EFFECTS OF CULTURE ON LICENSED NURSES' VIEWS ON LIFE-PROLONGING MEASURES

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A Project

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Abstract

EFFECTS OF CULTURE ON LICENSED NURSES' VIEWS ON LIFE-PROLONGING MEASURES

by

Margaret F. Weeks

Because of advances over the past 100 years in medical technology, end of life medical decision making has become a complex process. Licensed nurses are charged with the responsibility to explain implications of medical interventions, assist patients and families with decision making, and implement those decisions. The research was conducted with the position that an understanding of nurses’ views and practices could contribute to enhancing the scope and range of available choices for patients and families while increasing the comfort level of nurses in honoring such decisions. Interviews were conducted with 15 licensed nurses at a skilled nursing facility in Sacramento, full time employees each with several years of experience in working with patients at the end of life. The nurses’ varying views on life prolonging measures appeared to be related to years of experience and loosely related to culture and religious affiliation. Implications for social work practice included education and modeling for peers and advocacy for clients’ rights.

Joyce Burris, PhD, MSW

Date
DEDICATION

This work is dedicated to my wonderful family, whose support was essential to the completion of this project.

To Jonathan, my patient, loving, supportive, and understanding husband: Thank you. You believed in me, even when I doubted myself; you encouraged me when the task seemed too big; and you have waited patiently for the time when this would be completed, and you would “have your wife back!” I love you.

To my parents, Guy and Aldine Fuller: Although you are no longer with us, you remain the foundation of my life in every way. Thank you for instilling in me the love of learning and the joy of serving. It is because of you that I have chosen to be a social worker.

To my sister Priscilla: You have always believed in me and prodded me to step out in spite of fear. You are a wonderful role model and the best sister and friend ever.

To my children, Michelle, Micah, and Mason: I am so grateful for your love and encouragement. You are my inspiration and joy; may this work provide inspiration to you as you face life’s challenges.

And, to my sweet grandchildren, James, Aaron, Chance, Hope, Savannah, Seth, Grace, Jamie Lynn, and True, thank you for the delight and wonder you display for life. You give me reason to smile and hope for the future. God bless you!
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This project would not have been a success without the willing cooperation of Linda Turner, D.O.N. of Bruceville Terrace Skilled Nursing Facility, who granted permission for the study to be conducted, and provided support and encouragement that was invaluable.

I am grateful to the licensed nurses who volunteered to participate in the study. Their honesty and openness in sharing their opinions and experiences framed the research and taught me much. I learned a great deal about culture, spirituality, and values in general, and I gained great appreciation for each individual’s personal story.

The hundreds of elderly and frail patients with whom I have worked over the past ten years have been my inspiration in this research. They have given face, heart, personality, and individuality to the issues and decisions faced at end of life. They have taught me so much, and knowing them has enriched my life immeasurably. To them I owe deep gratitude.

I want to express my thanks to my field instructor Chrys Barranti, PhD, who provided guidance and support in this field placement internship. It was through her support that I was able to complete my internship and my research in this setting. Her enthusiasm and expertise were priceless.

Finally, I wish to acknowledge and express sincere appreciation to my project advisor, Joyce Burris, PhD. Her dedication, patience, and direction made it possible for me to complete this undertaking. Her feedback and suggestions were essential factors that contributed much to the quality and success of this work.
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Chapter 1

THE PROBLEM

Introduction

The purpose of this study was to examine licensed nurses’ views of life prolonging measures in the context of their culture, experience, and training. This was accomplished by surveying licensed nurses who work in a large skilled nursing facility where most patients are approaching the end of life or actively dying. This research was conducted with the position that an understanding of nurses’ views and practices could contribute to enhancing the scope and range of available choices for patients and families while increasing the comfort level of nurses in honoring such decisions.

Background of Problem

With the technical advances in medical interventions since the turn of the 20th century, the range of choices has become more varied and more complex for medical professionals as well as for patients and families. In the skilled nursing setting, where most patients are elderly and chronically ill, patients and nurses will inevitably find themselves wrestling with these decisions. Dealing with death is challenging for all involved, and making decisions about prolonging life is, for most, an emotional and taxing process. Nurses are an essential component of the decision making process in hospitals and nursing homes. Their attitudes and feelings are experienced by patients and families throughout the process. Because patients and families are vulnerable and upset, they may be particularly sensitive to nurses’ comments and judgments. If nurses fail to assess their own attitudes and then fail to consciously respect and honor the values and decisions of their patients, the dying experience has the potential to be negatively affected.

Just as one’s life views come from life experience, spirituality, education, and culture, so
too, are one’s views of death and dying be similarly formed. Knowledge and understanding of
the effects of culture on nurses’ death perspectives can be the beginning of an education process
within the work setting that can increase sensitivity, awareness, compassion, honor and respect.

Statement of Research Problem

The research problem is that there is a lack of understanding of how nurses’ views of
death evolve, how this evolution is influenced by all aspects of culture, and how the affect of such
views shapes their stance on life prolonging measures.

Purpose of Study

The primary purpose of the study is to examine nurses’ views on life sustaining treatment
in the context of their cultural backgrounds. The study will produce a body of knowledge
outlining the values and influences of the nurses. As a secondary purpose, this study will form
the basis for an enhanced approach to staff development in the area of death and dying, cultural
knowledge, and honoring patients’ rights.

Personal Interest in the Problem

Having worked as a Social Worker in Hospice for eight years and in a nursing home for
three years, this researcher has personally witnessed the profound affect that nurses’ attitudes
have on the quality of a death experience for both the patient and the family. Patients and
families can feel torn, angry, frustrated, and misunderstood if their professional caregivers fail to
honor their unique desires and cultural needs. Conversely, the death process can be one of
validation, growth, and affirmation when infused with warmth, positive regard, respect, and
understanding. Working in the nursing home setting with nurses from a wide variety of ethnic
and cultural backgrounds, this researcher has witnessed situations in which patients and family
members have felt devalued and misunderstood because their wishes fell outside the realm of
acceptance of the professional nurses providing their care. It is hoped that participation in this
study will stimulate nurses to examine their own personal feelings toward death and dying, become aware of their attitudes, and embrace further training related to death and dying. This opens the door to improved quality of care for terminally ill patients.

Theoretical Framework

In addressing sensitive issues of culture and death, this study utilizes the ecosystems perspective, which is an eclectic approach focusing on how people fit together with their environments and how they then adapt, grow, and relate to each other. Ecosystem is defined as follows: “the complex of a community of organisms and its environment functioning as an ecological unit” (Merriam-Webster, 2008, p.394). In this perspective, people interact with each other, engaging in transactions with each other and their environment. It includes the person-in-environment system, in which people cannot be considered separately from their external circumstances; behavior results from adaptation to the environment and other people. Miley, O’Melia, and DuBois (1995) state that “we create our own tradition and legacy just as we respond to our cultural and ethnic heritage” (p. 36). The transactions between people and systems can be functional and positive, or they can be deficient and negative. This theory emphasizes that humans are flexible and can adapt more functional processes in response to needs (Miley, et al., 1995).

This perspective explains the development of cultural beliefs regarding death and dying. As people experience encounters with death, they adapt their behaviors and beliefs in an effort to cope with fear, sadness, and helplessness. Much of their resultant values stem from their connection with their own culture, as they learn from others the appropriate way to respond.

The value of ecosystems theory in the context of this research problem is the “fundamental principle. . . . . that states that a change in one part of the system creates a change in another part of the system, which in turn changes the functioning of the entire system”
(Miley, et al., 1995, p. 43). Thus we see that as professionals expand their knowledge and their openness to other viewpoints, change can occur, benefiting them, their patients and families, and the experience of the interdisciplinary team as well. Ecosystems theory provides a positive atmosphere for growth because it is based on the concept that change is possible, and has a ripple effect from the individual outward to the larger system.

The ecosystems framework, when applied to a hospital setting, encourages the following formula: 1) Relationship building with clients, which for this research includes nurses and patients and their families; 2) Assessment of the functioning of the internal and external factors that impact the client system; and 3) Designing and putting change into practice (Miley, O’Melia, & Dubois, 1995). Greene (1991) describes ecosystems perspective as one which draws from a broad knowledge base and includes a blend of ideas from many human behavior and social work practice theories, including ecology; anthropology; ego, Gestalt, and humanistic psychology; general systems theory; role and stress theories; and the dynamics of power relationships. Key concepts of the ecosystems framework are that the person and his environment cannot be separated, and that they influence and shape each other in a reciprocal relationship. In this mutual influence, through transactions (exchanges between the person and his environment), the person-environment unit is changed. Focus is on process, which examines the progression of change over time. Transactions may be adaptive or maladaptive, and are assessed as “goodness of fit:” the degree to which the person’s needs and the environment qualities agree. Maladaptive transactions generate life stress; goodness of fit is insufficient, causing the person strain and tension. The ecological perspective on development highlights the influence of the environmental system on the person’s way of relating to others, self-esteem, role performance, and adaptiveness, including coping skills. This perspective emphasizes the life model, which encourages strengthening the person’s coping abilities while improving the qualities of the
environment (Greene, 1991).

Through contemplating behavior, examining and analyzing origins of behavior, and presenting possibilities for understanding and respect, improvement becomes not only possible, but inevitable.

In exploring the formation of cultural beliefs and practices, this study also utilizes relational-cultural theory (Banks, 2005), which, like ecosystems theory, also involves mutuality and the impact that people have on each other. Individuals’ internal patterns contain prior relational experiences, which carry forward to new relationships. Thus, when two people interrelate, they bring to the encounter their previous associations, attachments, experiences, and images. As they connect with each other, the relationship benefits from awareness of, learning about, appreciating, and valuing diversity. Both parties then experience mutual empowerment, in which strength and courage are enhanced, relationships are deepened, and differences are respected.

**Research Questions**

This study attempts to explore two basic questions: 1) What effects does culture (including ethnicity/race, country of origin, spirituality/religion, educational level, place of training, and coursework in death and dying) have on nurses’ views of life prolonging measures? 2) What strategies might enhance cultural sensitivity and respect for patient and family decisions?

**Assumptions**

The underlying assumption in regards to this research is that nurses are unique in their views of death and dying, their comfort level in discussing and dealing with death, and that their personal and professional experiences affect their attitudes toward life prolonging interventions.

**Justification**

Hopefully, this research will be used to increase confidence of patients to make their own
health care decisions and raise expectations that their decisions to be honored. Social Workers have the responsibility to advocate for the patient, to work collaboratively with other disciplines, and to support self determination of our clients. As the population of the United States ages, the need for care, advocacy, and support for the elderly increases.

