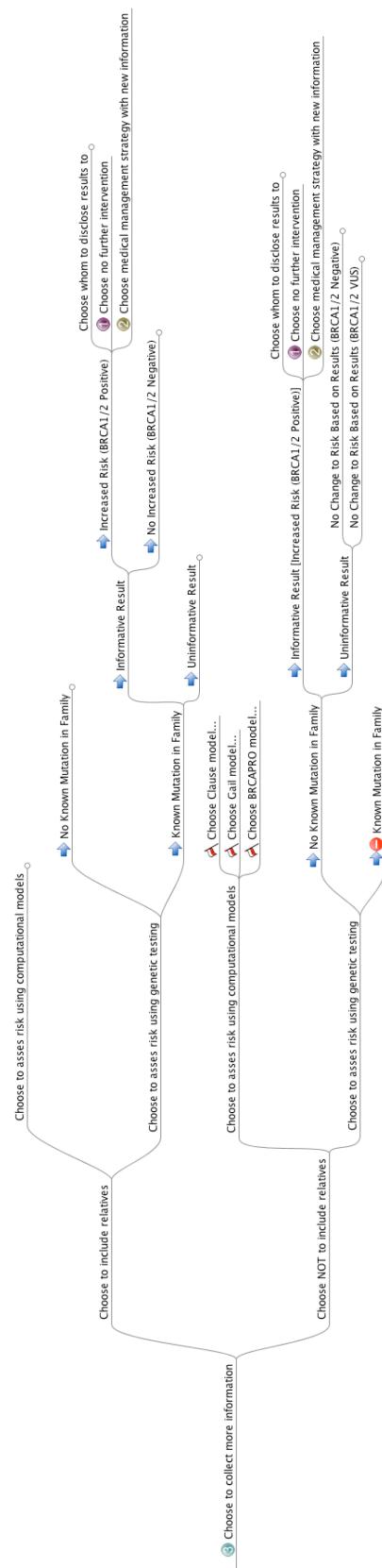


Figure 7.5: Further foliation of reference node [3] of the generic HBOC decision tree.

Additional information is captured in Figure 7.5 that warrants comment. Here, we see that whether one chooses to include relatives in the information collection process or not, if one receives an informative positive result, then one is still likely to face a decision of whom to disclose the results to. If one receives positive results one will also face choices regarding whether to consider medical management of one's risk or not. By including these reference nodes, the generic HBOC decision tree captures the fact that any patient always has a choice to refuse treatment that is medically warranted for her circumstances. If she chooses not to medically manage her risk, then this leads to certain outcomes, represented in Figure 7.4 by node [1]. If she chooses to medically manage her risk in light of the new information given by test results, then this leads to further choices, represented by node [2].

Returning to the reference node [3], it is also important to describe how branches may terminate. Looking at the outcome of a person receiving an informative result of being at increased risk again, we see that the choice node following it that is not a reference node may be further foliated. There is a tiny circle at the end of it. If we foliate this further (not represented here), then we find that one may choose not to disclose these results, choose to disclose them oneself, or choose to have a health care provider disclose the results. Various outcomes might be represented downstream from this choice. In this generic tree, these branches terminate with two terminal outcomes: the recipient of disclosure receives or does not receive genetic testing. This captures that the disclosure node is a natural, albeit arbitrary, point to terminate the reasoning that originates with considering whether to collect more information, as it signifies sharing that information with others. Once the choice to share collected information with others is made, other outcomes and decisions follow, but they may not be relevant to the generic person who is confronted with an HBOC choice.

For a generic agent there is no limit to the amount of foliation that can be performed for the branches downstream of the three basic choices represented in Figure 7.3, because there is nothing that we know about her that precludes any information downstream of these choices from being relevant. Unlike in Ellen Macke’s or Alicia’s cases, we do not know anything about the generic agent’s personal history or circumstances from which we can infer that some choices are not actually open to her, or some outcomes are so unlikely as to be negligible.

Another way to put this is that for the generic agent there is no information available that justifies any pruning strategy at all for searching, selecting, and integrating information relevant to HBOC decision-making. If the generic agent were particularized in some way then this would change the relevance of some of the represented information for her circumstances. For example, if we knew that this person had no living relatives to include in the process of collecting more information, then this would make the node “choose to include relatives” and all nodes downstream from it irrelevant for that individual. In this way, a more particular decision tree could be constructed by pruning the branches of the generic HBOC decision tree. And the pruning strategy could be justified in light of what is known about that person. Knowing more about a patient’s practical identity thus provides constraints on what information is relevant for her decision-making.

However, the abstract, generic agent is one for which we have no particular information that could justify a pruning strategy. Consequently, if we were to foliate the other branches in Figures 7.3 through 7.5 that can be further foliated, then what would result would be a decision tree that represents all of the different choices, outcomes, and terminal outcomes that are of relevance under a circumstance where nothing else is known about a person other than that she is a candidate for HBOC. To use terminology defined in Chapter 3, these would be

circumstances under which we have no subjective or objective knowledge about the person, except for what was given in defining the generic agent. A decision tree describing these circumstances would be a case in which all possibly relevant information should be included and logically organized. Such a tree, which I call a *generic HBOC decision tree*, is rendered in Figure 7.6.

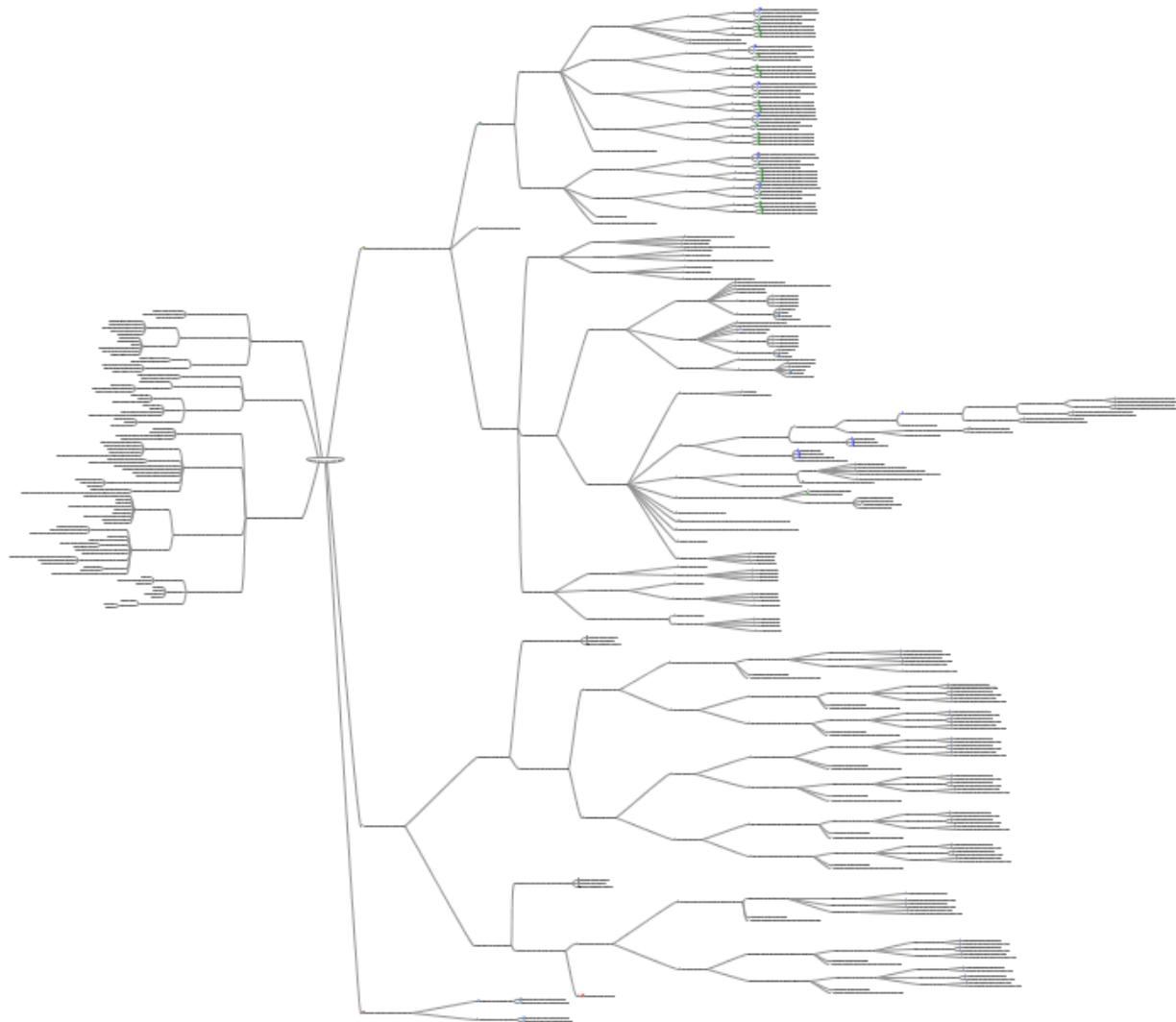


Figure 7.6: A fully foliated generic HBOC decision tree.

When represented statically as a figure on an 8.5" x 11" sheet paper, a generic HBOC decision tree is useful only for capturing the comparative complexity of all of the information

that might be relevant to an agent's choice, if she were in the circumstances modeled by the focal, or stem, node of the tree. Knowing that each node in Figure 7.6 is either a choice or an outcome, one can perceive that a significant amount of information is relevant to HBOC decision-making under conditions where nothing is known that constrains the possible relevance of any piece of information. However, viewed in this way it is impossible to discern which choices and outcomes are being modeled. To do this requires viewing the electronic generic HBOC decision tree file using FreeMind software.

If viewed using the correct software, the generic decision tree for HBOC can be used dynamically as a heuristic device. The decision tree has been created using freely available software that runs across platforms and requires little computational resources. Thus, it could be downloaded by anyone. And anyone could open up a file I have created and explore the informational structure of a generic HBOC decision. Furthermore, anyone could explore the implications of different choices in the way that I have in the different figures above, by collapsing nodes and expanding them. Or in other words, anyone can use this computational tool to consider the implications of different pruning and foliating strategies, depending upon her intuitions about the relevance of different information mapped using the software. And the map can be updated as the end user warrants. More information can be added or existing information can be restructured.

In this way, we can also use Figure 7.6 to draw a comparison to the other choices we have discussed in detail, Alicia's and Ellen Macke's choices. If we compare Figure 7.6 with the best tree we could render when considering everything Alicia reported about her circumstances (Figure 7.2), this shows that far more information may be considered and organized than what is found in Alicia's case. Although we already came to this conclusion when comparing Alicia's

case to Macke's, this substantiates and further qualifies our conclusion. We can still say that Alicia's case of decision-making was poor because it was missing important information. However, now we are able to qualify this claim more strongly: we can look at the two figures next to one another and show that Alicia's is far more sparse and poorly organized than the generic tree. Alicia does consider *some* relevant information, but she does not consider anything nearing *all* of it. Furthermore, since we already accepted the claim that Alicia's case was a clear instance of poor decision-making, we might further specify that it was poor precisely because it failed to consider all of this information.

7.3.2 A Good Choice in Relation to the Ideal

If Alicia's choice remains a poor one when rendered in decision analytic terms and compared to the generic HBOC decision tree, then what about Ellen Macke's? In light of what we know about Macke's choice, I believe it is a good choice. And what's more, I believe explaining why with reference to decision analytic concepts provides an opportunity to distinguish between ideal reflection in medical decision-making and a lower threshold of reflection that nevertheless remains good.

As I say above, Macke's choice appears to be a good one because she searches through, samples from, and integrates an adequate amount of information. At the beginning of this section, I described this as a sort of reflection, which I asserted Alicia's case lacks. Yet Macke's case clearly is not ideal, if by ideal we mean considering all of the possible information of relevance for one's choices. Consider, for example, that Macke focuses narrowly on the outcome of increased or decreased probability of cancer recurrence as the primary outcome of interest to her. From this she concludes that radical mastectomies and prophylactic oophorectomy are the right choices for her.

Given the aforementioned limitations of Macke's narrative, we do not know how many other outcomes she considered when making her decisions and which of them she deemed particularly relevant. We know that she considered the effect oophorectomy would have on her chances of bearing children, but that since she and her husband did not want children she deemed this an unimportant outcome. We also know that she and her family members talked about the consequences of surgery and that she considered post-operative consequences, including wearing prostheses and how that might effect her relationship with her husband sexually and otherwise, among other things. Macke also notes that she considered the implications of having different medical insurance, which implies that she considered the financial implications of undergoing treatment. Yet, neither consideration of financial factors nor psychosocial factors including sexuality and personal well-being were deemed most relevant for her. And it is not clear that she considered whether a constellation of such factors was sufficiently relevant to outweigh the importance of decreasing the chance of cancer recurrence.

Given her conversations with others and her intuitions, Macke felt that the most important variable for her was reduction of the likelihood of one outcome, cancer recurrence. However, it is not clear whether Macke considered a number of relevant factors that scholars believe might be relevant to HBOC decision-making. These factors are captured in the roots of the generic tree in Figure 7.6, although they cannot be individually discerned from that diagram. To see them, one must prune the decision tree by collapsing some of the branches. This has been done in Figure 7.7.

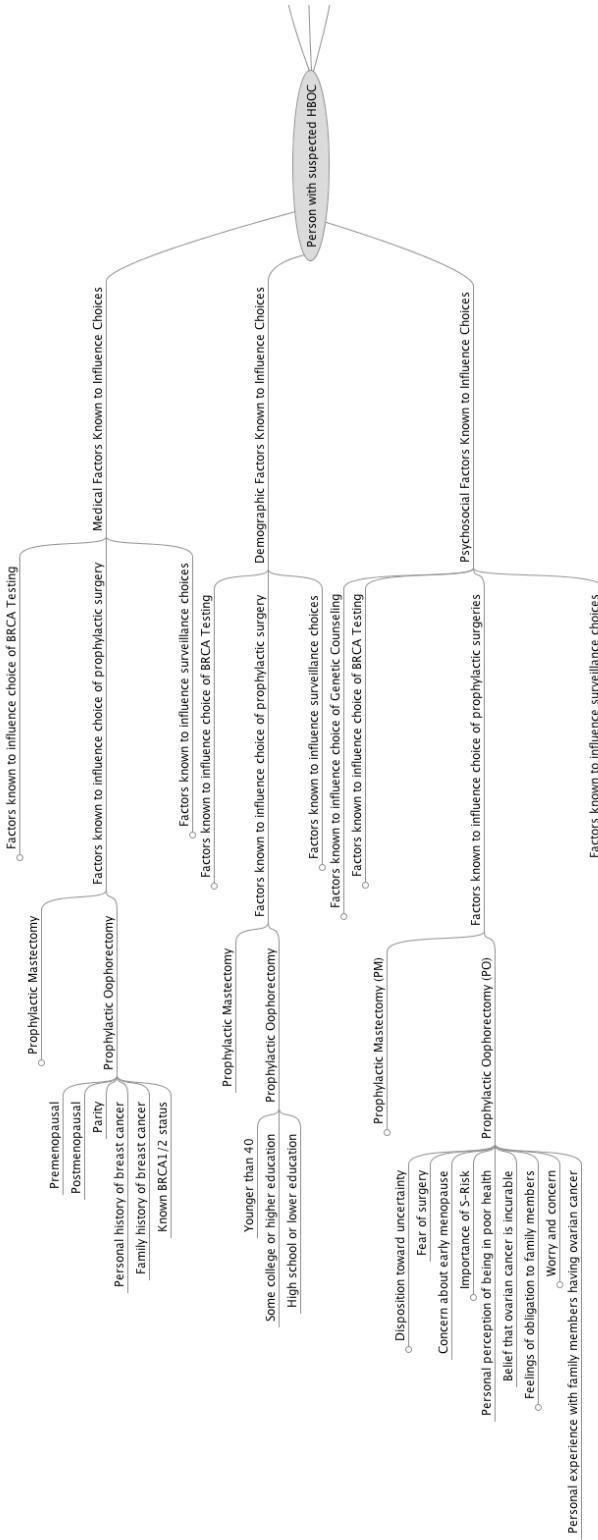


Figure 7.7: Partially foliated roots of a generic decision tree for HBOC, with an emphasis on the factors related to prophylactic oophorectomy decisions.

Figure 7.7 focuses on factors that researchers have investigated for their influence on choices relating to prophylactic surgery.⁹⁰ Looking at the psychosocial factors that may influence such decisions, we see an individual's disposition toward uncertainty, fear of surgery, the importance of their subjective knowledge of risk to them,⁹¹ feelings of obligation to family members, worry and concern, and other factors. Some of these factors admit of further distinctions. For example, obligations to family members include whether promises were made to dying family members, whether the agent feels obligated not to be a caregiving burden to another person, or whether the agent feels obligated to help raise children with a family member. Likewise, worry and concern includes worry and concern about both libido and about infertility.

Using this way of representing the factors that are relevant to choices, we can consider the limitations of Macke's decision-making in a new way. That is, we can ask whether Macke considered such things as what her personal disposition to uncertainty is, whether she perceived herself to be in poor health, whether she felt certain obligations to her family members, and whether she had personal experiences with family members who had ovarian cancer. We know from her narrative that she was certainly aware that family members had previously had ovarian cancer. But, we do not know if Macke explicitly considered the extent to which her interactions with these family members influenced her decision-making. It is also evident from Macke's

⁹⁰ The specific studies used to generate the generic HBOC decision tree were a subset of those covered in Table 5.1, including Anderson et al. 2006; Hallowell et al. 2004; Miller et al. 2010; Olaya et al. 2009; Staton et al. 2008; Prospero et al. 2001; Esserman and Kaklamani 2010; Ormondroyd et al. 2012; De Leeuw et al. 2008; Croyle and Lerman 1999; Braithwait et al. 2006; Lynch et al. 1997; and Eisen et al. 2000.

⁹¹ This is distinguished from "objective risk" or risk that is estimated objectively using genetic, computational, or other models, and risk that is perceived and reported by an agent irrespective of such estimates (Croyle and Lerman 1999).

narrative that she was discomforted by perceptions of being at increased risk for cancer, which is common for persons who have suspected HBOC. But it is not clear that Macke considered whether this feeling of being at increased risk, as distinguished from an objective assessment of risk, might have influenced her decision-making.

Macke did, however, consider the importance of a number of medical factors that, if present, have been shown to relate to HBOC decision-making. One of the guiding themes in Macke's narrative is her family's quest for information about their genetic status. She and her family members enrolled in a research study that predated BRCA testing. The results indicated that she and others had a mutation that would now be interpreted as a *BRCA1* mutation. She also considered her family history as well as her desire to have children, which is related to current and future parity. And, at the time of her double mastectomies, Macke was aware that she had cancer, knowledge that has been shown to influence choices of mastectomy and BRCA testing, which is captured by the roots of the generic HBOC decision tree but is not shown in Figure 7.7.

Thus, although Macke does not appear to have considered some information that was relevant to her decision-making, she did consider a significant amount of information. And she logically organized that information, exploring the possible relationships between the choices she faced, the outcomes that were likely, and the outcomes she strongly preferred. In this sense, Macke reflected on her circumstances carefully and thoroughly: she identified her options, their likely outcomes, and assessed their meaning for her.

Macke's reflection can be represented diagrammatically by using the generic HBOC decision tree as a starting point and pruning all nodes that were not considered in her decision-making. If we identify all of the nodes in the generic tree that lead to choices, outcomes, and factors that Macke *did not* consider, then each of these can be pruned by being collapsed. After

performing this exercise, the resultant diagram represents the information that Macke did consider. However, some of the items downstream of these nodes may not have been mentioned in Macke's narrative, although for each node at least one of them was. Thus this method overestimates some of the terminating nodes in the resultant diagram. In this sense it is overly foliated to some degree. Regardless of this overestimation, the resultant diagram provides a heuristic for qualitatively representing how much information Macke considered and her organization of it (Figure 7.8).

Having performed this exercise, we may now compare the tree in Figure 7.8 to the other decision analytic representations of choices in this chapter. Call this "Macke's tree." If we compare Macke's tree to the generic HBOC tree, then we see that hers is more pruned. Macke takes fewer downstream choices to be relevant for her, given her circumstances. However, Macke's circumstances are in a sense represented by the roots of the tree. And this shows that by comparison to the generic HBOC tree, her circumstances are also less complex, in that her roots are also more pruned. So, there is a certain balance between the level of pruning of the roots and branches of Macke's decision tree. Each are well foliated, which indicates that significant information was considered. But neither is as well foliated as the generic HBOC tree.

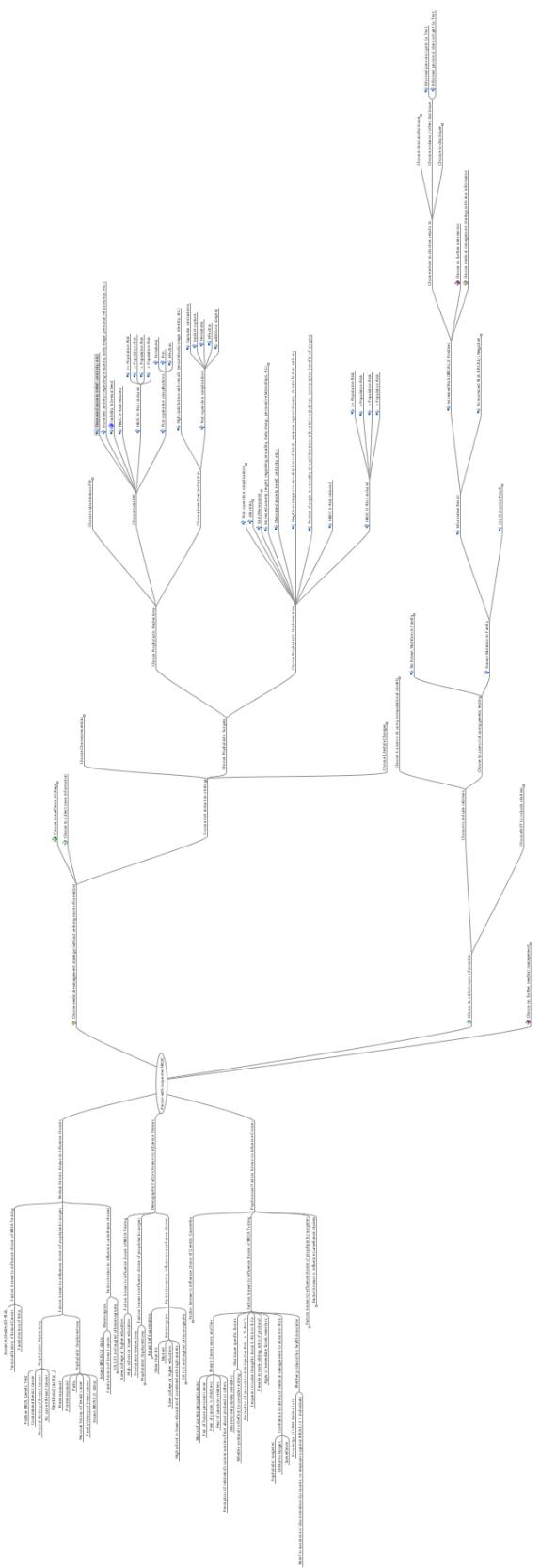


Figure 7.8: An HBOC decision tree pruned to represent Ellen Macke's choice.

