

**FAILING ELDERLY PATIENTS WITH CHRONIC ILLNESS:
WHY AUTONOMY NEEDS RECONSIDERATION**

by

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ABSTRACT

Background

Eating and drinking are meaningful human activities through which we give, receive and share food and maintain social relations. Elderly people are at risk for chronic conditions, due to decline in functional reserve, increased vulnerability to diseases and the effects of polypharmacy. Many of them are physically and psychologically burdened by swallowing difficulties (dysphagia). Therapeutic “non-compliance” is a challenge for speech-language pathologists, for patients often do not follow through with recommendations. This is a classic conflict between two ethical principles: respect for autonomy, which is the patient’s right to make medical decisions, and beneficence, which is the clinician’s duty to do good and prevent harm.

Aim

To explore the ways in which patient autonomy and clinician beneficence can be balanced in the process of clinical decision making.

Method

The research strategy is the critical review and synthesis of literature where the data are obtained from the fields of bioethics, philosophy, medical anthropology, literary studies, and health communication.

Result

Western medicine operates largely on principlism, which is based on the use of four ethical principles: respect for autonomy, beneficence, nonmaleficence, and justice. In recent years there is grown interest in narrative ethics, an approach leading from the individual's life story. Speech-language pathologists' support of elderly patients with chronic dysphagia and families in their decision making may benefit from a synthesized approach combining principlism and narrative ethics. Speech-language pathologists may be unusually well qualified to consider this approach, for we are the communication experts uniquely trained to appreciate narrative as a discourse ability.

Clinical Significance

Speech-language pathologists need to focus on the bigger clinical picture to consider the costs and benefits of long-term eating and drinking decisions and the effects of their well-intended interventions on patients' lives. Patients' narratives reveal their identities and what matters most to them. Empowering elderly patients to make autonomous decisions about eating and drinking involves forming partnerships in the therapeutic relationship and listening to and acting on their narratives. Using narratives to align care to patients' values and preferences may help speech-language pathologists establish joint goals with patients and reduce "non-compliance."

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PREFACE AND ACKNOWLEDGMENTS

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For clarity, male pronouns will be used when referencing the patient/teller. Female pronouns will be used when referencing the clinician/listener.

1.0 INTRODUCTION

Chronic conditions are defined as “...health problems that require ongoing management over a period of years or decades...[T]he one feature that unites them all is that they typically affect the social, psychological and economic dimensions of a person’s life” (World Health Organization, 2005, p.13). Many elderly people have chronic swallowing problems and need to make decisions regarding eating and drinking. In clinical practice, clinicians often encounter a conflict between two ethical principles: autonomy, which is the patient’s right to make medical decisions, and beneficence, which is the clinician’s duty to do good and prevent harm.

1.1 CHRONIC ILLNESS

Chronic conditions affect the lives of thousands of people in the United States (U.S.). Figures from 2012 show that approximately half of American adults had one or more chronic conditions, while one in four adults had two or more chronic conditions (Centers for Disease Control and Prevention, 2016).

The terms “disease” and “illness” are often used interchangeably, but there are qualitative differences between them (Cassell, 1991; Kleinman, 1988; Tauber, 2005). Disease refers to abnormalities in the structure or function of the body and is a biomedical classification (Eisenberg, 1977). Illness is a psychosocial construct that involves how individuals, their

families and other people experience and perceive disease. It is important to distinguish between the two terms, because illness experience is what affects a patient's coping strategies and responses to diseases.

Chronic conditions include heart disease, diabetes, renal failure, and chronic obstructive pulmonary disease. These conditions may not be as dramatic or high profile as acute conditions but do affect individuals for an extended period of time. Chronic conditions lead to chronic illness, which refers to the personal experience of living with the burden of diseases. Patients experience a disruption of everyday life, for they can no longer participate in some of the activities they used to enjoy.

The elderly are a vulnerable population and are generally more susceptible to chronic conditions. Nearly two thirds of beneficiaries of Medicare, who were 65 and older, had two or more types of chronic conditions and accounted for 95% of Medicare expenditures (Wolff, Starfield, & Anderson, 2002). The presence of chronic conditions increases the risk of developing functional limitation among the elderly. In people 70-79 years of age with three or more chronic conditions, 17% reported moderate functional limitation such as limitation in walking and bathing. This increased to 49% in people 80 years or older (Dunlop, Manheim, Sohn, Liu, & Chang, 2002).

1.2 EATING, DRINKING, AND SWALLOWING PROBLEMS

The word "dysphagia" is derived from the Greek words "dys" (difficulty) and "phagia" (to eat), which literally means difficulty swallowing. Dysphagia co-occurs with many chronic conditions and is secondary to impairment in the anatomy or physiology of the swallowing process in which

food is transferred from mouth to stomach. Dysphagia can lead to serious consequences, such as airway obstruction or chest infections resulting from bacteria entering the lungs from the mouth. Individuals with dysphagia may also reduce dietary intake, which puts them at risk for malnutrition and dehydration. This can be caused by difficulty swallowing food and drink, the medical conditions that result in dysphagia, or both.

Dysphagia can be caused by discrete neurologic disorders (stroke, brain injury), neurodegenerative diseases (dementia, amyotrophic lateral sclerosis), or trauma, or it can develop as a side effect of medications or treatment, such as surgery, radiation and chemotherapy. The most commonly reported etiology is stroke, followed by other neurological causes and head and neck cancer (Bhattacharyya, 2014). Dysphagia can be acute or chronic. Over 50% of patients have swallowing impairment after an acute stroke but the majority of them recover functional swallowing ability within one to six months (Groher & Crary, 2010).

Approximately 9.44 million adults in the U.S. report having swallowing problems, which means that one in 25 adults experience dysphagia annually (Bhattacharyya, 2014). Of patients, 31.7% reported that they had a moderate swallowing problem, while 24.8% reported their problem as major/very major (Bhattacharyya, 2014). Chronic dysphagia refers to swallowing difficulty that lasts for more than six months (Groher & Crary, 2010). Chronic dysphagia is a devastating condition greatly affecting patients' quality of life, because eating and drinking are integral to the human experience. Patients with chronic dysphagia can no longer enjoy the pleasurable experience of eating and drinking. Impairment in swallowing impacts their ability to participate in ordinary but meaningful activities such as sharing food with family at the dinner table or having a drink with friends in a bar.

Aging decreases functional reserve and pathological insults are likely to exceed the remaining functional capacity. Advancing age is associated with more adverse health conditions and comorbidities. Some of the common chronic conditions such as diabetes mellitus, chronic obstructive pulmonary disease, and renal failure can cause dysphagia (Barczy, Sullivan, & Robbins, 2000). Dysphagia due to abnormal esophageal motility can occur in diabetes mellitus (Forgács, Osváth, Kéri, & Fábrián, 1979; Hüppe et al., 1992). Dysphagia in chronic obstructive pulmonary disease is caused by impaired coordination between breathing and swallowing as well as esophageal functional abnormality (Good-Fratturelli, Curlee, & Holle, 2000; Mokhlesi, 2003; Mokhlesi, Logemann, Rademaker, Stangl, & Corbridge, 2002; O'Kane & Groher, 2009). Dysphagia in chronic renal failure is linked with xerostomia and decreased level of alertness (Pinto, Silva, & Pinato, 2016; Vesterinen, Ruokonen, Furuholm, Honkanen, & Meurman, 2012).

Managing multimorbidity in the elderly is a great challenge for health care professionals. While most guidelines for clinical practice focus on the management of a single condition, many elderly patients have multiple medical conditions rendering clinical management and decision making difficult tasks (American Geriatrics Society Expert Panel, 2012).

1.3 CLINICAL DECISION MAKING

Decision making is generally regarded as a deliberative process in which individuals recognize the need to make decisions, identify options, collect information to aid decision making, weigh the pros and cons of different options, compare options against their personal values, choose an alternative and implement it. However, work in neuroscience has shown that emotions play an

important role before we arrive at a decision (Bechara & Damasio, 2005; Bechara, Damasio, & Damasio, 2000; Bechara, Damasio, Damasio, & Lee, 1999; Bechara, Tranel, & Damasio, 2000).

In practice, the clinician collects, interprets and evaluates data before recommending an action based on the best available evidence (Tiffen, Corbridge, & Slimmer, 2014). The clinician learns about the patient's problem by looking into his medical history and performing clinical and instrumental examinations. The clinician then uses her clinical expertise to interpret these data and makes hypotheses about the causes of the patient's symptoms. After a diagnosis is made, she uses the best available research evidence to form a treatment plan. The speech-language pathologist (SLP) plays an important role in the process of making long-term eating and drinking decisions. She evaluates the patient's swallowing function and makes a recommendation to manage dysphagia, which should protect or enhance the patient's quality of life.

In recent years, there has been a push for shared decision making. The clinician and the patient jointly engage in the task of decision making and the patient is informed of the available options to determine preferences (Elwyn et al., 2012). Shared decision making is a model for clinical practice in which the clinician and the patient collaborate to make decisions together and the patient is supported to express his goals and preferences in the decision making process. This preferred model of clinical decision making is advocated with reference to "patient autonomy".

1.4 PATIENT AUTONOMY

The concept of patient autonomy stands at the heart of contemporary medical ethics. The basic idea is that patients have the right to accept or refuse medical interventions. Patient autonomy is

widely acknowledged in medical practice and a number of professional health organizations uphold the importance of respecting patients' autonomy.

- Opinion 1.1.4 of the American Medical Association Code of Medical Ethics states that “[a]utonomous, competent patients control the decisions that direct their health care” (American Medical Association, 2017, p.3).
- Provision 1 of the American Nurses Association Code of Ethics (2015) states that the nurse must respect autonomy and dignity of the patient (American Nurses Association, 2015).
- The American Occupational Therapy Association Code of Ethics (2015) states that “[o]ccupational therapy personnel shall respect the right of the individual to self-determination, privacy, confidentiality, and consent” (American Occupational Therapy Association, 2015, p.4).
- The American Physical Therapy Association Guide for Professional Conduct (2013) provides interpretation of the Code of Ethics for physical therapists. According to its interpretation of Principle 2C, “Physical therapists shall provide the information necessary to allow patients or their surrogates to make informed decisions about physical therapy care or participation in clinical research” (American Physical Therapy Association, 2013, p.4). It notes, “Ultimately, a physical therapist shall respect the patient’s/client’s right to make decisions regarding the recommended plan of care, including consent, modification, or refusal” (p.4).
- The American Speech-Language-Hearing Association Code of Ethics is unusual in that patient autonomy is not discussed (American Speech-Language-Hearing Association, 2015).

1.5 CLINICIAN BENEFICENCE

Beneficence is a fundamental concept in the history of medicine and has been the goal of medicine since the time of Hippocrates (Beauchamp & Childress, 2001). Clinicians have specialized skills and knowledge that allow them to help patients. According to the concept of beneficence, clinicians are obliged to do what is good for their patients and prevent harm. Clinicians are also required to balance benefits against possible costs of an action.

1.6 AUTONOMY VS. BENEFICENCE

Patients have the right to make medical decisions without interference, which should be respected by clinicians. Clinicians also have an obligation to act in patients' best interests. In clinical practice, autonomy and beneficence are often in conflict. For SLPs, management of signs and symptoms of dysphagia is important to minimize the risks of adverse health conditions but patients may have very different views about what constitutes the *most important* aspect of care. Some causes for patients' failure to follow through clinicians' well-intended recommendations include poor patient-clinician communication, low social support, financial problems, and dissatisfaction with diet modifications. Consequently some SLPs discharge "non-compliant" patients from their caseloads on the grounds that clinician beneficence has to be sacrificed in order to express respect for patients' autonomy.

1.7 SUMMARY

The conflict between patient autonomy and clinician beneficence poses a challenge for SLPs. How can clinicians balance autonomy and beneficence in the process of clinical decision making? How should autonomy be interpreted in chronic care? With these questions in mind, I will explore the goal of care for patients with chronic dysphagia by discussing the ways in which the interpretation of the principle of respect for autonomy may need to be reconsidered to optimize care.

2.0 PRESENTATION OF THE THESIS

I argue that the principle of respect for autonomy and its current interpretation do not help resolve ethical conflicts in clinical practice and that this principle and its most common interpretation are not applicable to the context of chronic care. I argue that we should look to narrative ethics, which is an approach highlighting the personal aspects of illness and the importance of focusing on patients' lives in clinical decision making. I argue that we should use a synthesized approach in which the principle of respect for autonomy and narrative ethics are combined. This new approach will help balance patient autonomy and clinician beneficence by gaining a deeper understanding of what is best for patients within the context of patients' lives and guiding joint goals with them.

In Chapter 3, I explore the problems posed by chronic illness and the reasons why the elderly are particularly vulnerable. Next I show that eating and drinking are a unique and meaningful human experience through which we meet our nutritional, dietary and emotional needs. Then I discuss swallowing disorders as well as physical and psychosocial consequences that patients experience. Last I discuss clinical decision making, especially decision making associated with eating and drinking.

