

**Ethical Reasons to Involve Demented Patients in Their Care  
and Why Physicians Fail to Do So**

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## **Ethical Reasons to Involve Demented Patients in Their Care and Why Physicians Fail to Do So**

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This paper explores the syndrome of dementia and the way in which it affects a person's capacity to make a medical decision. The symptoms of dementia exist along a continuum, meaning that a patient will begin with a mild form of dementia and then progress to a more severe form of this syndrome. This paper argues that although demented patients generally do not have the capacity to make medical decisions, some demented patients, because of the continuum nature of the syndrome, can participate in the planning of their care and, in some cases, participate in the informed consent process. It maintains that the principles of respect for autonomy and dignity, beneficence, and justice provide ethical reasons for involving demented patients in the care when they are capable to do so. Moreover, this paper contends that ageism, sexism, and hypercognitivism are biases that likely affect the way in which physicians view their demented patients, and consequently, the intersectionality of these three biases may play a role in a physician's disregard for an elderly demented patient's involvement in the planning of their care. Finally, the way in which physicians' interpret the idea of "involvement" provides further reasons to explain why physicians sometimes exclude demented patients in participating in decisionmaking. This paper concludes by providing some suggestions for positively involving demented patients in care planning.

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## 1.0 CHAPTER ONE

During the fall of my second year of graduate education, I participated in a practicum to facilitate my training in bioethics. During this practicum, I had the opportunity to shadow physicians of a local hospital on a service specializing in geriatric care. As one might expect, these physicians saw a large number of patients suffering from dementia. As I saw patient after patient come into the hospital for care, it was not long before I noticed a disturbing trend. Demented patients, regardless of the severity of their dementia, were rarely included in conversations in which their medical problems and treatments were being discussed and addressed. This observation was troubling, yet intriguing.

The National Institute of Neurological Disorders and Stroke and the U.S. Congress Office of Technology Assessment estimate that approximately 6.8 million people in the United States are living with dementia and it is projected that 1.8 million of those individuals are living with a severe form of dementia ("Dementia: Hope Through Research," 2007). There is an additional number people who are affected by this syndrome as a result of witnessing a loved one suffer from their diminishing mental state. Because of the high prevalence of dementia, it is important that in addition to the great loss of cognitive capabilities that demented individuals experience through their struggle with dementia, they do not also lose the opportunity to make decisions or express preferences for their medical treatment when they remain capable of doing so.

Relying on published literature, this paper establishes that symptoms of dementia exist as a continuum, and argues that this continuum nature of dementia needs to be properly assessed and appreciated by medical professionals. It then argues that although a significant portion of dementia patients cannot make informed medical decisions, many still possess the ability to express to family, friends, and their medical staff their preferences and values in regard to their lives, that these expressions can be useful to those making decisions on their behalf, and thus, that it is ethically incumbent upon medical professionals to solicit these expressions and take them into account. Ethical warrant for allowing these patients to participate in medical decision making is based on the principles of respect for autonomy and human dignity, beneficence, and justice. Finally, this paper explores the reasons why physicians often fail to include demented patients in conversations about their care or in the informed consent process and provides an ethical analysis of plausible explanations for this phenomenon.

## **1.1 DISTINGUISHING KEY CONCEPTS: DECISIONAL CAPACITY, AUTONOMY, AND DIGNITY**

Decisional capacity<sup>1</sup> is a prerequisite for decision making in a variety of contexts, including health care decision making. Accordingly, the assessment of such ability is vital to the medical

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<sup>1</sup> Decisional capacity and competence are distinguished by the setting in which the concepts are used. Decisional capacity is a determination made by medical and health professionals, while competence is a legal assessment (Parker and Samakar, 2004). In this paper both terms are used to refer to a person's ability to perform a specific task, namely, decision making.

field. The determination of whether a person possesses decisional capacity establishes whether she has the ability to make an informed decision and whether others have the obligation to respect her decision. Thus, the evaluation of decisional capacity acts as a system of gate-keeping for informed decisions and is required for a physician to respect a patient's preferences regarding treatments (Parker and Samakar, 2004).

The syndrome of dementia inhibits decisional capacity and consequently prevents most demented individuals from making competent informed decisions. In order to understand how dementia affects decisional capacity or decisionmaking capacity and the role that decision making plays in health care, one must understand what it means to possess and use decisional capacity.

There are four abilities that one must possess to be able to make an informed medical decision. First, one must have the ability to understand the information that is material to making a decision; in medicine, the decision is frequently in regard to a potential treatment. During the disclosure component of the informed consent process, the information disclosed must include the patient's diagnosis, the prognosis associated with treatment, and all alternatives to the treatment including the option of forgoing treatment. Additionally, the physician must disclose the risks and benefits of the treatment and each alternative to having the treatment, as well as the physician's recommendation regarding the decision. After the patient receives all the material information regarding the proposed treatment, she must have the ability to apply this information to her own life and evaluate the alternatives against her own beliefs, values, and preferences. This appreciation and evaluation requires the abilities to reason and deliberate. In other words, the person must be able to project or envision the consequences of each potential course of action based on the information provided and be able to determine which alternative is

most compatible with her current way of life and desired future way of life. Therefore, it is important that the person's set of values and preferences be reasonably constant so that she can weigh options in light of these values and preferences. Finally, the person must have the ability to communicate the decision made. Communication can be aided for patients who are incapable of oral communication, for example, by providing writing materials (Buchanan and Brock, 1990). To have decisional capacity is to be able to have goals and values, understand information, weigh options according to one's own preferences and values, and communicate a decision.

In health care, decisional capacity or competence is not assessed to determine a global attribute of a person, but rather her decisionmaking ability in relation to a specific decision. Consequently, a competence determination cannot be made unless the particular decision is specified. A person may have the capacity to make one decision, while lacking the ability to make another decision. Moreover, at a certain time, a person may not have the capability to make a particular decision, but at different time and under different circumstances, may have the competence to make the decision she was unable to make previously (Faden and Beauchamp, 1986). This is an essential point when considering decisional capacity and dementia.

Examination of the process of competent decision making reveals the relationship between decisional capacity and autonomy. 'Autonomy', from the Greek words *auto*, meaning the self, and *nomos*, meaning rule, is a term that can be traced back to ancient Greece where it once referred to self governance in the city-state. In moral philosophy, autonomy now refers to self-determination (Faden and Beauchamp, 1986). To have autonomy is to have rule of oneself, including being able to make decisions without undue constraints caused by insufficient understanding or undue pressure from restrictive influences (Beauchamp and Childress, 1989).

When others are obligated to respect the competent decision of a patient, the patient is allowed to be self-ruling with regard to her care and her bodily integrity. The components of the informed consent process are designed to provide the patient with the information and to ensure the absence of controlling influence by others necessary for the patient to be self-ruling.

The notion of autonomy applies not only to persons, but also to actions, and in bioethics it is the autonomy of actions—specifically, the autonomous nature of specific medical decisions—that has received the most analysis (Beauchamp and Childress, 1989) (Faden and Beauchamp, 1986). An autonomous person is one who generally possesses the capability to act independently and to be in control of the decisions that affect her life, while an autonomous action is one that exhibits the agent’s use of this capability on a particular occasion (Faden and Beauchamp, 1986). It is certainly possible for an autonomous person to make a non-autonomous decision, because the general capacity to act autonomously is not a guarantee that one always has autonomy or will act autonomously. A nonautonomous action can be performed by a generally autonomous person on the basis of ignorance in regard to the particular decision or because of duress from outside sources. In a medical context, it is possible that an autonomous patient fails to be competent to give an informed consent for a particular treatment or medical technique as a result of symptoms of her illness, anxiety, or other such factors. Faden and Beauchamp believe that there are three criteria necessary in order for a person to act autonomously. A person has acted autonomously if she has acted intentionally, with understanding, and without controlling influences (Faden and Beauchamp, 1986). Because the latter two criteria can be exhibited in degrees, Faden and Beauchamp argue that an action can be more or less autonomous, i.e., that autonomous actions admit of degrees.

On the other hand, it is also possible, in certain circumstances, for a generally nonautonomous person to make an autonomous decision. For example, children are not normally considered autonomous agents and competent decisionmakers, especially when it comes to medical decision making. The decisions and choices made by a child are not typically held as binding. However, suppose a young child were asked whether or not she wished to have chocolate or vanilla ice cream. She looked at her the two choices before her, thought for a moment, and then chose chocolate. The child understood the particulars of the decision. If she wished to have ice cream then she would have to decide which flavor she wished to have being that her choice was either chocolate or vanilla. She could not choose strawberry. She selected the chocolate intentionally after deliberation and without any particular person forcing her to select chocolate. It can be said that she acted with understanding, with intention, and without controlling influences. As a result, the child, usually considered nonautonomous, made an autonomous decision. This point is significant because of its relevance to the capability of a demented patient. A demented patient, who is generally nonautonomous, may have the ability to make some autonomous and competent decisions about matters that are pertinent to her care and quality of life, even if she is not competent to make treatment decisions.