And this is as one would expect in light of Macke's narrative. If, for the sake of argument, we take her narrative as a complete representation of her decision-making, then there are factors that she does not consider but that could have been relevant to her, given all that we now know about hereditary breast and ovarian cancer and decision-making related to it, but that she could not have known over fifteen years ago. And the diagram of her choice captures this; it shows that her tree is sparser in both directions than the generic HBOC tree. However, given the significant amount of information captured by the generic tree, this is not surprising. Even if the information could have been gained fifteen years ago, one would not have expected Macke to have considered that much information, because some of it was simply not relevant. Furthermore, some of the information was mutually inconsistent in ways that would make it incoherent to consider at the same time. One cannot, for example, have breast cancer and not have breast cancer. One also cannot both have no children and worry about disclosure of one's genetic testing results to one's children. And one cannot have breast cancer and at the same time elect to undergo chemo-preventative pharmacologic treatment.

Macke's tree may also be compared with Alicia's choice, when represented in decision analytic terms. The two are recognizably different. Macke's is larger and its structure is more logically well organized.⁹² Thus, if we suppose for the sake of argument that Macke's choice is a good one, then this is yet another way to capture the intuition that Alicia's choice is a poor one. Diagrammatically rendered into decision analytic terms and compared with a good choice, Alicia's appears to be deficient in the amount of information considered and the logical

⁹² This could be merely a feature of the different modeling practices that were used to generate Macke's tree and Figure 7.2. It might be the case, that is, that if we render Alicia's narrative in the fashion that overestimates in the way described above, Alicia's choice would look more well-organized and would include more information. Yet, the qualitative differences in Alicia's and Macke's narratives suggest otherwise.

organization of that information. Alicia's choice is therefore shown not only to be below an ideal threshold of information considered and logically organized, but also to be below a good threshold as well.

If one accepts the claim that Macke's choice was a good one, then I believe this provides a means for demarcating between a very high threshold of reflection for ideal medical decision-making and a lower threshold of reflection for good medical decision-making. On this account Macke's choice can be seen as prototypical of good decision-making, while also being seen as falling short of ideal decision-making. Ideal decision-making can then be defined as requiring reflection over all of the possible factors that might be relevant to *any* agent under circumstances like one's own. It requires considering all possible choices, all possible outcomes related to them, and evaluating all of these for a generic person, who is by definition one with widely varying possible circumstances because so little is known of her. Good decision-making can then be defined by contrast as requiring reflection over all of the factors that are relevant to one's own circumstances, all of the choices that are entailed by fully considering one's circumstances, all of the outcomes that are related to those choices, and evaluating all of these for oneself, given one's circumstances.

7.4 Medical Reflective Equilibrium

If the analysis of the previous section holds, then from it we may define an account of reflection in terms of reflective equilibrium for particularly medical circumstances. By introducing two types of skepticism above and following others in holding that only one requires consideration, we have been led back to the notion of reflection as of central import for justification of normative claims. And we have illustrated the meaning of sufficient reflection in medical choice

ostensively, by considering three different cases of choice, two of which were real – in that they were drawn from narrative reconstructions of actual events – and one of which was ideal. We thus have some understanding of the differences between ideal, good, and poor choices in medicine, or at least in HBOC decision-making. All that remains is to clarify the demarcation points between them in such a way that allows for generalization to medical decision-making in general, rather than HBOC decision-making in particular. This section will take those tasks in reverse. It first draws on the definition of reflective equilibrium given in the previous chapter to put forward an abstract, general account of *medical reflective equilibrium* (§ 7.4.1). Then it draws on a distinction between satisficing and optimizing accounts of choice from Herbert Simon to formalize the demarcation between ideal and good decision-making illustrated ostensively above (§ 7.4.2).

7.4.1 *Reflective Equilibrium in Medicine*

Chapter 6 reviewed the procedural account of ethical justification commonly known as reflective equilibrium in considerable detail. There I demonstrated that there are diverse views concerning what reflective equilibrium is. Some take it to be an ideal procedure for justifying particular normative claims that govern the actions of particular agents. That is, some take it as a procedure for rigorously and fully describing one's practical identity such that norms governing actions in one's circumstances follow. Others take it to be an ideal procedure for justifying higher order principles, from which we might derive lower order principles that will serve as norms to be used for generating action guidance for individuals or groups. Similarly, some take reflective equilibrium to be a procedure that a single person performs alone, while others take it to be a procedure that persons perform together when deliberating.

Although there are differences in how we might interpret reflective equilibrium, despite these, there is a common core to the notion. Recognizing this, I proposed a definition of reflective equilibrium in Section 6.1.4. There, reflective equilibrium is defined in terms of six sets of information and four procedures by which they are iteratively, and perhaps recursively, generated. Using this framework, we may define an interpretation of reflective equilibrium for medical circumstances, by interpreting these six sets of information and four procedures in a way that is consistent with the account of medicine given in Chapter 3 and the account of reflection in medicine given above. In the next section, it will be argued that this account of medical reflective equilibrium as a procedural approach for justifying ethical medical choices is also consistent with the description of medical decision-making systems provided in Chapter 5.

7.4.1.1 Reflective equilibrium reiterated

Reflective equilibrium may be described in terms of six sets of information and their relationships, described in terms of four sub-procedures for their production. Reflective equilibrium begins with an agent who makes initial moral judgments or $\{IMJ\}$. This set of information is then constrained by the agent's logico-epistemic standards, as the agent selects a subset of information contained in $\{IMJ\}$ based on which constituents of $\{IMJ\}$ meet those standards. The result is a second set of information, the agent's initial considered moral judgments or $\{CMJ_i\}$. The agent then explicates the constituents of $\{CMJ_i\}$. There is no shared definition of this step of "explication" across accounts of reflective equilibrium in ethics; however, it may be understood as a cognitive activity of abstracting away from the constituents of $\{CMJ_i\}$ to provide a summary of them as well as additional information from which they might relate as a derived claim relates to the more complex claim of which it is a derivation. What is important is that explication is taken to be a sub-procedure that results in the third set of

information, which is an initial set of moral principles $\{\text{MT}_i\}$. This set of information is then brought into coherence with $\{\text{CMJ}_i\}$. Thus, another sub-procedure – the engendering of coherence – results in a fourth set of information, the set of $\{\text{CMJ}_i\}$ and $\{\text{MT}_i\}$ after they are brought into coherence. This set is represented by the ordered duplet, $\langle \{\text{CMJ}_N\}, \{\text{MT}_N\} \rangle$, or an agent's considered judgments and moral principles at narrow reflective equilibrium.

As was discussed in the last chapter, narrow reflective equilibrium is widely regarded as insufficient for ethical justification. Consequently, understood as a procedure that is sufficient for this aim, reflective equilibrium includes additional steps. Next, the fifth set of information, initial background theories, is appealed to in order to check the quality of the duplet at narrow equilibrium. Proponents of reflective equilibrium also do not share a definition of this information. However, it can at least be understood as including any or all claims related to or derived from empirically supported theories or scientific models, represented by the set $\{\text{BT}_i\}$. A more precise account of $\{\text{BT}_i\}$ could be given, but this suffices to capture the notion of background theories as it is used in discussions of reflective equilibrium. Presumably, $\{\text{BT}_i\}$ is not infinite, so therein lies a final sub-procedure – the selection of the distinct constituents of $\{\text{BT}_i\}$ that are then used as further checks on the quality and relevance of the narrow set. The final step of (wide) reflective equilibrium is then to bring $\{\text{BT}_i\}$, $\{\text{CMJ}_N\}$, and $\{\text{MT}_N\}$ into coherence, forming an ordered triplet. The resultant set defines the conclusion of the reflective equilibrium procedure. It is a set of considered moral judgments, moral principles, and relevant background theories known as wide reflective equilibrium or $\langle \{\text{CMJ}_W\}, \{\text{MT}_W\}, \{\text{BT}_W\} \rangle$.

So understood, reflective equilibrium is constrained by the origins of two sets of information, $\{\text{IMJ}\}$ and $\{\text{BT}_i\}$. There are no routes within the procedure for incorporating additional information. Initial moral judgments are the starting point of reflection. And

background theories serve as additional, rather unconstrained sources of information that can be taken as relevant for reflection.

However, in addition to these two constraints on the content over which reflective equilibrium acts, it also includes other procedural constraints as described above. One of these procedural constraints arises initially, as $\{\text{IMJ}_i\}$ is constrained according to the agent's logico-epistemic standards. Another procedural constraint arises when the process of "explication" is performed to generate $\{\text{MT}_i\}$ from $\{\text{CMJ}_i\}$. A third procedural constraint is the bringing about of coherence, performed to reach narrow and wide equilibriums. The final procedural constraint is the selection of "relevant" background theories.

7.4.1.2 Medical reflective equilibrium defined

To develop an account of reflective equilibrium in medicine, I describe sets of information and procedures that are analogous to those in the generic account of reflective equilibrium. As with reflective equilibrium in general, we may say that there are two sources of information that constrain reflection in medical contexts. One is information from medical theory and allied sciences, which we may define loosely as *comprehensive biopsychosocial information* or $\{\text{CBI}_i\}$, which is an analogue to $\{\text{BT}_i\}$. Thus, one origin of information integral to reflection in medicine is the comprehensive background understanding of the persons who participate in medical care, including physicians, patients, and others, just so long as they are characterized objectively by empirical research. As the discussion in early chapters would indicate, the constraints on inclusion in this category are minimal. How we adjudicate what counts within it would thus be a very real and very important question. But it is one that is left open at the current level of abstraction.

The other informational constraint on reflective equilibrium in medicine arises from judgments made about particular persons, especially particular patients. Patients make judgments about their own health. For example, women with suspected HBOC make judgments about their personal risk of cancer, the impact prophylactic surgery will have on their sexuality and anxiety, and the impact learning their objective risk and disclosing it to others will have on their relationships with family members. Other judgments of a perhaps more pedestrian variety may be expected for different putative illnesses. Someone with a stomach bug may judge himself to be vomiting more than usual. He may be of the opinion that he feels feverish, cold, and achy. Or he may be of the opinion that he ate something that had spoiled and will be ‘back to normal’ after a good night of rest.

Others also make judgments about particular patients in medicine. One presumes health care providers routinely make a wide range of judgments about patients, many of which are related to the reasons that patients are in medical care and some of which are not so related. Family members also make judgments about patients. And representatives of health care institutions, including insurers and hospitals make judgments about patients. In Macke’s case, for example, she communicated with a number of people during the process of making medical decisions (Table 4.2). We can assume that each of these persons made judgments about Macke’s health. And we know that many of them communicated some of those judgments while participating in her medical decision-making.

I propose to call these judgments *health judgments*. In medical reflective equilibrium, they stand in the procedure as initial moral judgments stand in reflective equilibrium for justifying ethical claims. Thus, the set {HJ} in medical reflective equilibrium is analogous to the set {IMJ} in reflective equilibrium.

However, as I conceive of medical reflective equilibrium, there are two crucial differences between the set of health judgments and the set of initial moral judgments that strain the analogy between them. Initial moral judgments are understood to be the judgments agents form initially with regard to some ethical matter under certain circumstances. Thus, the judgments appear to arise in response to specific circumstances; they are not described as privileged ethical intuitions that agents bring to bear whenever circumstances arise that warrant moral perception. Beyond the obvious point that health judgments are not about ethical circumstances but about health, and in particularly medical circumstances, health judgments also differ from initial moral judgments in that they are not “initial.” As I conceive them they do have basic normative content, irrespective of the circumstances that provoke them.

It seems inappropriate to conceive of health judgments as “initial” responses to some circumstances because, as we saw in Macke’s and Alicia’s cases, individuals who make health judgments do so over time and in light of experiences that may have happened at widely divergent times in their lives. Likewise, as we saw in the case of Dr. Bear and Ms. Roth (§ 5.5.2.3), physicians often make health judgments based on the reports of others as well as judgments based on their discussions with patients, clinical examinations of them, and other information. Thus, the qualifier, “initial,” is inapt for health judgments because it spuriously connotes a temporality to the judgments that is inappropriate in medicine.

Furthermore, the way initial moral judgments are described in the case of reflective equilibrium suggests that the set {IMJ} is empty before the judgments arise under the specific circumstances of reflection. If this is the case for {IMJ}, it is not the case for {HJ}. Given that health judgments are defined as pertaining to a specifically medical context, the set is never empty. It at least includes some basic assumptions about that medical context. That is, it

includes claims that demarcate the set {HJ} from other conceivable sets, such as the set of mere judgments, {J}, or the set of judgments about the weather {WJ}. Although these latter two sets are fancies, they nevertheless serve to make the point: health judgments are about something and they are related to a particular context. They are about a person's health and they are made in the context of health care.

In Chapter 3 I defended a particular account of the conceptual foundations of medicine, which I argued provided a way of characterizing the uniquely medical circumstances for which the model of choice under development would be applicable to. Those conceptual foundations take the form of two Basic Aims, which I argue capture the basic goals of medicine well. Drawing on that analysis, I contend that the Basic Aims may be reiterated here to define medical reflective equilibrium. In order to do so, I suggest that the set of health judgments be understood as containing a privileged set of information, namely, a definition of the basic aims of medicine. These aims constrain the actions of participants in medical care because they provide a description of the aims of care. Thus, {HJ} should be understood as containing the Basic Aims defined in Section 3.1, and they serve as basic principles that may govern the actions of participants of care, including patients, physicians, and others.

Characterizing the Basic Aims as privileged constituents of the set of health judgments radically constrains {HJ} in ways that {IMJ} is not constrained. Recall that Aim I is to fully describe the patient's condition objectively and subjectively, while Aim II is to treat the patient via means that are consistent with the patient's state of health, as defined in Aim I. If {HJ} is understood as containing these aims, then this means that as the sub-procedures defined above are performed on {HJ} meeting these aims will be required in order for {HJ} to be fully populated. Thus, whereas an agent performing reflective equilibrium begins with initial moral

judgments that must meet certain logico-epistemic standards before being used as the basis for generating $\{\text{CMJ}_i\}$, an agent performing medical reflective equilibrium begins with health judgments that must meet both logico-epistemic standards and the standards entailed by having certain basic goals, the goals of medicine.

Just as with reflective equilibrium, in medical reflective equilibrium $\{\text{HJ}\}$ and $\{\text{CBI}_i\}$ constitute the two sets that constrain how information can enter into the procedure. Yet, merely identifying $\{\text{HJ}\}$ and $\{\text{CBI}_i\}$ does not complete the description of medical reflective equilibrium. Other sets of information are also necessary, although they require less description since they are more clearly analogous to constituents of reflective equilibrium than $\{\text{HJ}\}$ and $\{\text{CBI}_i\}$ are.

Medical reflective equilibrium begins with $\{\text{HJ}\}$, though these are not “initial,” as was mentioned above. Then an agent filters or adds to $\{\text{HJ}\}$ in accordance with the extent to which its members meet its logico-empirical standards, which are subject to the additional constraints conferred by including the Basic Aims of medicine as privileged, but defeasible, constituents of $\{\text{HJ}\}$. The remaining judgments may be called *considered health judgments*, forming the set $\{\text{CHJ}_i\}$. Next, the agent formulates a set of *particularly salient information* that explicates the members of $\{\text{CHJ}_i\}$. Just as the moral principles in $\{\text{MT}_i\}$ are understood as summarizing the constituents of $\{\text{CMJ}_i\}$ while also serving as claims from which they might be derived, particularly salient information may be understood as information from which the members of $\{\text{CHJ}_i\}$ could be inferred, but which also serves to describe $\{\text{CHJ}_i\}$ more tersely. This set may be represented as $\{\text{PSI}_i\}$. The next step in medical reflective equilibrium is then to check that in explicating $\{\text{CHJ}_i\}$ nothing is missing, nor has anything been inaccurately misrepresented. That is, $\{\text{PSI}_i\}$ and $\{\text{CHJ}_i\}$ are brought into coherence, which includes adjudicating logical

inconsistencies between members of the sets by either introducing new terms from $\{HJ\}$ that show them to be consistent or removing one of the pairs of inconsistent terms in accordance with which of the remaining pairs is more consistent than the other. The result is an analogue to narrow reflective equilibrium in medicine (NREM) or $\langle \{CHJ_N\}, \{PSI_N\} \rangle$.

The final steps of medical reflective equilibrium are familiar. One then selects relevant information from the comprehensive biopsychosocial information and brings it into coherence with the duplet formed at NREM. This results in *wide reflective equilibrium in medicine* (WREM) or simply medical reflective equilibrium. Altogether, the procedure may be schematized as follows:

- (0) An agent (A) begins in the initial state, with a set of *health judgments*, $\{HJ\}$.
- (1) In the first step, A filters and adds to $\{HJ\}$ according to the extent to which individual members of the set meet its logico-epistemic standards and the Basic Aims of medicine. The remaining judgments may be called *considered health judgments*, forming the set, $\{CHJ_i\}$.
- (2) In the second step, A formulates a set of *particularly salient information* that explicates the members of $\{CHJ_i\}$, forming the set $\{PSI_i\}$.
- (3) In the third step, A brings $\{CHJ_i\}$ and $\{PSI_i\}$ into coherence by considering the extent to which members of each set are consistent and selecting for satisfactory logical consistency. The resulting ordered pair is said to be in *narrow reflective equilibrium in medicine* (NREM), represented as: $\langle \{CHJ_N\}, \{PSI_N\} \rangle$.
- (4) In the final step, A considers additional sources of information, represented as the set of *comprehensive biopsychosocial information*, $\{CBI_i\}$. Once this information is brought into coherence with the previously coherent ordered pair, the resulting ordered triple is said to be in *wide reflective equilibrium in medicine* (WREM), represented as: $\langle \{CHJ_w\}, \{PSI_w\}, \{CBI_w\} \rangle$.

If we understand medical reflective equilibrium as a way to further specify what it means to adequately reflect on one's circumstances when making medical choices, then the procedure may be understood as providing normative constraints for the model of medical decision-making under development. On this view, medical reflective equilibrium describes a

type of reflection that is adequate to justify the claims made on agents when making medical choices. It is thus a way of describing reflection sufficiently to meet the objections of the reasonable skeptic. Recall that this skeptic recognizes that reflection is something that persons do when making choices but does not believe that it alone is adequate to the justificatory task. However, by specifying a particular type of reflection that is up to the justificatory task, as I believe medical reflective equilibrium is, the reasonable skeptic's concerns may be met. Of course, whether this is the case will depend on whether the reasonable skeptic agrees that this account of reflection is up to the task of justification. There are reasons to think she would not.

7.4.2 A Satisficing Threshold for Ethical Medical Choice

The reasonable skeptic might respond to this depiction of ideal choice by objecting that even if the representational conventions proposed above are accepted for the sake of argument, it remains entirely unclear how appealing to these abstractions amounts to a justified account of reflection in medicine. It seems, she might continue, that the two particular concerns discussed in the last chapter remain in play and have yet to be adequately met. That is, on the reflective procedure just described there are still only two sources of information that constrain it. Furthermore, although four procedures have been enumerated for transforming that information, the procedure still rests on coherence and coherence-like selection procedures. And it is not clear just what these constraints amount to. They could enshrine poor quality information or require such a significant amount of searching that considering enough information would paralyze the agent performing the procedure. In other words, the reasonable skeptic can simply reassert the no guarantees objection against medical reflective equilibrium.

This is a serious objection to the account given here, and it can only be responded to in stages. In this sub-section I argue that distinguishing between optimizing and satisficing choice

provides one route to responding to it. As I envision it, reflection in medical choice requires consideration of information that meets only a satisficing standard, not an optimizing one. If we understand choice this way, then it provides a means of replying to concerns about supercomprehensiveness. This threshold of consideration, that is, does not require agents to consider all possible information, though it does require them to consider a sizeable amount of information. Yet, making this move to respond to the skeptic further underscores the importance of the idiosyncrasy objection, which is discussed in the next section.

7.4.2.1 Satisficing versus optimizing

A distinction between satisficing and optimizing choice may attributed to Herbert Simon, who is also known for re-introducing the term “satisficing” into the English language (Simon 1956). It has been argued that Simon’s interest in the concept of satisficing predates his use of the term by almost a decade (Brown 2004). Regardless, it is clear that Simon became preoccupied with the concept after he first described it, and spent much of his subsequent scholarly efforts endeavoring to better characterize it and show its usefulness for understanding an extraordinarily wide range of cognitive and behavioral phenomena. For our purposes, considering the nature of the distinction as it applies to decision-making, and in particular what it says about constraints on choice, will be must useful.

As Simon describes satisficing, the concept can only be understood by contrast to its alternative, an optimizing or maximizing account. What is important are the assumptions that lie behind this alternative account of choice, which arise within the context of rational choice theory in economics. According to Simon, the theory “underlying neo-classical economics postulates that choices are made: (1) among a given, fixed set of alternatives; (2) with (subjectively) known probability distributions of outcomes for each; and (3) in such a way to

maximize the expected value of a given utility function” (Simon 1997, 291). Thus, this theory assumes that when making choices agents know all of the possible alternatives and they are fixed. It also assumes that all outcomes are known, as are probability estimates for them. Finally, it assumes that all outcomes have been evaluated, which is represented by their having explicit utility values or by those values being readily derived from the agent’s utility function that ranges over the outcomes, under the conditions of choice. In other words, rational choice theory assumes that for any given decision-making circumstances agents are able to identify all of the options in the abstract variables represented by the generic decision tree in Figure 6.3 and define all of the variables therein, under those circumstances.

In response to these assumptions, Simon proposes that they are unlikely to be true of actual decision makers, the persons whom economic models may be taken as applying to. Thus, he suggests that an alternative account of rationality is appropriate, which he famously terms “bounded rationality,” and which we will not be able to do sufficient justice to in this brief presentation (see Gigerenzer 2010). In brief, Simon proposes,

Theories of bounded rationality can be generated by relaxing one or more of the assumptions of [neo-classical] theory. Instead of assuming a fixed set of alternatives among which the decision-maker chooses, we may postulate a process for generating alternatives. Instead of assuming known probabilities, we may introduce estimating procedures for them, or we may look for strategies for dealing with uncertainty that do not assume knowledge of probabilities. Instead of assuming the maximization of a utility function, we may postulate a satisficing strategy. (Simon 1997, 291)

Where rational choice theory assumes that agents make choices by *maximizing* or *optimizing* a particular value, says Simon, bounded rationality postulates that agents make choices another way, by *satisficing*.