In Chapter 4, I first explore the concept of autonomy in a historical context with special attention paid to its philosophical and legal significance. This is followed by a presentation of the rise of patient autonomy in contemporary medical ethics and a discussion of its limitations.

In Chapter 5, I first explore the history and theoretical framework of narrative ethics. Then I outline two approaches in narrative ethics, “the stories we read” and “the stories patients tell.” This is followed by a discussion of the limitations of narrative ethics. For the purpose of the current discussion, the terms narrative/story are used interchangeably.

In Chapter 6, I present the case of George and two possible scenarios deriving from using different approaches in clinical decision making. In scenario one, the clinician bases her clinical decision making on the common interpretation of the principle of respect for autonomy. In scenario two, the clinician uses a synthesized approach combining principlism and narrative ethics. I will compare and contrast the two scenarios and provide an analysis of each.

In Chapter 7, I first explore the clinical implications of using the synthesized approach when working with elderly people with chronic dysphagia. I will discuss SLPs’ unique role as communication experts in the clinical setting as well as areas that we still need to work on with respect to quality care delivery. I also discuss the research implications of this work.

My research strategy is the critical review and synthesis of literature where the data are obtained from the fields of bioethics, philosophy, medical anthropology, literary studies, and health communication. I mostly draw on literature concerning patient-physician relationship and communication. The application of this material is highly relevant in the context of my discussion, because the problems frequently encountered by SLPs in the clinical setting are similar to those encountered by physicians.

3.0 CHRONIC ILLNESS AND DYSPHAGIA

With the rise of chronic conditions, the patient-clinician relationship is potentially a long-term one and chronic illness often becomes part of the patient's identity (Charles, Gafni, & Whelan, 1997). Aging is associated with physiological changes that put the elderly at risk for adverse health outcomes. Many elderly people suffer from chronic dysphagia, which causes physical discomfort and affects psychosocial well-being. These patients can no longer participate in some of the activities that are important, including eating and drinking. Being a fundamental principle in medical ethics, autonomy requires SLPs to empower patients to make decisions regarding how they want to manage their long-term eating and drinking.

3.1 CHRONIC PROBLEMS

In the literature the definitions for the term "chronic conditions" are heterogeneous. When selected definitions of "chronic disease" and "chronic conditions" used in academia, government, and other settings were compared and contrasted, the following themes were identified: long duration, functional limitation, need for ongoing medical care and incurability (Goodman, Posner, Huang, Parekh, & Koh, 2013). Not all of these themes are exclusive to chronic conditions. For example, functional limitations can also be experienced by patients who are acutely ill. Yet it can be derived from these themes that chronic care is framed by the

longevity and complexity of such conditions. Some have proposed that chronic illness should be defined by patients who are chronically ill, insofar as they live with the conditions and have a true understanding of what the term means (Price, 1996).

The number of people diagnosed with chronic conditions, variably defined, is on the rise. It has been estimated that 171 million Americans, which is nearly half (49.2%) of the population, will be affected by chronic diseases by 2030 (Wu & Green, 2000). Chronic diseases were also responsible for seven of the top ten causes of death in 2010 including heart disease, cancer, chronic lower respiratory disease, stroke, Alzheimer's disease, diabetes, and influenza and pneumonia (Centers for Disease Control and Prevention, 2016).

Long-term care is estimated to account for 78% of health expenditures in the U.S. Chronic conditions make coordination of care difficult: the average patient on Medicare with one chronic condition sees four different physicians annually and the number increased to 14 when the patient has five or more chronic conditions (Vogeli et al., 2007). Chronic conditions also make self-care challenging: patients struggle to remember all of the instructions from different providers and they also suffer drug interactions due to taking multiple medications (Vogeli et al., 2007).

Patients who are chronically ill are often more knowledgeable than clinicians about their conditions such as symptoms, responses to certain types of treatment, and impact on life, because they experience illness first hand and live with these conditions for an extended period of time (Watt, 2000). Many chronic conditions are not immediately life-threatening and their management often depends on self-care, which relies on the patient's ability to manage symptoms, cope with physical and psychosocial consequences and make adjustments to lifestyles (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). The patient also has to get on with his

daily life including dealing with social, familial and financial matters while managing his chronic conditions. Decision making in chronic care is a complex process that requires active patient participation over a longer period of time. (Montori, Gafni, & Charles, 2006).

Chronic conditions are not addressed in clinical education to the same degree as acute conditions. The clinical education of prospective physicians mainly emphasizes the diagnosis and treatment of acute conditions, whereas most graduates mainly work with patients with chronic conditions (Nair & Finucane, 2003). It is recommended to strengthen "...education in chronic illness and disability management in curriculum for health care professionals, including education on specific topics of secondary conditions and aging with disability" (Institute of Medicine, 2007, pp. 8-9). The American Geriatrics Society expert panel (2012) has suggested that in order to improve care for elderly patients with multimorbidity, curriculum development and training in this area are needed. Training should move away from a single-disease approach and instead use a patient-centered approach, improving communication skills and forming partnerships with family and friends when providing care.

3.1.1 Impact on the patient

Everyday life is characterized by habits, routines, and familiarity. Eating, drinking, and sleeping are some of the activities that we take for granted (Felski, 1999). Chronic illness disrupts an affected individual's life by alienating him from the comfort and stability brought about by everyday routines and influences the extent to which he is able to participate in meaningful activities.

The International Classification of Functioning, Disability and Health (ICF) describes health, health-related conditions, and disability in both medical and psychosocial terms. It

recognizes that impairments in body structures and functions can limit a person's ability to perform certain activities and restrict his participation (World Health Organization, 2001). The ICF model provides a framework for understanding chronic conditions and their impact on the patient. By definition, chronic illness affects a person for an extended period of time during which the illness becomes the new norm and may impose limitations on participation in a wide range of activities.

A feeling of powerlessness is often experienced by individuals with chronic illness (Hummel, 2013), especially those with degenerative conditions. As diseases progress, these individuals feel as if they have no control over their situations. Their ability to participate in activities is not determined by themselves but is restricted by conditions that exert an external force threatening their autonomy.

Patients with chronic illness often experience the loss of sense of self and the need to form a new self-image in which illness becomes part of their personal and social identities (Larsen, 2013). Many patients withdraw from social relationships due to physical limitations or embarrassment and experience social isolation (Biordi & Nicholson, 2013).

Health-related quality of life is a multifaceted construct and is not confined to physical health but also encompasses psychological well-being and social roles. Because everyone has different values and goals in life, what constitutes quality of life is subjective and varies from person to person. Quality of life is frequently measured by collecting data regarding the effects of illness on patients' daily life and assessing whether therapy goals are attained (Schirm, 2013). A large number of studies have investigated the impact of chronic conditions on patients' quality of life and found that health-related quality of life is negatively affected by chronic illness

(Fortin et al., 2006; Fukuoka, Lindgren, Rankin, Cooper, & Carroll, 2007; Llewellyn, McGurk, & Weinman, 2005; Royer, 1998)

Chronic conditions not only have an adverse impact on individuals but may also bring suffering to the whole family and social and work environments. Facing chronic illness, the social world within the family is disordered and needs to be reconstructed. Chronic illness places demands on families at three times: in the initial state of crisis at the onset of a condition, around chronic management of illness and during the terminal stage of the illness.

Brody (2003) observes that the role of the family is poorly defined in the context of chronic illness and that family members often experience loss of previous assumed social roles. Take the example of a married couple who occupied the roles of husband and wife respectively. The wife took care of her husband who had Alzheimer's disease and reported that "I'm not like a wife and not like a single person either" (Biordi & Nicholson, 2013, p.110). Her husband's chronic progressive illness had a great impact on her life: she lost her wifely privileges and took up new responsibilities as the caregiver.

Chronic conditions can lead to increased financial strain for the affected individual and his family (Schirm, 2013). A person with chronic illness may have to decrease or end work, resulting in reduction or loss of income for the family. He may lose his health insurance due to termination of employment. If he needs assistance on a daily basis, the family caregiver may have to decrease or end workforce participation or hire a caregiver. Additional burdens include costs of medications, transportation, and special needs diet, not all of which are covered by health insurance.

The terms "family caregiver" and "informal caregiver" are often used interchangeably to refer to somebody who supports and cares for the sick person without pay and who has a

personal relationship with the sick person. Examples include family, friends, and neighbors (Pierce & Lutz, 2013). When caring for a sick person who is totally dependent on others, the family caregiver is responsible for two types of care on a daily basis: health-related care such as administering medications and social care including both functional and affective assistance. The family caregiver provides functional assistance by assisting the sick person with basic activities of living such as eating, bathing, and getting around. The caregiver also provides affective assistance or emotional support by conveying caring and concern to the sick person and helping him integrate into normal life (Pierce & Lutz, 2013).

Since caregiving involves both physical and emotional demands, many caregivers experience stress, which is categorized as either strain or burden (Pierce & Lutz, 2013). Strain is associated with the hardship and conflicting feelings one experiences as a caregiver. For example, spouses of those with chronic illness are often physically and emotionally strained and may experience the “tug-of-war phenomenon” in which they are exhausted, frustrated and angry but are ashamed of such emotions (Corbin & Strauss, 1988). Many factors contribute to caregiver burden including the amount of care required for the sick person, the level of stress experienced by the caregiver, and financial strain (Pierce & Lutz, 2013).

3.1.2 Non-compliance

Non-compliance is a term used to refer to the “disobedient” patient. It implies certain degrees of authority and control on the part of the health care professionals and it is difficult to ignore the negative connotations underlying the term. This term is widely used in the clinical setting where the patient is labeled as non-compliant if he does not follow what is recommended by the health care professional.

The number of people with chronic conditions such as hypertension and diabetes was on the rise in the second half of the 20th century. With the emergence of effective pharmaceutical interventions, patients were able to take care of their chronic conditions at home. Non-compliance gained considerable interest in 1960s and 1970s, for clinicians discovered that some patients did not take their pills at home. This clinical phenomenon emerged as an area of research on its own with articles discussing “the diagnosis and management of patient non-compliance” published in the *Journal of American Medical Association* (Greene, 2004, p.327).

In 1974 two Canadian physicians, David Sackett and Brian Haynes, known as the “fathers” of evidence-based practice, provided an operationalized definition of “patient compliance”: “the extent to which the patient’s behaviors (in terms of following medications, following diets, or executing other life-style changes) *coincides* with the medical prescription” (cited in Greene, 2004, p.332, emphasis added). Sackett suggested that the interest in patient non-compliance research partly stems from clinicians’ wish to “get their god-damned patients to take their god-damned pills” (cited in Greene, 2004, p.332).

Interest in non-compliance also derives from the fact that the number of malpractice suits drastically increased in the 1970s, which alerted clinicians to the effects of emergent patient autonomy. It is in this sense that data collection with respect to patient non-compliance becomes an important part of defensive practice. With data about patient non-compliance in hand, physicians are exempted from being held responsible for therapeutic failure: the patients themselves are to be blamed for non-compliance to the treatment regimens (Greene, 2004).

Decades of research has shown that as many as 50% of patients do not follow through treatment recommendations (Barber, Parsons, Clifford, Darracott, & Horne, 2004; Boczkowski & Zeichner, 1985; M. R. DiMatteo, 1994; M Robin DiMatteo, Giordani, Lepper, & Croghan,

2002; Dunbar-Jacob & Mortimer-Stephens, 2001). Some of the most common barriers to self-management reported by patients include depression, fatigue, poor physician communication, low family support, and financial problems (Jerant, von Friederichs-Fitzwater, & Moore, 2005). Many patients with chronic conditions change the timing and amount of their medications, because the treatment plan interferes with their preferred lifestyle (Thorne, Paterson, & Russell, 2003).

“Compliance” has been increasingly recognized as an inappropriate term, due to its underlying connotation that patients are passive recipients of care (Brown & Bussell, 2011). It is important to note that health care professionals often use the term in a paternalistic manner, whereas Sackett and Haynes’s definition of “compliance” implies a much more equal status between the patient and the clinician by using the word “coincide.” Greene (2004) has noted that articles submitted to medical journals containing the term “non-compliance” are often sent back with instructions to revise the term to “non-adherence.” Adherence to long-term therapy is defined as “the extent to which a person's behavior - taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (World Health Organization, 2003, p.3). Following this definition, “non-adherence” should be distinguished from “non-compliance” as defined by Sackett and Haynes: a non-adherent patient agrees with the recommendations but his behaviors do not correspond with recommendations, whereas a non-compliant patient is one whose behaviors do not correspond with recommendations and it is irrelevant whether he agrees with recommendations or not. In clinical practice, the two terms are often used interchangeably and clinicians use either of these terms to describe the following behavior: the patient with whom the clinician has created a goal

does something differently than what is recommended by the clinician, regardless of whether joint goals are established.

3.2 CHRONIC ILLNESS IN THE ELDERLY

Elderly people are more susceptible to chronic conditions than their younger counterparts due to a number of factors. “Elderly” is defined as aged 65 or older (U.S. Bureau of the Census, 1996). It has been estimated that between 2012 and 2050, the elderly population in the U.S. will almost double from 43.1 million to 83.7 million (Ortman, Velkoff, & Hogan, 2014). Ninety-nine percent of Medicare expenditures are for beneficiaries with at least one chronic condition, while those with more than five account for two thirds (Partnership for Solutions, 2004).