Moreover, if we think of autonomy somewhat more broadly and in a way that Faden and Beauchamp specifically disavow in their analysis of autonomy in medical decision making, we can find other reasons to consider autonomy in the context of decision making for and with generally nonautonomous demented patients. Faden and Beauchamp deny that authenticity for autonomy should be required for informed consent because they believe that authenticity is too high a standard for autonomous decision making. If unlike Faden and Beauchamp we think of autonomy in terms of authenticity, in terms of what makes one person a unique individual, then it

may be possible to think of different decisions as being more or less appropriate to (or reflective of) those features that distinguish the patient as a person. It may make sense to say that, even in the absence of the deliberative abilities necessary for decisional capacity, a demented patient's preferences may nevertheless be more or less authentic and her expression of them may be deemed an attempt to be self-ruling. Some expressions of a preference, for example, a choice of ice cream flavor may be a "mere" expression of preference. Other expressions of preference may be more enduring, may reflect the patient's deeper values and interests, or may seem to reflect the patient's more fundamental features of the patient's current self (for example, never to be bothered during a favorite television program, or never to be paired at dinner with a particular fellow patient). In some cases, there will be continuity in values, preferences, or aspects of character and personality from the patient's pre-dementia state into her period of dementia; her family and friends may consider those values, preferences, and traits to be the "authentic" ones, as they are part of the fabric of their relationship and interactions with the patient. Balancing respect for the values and interests of the enduring, authentic self (the pre-dementia person who becomes demented) and those of the current authentic self (the patient who is demented) is one of the challenges of decision making in this context, and a challenge beyond the scope of this analysis. The issue is raised, however, to point to the multiple notions of autonomy relevant to thinking about the involvement of demented patients in their care: the autonomous character of both decisions and of persons, and autonomy considered as self-rule or as authenticity.

However it is conceived, strictly as self-rule or also as something akin to authenticity, autonomy is considered a good, something of value. As a value, it is the foundation of the ethical principle of respect for autonomy, more appropriately deemed respect for persons or respect for dignity (The Belmont Report: Ethical Principles and Guidelines for the Protection of

Human Subjects of Research., 1979). To demonstrate respect for a person's autonomy, as defined by Faden and Beauchamp, is "to recognize with due appreciation that person's capacities and perspective, including his or her right to hold certain views, to make certain choices, and to take certain actions based on personal values and beliefs" (pg. 8). Therefore, to infringe upon another person's autonomy would be to disregard her values and preferences and instead impose one's own values and preferences (Beauchamp and Childress, 1989).

Although the value of autonomy is the basis for the principle requiring respect for persons, fulfilling this principle does not entail merely respecting another's right of self-rule. The principle of respect for persons encompasses two major ideas. To evidence respect for persons is, first, to recognize and respect the autonomy of those who are indeed autonomous and, second, to protect the interests or welfare, and respect the dignity or inherent worth, of those who are not autonomous (The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research., 1979). However, the word 'protection' can employ multiple meanings. In some cases, such protection involves providing for the material needs of those who cannot provide for them themselves, as parents protect and provide for children. In some cases, respect for persons requires protecting generally autonomous persons from their own nonautonomous actions, as when a drunk friend is prevented from driving home or generally a autonomous person is deemed incompetent to make a medical decision because her anxiety prevents her from adequately understanding relevant details about her proposed treatment. Most importantly, one can protect a person by acknowledging and respecting her needs and showing respect for her dignity or inherent value as a person.

The word 'dignity' comes from the Latin words *dignus* and *dignita* (Schulman, 2005). Having dignity, in the general sense, can mean having self-respect and being valued by others

(Lothian and Philp, 2001). However, the role dignity plays in bioethics is not exactly clear. There seem to be four different, but interrelated accounts of dignity. Ancient Greek and Roman literature defines dignity as “worthiness for honor and esteem.” This classical concept of dignity describes an individual who represents superiority and honor (Schulman, 2005). In the biblical sense, dignity results from the account that man is made in the image of god and as a result that humans are in a sense “godlike.” As a result, they are provided an intrinsic dignity or value. This notion of dignity encourages individuals to value others as God would value them (Schulman, 2005), and this Judeo-Christian conception of dignity seems to be incorporated in many references to the dignity of person in the bioethical context and even in health policy (Bioethics, 2002).

Immanuel Kant described dignity as the inherent worth belonging to all rational persons. Kant’s emphasis on rationality as the basis for dignity fits neatly with bioethics’ emphasis on decisionmaking ability. According to Kant, persons have dignity as a result of their autonomy; therefore, Kant has difficulty accommodating, in his moral philosophy, respect for children, the demented, and others who lack autonomy and especially those who will never develop autonomy (Kant, 1998). Finally, dignity can be understood in terms of 20<sup>th</sup> century constitutions and international declarations as a belief in a person’s right to life, liberty, and the pursuit of happiness or to life, liberty, and property (Schulman, 2005). Some of these expressions refer to the need for governments and societies to provide the material conditions necessary for people to pursue their life plans, to craft authentic lives or at least live minimally decent ones. The inherent worth of the person, her capacity for crafting a life that is her own, is considered in itself to exert a demand on others to provide basic, minimal conditions necessary for the exercise of

this capacity. Here the dignity of people rests less with their rationality and more with their unique capabilities as human persons and their potential to lead authentic lives as individuals.

This paper will consider dignity to be the inherent worth of a human being without regard for his or her cognitive abilities or capacity for autonomous action. Daniel Callahan, for example, argues that autonomy is not the basis of human dignity; it is simply one element comprising it. He states, “The value of a human life should never be confused with the right or capacity to make choices, to direct our own lives, or to be free as citizens and persons” (Callahan, 2002) (pg. 129). In fact, it might be said that valuing the autonomy of person, is only respecting one of her four needs, specifically, her cognitive need. People also have an emotional need, i.e., a need to have love, support, and care from others and the need to communicate feelings and emotions. They also have a need for relationships with other people that are filled with respect, commitment, dependability, and affection. Lastly, people have a value need, which is the need not only to develop and hold values, beliefs, and preferences, but also to have these respected by others (Callahan, 2002).

The next section explores dementia and its effects on decisional capacity and competence. It is possible for one to respect and care for demented patients who are not autonomous or capable of decision making by remembering that, in spite of their lack of autonomy, they are still people whose dignity should to be acknowledged and respected.

## 1.2 DEMENTIA AND DECISIONAL CAPACITY

The National Institute of Neurological Disorders and Stroke and the U.S. Congress Office of Technology Assessment estimate that approximately 6.8 million people in the United States are living with dementia, and it is projected that 1.8 million of those individuals are living with a severe form of dementia ("Dementia: Hope Through Research," 2007). Alzheimer's disease, affecting roughly 4.5 million Americans, is the most common cause of dementia among the elderly, defined as those age 65 years and older. One in every ten elderly individuals is affected by Alzheimer's disease. Additionally, of those individuals considered very elderly, age 85 years and older, approximately half are affected by Alzheimer's disease ("The Numbers Count: Mental Disorders in America," 2006). Alzheimer's disease is associated with 60 % of all cases of dementia ("Dementia," 2007). While dementia is common among the very elderly, it is not believed to be a normal part of the aging process ("Dementia: Hope Through Research," 2007).

Dementia is defined as a loss of cognitive functioning, such as rational thinking, memory, reasoning, language, and certain motor skills that is severe enough to hinder the way in which a person experiences and conducts her daily life and relationships. Dementia is a syndrome, a group of symptoms, rather than a disease itself, though it may accompany certain diseases or conditions. Many of these symptoms involve changes in the person's memory, in which she forgets familiar places and people. Demented persons also experience changes in their mood and feel anger and fear in reaction to the alterations that are occurring to their memory as a result of their dementia. Furthermore, demented persons often experience a change in their ability to communicate, such as being at a loss for words when trying to speak or a decrease in their capability to write or read ("Facts about Dementia," 2007). A dementia diagnosis is made only

if consciousness remains while two or more brain functions are severely impaired ("Dementia: Hope Through Research," 2007).

Minor memory loss can be a result of normal aging. However, a person may be experiencing, or be at increased risk for, dementia if she is unable to make new memories; relies considerably on memory helpers; finds difficulty or confusion with familiar words, people, places or actions; experiences loss of interest in responsibilities or hobbies; or begins to make bad judgments or decisions that are uncharacteristic ("Facts about Dementia," 2007).

Different pathologic or structural changes that occur in the brain differentiate the types of dementia ("Dementia," 2007). Among the elderly and very elderly, dementia is typically caused by nerve cell degeneration such as in the case Parkinson's and Alzheimer's disease. Alzheimer's disease is a result of the death of neurons in the cortex area of the brain, the area of the brain responsible for memory. Parkinson's disease, on the other hand, is caused by an excess of the neurotransmitter dopamine in the brain, the neurotransmitter responsible for movement. These types of dementias are related to age and are progressive, irreversible, and incurable. Dementia with Lewy Bodies, primarily connected to Parkinson's disease, but also appearing to have a link to Alzheimer's disease, is a dementia that is differentiated from other dementias by the appearance of tiny protein structures found on nerve cells within the brain. These protein structures, called Lewy Bodies, cause visual hallucinations, delusions, and movement disorders. Other incurable causes of dementia are multi-infarct dementia, which describes brain cell death due to several small strokes that cause blood supply to be stopped to parts of the brain ("What Types of Dementia Are There?," 2007), as well as dementia caused by diseases such as HIV or Huntington's disease, and by infections affecting the spinal cord and brain like Creutzfeldt-Jakob disease ("Facts about Dementia," 2007).