Following Simon, we may define optimizing decision-making as choosing the best available alternative according to a single criterion (*ibid.*, 295). That is, an optimizing choice occurs when a decision-maker identifies a specific criterion – usually the maximization of utility or value – and then chooses the single alternative meeting this criterion. Optimizing choice is computationally costly, because it requires sampling all possible alternatives; and it also requires evaluating all outcomes relative to one another in light of the single criterion of evaluation and selecting the best one. In the case of maximizing utility, optimizing choice requires assuming that decision makers know all possible alternatives and are fully (perfectly) informed about the probabilities of outcomes and their utilities. Only if this is the case can a decision-maker be said to maximize utility, for if a probability estimate or utility value is unknown, then it is impossible to say whether the expected value of an outcome is higher or lower than others. Consequently, any choices that terminate with this outcome may have higher or lower expected values than other alternatives simply because they are left undefined in the computational sense. Thus, without full knowledge and the computational capacity to calculate values, optimizing is not possible.

Given the notorious lack of empirical support for this account of choice (see *ibid.*, 319-335), Simon puts forward an alternative. On this view, we assume knowledge is incomplete, computational capacities are limited, and thus, that maximizing a single criterion is an inadequate normative and descriptive account of choice. Or in other words, “theories of bounded rationality...insist that the model of human rationality must be derived from detailed and systematic empirical study of human decision-making behavior in laboratory and real world situation[s]” (*ibid.*, 294). And what this systematic study shows, he concludes, is that computational complexity, limited resources, multiple (competing) objectives, sub-optimal

knowledge (of probabilities or evaluations), and multiple criteria of evaluation are the norm in decision-making across environments. Each of these constrain choice, making optimization impossible under natural conditions. As he notes,

Faced with a choice situation where it is impossible to optimize, or where the computational cost of doing so seems burdensome, the decision maker may look for a satisfactory, rather than an optimal, alternative. Frequently, a course of action satisfying a number of constraints, even a sizeable number, is far easier to discover than a course of action maximizing some function. (*ibid.*, 295)

When a decision maker satisfies a sizeable number of constraints but does not seek to satisfy all possible constraints, then that decision maker is “one who chooses an alternative that meets or exceeds specified criteria but that is not guaranteed to be either unique or in any sense best, [it is one who] is said to satisfice” (*ibid.*, 295).

Now, satisficing is not a panacea. It is useful for providing an alternative to an optimizing account of choice that guides decision makers to search through all possible information, evaluate all possible options, and estimate probabilities for all possible outcomes. Thus, it provides a lower and more reasonable standard for information search, selection, and integration. But it remains unclear what that standard amounts to in general.

According to Simon, one can imagine a “satisfaction criterion” for deciding when satisfactory alternatives have been identified in a context of choice. This criterion can be weaker than the criterion of all possible information that is assumed under a rational choice framework. If one adopts a bounded rationality framework, that is, then, “the criterion can be multifaceted, without a need for comparability across facets...the list can be as long as we please, and there is no need to specify how much of one of these requirements would be traded off for a given improvement in another” (*ibid.*, 323-324). What determines how long the list will be and what

trade offs will be legitimate will depend on the empirically known and knowable constraints under the circumstances.

Thus, by adopting a satisficing criterion for discriminating between relevant and irrelevant alternatives or information, and discerning when it is prudent to stop searching for more alternatives or information, one thereby adopts a highly contingent account of choice. The thresholds are determined largely by the context of decisions and by the computational capacities of decision makers. Some environments will warrant longer lists than others. Some decision makers will be less capable of computing the value of trade offs than others. And this will depend upon empirical investigations of those environments and agents who make choices.

7.4.2.2 Satisficing and supercomprehensiveness

The reasonable skeptic might think my account of medical reflective equilibrium requires an optimizing threshold of choice, where agents must sample all possible information, identify all possible options, assess the values of all possible outcomes for the patient under consideration, and estimate probabilities for all possible outcomes. However, this is not the case. And this can be readily understood by appealing to a satisficing threshold for information search, sampling, and integration in the medical context.

As we have defined it here, “the medical context” is defined in terms of the Basic Aims of medicine, which I have argued provide a description of what is uniquely medical about the sorts of decisions that have preoccupied us in this analysis. Simon’s account of bounded rationality postulates that agents choose in the face of enumerable constraints, and this is why neo-classical theories of choice are inapt: they fail to accommodate what is known about the limitations of decision makers. In the case of medical choice, the Basic Aims may be reiterated once again as a means of providing initial epistemic constraints on choosing. They postulate a

kind and an amount of information that must be gathered for a choice to meet the basic goals of medicine. These goals may be discovered or reasoned to be inapplicable to a particular set of circumstances. However, by placing the Basic Aims as privileged information in {HJ}, this represents their priority; they are taken to be constraints on choice that are strong, and that absent overriding information must be met. But they are constraints that may be removed under appropriate operations of the reflective equilibrium procedure.

In addition to the Basic Aims, the account of choice above also recognizes other constraints on medical decision-making. These include the procedural constraints of coherence, logico-epistemic standards that are coherence-like if they are distinguishable from coherence at all, and the explication step that transforms {CHJ} to {PSI_i}. The constraints also include the comprehensive biopsychosocial information {CBI}, which is a potentially redundant and vast threshold of information that must be met, although it is one that requires its own selection procedure of “relevance” discussed above.

Each of these constraints must be interpreted with some empirical content in the case of an actual decision, just as Simon described the generation of lists in light of empirical knowledge of the environment and cognitive capacities of choosers under some circumstances. Consider the case of HBOC. To make a good HBOC decision requires conversing about the factors that one could anticipate being relevant to the circumstances. This requires sampling information from a comprehensive list of known factors that bear on or influence choice, for example, as represented in Table 5.1. And this may be represented as {CBI}. Only in cases where this information is considered may choices be good. However, this does not necessarily require considering as much information as is depicted by the generic HBOC decision tree in Figure 7.6. Rather, as in Macke’s case, only a subset of that information will be relevant. And

what is relevant can only be determined after enough information has been searched for. What further constrains determining how much information is enough is additional empirical information, such as what factors are known to influence choice and the subjective information shared by a candidate for HBOC with her family, friends, providers, and others, as was described in Macke's case. Thus, in the case of good HBOC decision-making, we should see just what Simon suggests when describing a satisficing criterion for information search, sample, and integration. We see the consideration of a significant amount of information, and enough information to be consistent with the Basic Aims. But we do not see a consideration of all possible information.

The reasonable skeptic may object to this account. She might, for example, remain unconvinced that this is consistent with what we should expect of agents who are making decisions. She might agree that satisficing does set a threshold of information required to make choices that is sufficient to meet concerns about supercomprehensiveness, but nevertheless think that it demands too much of the people who will be making the medical decisions that medical reflective equilibrium is supposed to apply to.

My response to this worry is that the sorts of agents who make medical decisions are those that were described in Chapters Four and Five. They are distributed medical decision-making systems. They are groups of persons who collect, process, share, and transform information together. And they do so with the aim of making a good medical choice for a particular patient under particular circumstances. Furthermore, in committing themselves to such aims, they may be described as working together to meet the Basic Aims of medicine.

Now of course, a rejoinder may follow from the reasonable skeptic. She may acquiesce to the view that sheerly by reiterating this description of medical decision-making systems the

concerns about supercomprehensiveness may be met by also accepting a satisfying criterion for information search, selection, and integration. However, the reasonable skeptic may reply that it is unclear why a group of persons should be the proper referents of “an agent (A)” in medical reflective equilibrium, rather than a single individual. She might accept, then, that persons predominantly *do* make choices in groups. But she would follow to ask whether they *should*. To answer this question requires embracing the second aspect of the no guarantees objection. Idiosyncrasy, that is, is an important worry for medical reflective equilibrium. However, it may be responded to by requiring that certain sorts of individuals work together in making medical choices. Thus, by considering idiosyncrasy again in the particularly medical context of medical reflective equilibrium, I believe we arrive at the normative importance of social interaction in medical choice.

7.5 Medical Decision-Making as a Social Activity

When we consider Ellen Macke’s decision-making and find it to be good, this suggests a rather simple intuition, that to be good others should decide like Macke did. Whether this simple response is justified depends on its particulars. What does it *mean* to decide like Macke did? That is, what aspects of Macke’s decision-making process make it good? What aspects of her choice ought to be emulated? And what aspects are those for which emulation would be irrelevant when striving to make a good choice?

I have argued that what was good about Macke’s choice is that it considered a sufficient amount of information. Given my arguments, what I mean by this is that Macke’s choice met the Basic Aims of medicine, and that it did so in a way that can be described as being sufficiently reflective. The level of reflection this requires, I have further said, is not that of the

rational optimizer, or one who maximizes the expected value of outcomes, subsequent to searching for all possible information and ordering it in terms of a single criterion of value. Rather, a more reasonable threshold for information search, selection, and integration defines sufficient reflection for medical choice: it may be defined as a satisficing threshold.

A question remains, however, regarding whether this account of reflection in medical choice is one that can be met by other agents, even distributed cognitive ones. It might be the case that – even if one accepts that contentious description of decision makers – agents who make medical choices will often or sometimes fail. If so, then there is no guarantee that medical reflective equilibrium will lead to laudable choices at equilibrium. Rather, it may or it may not, depending upon what information the procedure begins with and what information is accessed as it is performed. That is, granting for the moment that my account of medical reflective equilibrium is sound and my descriptive account of choosers holds, it may nonetheless result in the enshrinement of idiosyncratic, blameworthy choices.

This is indeed an important worry. Responding to it requires first reconsidering the sense of skepticism that motivates it and further distinguishing it into subsidiary worries (§ 7.5.1). Then, I argue that either the skeptical response amounts to a request for empirical validation of my model or a commitment to a particular thesis concerning the irreducible subjectivity of evaluative language (§ 7.5.2). My response to this is to accept the request for empirical validation and to dispute the substantive thesis about the nature of normative language (§ 7.5.3). Consequently, I conclude that although the skeptic may remain unconvinced by my argument, ultimately her position rests on contentious premises regarding the nature of practical reasoning. I leave it to the reader to accept or reject the skeptic's account. If she rejects it, then this marks in favor of my view.

7.5.1 Two Interpretations of Idiosyncrasy for Medical Choice

Above, I considered two types of skepticism, which I termed reasonable and unreasonable skepticism. Recall that the unreasonable skeptic was described as such because she refuses to accept her own use of ethical discourse. She is portrayed as being compelled to choose a stance that is apparently practically irrational or to accept that she cannot meaningfully use moral language. The skeptic, that is, either can refuse to engage in ethical discourse, and thus espouse complete practical normative skepticism, or she can recognize her own use of typical normative language. If she chooses the latter, then by doing so she commits to the view that others can understand her terms, others can reflectively evaluate her moral claims, and others can come to share her reasons and conclusions. Or others can reject her moral claims and engage in disagreement with her.

If the skeptic has gone this far, then she succumbs to arguments like Korsgaard's. She must admit that *she* takes herself to reflect upon, assert, and endorse normative discourse, and thus, normative commitments. And in accepting this, she will be compelled by argument to accept that there are sources of normativity. Thereafter, the issue is what justifies normative claims, not whether they are justifiable. And hence, upon pain of forsaking her commitment to being able to reflectively endorse her own reasons for actions, she must accept that justification is possible. And so, she must be reasonable about her skepticism. She must at least accede it is possible to sway her with justification. But yet the question remains of whether she will accept a given justification.

A similar strategy can be deployed in order to persuade the skeptic that the procedure of medical reflective equilibrium provides justified action guidance for an individual who faces a

medical choice. We may ask, that is, what the skeptic's response to participating in medical choice might be. She might, as empirical studies discussed in Chapter 2 suggest, exhibit any of a range of preferences regarding her involvement in choice. She might seek information or she might not. She might want to be responsible for making decisions or she might not. Her preferences might also lie in between these poles. That is, she might adopt any number of positions regarding how, for her, decision-making ought to go.

What is important, however, is that the skeptic has a view on the matter. If the skeptic can perceive herself as a participant in decision-making, then she can recognize the importance of deliberating about the factors involved in a particular choice. She can see herself, that is, having preferences and values that relate to outcomes that might follow from her predicament. If the skeptic can agree that this is the case, then presumably she can agree that her preferences and values matter, that it is important to take them into account when making medical choices. As such, the skeptic can see that sharing information about her assessment of the past, present, and future circumstances is an important component of reflectively choosing while receiving medical care.

If the skeptic can go this far with me, then she must accept that reflection is important for good medical decision-making. So Korsgaard's strategy pays off because it compels the skeptic to recognize the importance of reflection. But, there are any number of ways to reflect and it is not clear that in accepting the importance of reflection the skeptic must accept the account of wide reflective equilibrium in medicine I have argued for. The skeptic may believe an alternative approach to justification is better or simply doubt that WREM will work.

By worrying about idiosyncrasy, the skeptic appears to be worrying about the latter: she appears to doubt the possibility that the medical reflective equilibrium procedure is instantiable

in practice. It is not that the skeptic has an alternative account of justification. Rather, she worries that in practice people will be unable to search, select, and integrate information in the way required by medical reflective equilibrium. Thus, their resulting “equilibria” will merely be a composite of their idiosyncratic and unjustified views.

As a practical worry, I cannot adequately respond to this question. To assert that medical reflective equilibrium is guaranteed to produce a set of laudable, justified judgments at equilibrium would be to overstep the argument. It would be hubris. Whether the action guidance generated by medical reflective equilibrium indeed results in such judgments is an open, empirical question. It cannot be settled by argument over the nature of the procedure, the nature of normativity, or the nature of skepticism. Rather, it may only be settled by additional argument based on testing whether the procedure is instantiable, and if so, what its effects are. The way to overcome this skepticism is to generate an operational account of medical reflective equilibrium that can be tested and to see its results. Only with results showing the positive effects of medical reflective equilibrium might the skeptic thus be swayed.

However, the skeptic’s position is not intended to be an empirical skepticism. As Korsgaard and others characterize it, reasonable skepticism amounts to a conceptual objection; it espouses a claim about the nature of the justification, the nature of how participants in deliberation might sway one another by giving reasons. The skeptic appears to hold that although she proffers and accepts reasons, reasons may nevertheless fail to justify. And this is a global worry. The skeptic appears to hold there is something about the nature of reasons that makes their efficacy in argument always an open question.

7.5.2 Two Ways to Be Skeptical About Evaluative Information in Medical Choice

Understanding the skeptic in this way suggests that there is another interpretation of idiosyncrasy than that it is an empirical worry. The skeptic may be interpreted as making a conceptual claim about the nature of the information that the medical reflective equilibrium procedure acts upon. That is, the skeptic may be understood as worrying that there is something about the kind of information that must be searched for, selected, and integrated that makes it conceptually impossible to bring that information into coherence.

I see two forms that this worry takes. On one, the skeptic might worry that a single individual will be unable to fully describe herself in both objective and subjective terms because this requires a certain duality of perspective that we should not expect agents to be able to adopt when making choices for themselves or others. The skeptic doubts, that is, that the individual or anyone else will be able to keep the “double set of books” Misak suggests are needed to improve our understanding of ethical medical choice. Thus, if an individual cannot fully describe herself, she will be unable to meet the Basic Aims or the satisficing threshold. Consequently, the procedure will not reach a terminal state, and the individual will be left with a set of judgments that has not been sufficiently reflected upon.

I agree with the skeptical intuition here. And I have given evidence in Chapter 2 in support of the view that neither physicians nor patients nor surrogate decision-makers are going to be equipped to perform medical reflective equilibrium alone. To adequately perform medical reflective equilibrium other participants will be necessary, because of the epistemic differences in the type of information that is required to meet the Basic Aims and the amount of information that is required to meet the satisficing threshold.

Yet, if this is so, then a response to this aspect of the skeptical concern is available in theory. Medical reflective equilibrium should be performed by groups of persons interacting with cognitive tools or artifacts. The number of elements brought into a decision-making system should be determined by the complexity of the choice, as it emerges. If meeting the Basic Aims requires that a significant amount of information must be collected about the patient in both personal and scientific terms, as is the case in hereditary breast and ovarian cancer, then the number of elements required will be higher than if the choice is less complex. In such cases the doctor-patient dyad will not suffice. In less complex cases it will. However, in all cases it is assumed that at least some artifacts will be required to describe the patient's state of health in scientific terms, if not also in personal terms. Thus, understood as a distributed cognitive system, it is unlikely that a dyad will suffice for successfully performing the medical reflective equilibrium procedure if artifacts are also modeled as part of the system.

This response underscores the second form of the worry that there is something about the kind of information that must be searched for, selected, and integrated by the medical reflective equilibrium procedure that makes it conceptually impossible to bring that information into coherence. The reasonable skeptic may doubt that people can communicate in a way that facilitates the requested integration of information. She may feel that when she makes claims about the state of affairs she is offering her idiosyncratic opinion. And this is especially true if we are thinking about her assessment of the value of a particular outcome when participating in a medical decision-making system. She may, for example, hold that it is not right to disclose information to a teenager about her mother's increased risk of breast cancer. She may disvalue this action, that is. And this could be so irrespective of what role the skeptic envisions herself

taking in the decision-making system. She may be a caregiver, a provider, or a patient, and still disvalue sharing such information in this way.

To put it another way, the skeptic may take a reasonable position on the issue of whether one has a “duty to disclose” her test results to teenage minor children and other such ethical issues. And she may believe it is possible to share her view with other persons, including participants in decision-making. But she may nevertheless doubt – and doubt strongly – that it is possible for other participants in deliberation to do much with her view. She may not believe, that is, that her evaluation can be seen as a piece of information, as something that another person can corroborate or discredit. She may believe that such information is an ineliminably partial report of ineffable personal feelings that are codified in ones personal ethics, but that cannot be criticized by others because of its incorrigibility. Thus, the skeptic may worry that medical reflective equilibrium will be guaranteed to result in idiosyncratic views because it is not possible for others to criticize her values, her assessment of the current or possible future states of affairs. Thus, it is not possible to perform the procedure as I have envisioned it because there is a certain incommensurability between the way one participant describes the circumstances in value-laden terms and another participant describes them.

7.5.3 On Ethical Deliberation in Social Groups

My response to this skepticism has been anticipated elsewhere in this work. I have already defended a view of the epistemological foundations of medicine in terms of two different types of claims, and I have already intimated that there is a certain incommensurability between them. I claim that at least in discourse about a patient’s well-being, when one makes subjective claims one is reporting on how things seem from an ineliminably first-person perspective. Once one deliberates with another person about the state of affairs, this act of deliberation entails that the

other person may criticize, dispute, reject, accept, or endorse one's terms. These disputative activities, I claim, are the ways in which we grant some level of objectivity to our subjective claims about health and related matters. They are the ways subjective claims become objective claims, by being rendered in shared terminology that multiple agents agree is in some sense a veridical representations of the state of affairs.

Thus I concede that skepticism presents a real worry. However, I am not convinced that this skepticism is distinctly an issue for evaluative language. In Chapter 3 I argued that scientific terms are themselves value-laden, and thus, that to think of a strict distinction between science-as-objective and art-as-subjective is inadequate. Rather, there are many ways to generate objective claims, one of which is by mere stipulation, by agreement under the circumstances. This is perhaps the weakest form of objectivity, but it is a form of objectivity nevertheless. It remains distinct from subjective claims.

But by making this concession to the skeptic, I do not thus agree that this subsidiary interpretation of idiosyncrasy is valid. Rather, by making this concession, I have pinpointed the issue for the skeptic, which I take to rest with whether evaluative language may properly be the subject of rational criticism. The skeptic would see all evaluations of outcomes in medical decision-making as irreducibly subjective, as only communicable using subjective claims. However, I dispute this. I believe that evaluative language about what is good, bad, right, wrong, or permissible – including discussions of morality and ethics – may be objective in at least the weakest sense. Moreover, I take it that if I can persuade the reasonable skeptic to believe this, then all that is left of the idiosyncrasy objection is a request for empirical validation of my account. If so, then the reasonable skeptic and I agree.

To persuade the skeptic that evaluative language may properly be the subject of agreement and disagreement is to convince her that evaluative language is structured such that it is open to rational criticism. In recent work, Misak has argued for this view in light of her personal experiences making medical choices. Through considering her account of the role of first-person narrative in ethical deliberation, I aim to at least show the skeptic that she makes substantive commitments about evaluative discourse that run counter to our conception of deliberative reflection. In ordinary language, “deliberation” may be understood in terms of personal and group reflection because the word has two senses. Deliberation has a first-person sense of reflective cognition and a third-person sense of the participation of an individual in a reflective group.⁹³ My aim here is to provide an account of the second sense of deliberation and to capture the ways that reflective agents can share information when making ethical medical choices. I contend that to do so we should both make subjective claims and also render these claims in objective terms as we come to agreement on shared terms while deliberating together.

Recall from Section 7.1.3 that Misak experienced ICU psychosis and other ills subsequent to treatment for ARDS and multiple organ failure. While hospitalized, Misak hallucinated that she was being raped and tortured by her providers. As she initially recovered in the hospital, and later at home, she struggled to make sense of her experiences. She was led to discount the credibility of her experiences and her judgments of the state of affairs she perceived by discussing her care and experiences with family members and others. Ultimately, this moved her to argue against the current emphasis on autonomy-based informed consent and

⁹³ This duality is captured in the definition of “deliberation” and cognates like “deliberate” and “deliberative.” See, for example, the *Oxford English Dictionary*.

for a more multifaceted view of medical decision-making based in part on recognizing the experiences of patients in contexts like critical care (Misak 2005).

Misak's experiences and reflections also moved her to put forward another argument against a skeptical response to her position that is useful for us. The skeptic, she says, may respond to her claims about the over-emphasis of autonomy by asserting it is inappropriate to cite first-person autobiographical narratives in the course of justifying ethical theory. The skeptic, says Misak, might hold "narratives are not simply chronological accounts of events. They are accounts that give coherence or shape to events and thus are freighted with interpretation, motivation, and other dents to what we think of as objectivity" (Misak 2008, 616). By undermining objectivity, such narratives may "toss us into a sea of individual experiences and perspectives, full of irresolvable conflict, contestability, and variability" (*ibid.*, 617). Consequently, there is no reason, so the skeptic says, for thinking that there are any grounds to critically evaluate autobiographical narratives. And since they are not amenable to criticisms, such narratives cannot be used as evidence in rational deliberation. They are insufficiently objective, or what is the same, overly subjective.