Aging causes organs to gradually lose function and reduces the functional reserve, which is the ability to adapt to physiological stress (Resnick & Marcantonio, 1997). Elderly people are less able to physically compensate for impairments and are more vulnerable to disease and mortality compared to younger people (Fedarko, 2011). Sarcopenia refers to an age-related loss of muscle mass and muscle strength and is an important cause of decline in functional independence among the elderly (Walston, 2012). The increased vulnerability resulting from the accumulation of multiple impairments in the elderly is known as frailty, a major reason why the elderly are at high risk of experiencing geriatric syndromes (Tinetti, Inouye, Gill, & Doucette, 1995).

The term “geriatric syndrome” is used to refer to some health conditions such as delirium, falls, incontinence, functional decline, and frailty that many elderly people have in common. Each of these conditions is a geriatric syndrome but does not fit into discrete disease

categories. Geriatric syndromes often have multiple causes, because multimorbidity, use of medication, and the interlinking of comorbidity and medication-induced side effects are common in elderly people (Resnick & Marcantonio, 1997). Geriatric syndromes are prevalent in the elderly and have substantial impact on their quality of life (Inouye, Studenski, Tinetti, & Kuchel, 2007). Among community dwelling women aged 65 years or older, 34.4% had one geriatric syndrome, and 8.2% had two or more (Rosso et al., 2011). Chronic diseases (coronary artery disease, congestive heart failure, and diabetes mellitus) and geriatric syndromes (urinary incontinence and injurious falls) often co-occur in elderly people (Lee, Cigolle, & Blaum, 2009).

Elderly people in the U.S. with multiple chronic conditions take an increased number of medications, largely due to the fact that clinicians apply recommendations from multiple single-disease clinical practice guidelines (Dumbreck et al., 2015). This leads to polypharmacy, which refers to the unpredictable and harmful interactions of drugs. The negative outcomes associated with polypharmacy include high health care costs, an increased risk for adverse drug reactions, functional decline, cognitive impairment, and multiple geriatric syndromes (Hajjar, Cafiero, & Hanlon, 2007; Maher, Hanlon, & Hajjar, 2014). Much morbidity in elderly people is due to inappropriate prescription, which leads to adverse drug reactions. Elderly people are at risk for adverse drug reactions, because they are more likely to be on multiple medications (Lindley, Tully, Paramsothy, & Tallis, 1992; Pirmohamed et al., 2004; Routledge, O'Mahony, & Woodhouse, 2004). Up to 50% of adverse drug reactions in elderly people are preventable (Pretorius, Gataric, Swedlund, & Miller, 2013).

3.3 EATING, DRINKING, AND SWALLOWING

Ruth Reichl, a chef and food writer, gives a description of the multifaceted nature of food:

There is the purely simple refreshment of eating good food. There is the nourishment that comes from the communion of the table, the airing of ideas and fostering of friendship. And there is the poetry of the senses available to anyone willing to open himself to the experience in all its sensual complexity (Reichl, 2005, p.5).

Eating and drinking are activities through which we sustain our existence. While it is physically necessary for us to eat and drink to take in nutrition and stay hydrated, food and drink are much more than that. Our food choices cause changes in our psychological and physiological mechanisms and vice versa. Meals decrease arousal and irritation and increase calmness and positive affect (Gibson, 2006). We generate emotional responses when having preferred foods and perceive that experience as pleasurable and rewarding. At times we prefer comfort food, because it brings us tremendous sensory and psychological satisfaction.

For most people, what matters is the experience associated with food and drink, which is often shaped by the contexts in which eating and drinking take place. The role of food is twofold and makes the link between nature and culture: while it is natural for us to feed ourselves for the sake of nutritional values, how we eat is a cultural phenomenon (Domzal & Kernan, 1993; Farb & Armelagos, 1980; Montanari & Sonnenfeld, 2006). Food is metaphorical in that

it is a companion (popcorn with movies), a rejuvenator (Gatorade), and a source of fun (M&Ms). It is safety (our favorite ice cream flavor), love (a romantic dinner; the "aphrodisiac" potency of chutney, goose brains, oysters), or adventure (some exotic ethnic specialty) (Domzal & Kernan, 1993, p.5).

Food-related activities are endowed with meanings: children are taught table manners when they are young; deals are made during business lunches; courses should be served in the right order at

a formal dinner; different foods are appropriate for different occasions. A shared meal is a social event where we initiate and maintain relationships with our families, friends, and colleagues. The act of sharing meals has symbolic significance in that it reflects our social identities and reveals the structure of social relationships in our society (Murcott, 1982). By sitting at the same table, the experience of eating not only involves enjoyment of food and drink but also sharing of thoughts and emotions.

Food-related activities vary greatly across traditions, and different cultures attach different meanings to food and the ways in which food is served (Counihan & Van Esterik, 1997). Food as a symbol also carries religious significance and is an important part of religious rituals (Bynum, 1997; Soler, 1997). For instance, for Catholics, the act of swallowing bread and wine signifies active participation in the Eucharist (Rourke & Leslie, 2013; Wirzba, 2011).

Swallowing is an indispensable part of eating and drinking, as it allows food to be transferred to the digestive tract. To a great extent a healthy swallow is what makes our experience of eating and drinking pleasant and enjoyable and most healthy people do not notice or think about their swallows during meals.

3.3.1 Swallowing Impairment (Dysphagia)

Individuals with dysphagia experience difficulty moving solids or liquids from mouth to stomach. Dysphagia is not a disease of itself but a disorder caused by other conditions. Elderly people are more likely to experience swallowing problems than young people (Leder & Suiter, 2009). The effects of aging on the swallowing mechanism include reduced tongue pressure, longer duration of swallow, increased airway penetration, and sensory changes (Ney, Weiss, Kind, & Robbins, 2009). Although aging may make swallowing less efficient, aging alone does

not cause dysphagia (Ratnaike, 2002). Dysphagia affects oral, pharyngeal and esophageal stages of swallowing and the presentation of dysphagia varies including food spillage from the oral cavity, nasal regurgitation, choking, and coughing. Chronic dysphagia may be related to negative outcomes such as poor prognosis for immediate and long term survival, poor rehabilitation outcome, long hospital stay, increased likelihood of readmission, increased co-morbidities, and adverse health outcomes such as malnutrition and dehydration (Miller & Carding, 2007).

A healthy swallow in elderly people is characterized by prolonged duration in all stages of swallowing compared to that in younger people (Lof & Robbins, 1990). The structure and function of swallowing musculature deteriorates with age, causing normal changes in swallowing biomechanics (Eibling & Coyle, 2017). Presbyphagia is the term used to describe normal variations in swallowing biomechanics due to aging (Robbins, Hamilton, Lof, & Kempster, 1992).

Decreased functional reserve means that elderly people are vulnerable to acute illness and age-related medical conditions (Robbins, Langmore, Hind, & Erlichman, 2002). In turn they are more likely to have dysphagia, which is secondary to diseases, disorders, and treatment of medical problems (medication side effects, surgery, chemotherapy, and radiation) (Humbert & Robbins, 2008).

3.3.2 Intervention

The goal of dysphagia management is to maintain health, prevent adverse health outcomes such as malnutrition, dehydration and chest infections and increase enjoyment in oral intake. There are two types of dysphagia management: rehabilitative and compensatory. Rehabilitative interventions restore swallowing function by targeting swallowing musculature or neural

circuitry and improving the impaired swallowing physiology (Robbins et al., 2005; Shaker et al., 1997; Troche et al., 2010). Compensatory interventions aim to immediately reduce the effects of the impaired swallowing biomechanics. Compensatory strategies include modification of the environment (e.g., turn off TV to concentrate on swallowing), postural adjustments (e.g., head turn, chin tuck), swallowing maneuvers (e.g., Mendelsohn maneuver, supraglottic swallow), and diet modifications (e.g., modified solids, thickened liquids) (Rosenvinge & Starke, 2005). Patients with chronic dysphagia are physically burdened by this condition, for they may have to manage their swallowing problems by employing compensatory strategies, which are on top of the chronic diseases themselves. They may also have to live with the psychosocial and emotional sequelae of swallowing difficulties.

3.3.3 Consequences

Eating and drinking are social activities. Dysphagia decreases patients' quality of life and negatively affects patients' psychosocial well-being. A study investigating the psychosocial effects of dysphagia has shown that among patients with ages ranging from 55 to 80 years or older, only 45% found eating and drinking to be an enjoyable experience, 41% experienced anxiety or panic during meals and 36% avoided eating with others (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002).

Patients with dysphagia are more likely to experience social isolation and tend to avoid eating out with others because of embarrassment, the need for assistance during meals, the need to modify diet consistency, and less interest in food (Farri, Accornero, & Burdese, 2007). Patients with Parkinson's disease and their caregivers reported that mealtime enjoyment is decreased due to slowness of eating, choking or fear of choking, modified diet as well as a

feeling of guilt for disrupting normal family lifestyles and burdening caregivers (Miller, Noble, Jones, & Burn, 2006).

When comparing and contrasting psychological issues perceived by patients with acute and chronic dysphagia, it was found that patients with acute dysphagia were mostly concerned about choking to death which is about immediate survival, whereas those with chronic dysphagia were more affected by physical and psychological discomfort. The main themes for chronic patients were “depression in the form of deprivation, loss, and nostalgia,” frustration, and embarrassment (Martino, Beaton, & Diamant, 2010, p.31). These individuals were unable to have desired foods and longed for their eating experience prior to having swallowing problems. Chronic choking episodes cause physical discomfort as well as embarrassment. Some of these patients were losing hope for swallow recovery (Martino et al., 2010).

Dysphagia also has a negative impact on the lives of family members and caregivers of affected individuals. Caregivers of patients with head and neck cancer reported that dysphagia disrupted normal family lifestyle and social relationships associated with eating and drinking. Caregivers did not expect dysphagia to be chronic and that they had to adjust to their new roles and perceive the situation as the “new normal.” Caregivers also wanted more support and suggested that information provided to them should be practical, personalized and in “patient language” (Nund et al., 2014).

“Non-compliance” poses great challenge for SLPs working with patients with swallowing problems. A study has shown that only 36% of patients with dysphagia followed through with SLPs’s diet recommendations (Leiter & Windsor, 1996), leading to adverse health outcomes such as chest infections and high mortality rates (Low, Wyles, Wilkinson, & Sainsbury, 2001). Dissatisfaction with diet modifications is reported by SLPs as the primary reason why patients

choose not to adhere to advice (King & Ligman, 2011). Another reason could be that patients are burdened by the management of symptoms, which adds responsibilities to both patients and caregivers such as learning and implementing swallowing maneuvers, modifying diet, financial matters and maintaining use of feeding tubes (Plowman-Prine et al., 2009).

In one study, the author defined non-compliance with dysphagia recommendations as:

a dysfunctional coping strategy in which the patient attempts to avoid, escape, or withdraw from the situation even though such avoidance is physically impossible (Livneh, 1999). Noncompliant patients with dysphagia are confronted with serious swallowing problems with which they do not want to have to deal. Psychologically, they have to substantiate to themselves and to others their refusal to comply with medical recommendations (Colodny, 2005, p.63).

Following her definition of non-compliance as denial, Colodny interviewed 63 patients with dysphagia and summarized their reasons for non-compliance into eight categories: open denial, dissatisfaction with diet modifications, calculated risk, rationalization despite contrary evidence, minimization of their problem, verbal accommodation while being non-compliant, projection of blame toward the SLP, and deflection of non-compliant behavior by referring to an external authority (Colodny, 2005).

It is important to note that Livneh's (1999) paper from which Colodny's definition was derived is on the role of coping strategies and how they are used as psychosocial adaptations by patients with chronic heart diseases. Non-compliance is briefly mentioned when Livneh discusses how non-compliance due to denial may lead to increased risks for adverse health outcomes (e.g., reinfarction and hospitalization). From Livneh's paper one could at best conclude that some of the patients who do not follow through recommendations are in denial of their problems, but it does not mean that all "non-compliant" patients are in denial. Colodny's definition of non-compliance is highly paternalistic and is constructed from the clinician's

perspective. Her categories of reasons for non-compliance are questionable, as some of the reasons listed (e.g., assuming a calculated risk, verbal accommodation while being noncompliant, projection of blame toward the SLP) are patient behaviors rather than reasons to not comply. We need to learn more about the patients' side of the story to explore the reasons why they choose not to take our advice.