Delimitations

This study is exploratory and qualitative. The limitations for this study include its small sample size and the use of a convenience sampling procedure. The results of this study cannot be generalized due to its narrow scope.

Definitions of Terms

*Culture*: Culture, according to Lopez (2006, p. 93 – 94), refers to common elements or characteristics within one’s sociological grouping. . . . having distinct values, beliefs, behaviors, language, rituals, customs or traditions. . . . [It] can include such things as developmental stage of life, profession, educational level, geographic affiliation, gender, and socioeconomic status. . . . individuals can easily affiliate with several cultures.

Giger et al., (2006) state that over time, through imprinting the mind with intellectual, artistic, social, and religious influences, culture emerges as a patterned behavioral response. They add that it is influenced by shared group practices, beliefs, and norms, and these shape how people think and behave. These unique expressions of who people are become acceptable as they are lived out over time and are passed down to succeeding generations.

Life experience comes out of normative events in people's lives that includes a socialization process that guides people’s decisions in terms of who and how to mate, how and why to choose to have or not have children, parenting practices, educational pursuits, and views and practices of life and death. Ethnicity evolves from ancestry shared with others. Ethnic
traditions may be observed intellectually or experienced personally, with one’s societal group (Lopez, 2006). Harper, Lartigue, and Doka (2001) define culture as a way of life. It comes from a shared identity and includes clothes, foods, other tangibles, ideals, beliefs, values and attitudes, and influences a person’s assumptions about life and worldview. It includes ethnicity, religion, social class, physical limitations and lifestyle.

life prolonging measures: In practice and in law, these definitions are varied; most often the focus is on particular medical treatments instead of expanding quality of life or extending life. The result is that patients frequently receive unwanted interventions and treatments. Life sustaining treatments prolong life, enhance the quality of life, maintain or improve specific bodily functions, and support life for a temporary period of time; they can be dramatic and extraordinary, such as mechanical respirators and organ transplants, or less so, such as drugs, artificial nutrition, and IV hydration.

Many people take into account current and expected future quality of life as important when considering life prolonging measures. Others, however, wish to extend life regardless of quality. Possibly they define life sustaining treatments as those which prolong life, while the others define the same interventions as those which prolong dying.

Patient Self Determination Act: The legal basis for the advance directive (which was authorized under California’s 1976 Natural Death Act) was the right to refuse treatment derived from the American Hospital Association’s 1973 Patient’s Bill of Rights (Luptak, 2004). The first federal legislation which supported the right to refuse life-sustaining treatment was the Patient Self-Determination Act of 1990 (Luptak, 2004). Its primary intent was to decrease unwanted medical treatment, thereby reducing the costs of health care. This Act required any health care facilities that received Medicare and Medicaid reimbursement to inform and educate patients, staff, and the public about advance health care directives (Luptak, 2004; Sollins, 2007).
dying: When dying begins is difficult to determine. It is a concept that Bern-Klug (2004) terms “vague, confusing, and unclear” (p. 57). Some believe that dying begins when one is born; others believe it is when one acquires a fatal condition, when a physician recognizes that condition, or when the patient is informed of his terminal illness; others assert that dying begins when the facts of the situation are understood and believed by the patient; finally, some believe it is when nothing more can be done medically to cure the illness and assure life.

Because of this variety of definitions, communication and planning becomes even more complicated and fraught with emotion (Bern-Klug, 2004). Generally, physicians consider the degree of certainty of death and the time frame in which death is likely in deciding when to tell patients that they are dying. Many doctors believe that a terminal prognosis takes away hope, and will therefore hesitate to give a patient a terminal diagnosis. Especially in some illnesses, such as heart disease, chronic respiratory diseases, and end stage kidney disease, it is often unclear when further interventions are no longer beneficial. “Some people die with advanced multiple chronic conditions, but are never considered to be dying” (Bern-Klug, 2004, p. 58). Bern-Klug (2004) has termed this state “the ambiguous dying syndrome.” She asserts that professional health care providers, policy makers, and nonprofessionals mistakenly assume that most people will know that they are dying. The reluctance of the patient and family to accept terminality, along with the complexity of establishing when a person is dying contribute to this problem. Because most people now die of chronic conditions, professionals, patients, and families can deny terminality until death is at hand. Many then lose the opportunity for planning, searching for meaning, and finding closure, along with palliative and end-of-life support and care (Bern-Klug, 2004). Such patients are physically compromised and could die from an infection or a cold, or they could survive in this vulnerable condition for weeks, months, or years. Terminality is often uncertain until death is imminent. Lynn and Harrold (1999) assert that earlier generations may have had so
much experience with dying that most people knew how to recognize approaching death. They add that “[a] hundred years ago most adults died quickly from infections or accidents” (p. 8). Most people today expect to die suddenly from a heart attack, for instance, or to become progressively sicker until they die. However, with chronic diseases, episodes of being very ill are interspersed with periods of relative wellness. Death is a possibility during any of the acute periods, but repeated survival will make it difficult to know when the end of life will come.

Summary

Nurses may have preconceived attitudes about death and dying. As these attitudes affect their beliefs about end of life interventions, they also have a profound effect on the patients in their care. Cultural factors can produce very different views. When patients’ views and nurses’ views differ, the potential exists for conflict and negative outcomes.
Chapter 2
REVIEW OF THE LITERATURE

Introduction

Recent advances in medical technology have improved survival rates of those with life threatening illness and injuries. These same advances have greatly complicated and increased the types and numbers of decisions that patients and family members face. Licensed nurses often find themselves explaining treatment and medical intervention options and assisting patients and families in their decision making. Many nurses feel uncomfortable, inadequate, and afraid in addressing these issues. Nurses who feel uneasy talking about life and death decisions are working with patients and families who themselves are experiencing physical and emotional pain, and dealing with their own distress with the discussion. The nurses may be overwhelmed by their own emotions, and yet be required to support and comfort those with whom they are working.

We live in a society that tends to avoid thinking about and discussing death; rather we focus on maintaining youth and health. Generally death and dying are unmentionable subjects of conversation. Drugs, religion, sex, and politics, once taboo, are routinely talked about; but most people still feel uncomfortable discussing death. “Our most certain commonality as people --- that we will all die --- goes unexamined” (Kramp & Kramp , 1998, p. 20).

Keigher (2001) quotes George Soares from his speech “Reflections on Death” (January 1994) presented at the Alexander Ming Fisher Lecture Series, Columbia Presbyterian Medical Center, New York:

In America, the land of the perpetually young, growing older is an embarrassment, and dying is a failure. Death has replaced sex as the taboo of our times. . . . Only our preoccupation with violence breaks through this shroud of silence. Killing yes; dying, no (p. 131).
Death in Western Society throughout History

In ancient times, death was considered a process that could not be prevented or stopped. Instead the focus was on deriving meaning out of dying and engaging in the process as comfortably as possible in the presence of family and friends. In the Middle Ages, death was a public event, with the whole community gathered at the deathbed (Anderson, 2001). The fight against death began to emerge in the 16th and 17th centuries, with people usually dying at home being cared for by family members (Luptak, 2004). Attitudes toward death have continued to gradually change since the turn of the twentieth century. At that time, most people lived in rural settings, with extended family in the same house or nearby. Young and old people experienced birth and death as natural processes of life. Usually people died at home with family present. Family members then washed and prepared the deceased for burial. The body was displayed in the parlor, and family members often sat vigil with the body until the funeral. Children and adults attended the funeral and burial. This gave ample opportunity for all present to learn about death and to incorporate it into their experience as a normal, though painful, part of life. Luptak (2004) states that: “The 1800s birthed public health and the betterment of housing, food, and water supply, working conditions, and methods of medical care. As causes of disease were discovered, hospitals became viable institutions for the study and treatment of sick people, and the dying process became ‘medicalized’” (p. 8). Public health programs and treatment for infectious illnesses and parasitic diseases brought dramatic improvements in delaying death, especially for young people (Bern-Klug, 2004). As our society became more urban, families began to live in smaller nuclear units. Often they live far from extended family. Changes in lifestyle, causes of death, and medical interventions have birthed a trend in which most people rarely experience death firsthand for much of their lives. Most children grow to adulthood without having witnessed a death or a funeral. Because of the distance of extended families,
mourning may be distant and impersonal. With advances in medical care, most deaths now take place in hospitals and nursing homes, with professionals replacing family as caregivers (Anderson, 2001; Keigher, 2001; Luptak, 2004). The preparation of the deceased for burial is also done by professionals, and the viewing takes place at the funeral home or church rather than the family’s parlor.

Because people are living longer today than they did a few generations ago, they tend to be sicker, and the dying process is slow and progressive. As medical interventions increase, the strong desire to live and the fear of dying have grown into strongly debated and controversial moral, ethical, and legal issues. While some may embrace the end of life with minimal resistance, others look to the medical profession and life sustaining interventions to add years to their lives, choosing quantity over quality. For many people, death is fought to the farthest extent possible, at enormous physical, emotional, and financial cost.

How Americans View Death

There are deep divisions in how Americans view death and debility. Some see withholding or withdrawing life sustaining measures as an act of mercy. Others see it as an act of murder. Some think that patients have inherent human dignity, that they deserve the right to interventions; others believe that keeping patients alive indefinitely with little or no quality of life or awareness is itself an indignity. Still others think that what the patient would have wanted is what is most important; and others feel that withholding or removing treatment equates to abandonment (Cohen & Kass, 2006).

Ufema (2004) speaks of increased options as a result of improved medical technology. In the past, life expectancy was relatively short, and people lived their lives with the knowledge of relative powerlessness over end of life circumstances. However, modern Americans tend to see the dying process as an affront rather than a natural part of life; they do not see it as a concluding
chance for individual growth and development. As individuals expect to live for 80 or 90 years they may engage in “a demand to continue living at all costs” (Ufema, 2001, p. 66). Many people mistake quantity of life for quality of life, and tend to forget that most definitions of quality of life include good health. As life expectancies continue to rise, the fastest growing segment of the population is people over the age of 85.

Today, death usually takes place in a hospital, in a high tech environment, after many years of chronic illness and decline. This includes, in many cases, dementia, which relentlessly destroys the mind and body; patients lose awareness and self-control. Because they can no longer feed, bathe, or toilet themselves, they frequently live out their final years in an institution, requiring many years of extensive, costly, and exhausting care. Ufema (2001) questions the rationale of maintaining patients on ventilators and vasopressors, and advises medical professionals to acknowledge the wish of patients to live longer, but to discuss with honesty and compassion the drawbacks of continued treatment. She emphasizes that the manner of death is more important than the timing, and suggests that quality of life is important: families and patients can find dignity and strength not found in medical intervention as they talk, laugh, and cry together in the limited time left. Cohen & Kass (2006) refer to a “series of small dyings on the way to death” (p.34). They state that as advances in medicine result in cure of deadly illness, many people experience longer life, but paradoxically, also endure longer and greater debility and incapacity.