Although not common in the elderly, there are many forms of dementia which can be treated and cured. These include dementia resulting from nutritional deficiencies and metabolic disorders, operable tumors, infections, hormone imbalance and dementias resulting from long-term substance abuse ("Dementia," 2007). Additionally, head injury, reactions to medications, poisoning, anoxia or hypoxia, and heart and lung problems are causes of dementia that may be treated and cured ("Dementia: Hope Through Research," 2007). Although most of the dementias that affect the elderly cannot be cured, there are some medications, including Aricept, Exelon, and Reminyl, that can partly or temporarily lessen the symptoms ("Facts about Dementia," 2007). Dementias affecting elderly people are normally progressive, and depending on the type of dementia, the syndrome can progress slowly over many years. This is usually the case for Alzheimer's disease and Parkinson's disease, the dementias that are most prevalent among the elderly ("Dementia," 2007).

Due to the progressive nature of dementia, the symptoms can be viewed as presenting a continuum or spectrum of severity. At one end of the spectrum, a demented person could simply be misplacing her keys or forgetting the time of her doctor's appointment, while at the other end of the spectrum, the person could fail to recall family and close friends or mistake them for others. The experience and progression of dementia is unique for each person. At one of the continuum, mildly demented persons may retain the capacity to make decisions regarding their lives, whereas at the opposite end of the continuum, the severely demented may lack competence completely. In order for one to have the capacity to make a medical decision, one must be able to understand the information relating to the decision. Much of the time, dementia causes such a decrease in cognitive functioning that a demented patient can longer comprehend the information provided to her from a medical professional. Or, in the event that she can understand, dementia

may prevent her memory from retaining the information. Additionally, to be able to make a medical decision or give informed consent, one must have the ability to express values and preferences and in turn, apply those values to a decision. Dementia may inhibit persons from executing the reasoning skills necessary to make a decision of this sort. Thus, many demented individuals lack decisional capacity necessary for medical decision making (Buchanan and Brock, 1990).

As a result of the continuum or spectrum-like nature of the symptoms comprising dementia, it is essential for medical professionals to continuously assess the capabilities and competence of their demented patients, as a way to ensure they are respecting their patients' autonomy to the extent that it still exists. Although physicians may find that few demented individuals have the capacity to make medical decisions, even in the latter stages of their dementia, patients may have the ability to value and express preferences about their lives. The final section of this chapter argues that demented patients can express their values and preferences in regard to their care and that they should be encouraged to do so. The goal of this final section is to explore the ethical reasons that medical professionals should involve demented patients in their care.

### **1.3 ETHICAL REASONS TO INCLUDE DEMENTED PATIENTS IN THEIR CARE**

Most often individuals suffering from dementia do not possess the decisional capacity necessary to make the series of informed decisions that arise across the course of their long-term care. However, there are reasons that it is ethically appropriate to include such individuals both in

decision making insofar as possible, and more generally in the planning of their care. Discussion of these reasons will be organized in relation to the ethical principles of respect for autonomy and human dignity, beneficence, and justice.

It has been established that most elderly individuals who suffer from dementia are no longer autonomous agents. Yet some may be able to make some autonomous decisions or at least to express their preferences in ways that are relevant to health care decisions and other decisions relevant to their quality of life. Because of the continuum-like symptoms of dementia, it is possible that a demented individual may have the capacity to make a decision or participate in a conversation when decisions are being made, despite her general lack of autonomy. The principle of respect for autonomy provides ethical justification for allowing demented patients to make the decisions that they are capable of making. Someone who lacks the capability to make a treatment decision may nevertheless be capable of expressing a preference about, or making a decision regarding, a sunny or shady room in a long-time care facility. Someone who is not competent to refuse to take her medication may nevertheless be competent to refuse liver and onions for dinner.

Buchanan and Brock discuss the idea of a decision-relative standard for competence, meaning that a judgment of whether a person is competent to make a decision is based upon the person's capacities, as well as upon actual elements of the decision including the amount of risk involved and the information requisite for making the decision. This particular standard views competence in terms of a threshold. A decision-relative standard of competence asserts that competence should be more thoroughly assessed (i.e. have a higher threshold) for decisions that bear more risk. For example, a decision to reject a recommended treatment would require a higher threshold of competence than the decision to accept a recommended treatment. The idea

of competence determination involving a threshold that one either attain or not results from the sorting function that competence determination plays: it sorts decisions into those that must be respected by physicians and those that may perhaps be overridden for the sake of protecting the patient's welfare interests. A patient either is or is not competent to make a particular decision. The idea of requiring a higher threshold for a riskier decision again stems from the desire to afford protection to patient's welfare interests; the riskier decision exposes the patient to a larger range or degree of harms. Furthermore, a decision that yields more risk will frequently involve more information and therefore require a greater level of understanding than a less risky decision (Buchanan and Brock, 1990).

This way of conceptualizing competence for decision making supports the participation of demented elders in their care. An elderly demented patient may not have the level or degree of competence required to make a decision about whether or not undergo a surgical procedure, a decision that bears much risk, but may attain the threshold of competence to make a decision about whether or not she wishes to eat her dinner inside or out on the patio, a decision that has very minimal risk. Despite its minimal risk, however, the decision about dinner venue may have substantial impact on the quality of her daily life. Moreover, being allowed to make the decision affords the patient benefits both by being able to avoid conflict regarding where she eats and being afforded the opportunity to feel effective in making a decision that is respected. Although it is a relatively small matter, the patient is able to be self-ruling regarding her dinner venue, and she is enabled to express and make effective her wishes, to make a small self-authored plan and act on it, a small sign of authenticity.

The principle of respect for human dignity provides further ethical reasons for physicians to encourage demented patients to participate in their care. Although demented patients are

generally not considered rational and by some standards would not be deemed worthy of respect for their dignity, they are “persons in the social sense” and therefore deserve respect (Jecker, 1990). Nancy Jecker argues that social personhood grants moral status by reason of the place such individuals hold in the lives of others. For this reason, she argues, anencephalic infants, and by extension, demented elderly individuals are considered persons. According to Jecker, there are three reasons to support granting the status of social personhood to demented individuals. First, it is argued that this practice of assigning social personhood is justified if it produces more good than harm. Viewing demented individuals as persons, and thereby as moral agents worthy of respect, would only help to strengthen the argument that demented elders should be included in the planning of their care. Subsequent paragraphs will suggest that material benefits result from such inclusion and help establish that respect for the demented and their inclusion in care planning are two essential goods that seem to outweigh possible harms, such as confusion of the patient as a result of the complex medical information.

Second, just like anencephalic infants, demented elders are the subject of human tragedy (Jecker, 1990). It is a tragedy, after a lifetime of having the capacity to make decisions and be in control of oneself, to slowly lose this ability to dementia. The loss of this capacity evokes a certain sense of grief and sadness among people regarding these patients that would not be evoked with regard to nonpersons. The final reason to accord social personhood status to the demented elderly is that they are human (Jecker, 1990). Severely demented patients have lost a sense of their prior selves. However, despite their loss of cognitive abilities, by virtue of being human, demented patients have inherent worth. They have human dignity in the sense Callahan identifies. As a result, demented patients are people who deserve respect and attention paid to their needs. By merely including a demented patient in the planning of her care and encouraging

her to make treatment decisions when possible, her cognitive, emotional, relational, and value needs can be met.

Moreover, the ethical requirement of beneficence provides ethical warrant for including demented patients in decisions about their care. Based on the principle of beneficence, a medical professional should act in a way that promotes the welfare of her patients. Her actions should not impose harm, but aim to prevent and eliminate harm when possible. Specifically, she should not inflict unnecessary pain, injury, or disability, but rather work to eliminate disease and suffering when possible (Faden and Beauchamp, 1986). First of all, autonomy and beneficence typically work in concert. Patients who are autonomous are more likely than others (including doctors) to make decisions about their care that are in accordance with their values and interests because only the patient truly knows her values and beliefs and which decision is most compatible with such beliefs. A decision that is contrary to such values can cause hurt and detriment to a patient. By providing the proper information to a patient, a patient who has decisional capacity can make the most appropriate decision regarding her care. Thus, by obtaining informed consent, the physician can be said to be helping to promote her welfare and preventing harm caused by making a decision contrary to the patient's values.

Although most dementia patients lack the decisional capacity to make informed decisions about their care, the principle of beneficence still supports involving them in their care planning to the extent possible. First, if a physician regularly assesses a patient, diagnosed with dementia, to determine whether she has the capacity to make an impending medical decision, the clinician can prevent undue harm caused by failure to recognize the remaining decisional capacity of the patient when it is present. If it is determined that such patients do not possess the capacity to make an informed decision, a physician can solicit preferences from a demented patient which

can be used by clinical staff and the patient's family to help make a decisions on her behalf and otherwise direct her care in a way that maximally accords with her values. By encouraging the patient's participation in her care and in the planning of her care, the physician is acting to promote the welfare of the patient by allowing her care to reflect her authentic self to the degree possible and by allowing her the material benefits resulting from the process of participating in her care.

One of these material benefits is that the involvement of a demented patient in her care promotes her welfare by making her feel as if she has control over her care. Whether or not the demented patient is the ultimate decision maker, treating the patient as though she is a participant in the decisionmaking process promotes the welfare of the patient by making her believe that the medical decisions that were made were a result of choices that she made, rather than a decision that was made for her or forced upon her. This may encourage the patient to more fully comply with the treatment decision. This line of reasoning reflects the reasons Carl Schneider discusses in his analysis of the therapeutic argument for involving patients in medical decision making, indeed for having them exercise decisional authority whenever possible (Schneider, 1998). Undertaking to make a demented patient feel as though she is participating in her care, even though she is not the ultimate decision maker, may seem deceptive. However, if the physician and family of the patient are actually working to include the patient in her care by actively soliciting her preferences and values, they are not deceiving the patient. These preferences and values are used by the medical staff and family of the patient to help make decisions and direct the patient's care, thus the patient *is* a participant in her care.