A number of studies and anecdotal reports have shown that patients often react adversely to thickened liquids. Patients with dysphagia following stroke who were advised to have thickened liquids failed to meet their daily fluid requirements (Finestone, Foley, Woodbury, & Greene-Finestone, 2001). A group of people without dysphagia drank thickened liquids and were asked about their perception of the long-term use of thickened liquids. On average the participants reported that they would be willing to sacrifice four years of a ten-year lifespan not to be restricted to thickened liquids (Lim, Mulkerrin, Mulkerrin, & O'Keeffe, 2016). The researchers have concluded that thickened liquids significantly lower patients' quality of life. While patients with dysphagia are at greater risk for malnutrition (Dahl, Whiting, & Tyler, 2007; Durant, 2008; Foley, Martin, Salter, & Teasell, 2009), one of the reasons for this is that patients do not like the texture and appearance of pureed diet and tend to eat less (Hotaling, 1992; Keller, Chambers, Niezgodna, & Duizer, 2012).

3.4 CLINICAL DECISIONS ABOUT EATING AND DRINKING

Ideally there are several important steps in the process of clinical decision making (Hajjaj, Salek, Basra, & Finlay, 2010):

- Recognizing the problem and discussing potential solutions

- Providing information on a case-to-case basis
- Checking the patient's understanding and preferences
- Reaching an agreement with the patient regarding intervention and implementing it
- Setting up follow-up treatment visits
- Evaluating treatment outcome.

Once a patient is diagnosed with dysphagia, clinical decisions need to be made about eating and drinking. Such decisions follow the pattern of any other decision making process and can have a huge impact on the patient's and his caregiver's life, for eating, drinking and sharing meals are fundamental to how we live our lives. For the SLP, an important part of managing dysphagia is for the patient to maintain adequate nutrition and hydration while ensuring the safety of swallow function and decreasing risks of aspiration. The SLP may also need to contribute to the medical team's implementation of an alternative treatment plan if the patient or his family members reject the initial recommendation.

Shared decision making has been regarded as the ideal model of clinical decision making in which there should be much patient involvement (Charles et al., 1997). In this model, the patient and the clinician jointly discuss the goal of care and then determine the best way to achieve such goals. In the last few decades, the importance of patient participation in medical decision making has been emphasized. The patient has the right to accept or refuse a course of medical interventions and the clinician should respect such right to self-determination and information. This right is referred to as "patient autonomy."

Respect for autonomy, along with beneficence, nonmaleficence and justice, is an important ethical principle in medical ethics (Beauchamp & Childress, 2001). Despite the push for patient autonomy, it is often not addressed properly in clinical practice. Clinicians do not

want to infringe on their patients' autonomy, sometimes resulting in poor care such as patient abandonment (Crugel, Treloar, & Euba, 2008), which is broadly understood as clinicians' failure "...to maintain relationships with patients who came under their care and expected these relationships to continue" (Han & Arnold, 2005, p.1240).

A general overview of autonomy will be presented in the next chapter by exploring its historical, legal and clinical significance. This will be followed by a discussion of the problems posed by the interpretation of the principle of respect for autonomy in the clinical context.

4.0 AUTONOMY

The word “autonomy” is derived from the Greek words “autos” (self) and “nomos” (law, governance), a term originally used to refer to self-legislation in Greek city-states (Beauchamp & Childress, 2001). Autonomy is defined as “liberty to follow one's will; control over one's own affairs; freedom from external influence, personal independence” (Oxford English Dictionary, 1989a). Traditionally autonomy is linked with independence and individualism in philosophy and politics. The issue of patient autonomy emerged in the 20th century when key legal cases raised questions about the patient’s role in medical decision making. During the last three decades, respect for patient autonomy has been established as a fundamental principle in modern western medical ethics. The basic idea is that human beings are rational and independent agents who are capable of self-governance and that they have the right to make their own medical decisions. They are responsible for the choices they make and their right to make such choices should be respected. However, the underlying premises of principled autonomy are at best flawed and the application of this principle to the context of medical care comes with challenges.

4.1 HISTORY

The 17th and 18th centuries were marked by a series of political, social and intellectual changes. A transition took place in which monarchical legitimacy and religious authority were weakened.

The new social and political order was one in which democracy, freedom, and equality were placed at the center. An intellectual movement called the Enlightenment took place during this period of time, which saw dramatic revolutions in science, politics, philosophy, and government. In light of the changing climate, philosophers proposed different theories of moral and political philosophy to justify and guide the newly formed secular social order (Tauber, 2005).

John Locke, a 17th-century British philosopher, argued that men are naturally free and equal and that men are entitled to certain rights (life, liberty, property). His liberal political theory redefined individual rights, citizenship, and religious freedom and references to him were made in the Declaration of Independence and in the U.S. Constitution. His political philosophy also provided a key foundation for American individualism. Locke's conception of an individual echoed that of other Enlightenment thinkers: a detached and knowing observer who is rational, independent, objective and free of bias; an autonomous agent who has political rights and obligations and acts according to his own reasons and wishes (Tauber, 2005).

Immanuel Kant, an 18th-century German philosopher, argued that human beings are obliged to obey certain ethical principles unconditionally. His rule-based account of autonomy rests in a view that mirrors the ideals of the Enlightenment, namely, human beings are rational. These ethical principles are universally accessible via practical reason, which enables human beings to know what is the right thing to do. By exercising practical reason, individuals act morally independent of subjective desires and wants (Tauber, 2001).

Kantian autonomy is not personal independence or preference (O'Neill, 2002). For Kant, acting autonomously does not equate with acting freely according to one's personal desire or feeling. Rather an individual is acting autonomously only if he acts on self-legislated principles of moral law, which can be derived from reason. In his *Groundwork for the Metaphysics of*

Morals, he wrote, “The principle of autonomy, is, therefore: to choose only in such a way that the maxims of your choice are also included as universal law in the same volition” (Kant & Gregor, 1996, p.89). This means that a behavior would be deemed moral only if it could be universalized. An example of such a universal law is “Do not lie,” which suggests that lying is unjustifiable in any circumstances. The reasoning behind this is that if there were a universal law stating that lying is acceptable, lying would become a prevalent phenomenon, which would be detrimental to social functioning.

This brief historical account of autonomy shows that “the autonomous individual was *invented*” (Tauber, 1999, p.31, italics in original) and that autonomy should be understood in the particular historical context where it was constructed. Locke’s and Kant’s accounts have one thing in common; that is, their conception of an individual is an idealized “atomistic self,” who is isolated from historical context and social relations and is devoid of emotions. In Kant’s view, rationality is what makes us uniquely human and he grounds autonomy in our cognitive capacities. He does not take into account the fact that human beings are biological, social and psychological beings who not only reason but also have emotions, desires, and wants (Williams, 1985). Further, being fundamental to individualism, autonomy is a distinctive western liberal concept. It is constructed from and is meaningful only in a particular culture and social context (Schneewind, 1998).

4.2 LAW

The concept of autonomy has important legal implications (Schneider, 1998). In 1914 a patient named Mary Schloendorff sued her surgeon and the hospital on the grounds that a tumor was

removed without her consent when she was in an exam under ether anesthesia. She argued that she had agreed to go through only an exam but not an operation ("*Schloendorff v. Society of New York Hospital*," 1914). The presiding judge, Justice Benjamin Cardozo wrote: "Every human being of adult years and sound mind has a right to determine what shall be done with his body, and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages" ("*Schloendorff v. Society of New York Hospital*," 1914). The ruling in this case was historically significant in that it was based on the concept of autonomy and affirmed the patient's right to self-determination, but it still took decades before patient autonomy became a professional standard in health care (Green & MacKenzie, 2007).

In 1960 Mrs. Irma Natanson sued her radiologist for severe injuries from cobalt therapy following mastectomy. She had given her consent to the proposed treatment but claimed that she was ill informed of the nature of treatment and associated risks ("*Natanson v. Kline*," 1960). Justice Shroeder (1960) acknowledged the legal significance of self-determination and wrote: "A doctor might well believe that an operation or form of treatment is desirable or necessary but the law does not permit him to substitute his own judgment for that of the patient by any form of artifice or deception" ("*Natanson v. Kline*," 1960). This suggests that even if a physician has good intentions and knows what is medically best for the patient, she has no right to impose her judgment upon the patient.

The Patient Self Determination Act (1990) is a federal law that requires providers (hospitals, nursing homes, and home health agencies) receiving Medicare and Medicaid reimbursement to offer written information regarding patients' right to make medical decisions and to prepare an advance directive for patients who have the capacity to do so (Bottrell, 2007). Capacity refers to patients' ability to make decisions regarding his own care. Providers are not

allowed to discriminate against patients with or without an advance directive and should also educate their staff and the community about advance directives. Patients are entitled to make medical decisions and determine the kind of care they want to receive at the end of their lives.

Health care professionals are required by law to obtain informed consent from their patients before initiating treatment. Despite the fact that informed consent is often understood as the patient's signature on a form indicating that he agrees to some procedure, it is more than that. Informed consent is the process in which the clinician discloses the potential benefits, risks, and alternatives associated with medical decisions to enable the patient to be informed, so that he can give consent to a course of treatment (Appelbaum, 2007). The implication is that health care professionals must make appropriate information accessible to the patient, so that he understands the nature of the medical decision that he is making.

4.3 MEDICAL ETHICS

Before the 1970s, health care ethics followed the Hippocratic tradition, which was based on the paternalistic attitude toward medicine and health care delivery was concerned with maximizing medical benefits to patients and minimizing harm and disease (Beauchamp, 2007). The term "paternalism" derives from "pater" (father) in Latin. Traditionally the father figure was responsible for protecting children from harm and danger and this stance was linked to concepts such as authority and restraint (Agich, 1993). In the paternalistic model, the physician uses her expertise to determine the patient's medical condition and to identify tests and treatments that most likely serve the best medical interests of the patient. Patient choice and participation are limited, because this model assumes that the physician knows and does what is best for the

patient (Emanuel & Emanuel, 1992). For many years, paternalism remained the desirable model for patient-clinician relationship, because medical dominance was regarded as necessary for healing and was justified on the grounds that this approach would serve the patient's best medical interests. The imbalance of power served to establish the physician's authority and encourage compliance on the patient's part (Lupton, 2003).

This paradigm shifted in the second half of the 20th century. Medical paternalism was under increasing scrutiny by bioethicists, some of whom understood their criticism as the reason for bioethics to emerge as a new field of study (Hinkley, 2012). Beauchamp and Childress published the first edition of *Principles in Bioethics* in 1979, which has become a classic textbook in the study of biomedical ethics. In each of the subsequent editions, they discussed the problem of medical paternalism in clinical decision making in length and proposed a new model partly in reaction to paternalism. Their model is based on ethical principles that could be easily understood and applied by professionals from different fields and could be used as norms for solving difficult problems in clinical medicine or biomedical research (Beauchamp, 2007).

Beauchamp and Childress (2001) have argued for an approach to medical ethics called principlism, which is based on the use of four ethical principles: respect for autonomy, beneficence, nonmaleficence, and justice. This approach derives from the Enlightenment tradition in which human reason applies a system of universally true moral standards to different situations. The four principles guide clinicians' decision making in the clinical encounter and offer solutions to medical dilemmas. The four principles have equal importance, meaning no one principle trumps another.

Beauchamp and Childress's (2001) principle of respect for autonomy is based on their account of personal autonomy. They describe personal autonomy as:

...self-rule that is free from controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice. The autonomous individual acts freely in accordance with a self-chosen plan, analogous to the way an independent government manages its territories and sets its policies (Beauchamp & Childress, 2001, p.58).

According to the principle of respect for autonomy, health care professionals have two obligations. Patients' autonomous actions should not be interfered with and clinicians should enable patients' decision making by disclosing relevant information and making options available to the patient. The patient should be respected for his right to make choices based on personal beliefs and values. When a patient makes an informed decision by refusing medical interventions, the principle of respect for autonomy suggests that such a decision must be respected (Beauchamp & Childress, 2001). It is in this sense that the principle of respect for autonomy provides clinicians with both ethical and legal guidelines for action.

In the last few decades, the concept of patient autonomy has been widely discussed in medical ethics. A PubMed search on 12 March 2017 using the term patient autonomy yielded 16,657 results (filters applied: Species: Humans). That the principle of respect for autonomy trumps physician best advice has important clinical implications. The nature of the patient-clinician relationship has fundamentally changed; that is, decision making has become a shared process in which both parties have a say. Good patient-clinician communication is necessary in this process: clinicians should not only provide patients with all relevant information but also make such information easily accessible to patients. Clinicians are obliged to respect patients' autonomy by communicating truthfully to patients and enabling them to actively make treatment decisions that represent their own wishes.

4.4 LIMITATIONS

Principlism is very influential in the field of medical ethics. It has become the dominant approach for resolving ethical conflict in clinical practice. However, a number of problems are associated with principled personal autonomy.

4.4.1 Autonomy and decision making

The principle of respect for autonomy paints an idealized picture of how patients make medical decisions: the patient assembles relevant information regarding the choices offered by the clinician, reflects on his own values, goals, and beliefs in the light of the choices, analyzes all factors carefully and makes a rational choice after deliberation. While this may reflect bioethicists' and clinicians' expectations of how patients should make decisions, it is not how patients make decisions in real life.