With the increase in life expectancy and physical debility comes an increased need for caregiving. As the need for caregivers rises, the availability of family caregivers is declining. Family size has decreased, families are more transient and less stable, and most women (traditionally, the caregivers) work outside the home. The burdens of long term caregiving is testing the strength of modern families. Members of the sandwich generation, those raising
children while assisting their elderly parents, may question why they sacrifice so much, for parents who live with ongoing loss of ability and wellbeing. And, they may come to believe that the death in this case is preferable to life filled with greatly diminished health and loss of dignity (Cohen & Kass, 2006).

Many people worry about the likelihood of living indefinitely on machines in a greatly weakened condition, or the indignity of being a permanent burden on loved ones, a living body without a life, a dependent resident of a nursing home. Bern-Klug (2004) asserts that it appears that the medical system ignores basic human needs and exposes the dying and their families to painful, undignified, and futile interventions, thereby increasing their anguish and suffering.

Traditional medical ethics stresses care and cure. But it “has also long taught that benefiting the life that a debilitated person still has does not mean taking every possible medical action to extend it” (Cohen & Kass, 2006, p. 38). Thus life sustaining treatment may and possibly should be withheld or withdrawn when the interventions themselves cause unnecessary suffering for the patient or get in the way of the comfort of one who is actively dying. This requires weighing the burdens of treatment and considering the hardship of living with a terrible illness. Patients and families must often choose from unpleasant and equally undesirable alternatives.

A century ago, Dr. William Osler could write: “Pneumonia may well be called the friend of the aged. Taken off by it in an acute, short, not often painful illness, the old man escapes these cold gradations of decay so distressing to himself and to his friends (Cohen & Kass, 2006, p. 38).

Therefore, allowing someone to die, rather than burdening them with life extension could be seen as compassionate and kind. Seeing death as part of the natural order promotes acceptance of death in its proper season, honoring it with respect and dignity.
Views of Death in other Cultures

Perceptions of death and dying are very diverse for different cultures and faith traditions. Hindus attain their death. While Jews traditionally view death as a conscious and purposeful act of giving oneself away, Christians believe that they should be conscious of approaching death, so that they can repent and be absolved of their sins. The Chinese mostly see death as natural, and value the right to choose death. They welcome an awareness of an imminent transition into the sphere beyond death, and adopt a decision to depart this life. In the Indian metaphysical philosophy, one should not fear death because it is natural and joyful. The Muslims’ beliefs vary widely due to differences in national, ethnic, tribal, and folk cultures, but generally death is seen as a transition into a new realm of existence (Darr, 2002).

There are also differences across cultures regarding control over dying. In many cultures it is not appropriate for humans to make the decision to end life or let someone die. Keeping loved ones alive at all costs is not only culturally appropriate, but a moral obligation as well. Thus what is seen and endorsed as advantageous for one group may not be appropriate and beneficial for another group that has a different value system, frame of reference, or life experience (Johnstone & Kanitsaki, 2009).

Truth Telling and Honesty

Truth telling can differ from culture to culture, especially if the illness is serious and/or life-threatening (Darr, 2002; Giger, Davidhizar, & Fordham, 2006). In some cultures maintaining hope comes from protecting the patient from full knowledge of their condition (Barclay, Blackhall, & Tulsky, 2007). Variations in the laws among different countries also affects truth telling. In Slovakia, doctors are prohibited by law from telling patients the truth about their illness, but Polish law upholds a patient’s right to health information. Italy and the United States value a patient’s right to know, moderated by compassion and sensitivity of the
doctor, in collaboration with family members. Saudi Arabia and Egypt, both predominately Muslim societies, stress kindness and compassion. While Islamic law emphasizes personal autonomy, to avoid emotional suffering for the patient, consent for treatment is usually given by the family. Strong cultural traditions prevail, and physicians are viewed as authority figures. A blending of respect for patient’s autonomy and beneficence in acting in the best interest of the patient is the norm in the Hindu culture. Families decide how much to disclose and rarely tell the truth to terminal patients in Japan; there doctors are the final authority who pursue the best outcome for the patient. Because the Chinese revere life as sacred, treatment to extend life is expected, and patients are not told if their illness is dire; it is discussed with their spouse or family, and by tradition, patients do not self-determine their lives. Jews see death as an atonement; therefore, the dying process should not be delayed or interfered with. Christians believe that all must die because of sin, and death should be peaceful and mournful. The common theme for all the major religions is the belief that life is a sacred gift (Darr, 2002).

Ease of Accepting Death

Elizabeth Kübler-Ross has long been considered one of the leading researchers and experts in death, dying, and grief. She was a pioneer researching the experiences and feelings of the dying. Elizabeth Kübler-Ross outlined four types of people who would likely countenance death with less difficulty than others: (1) rural populations who have daily contact with death, and view it as nature creating opportunity for new life; (2) the very young, who are innocent and who unquestioningly accept what happens to them; (3) those who are extremely impoverished and may frequently encounter death due to inadequate diet and the absence of health care; and finally, (4) the religious who view death as part of a divine plan or grand scheme; they may also believe in an afterlife, seeing this life as a journey to that which comes after, and which may be seen as more important than this life (Younozai, 1993).
Culture and Health Care

Increasing numbers of culturally diverse people are immigrating and becoming residents in Western society. Their various customs and traditions are often perceived as very different and strange within American culture (Anderson, 2001). Giger et al. (2006) recommend that health care providers need to be aware of increasing diversity in the population, and avoid making assumptions that impede individualized and culturally competent care.

All people have the right to maintain their ethnic traditions, languages, and religious identities. These cultural traditions encourage the expansion of individual choice and people’s right to live and be as they wish (Johnstone & Kanitsaki, 2009).

Providers trained in the Western biomedical model will encounter patients from diverse cultural backgrounds whose belief systems are very different from each other, presenting challenges in terms of languages or communication, understanding, and treatment. Planning for the increasing ethnic, racial and cultural diversity in the U.S. is essential to providing beneficial and effective care for the elderly (Yeo, 2009). By influencing people’s perceptions of illness, cultural beliefs affect how individuals utilize and interface with the health care system. This can be especially true in death and dying, because culture has enormous influence on the meaning and experience of the end-of-life (Giger et al., 2006; Johnson, Kuchibhatla, & Tulsky, 2008).

Myth of Cultural Diversity

Often professionals make the mistake of thinking that their patients share their values and preferences, especially if the professionals view the patients as having an identity resembling their own. Caregivers need to recognize that each patient-professional encounter is a cross-cultural experience, and that diversity exists even with those they see as similar to themselves. In seeing others as similar to themselves, they may fail to explore their values, preferences, and culturally unexpected choices. People from different cultures may have different beliefs and
understanding of life and death, together with what brings out their emotions, how appropriate those feelings are, and ways of coping with emotions that cannot be openly articulated. Even within American culture such differences occur. Professionals must overcome their assumptions and work to know and appreciate people on their own terms (Rosenblatt, 1993). Farber and Farber’s (2006) Respectful Death model sees the patient and family as the experts, honors cultural differences, and invites them into a protected place where they are heard and respected. Thus, it encourages collaboration, communication, and understanding.

**Spiritual Component**

Differences in religious beliefs can lead to different attitudes towards end-of-life-decisions. Disparities in religious tenets, variations in patient and family perspective, and different spiritual views of professionals can lead to different outcomes. Often professionals are more conservative in end-of-life issues when they openly acknowledge that their religious beliefs influence their decision making. Therefore, medical professionals need to be aware of variations in spiritual beliefs and must understand how to integrate this into communication about end-of-life decisions (Rurup, Onwuteaka-Philipsen, Pasman, Ribbe, & van der Wal, 2005).

Blank and Merrick (2005) point out that religious and spiritual issues are an exceptionally crucial element in death and dying policies and practices, and in some cultures they are the single most important factor. Van Ness, Towle, O’Leary, & Fried (2008) state that anthropological and sociological studies support this view; religious beliefs and behaviors influence people’s attitudes about lifestyle and medical decisions. Even more than in other areas of medicine, end-of-life issues underscore the importance of religion and spirituality as considerations that must be addressed and respected.

“In Christian Europe [in the Middle Ages], it was only at death that one was freed from the bonds of physical life and allowed access to eternal glory” (Anderson, 2001, p. 18).
In contemporary times, the Catholic Church’s views of life-sustaining treatments are well defined in an address given by Pope John Paul II to the Participants in the International Congress on “Life-sustaining Treatments and Vegetative state: Scientific Advances and Ethical Dilemmas” on March 20, 2001. His Holiness states that a patient in a vegetative condition may not appear to be aware of self or the environment, and may not interact with others or respond to stimuli. However, he points out that many have awakened after proper treatment and therapy, or at least partially recovered. Therefore, medical professionals cannot predict with accuracy whether a patient will recover or not.

He emphasizes that the fundamental worth and personal dignity of human beings are not changed by illness or disability, and that patients therefore retain the right to nutrition, hydration, hygiene, warmth, and, to the extent possible, the prevention of complications associated with being bedbound. These complications include muscle atrophy, contractures, and skin breakdown or pressure ulcers. He states that these patients deserve rehabilitative therapy and should be observed carefully for clinical indications of eventual recovery. He particularly stresses that artificial nutrition and hydration “always represents a natural means of preserving life, not a medical act,” and that such interventions should be viewed as “ordinary and proportionate, and as such as morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.” Regardless of fading prospects for healing, or amount of time spent in a vegetative state, according to the Pope, one cannot ethically justify stoppage of these treatments. Withdrawal of artificial nutrition and hydration can only result in death, and for that reason must be viewed as euthanasia. Therefore “it is necessary to promote the taking of positive actions as a stand against pressures to withdraw hydration and nutrition as a way to put an end to the lives of these patients.”
Perceptions of Death and Dying

Cultural beliefs and values in are likely to be stronger and more easily identified in other countries than they are in the United States (Darr, 2002); however, health care providers need to take these issues into consideration when providing services to clients of diverse cultural, ethnic, and religious backgrounds. Education and sensitization of staff is essential, especially in dealing with terminal illnesses.

Patient’s beliefs about death, dying, and illness may impact how they cope and what decisions they make about their care. “[M]uch of what must be done to prepare for death involves cognitively processing the impact of a terminal diagnosis” (Arnold, 2002, p. 454). Many may decide on palliative or comfort care, while others may opt for life extension or aggressive treatment. Such decisions will be culturally influenced.