Additionally, allowing a patient to feel that she has some control over her care, may work almost like a self-fulfilling prophecy. "The self-fulfilling prophecy is, in the beginning, a false

definition of the situation evoking a new behavior which makes the original false conception come 'true' ” (Merton, 1968)(pg. 477). This is the effect that sometimes occurs with demented patients who are afforded a greater degree of control over their lives than if all decisions are made for them without their input. Although a demented elderly patient may not be making the final decision or choice in regard to her care, by treating her like she is participating in the planning of her care, she believes that she is participating. This sense of control and participation helps her to more fully comply with the treatment, thereby helping her to improve medically. In the case of other, treatable diagnoses, adherence to a treatment regimen promotes more rapid return to health (Schneider, 1998). In the case of most elderly demented patients, pre-dementia health can never be restored. Nevertheless, their being more compliant with other treatment for secondary conditions may result in faster recovery, while being cooperative with care-givers' instructions may lead to their receiving better care-giving, as well as a more pleasant interaction with their care-givers. Thus, giving patients, including those with some cognitive impairment, a sense of participation and a sense of having control over and responsibility for their environment, may in itself enhance their quality of life.

Finally, participation in the dialogue involved in medical decision making and care planning may help to prevent, or at least help lessen, the decline in their cognitive capacity and have other positive health benefits. Regardless of whether a demented patient retains sufficient cognitive ability to be able to make an informed decision, receiving information about her care from her physician or other medical professional and having her input solicited may promote, however slightly, a process of thought and deliberation, and even possible understanding about her situation. Increased understanding may at least temporarily counter the confusion about surroundings, interventions, and daily routines that often plagues demented patients. Although

the understanding may not persist long past the conversation or perhaps may not persist at all, the thought and deliberation evoked by this type of conversation may help to preserve what cognitive skills persist, thereby serving to satisfy the patient's cognitive need. Participation in the care planning discussion serves to address the patient's emotional and relational needs.

By being involved in the planning of her care, ideally, the demented patient may begin to form a bond with her physician, a bond that was conceivably lost as a result of the dementia or that may never have existed in the first place. The formation of this bond is a result of the recognition and acceptance, by both the physician and the patient, of the care relationship. As described by Joan Tronto, the care relationship includes four phases: caring about, taking care of, care-giving, and care-receiving (Tronto, 1993).

In the "caring about" phase, a need for care is acknowledged. In a physician and patient care relationship, the patient and often the patient's family recognize a problem or suspect a need for care may exist and seek assistance from a physician to meet this need. The physician examines the patient and decides whether care is, in fact, necessary and whether the need is something that can be "taken care of" given the state of medical science, expertise of the physician, and level of resources, such as money, time, emotional resources, and workload, of the parties involved. Second, in the "taking care of" phase, the responsibility to attempt to meet the need for care is assumed by the physician, and she decides how she will act to address the unmet needs of the patient. This phase of caring should include input from the patient in the form of her expression of values and preferences in regard to the care the physician will provide. This is the phase of the care relationship in which, ideally, the bond with the physician is truly formed. When conversations are taking place in regard to the care of the patient *with* the patient

instead of *about* the patient, she may feel a greater sense of loyalty and commitment to her care on the part of her physician. Thus the physician, in part, satisfies her relational need.

Moreover, as part of this conversation with the patient, the physician should invite the patient to express preferences about her care, even if she lacks the capacity to retain decisional authority. By inquiring about her values and preferences, the physician provides an opportunity for the patient to communicate her values, even if only implicitly, to her physician and family, thereby satisfying what Callahan would term the patient's value need. Moreover, this conversation may also offer the patient the opportunity to express not only her values and preferences, but also her feelings and emotions about her dementia. In return, the physician and the patient's family can provide comfort and support and in doing so, help to satisfy the patient's emotional need.

"Care-giving," the third phase, includes the actual meeting of needs. In a medical relationship, this phase may involve performing a procedure, providing treatment, or prescribing medication to meet the physical, medical needs of the patient. In addition, the emotional, relational, and value needs of the patient may be met if care is given in a way that respects the patient's dignity and inherent worth, expresses kindness and regard, provides a feeling of relatedness, and respects the values and preferences expressed by the patient.

The final phase of caring is the "care-receiving" phase in which the object of the care, the patient, responds to the care she has received. This phase is important because it provides evidence of whether the need of the patient has been fulfilled (Tronto, 1993). The patient's willingness to receive care may be increased by her participation in the plans for care. If she does not participate in her care planning, changes in her treatment (for example, a new medication or a move to a different room or facility) may take the patient by surprise and be

disruptive to what understanding she has of her situation. If instead, she is at least kept informed of proposed changes, or allowed to participate in decisions about her care to the extent she is capable, then she may be more likely to receive care in the beneficial mode in which it is offered. To the extent that a patient's understanding can be fostered, misunderstanding of care-givers motives and actions can be avoided.

Even patients whose dementia is so severe that they cannot understand explanations of their care plans, and who certainly cannot contribute reliable opinions about their own care, can nevertheless benefit indirectly from being included in some limited ways in their care planning. Treating a patient as though she deserves an explanation of what is happening to her evidences respect for her inherent worth as a person. Therefore, it is respectful to say, even to a patient who may not comprehend, "Mrs. Jones, we are going to take you to the gynecologist today for your annual examination. Dr. Brown wants to be sure that you are just as healthy as you were last year. We do not want you to be sick." Of course, if such a description upsets a severely demented patient who likely does not understand what is said, then a care-provider may justifiably avoid discussion. Other patients, however, may be comforted to know that someone is speaking to them as they are being moved from one place to another. Moreover, those surrounding the patient witness the patient being treated respectfully, as a member of the moral community, a person in the social sense, and they may be more inclined to care for the patient's interests in virtue of witnessing that treatment.

The four phases of caring must be achieved for a care need to be fulfilled. Furthermore, working to achieve the requirements of each phase of caring provides the grounds for a bond between a patient and her physician. The physician will recognize both a need for care from her patient and her duty to address that need; and, the patient, by participating in the planning of her

care, will be better prepared to acknowledge her need for care and to receive the care provided by the physician.

Thus, multiple welfare-oriented reasons support the inclusion of demented patients in their care planning. Doing so helps to meet the demands of the four phases of caring identified by Tronto. Such inclusion also helps to address the four types of basic needs that Callahan considers constitutive of human dignity or worth. Involving demented patients in their care has a myriad of practical benefits that may enhance their quality of life and the quality of care-giving they receive. Finally, to the extent that they retain capacity for making some decisions, even if they are only competent to make low-risk, quality of life decision (like choice of food, TV program, or roommate), providing such demented patients with the opportunity to exercise their decisionmaking ability respects their autonomy, may help to preserve such cognitive functions, and affords them a sense of control and efficacy, in which most people have an interest.

A third ethical principle, the principle of justice, also supports involving elderly demented patients in their care. The principle of justice holds that a person should be treated “according to what is fair, due, or owed” (Faden and Beauchamp, 1986). Therefore if a competent patient has the right to participate in her healthcare decisions and the planning of her care, then justice is served only when such a patient is allowed to exercise this right to make decisions. The failure to respect the remaining, albeit limited, decisional capacity of a demented patient by excluding her in decision making and planning of her care is unjust.

Moreover, justice demands that actions be based upon relevant characteristics. Justice demands, for example, that a worker be hired on the basis of her qualifications, not her relationship to the personnel manager, her gender, or her personal beliefs. Similarly, justice requires that respect for a patient’s decision (or opportunities for a patient to give informed

consent) be based on relevant characteristics of the patient—namely, her ability to give informed consent, her decisional capacity, or competence to make a decision. If elderly demented patients are excluded from decision making about their care simply because of their age or their diagnosis, when in fact they possess the relevant capacity to participate in medical decision making, then this is contrary to the demands of justice.

The next chapter will suggest that, in fact, elderly demented patients are frequently excluded from medical decision making and from participating in decisions relevant to their care because they have certain disempowering characteristics related to their age and sex, and because of assumptions made about their cognitive capacity. Ageism, sexism, and hypercognitivism intersect to bring about inequity, to disempower the demented elderly, and to place them at a disadvantage in the medical decision making process. Even the general lack of decisional capacity should not lead physicians to avoid involving demented patients in their care, but instead the principle of justice, along with the principles of beneficence and respect for persons and their inherent worth, should encourage physicians to find alternate ways to include such patients in their care.

The ethical principles of respect for autonomy and human dignity, beneficence, and justice provide ethical justification for physicians and other medical professionals to include demented patients in the planning and execution of their care, as well as in decision making to the best of the patient's capability. Nevertheless, physicians often fail to include dementia patients in conversations about their care or in the process of informed consent. Chapter two provides an ethical analysis of plausible explanations for this phenomenon.