Carl Schneider, a professor of law at the University of Michigan, has noted that it is common to see patients making quick decisions without having all relevant information. Patients' medical decisions often take practicality into account and rest on nonmedical grounds. For example, one patient with kidney disease intended to make his decision regarding dialysis solely based on whether the method would interfere with his bowling schedule (Schneider, 1998). Patients who are well-educated and reflective also make medical decisions based on "intuition, instinct, impulse" (Schneider, 1998, p.95), but such decisions are not necessarily bad ones and may reflect consideration of what patients care about the most.

In his *Descartes' Error*, Antonio Damasio, a neuroscientist, argues that decision making is a complex process in which emotions have a critical role and that emotions are indispensable

to “rationality” (Damasio, 2005). He has studied many patients with damage in the ventromedial prefrontal cortex, an area in the frontal lobe important for social decision making and emotional processing (van den Bos & Güroğlu, 2009). Despite the fact that their intelligence and other basic cognitive functions such as attention, memory, and perception are not affected by the damage, their emotional processing is impaired. These patients characteristically appear to be calm and detached. Damasio describes their situation as “*to know but not to feel*” (p.45, italics in original).

With reduced emotions these individuals lose their ability to make decisions, especially when they are situated in a social environment in which they are required to make decisions about personal matters. They are unable to plan for the future or make decisions in a way that is advantageous to them. To illustrate this point with a simple example, one patient was given two alternative dates for a laboratory visit. He went into an endless cost-benefit analysis by giving reasons for and against each of the two dates until he was told by the researchers to come on a certain date. Damasio (2005) calls this scenario “the limits of pure reason” (p.192). The patient was rational but unreasonable: after rationally reasoning through the problem and comparing options and possible outcomes, he was unable to make a simple decision, namely, picking a date. Therefore, evidence from cognitive science lends support to the view that decision making is not as rational as some bioethicists think and that emotions play a very important role in the decision making process.

4.4.2 Interpretation of the principle

Clinicians often interpret the principle of respect for autonomy based on the informative model. In this model the goal of patient-clinician communication is for the clinician to provide the

patient with all relevant information about his health condition and treatment options, for the patient to make medical decisions in accordance with his wishes and for the clinician to use her expertise and skills to execute interventions chosen by the patient (Emanuel & Emanuel, 1992). The clinician is the technical expert who receives authorization from the patient and executes procedures according to the patient's decision. Following this interpretation, autonomy is often reduced to the procedural requirements for informed consent (O'Neill, 2002). In clinical practice, the course of enabling patients to make autonomous decisions is often reduced to a signature on a form after sharing information which may or may not have been understood by the patient.

It is important to note that the mere presentation of treatment options does not necessarily enable patients to make autonomous decisions. A large number of patients have limited health literacy and it is difficult for them to fully understand and integrate the amount of scientific information and make informed clinical decisions. Patients seek help from health care professionals precisely because professionals have specialized knowledge that patients do not. There is always a power dynamic in the patient-clinician relationship due to the inequality of knowledge and experience and clinicians cannot expect patients to know what experts do (Tauber, 2001).

Epstein and Street (2011) describe a case in which a retired professor of epidemiology was diagnosed with pancreatic cancer. Initially he was certain that he would not want chemotherapy but hesitated after being informed that there was a 30% chance that his life could be extended by two to three months if he pursued chemotherapy. He felt that he was not able to rationally analyze the situation and make the best decision, due to the strong emotions that he was experiencing: "...he was often overwhelmed rather than enlightened by more information" (Epstein & Street, 2011, p.45). In this case, the professor reasoned carefully and weighed all

relevant information - conflicting recommendations from physicians, research evidence, treatment options, his broad values - desire to live, avoid suffering, avoid iatrogenic harm, and his personal preferences - no chemotherapy, but he still struggled to make a decision (Epstein & Street, 2011). This case shows that facing illness, patients are often in bodily discomfort and emotional distress. When presented with vast amounts of new information and expected to make personal choices about their own body, it is understandable if patients feel that they are unable to think clearly (Tauber, 2001).

Alfred Tauber, a hematologist, describes his experience as a patient having a kidney stone. He shows that decision making can even be difficult for those who have expert medical knowledge of their own disease. Tauber suffered from acute pain, was brought to the hospital and was not able to think clearly because of great distress. The urologist's counsel was ambiguous, because he knew that his patient had the knowledge to make an informed decision. Tauber writes, "I was immobilized. I could not make the decision. I kept thinking that maybe one more day was all I needed. I knew the risk of surgery, the postoperative recovery, etc., and still I procrastinated" (Tauber, 1999, p.63). Tauber used his medical knowledge to weigh the pros and cons of surgery, yet he was indecisive and avoided decision making. His hesitation shows that personal decision making can be very difficult for many patients when they are physically and psychologically distressed. It also shows that the patient can still be confused about decision making even when knowing a great deal about his medical conditions and treatment options.

4.4.3 Autonomy and culture

Principlism presumes that the four principles are universally applicable. The moral reasoning underlying principlism fails to acknowledge the multiplicity of our contemporary social world.

Morality and medicine are understood differently by people coming from various cultural, religious and ethnic backgrounds. They may have distinctive views regarding illness, suffering, and the nature of healing. Culture, religion, and ethnicity can have an impact on how patients and their family members interpret “autonomy” (Turner, 2001).

One study investigated elderly people’s attitude toward the disclosure of diagnosis and prognosis of a terminal illness and toward end-of-life decision making. Participants came from four ethnic groups: African American, European American, Korean American, and Mexican American. It was found that African Americans and European Americans favored truth telling and autonomous decision making, whereas Korean Americans and Mexican Americans were more likely to defer decision making to their families (Blackhall, Murphy, Frank, Michel, & Azen, 1995). In traditional Turkish culture, the self is seen as situated within the context of familial relations. Paternalism and beneficence trump personal autonomy with regard to medical decision making (Kara, 2007). In the Italian culture, autonomy (autonomia) is often understood along similar lines as isolation (isolamento), for the patient could feel isolated when overwhelmed by a vast amount of complicated and fearful information. Not disclosing information to the patient is seen as an act keeping the family together and protecting the patient from suffering alone and from being frightened by the diagnosis (Surbone, 1999).

4.4.4 Relational autonomy

As a western liberal construct, the principle of respect for autonomy is individualistic in nature and emphasizes independence and rational free choice (Agich, 1993). It is an idealized account of human agency and overlooks the fact that individuals function within relationships. It does not acknowledge the interdependence of individuals with each other and with the social environment

(Entwistle, Carter, Cribb, & McCaffery, 2010; Jennings, Callahan, & Caplan, 1988; Mackenzie & Stoljar, 2000; Mars, Kempen, Widdershoven, Janssen, & van Eijk, 2008). A relational understanding of autonomy is more accurate, because it takes account of an individual's relationships and social contexts. Relational autonomy "...is exercised within relationships and social structures that jointly help to shape the individual while also affecting others' responses to her efforts at autonomy" (Sherwin, 2012, p.24). This modified view emphasizes that autonomy is achieved through the reciprocity of relationships and that supporting relationships do not diminish patient autonomy but enhance it. By placing autonomy within a broader context, we see that there is mutual negotiation of options and choices in the decision making process and that autonomous decisions are made through collaboration between the patient, his family and clinicians (Tauber, 2005).

4.4.5 Application of the principle

The principle of respect for autonomy aims to protect and empower patients, but the application of the principle to clinical practice is difficult in that the principle is an abstract theoretical construct and only guides actions in a general direction. Ethical dilemmas in clinical cases often involve conflicts and can be very complex, whereas the principle of respect for autonomy offers no specific guidelines with regard to what clinicians should do in particular contexts and situations.

It is important to note that:

[n]either the "facts" nor our "experience" come to us in discrete packets which simply await the appropriate moral principle to be applied. Rather, they stand in need of some narrative which can bind the facts of our experience together into a coherent pattern and it is thus in virtue of that narrative our abstracted rules, principles, and notions gain their full intelligibility" (Goldberg, 2001, p.242).

In the next chapter, I explore narrative ethics as a complementary approach to principlism and the ways in which it can overcome some of the limitations of principlism.

5.0 NARRATIVE ETHICS

“Narrative” is defined as “[a]n account of a series of events, facts, etc., given in order and with the establishing of connections between them; a narration, a story, an account” (Oxford English Dictionary, 1989b). Narrative ethics is a form of ethical reasoning derived from the thought that narrative is an essential part of human interaction and activities and that important moral insights can be derived from narratives. When applied to the clinical practice, narrative ethics requires clinicians to be engaged in patients’ narratives and consider how psychological and social factors affect patients’ illness experiences. Some proponents of narrative ethics suggest that narrative ethics is a complementary approach to principlism, whereas others argue that it should replace principlism.

5.1 HISTORY

Story-telling is an interactive process that is meaningful to both the teller and the listener. A narrative can be set in either real or imaginary contexts and is told by the teller with particular intentions in mind. He partially controls how the audience interprets and reacts to the story by selecting what story he is going to tell, using relevant literary features and vocabulary and adding appropriate intonation and facial expressions. The listener interprets the meaning of the story based on literal interpretation, inferences, and her own life experience.

For thousands of years, human beings have engaged in story-telling, which is a uniquely human activity. Stories embody beliefs and values of particular cultures and social contexts (Hsu, 2008). In ancient times, stories of different genres (epic, fairy tales, fables, and myths) were told and passed down to future generations orally and through writing. The Celts, for example, passed down their history and literature orally and did not have written language until Latin was adopted as the common language in the 6th century (Ellis, 1998; Laing, 2006). In traditional African cultures, storytelling was an important tradition. The storyteller, also known as griot, was well respected for keeping and telling stories about the past and the present (Banks-Wallace, 2002; Kouyate, 1989). Oral traditions not only reveal parts of history coming from people inside certain cultures and communities but also show how people have selected topics of their interest and interpreted the past (Vansina, 1985). Collections of short stories are found in scriptures such as the Bible and the Ramayana (Van Seters, 1997). To date, many ancient stories are still enjoyed by a wide variety of audiences, such as *Aesop's fables* and Homer's *The Odyssey*.

Aristotle, the ancient Greek philosopher, proposed one of the earliest accounts of narrative theory in his *Poetics*, and his discussion was largely concerned with tragedy. For him, tragedy consists of six elements: plot, character, thought, diction, spectacle, and melody. He noted that the plot is the most important element of a tragedy and that the concept of “peripeteia” (an unexpected reversal of situations) is key to the plot, which reflects parts of our human experience and arouses emotions in audience members such as fear and pity.

Alasdair MacIntyre, a 20th century Scottish philosopher, argues that a human life is in the form of a narrative and that human beings are story-telling animals. He writes, “Each of us being a main character in his own drama plays subordinate parts in the dramas of others, and each

drama constrains the others” (MacIntyre, 2007, p.213). For MacIntyre, human actions should be understood only within the context of narrative histories, which consist of both narratives constructed by individuals and narratives of particular communities and cultures.

Martha Nussbaum, a 20th century American philosopher, draws examples from the works of Henry James, Charles Dickens, and Marcel Proust to illustrate the ethical importance of literary narratives, especially novels. For Nussbaum, good literary works broaden readers’ experience, engage them in moral imagination and enable them to see the particularities of human experience and situations and imagine what it feels like to live the life of another person (Nussbaum, 1995). Reading literary works attentively will cultivate readers’ moral perceptions and shape their moral development, so that they become “finely aware and richly responsible” (Nussbaum, 1990, p.148). She appeals to the cognitive role of emotion and argues that emotions are “discriminating responses closely connected with beliefs about how things are and what is important” (Nussbaum, 1990, p.41). For her, emotions embody our values and beliefs, reflect what we care about most and play a key role in forming good moral judgments (Nussbaum, 2001).

5.2 THE STORIES WE READ

Traditionally bioethics is concerned with the study of principles (Pellegrino, 1993). In more recent years, narrative ethics has emerged as an alternative way of ethical reasoning. Narrative ethics challenges the biomedical model, which dominated western medicine in the 20th century and still influences the ways in which many clinicians understand health and illness (Morris, 2002). According to the biomedical model, disease results solely from disordered biological

processes. This model is reductive in that it does not account for psychological, social and cultural factors that affect how a patient perceives and experiences his illness.

Narrative ethics embraces a biopsychosocial model, proposed by psychiatrist George Engel in 1977. Engel argues that the biomedical model supports a limited understanding of illness and that this model cannot adequately respond to patients' suffering. He believes that a holistic understanding of patients' illness requires consideration of illness from biological, psychological and social perspectives (Engel, 1977).

One narrative approach to bioethics is called "the stories we read," which mostly focuses on reading, listening to or viewing stories through literature, films, or plays. These activities are a means by which clinicians are able to gain moral knowledge and shape their own moral perceptions. Clinicians are first trained to interpret meanings of a story using literacy skills. The same skills can be used toward resolving ethical dilemmas in medicine, as clinical practices are literary texts to which literary criticisms can apply (Nelson, 2004).