Misak's skeptic adopts the same stance as the reasonable skeptic I envision. She accepts that we typically report upon our experiences. She also accepts that such reports figure into our reasoning about what is good under the circumstances. But she disputes the claim that these reports *should* serve as justifications. In response to the skeptic, Misak argues that autobiographical narratives are essential sources of knowledge in ethical deliberation and that they are open to rational criticism. Thus she concludes we cannot help but to take them into account when deliberating about what is right.

In support of her claim that narratives are legitimate sources of knowledge, Misak asserts an epistemic thesis she attributes to Peirce and Quine about the relationship between knowledge and experience. Misak argues that perceptual experience is not unvarnished and raw. Rather, “everything we experience is interpreted—the experiential data that we possess are not raw experiences but rather beliefs about what we experienced. The best we can say about our perceptual judgments is that they are indexes of the actual clash between us and the world” (*ibid.*, 620). Thus, Misak claims that whereas we commonly accept the authority of perceptual judgments, we ought to also similarly accept the authority of ethical judgments. “Our perceptual judgments,” she says, “are authoritative in that they force themselves upon us—we have no choice but to pay attention to them. They arrive uncritically, and then we subject them to reason and scrutiny...this is simply the epistemic situation in which we find ourselves” (*ibid.*). Ethical judgments are similarly authoritative in that they force themselves upon us. We cannot help but evaluate our circumstances, the states of affairs we find ourselves in. Consequently, we cannot help but see our ethical judgments as legitimate sources of knowledge because we cannot help but make, proffer, and reflect upon them when acting reflectively and deliberatively.

Misak’s argument here is strikingly similar to Korsgaard’s discussed in Section 7.1. Like Korsgaard, Misak claims that anyone who deliberates, argues, or purports to hold a view based on certain reasons presupposes that some beliefs can be better than others. Even the reasonable skeptic, that is, presupposes beliefs can be improved upon and can be mistaken. According to Misak, “these are marks of objectivity—they are indicators that we take ethics to be aimed at getting matters right” (*ibid.*, 621). Much like Korsgaard, and also Williams, Misak concludes that one cannot use ethical language, one cannot engage in moral discourse, without presupposing that such discourse is corrigible. Thus, she concludes that the skeptic who argues

that first-person descriptions of the state of affairs in ethical and evaluative terms cannot figure into rational deliberation must be mistaken, for it is presupposed in the logic of such discourse that it can be critically evaluated, altered in light of opposing reasons, and so forth. To think otherwise is to use such terms disingenuously, to engage in ethical discourse nominally but not substantively.⁹⁴

Thus, for Misak, when we provide narrative accounts of our experience we provide accounts of how they are for us, and those accounts may be critically evaluated. They may also provide opportunities for interlocutors to see things our way, to perceive the situation as we do, including the norms that we take to be binding under the circumstances: “When we reflect upon and describe those experiences which embody moral responses, we can gain epistemic access to values or norms. This is not a privileged access, although the having of highly distinctive experiences can mean that the experience is not easily reproducible by others and hence the experiencer has a ‘privilege’ which others might not—the privilege of having had those experiences” (*ibid.*, 623). Sharing a narrative of one’s first person experience is thus sharing a bit of data. And the data are judgments about the state of affairs from the, perhaps retrospective, perspective of a participant. But this does not make them infallible. Misak’s account of her own hallucinations during ICU psychosis makes the point: she certainly perceived her circumstances in moral terms and she was led upon reflection and deliberation to believe that her judgments were misinterpretations.

Misak’s argument is that one’s experiences are important sources of information for rational deliberation, and moreover, that they are open to criticism when shared with others

⁹⁴ In *Truth, Politics, Morality: Pragmatism and Deliberation*, Misak (2000) provides a sustained defense of her epistemic and ethical theses.

during deliberation. As Misak puts it, her argument applies to ethical theory broadly. It leads to conclusions about the types of information that are legitimate in philosophical ethics. However, her argument can also be applied more narrowly, to ethical medical choice.

The epistemic claim that Misak attributes to Peirce and Quine is one that we have discussed throughout this thesis. In Chapter 3 I argued that standard ways of characterizing the conceptual foundations of medicine are insufficient. Instead, I suggested that we should see medicine as resting on a distinction between two types of knowledge, objective and subjective knowledge, and that this knowledge can be understood in terms of the ways that people communicate with one another. And in Chapter 5 I described medical decision-making systems in terms of groups of persons who work together to solve the task of describing a patient's state of health in subjective and objective terms. Throughout, I have described and adopted an epistemology of medicine that recognizes its fundamental duality. Given its conceptual foundations, I have argued it is most sensible to view medicine as a science, once we understand scientific claims as coming in different forms of objectivity.

I have thus described medicine as having two Basic Aims, and I have anchored decision-making to these two aims by describing them as defeasible initial conditions of medical reflection. To meet the Basic Aims requires a certain sort of communication, a certain sort of information sharing. The skeptic might think of information sharing as merely the description of one's unique, value-laden perception of events; that is, as the report of incorrigible perceptions of the way things are for her only. However, Misak's argument suggests why this would be mistaken. To *say* that the state of affairs is one way or another is to invite critical evaluation of one's claims, even if the claim is about how the state of affairs seems to oneself. Speaking of one's experience in this sense is not speaking of it as an aside, a description of affairs that runs

parallel to or supervenes upon rational deliberation. Rather, speaking of one's experience is central to deliberation about what is right when participating in medical care. As Misak notes, when one provides reasons, one does so in a way that they are corrigible. When one engages in the activity of describing the state of affairs in subjective, personal terms, then one invites discussion of those terms, which may be accepted, disputed, endorsed, assented to with suspicion, and so forth. One, that is, invites her discussant to *perceive* the world as she does and to deliberate about what he or she sees.⁹⁵

Following this reasoning, I suggest that the skeptic may not see things as I do. In particular, she may not see the activity of deliberating about what should be done as I do. I see it as an activity whereby persons communicating with one another make claims about what the state of affairs is, make claims about their assessment of it for them or for others, and then come to agreement about what terms are appropriate for describing what is the case and what should be done. The skeptic may see evaluative language as ineliminably partial, personal, and privileged. From this she may conclude that it is not possible to meaningfully criticize, dispute, accept, or endorse such language when deliberating.

At this point, the disagreement between the skeptic and me is revealed as a disagreement about the nature of evaluative language. One may hold that persons can deliberate meaningfully about the terms employed to describe what is the case and what ought to be done, given that it is

⁹⁵ Martha Nussbaum develops an interpretation of reflective equilibrium she calls “perceptive equilibrium,” which emphasizes the perceptual aspect of ethical deliberation. She draws attention to the phenomenon of viewing circumstances in particularly moral terms and the divergent types of perceptions individuals may have. Part of living well, she claims, is perceiving rightly. So she argues that reflective equilibrium is insufficient if it focuses only on bringing propositional content into equilibrium. Rather, she claims it also needs to account for the way we see the circumstances, which must also be brought into coherence with the way we understand them (Nussbaum 1990, 174ff.). Further consideration of Nussbaum’s account lies beyond the scope of the present argument.

the case. Or one may hold that persons can deliberate meaningfully about the terms employed to describe what is the case but cannot deliberate meaningfully about what ought to be the case. One might also hold that there are no prospects for meaningful deliberation. I claim that if one accepts that meaningful deliberation is possible, then in the case of medical decision-making I have presented an account of how to meaningfully deliberate. One should employ the procedure of medical reflective equilibrium. This requires searching, selecting, and integrating a certain kind and amount of information. And this further requires incorporating other participants in the process of information search, selection, and integration.

7.6 Normative Adequacy

The aim of this thesis is to put forward a new normative account of medical decision-making. In Chapter 2, I described normative claims as those that imply norms or are derived from them. Norms, I said, are standards, such as of behaving, reasoning, feeling, and acting. Moreover, I suggested that any model of decision-making in medicine must be normatively adequate. This means it must generate normative claims, at least for ideal agents captured by the model (§ 2.3.1).

In the current and previous chapters, I have articulated an account of medical decision-making that meets the standard of normative adequacy. My account began by appealing to a coherentist account of ethical justification, reflective equilibrium (§ 6.1). I appealed to this view because it has certain features that seemed likely to make it attractive to a wide variety of individuals. It is non-foundationalist, thus it justifies norms through a procedure that apparently does not require one to beg questions about what it is right or good. Given that medical decisions are made by all types of persons, this anti-foundationalism promised to be well suited

to the pluralism that one finds in medical practice. However, reflective equilibrium was found to be less attractive once it was described in detail. It was shown to be amenable to a range of interpretations, although I argued that the view could be defined schematically in terms of the core commitments that seem most defensible across these interpretations. And it was also shown to rest upon a concept of coherence that appeared too thin to do the justificatory work required of it. As an account of how to justify higher order ethical principles, I argued that reflective equilibrium falls to the no guarantees objection: it cannot guarantee laudable results because it will either require too much cognitive effort by those who perform the procedure or it will merely generate idiosyncratic results based on the views it begins with (§ 6.2). I suggested that to respond to this one could define an alternative, expanded account of coherence such that the reflective equilibrium procedure is more defensible against the no guarantees objection.

To develop a redefined account of coherence, I began by introducing a decision analytic framework for characterizing medical choice. I argued that decision trees could be used to represent particularly important information in medical choices. They emphasize the choices, outcomes, and evaluations that may be made during decision-making. And they capture this information in a way that also emphasizes its logical structure. Thus, I proposed that one could begin with a generic decision tree and then envision a new account of reflective equilibrium that is based not only on coherence but also on justifications of the procedures for selecting information to be included or excluded in cases of incoherence (§§ 6.3-6.6). Following decision analytic accounts, I accepted that strategies for pruning and foliating decision trees could not be defended in principle. Rather, particular strategies can only be defended under particular circumstances.

In this chapter, I aimed to put forward an alternative interpretation of reflective equilibrium for the particularly medical context. I have recast the task in terms of describing an account of reflective equilibrium for justifying particular claims for persons in particular circumstances, rather than for justifying higher order ethical principles. I have used the conceptual device of two different forms of skepticism to draw attention to the problems that might arise when developing this form of reflective equilibrium, which I call medical reflective equilibrium. The reasonable skeptic, I have argued, is the only skeptic that I must persuade with my account (§ 7.1). Leveraging common tropes in philosophical ethics, I define her as accepting that reflection is an ordinary human activity. I also portray the skeptic as holding that human actions are beholden to reasons insofar as we develop practical identities and from them we check the consistency of our actions with who we are by considering our reasons. And I claim that the skeptic accepts that we share reasons with one another, although I recognize she doubts that the reasons we share can ever be adequately justified.

Responding to the skeptic, I argue that we can distinguish between different types of choices in terms of the kind and amount of information they consider. I introduce a new case study in hereditary breast and ovarian cancer that I contend is a poor case of decision-making. After depicting this case using decision analytic concepts, I argue that it is poor because it is deficient in information (§ 7.2). Having shown that decision analytic concepts can be used to characterize a poor case, I then propose to use them to represent an ideal case. I introduce the generic HBOC decision tree (Figure 7.6) to capture all of the information that might be relevant for a generic woman who is a candidate for HBOC. I take this diagram to capture all of the information that is relevant for such a choice.

There are a number of contentious aspects of this project. I believe that the generic HBOC decision tree may be the most contentious of them all. I describe it as representing all of the information that might be relevant for a generic woman who is a candidate for HBOC; however, that is not quite accurate. At best, the generic HBOC decision tree represents all of the information that has been empirically studied for its potential influence on HBOC decision-making. Some of the information describes factors that might influence a woman's choices. Other information describes choices that women typically face. And yet other information describes the outcomes they may experience. Yet even though I have described the generic HBOC decision tree as representing an "ideal" choice, it is nevertheless short of the ideal if that requires having *all possibly relevant* information.

Despite this shortcoming, I believe the generic HBOC decision tree suffices as a heuristic device. It represents the significant amount of information that has been considered to be relevant for HBOC decision-making in empirical studies of choice. And it shows how that information may be logically organized. Using it, I argued it is possible to depict a good HBOC medical decision, Ellen Macke's choice. Having done this, I argued that we can see why Macke's choice was a good one, because it was sufficiently reflective. With the participation of her family and providers, Macke searched for, selected, and integrated a sufficient amount of information to fully identify her choices and their possible outcomes, and to evaluate many of those outcomes for her, in terms that were personally relevant for her.

If Macke's choice is a good one in this sense, then I argued we can schematize a general account of good decision-making in terms of the search, selection, and integration of a certain kind and amount of information. I define this as medical reflective equilibrium by analogy to reflective equilibrium (§ 7.4). The determinative constituents of medical reflective equilibrium

are two sets of information, health judgments {HJ} and comprehensive biopsychosocial information {CBI_i}, which are analogous to initial moral judgments {IMJ} and background theories {BT_i}, respectively, in wide reflective equilibrium. Performing medical reflective equilibrium requires identifying the information necessary to constitute each set and to transform them into a coherent set of information at equilibrium. I define this in terms of four coherence-like procedures, and I take this to be a redefined and expanded account of coherence than is articulated in the received account of reflective equilibrium. It is also targeted at justifying particular normative claims about particular persons in particular circumstances, and in this way is different than the general account of the procedure.

So understood, I argue just above that medical reflective equilibrium provides a normative account of medical decision-making. On this account, persons who face medical decisions are guided to search for sufficient information to describe their situation in personal and scientific terms. Thus they are guided to meet the Basic Aims of medicine, which will entail incorporating other persons and cognitive tools into the decision-making process. Persons are, in this sense, guided to deliberate in groups when making medical decisions. Medical decision-making thus should be a social activity.

8.0 CONCLUSION: A NORMATIVE MODEL OF MEDICAL DECISION-MAKING

8.1 Summary

This dissertation has defended the claim that medical decisions should be made by groups of persons acting together, not by individuals acting alone. Defending this view required considering a variety of arguments, introducing a few distinctions, proposing and countering a couple of objections, and doing all of this in the context of a number of different philosophical debates. The reader who has suffered through my prose and the convolutions of my argument has my sincere thanks and gratitude. Let me retrace our steps and then discuss some of the most pressing open questions the analysis has left us with, as I see it.

I began in Chapter 2 by introducing three popular models of medical decision-making. Two of these have been put forward predominantly by an interdisciplinary group of philosophers, physicians, and legal scholars. They are beneficence-based paternalism and autonomy-based informed consent. The other view, the shared decision-making model, has been developed largely by a different interdisciplinary group of physicians, sociologists, and bioethicists as a response to the perceived failings of informed consent. I argued for a

distinction between two criteria that any model of medical choice must meet that aids in characterizing the differences between these popular accounts. To be descriptively adequate, a model of choice must be consistent with descriptive claims, which are roughly defined as ones that describe events and states of affairs irrespective of any extent to which these descriptions imply or derive from norms. To be normatively adequate, a model of choice must produce claims that imply standards for action; they guide agents to act a certain way under the circumstances. Paternalism and informed consent, I contend, are descriptively inadequate. Shared decision-making is normatively inadequate. Because none of the existing models of choice in medicine is sufficiently adequate, my aim for this project has been to develop one that is. I offer a new normative model of medical decision-making that is also descriptively adequate.

One of the problems I see with existing normative models of medical choice is that they begin by focusing on moral and legal concerns in general, which they then apply to medicine. I believe this approach is mistaken because it obscures assumptions that must be made about the unique context of medicine within which medical decisions arise. To counter this issue, in Chapter 3, I make clear that my model rests upon assumptions about the “essence” of medicine. I argue that standard distinctions for characterizing the philosophical foundations of medicine are inadequate for a variety of reasons, which I discuss in detail. This discussion leads me to offer an alternative framework for understanding medicine, in terms of two basic aims. One basic aim is to understand patients’ experiences of illness or well-being in both subjective and objective terms. The other is to intervene upon patients’ states of health in ways that are consistent with this understanding. This characterization of medicine rests on an epistemic distinction between two ways of knowing about persons’ health, subjectively and objectively,

and consequently, two basic ways of communicating when making medical choices. I propose that physicians, patients, and others involved in care communicate in subjective terms, which are reports of experiences from the subjects' perspective, including experiences of illness or well-being. These persons also communicate in objective terms, which are reports about experiences of illness or well-being from the observer's perspective. Given this orientation, I propose to understand medicine as being a form of dialogue. Medicine is inextricably about communication for the sake of understanding patients' experiences, though it is also about intervention with the aim of healing, subsequent to sufficient understanding.

Having described the context of medicine, I then argue for a descriptive account of medicine based upon a detailed case study of a particular choice for a particular type of cancer, which I then interpret through the theory of distributed cognition. In Chapter 4, I introduce the case of Ellen Macke. Macke comes from a family where hereditary breast cancer is an unfortunate fact. Many in her family have had it, many have died from it, and many have suffered through treatment for it. Macke's narrative describes her own decision-making as distributed across a number of individuals, who help Macke understand the choices that she faces, the outcomes that might follow from her actions, and the meaning those outcomes could have for her. Thus, in Chapter 5, I propose to characterize Macke's choice in terms of distributed cognition. As a conceptual framework, distributed cognition adopts the computational metaphor common in cognitive science and applies it to groups of persons working together to solve tasks. Persons may be understood as forming interconnected information processing networks that bring in information from the environment, process it, and share that information through the network. From these information processing activities, a complex representation of the problem emerges that includes the constraints on possible

solutions to it. When such systems work well, they lead to solutions to constraint satisfaction problems. Looking at Macke's choice as such a problem, I suggest an architecture of communication emerges between Macke and participants in her medical decision-making. Just as the navigational team modeled by Hutchins (1995) can be described as an interconnected network (Figure 5.2), I argue Macke's decision-making team can be analogously modeled (Figure 5.3). Representing Macke's choice in this way draws attention to the many persons and computational tools (artifacts) that are involved in it or are absent. Thus, I conclude that this representation suffices for showing that medical decisions are social; they are made by groups of persons interacting together, rather than individuals acting alone.

If medical decisions are social, this does not entail that they should be. To propose a normative account of medical decision-making requires a different argument than a descriptive account does. I give this argument in Chapters 6 and 7. I begin by introducing Rawlsian reflective equilibrium, a common though misunderstood account of ethical justification. I clarify what I take this view to be and then I consider a number of popular, pressing objections against it. To respond to these objections, I introduce some basic concepts from decision analysis, including the notions of choices, outcomes, utilities, and expected values, which are used in the construction of decision trees. Next, in the final substantive chapter, I argue for a modified account of reflective equilibrium that I call medical reflective equilibrium. My account differs from traditional reflective equilibrium in that it is designed to explicate the kind and amount of information that must be considered when making particular choices for particular persons in the medical context. Making such choices, I argue, requires considering sufficient information to meet the basic aims of medicine. Given the way that the basic aims are defined, I argue that performing the medical reflective equilibrium procedure adequately

requires multiple participants in decision-making. Throughout the chapter, I use the device of distinguishing between two types of skepticism to distinguish between two different foils for my argument. Focusing on reasonable skepticism leads me to further defend my epistemic distinction between subjective and objective knowledge, and to argue that something like it must be presupposed in order to understand the normative force of ordinary ethical discourse. If so, then I further argue that to adequately meet the goals of medicine requires the participation of multiple individuals working together to fully describe patients' health states and interventions that might alleviate them. Consequently, I conclude that medical choices are and should be social.

8.2 Open Questions

As I have said, defending my view of medical choice required me to put forward numerous arguments and make a few distinctions in the context of a number of different philosophical debates. I am not so foolish as to think that my understanding of these arguments, articulation of those distinctions, and characterization of those debates will all be sound or prudent. Thus, there remain a number of open questions about how persons do and should make medical decisions. I summarize a few of these below, as they follow from my account.

8.2.1 *Legal Doctrine and Theories of Choice*

In their account of informed consent, Berg et al. (2001) suggest that a “process model” of informed consent is warranted. Similarly, other authors have proposed a relational account of autonomy (*e.g.*, Kukla 2005). What appears to be motivating philosophical moves like this is a felt need for a new account of decision-making than what arises out of informed consent, when that is understood as a legal doctrine in the sense familiar to Faden and Beauchamp (1986). I

sympathize with Berg et al.’s view that informed consent is a complex account of what choice is and should be (as discussed in § 2.1). However, I believe it is not at all clear whether and how current legal doctrine might accommodate a “process model” like my own were to gain widespread adoption.

In this work, I have almost completely ignored informed consent as a legal doctrine. By consequence, I have little to say about the prospects of my account being consistent with current legal theory of informed consent, for example whether for research or for recovery in the case of malpractice. Understanding decision-making in terms of systems of agents working together might imply that responsibility is distributed across these persons. This might require a change to disclosure standards, because disclosure might be recognized as something that can be distributed too. Presumably, if responsibility is in this sense distributed, then its distribution will be unequal. My intuition is to think of this in philosophical terms of group agency and group responsibility (*e.g.*, Smiley 2011). Yet, this surely would have legal ramifications too. What those ramifications could be remains an open question.

It might be the case that my account of decision-making is consistent with the shared decision-making model, which some states have proposed including in health care related legislation (King and Moulton 2006; Kuehn 2009). However, my aim has been to propose a normative account of medical decision-making as a social activity and it is unclear whether proponents of SDM would find my account consistent with their views. By describing my normative account in epistemic terms, I believe it is consistent with claims made by proponents of SDM. Yet, more work must be done to produce an explicit argument to this conclusion, as well as to consider its implications for legal doctrine.

8.2.2 *Empirical Validity and Theories of Choice*

Drawing on Hutchins' account of cognition in the wild, I have argued for an understanding of decision-making that might be referred to as "decision-making in the wild," were it not for the patent hubris that locution would imply. By considering empirical studies of choice, I have aimed to give an account that is consistent with what is known about decision-making empirically. However, there are two problems with approach as it has been given above. First, it is partial, in that it considers only some of the empirical studies of medical choice. Second, it is sparse, in that existing research on choice in medicine is itself partial; there is much more to be known about the phenomenon than what is currently captured by empirical research.

I can conceive of a number of empirical approaches to testing my model of medical decision-making and contributing to our empirical understanding of choice as it arises in actual medical practice. One that is particularly interesting would be to perform a longitudinal ethnography of choice like Hutchins performs in the case of navigation. However, there are a number of reasons why this approach is likely to be prohibitively difficult. For one, medical decision-making is distributed across far larger spaces and times than navigation. Although a navy ship is a large object, most of the information processing that is required to perform the fix cycle occurs in a 335 square foot space, and the rest of it is localized in a few small spaces in discrete locations on the ship. By contrast, in Macke's choice, information processing occurred in her home, in physician's offices, at a family retreat, at her sister's and cousin's houses, and other places as well. If it were at all possible to measure such information processing in even a composite of actual distributed medical decision-making systems, it would be difficult and expensive to do so.