## 2.0 CHAPTER TWO

### 2.1 TREATMENT OF THE ELDERLY AND THE INTERSECTION OF AGEISM, SEXISM, AND HYPERCOGNITIVISM

The first chapter discussed sound ethical reasons why medical professionals should include patients suffering from dementia in their care, yet despite these rationales for the involvement of such patients, I noted that many physicians fail to do so. This chapter proposes reasons why physicians exclude demented patients from discussions about their care. Analysis of this phenomenon relies on and explicates the notion of the intersectionality of ageism, sexism, and hypercognitivism. Moreover, this chapter examines how physicians' interpretation of "involvement" affects the care they provide to demented patients.

'Ageism' is a term that was coined by Robert Butler in 1968 to describe the "aversion, hatred, and prejudice toward the aged and their manifestations in the form of discriminations on the basis of age" (Barrow and Smith, 1979) (pg.8).<sup>2</sup> Ageist attitudes and the discrimination that results from them are a consequence of historical, psychological, social, and cultural forces. As our world is advancing both technologically and industrially, people have to continuously update

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<sup>2</sup> It is interesting to note that Barrow and Smith's book, [Aging, Ageism, and Society](#), is over 30 years old. Yet, the ideas that are discussed within it, including the chapters on and relating to ageism, are still relevant today.

their knowledge and skills in order to maintain their position in their field of work and in their life (Barrow and Smith, 1979). As people get older, they may struggle with their ability to grasp and retain new information within their field of work and perhaps also with certain advances that affect everyday life. This struggle may make elderly people seem less valuable within a work environment and create or augment the negative attitudes and discrimination already faced by the elderly (Barrow and Smith, 1979).

The fast paced culture of the United States is one that encourages our citizens to be fast moving. This is shown through our favor of “drive-thrus” rather than “sit-down” restaurants and our preference for writing emails rather than letters. We drive at speeds exceeding proper speed limits and scorn slow drivers (Barrow and Smith, 1979). This fast paced culture is frequently not conducive to the slower paced movements, thought-processes and interests of the elderly. Many of the elderly do not have either the physical or mental capacities to keep pace with the tempo of the dominant culture, thus contributing to the attitudes of ageism, which results in discrimination toward the elderly.

Social changes contribute to ageism through the formulation of a generation gap (Barrow and Smith, 1979). As our world changes socially, the values of the elderly population may become slightly or even considerably different from the younger generation’s, thus creating a gap in world view, belief system, priorities, attitudes, and value systems. The United States has seen a continuous trend in changing morals and values since the 1960s, a time noted for the social changes that occurred. Since this time, the Supreme Court has legalized abortion, the women’s movement exerted political and social influence, feminism provided a critique of social relationships previously accepted unreflectively, and drug use has escaped ghettos and found its way into middle class lifestyles (Britannica, 2007). Family structures have diversified making

room for the co-habitation of both heterosexual and homosexual couples, as well as, families of mixed races and cultures. The traditional gender roles of a stay-at-home mother and working father have been replaced by working mothers and single parent families. Additionally, the number of individuals who divorce each year is only slightly less than half of the number who marry per year ("Marriage and Divorce," 2007). Consequently, the stable 1950s traditional family with what were then "conventional values" seems to have become an outdated notion. Many of the elderly may still hold onto the traditional values of that period, leading to a conflict with the more diverse values of today. The disagreement in personal values may result in a gap between the conflicting groups and in ageist attitudes on the part of each group toward the other, but especially on the part of the dominant, younger generation(s) (Barrow and Smith, 1979).

Finally, psychological factors may contribute to ageism. The term 'old' seems to be a detestable term to both the young and the old. The young fear old age, or perhaps more accurately, the young are apprehensive about growing older. Old is viewed as the polar opposite of young, and youth is considered desirable. According to a type of "dichotomous thinking," what Iris Young terms "the logic of identity," if one end of a polarity is desirable, the end deemed opposite is considered undesirable, worthless, or even detestable. To be young is to be attractive, active, alive, and alluring (Barrow and Smith, 1979). By this way of thinking, to be not-young or old is to be ugly, sedentary, dead, and undesirable.<sup>3</sup> Rather than being able to recognize a spectrum of age and attributes appropriate to each, according to Young's analysis of

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<sup>3</sup> The following three pages summarize Iris Marion Young's ideas in her book, Justice and the Politics of Difference, as they relate to this paper. The summaries reflect conversations that took place between Dr. Lisa Parker and me, and for the most part echo Dr. Parker's own words.

the logic of identity, we fix on the positive attributes of one end and denigrate all attributes that are not associated precisely with that desirable pole. Young focuses her analysis on the dyads of male/female and the attributes associated with them: rational/emotional, public/private, independent/dependent, forceful/weak, able-bodied/disabled. Interestingly, many of those attributes associated with males and the male sphere are also associated with the young as opposed to the old who with age may become more emotionally labile, less cognitively facile and acute, less physically vigorous, and more bound to homes and private spaces outside of the public eye. Young's analysis suggests that dominant patterns of Western thought create dichotomies (e.g., male/female, young/old), associate all positive attributes with the dominant pole, and then consolidate the power, position, and privilege of those in the dominant position by denigrating and assimilating all negative attributes to the non-dominant pole. This process involves ignoring the positive, valuable aspects of the other ("Other") half of the dichotomous pairs. Even though there are positive, valuable aspects of experiencing emotion and being emotional, occupying the private sphere, or being quiet and reflective (rather than constantly vigorously active), to secure the powerful social position, those in power tend to consider such attributes and activities "lesser." Being other-than the dominant good way of being is to be lesser. The Other is devalued and often actively denigrated. Young argues that this way of thinking is a system of thinking, a pervasive way of thinking and viewing the world that is difficult to avoid or combat. Those in a non-dominant position (women, the elderly, the disabled) would have to take active steps to get outside of this system of thought or viewpoint. Many who are not consciously aware of it simply act to accommodate themselves to it, within the system of dichotomous thinking (Young, 1990). People who avoid disclosing their age to others illustrate not only our fear of aging and our fear of being viewed as old by others, but also

the way in which those occupying a non-dominant position in a dyad (here, young/old) seek accommodation within this oppressive system of dichotomous thinking. Other examples that illustrate both the system of dichotomous thinking and our fear of aging is the “mid-life crisis” or the “over 29 syndrome” when the young come to recognize that youth is not everlasting (Barrow and Smith, 1979). Instead of viewing aging positively, as a continuous process that brings different positive experiences and challenge along the lifespan, those in early and later mid-life view any stage that is not young and thus good as being a crisis or as a pathological syndrome, a putative bad.

The loss of youth may not be the only loss people experience as they age. In fact, people may view aging as a series of losses (Bartky, 1999). As Sandra Lee Bartky discusses, the losses that aging brings may contribute to a person’s fears about aging. Each person will not experience the same losses. Those who are fortunate may experience very few losses, while those who are unfortunate may experience several, perhaps devastating losses. Of course, even this comment embraces a sort of dichotomous thinking. It might be that many losses bring opportunities for personal growth or “clear the decks” for new relationships or experiences, but generally the losses associated with growing old are not viewed this way. Such losses include: loss of social groups and professional networks due to retirement and death, loss of a spouse or companion, loss of home to live in a retirement community or nursing facility, loss of mental and physical abilities including sight and hearing, and finally, loss of life due to death (Bartky, 1999). Consequently, the care needs that result from these many losses, especially the loss of mental and physical abilities, may create in the elderly a sense of vulnerability and dependence on others. To be vulnerable and dependent on another is to lose some control and power over one’s life (Tronto, 1993). This is yet another loss experienced by people as they age.

Upon examining this view of aging as a series of losses, it is no wonder that people are apprehensive about growing older. This apprehension is partly due to the experiences of loss themselves, the grief, sadness, and fear associated with the loss of loved ones, familiar surroundings and activities, and one's familiar place and status in the world. These emotions are likely made more negative, more unpleasant to experience, by the dichotomous way of viewing each of the events. If having a life partner, job, career, and home is good, then losing these is bad. If having friends and being physically and socially active in the world is good, then losing friends and becoming less active is bad. Viewing the goods of life as one of a dichotomous pair and not considering each good or experience on a continuum contribute to the negative experience of the loss of a good. It may seem impossible to consider having a partner or spouse as a continuum experience rather than a yes/no situation in which one has a spouse or does not. Nevertheless, in reality couples are closer at some times than at others, with the loss of a spouse through death being the most extreme separation. Recognizing a spectrum of experience might enable a widow or widower to recognize similarities between her/his current situation and earlier days when war, job demands, or demands of other relatives reduced the experience of being a couple, while still feeling the presence of the partner in her/his life. Similarly, while an elderly person may no longer be employed after approximately fifty years on a job, by rejecting dichotomous ways of thinking, a person might be able to think of other times when employment seemed less important to self-identity (e.g., early years when one only worked in order to finance being with friends, or when having young children seemed to occupy the whole of one's emotional energy). The loss of a loved one or of employment and its satisfaction and socialization is sad. But the loss of identity associated with being part of a couple or with being employed (e.g., *being* a teacher) can make the sadness worse. Avoiding or softening the

dichotomous ways of viewing the pairs that make up identity (active/inactive, employed/out-of-work) might reduce the emotional burden associated with the losses that inevitably occur in the later decades of life.