This approach was introduced to U.S. medical schools when Joanne Trautmann became the first regular full-time faculty member teaching literature at Pennsylvania State University College of Medicine in 1972 (Jones, 2013). The goal of studying literature was to complement medical education by helping prospective physicians develop clinical competencies in observation and interpretation, encouraging students to reflect on the practice of medicine and teaching them how to respond empathetically to patients and their families (Hunter, Charon, & Coulehan, 1995). In the 1980s, medical education programs started to incorporate courses in medical humanities and professional ethics (Martinez, 2009). To date, a number of medical schools offer courses in medical humanities, which allow students to explore topics in bioethics, literature, medical history, anthropology, and theology. The purpose of this multidisciplinary

approach is to help students better understand how illness impacts the lives of patients and their families and apply knowledge learned from these fields of study to clinical practice. Research has shown that training in narrative ethics helps residents understand the contexts of patients' illness experience and develop empathetic communication skills (Arntfield, Slesar, Dickson, & Charon, 2013; DasGupta, Meyer, Calero-Breckheimer, Costley, & Guillen, 2006; Goodrich, Irvine, & Boccher-Lattimore, 2005).

Rita Charon, a physician and a literary scholar, has offered a detailed literary analysis of Henry James's *The Wings of the Dove* to illustrate "the stories we read." The story is narrated using the first-person-plural pronoun "we" and the narrator has full knowledge of the inner monologues of the characters. For Charon, this is not an arbitrary construction but allows the reader to co-create the story with the narrator and see the multifaceted and personal reasons behind the characters' moral choices. This is not a moral story in which the world is black and white but a story with an ethical dimension, allowing the reader to explore key themes such as mortality, suffering, and pain and different beliefs and choices about the right ways to live. By reading the novel, the reader is invited to reflect on the moral complexity of the story and make her own judgment about it. Charon argues that reading literary works as such has bioethical implications, precisely because the moral ambiguity depicted in the novel is also found in the clinical setting (Charon, 1997).

Proponents of "the stories we read" argue that knowledge and skills drawn from disciplines outside of medicine, such as anthropology, philosophy, psychology, religion, and drama help clinicians better appreciate the complexity of moral dilemmas in medicine. Moral dilemmas in the clinical setting often stem from conflicts in relationships. The narrative approach unites literacy scholarship and ethics and offers a unique way of resolving such dilemmas. A

reflection on different values and beliefs through narratives helps clarify perspectives and allows multiple voices to be heard (Martinez, 2009). Readers use literary skills to interpret the meaning and structure of a story, and methods of literary analysis can be used to help clinicians better understand patients' stories (Montello, 1997).

5.3 THE STORIES PATIENTS TELL

Another narrative approach is called “the stories we tell,” which mostly focuses on illness narratives (Nelson, 2004). The basic idea behind this approach is that human beings are story-telling animals. We attach meanings to our particular life experiences, and we convey meaningful experiences to other people in the form of story-telling (Brody, 2003). Patients are seen as narrators of their own story and they give meaning to their illness by constructing their own illness narratives (Kleinman, 1988). Story-telling is the patient's way to convey the experience of being ill and to respond to the impact of illness and its treatment. The therapeutic encounter consists of telling and hearing illness narratives (Nelson, 2004). In recent years the use of narrative in psychotherapy has grown (Lewis, 2011; Riessman & Speedy, 2007; Speedy, 2007).

From the 1980s onwards there has been an increased interest in the importance of “the stories we tell.” Harold Brody is a family physician and his *Stories of Sickness* discusses the ways in which patients' illness narratives inform clinical practice. Arthur Kleinman, a psychiatrist, explores the concept of suffering in his *The Illness Narratives*. For him, a patient's worldview differs from that of health care professionals trained in the biomedical model. Narratives are a powerful means of conveying the patient's first-hand experience of illness and

suffering. Arthur Frank is a sociologist and has written about his own chronic illness (heart disease and cancer). In his *The Wounded Storyteller*, Frank argues that chronic illness and its treatment have an impact on patients' self-identities and that patients are able to voice their self-understanding through story-telling. He encourages patients to tell their own stories so that they do not lose their self-identities by submitting to the reductionism inherent in the biomedical model (Frank, 1995).

Anecdotal reports, especially patients' unverified accounts, usually rank lowest in the hierarchical system of evidence-based practice, but patients' narratives convey important truths about what it means to be human by describing emotions (Greenhalgh, 2006). Illness narratives are told from the patient's perspective and reveal the impact of illness on his self-identity. They situate the patient and his illness within a biographical context. Symptoms are contextualized and viewed within the framework of an individual's life. Narratives are a unique means of getting to know "*how we got there*" (Montello, 2014, p.S3, italics in the original), that is, how patients arrive at the ethical dilemma in which they find themselves. Narratives provide meaning, context, and perspectives for a patient's suffering and help clinicians gain a deeper insight into how, why and in what way the patient is ill (Greenhalgh & Hurwitz, 1999).

Pathography is a literary genre that refers to autobiographical accounts of the illness experience. The wide popularity of pathography illustrates the discontentment of the public with medicine based on the biomedical model, which leaves little room for the psychosocial dimension of illness (Tauber, 2005). Pathography reveals that illness has various dimensions that go beyond medical treatment, including patient experience from the first-person point of view and the effect of illness on family and friends and the patient's wider social world (Hawkins, 1999). Authors of pathography write to come to terms with their illness, to share their experience

about what it feels like to be a patient and to criticize the current practice of physicians and other health care professionals (Aronson, 2000).

Illness narratives are told in a variety of contexts. The clinician usually initiates the therapeutic encounter by collecting data regarding the patient's past medical history and information regarding his symptoms. When told during a clinical encounter, a patient's illness narrative has the instrumental value of helping the clinician diagnose and treat medical conditions. The patient may convey his physical and emotional distress in the form of oral narratives when talking to family and friends in daily conversations. Illness narratives are important for the study of illness as opposed to disease and patients are invited to talk about their experience of being ill in research interviews (Hydén, 1997).

Narratives of illness can be categorized into three genres (Frank, 1995):

- restitution narrative: the patient-hero's struggle against serious illness is successful;
- chaos narrative: the patient-hero tells stories about how much he cannot make sense of his serious illness; and
- quest narrative: the patient-hero tells stories about his journey of illness in which he tries to find meaning and goals in life.

Elliot Mishler, a professor of social psychology of Harvard, examined conversations between patients and physicians and found that physicians frequently fail to understand what patients try to tell them and that physicians often dismiss stories as trivial and irrelevant (Mishler, 1984). Mishler suggests that narratives from patients' viewpoints reflect a critique of medical practice based on the biomedical model. Many clinicians speak with the voice of medicine, which is alleged to be an objective and decontextualized account of diseases using technical terminology and jargons. Patients speak with the voice of the lifeworld, which is a

subjective account of their experiences of illness in everyday life. The clinician and the patient, who speak in two different voices, do not communicate well in the clinical encounter, because they have different ways of making sense of the problem at stake. The voice of the lifeworld is often unheard, because it is usually the clinician who dominates the conversation (Mishler, 1984).

Carl Elliott, a philosopher, has made a similar observation about clinical practice in psychiatry, but his concern can be broadened to patient-clinician communication in general. He notes that clinicians often speak the language of mechanism to explain the biomechanics of the human body and pathophysiology to patients, whereas patients use the language of persons to explain their medical conditions, talk about their experiences, intentions, and desires. The two languages differ fundamentally, insofar as they stem from different ways of explaining and understanding medical problems (Elliott, 1999).

According to narrative ethics, the stories patients tell provide patient-centered perspectives and help bridge the gap between the objectivity of scientific knowledge and the subjectivity of individual cases. While competent clinical skills are a prerequisite for practicing narrative-based medicine, narrative ethics requires clinicians to appreciate patients' signs and symptoms as elements of their suffering and find out what problems patients and their families might have in their lives due to patients' illness (Greenhalgh, 2006). Clinicians need to consider biological, psychological and social aspects of illness and their interwoven relationships when understanding illness and providing health care.

Illness narratives are not monologues, rather they are dialogues jointly constructed by the patient and the clinician (Brody, 2003; Greenhalgh, 2006). Charon has proposed the concept of narrative competence, which is "the competence that human beings use to absorb, interpret, and

respond to stories” (Charon, 2001, p.1897). A clinician who has narrative competence recognizes the patient as the author of his illness narrative, which is key to understanding his suffering. She sees a patient’s suffering and his coping with the illness as a story within his lifeworld and joins him in exploring what it means for him to be ill (Greenhalgh, 2006).

5.4 LIMITATIONS

Narrative ethics provides an alternative means of guiding ethical decision making and is more concerned with the particularities in ethical dilemmas. A narrative approach views ethical reasoning in light of emotions and desires rather than solely in light of reason and rules. However, the clinical application of using a narrative approach in isolation is problematic in a number of ways.

While Charon proposes that narrative ethics is complementary to principlism and help shape and understand the four principles, Brody and Frank have taken a more radical approach and argue that clinicians should be able to gain moral insights from narratives without appealing to principles. It seems unnecessary to overthrow principlism, as the four principles are helpful and offer clinicians a framework for reflecting on conflicts, identifying ethical dilemmas and categorizing happenings (Connelly, 2002).

A challenge to “the stories we read” approach is that not all stories help cultivate moral perceptions and it is unclear as to what kind of literature students and clinicians should read and who is qualified to make that judgment (Nelson, 2001). Learning and mastering the skills required in narrative competency including literary criticisms takes a considerable amount of time and effort. Reading literature in the classroom is very different from listening to and

understanding patients' narratives in the clinical setting. One may question how applicable this approach is. By contrast, principlism can be easily taught to health care professionals and is applicable to a wide range of difficult clinical ethics cases.

When using "the stories we tell" approach, understanding a patient's life stories requires interpretation, which is always open to bias. Different clinicians have different values and beliefs and can produce drastically different interpretations of the same illness narrative. How can one determine if one interpretation is better than the other? Narrative ethics has a loose theoretical background and does not offer norms with regard to interpretive acts. One might argue that the four principles also need to be interpreted before they can be applied to clinical practice, but at least principlism is a much more systematic approach with a robust theoretical construct. Although narrative ethics may be helpful in some contexts, not all patients are interested in revealing their feelings or telling their life stories (Kalitzkus & Matthiessen, 2009). In such cases, it is likely that clinicians would still need ethical principles to guide their clinical practice.

6.0 APPLICATION OF A SYNTHESIZED APPROACH

The common interpretation of the principle of respect for autonomy alone does not help solve the conflict between patient autonomy and clinician beneficence, whereas a synthesized approach combining principlism and narrative ethics does. The case of George will be presented to demonstrate that using different approaches in the clinical decision making process results in different outcomes. The first scenario illustrates decision making using the common interpretation of the principle of respect for autonomy. The second scenario illustrates decision making using a synthesized approach combining principlism and narrative ethics. Case descriptions will be followed by analyses as well as comparison and contrast of the two scenarios.

6.1 THE CASE OF GEORGE AND HIS POVITICA

George is a 78-year-old retired electrical engineer. He was born in Croatia and immigrated to the U.S. with his family when he was 11 years old. His wife died of a brain tumor two years ago. Since then he has been living with his eldest daughter, for he is not accustomed to taking care of or cooking for himself.

George has a medical history of atrial fibrillation, hypertension, and diabetes mellitus. He had developed a kidney stone over the years due to not drinking enough fluids and had to go

through surgery to remove it seven years ago. He broke his hip as a result of a ground level fall four years ago and developed pressure ulcers at that time. He sustained a stroke recently, leaving him with right-sided weakness and moderate-severe oropharyngeal dysphagia. George was discharged from an acute care hospital with a modified diet consisting of puree and honey thick liquids. He was advised to visit an outpatient swallowing disorders clinic on a regular basis.

George comes to the clinic for a follow-up visit accompanied by his daughter. He tells the SLP that he has been doing his swallowing exercises and is eager to know if his swallowing function has improved. He reports that he has been following a pureed diet prepared by his daughter most of the times and that he has been thickening his drinks inconsistently. His daughter expresses concern about her father's fluid intake and fears that he would be at risk for dehydration, for he hates the taste of thickened liquids and tends not to drink much water throughout the day. George reports that sometimes he would "cheat" and try small bites of solids. For example, he would occasionally have fries when playing poker at the bar.

6.2 SCENARIO ONE

The SLP tells George that progress could be slow, as demonstrated by overt signs and symptoms of aspiration in the clinical swallowing exam. She reminds him of the adverse health outcomes associated with aspiration and stresses the importance of strictly adhering to the safest diet consisting of pureed food and honey thick liquids. George and his daughter communicate understanding.

In their next visit, the SLP learns that George has not followed through her recommendations. He has been eating solids more often since the last visit and has stopped using thickening agents in his drinks.

The SLP feels as if there is no point in keeping this patient on her caseload. Even though she has explained the risks of aspiration in accessible terms several times, George has never really taken her advice. The SLP feels uncomfortable making recommendations outside the norm, because she has been trained that the goal of dysphagia management is aspiration prevention. She also fears that if she were to make less restrictive diet recommendations and subsequent problems developed, she would be culpable.