Advance Directives

Patients frequently see advance health care directives as a method of obtaining desired care rather than avoiding unwanted treatment. This may be a response to managed care and insurance agendas of cost containment, which many believe can lead to withholding of desired care, especially comfort or palliative interventions (Tilden, Nelsen, Dunn, Donius, & Tolle, 2000). Health care professionals can further patient autonomy by initiating advance directives, educating patients on form completion, discussing future health care choices, and encouraging patients to execute the directive (Black & Emmet, 2006).

Advance care planning is a process that helps people determine their preferences for treatment, and becomes a communication process through which a person can instruct their legal proxy and/or their medical care providers (Pearlman, Cole, Patrick, Starks, & Cain, 1995). Research has shown that patients and family members are often hesitant to make decisions or are not aware that decisions need to be made unless they receive direction from their health care
provider; they are more likely to complete an advance directive when they are supported and guided by well-trained professionals. (Lacey, 2006; Pearlman et al.). Johnstone & Kanitsaki (2009) speak to the importance of cultural sensitivity in assisting with advance planning:

Emerging international research is increasingly suggesting that there are significant ethnic disparities in factors influencing end-of-life decision making and care. . . . [C]hoices around end-of-life decision making may be more related to ethnicity and culture than to age, education, socio-economic status or other variables. . . . Given the profound influence that culture has on how people perceive, experience, and practice health, and on how health care is planned, delivered, and evaluated, a critical examination of the ethical underpinnings of advance care planning and delivery in multicultural health care contexts is warranted (p. 406).

People who are bi- or multi-lingual or of minority culture are less likely than others to trust health care policies and practices, or to complete advance directives, seeing them as interfering with more appropriate family decision making; they are more likely to engage in family or group decision making and to pursue aggressive and life-sustaining treatment (Johnstone & Kanitsaki, 2009).

**Basic Decision Making Procedures**

The basic decision making procedures are (1) do-not-resuscitate orders, (2) protocols that indicate treatment goals (such as cure or quality of life), and (3) documents that spell out thorough and comprehensive treatment plans. Resuscitation or CPR (cardiopulmonary resuscitation) consists of chest compressions and emergency breathing to restore cardiac and respiratory function in a patient whose heart and/or breathing have stopped. Resuscitation may also include other interventions such as suctioning the airway, administration of oxygen, and administration of drugs to stimulate the heart (Cleveland Clinic). Terminally ill patients and their
families face extremely difficult medical choices.

Strong emotional reactions, such as anticipatory grief and depression; significant social factors, such as the burden the illness places upon the family; and an intense psychological and biological desire to live will greatly influence these decisions (Weiner & Roth, 2006,). When making end-of-life decisions, factors to consider include the kind of illness, expectation for recovery, burdens of treatment, family concerns, and personal goals, values, beliefs, and priorities (Rodriguez & Young, 2006). In order for patients to make meaningful decisions, they must fully understand the disease and its prognosis along with knowledge of their overall state of health; that is, whether they are frail, robust, or dying (Gillick, 2009). Prevention, cure, life extension, and achieving a comfortable death are all possible treatment goals. The decision making process needs to incorporate the beliefs and values of the patient, the expected course of the disease, and balancing risk and benefits of proposed medical treatments and interventions.

**Patient Autonomy**

As life expectancy continues to increase, quantity of life is stressed, but quality may be compromised by chronic debilitation, cardiovascular and cerebrovascular diseases, cancer and/or dementia. Most patients take multiple medications for those illnesses, which can further “impair cognitive, expressive, and motor abilities” (Smith, Kotthoff-Burrell, & Post, 2002, p. 83). Older adults, then experience loss of independence and may have diminished ability in terms of communication. These losses make it more difficult to ensure that their wishes are respected.

While respect for autonomy is highly valued in the United States (Giger et al., 2006), for other cultures it may be less important than the needs of the group, and therefore group decision making may be the norm. Smith (2008), et al. note that

> even in Western culture, it would be an impoverished notion of autonomy that focused only on rights, even the right to make decisions. A richer conception
is that autonomy represents the freedom to express one’s true self through defining behaviors, the idea that an individual’s values, beliefs, and/or preferences are authentically reflected in considered and voluntary actions. . . . .what one chooses to do affirms what one is (p. 98).

It is important to remember that, while autonomy is highly regarded in mainstream American culture, others may not value it (Gizer, Davidhizar, & Fordham, 2006). Some ethnic groups ---Italian, Chinese, Greek, Ethiopian --- consider autonomy to be burdensome to patients who may be too sick and too poorly informed to make meaningful decisions. And many groups - -- Bosnian, East Asian, Korean Americans, Japanese, Middle Eastern Lebanese, Mexican Americans, African Americans, Greek Australians --- attach great importance to decision making by group consensus and family rather than individual choice. Health providers must expand their definition of autonomy to include respect for individuals and respect for personal choices; this includes honoring the cultural values with which people enter the decision making process, together with respecting each person’s linguistic, ethnic, and spiritual/religious uniqueness. Care should be exercised to communicate end-of-life health information in a way that is culturally appropriate and meaningful to the patient; failure to do so can result in misunderstanding and misinterpretations that could have serious consequences (Johnstone & Kanitsaki, 2009; Johnson et al., 2008; Giger et al., 2006; Barclay et al., 2007; Yeo, 2009).

**Nursing Home Setting**

While end-of-life decision making is always difficult and filled with emotion, it frequently becomes more complex in the nursing home or skilled nursing setting. More often than not, the patient is unable to articulate his or her wishes or participate in the decision process. The nursing home Interdisciplinary Team will play a major role in assisting the family with decision making. The process is complicated by different professional disciplines’ various views
on patient autonomy and by the close relationship many of the team members have likely
developed with the patient, resulting in potential stress and distress to staff. Focusing on patient
and family preferences (via real time conversations or written advance directives) can smooth the
process. Ethical issues can be resolved through collaboration with the family and ethics
committee (Chichin & Meezy, 2002).

Over half of those residing in assisted living and nursing homes suffer from dementia.
Because of the need for ongoing and high levels of care, most people who have dementia live
their final days in long-term confinement. Thus a large part of long-term care is providing end-
of-life care. Most decision making for those patients is done by proxy due to ongoing cognitive
deterioration (Sloane, Zimmerman, Williams, & Hanson, 2008).

A growing body of research is finding that medical interventions for end-stage dementia
frequently fail to sustain and maintain quantity and quality of life. Most families see artificial
nutrition as a demonstration of love and concern for their dying relative (Gillick, 2009). Many
think that inserting feeding tubes in patients who have swallowing deficits prevents aspiration
pneumonia and starvation. However, studies indicate that there are higher, not lower, rates of
aspiration pneumonia in patients with feeding tubes, and those patients with feeding tubes have
similar survival rates to those without.

The use of IV hydration to prevent dehydration, once thought to promote comfort, is now
known to prolong dying and increase edema (swelling). Withholding IV hydration may be
considered a comfort measure because it allows the patient to slip into a coma (Lacey, 2006) and
triggers the body to produce endorphins (comfort inducing, pain relieving hormones).

Antibiotic treatment for infections in end-stage illnesses increases the likelihood of repeat
infections, and the effectiveness of the antibiotics over time (Lacey, 2006). Most hospices
promote the use of antibiotics for comfort only; this means not treating pneumonia, but opting
to treat a painful condition such as a urinary tract infection.

CPR is an intervention that is physically traumatic, often resulting in bruising, fractured ribs, and punctured lungs. While reasonably effective in younger, otherwise healthy people, it is almost 100 percent ineffective in people who are frail or severely ill (Lacey, 2006).

These life sustaining interventions, long thought to be beneficial, have been shown in studies to instead be detrimental. They do not improve quantity or quality of life in most cases, and may increase and prolong suffering (Lacey, 2006).

**Impact of Life Saving Interventions**

In mainstream American culture, personal autonomy is highly valued. Independence and self-sufficiency are extremely important to most people. The slow decline of physical and mental ability, the protracted and distressing dependence is perhaps the most demeaning experience many can imagine. Nearly all people are tremendously worried about becoming incompetent or being a burden on others. Many patients whose lives are saved in emergency rooms or intensive care units of acute care hospitals never regain former functioning. They may not even regain consciousness, and will likely be dependent on long term care facilities or their families for the remainder of their lives (Guillemin, 1992; Kwok, Twinn & Yan, 2006).

**Conflicting Interests and Dilemmas**

As the number of people involved in a decision making process increases, that process is made more complicated and difficult. Often the numbers increase to include not only the patient and health care provider, but also multiple family members and members of the Interdisciplinary Team.

Not infrequently, family members may try to override the designated proxy. It is important for professionals to remember that family members have every right to take part in decision making, but final authority rests with the legal decision maker. Professionals will need
to clarify surrogate decision making and implement the decisions made by the legal proxy (McCullough, Wilson, Rhymes, & Teasdale, 2002).

Health care professionals may have become accustomed to honoring advance directives and may have a greater comfort level than family members with withholding or withdrawing life sustaining measures. Problems arise when such treatment seems to be inappropriate or useless, but the family is not ready or willing to give up. Families may not always act in the best interests of the patient, because they may be more concerned with their own needs and wishes. Many nurses report that life sustaining treatments are overused for patients with a poor prognosis. Professionals have an ethical obligation in this situation to establish the atmosphere of trust and utilize the skills needed for collaborative communication to work through these disagreements. Treatment in these situations is seldom totally futile, but may produce burdens or risks that outweigh benefits to the patient. Through well-timed, candid and supportive dialogue, most family members can gain understanding of the risks versus benefits perspective. Gentle reminders to family members to base decisions on their understanding of what the patient would want rather than their own personal wishes can reduce the pain associated with responsibility for difficult decisions (Pierce, 2006; Silén, Svantesson & Ahlström, 2008).

However, in some situations, futile interventions carry little or no perceived harm to the patient; in these cases, cultural competence requires honoring patient and family requests for that symbolic care. Traditional Western medicine frequently conflicts with other cultural norms and beliefs. Therefore, emphasis on autonomy will need to be moderated utilizing cultural sensitivity and respect (Gillick, 2009) in order to ensure patients’ and families’ rights to self-determination and independent decision-making.

Respectful Death versus Good Death

Farber and Farber (2006) assert that medical professionals tend to disregard personal
wisdom and individual experience of the patient. When professionals blindly rely on their expert training, suffer from a lack of self-awareness, or have a particular bias, the result can be professional mindlessness. They will likely be insensitive to the patient’s goals and wishes. Since the term good death implies a value judgment, Farber and Farber (2006) developed their Respectful Death model, which redefines good death by integrating the lived experience of the patient and family. Respect implies an opportunity to merge values, cultural differences, and professional expertise, creating a shared story, working toward common goals, and honoring the values of all participants.