The fear of death and dying is another psychological factor that contributes to ageism. People commonly link together aging with death because they believe that the older we become, the closer we find ourselves to death. However, death can and does occur at any age. As Sara Ruddick explains, “death is the terminus not of aging, but of life.” Dealing with the fear of death is a lifelong task (Ruddick, 1999). A person who has never experienced a death may not fully understand death and may never have managed her feelings about it. In fact, some people have even developed an intense fear about dying. As a result, the feelings harbored about death may be expressed in the form of discrimination toward and devaluation of the elderly. After all, our society is dedicated, even arguably obsessed with defeating death (Gadow, Spring 1996). Offering an analysis similar to Young’s, Sally Gadow explains that our society’s “central values include autonomy and productivity.” Therefore it seems rational “to marginalize those who are physically and financially dependent” (pg. 36). Because most elderly are unable to be a productive part of our society, it is easier for people to view death as natural for them. Gadow describes this as the age/death connection: “The construction of death as natural in old age saves rationalism by sleight of hand, making (some) death socially tolerable by making (all) old age tolerable” (pg. 37).

It is a combination of social, cultural, historical, and psychological factors that contribute to ageism. In turn, ageism likely plays a role in physicians’ development of a preconception that elderly persons are unable to participate in conversations about their care. Ageism, coupled with features of the medical environment may lead many medical professionals to believe that elderly

patients as a whole are unable to understand the complex medical jargon that may accompany a discussion about medical care. In addition, physicians are busy, and as a result of both the profession and a culture that encourages people to work and move at a fast pace, they may feel as if they do not have the time to properly explain the technicalities of a medical decision to an elderly patient, especially an elderly patient with some degree of dementia. They find it easier and perhaps less time consuming to provide medical information to a family member who is often of a younger age than the patient herself.

Also playing a role in a physician's disregard for an elderly demented patient's participation in her care is sexism, characterized as beliefs and attitudes reflecting stereotypes regarding a person's sex or gender, rather than individual attributes, as well as discriminatory actions based on those beliefs. There seem to be two ways in which sexism may affect physician's treatment of the demented elderly. First, women are disproportionately represented among the elderly. At any age, men typically have a higher death rate than women, which by old age results in a disproportionate number of elderly women. In 1994, there were 20 million elderly women to 14 million elderly men, ages 65 and older. This is a ratio of three to two. As age increases, the difference in the number of elderly men and women grows larger. At ages 65 to 69, the ratio is six women to every five men, and at ages 85 and older, the difference increases five to two (Bernstein, May 1995). As a result, any actions by physicians, including those that exclude elderly demented patients from participating in their care, are going to affect disproportionately more women than men. In this sense, sexism results from, but does not cause physicians' discriminatory actions. In effect, a sexist outcome occurs: more women are excluded from participation in their care than men.

Sexism plays a second more important and more obviously sexist role in the treatment of the elderly, particularly the demented elderly. It seems that whether they are male or female, as they age, people are gendered female. To be “gendered female” means to be viewed and treated in ways that are associated with being female. Given Young’s idea of dichotomous thinking discussed earlier, being treated in ways associated with being female really means to be treated as not ideally male, or as no longer fulfilling the ideal of male, i.e., as no longer rational, active, able-bodied, present in the public sphere, independent, and so on.

This phenomenon of the elderly becoming gendered as female occurs for a couple of reasons. Most elderly people are eventually in need of care. As was discussed in the previous section on ageism, this care need is often the result of diminished or even near total loss of mental and physical capabilities. These elders are now in a position of dependence and vulnerability as a result of their care needs (Tronto, 1993). To be vulnerable and dependent on another closely resembles another stage in a person’s life: childhood. Children are dependent on their parents for shelter, food, and care. In quite the same way, an elder also becomes dependent on another to provide for these needs. Traditionally, women were also considered dependent and vulnerable. The conventional family of the 1950s was composed of a working man and a stay-at-home woman whose duty was to be a mother to her children. She was, most often, without an income and left to depend on her husband financially. She was vulnerable and relatively powerless, a care-receiver, much like many of the elders today who are left to depend on their adult children and their nursing facilities. Also, women typically have the intimate duties of care-giving, while men have the more powerful public-sphere duties of caring about and taking care of (Tronto, 1993). However, no matter a person’s sex, an elderly person comes to be gendered female as a consequence of the position occupied in the hierarchy of the phases of care.

An elder, like a woman or child, is most often in the position of care-receiver, as opposed to care-giver or the person who takes care of care needs. This position of dependence, vulnerability, and relative powerlessness of the elderly resembles that of a woman and a child, not a (stereotypical or ideal) man.

A second way that old age is gendered female concerns the idea of life as a career. This career fits into three age periods: youth, adulthood, and old age. In a culture where productivity is central to being considered an important part of society, these three age periods in a person's life match with the career stages in a person's life: schooling, work, and retirement. Unlike school and work, however, retirement is not typically a place of learning, a time of development of abilities and skills, or an activity that will place a person in a position to benefit society. Without any kind of productive role in society, the idea of life as a career makes retirement seem like the end of life, even if a person has many years of life remaining (Walker, 1999). The retirement stage of a person's life is different, though, for a man and a woman. By retirement, a man has lived his youth and adulthood as a series of public-sphere roles that together fashioned a career. He has had the roles as a son and student, husband, father, head of household, and worker. Then upon reaching retirement, he finds himself "role-less" (Walker, 1999). A woman, on the other hand, has had a different "career" formed through domestic responsibilities and raising children; her role has been defined in terms of the needs of others. In her later years, she may also find herself without her previously defined role as a care-giver, without someone to care for, and may instead, find herself in need of care. Because most elderly women outlive their male companions, they will often be left widows without even a spouse to care for. The role of women as stay-at-home wives and mothers who were not productive in the public sector in terms of earning an income for their family, leaves them without a publically recognized, socially

valued, career-related role, much as men experience upon reaching the retirement age. In retirement, without a socially valued role, men, like women throughout their lives, are seen as without a social role, as no longer promoting the productivity of the society (Walker, 1999). In this way, according to this life-as-career model, role-less retirement-age elderly men are gendered female. Their role, or lack thereof, is feminized, assimilated to the traditional female role-lessness.

Finally, Young addresses the dichotomy between reason and feeling, which has particular relevance to old age and the way that it is feminized. “The bourgeois world instituted a moral division of labor between reason and sentiment, identifying masculinity with reason and femininity with sentiment and desire” (pg. 110). In addition, the public and private realms depend on this dichotomy. “The impartiality and rationality of the state depend on containing need and desire in the private realm of the family. The public realm of citizens achieves unity and universality only by defining the civil individual in opposition to the disorder of womanly nature, which embraces feeling, sexuality, birth and death, the attributes that concretely distinguish persons from one another. The universal citizen is disembodied, dispassionate (male) reason.” (pg. 110) Thus, women have traditionally been omitted from the public realm (Young, 1990); even when women do participate in the public sphere, they are expected to avoid emotionalism, perhaps to an even greater degree than male counterparts.

This prizing of the avoidance of emotionality has particular relevance for consideration of old age and for understanding how being old is gendered female. In addition to the dependence, vulnerability, and feeling of being without a social role experienced by an elderly man, many may begin to express emotions they once concealed in fear they would not be seen as the calm and composed man expected by society. An elderly man may vocalize his love for family

members, find himself choked up when speaking about a sentimental memory, or even tear when watching a sad movie. These are the emotions traditionally reserved for women and kept in the private sector of society, but when expressed by men, advance the notion of elderly men as gendered female. This increased emotionality may result from the greater opportunity to express emotion, as the elderly are more outside of the public sphere and in more intimate space and care-receiving relationships, as well as from the subtle erosion of psychological control over emotion (“filters” and “controls”) that is sometimes witnessed among older people.

Sexist attitudes and discriminatory actions thus affect the treatment of the elderly in a couple of ways. First, because any systematic way of treating the elderly will have a disproportionate effect on women who constitute a larger proportion of the elderly population, especially the old old. Second, because sexist attitudes may result in less than optimal, unethical, treatment of the elderly as both male and female elders are devalued as old age is feminized. As a result of being feminized or gendered as female, elderly patients, particularly the demented who lack rational cognitive abilities while often retaining emotional responsiveness, may experience features of the doctor-patient relationship typical of the experience of female patients. Female patients are often viewed as being weaker than their male counterparts; their pain reports, for example, are taken less seriously (Wolf, 1996). Physicians have traditionally thought of female patients as lacking courage to deal with the physical hardship and emotional burden of serious illness and have hidden diagnoses from them (Wolf, 1996). Moreover, women are viewed as craving relationship and also as being compliant with authority figures (Wolf, 1996). Similarly, elderly demented patients, even the mildly demented, may be viewed as unable to cope with bad news, as not wanting to participate in healthcare decision making, and as willing to settle for any sort of relationship with the doctor, even one which is not truly relational and

attentive to their needs and abilities as individuals. This is especially true given the traditional view of elderly demented patients as child-like and dependent.

Finally, because many patients, even those with intact cognitive abilities, do not want to retain decisional authority regarding medical decisions (Schneider, 1998), because this view is more prevalent among elderly patients (Schneider, 1998), and because many demented patients lack cognitive ability requisite to retain decisional authority, many physicians may leap to the conclusion that elderly demented patients do not want to participate in decision making at all. This leap is a product of the sort of dichotomous all-or-nothing reasoning that Young criticizes. Just as the dichotomous world view results in ageism and sexism, it leads to the third bias that impedes the involvement of the elderly demented in their care, namely, hypercognitivism.