George has always respected the SLP's expert advice, but he feels that she lectures him at every visit about the risks of "food and drinking going down the wrong pipe." He is frustrated that his swallowing problems are chronic and fears that he will be restricted to a modified diet for the rest of his life.

The SLP presents George and his daughter with two options: he could either strictly adhere to the safest diet or he could have food and drink of "unsafe" consistencies if he accepted the risks of aspiration. The SLP also restates the risks associated with aspiration. After George indicates that he prefers the second option, the SLP tells him that she fully respects his choice and that at this point there is nothing else she could do for him. George is discharged from her caseload.

6.3 ANALYSIS OF SCENARIO ONE

Ethical dilemmas in the clinical setting often stem from conflicts in perspectives. Scenario one illustrates a classic conflict between the principle of respect for autonomy and the principle of beneficence. What can be done when there is a discrepancy between the patient's wish and the clinician's judgment about what serves the patient's best interest?

The SLP interprets the principle of beneficence as promoting George's health and preventing adverse health outcomes associated with aspiration. She feels that she has an obligation to act in accordance with this principle by recommending the safest diet. She thinks that by discharging him, she is respecting George's right to determine his treatment plan.

The SLP has good intentions and thinks that her recommendations will do good for George's physical health, but her interpretation of beneficence solely focuses on aspiration prevention. She fails to see things in the bigger clinical picture where other health concerns such as dehydration should also be addressed. Her narrow view of beneficence also overlooks the importance of George's overall well-being and quality of life. The SLP does not explore the reasons why George does not follow through her recommendations, nor does she ask him about the impact of his chronic swallowing problems on his everyday life.

In this scenario, patient autonomy trumps clinician beneficence. George is fully informed of the risks of aspiration and makes the decision to proceed with an unmodified diet. A question remains: has the clinician fulfilled her duty to do good and prevent harm for George?

6.4 SCENARIO TWO

The SLP decides to take a step back and understand George's problem with eating and drinking as part of his lifeworld. She reflects on how frustrating the condition would be for him. She invites George to tell her about what goes on in his life to find out what matters most to him.

George starts off by saying that Thanksgiving is approaching and that he misses povitica (nut rolls) more than anything else. Povitica was his favorite food in childhood and his grandmother used to make many loafs during the holiday season and gave them to extended families and friends as a gift. George laughs over the fact that his daughter once tried to liquidize povitica but the taste was awful. He also tells the SLP that his daughter is a nurse with a busy work schedule but takes good care of him by "making me baby food every day."

George was happily married for more than 50 years and had a difficult time coping with life without his wife. Since then his highlight of the week had been gathering with his friends at the local bar every Saturday where they would have lunch, drink beer and play poker. Everything has changed after the stroke: he is unable to share meals or drinks with his friends any more. His daughter offered to prepare him a modified diet so he can bring it to the gathering, but he is too embarrassed to eat his special meal in public. He soon stopped going to the bar.

The SLP understands that George misses the sharing of meals with his friends and that he misses ethnic foods, which are part of his identity. She states that chest infections are caused by a variety of factors including the volume and pH of the aspirated material. She proposes that given that George receives meticulous oral hygiene care before oral intake and stays in an upright position during eating and drinking, he could have a small glass of beer and a small amount of moistened soft solids on Saturday. The SLP expresses understanding of the daughter's concern about dehydration and endorses George's wish to drink unthickened liquids. His daughter is

encouraged to keep track of the type and amount of unmodified food and drink he has had and bring the food diary to their next follow-up visit. His temperature should be closely monitored daily and he should go and see a doctor if he develops fever, chest pain or shortness of breath. Finally the SLP states that while she would not want to see George getting chest infections, she equally would not want to see him developing other medical problems due to dehydration or being left out on social occasions. While there are risks in everything, she believes that these are ones that are worth taking.

In their next visit, George's daughter reports that he drinks enough liquids daily. He is "as happy as a clam," because he has gone back to his routine of sitting with his friends at the bar and drinking beer. He takes the SLP's recommendation regarding oral hygiene seriously and cleans his teeth carefully every day. He sat with his family and friends at the dinner table during Thanksgiving and had a few small pieces of povitica (sugar free version). George reports that he followed the SLP's instructions by putting lots of butter on povitica and chewing it very well before swallowing it. At other times, he almost always follows a pureed diet. No adverse health outcomes are noted at this point.

6.5 ANALYSIS OF SCENARIO TWO

Applying the principle of respect for autonomy in the clinical setting provides a framework for ethical reasoning and enables the clinician to honor George's choice. Narrative ethics allows the clinician to understand what matters to him and his daughter. The synthesis of principlism and narrative ethics successfully resolves the ethical dilemma, which arises from George's preferences and values in everyday life and his interactions with his social world. George's

stories resolve the conflict between autonomy and beneficence and help establish a common frame for addressing the problem. His narrative about his chronic dysphagia is about him coping or failing to cope with the challenges of living with this condition. It is also about the role of his daughter in managing his health conditions. The tasks of explaining and implementing recommendations are much easier when they are guided by a joint goal established by George, his daughter, and the clinician.

The SLP understands George's illness within the context of his life story. She practices narrative ethics by encouraging him to share his story, actively listening to his concerns and carefully interpreting his illness narratives. There is less expert talk by the clinician; but rather three people try to define the problem and jointly discuss and decide what is most beneficial for George. After establishing a shared understanding of his swallowing problems and its impact, the SLP uses the patient's narrative to guide forming a treatment plan. She proposes an individualized treatment plan based on the values and beliefs narrated by the patient and ensures that there is mutual agreement about its implementation. She has the bigger clinical picture in mind and recognizes that the best treatment plan is one in which different aspects of life including swallowing problems, social isolation, pleasure of eating and drinking, and risk of dehydration can be balanced.

This scenario demonstrates that a plan is meaningful only if the patient identifies with its goals. In many cases, exploring the patient's narratives fully and generating goals that align with his preferences reduce "non-compliance." When there is good communication between both parties and trust is established, the patient may be more tolerant of restrictive diet practice and behavioral modifications.

7.0 CLINICAL AND RESEARCH IMPLICATIONS

The synthesized approach combining principlism and narrative ethics empowers patients with chronic dysphagia to make autonomous decisions. This approach effectively resolves the classic conflict between patient autonomy and clinician beneficence in the clinical setting and is equally applicable to other patients with disorders addressed by SLPs. Given that this ethical dilemma is frequently encountered by SLPs, this finding has profound clinical and research implications.

7.1 COMMUNICATION

Communication is a core clinical skill for health care professionals. Patient-clinician communication has three functions: forming a good inter-personal relationship, exchanging information, and making decisions about treatment (Ong, De Haes, Hoos, & Lammes, 1995). Effective communication is defined as: “The successful joint establishment of meaning wherein patients and health care providers exchange information, enabling patients to participate actively in their care from admission through discharge, and ensuring that the responsibilities of both patients and providers are understood” (Joint Commission, 2010, p.1).

Effective patient-physician communication is the basis of quality patient care and is associated with positive clinical outcomes such as patient adherence to treatment (Stewart, 1995; Vermeire, Hearnshaw, Van Royen, & Denekens, 2001; Zolnierek & Dimatteo, 2009), greater

patient satisfaction (Flocke, Miller, & Crabtree, 2002), improved physiological measures such as control of blood pressure and blood sugar, and good psychological functioning of the patient (Stewart, 1995).

7.2 COMMUNICATION EXPERTS

SLPs assess, diagnose and treat communication and swallowing disorders in adults and children and incorporate elements of evidence-based practice to make clinical decisions. We have the specialized knowledge that allows us to understand the biomechanics of normal and disordered swallowing and to manage swallowing disorders. We are trained to be beneficent providers and expect patients to accept our recommendations. We sometimes disapprove of patients' choices when they choose not to take our advice.

SLPs are familiar with the concept of narratives, which usually have two structures: setting (characters, place, time) and plot (conflict, solution) (see Figure. 1: Narrative elements per SLPs).

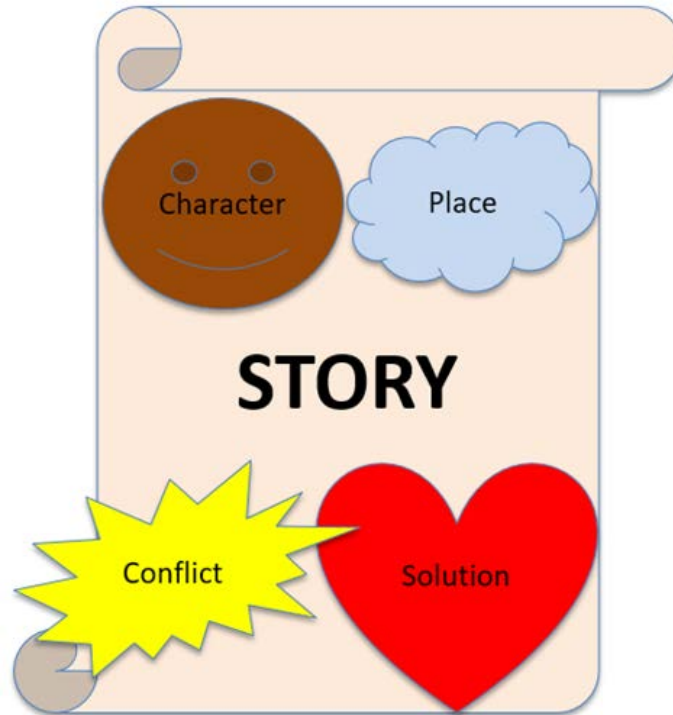


Figure 1 – Narrative elements per SLPs

Storytelling involves the teller producing the narrative, which is in turn understood by the listener. The production and comprehension of narratives encompass all areas of language including phonology, morphology, syntax, semantics and pragmatics (American Speech-Language-Hearing Association, 2007). In child language development, understanding comes before language usage. Child language development involves development in narrative skills and deficits in such skills may negatively impact a child's academics, which requires the comprehension of texts and production of spoken and written narratives. Deficits may also affect the child's social interaction with peers in that socialization almost always requires the comprehension and production of personal narratives to express emotions and feelings. Acquired communication disorders (aphasia, cognitive communicative disorders, dysarthrias, and apraxia of speech) impact adults' ability to comprehend and/or produce spoken or written narrative discourse. This affects patients' participation in meaningful activities in daily life and lowers

their quality of life (Shadden, Hagstrom, & Koski, 2008). SLPs are uniquely equipped with the knowledge and skills to appreciate spoken and written narratives as a linguistic and discourse ability and work with both children and adults on narrative skills (Hinckley, 2008).

7.3 DEFENSIBLE PRACTICE

Clinicians may be fearful of litigation and argue that they have to make conservative recommendations due to the prevalence of medical malpractice suits in the U.S. This results in defensive practice, which deviates from standard provision of care (Studdert et al., 2005). According to Rule M of the ASHA Code of Ethics, the practice pattern for SLPs should be one in which the clinician "...shall use independent and evidence-based clinical judgment, keeping paramount the best interests of those being served" (American Speech-Language-Hearing Association, 2015, p.5).

SLPs use evidence-based practice to provide care and make clinical decisions. Evidence-based practice is not only about randomized control trials but requires the integration of scientific evidence, clinical expertise, and patient/caregiver preference. SLPs' fear of aspiration may not be based on the best available evidence. While we think that we are acting in the best medical interests of patients, we also need to know that managing dysphagia alone will not decrease the risk of adverse health outcomes. Other factors such as dependent for feeding, oral hygiene, and multiple medical conditions would also increase the risk of chest infections (Langmore et al., 1998).

The Patient Self Determination Act (1990) states that patients have the legal authority to participate in care planning and make medical decisions, refuse medical interventions, prepare an

advance directive and be given information about how the provider implements these rights. Good communication is the first step toward defensible practice. SLPs must explore patients' goals and preferences, keep them fully informed of the treatment options and empower them to make the decision based on what is best for them (Leslie & Casper, 2015).

Documentation is an important part of clinical practice. Clinicians keep written records of what happened during clinical encounters with patients, families, and other professionals. Clinical records should show that clinicians use their knowledge and skills to formulate appropriate assessment and treatment plans (American Speech-Language-Hearing Association, 2017). We need to justify providing services that are skilled and medically necessary and also need to document patients' improvement in response to intervention and provide clear rationale for continuation/discontinuation of the treatment plan (Centers for Medicare and Medicaid Services, 2014). It is not enough for clinicians to provide patient education. We need to ensure that patients understand the information provided including the risks and benefits associated with different options. We should include patients and their family members in the clinical decision making process in which clinicians facilitate informed choices by providing information and both parties jointly establish relevant and meaningful goals. Our practice is defensible as long as we document the process of gaining informed consent for the plan of care.

7.4 WHAT SLPS STILL NEED TO DO

We SLPs recognize that as clinicians we have the duty to maximize a patient's best interests. We often interpret the principle of beneficence as minimizing the risks of aspiration and the associated adverse health outcomes. Many of us have taken for granted that the goal of

dysphagia management is aspiration prevention. SLPs frequently bring up the issue of “non-compliance” on the discussion board of ASHA Special Interest Group 13 Swallowing and Swallowing Disorders and ask about whether patients who do not follow through recommendations should be discharged. In clinical practice, such patients are often labeled as non-compliant, unreasonable and difficult. But are we providing quality patient care by readily discharging patients because they refuse our recommendations?