A respectful death includes the commitment of an assurance that the professional caregiver will provide services for the patient through the death and beyond. It also involves connection, which comes from fostering a unique relationship of unconditional acceptance and respect (Farber & Farber, 2006) in which any topic (medical or other) can be discussed in response to patient and family desires. Bern-Klug (2004) asserts that if the physician is undecided or uncomfortable with giving a grave prognosis or diagnosis, respecting the patient requires asking what the patient wishes to know and inviting discussion. Patients have the right to engage in their preferred coping mechanisms, and that includes the option of denial. Finally, respectful death embraces the consciousness of taking the personal history of the patient together with the personal and professional significance of the caregiver’s experience, while respecting the shifting context and experience of the disease.

When patient and family goals are intertwined with professional expertise, the end-of-life process can be meaningful and memorable, the patient can have the best possible quality of life as they define it, and the result is not a good death, but a respectful one.

The Respectful Death model is built on several assumptions and beliefs. These include the belief that professionals, although experts, do not have all the answers. It honors the concept
that every patient and family meeting is cross-cultural, because patients and families are the
experts regarding their own needs and expectations. Also included is the idea that when there is
uncertainty of outcome and loss of control, innovative and shared problem solving can emerge
and flourish. As professionals encourage patients and families to talk about concerns and hopes,
the result is a fuller and more meaningful life in harmony with their values and goals (Farber &
Farber, 2006).

*The Patient as a Whole Person*

Treating the patient as a whole person, not just a collection of symptoms and diagnoses,
is key to an effective partnership between patient and professional. Empathic listening and
hearing their stories will help us understand their values, how they make decisions, and their
objectives for their health care.

The best way to ensure the appropriate medical treatment in conformity with patient
wishes is to establish clear goals about the plan of care. This can be facilitated through the use of
open-ended questions. Smith and O’Neill (2008) suggest the following examples:

“What makes life worth living for you?

What are your most important hopes?

What are your biggest fears?

What would you consider to be a fate worse than death?” (p. 462).

Ufema (2001) suggests honest and direct communication and avoiding euphemisms. She
counsels caregivers to pay close attention to what the patient says, and to refrain from attempts to
sway him or her to one’s own viewpoint or belief. Bern-Klug (2004) emphasizes the social work
strengths perspective, assuming that people make effective and appropriate choices when given
complete information. Active listening on the part of professionals, enables patients and families
to deal with feelings and consider treatment choices and interventions in a supportive setting.
Young and Rodriguez (2006) stress using appropriate language, being sensitive to culture and education, articulating realistic aspirations, and communicating the diagnosis honestly even with all its ambiguity.

**Communication**

The quality of professionals’ communication can facilitate or impede the understanding that patients and families have regarding how serious an illness is, how ready they are for death, and what interventions might be acceptable (Colclough & Young, 2007). A number of techniques can help improve the communication process, such as preparing oneself for the encounter, creating a supportive environment, using appropriate nonverbal behaviors, and expressing empathy.

Open ended questions, emphasis on the psychological and emotional aspects of the health challenge, and summarizing and clarifying areas of inadequate comprehension can help draw out patient fears and questions (Barclay, et al., 2007). Speaking to personal values in a sensitive way through an individualized approach highlights what patients view as meaningful and honors cultural factors (Black & Emmet, 2006).

Several factors have been found to be related to the communication methods of nurses. Older, more mature nurses with more years of experience, tend to disclose information and interact with families more readily than less seasoned nurses. Those who have personal experience with executing an advance directive or serving as a proxy decision maker, tend to be more inclined to initiate discussions about advance directives. More experienced nurses are likely to assign priority to advance planning, experience greater comfort levels in initiating the discussion, and working with patients and families. Effective communication by nurses is highly beneficial to patients and providers as they engage in the challenging process of advance care planning (Black & Emmet, 2006).
Meeker and Jewski (2008) reported that family decision makers rely heavily on information from medical providers when deciding on interventions. Often they are distressed by receiving conflicting information from different professionals. In addition to spoken information from clinicians, family members may search for additional information about their loved one’s condition by scrutinizing and interpreting the caregivers’ behaviors. When information provided by doctors and nurses is confirmed by family members’ own observations of the patient and by professionals’ behaviors, decision makers are able to proceed with increased confidence.

**Ethical Issues**

Issues for professionals to be aware of as they assist patients and families include respect for patient autonomy, and have been operationalized by the following:

1. advance directives;
2. maintaining awareness of medical authoritarianism;
3. moral reasoning of staff, which might be influence by loyalty to hospital or physician versus respect for patients’ wishes;
4. truthfulness with patients and families;
5. necessity to treat the patient’s proxy in the same way that the patient would be treated in areas of truth in diagnosis, prognosis, and informed consent for treatment. Another consideration is justice; should scarce resources, such as blood transfusions, be utilized for someone whose condition is terminal, or would this be considered “misuse of health care resources that could better be used by individuals to whom they would benefit (Chichin & Mezely, 2002, p. 75)?” Professionals should also be cognizant that all team members are influenced by their own personal and professional values. These include scientific, ethnic, religious and ethical values. Interventions that are viewed as kind and charitable in one country or culture may be seen as harmful or evil in another. Medical professionals need to value and respect patient autonomy by acknowledging and honoring those beliefs (Chichin & Mezely, 2002).

When a discussion about goals of care goes poorly, then the decision-making process is
impaired, and patient suffering increases (Weiner & Roth, 2006). Physicians often do not do a good job of explaining particular medical conditions, potential care or the patient’s underlying state of health (Gillick, 2009). However, when medical information is shared appropriately, family members better understand treatment options (Colclough & Young, 2007). By tradition, physicians tend to be paternalistic. Furthermore, they are trained to cure disease and preserve life. Therefore, doctors may be reluctant to withhold or withdraw life sustaining treatment, and may see the death of the patient as a personal failure. Many nurses, too, are not comfortable in permitting a patient to die without some effort to extend life; this has been termed “maternalism,” a wish to protect and care for their patient. Social Workers, on the other hand, value self-determination, and because their connection with the patient may be less intense and personal, they may be more accepting of patients’ decision to limit treatments and procedures, and less sympathetic of doctors’ and nurses’ feelings.

Clearly the perception of team members can be diverse. Some may be supportive of withdrawing life support and others may embrace extending life to the fullest extent possible. They may believe that withholding or withdrawing life sustaining measures equates to denying necessary treatment, or they may see it as eliminating burdensome interventions and relieving suffering (Chichin & Mezey, 2002).

Practitioners must display appreciation and respect for cultural diversity. With professional support and supervision, they can process their reactions to the situations and people they face. Utilizing respect and understanding toward ethnicity and culture facilitates empathy and honors patients and families (Lopez, 2006).

**Difficulties Faced by Professionals**

Some caregiving professionals may be uncomfortable with discussing end-of-life issues with patients and families. These
conversations are delicate in nature and may elicit anxiety. . . . avoidance and denial. . . . Discussions related to death and dying, and culture and ethnicity, often fall into this delicate basket of uncomfortable professional conversation. In some ways, these topics are similar in that they have an impact on every human being and thus, cannot be completely avoided as they cut to the core of our personal self. Issues surrounding death and dying can create feelings of discomfort and may contribute to an experience of disquiet for the helping professional who is in denial about, or who does not wish to, face his or her own mortality. Becoming aware of one’s cultural and ethnic values and beliefs can also create concerns, often raising issues of how one fits with self, others, and in the world (Lopez, 2006, p. 91).

Rosenblatt (1993) posits that human service providers and social scientists operating from mainstream American culture have perhaps been unintentionally ethnocentric, making it difficult to comprehend, respect, and cope with the realities of people from other cultures. American theory, research, practice, and culture are often accepted as universal truth. Clarification of one’s own beliefs and values is essential to the process of respecting the beliefs and values of others. Workers need to look closely at their own personal cultural beliefs and values about death, and evaluate their experiences with grief and loss. A deep examination of how and to what degree culture and ethnicity affect their perceptions of life, death, terminal care, family input, decision making and medical authority is imperative, together with an analysis of how they view patient autonomy and group or family decision making (Lopez, 2006).

*Individual Values*

Total objectivity by helping professionals is impossible. All caregivers come to the therapeutic relationship with their own histories, life experiences, biases and beliefs, desires and fears; the patients’ feelings and behaviors are then viewed through that subjectivity.
Professionals must remain aware of their biases and issues, while at the same time accepting their humanness and imperfection. The ability to empathize with clients enables caregivers to better understand, support, and help. However, recognizing, scrutinizing, and understanding their emotional response is also necessary for caregivers to control and regulate countertransference issues. Lopez (2006), defines countertransference as:

A defense mechanism experienced by the helping professional when working with a particular patient or family. In response to the patient’s ethnicity or culture, the professional may be reminded of a previous experience and transfer his or her reactions into the current relationship. . . . . the impact on the helping process can be significant and can create barriers in the therapeutic relationship and, thus, in the ability of the professional to be truly helpful (p. 98).

Thus caregivers can experience countertransference when working with terminal patients. Losses experienced by patients and families can mirror caregivers’ personal losses. These losses, especially if recent or unresolved, may bring up anger and pain, and may impact boundaries or professionalism. Witnessing sorrow in others may induce anticipation of future grief and may force acknowledgement and confrontation with their own mortality. Therefore, workers must be aware of their own internal triggers and their emotional reactions to the experiences of others. “The object is not to eliminate countertransference, but to follow and understand it --- so that [professionals] can more deeply know [their] patients, without acting out [their] own issues” (Katz, 2006, p. 279).

 Increasing Cultural Sensitivity

Caregivers can increase their cultural sensitivity by following three steps outlined by Harper, et al. (2001). First, they must be self-aware; they must know themselves. In examining their own roots, they will begin to understand how culture has influenced their values and beliefs,
and how these have evolved over a lifetime. They will see the weaving of ethnicity, culture, class, gender, and religion in their family groups. Second, caregivers must approach culture with an openness and willingness to learn, and with respect for the culture of their clients (Giger et al., 2006). This includes not just studying about them, but being taught by them. Harper et. al. (2001) speak of utilizing “enlightened ignorance. This means not assuming knowledge but asking questions: ‘I don’t know much about your culture; what can you tell me that will help me understand what I need to know’” (p. 149)? Third, with practice caregivers make their interventions more effective and their clients more comfortable, and at the same time the professionals learn and grow, too. Through this culturally sensitive practice, they are able to accomplish their work of assisting families and patients through a difficult time.