There are two senses of hypercognitivism. The first and more fundamental sense is the idea of placing very high value on cognition and rationality. The second, resulting from the first, is the idea that a higher moral status and personhood should be given to individuals possessing full cognitive abilities (Post, Spring 1998). This sense of hypercognitivism views cognition as the criterion of personhood.

As in Young's analysis, dominate patterns of Western thought create dichotomies between the attributes associated with the dyad of male/female. One example of these dichotomies is rational versus irrational, emotional, and spiritual. If rationality is deemed desirable, as it is within Western society, then emotionality, irrationality, and spirituality are deemed undesirable or even detrimental. Under this sense of hypercognitive thinking, high value is placed on rationality, and thus, high value is placed on those persons who are reasonable, logical, composed, and objective. Those persons who possess the opposite of such valuable attributes are not valued as persons and are therefore degraded. Such valorizing of rationality

places at a disadvantage within our society those individuals who are irrational, such as those persons suffering from dementia. Holding such a hypercognitivist view might lead people to choose medical interventions that had the greatest chance of preserving or promoting a patient's cognitive abilities, perhaps at the expense of other goods (like comfort) or might lead them to discount the value of interventions that do not preserve cognition but that afford other sorts of benefit.

Given this prizing of rationality, it is little wonder that some consider the capacity for rational cognition to be the mark of being a person. A hypercognitivist account of personhood would contend either that only those with such capacities, either currently or potentially, are persons, or at least would accord higher moral value to those who possess full cognitive abilities. Under these hypercognitivist theories of personhood, severely demented persons are not recognized as persons at all, or in any case, they are not given the same status as those persons who have all their cognitive abilities intact. By considering demented individuals as nonpersons or as persons with diminished moral status, these individuals are deprived of recognition of the emotional, value, and relational facets of human dignity, as well as being deprived of the opportunity to exercise what minimal cognitive capacities may remain despite the dementia (Post, Spring 1998). Arguing against such hypercognitivist views, Steven G. Post claims that "persons who lack certain empowering cognitive capacities are not nonpersons; rather, they have become the weakest among us and are worthy of care." He also asserts that "the hypercognitivist value system that shapes personhood theories of ethics is merely an example of how our culture's criteria of rationality and productivity blind us to other ways of thinking about the meaning of our humanity and the nature of humane care" (pg. 72). Like Young, Post criticizes a

dichotomous approach, the all-or-nothing way of viewing cognition and the all-or-nothing way of viewing persons based upon their cognitive capacity.

If physicians embrace a hypercognitivist value system, they may indeed fail to view a demented patient as a person. The content of medical training may provide a reasonable explanation for physicians' high value of rationality and their adoption of a hypercognitivist attitude. Medical students are admitted to medical school largely on the basis of their ability to demonstrate acute cognitive abilities and rational thought. Their undergraduate science training is a prerequisite for admission. Their overall and quantitative scores on the Medical College Admissions Test (MCAT) are critical for admission. Then, they endure four years of medical training, studying mostly science. During their clinical years, the teaching of evidence-based medicine is crowding out teaching students to pursue their hunches. Medicine is increasingly a science, not an art. Moreover, as Tronto observes, it was only when the medical profession became associated with science that it moved from being a low social status, care-giving career to being a high social status profession (Tronto, 1993). Physicians aligned themselves with the rational and scientific and gained status in doing so.

Moreover, there are psychological reasons for physicians to avoid too much emotion in their practice. In the profession, many will cut open patients, remove and replace organs, witness patients suffer from incurable or untreatable diseases, and watch as patients die. As a result, many learn to avoid expressing emotion, and maybe even experiencing it, as a way to establish the distance necessary to continue to perform these necessary tasks on a daily basis. Physicians even learn to elude close relationships with patients for fear that those relationships may develop into deep emotional connections which may interfere with their performance as physicians. As Tronto discusses, physicians are encouraged to perform less of the caring role.

Those physicians who receive the highest status among their colleagues are the ones who do the least amount of direct care work, but instead are at the forefront of research in their field. They pass most of the caring aspect of the profession to another, often a nurse whose responsibility is to care and connect emotionally with a patient (Tronto, 1993). As a consequence of having a hypercognitivist value system, physicians may not find worth in a demented elderly patient's participation in treatment decisions or her expression of preferences regarding her care.

The notions of ageism, sexism, and hypercognitivism intersect to make elderly, demented persons, perhaps women more than men, at a greater risk for oppression and discrimination within our society. Physicians and other medical professionals may be knowingly or unknowingly acting upon the age, gender, or cognitivist biases that are present within our culture and that prevent them from deeming it compulsory to include elderly demented patients in their care or the planning of their care. The next section discusses how the intersection of these biases has more than a merely additive negative effect for the elderly demented.

## **2.2 THE INFLUENCE OF THE INTERSECTIONALITY OF AGEISM, SEXISM, AND HYPERCOGNITIVISM ON PHYSICIAN BEHAVIOR**

This section explores the notion of intersectionality and considers it as a method of analysis. As an example, it examines the way in which the intersectionality of ageism, sexism, and hypercognitivism, affected the way that courts constructed preferences for incompetent patients with regard to end-of-life decisions. It takes up this topic because the reasoning of the courts, as

reconstructed by Steven H. Miles and Allison August, illustrates the way that physicians may think, albeit less self-consciously and explicitly, about the elderly demented patients they see.

Intersectionality is a method in feminist thought that is used to understand the ways in which concepts of discrimination interact, usually with a exponential negative effect.

An intersectional approach to analyzing the disempowerment of marginalized women attempts to capture the consequences of the interaction between two or more forms of subordination. It addresses the manner in which racism, patriarchy, class oppression and other discriminatory systems create inequalities that structure the relative positions of women, races, ethnicities, classes, and the like. Moreover, intersectionality addresses the way that specific acts and policies operate together to create further disempowerment. For instance, race, ethnicity, gender, or class, are often seen as separate spheres of experience which determine social, economic and political dynamics of oppression. But, in fact, the systems often overlap and cross over each other, creating complex intersections at which two, or three or more of these axes may meet. Indeed, racially subordinated women are often positioned in the space where racism or xenophobia, class and gender meet. They are consequently subject to injury by the heavy flow of *traffic* traveling along all these roads ("Background Briefing on Intersectionality: Working Group on Women and Human Rights," 2001).

Thus, women of color may not only *be* economically disadvantaged, but be economically disadvantaged, at least in part, *because* they are women and members of a racial minority. Moreover, their being a member of a racial minority might not matter in the same ways if they were not also female or poor. In other words, a rich Black woman may live in material conditions much more like those of a rich White woman than those of a poorer Black woman. Or, being poor and Black she might have different opportunities open to her than if she were poor, Black, and male. While poor Black men are at higher risk of violent death than their female counterparts, they may have more paths toward social status and acceptance open to them than poor Black women. Intersectionality is a method of analysis that attempts to recognize and

analyze the interconnected, overlapping, and synergistic ways that features of a situation act to privilege or disempower people.

One such analysis is of gender differences within court decisions made regarding “right to die” cases (Miles and August, Spring-Summer 1990).<sup>4</sup> Although those studying the cases, Steven H. Miles and Allison August, focused on gender bias, the effects of ageism and hypercognitivism are also evident. They discovered that treatment preferences regarding whether the patient would have exercised the right to die, if competent to do so, were constructed by the courts for 75% of male patients, but only 14% of female patients. This pattern, of constructing preferences for male patients while leaving the decisions for female patients to family members, was witnessed over a 14 year period and was not attributable to chance, according to Miles and August. It was also not affected by the state where the court was located, age of the patient, or whether or not the patient was comatose or supported by tube feedings (Miles and August, Spring-Summer 1990). Even though age of the patient did not affect the trend or overall bias Miles and August identified, the effect of ageism in evident is some of the court’s language.

Miles and August suggest reasons for this bias in constructing patient preferences. Granted, the reasons they propose relate to courts that made decisions on behalf of patients whose incompetence was a result of permanent unconsciousness, while demented patients are mostly incompetent while consciousness remains. Still, many of the reasons suggested for the

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<sup>4</sup> This section does is not intended to argue that physicians discriminate more heavily with respect to their female demented patients rather than male demented patients; this discussion is intended only to suggest that a gender bias may occur and that women may be more affected by sexism than men.

bias in the courts may provide some insight as to why physicians exclude demented patients in the planning their care.

The first reason Miles and August offer for the gender difference is the court's view that a man's judgment is deemed rational, while a woman's is labeled as emotional. A man is seen as exercising careful deliberation and consideration, even in remarks made about end-of-life issues to his friends and family. Even when men's emotions are recounted to the court, they are viewed as "passionate convictions," rather than resulting from a "disordered mind" (pg.88). A woman, on the other hand, is seen as remarking out of emotion or as a reaction to a painful or stressful experience. Women and their remarks are even characterized as childlike. Their comments, often considered "off-hand," are considered not to reflect any careful thought, and are therefore, frequently disregarded by the courts (Miles and August, Spring-Summer 1990)(pg. 90).

Second, the courts considered women to lack the capacity to make moral decisions relating to health care. This is shown in the text of the decisions made by the courts. These decisions were made without any regard to or mention of the woman's values. When a decision was made to remove life-prolonging measures, it was made either because a written advanced directive existed or because family could show a consistent pattern of decision making with prior medical decisions made by the patient (Miles and August, Spring-Summer 1990). Third, the courts used different standards when examining the evidence of a man's preferences than a woman's preferences. It seems that courts only constructed past preferences for a woman when a very specific remark was made, while the court was willing to accept more general remarks to construct the preferences for a male patient. Past preferences were also constructed for a male patient simply based on his character. In contrast, even when a woman made a very specific

remark regarding life-prolonging measures, the remark is often portrayed as emotional and discarded (Miles and August, Spring-Summer 1990).