Labeling the patient as non-compliant is “an unfortunate and unjustified holdover from the olden days of rampant medical paternalism” (Brody, 2003, p.162). Many instances of non-compliance result from the clinician’s failure to explain options in accessible ways and to take account of the patient’s values and needs when forming a treatment plan. Clinicians often prematurely label a patient’s judgment as irrational, because they neglect the fact that the patient can have different values on the importance of longevity, quality of life, or risk taking (Katz, 2002). Sometimes we are inappropriately paternalistic by judging and questioning patients’ decision making when they disagree with us.

When a patient disagrees with us, we must not simply walk away or give up our responsibilities of caring for the patient but honor his choices (Leslie & Krival, 2010). Patients can refuse our recommendations for a variety of reasons. As clinicians, we need to find out about these reasons and explore the ways in which we may still be able to use our specialized knowledge to facilitate decision making by taking their values and needs into consideration. If the patient does agree with the clinician’s recommendations but does not follow them for some reason, the clinician and the patient may complete “a narrative task” together in which they discuss the reasons why the patient is unable or unwilling to carry out the agreed treatment plan (Meza & Passerman, 2011).

The patient's best interests need to be interpreted more broadly than "preventing aspiration." His medical interests are certainly harmed by choking during meals or developing chest infections but our well-intended recommendations may cause harm in other ways. A patient may suffer the associated morbidities of dehydration such as urinary or kidney problems because he does not like to drink thickened liquids. A patient may decrease his dietary consumption and be at risk for malnutrition, due to the modified diet appearing unappealing. A patient may suffer from depression caused by social isolation, because he no longer goes out for meals with family and friends. Since it is often difficult to draw a clear distinction between benefits and harms in the clinical setting, we must review the full clinical picture and balance costs and benefits on a case-to-case basis.

We must humanize our care of patients by adopting a holistic view toward health and illness. Clinicians who understand illness in terms of the biomedical model of disease often fail to deal with patients' concerns regarding the impact of disease which is what illness really is. This is especially true for those who suffer from chronic and incurable conditions (Toombs, 1987). By adopting the biopsychosocial model, clinicians may be able to see that a patient's dysphagia is more than abnormalities both in the anatomy and physiology of swallowing but is also a disruption to his lifeworld. Our knowledge of the biomechanics of swallowing should be framed by patients' values and goals and the impact of the swallowing problems on their families and social contacts.

As Hinckley (2008) has noted, SLPs have paid less attention to the social and emotional dimensions of clinical encounters than our colleagues in other professions such as clinical psychology, occupational therapy, and education. Part of the reason is that we are often taught to maintain a neutral stance and be emotionally detached from our patients to ensure that clinical

decisions are made objectively, but the therapeutic relationship is one in which emotions are already present. Patients with swallowing or communication disorders experience loss, sadness, anxiety, confusion, vulnerability, and anger and are often overwhelmed by their conditions and so do their caregivers (Luterman, 2006). At these times, emotional engagement rather than detachment allows the clinician to gain a better understanding of patients' suffering and plays an important role in clinical decision making (Halpern, 2001).

It is impossible to know what a particular patient's best interests are unless we start a conversation with him. Listening is an important tool in the clinical encounter. It is not only a tool serving the purpose of diagnosing and treating biomedical impairment but is also the key to understanding the patient's suffering and the ways in which his illness sets obstacles to participate in daily activities (Cassell, 1985; Kleinman, 1988; Mishler, 1984). Listening resembles reading a narrative in that the clinician-listener puts pieces of information together, interprets the sequence of events and identifies what all of these mean in this particular patient's life (Charon, 2001).

Montello (2014) has proposed that by drawing on four narrative elements (voice, character, plot, resolution), clinicians are able to make a "mattering map," the goal of which is "to discern what matters, what matters overwhelmingly, in the lifeworld the speaker describes" (p. S4). **Voice** allows us to find out from whose perspective the story is told. **Character** allows us to identify who is telling the story. **Plot** is about the twist in the story; that is, how the patient's life story is unexpectedly changed due to his illness. **Resolution** differs from solution in that difficult cases are often not solved but an effective way of addressing the problem helps move the story forward. Therefore, resolution should be understood as it is in music: "progressing from a dissonance to a consonance" (Montello, 2014, p.S5).

Given that they have specialized knowledge in narrative structures and in narratives as a linguistic ability, SLPs may have more appreciation of the concept of a mattering map and of its application in clinical practice. The solution to the conflict between autonomy and beneficence lies in the patient's life story (see Figure 2: Narrative elements per bioethicists), which can guide the patient and clinician to create a meaningful plan with which he identifies.

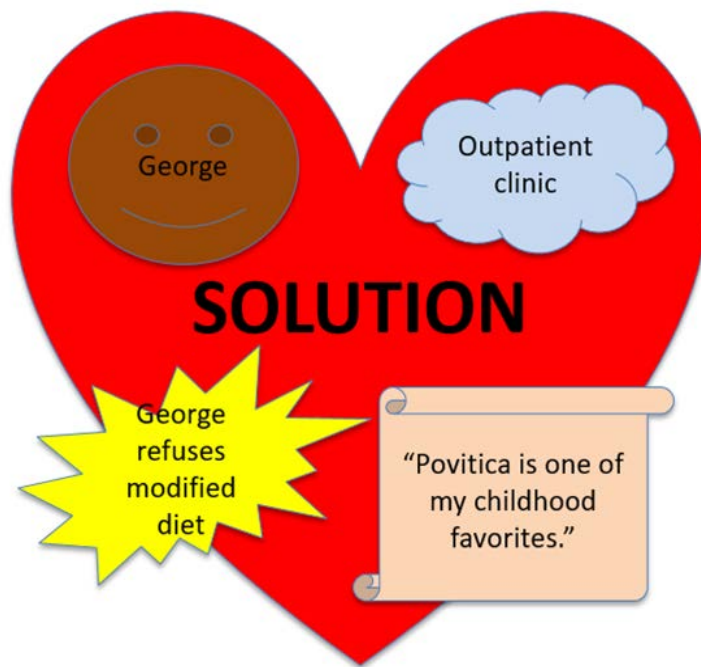


Figure 2 – Narrative elements per bioethicists

Historically SLPs's locus of care has focused on managing the signs and symptoms of dysphagia and preventing aspiration. Sometimes we overlook the fact that our well-intended interventions may be what burdens the patient. By asking a patient to tuck his chin every time he swallows, for example, he may never choose to go out for meals because he is too embarrassed to use that strategy in public. Clinical competence involves both the mastery of biomechanics of swallowing and an appreciation of how dysphagia and our interventions may impact patients' life. To facilitate informed decision making, we not only need to ensure that patients fully

understand the factors that increase or decrease the risk of chest infections, malnutrition, and dehydration but also take a step back and ask the following questions:

- What is the patient's goal?
- How actively does the patient want to be involved in his care?
- Does he want to use strategies and maneuvers while accepting the risks of aspiration?
- How is the patient's family or caregiver able to cope with the management of dysphagia?

The information obtained may help clinicians balance dysphagia management and other aspects of patients' lives. Care needs to be aligned with what matters the most to patients and clinicians should also use patient/caregiver preferences to inform recommendations. By gaining a better understanding of their preferences, the clinician may be better able to form an individualized plan guided by joint goals and patients and caregivers may be better engaged in the goals that take their life situations into consideration.

A narrative approach certainly does not work for all patient-clinician encounters. A patient with a broken leg looking for intervention may not be interested in sharing his life stories. He may find it comforting to listen to the language of mechanism spoken by the clinician in that he is looking for an expert to offer a technical solution. In subsequent visits, he may also choose to speak about his condition in decontextualized terms until he is asked a question relating to quality of life or activity participation.

When working with patients with multiple chronic conditions, clinical decision making often involves identifying and addressing tradeoffs (Ferris et al., 2017). It may be especially helpful to engage these patients in illness narratives so that the "voice of the lifeworld" can be heard and that they are empowered to talk about the impact of illness on their life as well as the

types of intervention they prefer. Narrative is a helpful tool for clinicians to find out whether their patients want to talk about issues other than the technical details of their medical problems.

7.5 FUTURE DIRECTIONS

Individuals with aphasia are encouraged to use personal narratives to talk about their experience of living with a communication disorder (Armstrong & Ulatowska, 2007; Fromm et al., 2011; Hinckley, 2006; Nakano & Hinckley, 2010; Shadden & Hagstrom, 2007; Ulatowska, Reyes, Santos, & Worle, 2011). Future research should address the illness narratives of elderly patients living with chronic dysphagia and this could be done using a qualitative method. Exploring the individualized nature of patient experience can allow clinicians to appreciate the uniqueness of each patient's illness experience. Deriving thematic categories from illness narratives may also help clinicians see the commonality of patients' experiences. Further research could also examine how cultural values including religious beliefs play an important role in making chronic care decisions about eating and drinking.

The current discussion is confined to patients who have the capacity to make medical decisions. Future research could explore the ways in which a narrative approach helps guide clinical decision making when patients lack the capacity to make such decisions.

Our identities as SLPs and our experiences of dealing with ethical dilemmas and professional issues inform clinicians' narratives, which are highly valuable in that they convey the clinicians' perspective of the healing relationship as well as the daily challenges they encounter in service delivery (Hinckley, 2008). Future research could address SLPs' narratives about the challenges associated with making long-term eating and drinking decisions.

Problem-based learning has been increasingly adopted in health professional education and has been pushed as a model of pedagogy in the field of speech-language pathology (Burda & Hageman, 2015; Ginsberg, Friberg, & Visconti, 2011; Raghavendra, 2009; Whitehill, Bridges, & Chan, 2014). Problem-based learning differs from traditional didactic approaches in that students are presented with cases for which they are required to figure out what areas of knowledge they need in order to solve the problem and to formulate appropriate assessment and treatment plans. Future research could explore whether case studies incorporating patients' illness narratives could help students better appreciate the psychosocial and emotional aspects of the illness experience and prepare them to be more effective and empathetic communicators in the clinical setting. Future research could also assess the value of developing curriculum focusing on teaching students the narrative skills of active listening and interpretation of patients' accounts.

8.0 CONCLUSION

Eating and drinking are activities fundamental to our human experience. Elderly people are more susceptible to chronic conditions and dysphagia, due to decreased functional reserve, increased vulnerability to diseases, and the effects of polypharmacy. Ethical conflicts occur in the context of making chronic care decisions regarding eating and drinking: patients often readily refuse clinicians' well-intended recommendations and clinicians are obliged to do good and prevent harm. The principle of respect for autonomy is too general to guide specific actions in clinical practice and is often interpreted in a way that does not fully empower patients to make autonomous decisions. Narrative ethics complements principlism by asking clinicians to actively listen to patients' illness narratives, find out about the psychosocial aspect of their illnesses and pay attention to issues such as culture, religion and ethnicity.

8.1 SUMMARY

SLPs' interpretation of the principle of respect for autonomy may be too restrictive: patients' refusal of our recommendations should not necessarily lead to discharge and respecting patients' autonomy consists of more than the presentation of treatment options for patients to choose from. Likewise, SLPs' interpretation of the principle of beneficence needs to expand and encompass the psychosocial aspects of living with chronic dysphagia. Our interpretation of patient

autonomy and our support of patients and families in their decision making may benefit from the synthesized approach proposed by this work, which is one that SLPs are unusually well qualified to consider.

Providing care to elderly patients with chronic conditions requires the best of both worlds: the principle of respect for autonomy points to a general direction, while narrative ethics complements principlism by filling the gap in clinical practice. The synthesized approach requires SLPs to empower patients to make autonomous decisions by engaging them in the narrative process of communication. After all, “[w]hat is spoken of as a ‘clinical picture’ is not just a photograph of a man sick in bed; it is an impressionistic painting of the patient surrounded by his home, his work, his relations. His friends, his joys, his sorrows, hopes, and fears” (Peabody, 1984, p.814).

8.2 LIMITATIONS

This paper is based on a traditional literature review, which has drawn on both qualitative and quantitative studies for review. A major limitation is that bias could have occurred in the author’s choice of literature and interpretations. In addition, due to the limited scope of this work, it is not possible for the author to explore all topics in depth.

8.3 CLINICAL AND EDUCATIONAL SIGNIFICANCE

Results from this work can better support clinicians to facilitate chronic care decision making regarding eating and drinking when working with elderly patients and enhance patient engagement by forming joint goals with which patients identify. We have the duty to respect patients' autonomy. We also have the duty to guard the well-being of our patients. Patients' narratives balance our seemingly conflicting duties. We need to form partnerships with our patients in therapeutic encounters and must not discharge them when they disagree with our recommendations. At these times, using a synthesized approach combining principlism and narrative ethics may allow us to step back, get to know what matters most to patients and their caregivers and align care with their goals.

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