Role of Social Workers

Arnold (2002) cautions that social workers must be aware of the influence of culture when discussing problems or concerns, as culture will influence the client’s definition of what constitutes a problem, openness to discussing the problem with the social worker, and the acceptance of specific types of interventions.

Building on the person-in-environment perspective, strengths based approaches, cultural sensitivity, and skills in psychosocial care, Social Workers are in a unique position to influence the experience of terminally patients in all settings. Implementing environmental or cultural change interventions, utilizing group process to increase resident and staff communication and Empowerment, and working collaboratively with the Interdisciplinary Team, they can improve care and quality of life for their patients (Vourlekis, Zlotnik, Simons, & Toni, 2005).

Social Workers can facilitate respectful treatment of the dying. By promoting dignity and control, adequate and decision making, and relief of suffering they can influence the experience of the terminally ill. Through direct practice and concern they set the example for other
professionals, and raise awareness of the need for skills in gerontological services. They can also work through interdisciplinary team activities to in-service other team members in cultural knowledge and sensitivity.

Social Workers can play a crucial role in policy development, staff education, and by leading discussions on ethics committees to make certain that patients’ wishes are honored. Utilizing social work skills in approaching the emotionally laden subject of dying, they can support elders in exploring end-of-life concerns with comfort and competence. They can educate other professionals in the issues involved in advance care planning, for example: decision making styles; patient desires such as where he or she prefers to die, persons she or he would like to see before dying, and distribution of belongings; patient’s understanding of their disease, previous encounters with death or loss; family and care provider communication patterns; spirituality; and legal advance directives (Luptak, 2004).

Role of Nurses

In health care decision making, the nurses’ role is vital. Often the nurse is the first to note a change of condition, indicating that important decisions need to be made (Sollins, 2007). Nurses need to determine if there is an identified decision maker, keeping in mind that the patient is the decision maker until they have legally turned the decision making over to a proxy, or until they are incompetent or unable to articulate their wishes. Nurses should be alert to whether medical interventions have been done that is in conflict with the patient’s stated desires, as may happen when a patient has been treated in an emergency room or acute care setting. Decisions made by proxy should be evaluated to assure that they are consistent with the patient’s wishes. Nurses should be aware of whether or not the physician has given a terminal diagnosis. And nurses should be alert to unclear or complicated issues and the possible need for review by the interdisciplinary team or an ethics committee. Sollins (2007) recommends that nurses can
function as resident advocates by recognizing when competent residents might need a social services visit to consider and discuss advance directive. In addition, nurses can notify the interdisciplinary team when a treatment initiated by another provider needs to be reviewed or when actions of proxies or family members need review to ensure they are in harmony with the patient’s wishes.

The nurses’ role also includes patient and family education, assisting in communication between medical professionals and the patient and family, and assuring that the patient receives the best comfort care and does not feel abandoned when the treatment goal changes from cure to palliation (Tilden et al., 2000; Kwok et al., 2006).

Irish (1993) quotes licensed nurses who speak of the misunderstandings that can stifle communication when there is a lack of cultural sensitivity. This can result in the a perception of the caregiver as an outsider rather that someone who can be trusted and in whom the patient can confide. The nurses acknowledge that increased knowledge of another’s culture leads to better care and service for patients and families. Finally, Irish quotes Eunice Peterson Johnson, RN: “Many of our employees --- about 30 percent of our nursing assistants --- are minorities, from Southeast Asian and Africa primarily. I was never aware of the extent of the cultural differences they were encountering here to work...sometimes with a dying patient. How hard this must be for them, especially when we don’t address some of these beliefs and practices more fully” (p. 172).

Johnstone & Kanitsaki (2009) state the responsibility held by nurses of undertaking the vital responsibility to ensure the successful planning, delivery, and evaluation of end-of-life care provided to patients of diverse cultural and language backgrounds. Cross cultural care research, theories, and knowledge must be used to develop and inform policies and practices. An evidence-based approach has the potential to improve end-of-life care for all patients and
families, not just those of ethnic minority affiliations.

Summary

End-of-life care requires sensitivity and compassion. Patients and families experience apprehension and grief; as they struggle with the responsibility for crucial decision making, they require respect for their autonomy and dignity. Professional health care providers bear a heavy burden of medical and ethical decisions. Problems with selecting a health care proxy, family conflicts, cultural values, and lack of knowledge of medical issues can interfere with appropriate care and treatment (Carmel, Werner, & Ziedenberg, 2007).

The collaboration of nurses with other disciplines in the health care setting is essential for policy and systems improvement related to patient preferences. Nurses’ rapport with patients and families, especially in the nursing home setting, increases their knowledge and understanding of patient’s desires and wishes. Advocating for their patients and enhancing communication between professionals and decision makers, they facilitate regard for culture, autonomy, and ensure that patient’s wishes are respectfully honored (Nelson, Dunn, Donius, and Tolle, 2000).
Chapter 3
METHODS

Introduction

This chapter will describe the research design and methods used for this study. Included in this discussion will be descriptions of the population being studied and sample design. Also included will be a description of the data, survey instrument, and plan for analysis of the results. This chapter concludes with a discussion of human subject protections and a summary.

Research Questions

Two questions were investigated by this study. 1) What are the effects of culture (including ethnicity/race, country of origin, spirituality/religion, educational level, place of training, and coursework in death and dying) on nurses’ views of life prolonging measures? 2) What strategies might enhance cultural sensitivity and respect for patient and family decisions?

Design

This study is a qualitative, exploratory, descriptive research design. This design enables the researcher to gain understanding of human behavior from the perception and point of view of the research participants. This design will enable the researcher to describe the variety of ways that participants see and process the death and dying experience (Yegidis & Weinbach, 2009).

Participants

The study population for this research consisted of licensed nurses (registered nurses and licensed vocational nurses) who are employed at a large skilled nursing facility in south Sacramento. The population was selected based on convenience; participants were approached in person by the researcher and invited to participate.

The target population for this study consisted of 15 individuals of diverse cultural and ethnic origins. Efforts were made by the researcher to include nurses from all four nursing units...
at the facility, as well as employees from multiple shifts.

Instrumentation

A survey instrument was developed by the researcher; the instrument consisted of an interview questionnaire and a short demographic survey. The questions for the interview (see Appendix E) were developed out of the interest of the interviewer and the researcher’s experience in working with terminally ill individuals. It was based loosely on the Preferred Intensity of Care form (see Appendix F), which is a standard form used in the skilled nursing facility to document patients’ decisions for treatments and interventions. The questions had to do with each participant’s views on life prolonging measures, the reasons for those views, and the influence of culture on formation of those views.

Data Gathering Procedures

Prospective participants were approached in person by the researcher, and invited to participate. Upon meeting with the participants, participants were given the informed consent form (see Appendix D) and asked to read and sign it. Participants were asked if they had any questions or concerns. If not, the digital recorder was turned on and the researcher asked each of the 20 interview questions followed by the 9 demographic questions. Notes regarding content of the interview were taken by the researcher during the interview process. Following each interview, the recordings were transcribed by the researcher. The notes and transcriptions were numbered.

Protection of Human Subjects

A human subjects application was submitted to the California State University, Sacramento, Committee for the Protection of Human Subjects from the Division of Social Work. This application was approved with a “minimal” risk category prior to the beginning of data collection; it was given an approval number of 09-10-080 (see Appendix A). Included in this
application was the informed consent form (see Appendix D), which includes information for participants about possible risk from participation and a referral source for counseling should participants experience emotional distress as a result of participating in the research.

After each interview, all written and transcribed data forms were numbered with no other identifiers. Digital recordings were erased. The transcriptions, informed consent signature pages, demographic information, and written notes were stored in a secure location in the researcher’s home. All content analysis was done without use of names or other identifying information. The only persons who had contact with the data were the researcher and the researcher’s thesis advisor. Upon completion and approval of the project all data are destroyed by shredding.

Data Analysis

A content analysis was conducted on the transcriptions of the interviews and notes taken by the researcher. In this analysis, the researcher was looking for common themes and trends among the responses.

Summary

This chapter contains description of methods employed in this research. This includes a description of the research design and the instrumentation used to gather data. Additionally, sections on research population, sampling method, data analysis, and human subjects protection information were included.
Chapter 4
FINDINGS

Introduction

Interviews were conducted with 15 licensed nurses at a skilled nursing facility in Sacramento. These 15 participants are full time employees each with several years of experience in working with patients at the end of life. The purpose of the study was to investigate the following research questions: 1) What are licensed nurses’ views regarding the use of life sustaining medical interventions at end of life? 2) What effect, if any, does culture have on those views? The purpose for exploring these questions was to develop an understanding of how nurses’ cultural backgrounds might influence their views, and whether differing views might influence patient and family decision making. 3) An additional objective for the study was to gather background information for in-service training.

The participants were asked 4 questions regarding life sustaining treatment, 3 questions regarding spirituality, and 2 questions regarding culture and ethnicity. In addition, the participants were asked 11 true/false questions regarding end of life symptoms and treatment (see Appendix E). Finally, demographic information was gathered for each participant.

For reporting purposes, study participants were given fictitious names to protect their confidentiality. The participants drew from their work experience as nurses caring for elderly, terminally ill patients, together with their cultural and religious backgrounds and personal beliefs in responding to the interview questions. This chapter will focus on the variety of responses from participants and will include quotes from interviews that refine and elaborate responses.

Findings

The participants were asked to answer the survey questions as if they were advising the family of an 80 year old or older patient with advanced dementia. All 15 participants initially
responded that they would determine patient/family wishes by checking for an advance directive, checking for a Preferred Intensity of Care (PIC) form (see Appendix F), or directly conferring with the family. In order to elicit their personal beliefs, the interviewer then asked them to answer the question based on what they personally thought was best for the patient. Most then chose to relate the questions to themselves or to their own family members. All but one participant was able, then, to give more definitive opinions; one, however, responded that she would need to consult with family (even if making decisions for her own parents or grandparents), as group/family decision making is the norm in her culture.

*use of feeding tubes.* The majority of participants, ten, felt that insertion of a feeding tube at end of life is not advisable. Of these ten, most thought that the patient’s poor prognosis and lack of quality of life were primary factors in their decisions to refrain from insertion of a feeding tube. Most cited lack of quality of life as the reason life should not be prolonged, and felt that comfort care is a better option. Hannah spoke of the cycle of life: “God made us human. We are born and we go.” In addition to poor quality of life, Amy stated that in her experience, patients in this situation who receive feeding tubes deteriorate rather than getting better: “Based on my experience, when patients are confused, on PEG tube feedings, it’s all down hill; bed sores are next.” Frances felt that it should always be a family decision.