I have tried to overcome this limitation to some extent here by citing many of the few studies that have performed detailed analyses of communication in medical decision-making. Another way to test the empirical validity of my model would be to perform a more rigorous review of such studies and to look for patterns that result. Perhaps certain behaviors are more common and certain conceptual tools for understanding them more robust. If so, further work could be done to test the ecological validity of these concepts and then to inquire about their compatibility with my approach. Whether such investigations would substantiate my account remains to be shown.

8.2.3 *Metaethics: Implications and Responses*

As the last chapter made clear, my normative account rests on largely unexplored metaethical assumptions about the "equality" of normative and descriptive language. Although it is apparently common in philosophy to believe that there is a fundamental difference between values and facts, I believe this is mistaken. This much is evident from my account of choice in medicine. However, what I do not make explicit is that I believe a sound, persuasive argument can be given for this view. My favorite is given by Sabina Lovibond (1983), although others have made it too. Indeed, one might imagine that a question about the relationship between the language one uses to describe how the world is and how it should be lies behind the question that marks the origins of philosophy, Socrates' question of how one should live (Williams 1985, 1). To answer the question presumably at least requires using language to say not only how one should live, but also how one should live given what appears to be the case.

My account has not set out to tackle the question of how one should live head on, nor has it offered a well-defended account of normative and descriptive language. Although, it has endeavored to be clear about the assumptions it makes about that language, and it has

endeavored to argue for a claim about how one should live in a narrow sense, the sense of how one should live if one is considering treatment under a certain Western style of medical care.

It is possible that my view could be undercut by challenging my metaethical assumptions. Articulating this problem and responding to it is work that remains to be done. However, some of the work has been forecasted above, although it too is likely to generate additional difficulties. I have attempted to provide a representational tool for describing the logical relationships between descriptive and normative terminology in my use of heuristic decision trees. As I mentioned above, the introduction of this representational convention is perhaps the most contentious aspect of my project, because it adopts a rather well understood representational tool that depends on a number of formal assumptions, jettisons those formal assumptions as preconditions for use of the tool, and then adds a backward-looking component to the representation (the “roots”) without sufficient justification of the cogency of this maneuver.

I recognize that heuristic decision trees may seem half-baked and foolhardy. Yet, I have been lead to introduce them while trying to think through the issue of how to represent ideal medical choice carefully and thoroughly. As I discuss just below, I also recognize there are many alternative approaches for understanding (rational) choice, and so, other representational conventions are available. However, I believe that decision theoretic accounts are the most consistent with the moral pluralism required for medical contexts. Decision analytic concepts only require that one categorize the choices, outcomes, and evaluations in order to represent choices. If one can do this, then with a relatively sparse set of tools much follows. However, fully justifying the heuristic decision tree concept requires more rigor and consideration of extant techniques than I have given here. This work also remains for the future. If it is done, I

hope that my approach will be shown to be consistent with other work on decision analytic approaches to ethical medical choice (e.g., Elwyn et al. 2001; Rao 2007). However, whether such approaches are truly useful for actual practice also remains an open question (see Schwartz and Bergus 2008). Furthermore, the amount of education that might be required to empower physicians, patients, other providers, and other caregivers to employ even heuristic decision analysis might be vast (Gigerenzer and Muir 2011). Whether it is, and if so, whether the social costs of instituting this education are ones we are willing to bear, also remain very open questions.

8.2.4 *The Pitfalls and Promises of Interdisciplinary Inquiry*

The study of decision-making is a thoroughly interdisciplinary effort. Had I appreciated that fully when embarking upon this project, it may have deterred me from doing so. As the reader undoubtedly knows by now, there is an evident pitfall to interdisciplinary inquiry, at least as I perform it: it is difficult to find common language and concepts for making one's claims, and this often necessitates tortuous jaunts into new territory as one moves from one field to another in search of the right account.

Nevertheless, a-jaunting we have gone. We have considered research and themes from bioethics, clinical medicine, philosophy of science, medical anthropology, biology, sociology, cognitive science, sociology of science, political philosophy, ethics, decision theory, and metaethics. As new themes have been introduced into the discussion, I have tried to keep focused on the topic at hand, how we people do and should make medical choices. However, invoking analyses and results from so many fields opens the analysis to criticism in two important ways: my subsidiary analyses becomes open to criticism from any of these fields, or the analysis may come off as dilettantish when taken as a whole.

Whether my account as a whole is consistent with the fields from which I have fashioned its many parts is an open question. To answer it requires isolating these inquiries from their place in this analysis and engaging with the fields that they most readily belong to in the form of presentations, workshops, and publications. Only to the extent that such work is received favorably will it be possible to claim that the work as a whole hangs together, that the parts from which it has been constructed are cogent independently of their relationship to the whole. The two parts that I have presented publicly have been favorably received, including on my objection to the dualist epistemology of medicine (Cunningham forthcoming) and account of Rawlsian reflective equilibrium (to be given at the American Philosophical Association Pacific Division Meeting in 2014). However, each required revision in light of peer review. I can only assume that this would be the case, and even more so, for the more contentious aspects of my account above, especially the heuristic decision trees. I look forward to learning whether my intuition is right. If it is, then it will be necessary to revise some of the conceptual pieces in my model. Only to the extent to which that challenge is met will the account as a whole resist the charge of dilettantism.

However, there is yet another pitfall of interdisciplinary inquiry that must be reckoned with, especially in the case of studying decision-making. Choice has been, and is, studied from a wide range of perspectives. And I have ignored or problematically glossed over many of them. Another important open question implied by my research is the extent to which it bears upon or is even consistent with these approaches. Work on decision-making can be bifurcated into two groups, those who are explicitly oriented to explicating decision-making and related phenomena in social terms and those who emphasize decision-making as a phenomenon of individual agents. Some of the research I have ignored or glossed on the decision-making of individual

agents includes work in behavioral economics (Bell et al. 1988; Kahneman et al. 1982; Kahneman and Tversky 1979, 2000; McNeil et al. 1982, 1988), neuroeconomics (Sanfey et al. 2003, 2006; Gold and Shadlen 2007), psychology (Baron 2000; March 1994), social psychology (Wegner 2002; Wegner and Sparrow 2007), and studies of rationality and ethics (Gigerenzer 2010; Gigerenzer and Goldstein 1996; Chase et al. 1998; Byron 2004; Millgram 2005; Colyvan et al. 2010; Binmore 2009; Ross 2005; Ross et al. 2007; Thagard and Millgram 1995; Thagard 1998, 2001). Some examples of research I have not adequately engaged with on the social nature of choice includes work in social neuroscience (Frith 2008; Frith and Singer 2008; Bahrami et al. 2010; Frith and Frith 2008), social psychology (Hinsz et al. 1997; Tindale et al. 2004; Stasser et al. 1989, 1995, 2000; Larson et al. 1996; Gigone and Hastie 1993, 1997; Sunstein and Hastie 2008), economics (Arrow 1951; Sen 1970; MacKay 1980; Sugden 2000), and some philosophical accounts of group agency (Schmitt 2003; Bratman 1999, 2009; Tuomela 1995; List and Pettit 2011; Laden 2012).

Each of these fields is not monolithic. Rather, each admits of its own sub-distinctions and competitive varieties. I believe some are consistent with my view and others are not. Working this out would take significant effort. Thus, innumerable other open questions are implied by the interdisciplinarity of this project. I hope to have the chance to formulate, pose, and perhaps even answer some of these questions in the future. I believe such a future is promising.

BIBLIOGRAPHY

- Ackerman, Terrence F. and Carson Strong (1989). *A Casebook of Medical Ethics*. New York: Oxford University Press.
- Aizer, Ayal A., Ming-hui Chen, Ellen P. McCarthy, Mallka L. Mendu, Sophia Koo, Tyler J. Wilhite, Powell L. Graham, Toni K. Choueiri, Karen E. Hoffman, Neil E. Martin, Jim C. Hu, and Paul L. Nguyen (2013). "Marital Status and Survival in Patients with Cancer." *Journal of Clinical Oncology* DOI: 10.1200/JCO.2013.49.6489.
- Anderson, Kristin, Judith S. Jacobsen, Daniel F. Heitjan, Joshua G. Zivin, Dawn Hershman, Alfred I. Neugut, and Victor R. Grann (2006). "Cost-Effectiveness of Preventative Strategies for Women with a *BRCA1* or a *BRCA2* Mutation." *Annals of Internal Medicine* **144**:397-406.
- Armstrong, Katrina, Ellyn Micco, Amy Carney, Jill Stopfer, and Mary Putt (2005). "Racial Differences in the Use of *BRCA1/2* Testing Among Women with a Family History of Breast or Ovarian Cancer." *Journal of the American Medical Association* **293**:1729-1736.
- Aronwitz, Robert A. (2005). "The Ethical dilemma of Genetic Testing." In Snyder, Lois (Ed.): *Ethical Choices: Case Studies for Medical Practice*. Philadelphia: American College of Physicians.
- Arora, Neeraj K. and Colleen A McHorney (2000). "Patient Preferences for Medical Decision Making: Who Really Wants to Participate?" *Medical Care* **38**:335-341.
- Anholt, Robert R. H. (2004). "Genetic Modules and Networks for Behavior: Lessons from *Drosophila*." *BioEssays* **26**:1299-1306.
- Anspach, Renée R. (1993). *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery*. Berkeley: University of California Press.
- Arnold, Robert M. (1989). "The Discourse of Medicine: The Dialectics of Medical Interviews [Book Review]." *Language in Society* **18**:116-121.

- Aristotle. (2000). *Nicomachean Ethics*. Translated by R. Crisp. New York: Cambridge University Press.
- Arras, John D. (2007). "The Way We Reason Now: Reflective Equilibrium in Bioethics." In B. Steinbock (ed.), *The Oxford Handbook of Bioethics*, pp. 46-71.
- Arrow, Kenneth J. (1951). *Social Choice and Individual Values*. New York: Wiley.
- Atkinson, Paul (1995). *Medical Talk and Medical Work: The Liturgy of the Clinic*. Thousand Oaks: SAGE Publications.
- Aulisio, Mark P. (2003). "Meeting the Need: Ethics Consultation in Health Care Today." In M. Aulisio, R. Arnold, and S. Youngner (eds.), *Ethics Consultation: From Theory to Practice*. Baltimore: Johns Hopkins University Press, pp. 3-22.
- Bachmann, Lucas M., Florian S. Gutzwiller, Milo A. Puhan, Johann Steurer, Claudia Steurer-Stey, and Gerd Gigerenzer (2007). "Do Citizens Have Minimum Medical Knowledge? A Survey." *BMJ Medicine* 5:14.
- Bahrami, Bahador, Karsten Olsen, Peter E. Latham, Andreas Roepstorff, Geraint Rees, and Chris D. Frith (2010). "Optimally Interacting Minds." *Science* 329:1081-1085.
- Barabási, László and Zoltán N. Oltvai (2004). "Network Biology: Understanding the Cell's Functional Organization." *Nature Reviews Genetics* 5:101-113
- Bardes, Charles L. (2012). "Defining 'Patient-Centered Medicine'." *New England Journal of Medicine* 366:782-783.
- Baron, Jonathan (2000). *Thinking and Deciding*, Third Edition. Cambridge, UK: Cambridge University Press.
- Barnard, David (1986). "'Ship? What Ship? I Thought I was Going to the Doctor!': Patient-Centered Perspectives on the Health Care Team." In N. M. P. King et al. (eds.), pp. 89-111.
- Battista, Renaldo N., Matthew J. Hodge, and Paolo Vineis (1994). "Medicine, Practice and Guidelines, the Uneasy Juncture of Science and Art." *Journal of Clinical Epidemiology* 48:875-880.
- Bell, David E., Howard Raiffa, and Amos Tversky (eds.) (1988). *Decision-Making: Descriptive, Normative, and Prescriptive Interactions*. New York: Cambridge University Press.

- Beauchamp, Tom L. and James F. Childress (2009). *Principles of Biomedical Ethics*, 6th Edition. Oxford: Oxford University Press.
- Bechtel, William and Bob Richardson (1993). *Discovering Complexity: Decomposition and Localization as Strategies in Scientific Research*. Princeton University Press.
- Berg, Jessica, Paul S. Applebaum, Charles W. Lidz, and Lisa S. Parker (2001). *Informed Consent: Legal Theory and Clinical Practice*. New York, NY: Oxford University Press.
- Berg, Marc (1996). "Practices of Reading and Writing: The Constitutive Role of the Patient Record in Medical Work." *Sociology of Health & Illness* 18: 499-524.
- Bernhardt, Boris C. and Tania Singer (2012). "The Neural Basis of Empathy." *Annual Review of Neuroscience* 35:1-23.
- Bermúdez, José L. (2003). *Thought Without Language*. New York, NY: Oxford University Press.
- Binmore, Ken (2009). *Rational Decisions*. Princeton: Princeton University Press.
- Bogen, James (2002). "Experiment and Observation." In P. Machamer and M. Silberstein (eds.), *The Blackwell Guide to Philosophy of Science*, pp. 128-148.
- Bogen, James and James Woodward (1988). "Saving the Phenomena." *The Philosophical Review* 97:303-352.
- Boorse, Christopher. (1975) "On the Distinction Between Health and Illness." *Philosophy and Public Affairs* 5:49-68.
- Boorse, Christopher. (1977) "Health as a Theoretical Concept," *Philosophy of Science* 44:542-573.
- Boorse, Christopher. (1997) "A Rebuttal on Health," in J. Humber and R. Almeder (eds.) *What is Disease?* Totowa NJ: Humana Press, pp. 3-134.
- Boorse, Christopher. (2011) "Concepts of Health and Disease," in F. Gifford (ed.) *Handbook of Philosophy of Science. Volume 16. Philosophy of Medicine*. Oxford: Elsevier B.V., pp. 13-64.
- Borgen, Patrick I., Arnold D. K. Hill, Katherine N. Tran, Kimberly J. Van Zee, Mary J. Massie, David Payne, and Carina G. Biggs (1998). "Patient Regrets After Bilateral Prophylactic Mastectomy." *Annals of Surgical Oncology* 5:603-606.

Botkin, Jeffrey R., Ken R. Smith, Robert T. Croyle, Bonnie J. Baty, Jean E. Wylie, Debra Dutson, Anna Chan, Heidi A. Hamann, Caryn Lerman, Jamie McDonald, Vickie Venne, John H. Ward, and Elaine Lyon (2003). "Genetic Screening for a *BRCA1* Mutation: Prophylactic Surgery and Screening Behavior in Women 2 Years Post Testing." *American Journal of Medical Genetics* **118A**:201-209.

Bradbury, Angela R., Linda Patrick-Miller, Brian L. Egleston, Olufunmilayo Olopada, Mary B. Daly, Cynthia W. Moore, Coleen B. Sands, Helen Schmidheiser, Preethi K. Kondamudi, Maia Feigon, Comfort N. Ibe, and Christopher K. Daugherty (2012). "When Parents Disclose *BRCA1/2* Test Results: Their Communication and Perceptions of Offspring Response." *Cancer* **118**:3417-3425.

Braithwaite, Dejana, Jon Emery, Fiona Walter, A. Toby Prevost, and Stephen Sutton (2006). "Psychological Impact of Genetic Counseling for Familial Cancer: A Systematic Review and Meta-Analysis." *Familial Cancer* **5**:61-75.

Brandt, Richard (1979). *A Theory of the Good and the Right*. Oxford: Clarendon Press.

Brandt, Richard B. (1990). "The Science of Man and Wide Reflective Equilibrium." *Ethics* **100**:259 278.

Bratman, Michael (1999). *Faces of Intention: Selected Essays on Intention and Agency*. Cambridge, UK: Cambridge University Press.

Bratman, Michael (2009). "Shared Agency." In C. Mantzavinos (ed.), *Philosophy of the Social Sciences*, pp. 41-59.

Brody, Howard (1987). *Stories of Sickness*. Yale University Press

Brown, Reva (2004). "Consideration of the Origin of Herbert Simon's Theory of 'Satisficing' (1933-1947)." *Management Decision* **42**:1240–1256.

Burns, Jeffrey P., Jeffrey Edwards, Judith Johnson, Ned Cassem, and Robert Truog (2003). "Do Not-Resuscitate Order After 25 Years." *Critical Care Medicine* **31**: 1543-1550.

Buchanan, Allen, E. and Dan W. Brock (1989). *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge, UK: Cambridge University Press.

Buckman, Robert (1992). *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore: The Johns Hopkins University Press.

Byron, Michael (ed.) (2004). *Satisficing and Maximizing: Moral Theorists on Practical Reason*. Cambridge: Cambridge University Press.

- Callahan, D. (1996). "The Goals of Medicine: Setting New Priorities." *Hastings Center Report* 25:S1-S26.
- Camerer, Colin (1995). "Individual Decision-making." In *The Handbook of Experimental Economics*, J. Kagel and A. Roth (Eds.), pp. 587-703.
- Caplan, Arthur L., H. Tristram Engelhardt, and James L. McCartney (eds.) (1981). *Concepts of Health and Disease: Interdisciplinary Perspectives*. Reading, MA: Addison-Wesley Publishing Company.
- Caplan, Arthur L., James L. McCartney, and Dominic A. Sisti (eds.) (2004). *Health, Disease, and Illness: Concepts in Medicine*. Washington, D.C.: Georgetown University Press.
- Carruthers, P., S. Stich, and M. Siegal (eds.) (2002). *The Cognitive Basis of Science*. Cambridge, UK: Cambridge University Press.
- Cartwright, Nancy (1999). *The Dappled World: A Study of The Boundaries of Science*. Cambridge, UK: Cambridge University Press.
- Cassell, Eric J. and Mark Siegler (1979). *Changing Values in Medicine*. New York: University Publications of America, Inc.
- Cassell, Eric J. (1985a). *Talking With Patients, Vol. 1: The Theory of Doctor-Patient Communication*. Cambridge, MA: The MIT Press.
- Cassell, Eric J. (1985b). *Talking With Patients, Vol. 2: Clinical Technique*. Cambridge, MA: The MIT Press.
- Cassell, Eric J. (1986). "Toward a Science of Particulars." *Hastings Center Report* 16:12-14.
- Cassell, Eric J. (1995). "Medicine, Art of." In *Encyclopedia of Bioethics*, 3rd Ed., S. G. Post (editor in chief), Farmington Hills, MI: Macmillan Reference USA, pp. 1732-1738.
- Cassell, Eric J. (2004). *The Nature of Suffering and the Goals of Medicine, 2nd Edition*. Oxford: Oxford University Press.
- Chambers, Rebecca (personal communication). Email message from Rebecca Chambers, Director of Investor Relations and Corporate Communications at Myriad Genetics on May 4, 2011.
- Chang, Hasok. 2004. *Inventing Temperature: Measurement and Scientific Progress*. New York: Oxford University Press.

- Charles, Kathy, Amiram Gafni, and Tim Whelan (1997). "Shared Decision-Making in the Medical Encounter: What Does it Mean? (Or at Least it Takes Two to Tango.)" *Social Science and Medicine* **44**:681-692.
- Charon, Rita (2001). "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust." *Journal of the American Medical Association* **286**: 1897-1902
- Charon, Rita (2006). *Narrative Medicine: Honoring the Stories of Illness*. Oxford: Oxford University Press.
- Charon, Rita (2008). "The Art of Medicine: Narrative Evidence Based Medicine." *The Lancet* **371**:296-297.
- Chase, Valerie M., Raph Hertwig, and Gerd Gigerenzer (1998). "Visions of Rationality." *Trends in Cognitive Science* **2**:206-214.
- Childress, James F. (2007). "Methods in Bioethics." In B. Steinbock (ed.), *The Oxford Handbook of Bioethics*, pp. 15-45.
- Churchland, Patricia S (1986). *Neurophilosophy: Toward a Unified Science of the Mind/Brain*. Cambridge, MA: MIT Press.
- Churchland, Patricia S. (2002). *Brain-Wise: Studies in Neurophilosophy*. Cambridge, MA: MIT Press.
- Churchland, Paul M. (1989). *A Neurocomputational Perspective: The Nature of Mind and the Structure of Science*. Cambridge, MA: MIT Press.
- Churchland, Paul M. and Clifford A. Hooker (eds.) (1989). *Images of Science: Essays on Realism and Empiricism*. Chicago: University of Chicago Press.
- Claes, Erna, Gerry Evers-Kiebooms, Andrea Boogaerts, Marleen Decruyenaere, Liever Denayer, and Eric Legius (2003). "Communication with Close and Distant Relatives in the Context of Genetic Testing for Hereditary Breast and Ovarian Cancer in Cancer Patients." *American Journal of Medical Genetics* **116A**:11-19.
- Clark, Andy (2008). *Supersizing the Mind: Embodiment, Action, and Cognitive Extension*. Oxford: Oxford University Press.
- Clark, Jack A. and Elliot G. Mishler (1992). "Attending to Patient's Stories: Reframing the Clinical Task." *Sociology of Health & Illness* **14**:344-372.
- Clouser, K. Danner, Charles M. Culver, and Bernard Gert (1981). "Malady: A New Treatment of Disease." *Hastings Center Report* **11**:29-37.

- Cohen, Andrew (2011), "Nature vs. Nurture: The Continuing Saga of the Gene Patenting Case." *The Atlantic*: Available at: <http://www.theatlantic.com/national/archive/2011/04/nature-vs-nurture-the-continuing-saga-of-the-gene-patenting-case/73359/>. Accessed April 24, 2011.
- Cohen, G. A. (1996). "Reason, Humanity, and the Moral Law." In C. Korsgaard, *The Sources of Normativity*, pp. 167-188.
- Cohen, Trevor, Brett Blatter, Carlos Almeida, Edward Shortliffe, and Vimla Patel (2006). "A Cognitive Blueprint of Collaboration in Context: Distributed Cognition in the Psychiatric Emergency Department." *Artificial Intelligence in Medicine*: **37**:73-83.
- Collins, E. Dale, Caroline P. Moore, Kate F. Clay, Stephen A. Kearing, Annette M. O'Connor, Hilary A. Llewellyn-Thomas, Richard J Barth Jr., and Karen R. Sepucha (2009). "Can Women with Early-Stage Breast Cancer Make an Informed Decision for Mastectomy?" *Journal of Clinical Oncology* **27**:519-525.
- Colyvan, Mark, Damian Cox, and Katie Steele (2010). "Modeling the Moral Dimension of Decisions." *Noûs* **44**:503-529.
- Cooper, Rachel (2002). "Disease." *Studies in History and Philosophy of Biological and Biomedical Sciences* **33**:263-282.
- Couzin, Jennifer (2003). "The Twists and Turns in BRCA's Path." *Science* **302**:591-593.
- Croyle, Robert T. and Caryn Lerman (1999). "Risk Communication in Genetic Testing for Cancer Susceptibility." *Journal of the National Cancer Institute Monographs* **25**:59-66.
- Cunningham, Thomas V. (Forthcoming). "Objectivity, Scientificity, and the Dualist Epistemology of Medicine." In G. Lambert, M. Silberstein, and P. Huneman (eds.), *New Essays in Philosophy of Medicine*. Published by Springer.
- Cunningham, Thomas V., Leslie P. Scheunemann, and Douglas White (in preparation). "How Informed are Surrogate Decision Makers About the Principles of Surrogate Decision Making in Actual Clinical Practice?"
- Curtis, J. Randall, Donald L. Patrick, Sarah E. Shannon, Patsy D. Treece, Ruth A. Engelberg, and Gordon D. Rubenfeld (2001). "The Family Conference as a Focus to Improve Communication About End-Of-Life Care in the Intensive Care Unit: Opportunities for Improvement." *Critical Care Medicine* **29**:N26-N33.

d'Agincourt-Canning, Lori (2005). "The Effect of Experiential Knowledge on Construction of Risk Perception in Hereditary Breast/Ovarian Cancer." *Journal of Genetic Counseling* **14**:55-69.

d'Agincourt-Canning, Lori (2006). "A Gift or a Yoke? Women's and Men's Responses to Genetic Risk Information from BRCA1 and BRCA2 Testing." *Clinical Genetics* **70**:462-472.