Lastly, “life support dependent men are seen as subjected to medical assault; women are seen as vulnerable to medical neglect” (Miles and August, Spring-Summer 1990) (pg. 87). Men on life support are viewed by the court as in jeopardy of being seen as dehumanized and in a condition that is degrading. Women, on the other hand, are seen as vulnerable and in need of aid. The family of a female patient may, for example, be viewed as having motives contrary to those of the patient when the family supports termination of life-sustaining treatment. As a result of this vulnerability, it is considered justified to seek court approval for surrogate medical decisions made on behalf of female patients (Miles and August, Spring-Summer 1990).

The parallels between the situation of the courts regarding incompetent (because permanently unconscious) patients and that of physicians viewing their elderly demented patients are instructive. To feel vulnerable within the context of medical care is not unique to end-of-life situations; rather, to be in a position where care is needed to is be is a situation of vulnerability (Tronto, 1993). The experience of vulnerability is also not exclusive to a woman. Both a men and women can find themselves needing care, and hence in a position of vulnerability. Tronto explains, “Vulnerability belies the myth that we are always autonomous, and potentially equal, citizens” (pg. 135). During a person’s life, he or she will go through periods of vulnerability, as well as dependence and autonomy. When a patient requires care from a person, the patients is put in a position vulnerability, which in turn, places the patient in an unequal relationship of authority (Tronto, 1993). For a demented patient, the unequal relationship may be quite common. However, it may not be the patient’s vulnerability that is the primary issue within this type of physician-patient relationship. The physician may recognize her own vulnerabilities or

fear of dependence when caring for a demented patient. Her own trepidation regarding old age may prevent her from including demented patients in conversations about care. To omit a demented patient from these types of conversations furthers the inequality of the relationship between the physician and patient thereby making the physician feel powerful and in control. The feeling of power, as well as lack of inclusion of the patient in conversations, averts the physician from facing her own fears and vulnerabilities regarding her future.

Additionally, many physicians may hold biases in regard to their elderly demented patients. They may see their patients in a way similar to the way the court system viewed terminally ill, incompetent female patients. They may see their female patients as emotional and easily pressured to surrender control of their care to their physician. They may view elderly men in terms of the “life as a career” approach and see them as no longer valuable to our society given that their age and then their dementia has left them role-less. A person who is no longer a value to society may also be viewed as not useful as a participating member of a medical conversation. Many of their elderly patients may be poor and lack adequate health care coverage. Often, being poor is equated with being powerless. These preconceptions and prejudices are not always expressed or acted upon independent of each other, but rather they may be tacit and may interact to further discrimination and negative attitudes. The intersection of ageism, sexism, and hypercognitivism may place the demented elderly, and especially women, at a greater risk for suffering discrimination within our society and a lack of involvement in the planning of their care or the informed consent process.

In addition to the influence of the intersectionality of ageism, sexism, and hypercognitivism on physicians, another issue may lead physicians to fail to involve demented

elders in their care. Physicians may also interpret the role of involvement in decision making differently. This idea is analyzed in the following section.

### **2.3 PHYSICIAN INTERPRETATION OF INVOLVEMENT**

The argument of this paper has been that demented patients may lack decisional capacity, but can still be involved in the planning of their care and, to some extent, the informed consent procedure. However, the idea of “involvement” seems to suggest different actions depending not only on the cognitive capacities of the patient, but also on the values and beliefs of the physician. There are at least two ways in which involvement could be interpreted by a physician. First, there is the dichotomous way of thinking of involvement: a patient can either participate completely in decision making and the informed consent process, in which the patient retains decisional authority, or the patient cannot participate at all. If the patient lacks competence or lacks the cognitive abilities to participate in an informed way in the discussion (even if decisional authority rests with a surrogate decisionmaker), a physician who embraces this dichotomous way of thinking of involvement may either ignore the patient, or may “include” her in a most condescending way, treating her like a child, cajoling her into compliance, often using the pronoun ‘we’ as though to include her. Such a physician may ask, “Are we ready to be examined today, Mrs. Jones?” without expecting or respecting a response.

There is, however, a second way of conceiving of involving a patient in her care. This second approach considers involvement along a spectrum. At one end is the ideal of a fully involved, competent patient who retains decisional authority, participates actively in the

informed consent process, and expresses her treatment decision. Moving away from this ideal, there may be ways to involve patients who lack decisional capacity, but who retain the ability to understand (though not reason and deliberate adequately) and who are able to express relevant preferences and values. At the other end of the spectrum would be the generally inexpressive, noncomprehending patient, who nevertheless may occasionally express what may be construed as preferences either by exhibiting degrees of pleasure or pain, or by uttering refusals as opposed to complying easily with treatment interventions and care-giving.

First, as was discussed in the first chapter, decisional capacity is the ability to declare goals and values, understand information, weigh options according to preferences and values, and communicate a decision. An autonomous patient is able to complete these four tasks in order to make an informed medical decision. A demented patient, on the other hand, is not autonomous, meaning that she is unable to make an informed medical decision. Many physicians recognize this inability and deem demented patients unable to participate in medical decisions. They have adopted an all-or-nothing approach to healthcare decision making.

Second, at the end of the dementia continuum is the severe form of this syndrome. At this end, demented elders often possess the cognitive capacity that resembles a child. A person with late stage Alzheimer's disease will have lost most of her memory and have immense difficulty recognizing otherwise familiar friends, family, objects, and places. She may have trouble walking, often becoming unsteady on her feet. She may also have trouble eating, controlling her bladder and bowels, and may have trouble speaking and understanding speech at certain times ("Facts about Dementia," 2007). The problems that are experienced by patients suffering from severe forms dementia are many of the same issues experienced by children. As a result, physicians seem to perceive severely demented patients as children and treat them

accordingly. Physicians lean in or bend down to speak with them, use an elevated tone, and offer rewards. Additionally, many physicians will even touch the patient on the arm or knee, almost condescendingly, perhaps forgetting that these are adult patients and that demented patients are not children.

It is typical for persons to lose, to some extent, their ability to understand and retain new information as they age, and dementia may in fact lead to a greater loss of this ability. However, this is only a generalization, and a patient needs to be assessed in order to determine her capacity to make a decision, as the symptoms of dementia exist on a continuum. It seems as though physicians have failed to understand that there are cognitive capacities of a demented patient that still exist. Moreover, the patronizing of an adult male or female is not the same as inclusion in the planning of care. Perhaps some demented patients cannot articulate or communicate a decision, while others cannot weigh the options according to their values. Despite these cognitive deficiencies, demented patients can participate in their care. Many can express their values about certain treatments or even about life in general. Healthcare decisions can often be inferred from these values and preferences.

There are some ways in which physicians can positively reconceptualize old age and involve patients in their care. For example, instead of viewing life as a career in which elderly men and women are left with a feeling of role-lessness upon reaching old age, it may be more appropriate to view life as a journey. Margaret Walker refers to this view of life as “a lateral integration of life” (pg. 107). She describes this view as embodying “no eventually unfulfillable demand for achievement or progress; it requires only normal awareness, capacities for feeling, and opportunities to belong to or with something other than or larger than oneself. The meanings in such a life are many, and we do not wholly control much less create them” (pg. 107). Life as a

journey sees a person's life as a continuous course that may be slowed down or stopped at times and that may be affected by things that cause the person to not always follow the straight path that is required for the view of life as a career. Instead of seeing life as linked to age or stages marked by phases in career, life is viewed as a series of lessons learned, pleasures, relationships, experiences, and events. To see life as a journey is to see your life as a part of the lives of other people, like family, friends, and partners (Walker, 1999). This way of viewing life, contrary to seeing life as a career, helps to eliminate the idea that life ends at old age or when a person loses cognitive capacity due to dementia, when a person can no longer be a productive member of society. Instead old age is marked by new and changing relationships, finding new pleasures, and enjoying new experiences.

Additionally, Sally Gadow suggests a model of personal engagement between a patient and her physician. "In that engagement, both persons are present as moral (not rational) agents, confirming or declining the meanings that each offers the other, until a narrative is composed about health and aging that both can accept. Their relational narrative is the reconstruction of their situation together, it has no wider validity" (Gadow, Spring 1996) (pg. 39). This paper argues that although most elderly demented patients do not possess the decisional authority to make decisions, they are still able to participate in their care. It may be that demented patients lack the ability to compose a narrative in a traditional linear sense; however, they can still play a role in the narratives of others-their families and professional care-givers-so that the idea of doctor and patient interacting to compose an acceptable narrative is still an instructive one. Physicians need to ask questions to determine each demented patient's individual level of decisional capacity and then engage patients by speaking to them directly, avoiding language that equates these adult patients to children. They need to actively seek their preferences and values

at the level that each patient is able to communicate them and determine the good each patient seeks for her life. Physicians should attempt, insofar as possible, to recognize and confront their biased attitudes and actions stemming from the intersection of ageism, sexism, and hypercognitivism. Then, they should attempt to see each patient as a unique individual capable of some degree of participation in the planning of her care and attempt to create conditions necessary to facilitate that degree of involvement.

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