Two participants felt that tube feeding should be initiated, but with conditions. Annie suggested tube feeding to give the family time to adjust, and to see if the patient continues to decline; however, she emphasizes that artificial feeding should only be used for a limited time period. Susie suggests that tube feeding be used for a year, and artificial nutrition be discontinued at the end of a year if there is no improvement in the patient’s condition.

Four participants felt that artificial nutrition should definitely be utilized for end of life patients. Melissa, Carol, and Frances stated that in their Asian cultures, this would always be the
correct choice. Carol stated that tube feeding would give the patient more years to live; she continued that if it was her family member, she would like to see them “just lying there with the feeding; it’s better that just letting them go.”

artificial hydration. Eleven participants approved of IV hydration for end of life patients; most deemed it necessary to prevent or eliminate dehydration. For those participants, dehydration had negative effects such as thirst and suffering. Carol stated that failure to provide IV hydration would end the patient’s life, as did Annie, who stated, “I can’t let my patient die of dehydration.” Maggie felt that “IV hydration will help the patient function. It will not deplete the functions of the system;” but she did feel that the “length of time [for IV hydration intervention] will depend on how sick the patient is.” Melissa alleged that “IV hydration is a good thing. It will give the patient longer life.” Three participants chose to utilize IV hydration, but for a limited period of time. Leslie replied that “IV hydration would be a help. Because, I think it’s kind of harsh, thinking of not giving anything to the patient if they can’t drink. It won’t hurt to give them that, unless the organs are failing. It’s not helping if we are just making him bloated or swollen. Kidney failure, organ failure: that’s the time to stop.”

Four participants said that they did not approve of IV hydration for end of life patients. They felt that comfort care was appropriate, and that IV hydration increased discomfort. Janice said, “No more IVs; no more PEG tubes. These things are painful for patients.” Rachel stated her opposition to IVs in more personal terms: “If I can’t take my water, or I can’t eat, don’t sustain me. I don’t have concerns about dehydration because the body is gonna do what it’s gonna do, and then God is gonna let you know you’re gonna go. If I can’t have my food or water, then I’ll just go.” Darlene was concerned about potential complications with IV hydration: “You can put them into fluid overload; you can make them worse than they already are. The body for centuries has died in cases like this in the natural way that’s comfortable, with no fluids and no
food; and the body can just do its natural course without assistance. And sometimes the things
that we do to assist in the dying process, assist to prolong the lack of quality of life, actually harm
the patient and provide more discomfort. [Stopping taking fluids and nourishment by mouth] is
the body’s natural way of doing things, so if that’s the course, that’s the course.” Helen’s views
were similar: “I think the body has its own natural way of handling dehydration, and messing
with the endorphins and that type of thing [by introducing IV hydration], that are meant to be the
dying process, just result in pain, discomfort, and agitation. It upsets the normal balance.”

*cardiopulmonary resuscitation.* Twelve participants expressed opposition to the use of
CPR in elderly patients. Several cited brittle bones leading to the danger of fractured ribs; some
mentioned poor prognosis and the undesirability of prolonging suffering; others referred to the
poor quality of life the person would return to: “the quality of life for an 80 year old is not as
good compared to a 50 year old who can enjoy life more. I think the 80 year old will appreciate it
more to just let go, than be given all these tubes and equipment that might just prolong his life
(Susie);” and others mentioned allowing nature to take its course due to the patient’s advanced
age and having lived a long, full life. Helen pointed out that CPR should not be done “just
because of the fact that it’s not going to work.” She went on to note that the patient likely would
have co-morbidities and would “be on a ventilator, and then the family would be stuck making a
worse decision, trying to pull their family member who’s alive technically, off machines to watch
them die. So I think that would be cruel for us to do that to them.” Darlene related this issue
specifically to her spiritual beliefs, stating, “My opinion is not to [perform CPR]. If I know
they’re saved, it’s no choice; if I know they’re going to heaven, and they know they’re going to
heaven, I wouldn’t do it.”

Two participants said that they would try CPR, because one has to do all one can to
attempt to sustain life. One participant again stated that the decision would need to be a family
one due to the expectations of her culture.

**antibiotic treatment.** The use of antibiotics was fully approved by ten participants and approved with limitations or conditions by two participants. Most of the ten saw the use of antibiotics as potentially beneficial, as infections could cause pain, difficulty breathing, and/or altered behavior and/or mental status. Hannah stated that she approves of treatment with antibiotics “because any kind of infection is uncomfortable.” Maggie particularly noted urinary tract infections and pneumonia as causing discomfort. Annie concurred, stating that “UTIs can cause confusion and hallucinations.” Amy, too, felt that “yes, for any infection, they still should have antibiotics, because they could be suffering, like [UTI] pain on urination.”

Two participants approved of the use of antibiotics, but only for comfort. Darlene would treat “if there’s a UTI, and they’re uncomfortable; if there’s a massive wound or breathing issues.” Helen would limit the use of antibiotics even more to: “any time an antibiotic would be used to promote their comfort, mainly with a UTI. I would think that that would be OK. That’s the only thing I would go after and treat. . . . I would treat for that, but not for pneumonia. I’m picturing that the patient is very confused and not able to function, and I wouldn’t do it, except for pain. I would not do it for a severe wound; I would use pain meds; the sepsis would probably take the patient.”

Three respondents stated that they would completely forgo antibiotic treatment. All three agreed that antibiotics would not be helpful, would prolong life and suffering, and that the patient should be allowed to die without futile treatment.

Eleven true/false questions were asked to further capture participants’ views on end of life issues (see Appendix E). Of the fifteen participants, eight agreed that pain and suffering are always present in the dying patient; six disagreed, and one stated “I don’t know.” Fourteen agreed that it is normal for patients to stop eating/drinking in the progression of terminal illness;
only one disagreed. All fifteen disagreed with the statement that patients are unable to hear once they are no longer responsive. Ten respondents agreed that IV hydration is necessary to prevent dehydration when the patient is no longer taking fluids by mouth; four disagreed, and one gave her answer as “yes and no.” Seven respondents agreed that antibiotics are useful and effective in treating terminal patients; seven disagreed, and one stated that “it depends.” Five participants agreed that working with dying patients is frightening; ten disagreed. Eight respondents agreed that withholding or terminating artificial feeding equates to starving the patient; seven disagreed. Five participants agreed that if patients talk about fear of death, nurses should reassure the patient that s/he shouldn’t worry; ten disagreed. Thirteen respondents agreed that use of sufficient narcotics to keep a patient pain free could cause heart and breathing to stop; two disagreed. Finally, three respondents agreed that people should be kept alive as long as possible; eleven disagreed, and one stated that it depends on the circumstances.

**Demographics**

Of the fifteen participants, fourteen stated that they affiliate or identify with a specific church or religion. One denied such affiliation, but stated that she was raised Catholic and believes that her spiritual/religious beliefs influenced her decisions “a lot.” Of the fourteen who affiliate with a specific church/religion, seven identify as Christian/Roman Catholic, six identify as Christian/Protestant, and one identifies as Hindu. Ten report active attendance at religious services, and four are not active in religious practice. Twelve of the fourteen report that their spiritual/religious beliefs influence their views on life sustaining interventions. This influence is reported to vary from “a little bit,” to “somewhat,” to “half and half,” to “a lot.” One respondent also reported that she affiliates with Christianity, but also with the Hmong culture and religion; therefore, she also believes in Shamans.

Regarding culture and ethnicity, six participants identified as Asian, one as Asian Pacific,
one as Asian Hmong, two as Filipino, one as Korean, one as Indian, one as African American, one as European/Swedish/English, and one as white. Seven were raised in the Philippines, five in the United States, one in Korea, one in Indonesia, and one in the Fiji Islands.

The survey group included fifteen licensed nurses, all female, employed in a large skilled nursing facility. Their ages ranged from 36 to 60, with a mean age of 41.6. Total years of education were 251, ranging from 14 to 22 years, with a mean of 16.73. One respondent reported having earned a high school diploma, two had Associate of Arts degrees, one had an Associate of Science degree, one had a Bachelor of Science degree, seven had Bachelor of Science in Nursing degrees, and one had an Master of Arts degree in gerontology. Number of years employed as licensed nurses totaled 176.5, ranging from 1/5 years to 24, with a mean of 11.77. Of the fifteen participants, eleven were Registered Nurses and four were Licensed Vocational Nurses. Number of years worked in long-term care totaled 128.5, ranging from 1.5 to 17 years, with a mean of 8.6 years. Acute care nursing experience totaled 47 years, ranging from zero to 16 years, with a mean of 3.1 years. The participants received their nurses’ training in the United States (7), the Philippines (5), Korea (1), Indonesia (1), and the Fiji Islands (1). Of the fifteen, thirteen respondents reported having had course work on death and dying while in training, one was unsure, and one reported no death and dying course work.

Because this research was explorative in nature, the purpose was to gather information and no efforts have been made to correlate the responses or to analyze results based on variables.

Summary

In this chapter, the data from the study was analyzed and discussed. Chapter 5 is a description of the conclusions and recommendations. The limitations of this study and the implications for social work practice and policy are also discussed.
Chapter 5
CONCLUSIONS AND IMPLICATIONS FOR SOCIAL WORK

Introduction
This chapter will describe the conclusions drawn from analysis of the data collected in the study. Included in this discussion will be a review of the findings, the relevance of the findings, and themes and trends. This chapter concludes with a discussion of implications for social work practice and a summary.

Review of Findings and Relevance
This study was initiated to explore the views of licensed nurses regarding life extension. The research was conducted with the position that an understanding of nurses’ views and practices could contribute to enhancing the scope and range of available choices for patients and families while increasing the comfort level of nurses in honoring such decisions.

The study was conducted in a large skilled nursing facility to gather information for the development of an expanded an improved in-service curriculum for teaching employees who work in this setting. The literature review yielded significant information on this subject when examining the views of white, professionals from a mainstream American culture working with members of minority culture groups; however, the review revealed only minimal information regarding views of individuals representing minority culture professionals who are working with patients from mainstream culture. The study was exploratory in design, with the purpose of determining if biases exist. Because this nursing facility employs large numbers of professionals of minority culture and ethnic groups, it was hoped that information from this study would be useful in planning and implementing in-service training classes for the staff.

The study did reveal differences in nurses’ views regarding prolonging life in elderly, chronically ill patients, as well as varying comfort levels in caring for the dying and discussing
these issues with families. Because of the exploratory, qualitative nature of the study, and the small sample population, extensive statistical analysis was not done. The data was, however, carefully examined looking for trends and themes.

Generally, the more experienced and/or older nurses appeared to exhibit a greater comfort level with these issues, together with a strong leaning toward quality of life rather than quantity of life. Several personalized the questions, answering as if speaking for themselves or a family member.