Daniels, Norman (1979). "Wide Reflective Equilibrium and Theory Acceptance in Ethics." *The Journal of Philosophy* **76**:256-282.

Daniels, Norman (1996a). *Justice and Justification: Reflective Equilibrium in Theory and Practice*. Cambridge, UK: Cambridge University Press.

Daniels, Norman (1996b). "Wide Reflective Equilibrium in Practice." In *Philosophical Perspectives in Bioethics*, L. Sumner and J. Boyle (eds.), Toronto: University of Toronto Press, pp. 98-114.

Darden, Lindley and Joseph A. Cain (1989). "Selection Type Theories." *Philosophy of Science* **56**:106-129.

Darwall, Stephen (2006). *The Second-Person Standpoint*. Cambridge, Mass.: Harvard University Press, 2006.

Daston, Lorraine and Peter Galison (1992). "The Image of Objectivity." *Representations* **40**:81-128.

De Leeuw, J. R. J., M. J. van Vliet, and M. G. E. M. Auseums (2008). "Predictors of Choosing Life-long Screening or Prophylactic Surgery in Women at High and Moderate Risk for Breast and Ovarian Cancer." *Familial Cancer* **7**:347-359.

Decety, Jean (ed.) (2012). *Empathy: From Bench to Bedside*. Cambridge, MA: The MIT Press.

Decety, Jean and William Ickes (eds.) (2009). *The Social Neuroscience of Empathy*. Cambridge, MA: The MIT Press.

Deber, R. B., N. Kraetschmer, and J. Irvine, (1996). "What Role Do Patients Wish to Play in Treatment Decision Making?" *Archives of Internal Medicine* **156**:1414-1420.

DeGrazia, David (1992). "Moving Forward in Bioethics Theory: Theories, Cases, and Specified Principlism." *The Journal of Medicine and Philosophy* **17**:511-539.

DeMarco, Joseph P. (1997). "Coherence and Applied Ethics." *The Journal of Applied Philosophy* **14**:289-300.

- DePaul, Michael R. (1993). *Balance and Refinement: Beyond Coherence Methods of Moral Inquiry*. London: Routledge.
- Devettere, Raymond J. (2010). *Practical Decision Making in Health Care Ethics: Cases and Concepts, 3rd Edition*. Washington, D.C.: Georgetown University Press.
- DeVito, Scott (2000). “On the Value-Neutrality of the Concepts of Health and Disease: Unto the Breach Again.” *Journal of Medicine and Philosophy* **25**:539-567.
- Dorval, Michael, Andrea F. Patenaude, Katherine A. Schneider, Stephanie A. Kieffer, Lisa DiGianni, Kathy J. Kalkbrenner, Janas I. Bromberg, Kathleen Calzone, Jill Stopfer, Barbara L. Weber, and Judy E. Garber (2000). “Anticipated Versus Actual Emotional Reactions to Disclosure of Results of Genetic Tests for Cancer Susceptibility: Findings from *p53* and *BRCA1* Testing Programs.” *Journal of Clinical Oncology* **18**:2135-2142.
- Douglas, Heather A., Rebekah J. Hamilton, and Robin E. Grubs (2009). “The Effect of BRCA Gene Testing on Family Relationships: A Thematic Analysis of Qualitative Interviews.” *Journal of Genetic Counseling* **18**:418-435.
- Douglas, Heather E. (2004). “The Irreducible Complexity of Objectivity.” *Synthese* **138**:453-473.
- Douglas, Heather E. (2009). *Science, Policy, and the Value-Free Ideal*. Pittsburgh: University of Pittsburgh Press.
- Dowie, Jack and Arthur Elstein (eds.) (1988). *Professional Judgment: A Reader in Clinical Decision Making*. Cambridge, UK: Cambridge University Press.
- Dresser, Rebecca (ed.) (2012). *Malignant: Medical Ethicists Confront Cancer*. Oxford: Oxford University Press.
- Driver, Julia (2009). “The History of Utilitarianism.” *The Stanford Encyclopedia of Philosophy* (Summer 2009 Edition), E.N. Zalta (ed.), URL = <<http://plato.stanford.edu/archives/sum2009/entries/utilitarianism-history/>>
- Dupré, John (1993). *The Disorder of Things*. Cambridge, Mass.: Harvard University Press.
- Easton, Douglas F., John L. Hopper, Duncan C. Thomas, Antonis Antoniou, Paul D. R. Pharoah, Alice S. Whittemore, and Robert W. Haile (2003). “Letters: Breast Cancer Risks for BRCA1/2 Carriers.” *Science* **306**:2187-2188.
- Edwards, Adrian and Glyn Elwyn (eds.) (2009). *Shared Decision-Making in Health Care: Achieving Evidence-Based Patient Choice*. Oxford: Oxford University Press.

- Edwards, A., G. Elwyn, K. Hood, C. Atwell, M. Robling, H. Houston, P. Kinnersley, and I. Russell. (2004). "Patient-based Outcome Results From a Cluster Randomized trial of Shared Decision Making Skill Development and Use of Risk Communication Aids in General Practice." *Family Practice* **21**:347-354.
- Edwards, Wade (1954). "The Theory of Decision Making." *Psychological Bulletin* **41**:380-417.
- Elmore, Joann G. and Gerd Gigerenzer (2005). "Benign Breast Disease – The Risks of Communicating Risk." *New England Journal of Medicine* **353**:297-299.
- Elwyn, Glyn, Adrian Edwards, Martin Eccles and David Rovner (2001). "Decision Analysis in Patient Care." *Lancet* **358**:571-574.
- Elwyn, Glyn, Adrian Edwards, and Paul Kinnersley (1999). "Shared Decision-making in Primary Care: The neglected second half of the consultation." *British Journal of General Practice* **49**:477-482.
- Elwyn, Glyn and Richard Gwyn (1998). "Stories We Hear and Stories We Tell...Analysing Talk in Clinical Practice." In T. Greenlagh and B. Hurwitz (eds.), *Narrative Based Medicine*, pp. 165-175.
- Emanuel, Ezekiel J. and Linda L. Emanuel (1992). "4 Models of the Physician-Patient Relationship." *Journal of the American Medicine Association* **267**:2221-2226.
- Ende, Jack, Lewis Kazis, Arlene Ash, and Mark A. Moskowitz (1989). "Measuring Patient's Desire for Autonomy: decision making and information-seeking preferences among medical patients." *Journal of General Internal Medicine* **4**:23-30.
- Ende, Jack, Lewis Kazis, and Mark A. Moskowitz (1990). "Preferences for Autonomy When Patients are Physicians." *Journal of General Internal Medicine* **5**:506-509.
- Engel, George L. (1977). "The Need for a New Medical Model: A Challenge for Biomedicine." *Science* **196**:129-136.
- Engel, George L. (1980). "The Clinical Application of the Biopsychosocial Model." *American Journal of Psychiatry* **137**:535-544.
- Engel, George L. (1981). "The Clinical Application of the Biopsychosocial Model." *The Journal of Medicine and Philosophy* **6**:101-123.
- Engelhardt, H. Tristram Jr. (1975). "The Concepts of Health and Disease." In H. T. Engelhardt, Jr. and S. F. Spicker (eds.), *Evaluation and Explanation in the Biomedical Sciences*, Dordrecht: Riedel, pp. 125-141.

- Engelhardt, H. Tristram Jr. (1976). "Ideology and Etiology." *Journal of Medicine and Philosophy* **1**:256-268.
- Erblich, Joel, Dana H. Bovbjerg, and Heiddis B. Valdimarsdottir (2000). "Looking Forward and Back: Distress Among Women at Familial Risk for Breast Cancer." *Annals of Behavioral Medicine* **22**:53-59.
- Ereshefsky, Mark (2009). "Defining 'Health' and 'Disease'." *Studies in History and Philosophy of Biological and Biomedical Sciences* **40**:221-227.
- Ericksen, Julia (2008). *Taking Charge of Breast Cancer*. Berkeley: University of California Press.
- Escher, M. and A.-P. Sappino (2000). "Primary Care Physicians Knowledge and Attitudes Towards Genetic Testing for Breast-Ovarian Cancer Predisposition." *Annals of Oncology* **11**:1131-1135.
- Evans, David. (2007). "Aristotle on the Relation Between Art and Science." In The Proceedings of the Twenty-First World Congress of Philosophy, Volume 10, I. Kuçuradi, S. Voss, and C. Güzel (eds.), pp. 21-30.
- Faden, Ruth R. and Tom L. Beauchamp (1986). *A History and Theory of Informed Consent*. New York, NY: Oxford University Press.
- Fisher, Sue and Alexandra Dundas Todd (1993). *The Social Organization of Doctor-Patient Communication*, 2nd Ed. Norwood, NJ: Ablex Publishing Company.
- Ford, Sarah, Lesley Fallowfield, Shôn Lewis (1996). "Doctor-Patient Interactions in Oncology." *Social Science & Medicine* **42**:1511-1519.
- Ford, Sarah, Angela Hall, Denise Ratcliffe, and Lesley Fallowfield (2000). "The Medical Interaction Process System (MIPS): An Instrument for Analysing Interviews of Oncologist and Patients with Cancer." *Social Science & Medicine* **50**:553-566.
- Forstrom, Lee A. (1977). "The Scientific Autonomy of Medicine." *The Journal of Medicine and Philosophy* **2**:8-19.
- Foulkes, William D. (2010). "Traffic Control for BRCA1." *New England Journal of Medicine* **362**:755-756.
- Fox, Renée C. and Harold I. Lief (1963). "Training for 'Detached Concern' in Medical Students." In H. I. Lief (ed), *The Psychological Basis of Medical Practice*, pp. 12-35.

- Fried, Terri R., Elizabeth Bradley, and Virginia Towle (2003). "Valuing the Outcomes of Treatment: Do Patients and Their Caregivers Agree?" *Archives of Internal Medicine* **163**:2073-2078.
- Frank, Arthur W. (1995). *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: The University of Chicago Press.
- Frith, Chris D. (2008). "Social Cognition." *Philosophical Transactions of the Royal Society B: Biological Sciences*, **363**:2033-2039.
- Frith, Chris D. and Tania Singer. (2008). "The role of social cognition in decision making." *Philosophical Transactions of the Royal Society B: Biological Sciences*, **363**:3875-3886.
- Frith, Chris D. and Uta Frith (2008). "Implicit and Explicit Processes in Social Cognition." *Neuron* **60**:503-510.
- Frosch, Dominick L. and Robert M. Kaplan (1999). "Shared Decision-making in Clinical Medicine: Past research and future directions." *American Journal of Preventive Medicine* **17**:285-294.
- Fulford, K. W. M. (1989). *Moral Theory and Medical Practice*. Cambridge: Cambridge University Press.
- Gafni, Amiram and Cathy Charles (2009). "The Physician-Patient Encounter: An Agency Relationship?" In A. Edwards and G. Elwyn (eds.), *Shared Decision-Making in Health Care: Achieving Evidence-Based Patient Choice*, Oxford, Oxford University Press, pp. 73-78.
- Gallese, Vittorio and Alvin Goldman (1998). "Mirror Neurons and the Simulation Theory of Mind-Reading." *Trends in Cognitive Science* **2**:493-501.
- Ganz, Patricia A., Katherine A. Desmond, Thomas R. Belin, Beth E. Meyerowitz, and Julia H. Rowland (1999). "Predictors of Sexual Health in Women After a Breast Cancer Diagnosis." *Journal of Clinical Oncology* **17**:2371-2380.
- Garber, Judy (1999). "A 40-Year-Old Woman With a Strong Family History of Breast Cancer." *Journal of the American Medical Association* **282**:1953-1960.
- Gaston, Christine M. and Geoffrey Mitchell (2005). "Information Giving and Decision-Making in Patients with Advanced Cancer: A Systemic Review." *Social Science & Medicine* **61**:2252-2264.
- Geller, Gail, Misha Strauss, Barbara A. Bernhardt, and Neil A. Holtzman (1997). "'Decoding'

Informed Consent: Insights from Women Regarding Breast Cancer Susceptibility Testing.” *The Hastings Center Report* 27:28-33.

Gert, Bernard, Charles M. Culver, and K. Danner Clouser (1997). *Bioethics: A Return to Fundamentals*. New York: Oxford University Press.

Gibson, P. G., P. I. Talbot, and R. C. Toneguzzi (1995). “Self-Management, Autonomy, and Quality-of-Life in Asthma.” *Chest* 107:1003-1008.

Giere, Ronald (2002). “Scientific Cognition as Distributed Cognition.” In P. Carruthers, S. Stich, and M. Siegal (eds.), *Cognitive Basis of Science*, pp. 285-299.

Gigerenzer, Gerd (2010). *Rationality for Mortals*. Oxford: Oxford University Press.

Gigerenzer, Gerd and Daniel G. Goldstein (1996). “Reasoning the Fast and Frugal Way: models of bounded rationality.” *Psychological Review* 103:650-669.

Gigerenzer, Gerd, and J. A. Muir Gray (eds). (2011). *Better Doctors, Better Patients, Better Decisions: Envisioning Health Care 2020*. Cambridge, MA: MIT Press.

Gigerenzer, Gerd, Peter M. Todd, and the ABC Research Group (2000). *Simple Heuristics that Make Us Smart*. New York: Oxford University Press.

Gigerenzer, Gerd, Ralph Hertwig, Eva van den Broek, Barbara Fasolo, and Konstaninos V. Katsikopoulos (2005). “‘A 30% Chance of Rain Tomorrow’: How Does the Public Understand Probabilistic Weather Forecasts?” *Risk Analysis* 25:623-629.

Gigone, Daniel and Reid Hastie (1993). “The Common Knowledge Effect: Information Sharing and Group Judgment.” *Journal of Personality and Social Psychology* 65:959-974.

Gigone, Daniel and Reid Hastie (1997). “The Impact of Information on Small Group Choice.” *Journal of Personality and Social Psychology* 72:132-140.

Gilbar, Roy and Ora Gilbar (2009). “The Medical Decision-Making Process and the Family: The Case of Breast Cancer Patients and their Husbands.” *Bioethics* 23:183-192.

Gohel, M.S., R.A. Bulbulia, F.J. Slim, K.R. Poskitt, and M.R. Whyman (2005). “How to Approach Major Surgery Where Patients Refuse Blood Transfusion (Including Jehovah’s Witnesses).” *Annals of the Royal College of Surgeons of England*, 87:3-14.

Gold, Joshua I. and Michael N. Shadlen (2007). “The Neural Basis of Decision Making.” *Annual Review of Neuroscience* 30:535-574.

- Gold, Natalie (ed.) (2005). *Teamwork: Multi-Disciplinary Perspectives*. New York: Palgrave Macmillan
- Goldie, Peter (1999). "How We Think of Others' Emotions." *Mind & Language* **14**:394-423.
- Goldman, Alvin I. (1992). "Empathy, Mind, and Morals." *Proceedings and Addresses of the American Philosophical Association* **66**:17-41.
- Goldman, Alvin I. (1999). *Knowledge in a Social World*. Oxford: Clarendon Press.
- Golin, Carol, Robin DiMatteo, Naihua Duan, Barbara Leake, and Lillian Gelberg (2002). "Impoverished Diabetic Patients Whose Doctors Facilitate Their Participation in Medical Decision Making are More Satisfied with Their Care." *Journal of General Internal Medicine* **17**:866-875.
- Gorovitz, Samuel and Alasdair MacIntyre (1976). "Toward a Theory of Medical Fallibility." *The Journal of Medicine and Philosophy* **1**:51-71.
- Gräfenhain, Maria, Tanya Behne, Malinda Carpenter, and Michael Tomasello (2009). "Young Children's Understanding of Joint Commitments." *Developmental Psychology* **45**:1430-1443.
- Green, Ariana (2008). *Decoding Breast Cancer: Young Women, Genetics, and Disease*. Unpublished Masters Thesis, University of Cambridge.
- Greenlagh, Trisha and Brian Hurwitz (eds.) (1998). *Narrative Based Medicine: Dialogue and Discourse in Clinical Practice*. London: BMJ Books
- Hacking, Ian (1983). *Representing and Intervening: Introductory Topics in the Philosophy of Natural Science*. Cambridge, UK: Cambridge University Press.
- Hall, Jeff M., Ming K. Lee, Beth Newman, Jan E. Morrow, Lee A. Anderson, Bing Huey, and Mary-Claire King (1990). "Linkage of Early-onset Familial Breast Cancer to Chromosome 17q21." *Science* **250**:1684-1689.
- Hallowell, Nina and Julia Lawton (2002). "Negotiating Present and Future Selves: Managing the Risk of Hereditary and Ovarian Cancer by Prophylactic Surgery." *Health* **6**:423-443.
- Hallowell, Nina, James Mackay, Martin Richards, Martin Gore, and Ian Jacobs (2004). "High-Risk Premenopausal Women's Experiences of Undergoing Prophylactic Oophorectomy: A Descriptive Study." *Genetic Testing* **8**:148-156.
- Halpern, Jodi (2001). *From Detached Concern to Empathy: Humanizing Medical Practice*. New York: Oxford University Press.

Hamann, J., S. Leucht, and W. Kissling (2003). "Shared Decision Making in Psychiatry." *Acta Psychiatrica Scandinavica* **107**:403-409.

Hanson, Mark J. and Daniel Callahan (eds.) (1999). *The Goals of Medicine: The Forgotten Issue in Health Care Reform*. Washington, D.C.: Georgetown University Press.

Hansson, Sven O. (ms). "Decision Theory: A Brief Introduction." Available at: <http://www.infra.kth.se/~soh/decisiontheory.pdf>

Hardwig, John (1990). "What About the Family?" *Hastings Center Report* **20**:5-10.

Harris, Kathleen M. (2001). "Contemporary Breast Imaging in the High-Risk Patient." In V. Vogel (ed.) *Management of Patients at High Risk for Breast Cancer* pp. 120-136.

Haslett, D. W. (1987). "What is Wrong with Reflective Equilibrium?" *The Philosophical Quarterly* **37**:305-311.

Hasting Center Report (1999). "The Goals of Medicine: Setting New Priorities." In M.J. Hanson and D. Callahan (eds.), pp. 1-54.

Heger, Monica (2011). "Mayo Clinic Plans 2012 Launch for Sequencing-Based Colon Cancer Panel." *GenomeWeb*. Available at: <http://www.genomeweb.com/sequencing/mayo-clinic-plans-2012-launch-sequencing-based-colon-cancer-panel>. Accessed on May 21, 2011 (subscription required).

Hempel, Carl G. (1966). *Philosophy of Natural Science*. Eaglewood Cliffs, NJ: Printice-Hall.

Herrmann, Esther, Josep Call, María Victoria Hernández-Lloreda, Brian Hare, and Michael Tomasello (2007). "Humans Have Evolved Specialized Skills of Social Cognition: The Cultural Intelligence Hypothesis." *Science* **317**:1360-1366.

Hesslow, Germund (1993). "Do We Need a Concept of Disease?" *Theoretical Medicine and Bioethics* **14**:1-14.

Hinsz, Verlin B., R. Scott Tinsdale, and David A. Vollrath (1997). "The Emerging Conceptualization of Groups as Information Processors." *Psychological Bulletin* **121**:43-64.

Hofmann, Bjørn (2003)". Medicine as *Techne* – A Perspective from Antiquity." *Journal of Medicine and Philosophy* **28**:403-425.

Hogarth, Stuart, Gail Javitt, and David Melzer (2008). "The Current Landscape for Direct-to-Consumer Genetic Testing, Legal, Ethical, and Policy Issues." *Annual Review of Genomics and Human Genetics* **9**:161-182.

- Horn, Peter (2003). *Clinical Ethics Casebook 2nd Edition*. Belmont, CA: Wadsworth Group.
- Hughes, Chanita, Andres Gomez-Caminero, Judith Benkendorf, Jon Kerner, Claudine Isaacs, James Barter, and Caryn Lerman (1997). "Ethnic Differences in Knowledge and Attitudes About BRCA1 Testing in Women at Increased Risk." *Patient Education and Counseling* **32**:51-62.
- Hunter, Kathryn M. (1991). *Doctor's Stories: The narrative structure of medical knowledge*. Princeton: Princeton University Press.
- Humber, James M. and Robert F. Almeder (eds.) (1997). *What is Disease?* Totowa, N.J.: Humana Press Inc.
- Hutchins, Edwin (1991). "The Social Organization of Distributed Cognition." In *Perspectives on Socially Shared Cognition*, L. Resnik, J. M. Levine, and S. D. Teasley (eds), pp. 283-307.
- Hutchins, Edwin (1995). *Cognition in the Wild*. Cambridge, MA.: MIT Press.
- Hutchins, Edwin (2001). "Cognition, Distributed." In N.J. Smelser and P.B. Baltes (eds.), *International Encyclopedia of the Social and Behavioral Sciences*, Oxford: Elsevier, pp. 2068-2072.
- Jacobsen, Paul B., Heiddis B. Valdimarsdotter, Karen L. Brown, and Kenneth Offit (1997). "Decision-Making About Genetic Testing Among Women at Familial Risk for Breast Cancer." *Psychosomatic Medicine* **59**:459-466.
- Jaeger, Werner (1957). "Aristotle's Use of Medicine as a Model of Method in His Ethics." *The Journal of Hellenistic Studies* **77**:54-61.
- Jemal, Ahmedin, Rebecca Siegel, Elizabeth Ward et. al. (2009). "Cancer Statistics, 2009." *CA: A Cancer Journal for Clinicians* **59**:225-249.
- Joffe, S., E. F. Cook, P. D. Cleary, J. W. Clark, and J. C. Weeks (2001). "Quality of Informed Consent in Cancer Clinical Trials: a Crosssectional Survey." *Lancet* **358**:1772-1777.
- Joffe, S., M. Manocchia, J. C. Weeks, and P. D. Cleary (2003). "What Do Patients Value in their Hospital Care? An empirical perspective on autonomy centred bioethics." *Journal of Medical Ethics* **29**:103-108.
- Jolie, Angelina (2013). "My Medical Choice." The New York Times, May 14, 2013 A25.

- Johansson, Mats and Linus Broström (2008). "Turning Failures in Successes: A Methodological Shortcoming in Empirical Research on Surrogate Accuracy." *Theoretical Medicine and Bioethics* 29:17-26.
- Joyce, Richard (2006). *The Evolution of Morality*. Cambridge, M.A.: The MIT Press.
- Kahn, Patricia (1996). "Coming to Grips with Genes and Risk." *Science* 274:496-498.
- Kahneman, Daniel (2003). "A Perspective on Judgment and Choice." *American Psychologist* 58:697-720.
- Kahneman, Daniel, Paul Slovic, and Amos Tversky (Eds.) (1982). *Judgment Under Uncertainty: Heuristics and Biases*. New York: Cambridge University Press.
- Kahneman, Daniel and Amos Tversky (1979). "Prospect Theory: An analysis of decisions under risk." *Econometrica* 47:263-291.
- Kahneman, Daniel and Amos Tversky (Eds.) (2000). *Choices, Values, and Frames*. New York: Cambridge University Press.
- Kagel, John H. and Alvin E. Roth (Eds.) (1995). *The Handbook of Experimental Economics*. Princeton, NJ: Princeton University Press.
- Kass, Leon (1975). "Regarding the End of Medicine and Pursuit of Health." *The Public Interest* 40:11-42.
- Kaufman, Sharon R. (2005). ...*And a Time to Die: How American Hospitals Shape the End of Life*. New York: Scribner.
- Kavanagh, Anne and Dorothy H. Bloom (1998). "Embodied Risk: My Body, Myself?" *Social Science & Medicine* 46:437-444.
- Keeney, Ralph L. and Howard Raiffa (1976). *Decisions with Multiple Objectives: Preferences and Value Tradeoffs*. New York: John Wiley and Sons.
- Kellert, Stephen E., Hellen E. Longino, and C. Kenneth Waters (2006). "Introduction: The Pluralist Stance." In *Scientific Pluralism*, S. Kellert, H. Longino, and C. Waters (eds.), pp. vii-xxix.
- Kendell, R. E. (1974). "The Concept of Disease and Its Implications for Psychiatry." *British Journal of Psychiatry* 127:305-315.

- Kenen, Regina, Audrey Ardern-Jones, and Rosalind Eeles. (2003). "Family Stories and the Use of Heuristics: Women From Suspected Hereditary Breast and Ovarian Cancer (HBOC) Families." *Sociology of Health & Illness* **25**:838-865.
- Kesselheim, Aaron, Robert M. Cook-Deegan, David E. Winickoff, and Michelle M. Mello (2013). "Gene Patenting—The Supreme Court Finally Speaks." *New England Journal of Medicine* **369**:869-875.
- King, Jaime S. and Benjamin Moulton (2006). "Rethinking Informed Consent: The Case for Shared Medical Decision-Making." *American Journal of Law and Medicine* **32**:249-501.
- King, Mary-Claire (2003). "Letters: Response: Breast Cancer Risks for BRCA1/2 Carriers." *Science* **306**:2188-2191.
- King, Nancy M. P. (1988). "Ethics Committees: Talking the Captain Through Troubled Waters." In N. M. P. King, L. Churchill, and A. W. Cross (eds.), *The Physician as Captain of the Ship*, pp. 223-241.
- King, Nancy M. P., Larry Churchill, and Alan W. Cross (Eds.) (1988). *The Physician as Captain of the Ship: A Critical Appraisal*. Boston, MA: D. Reidel Publishing Company.
- Klein, Karen and Stephen G. Pauker (1988). "Recurrent Deep Venous Thrombosis in Pregnancy: Analysis of the Risks and Benefits of Anticoagulation." In J. Dowie and A. Elstein (eds.), pp. 277-297.
- Klitzman, Robert (2007). *When Doctors Become Patients*. New York: Oxford University Press.
- Klitzman, Robert and Wendy Chung (2010). "The Process of Deciding About Prophylactic Surgery for Breast and Ovarian Cancer: Patient Questions, Uncertainties, and Communication." *American Journal of Medical Genetics Part A* **152A**:52-66.
- Kluger, Jeffrey and Alice Park (2013). "The Angelina Effect." *Time Magazine* **181**:30-33.
- Korsgaard, Christine M. (1996). *The Sources of Normativity*, ed. by O. O'Neill. Cambridge, UK: Cambridge University Press.
- Kraetschmer, N., N. Sharpe, S. Urowitz, and R. B. Deber (2004). "How Does Trust Affect Patient Preferences for Participation in Decision-making?" *Health Expectations* **7**:317-326.

- Kraybill, Ernest N. (1988). "Team Medicine in the NICU: Ship or Flotilla of Lifeboats?" In N. M. P. King, L. Churchill, and A. W. Cross (eds.), *The Physician as Captain of the Ship*, pp. 77-88.
- Kuehn, Bridget M. (2009). "States Explore Shared Decision-Making." *Journal of the American Medical Association* **301**:2539-2541.
- Kukla, Rebecca (2005). "Conscientious Autonomy: Displacing Decisions in Health Care." *The Hastings Center Report* **35**:34-44.
- Kuller, Lewis H. (2001). "The Epidemiology of Breast Cancer." In V. Vogel (ed.) *Management of Patients at High Risk for Breast Cancer* pp. 1-18.
- Laden, Anthony S. (2012). *Reasoning: A Social Picture*. Oxford: Oxford University Press.
- Lapham, Virginia E., Chashira Kozma, and Joan O. Weiss (1996). "Genetic Discrimination: Perspectives of Consumers." *Science* **274**:621-624.
- Larson, James R. Jr., Caryn Christensen, Ann S. Abbot, and Timothy M. Franz (1996). "Diagnosing Groups: Charting the Flow of Information in Treatment decision-making Teams." *Journal of Personality and Social Psychology* **67**:315-330.
- Larson, James R. Jr., Pennie G. Foster-Fishman, and Christopher B. Keys (1994). "Discussion of Shared and Unshared Information in Decision-Making Groups." *Journal of Personality and Social Psychology* **67**:446-461.
- Lelorain, Sophie, Anne Brédart, Sylvie Dolbeault, and Serge Sultan (2012). "A Systematic Review of the Associations Between Empathy Measures and Patient Outcomes in Cancer Care." *Psycho-Oncology* **21**:1255-1264.
- Lennox, James G. (1995). "Health as an Objective Value." *The Journal of Medicine and Philosophy* **20**:499-511.
- Lerman, Caryn, Barbara Biesecker, Judith L. Benkendorf, Jon Kerner, Andres Gomez-Caminero, Chanita Hughes, and Margaret M. Reed. "Controlled Trial of Pretest Education Approaches to Enhance Informed Decision-Making for BRCA1 Gene Testing." *Journal of the National Cancer Institute* **89**:148-157.
- Lerman, Caryn, Chanita Hughes, Robert T. Croyle, David Main, Carolyn Durham, Carrie Snyder, Aba Bonney, Jane F. Lynch, Steven Narod, and Henry T. Lynch (2000). "Prophylactic Surgery Decisions and Surveillance Practices One Year Following BRCA1/2 Testing." *Preventative Medicine* **31**:75-80.

Lerman, Caryn, Steven Narod, Kevin Schulman, Andres Gomez-Caminero, Karen Gold, Bruce Trock, David Main, Jane Lynch, Cecil Fulmore, Carrie Snyder, Stephen J. Lemon, Theresa Conway, Patricia Tonin, Giblert Lenoir, and Henry Lynch (1996). "BRCA1 Testing in Families with Hereditary Breast-Ovarian Cancer." *Journal of the American Medical Association* **275**:1885-1892.

Levinson, Wendy, Audiey Kao, Alma Kuby, and Ronald A. Thisted (2005). "Not All Patients Want to Participate in Decision Making - A national study of public preferences." *Journal of General Internal Medicine* **20**:531-535.

List, Christian and Philip Pettit (2011). *Group Agency: The Possibility, Design, and Status of Corporate Agents*. Oxford: Oxford University Press.

Lloyd, G. E. R. (ed.) (1984). *Hippocratic Writings*. New York: Penguin Putnam Inc.

Longino, Helen (1990). *Science as Social Knowledge: values and objectivity in scientific inquiry*. Princeton, NJ: Princeton University Press.

Longino, Helen (2002). *The Fate of Knowledge*. Princeton, NJ: Princeton University Press.

Lovibond, Sabina (1983). *Realism and Imagination in Ethics*. Minneapolis: University of Minnesota Press.

Lusted, Lee B. (1968). *Introduction to Treatment decision-making*. Springfield, IL: C. C. Thomas.

Lynch, Henry T., Stephen J. Lemon, Carolyn Durham, Susan T. Tinley, Chris Connolly, Jane F. Lynch, Jonathan Surdam, Ernest Orinion, Sue Slominski-Caster, Patrice Watson, Caryn Lerman, Patricia Tonin, Gilbert Lenoir, Olga Serova, and Steven Narod (1997). "A Descriptive Study of BRCA1 Testing and Reactions to Disclosure of Test Results." *Cancer* **79**: 2219-2228.

Machamer, Peter and Gereon Wolters (2004). "Introduction: Science, Values, and Objectivity." In P. Machamer and G. Wolters (eds.) *Science, Values, and Objectivity*, Pittsburgh: University of Pittsburgh Press, pp. 1-13.

Machamer, Peter and Heather Douglas (1998). "How Values Are in Science." *Critical Quarterly* **40**:29-43.

Machamer, Peter and Heather Douglas (1999). "Cognitive and Social Values." *Science and Education* **8**:45-54.

- Machamer, Peter and Michael Silberstein (eds.) (2002). *The Blackwell Guide to Philosophy of Science*. Malden, MA: Blackwell Publishers.
- MacKay, Alfred F. (1980). *Arrow's Theorem: The Paradox of Social Choice: A Case Study in the Philosophy of Economics*. New Haven: Yale University Press.
- Macke, Ellen (1996). "A Family History of Breast and Ovarian Cancer." In Theresa Marteau and Martin Richards (Eds.), *The Troubled Helix: Social and psychological implications of the new genetics*, Cambridge, UK: Cambridge University Press), pp. 31-37.
- Magnus, P. D. (2007). "Distributed Cognition and the Task of Science." *Social Studies of Science* **37**:297-310.
- Makoul, Gregory and Marla L. Clyman (2006). "An Integrative Model of Shared Decision Making in Medical Encounters." *Patient Education and Counseling* **60**:301-312.
- Malterud, Kirsti (1995). "The Legitimacy of Clinical Knowledge: Towards a Medical Epistemology Embracing the Art of Medicine." *Theoretical Medicine and Bioethics* **16**:183-198.
- Mangset, M., R. Førde, J. Nessa, E. Berge, and T. Bruun Wyller (2008). "'I Don't Like That, it's Tricking People Too Much...': Acute Informed Consent to Participation in a Trial of Thrombolysis for Stroke." *Journal of Medical Ethics* **34**:751-756.
- Mantsavinos, C. (ed.) (2009). *Philosophy of the Social Sciences: Philosophical Theory and Scientific Practice*. Cambridge, UK: Cambridge University Press.
- March, James G. (1994) *A Primer on Decision-making: How Decisions Happen*. New York: The Free Press.
- Marcum, James A. (2013). "The Role of Emotions in Clinical Reasoning and Decision Making." *Journal of Medicine and Philosophy* DOI: 10.1093/jmp/jht040
- Margolis, Joseph (1971). *Values and Conduct*. New York, Oxford University Press.
- Margolis, Joseph (1976). "The Concept of Disease." *The Journal of Medicine and Philosophy* **1**:238-255.
- Matloff, Ellen T., Heather Shappell, Karina Brierley, Barbara A. Bernhardt, Wendy McKinnon, and Beth Peshkin (2000). "What Would You Do? Specialists' Perspectives on Cancer Genetic Testing, Prophylactic Surgery, and Insurance Discrimination." *Journal of Clinical Oncology* **18**:2484-2492.

McKinstry, Brian (2000). "Do Patients Wish to be Involved in Decision Making the Consultation? A Cross Sectional Survey with Video Vignettes." *British Medical Journal* 321:867-871.

McMullin, Ernan (1982). "Values in Science." In *PSA: Proceedings of the Biennial Meeting of the Philosophy of Science Association*, Vol. 1982, Vol. 2, University of Chicago Press, pp. 3-28.

McNeil, Barbara J., Stephen G. Pauker, and Amos Tversky (1988). "On the Framing of Medical Decisions." In Bell, Raiffa, and Tversky (eds.) *Decision-Making*, pp. 562-568.

McNeil, Barbara J., Stephen G. Pauker, Harold C. Sox Jr., and Amos Tversky ([1982] 2000). "On the Elicitation of Preferences for Alternative Therapies." In Connolly, Arkes, and Hammond (eds.), *Judgment and Decision-Making*, pp. 272-280.

Meisal, Alan (1991). "The Legal Consensus About Forgoing Life-Sustaining Treatment: Its Status and Its Prospects." *Kennedy Institute of Ethics Journal* 2:309-345.

Mendick, Nicola, Bridget Young, Christopher Holcombe, and Peter Salmon (2010). "The Ethics of Responsibility and Ownership in Decision-Making About Treatment for Breast Cancer: Triangulation of Consultation with Patient and Surgeon Perspectives." *Social Science & Medicine* 70:1904-1911.

Meyer, Lennart and Anita Ringberg (1986). "A Prospective Study of Psychiatric and Psychosocial Sequelae of Bilateral Subcutaneous Mastectomy." *Scandinavian Journal of Plastic and Reconstructive Surgery* 20:101-107.

Miki, Yoshio, Jeff Swensen, Donna Shattuck-Eidens et. al. (1994). "A Strong Candidate for the Breast and Ovarian Cancer Susceptibility Gene *BRCA1*." *Science* 266:66-71.

Mill, John Stuart ([1861] 2001). *Utilitarianism*, 2nd Edition. Indianapolis: Hackett Publishing Company.

Millgram, Elijah (2005). *Ethics Done Right: Practical Reasoning as a Foundation for Moral Theory*. New York: Cambridge University Press, 2005.

Miller, Suzanne M., Carolyn Y. Fang, Sharon L. Manne, Paul F. Engstrom, and Mary B. Daly (1999). "Decision-Making About Prophylactic Oophorectomy Among At-Risk Women: Psychological Influences and Implications." *Gynecologic Oncology* 75:406-412.

Miller, Suzanne M., Pagona Roussi, Mary B. Daly, and John Scarpato (2010). "New Strategies in Ovarian Cancer: Uptake and Experience of Women at High Risk of Ovarian Cancer

Who are Considering Risk-Reducing Salpingo-Oophorectomy.” *Clinical Cancer Research* **16**:5094-5106.

Misak, Cheryl (2000). *Truth, Politics, Morality: Pragmatism and Deliberation*. London: Routledge.

Misak, Cheryl (2005). “ICU Psychosis and Patient Autonomy: Some Thoughts from the Inside.” *Journal of Medicine and Philosophy* **30**:411-430.

Misak, Cheryl (2008). “Experience, Narrative, and Ethical Deliberation.” *Ethics* **118**:614-632.

Mishler, Elliot G. (1984). *The Discourse of Medicine: Dialectics of Medical Interviews*. Norwood, NJ: Alex Publishing Corporation.

Mitchell, Sandra D. (2003). *Biological Complexity and Integrative Pluralism*. Cambridge: Cambridge University Press.

Mitchell, Sandra D. (2009). *Unsimple Truths: Science, Complexity, and Policy*. University of Chicago Press.

Montgomery, Kathryn (2006). *How Doctors Think: Clinical Judgment and the Practice of Medicine*. New York: Oxford University Press.

Munson, Ronald (1981). “Why Medicine Cannot Be a Science.” *The Journal of Medicine and Philosophy* **6**:183-208.

Muramoto, Osamu (1998a). Bioethics of the Refusal of Blood by Jehovah’s Witnesses: Part 1. Should bioethical deliberation consider dissident’s views?” *Journal of Medical Ethics* **24**:223-230.

Muramoto, Osamu (1998b). Bioethics of the Refusal of Blood by Jehovah’s Witnesses: Part 2. A novel approach based on rational non-interventional paternalism. *Journal of Medical Ethics* **24**:295-301

Muramoto, Osamu (1999) Bioethics of the Refusal of Blood by Jehovah’s Witnesses: Part 3. A proposal for a don’t-ask-don’t-tell policy. *Journal of Medical Ethics* **25**:463-8.

Murphy, Dominic (2006). *Psychiatry in the Scientific Image*. Cambridge, MA: MIT Press.

Nagel, Thomas (1979). *Mortal Questions*. Cambridge, UK: Cambridge University Press.

National Cancer Institute (2011). Available at: <http://www.cancer.gov>. Accessed April 28, 2011.

- Nordenfelt, Lennart (1987). *On the Nature of Health*. Dordrecht: Reidel.
- Nordenfelt, Lennart (1993). "On the Relevance and Importance of the Notion of Disease." *Theoretical Medicine* 14:15-26.
- Nordenfelt, Lennart (2007). "The Concepts of Health and Disease Revisited." *Medicine, Health Care, and Philosophy* 10:5-10.
- Nordin, Ingemar (2000). "Expert and Non-Expert Knowledge in Medical Practice." *Medicine, Health Care and Philosophy* 3:297-304.
- Novaes, Catarina D. (2012). *Formal Languages in Logic: A Philosophical and Cognitive Analysis*. Cambridge, UK: Cambridge University Press.
- Nussbaum, Martha C. (1990). "Perceptive Equilibrium: Literary Theory and Ethical Theory." In M. C. Nussbaum, *Love's Knowledge: Essays on Philosophy and Literature*, Oxford: Oxford University Press, pp. 168-194.
- Oktay, Julianne S. (2005). *Breast Cancer: Daughters Tell Their Stories*. Binghampton, NY: Haworth Press.
- Olaya, Windy, Pamela Esquivel, Jan H. Wong, John W. Morgan, Adam Freeberg, Sharmila Roy-Chowdhury, and Sharon Lum (2009). "Disparities in BRCA Testing: When Insurance Coverage is Not a Barrier." *The American Journal of Surgery* 198: 562-565.
- Ormondroyd, Elizabeth, Louise Donnelly, Clare Moynihan, Cornelie Savona, Elizabeth Bancroft, D. Gareth Evans, Rosalind A. Eeles, Stuart Lavery, and Maggie Watson (2012). "Attitudes to Reproductive Genetic Testing in Women Who Had a Positive BRCA Test Before Having Children: A Qualitative Analysis." *European Journal of Human Genetics* 20:4-10.
- Parker, Lisa A., Alan Meisel, and Melisa J. Hogan (2001). "Legal and Ethical Issues in Risk Assessment, Management, and Testing." In V. Vogel (ed.) *Management of Patients at High Risk for Breast Cancer* pp. 245-261.
- Parry, Richard. 2009. "Episteme and Techne." *The Stanford Encyclopedia of Philosophy*, E. Zalta (ed.). Available at: <http://plato.stanford.edu/archives/spr2009/entries/episteme-techne>
- Parthasarathy, Shobita (2005). "Architectures of Genetic Medicine: Comparing Genetic Testing for Breast Cancer in the USA and UK." *Social Studies of Science* 35:5-40.

- Pellegrino, Edmund D. (1999). "The Goals and Ends of Medicine: How Are They to be Defined?" In M.J. Hanson and D. Callahan (eds.), pp. 55-68.
- Pellegrino, Edmund D. and David C. Thomasma (1981). *A Philosophical Basis of Medical Practice*. Oxford: Oxford University Press.
- Ponder, Bruce (1997). "Genetic Testing for Cancer Risk." *Science* **278**:1050-1054.
- Priddy, Kevin L. and Paul E. Keller (2005). *Artificial Neural Networks: An Introduction*. Bellingham: The International Society for Optical Engineering.
- Proctor, Robert (1991). *Value-free Science? Purity and Power in Modern Knowledge*. Cambridge, MA: Harvard University Press.
- Prospero, Lisa S., Maureen Seminsky, Joanne Honeyford, Brian Doan, Edmee Franssen, Wendy Meschino, Pamela Chart, and Ellen Warner (2001). "Psychosocial Issues Following A Positive Result of Genetic Testing for *BRCA1* and *BRCA2* Mutations: Findings from a Focus Group and a Needs-Assessment Survey." *Canadian Medical Association Journal* **164**:1005-1009.
- Proulx, Stephen R., Daniel E. L. Promslow, and Patrick C. Philips (2005). "Network Thinking in Ecology and Evolution." *TRENDS in Ecology and Evolution* **20**:345-353.
- Puchalski, C. M., Z. S. Zhong, M. M. Jacobs, E. Fox, J. Lynn, J. Harrold, A. Galanos, R. S. Phillips, R. Califf, and J. M. Teno (2000). "Patients Who Want Their Family and Physician to Make Resuscitation Decisions for Them: Observations from SUPPORT and HELP." *Journal of the American Geriatrics Society* **48**:S84-S90, Suppl. S.
- Quine, W. V. O. (1963). *From a Logical Point of View: 9 logico-philosophical essays*. New York: Harper and Row.
- Quine, W. V. O. (1964). *Word and Object*. Cambridge, MA: MIT Press.
- Quine, W. V. O. (1993). "In Praise of Observation Sentences." *The Journal of Philosophy* **90**:107-116.
- Radden, Jennifer (1994). "Recent Criticism of Psychiatric Nosology: A Review." *Philosophy, Psychiatry, & Psychology* **1**:193-200.
- Raiffa, Howard (1968). *Decision Analysis*. Reading, Mass.: Addison-Wiley.
- Ramsey, Frank P. (1964). "Truth and Probability." In H. Kyburg and H. Smokler, eds., *Studies in Subjective Probability*. New York: Wiley.

- Rao, Goutham (2007). *Rational Medical Decision-Making: A Case-Based Approach*. New York: McGraw Hill Medical.
- Rawls, John (1951). "Outline of a Decision Procedure for Ethics." *The Philosophical Review* **60**:177-197.
- Rawls, John (1971/1999). *A Theory of Justice*. Cambridge, Mass.: Harvard University Press.
- Rawls, John (2005). *Political Liberalism: Expanded Edition*. New York: Columbia University Press.
- Ray, Jessica A., Lois J. Loescher, and Molly Brewer (2005). "Risk-Reduction Surgery Decisions in High-Risk Women Seen for Genetic Counseling." *Journal of Genetic Counseling* **14**: 473-484.
- Resnik, Lauren B., John M. Levine, and Stephanie D. Teasley (Eds.) (1991). *Perspectives in Socially Shared Cognition*. Washington, DC: The American Psychological Association.
- Resnik, Michael D. (1987). *Choices: An Introduction to Decision Theory*. Minneapolis: University of Minnesota Press.
- Reznek, Lawrie (1987). *The Nature of Disease*. London: Routledge and Kegan Paul.
- Richardson, Henry S. (1990). "Specifying Norms as a Way to Resolve Concrete Ethical Problems." *Philosophy and Public Affairs* **19**:279-310.
- Richardson, Henry S. (1994). *Practical Reasoning About Final Ends*. Cambridge, UK: Cambridge University Press.
- Rimer, B. K., P. A. Briss, P. K. Zeller, E. C. Y. Chan, and S. H. Woolf (2004). "Informed Decision Making: What is its Role in Cancer Screening?" *Cancer* **101**:1214-1228, Suppl. S.
- Ross, Don (2005). *Economic Theory and Cognitive Science: Microexplanation*. MIT Press.
- Ross, Don, David Spurrett, Harold Kincaid, G. Lynn Stephens (eds.) (2007). *Distributed Cognition and the Will: Individual cognition and social context*. MIT Press.
- Rotter, Debra L. and Judith A. Hall (1992). *Doctors Talking With Patients/Patients Talking With Doctors: Improving Communication in Medical Visits*. Westport, CT: Auburn House.
- Rubenstein, Wendy S. (2001). "The Genetics of Breast Cancer." In V. Vogel (ed.) *Management of Patients at High Risk for Breast Cancer* pp. 19-55.

- Sabatine, Marc S. (ed.) (2011). *Pocket Medicine: The Massachusetts General Hospital Handbook of Internal Medicine*. Philadelphia: Lippincott, Williams & Wilkins.
- Sachs, Lisbeth, Adam Taube, and Carol Tishelman (2001). “Risk in Numbers—Difficulties in the Transformation of Genetic Knowledge from Research to People: The Case of Hereditary Cancer.” *Acta Oncologica* **40**:445-453.
- Sackett, David L., Sharon E. Strauss, W. Scott Richardson, William Rosenberg, R. Bryan Haynes (eds.) (2000). *Evidence-Based Medicine: How to Practice and Teach EDM*. 2nd Ed. Edinburgh and London: Churchill Livingstone.
- Sackett, David L., William M. C. Rosenberg, J. A. Muir Gray, R. Brian Haynes, and W. Scott Richardson (1996). “Evidence Based Medicine: What it is and What it isn’t.” *British Medical Journal* **312**:71-72.
- Sade, Robert M. (1995). “A Theory of Health and Disease: The Objectivist-Subjectivist Dichotomy.” *The Journal of Medicine and Philosophy* **20**:513-525.
- Sagi, Michal, Luna Kaduri, Joel Zlotogora, and Tamar Peretz (1998). “The Effect of Genetic Counseling on Knowledge and Perceptions Regarding Risks for Breast Cancer.” *Journal of Genetic Counseling* **7**:417-434.
- Sanfrey, Alan G., George Lowenstein, Samuel M. McClure, and Jonathan D. Cohen (2006). “Neuroeconomics: Cross-currents in Research on Decision-Making.” *Trends in Cognitive Science* **10**:108-116.
- Sanfrey, Alan G., James K. Rilling, Jessica A. Aronson, Leigh E. Nystrom, and Jonathan D. Cohen (2003). “The Neural Basis of Economic Decision-Making in the Ultimatum Game.” *Science* **300**:1755-1758.
- Saunders, John (2000). “The Practice of Clinical Medicine as an Art and as a Science”. *Medical Humanities* **26**:18-22.
- Savage, Leonard J. (1954). *The Foundations of Statistics*. New York: Wiley.
- Schaffner, Kenneth F. (1993). *Discovery and Explanation in Biology and Medicine*. Chicago: University of Chicago Press.
- Schaffner, Kenneth F. (1999). “Coming Home to Hume: A Sociobiological Foundation for a Concept of ‘Health’ and Morality.” *Journal of Medicine and Philosophy* **24**:365-375.

Schenker, Yael, Greer A. Tiver, Seo Yeon Hong, and Douglas B. White (2012). "Association Between Physicians Beliefs and the Option of Comfort Care for Critically Ill Patients." *Intensive Care Medicine* **38**:1607-1615.

Schildmann, J., M. Grunke, J. R. Kalden, and J. Vollmann (2008). "Information and Participation in Decision-making About Treatment: a Qualitative Study of Perceptions and Preferences of Patients with Rheumatoid Arthritis." *Journal of Medical Ethics* **34**:775-779.

Schiller J. S., J. W. Lucas, and J. A. Peregoy (2012). *Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2011*. Maryland: Department of Health and Human Services Publication (No. [PHS] 2013-1584).

Schmitt, Frederick F. (2003). *Socializing Metaphysics: The Nature of Social Reality*. New York: Rowman and Littlefield Publishers.

Schneider, Carl E. (1998). *The Practice of Autonomy: Patients, Doctors, and Medical Decisions*. New York: Oxford University Press.

Schneider, Katherine A., Jill E. Stopfer, June A. Peters, Ellen Knell, and Gladys Rosenthal (1997). "Complexities in Cancer Risk Counseling: Presentation of Three Cases." *Journal of Genetic Counseling* **6**:147-167.

Smart, J. J. C. and Bernard Williams (1973). *Utilitarianism: For and Against*. Cambridge: Cambridge University Press.

Schwartz, Alan and George Bergus (2008). *Medical Decision Making: A Physician's Guide*. Cambridge, UK: Cambridge University Press.

Schwartz, Gordon F., Kevin S. Hughes, Henry T. Lynch, Carol J. Fabian, Ian S. Fentiman, Mark E. Robson, Susan M. Domchek, Lynn C. Hartmann, Roland Holland, David J. Winchester, and the Consensus Conference Committee (2008). "Proceedings of the International Consensus Conference on Breast Cancer Risk, Genetics, & Risk Management, April, 2007." *Cancer* **113**:2627-2637.

Schwartz, Marc D., Chanita Hughes, Joan Roth, David Main, Beth N. Peshkin, Claudine Isaacs, Carol Kavanagh, and Caryn Lerman (2000). "Spiritual Faith and Genetic Testing Decisions Among High-Risk Breast Cancer Proband." *Cancer Epidemiology, Biomarkers & Prevention* **9**:381-385.

Seckler, Allison B., Diane E. Meier, Michael Mulvihill, and Barbara E. C. Paris (1991). "Substituted Judgment: How Accurate are Proxy Predictions?" *Annals of Internal Medicine* **115**:92-98

- Sen, Amartya (1970). *Collective Choice and Social Welfare*. San Francisco: Holden-Day.
- Shalowitz, David I., Elizabeth Garret-Mayer, and David Wendler (2006). "The Accuracy of Surrogate Decision Makers: A systematic review." *Archives of Internal Medicine* **166**:493-497.
- Shoda, Yuichi, Walter Mischel, Suzanne M. Miller, Michael Dienfenbach, Mary B. Daly, and Paul F. Engstrom (1998). "Psychological Interventions and Genetic Testing: Facilitating Informed Decisions About *BRCA1/2* Cancer Susceptibility." *Journal of Clinical Psychology in Medical Settings* **5**:3-17.
- Siegler, Mark (1981). "The Doctor-Patient Encounter and its Relationship to Theories of Health and Disease." In Caplan et al. (eds) (1981), pp. 627-644.
- Simon, Herbert A. (1956). "Rational Choice and the Structure of the Environment." *Psychological Review* **63**:129-138.
- Simon, Herbert A. (1997). *Models of Bounded Rationality: Empirically Grounded Economic Reasons, Volume 3*. Cambridge, MA.: MIT Press.
- Simons, M. P., T. Aufenacker, M. Bay-Nielsen, et al. (2009). "European Hernia Society Guidelines on the Treatment of Inguinal Hernia in Adult Patients." *Hernia* **13**:343-403.
- Sivell, Stephanie, Glyn Elwyn, Clara L. Gaff, Angus J. Clarke, Rachel Iredale, Chris Shaw, Joanna Dundon, Hazel Thornton, and Adrian Edwards (2008). "How Risk is Perceived, Constructed, and Interpreted by Clients in Clinical Genetics, and the Effects on Decision Making: A Systematic Review." *Journal of Genetic Counseling* **17**:30-63.
- Smiley, Marion (2011). "Collective Responsibility." *The Stanford Encyclopedia of Philosophy* (Fall 2011 Edition), E. N. Zalta (ed.), URL = <<http://plato.stanford.edu/archives/fall2011/entries/collective-responsibility/>>.
- Sox, Harold C., Marshall A. Blatt, Michael C. Higgins, and Keith I. Marton (2007). *Medical Decision-making*. US: American College of Physicians.
- Szasz, Thomas S. (1974). *The Myth of Mental Illness*, rev. ed. New York: Harper and Row.
- Stalmeier, Peep F. M., Ivana J. Unic, Lia C. G. Verhoef, and Willem A. J. Van Daal (1999). "Evaluation of Shared Decision Making Program for Women Suspected to Have a Genetic Predisposition to Breast Cancer: Preliminary Results." *Medical Decision Making* **19**:230-241.

- Stasser, Garold, Dennis D. Stewart, and Gwen M. Wittenbaum (1995). "Expert Roles and Information Exchange During Discussion: the Importance of Knowing Who Knows What." *Journal of Experimental Social Psychology* 31:244-265.
- Stasser, Garold, Laurie A. Taylor, and Coleen Hanna (1989). "Information Sampling in Structured and Unstructured Discussions of Three- and Six-Person Groups." *Journal of Personality and Psychology* 57:67-78.
- Stasser, Garold and Sarah I. Vaughan (2000). "Pooling Unshared Information: The Benefits of Knowing How Access to Information is Distributed Among Group Members." *Organizational Behavior and Human Decision Processes* 82:102-116.
- Staton, Ashley D., Allison W. Kurian, Kristin Cobb, Meredith A. Mills, and James M. Ford (2008). "Cancer Risk Reduction and Reproductive Concerns in Female BRCA1/2 Mutation Carriers." *Familial Cancer* 7:179-186.
- Stewart, Moira, Judith Belle Brown, W. Wayne Weston, Ian R. McWhinney, Carol L. McWilliam, and Thomas R. Freeman (Eds.) (2003). *Patient-Centered Medicine 2nd Edition*. Oxon, UK: Radcliffe Medical Press.
- Stigglebout, A. M. and G. M. Kiebert (1997). "A Role for the Sick Role - Patient Preferences Regarding Information and Participation in Clinical Decision-Making." *Canadian Medical Association Journal* 157:383-389.
- Stigler, G. J. (1950). "The Development of Utility Theory." *Journal of Political Economy* LVIII:307-327; 373-396.
- Struewing, Jeffery P., Patricia Hartge, Sholom Wacholder, Sonya Baker, Martha Berlin, Mary McAdams, Michelle M. Timmerman, Lawrence C. Brody, and Margaret Tucker (1997). "The Risk of Cancer Associated with Specific Mutations of *BRCA1* and *BRCA1* Among Ashkenazi Jews." *New England Journal of Medicine* 336:1401-1408.
- Sugden, Robert (2000). "Team Preferences." *Economics and Philosophy* 16:145-204.
- Sunstein, Cass R. and Reid Hastie (2008). "Four Failures of Deliberating Groups." *John M. Olin Law and Economics Working Paper* No. 401.
- Suppes, Patrick (1967). "What is a Scientific Theory?" In S. Morgenbesser (ed.), *Philosophy of Science Today*. New York: Basic Books, 55-67.
- Suppes, Patrick (1974). "The Structure of Theories and the Analysis of Data." In F. Suppe (ed.), *The Structure of Scientific Theories*, University of Illinois Press, pp. 266-283.

- Sytsma, Justin (forthcoming). "Revisiting the Valence Account." *Philosophical Topics*
- Sytsma, Justin and Edouard Machery (2010). "Two Conceptions of Subjective Experience." *Philosophical Studies* **151**:299-327.
- Tambor, Ellen S., Barbara K. Rimer, and Tara S. Strigo (1997). "Genetic Testing for Breast Cancer Susceptibility: Awareness and Interest Among Women in the General Population." *American Journal of Medical Genetics* **68**:43-49.
- Tavtigian, S. V., J. Simard, J. Rommens et. al. (1996). "The Complete *BRCA2* Gene Mutations in Chromosome 13q-linked Kindred." *Nature Genetics* **12**:333-337.
- Teno, Joan M., Brian R. Clarridge, Virginia Casey, Lisa Welch, Terri Wetle, Renee Shield, and Vincent Mor (2004). "Family Perspectives on End-Of-Life Care at the Last Place of Care." *Journal of the American Medical Association* **29**:89-93.
- Thagard, Paul (1996). *Mind: Introduction to Cognitive Science*. Cambridge, MA: MIT Press.
- Thagard, Paul (2001). "How to Make Decisions: Coherence, Emotion, and Practical Inference." In E. Millgram (ed.), *Varieties of Practical Inference*, pp. 355-371.
- Thagard, Paul and Elijah Millgram (1995). "Inference to the Best Plan: A Coherence Theory of Decision." In, *Goal-Driven Learning*, D. Leake and A. Rams (eds.), Cambridge, MA: MIT Press, pp. 439-454.
- Thom, D. H., K. M. Ribisl, A. L. Stewart, and D. A. Luke, DA (1999). "Further Validation and Reliability Testing of the Trust in Physician Scale. *Medical Care* **37**: 510-517.
- Thornton, Tim (2007). *Essential Philosophy of Psychiatry*. Oxford: Oxford University Press.
- Tindale, R. Scott, Helen M. Meisenhelder, Amanda A. Dykema-Engblade, and Michael A. Hogg (2004). "Shared Cognition in Small Groups". In *Social Cognition*, M. B. Brewer and M. Hewstone (eds.), Malden, MA: Blackwell Publishing, pp. 268-297.
- Tomasello, Michael, Malinda Carpenter, Josep Call, Tanya Behne, and Henrike Moll (2005). "Understanding and Sharing Intentions: The Origins of Cultural Cognition." *Behavioral and Brain Sciences* **28**:675-735.
- Tuckett, David, Mary Boulton, Coral Olson, and Anthony Williams (1985). *Meetings Between Experts: An Approach to Sharing Ideas in Medical Consultations*. New York: Tavistock Publications.
- Tuomela, Raimo (1995). *The Importance of Us: A Philosophical Study of Basic Social Notions*. Stanford: Stanford University Press.

- Turner, Nicholas, Andrew Tutt, and Alan Ashworth (2004). "Hallmarks of 'BRCA-ness' in Sporadic Cancers." *Nature Reviews: Cancer* **4**:1-6.
- Tutt, A. N. J., C. J. Lord, N. McCabe, H. Farmer, N. Turner, N. M. Martin, S. P. Jackson, G. C. M. Smith, and A. Ashworth (2005). "Exploiting the DNA Repair Defect in BRCA Mutant Cells in the Design of New Therapeutic Strategies for Cancer." *Cold Spring Harbor Symposia on Quantitative Biology* **70**:139-148.
- Ubel, Peter A., Christopher Jepson, and George Loewenstein (2005). "Disability and Sunshine: Can Hedonic Predictions be Improved by Drawing Attention to Focus in Illusions or Emotional Adaptation?" *Journal of Experimental Psychology: Applied* **11**:111-123.
- Ubel, Peter A., George Loewenstein, and Christopher Jepson (2003). "Whose Quality of Life? A Commentary Exploring Discrepancies Between Health State Evaluation of Patients and the General Public." *Quality of Life Research* **12**:599-607.
- U.S. Cancer Statistics Working Group (2010). *United States Cancer Statistics: 1999–2006 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. Available at: www.cdc.gov/uscs. Accessed on May 19, 2010.
- van der Steen, Wim J. and P. J. Thung (1988). *Faces of Medicine: A Philosophical Study*. Dordrecht: Kluwer Academic Publishers.
- van Dooren, Silvia, Caroline Seynaeve, Adriana J. Rijnsburger, Hugo J. Duivenvoorden, Marie-Louise Essink-Bot, Carina C. M. Bartels, Jan G. M. Klijn, Harry J. de Koning, and Aad Tibben (2005). "The Impact of Having Relatives Affected With Breast Cancer on Psychological Distress in Women at Increased Risk for Hereditary Breast Cancer." *Breast Cancer Research and Treatment* **89**:75-80.
- van Roosmalen, M. S., P. F. M. Stalmeier, L. C. G. Verhoef, J. E. H. M. Hoekstra-Weebers, J. C. Oosterwijk, N. Hoogerbrugge, U. Moog, and W. A. J. van Daal (2004). "Randomized Trial of a Shared Decision-Making Intervention Consisting of Trade-Offs and Individualized Treatment Information for *BRCA1/2* Mutation Carriers." *Journal of Clinical Oncology* **22**:3293-3301.
- Velleman, J. David (1999). "A Right of Self-Termination?" *Ethics* **109**:606-628.
- Verp, Marion S., Shelly A Cummings, and Olufunmilayo I. Olopade (2001). "Cancer Genetics in the Clinic." In Mahowald et. al. (eds.), *Genetics in the Clinic*. St Louis: Mosby Inc., pp. 41-57.

- Vogel, Victor G. (Ed.) (2001). *Management of Patients at High Risk for Breast Cancer*. Malden: Blackwell Science, Inc.
- Von Neumann, John and Oskar Morgenstern (1944). *Theory of Games and Economic Behavior*. Princeton, N.J.: Princeton University Press.
- Von Winterfeldt, Detlof and Wade Edwards (1986). *Decision Analysis and Behavioral Research*. Cambridge University Press.
- Wacholder, Sholom, Jeffery P. Streuwing, Patricia Hartge, Mark H. Greene, and Margaret A. Tucker (2003). "Letters: Breast Cancer Risks for BRCA1/2 Carriers." *Science* **306**:2188.
- Wagner, Andreas and David A. Fell (2001). "The Small World Inside Large Metabolic Networks." *Proceedings of the Royal Society of London, Part B* **268**:1803-1810.
- Wakefield, Jerome C. (1992a). "The Concept of Mental Disorder: On the Boundary Between Biological Facts and Social Values." *American Psychologist* **47**:373-388.
- Wakefield, Jerome C. (1992b). "Disorder as Harmful Dysfunction: A Conceptual Critique of DSM-III-R's Definition of Mental Disorder." *Psychological Review* **99**:232-247.
- Walden, Kenneth (2013). "In Defense of Reflective Equilibrium." *Philosophical Studies* **166**:243-256.
- Waymack, Mark H. (2009). "Yearning for Certainty and the Critique of Medicine as 'Science'". *Theoretical Medicine and Bioethics* **30**:215-229.
- Wegner, Daniel (2002). *The Illusion of Conscious Will*. Cambridge, MA.: MIT Press
- Wegner, Daniel and Betsy Sparrow (2007). "The Puzzle of Coaction." In *Distributed Cognition and the Will*, D. Ross et al. (eds), pp. 17-37.
- Wegwarth, Odette and Gerd Gigerenzer (2011). "Statistical Illiteracy in Doctors." In G. Gigerenzer and J. A. M. Gray (2011), pp. 137-151.
- Weinstein, Milton C. and Harvey V. Fineberg (1980). *Clinical Decision Analysis*. Philadelphia: W.B. Saunders Company.
- Warneken, Felix, Karoline Lohse, Alicia P. Melis, and Michael Tomasello (2011). "Young Children Share the Spoils After Collaboration." *Psychological Science* **22**:267-273.
- Whitbeck, Caroline (1981). "A Theory of Health." In Caplan et al. (eds) (1981), pp. 612-626.

- White, Douglas B., Clarence H. Braddock III, Sylvia Bereknyei, and J. Randall Curtis (2007). “Toward Shared Decision Making at the End of Life in Intensive Care Units.” *Archives of Internal Medicine* **167**:461-467.
- White, Douglas B., Grace Malvar, Jennifer Karr, Bernard Lo, and J. Randall Curtis (2010). “Expanding the Paradigm of the Physician’s Role in Surrogate Decision-Making: An Empirically Derived Framework.” *Critical Care Medicine* **38**:743-750.
- Whitney, Simon N., Amy L. McGuire, and Laurence B. McCullough (2003). “A Typology of Shared Decision-making, Informed Consent, and Simple Consent.” *Annals of Internal Medicine* **140**:54-59.
- Winquist, Jennifer R., and James R. Larson Jr. (1998). “Information Pooling: When it Impacts Group Decision Making.” *Journal of Personality and Social Psychology* **74**:371-377.
- Wimsatt, William C. (2007). *Re-engineering Philosophy for Limited Beings: Piecewise Approximations to Reality*. Cambridge, MA: Harvard University Press.
- Williams, Bernard (1985). *Ethics and the Limits of Philosophy*. Cambridge, MA: Harvard University Press.
- Woodward, James (1989). “Data and Phenomena.” *Synthese* **79**: 393-472.
- Wooster, Richard, Graham Bignelli, Jonathan Lancaster et. al. (1995). “Identification of the Breast-Cancer Susceptibility Gene *BRCA2*.” *Nature* **373**:789-792.
- Wooster, Richard and Barbara L. Weber (2003). “Breast and Ovarian Cancer.” *New England Journal of Medicine*, **348**:2339-2347.
- Worral, John (2007). “Evidence in Medicine and Evidence-Based Medicine.” *Philosophy Compass* **2/6**:981-1022.
- Zachar, Peter (2000). “Psychiatric Disorders are Not Natural Kinds.” *Philosophy, Psychiatry, and Psychology* **7**:167-182.
- Zahavi, Dan (2005). *Subjectivity and Selfhood: Investigating the First-Person Perspective*. Cambridge, M.A.: MIT Press.
- Zaner, Richard M. (1990). “Medicine and Dialogue.” *Journal of Medicine and Philosophy* **15**:303-325.
- Zulman, Donna M., Eve A. Kerr, Timothe P. Hofer, Mcchele Heisler, and Brian J. Zimund-Fisher (2010). “Patient-Provider Concordance in the Prioritization of Health Conditions

Among Hypertensive Diabetes Patients." *Journal of General Internal Medicine* **25**:408-14.