Most of the participants identified with spirituality or religion, either through current religious practice or having been raised in a particular faith. Most also indicated that their religious and spiritual views influenced their views on prolonging life. Additional research could explore the degree of that influence.

The hospice movement is considered by many to set the standard for palliative or comfort care of the dying. They generally take the “less is more” approach, meaning that interventions are limited to those that promote comfort. Nothing is done specifically to prolong life. Patients receive adequate pain medication to keep them as comfortable as possible, even if that contains the risk of suppressing respiration and heart function with the possibility of hastening death. IV hydration is not done, as dehydration is believed to trigger release of endorphins, which enhance pain management and comfort; these patients do not appear to suffer from the sensation of thirst. Further, the belief is that the body is shutting down, kidney function is decreasing, and IV hydration puts the patient at risk for fluid overload, aspiration, and pneumonia. Since terminally ill patients gradually lose their appetite and over time stop eating, artificial nutrition via feeding tubes is not done. Again, there is risk of aspiration and pneumonia. Finally, antibiotics are generally used only as a comfort measure, i.e., to treat a condition that is causing pain and discomfort, such as a urinary tract infection. Pneumonia does not usually cause pain, so is not
treated with antibiotics; however, respiratory distress is relieved by administering oxygen.

Many of the nurses in this study were not in favor of artificial nutrition, especially for the long term; however, many of them did favor IV hydration, believing that treatment necessary. Several verbalized that they could not allow their patients to die of thirst or dehydration. Significant is the fact that eight of the participants in the study agreed with the belief that withholding or stopping tube feeding equates to starving the patient, even though ten of them would recommend against the use of artificial nutrition.

The majority of respondents stated that they would not recommend performing CPR on terminal patients, citing the risks of broken ribs and being maintained on a respirator, significant quality of life issues.

All fifteen participants verbalized the necessity of respecting patient and family choices as indicated on the Preferred Intensity of Care form (see Appendix F). The literature review indicates that many times, patient and family preferences are ignored; therefore, the use of this form and the nurses’ commitment to its use is a noteworthy factor in ensuring patient rights and self-determination.

Limitations to this study include the small sample size of 15 nurses and lack of statistically significant data. Future research might include a deeper exploration of the degree of the influence of spirituality on the participant’s responses and a larger sample size.

Implications for Social Work Practice and Policy

Social workers in older adult service programs, hospitals, nursing homes, and hospice will confront these issues in the course of their professional duties. Examination and analysis of the opinions and views of nurses can serve as a springboard for social worker to begin to engage in the necessary process of examining their own views in this area. Understanding the emotional and spiritual components of end of life issues is essential for self-awareness. Further, this same
knowledge can help inform their practice with elderly, frail, chronically ill, and terminally ill clients.

Social workers, as part of an interdisciplinary team, frequently work closely with nurses. Having an understanding of nurses' views can promote better team functioning and enhance communication. Often social workers will have the opportunity to model different responses and behaviors, as well as to respectfully present alternative beliefs and values. Social workers may be required or invited to teach in-service lessons, which provides a formalized setting for imparting new and different points of view. Finally, and perhaps most importantly, social workers function in the role of advocacy for their clients. Understanding that nurses may have views and approaches that are inappropriate for their clients, social workers can assist clients by assuring that their preferences are respected and their desires are accomplished.

Summary

In this chapter, themes and trends were identified and explored. Implications for social work practice were identified and discussed. In general, the nurses surveyed expressed varying views on life prolonging measures. These were not directly related to ethnicity and spirituality specifically; in the main variations in views appeared to be related to years of experience and more generally loosely related to culture and religious affiliation. Implications for social work practice included education and modeling for peers and advocacy for clients’ rights.
TO: Margaret Weeks                          Date: February 16, 2010

FROM: Committee for the Protection of Human Subjects

RE: YOUR RECENT HUMAN SUBJECTS APPLICATION

We are writing on behalf of the Committee for the Protection of Human Subjects from the Division of Social Work. Your proposed study, “Effects of Culture on Licensed Nurses’ Views of Life-prolonging Measures.”

__X__ approved as ______EXEMPT  _____ NO RISK  __X__ MINIMAL RISK.

Your human subjects approval number is: 09-10-080. Please use this number in all official correspondence and written materials relative to your study. Your approval expires one year from this date. Approval carries with it that you will inform the Committee promptly should an adverse reaction occur, and that you will make no modification in the protocol without prior approval of the Committee.
The committee wishes you the best in your research.

Professors: Teiahsha Bankhead, Chrys Barranti, Andy Bein, Joyce Burris, Maria Dinis, Susan Eggman, Serge Lee, Kisun Nam, Sue Taylor

Cc: Dr. Joyce Burris
APPENDIX B

Permission to Conduct Study

I hereby grant permission for Margaret Weeks to conduct a study of licensed nurses at Bruceville Terrace Skilled Nursing Facility for the fulfillment of thesis/project requirement for her Master of Social Work program at California State University Sacramento.

I understand that the purpose of the study is to evaluate the effect of culture on nurses’ views of life-prolonging measures. The results of this study may provide benefit to Bruceville Terrace SNF in the development of in-service training for staff to improve effectiveness of discussion of end of life decision making with our residents and their families.

I have reviewed the informed consent document and the survey questionnaire. I understand that the survey will take thirty (30) minutes or less to complete. Permission is granted for Ms. Weeks to approach and interview staff members who are willing to participate in the survey. I understand that interviews will be audio recorded and transcribed by the researcher. I further understand that the researcher’s thesis advisor will have access to the interview records, that the notes will be secured in a file folder at the researcher’s home for the duration of the project and then destroyed by June 2010. I understand that staff’s participation in the survey is voluntary, that participant’s confidentiality will be respected, and that the final report will not include any identifying information. I also understand that there is no risk to participants in this study as they will be answering questions that relate to their professional work and daily professional activities.

[Signature]
Linda Turner, RN
Director of Skilled Services
Bruceville Terrace

11/23/09

A Member of Catholic Healthcare West
APPENDIX C

Invitation to Participate

Attachment 3
Research Participation Cover Letter

Dear Prospective Research Participant:

You are invited to participate in a study conducted by Margaret Weeks for fulfillment of a thesis/project requirement for her Master of Social Work program at California State University Sacramento. The purpose of the study is to evaluate the effect of culture on nurses’ views of life-prolonging measures. The survey will take approximately thirty (30) minutes to complete. Written permission has been granted by Linda Turner, D.O.N., for licensed nurses to participate in the study if they are willing to do so. Supervisors will be available to provide patient care while participants are off the floor for the interview. Your participation in the study is voluntary and your confidentiality will by ensured. There is no compensation for participation in the study, but your contribution is greatly appreciated by the researcher.

Margaret Weeks, MSW Intern
Bruceville Terrace Skilled Nursing Facility
APPENDIX D

Consent Form

Attachment 1
Consent to Participate in Research

You are invited to participate in a research study that will be conducted by Margaret Weeks, a graduate student at California State University, Sacramento. This study will explore licensed nurses’ feelings and beliefs surrounding end of life health care decisions and the role that spiritual/religious beliefs and cultural identity may play.

Procedures:
After reviewing this form and agreeing to participate, you will be given the opportunity to set up a time convenient for you. The interview should take approximately 30 minutes. It will be audio taped. The tape will be transcribed and then destroyed.

As a participant in the interview, you can decide at any point not to answer any specific question or to stop the interview.

Risks:
The discussion of some of the topics of the interview may illicit an emotional response. Participants requiring support and/or counseling may meet with their nursing supervisor and/or may contact Mercy’s Employee Assistance Program at (916) 925-6400 for access to free counseling sessions.

Benefits:
By being part of this study you may gain insight into your own decision making process. In addition, this research may help others to further understand the connection between end of life decisions and cultural and spiritual influences. This information may be useful in providing culturally and spiritually appropriate support to patients, family members, and professionals as they participate in end of life decision making.

Confidentiality:
All information is confidential and every effort will be made to protect your anonymity. Your responses on the audiotape will be anonymous. Information you provide on the consent form will be stored separately from the audiotapes in a secure location. All audiotapes will be transcribed by the researcher. The researcher’s thesis advisor will have access to the transcriptions for the duration of the project. The final research report will not include any identifying information. All of the data will be destroyed upon completion of the project.
Compensation:
There will be no compensation for participation in this project.

Rights to withdraw:
If you decide to participate in this interview, you can withdraw at any point. During the interview you can elect not to answer any specific question.

Attachment 1 (continued)
Consent to Participate as a Research Subject

I have read the descriptive information on the Research Participation cover letter. I understand that my participation is completely voluntary. My signature indicates that I have received a copy of the Research Participation cover letter and I agree to participate in the study.

______________________________ agree to be audio taped.

Signature: ________________________________

Date: ________________

Thank you for your participation in this study. If you have any questions, you may contact me at 209-298-7207 or email me at margyann58@yahoo.com.

Or, if you need further information, you may contact my thesis advisor:

Joyce Burris, Ph.D.
c/o California State University, Sacramento
916-278-7179
APPENDIX E

Questionnaire

Interview Questions

Please respond to the following questions as if you were caring for an 80 year old (or older) patient with advanced dementia. What advice would you give to the patient’s family regarding end-of-life interventions?

1. If your patient was no longer taking food by mouth or could no longer safely swallow, would you recommend insertion of a PEG tube? Why or why not? If you recommended artificial feeding, would you recommend it indefinitely or for a time limited period? Please elaborate.

2. If that same patient had stopped taking fluids by mouth or could no longer safely swallow, would you recommend IV hydration? Why or why not? If you recommended IV hydration, would you recommend it be done indefinitely or for a time limited period? Please elaborate.

3. In the event that your patient’s heart and/or breathing stopped, would you recommend that CPR be administered? Why or why not?

4. For what conditions, if any, would you recommend antibiotics to be administered to your patient? Please elaborate.

Spirituality:

1. Do you affiliate or identify with a specific church or religion? If so, which one?

2. Do you actively attend church/synagogue/mosque/temple?

3. Would you say that your spiritual/religious beliefs influenced your above decisions? If so, to what degree?

Culture/ethnicity

1. How do you classify yourself with regards to race/ethnicity?

2. Were you raised in the United States? If not, where?

Dying Process

1. Pain and suffering are always present in the dying patient.

2. It is normal to stop eating/drinking in the progression of terminal illness.

3. Once patients are no longer responsive, they are unable to hear.

4. IV hydration is necessary to prevent dehydration when the patient is no longer taking fluids by mouth.

5. Antibiotics are useful and effective in treating terminal patients.

6. Working with dying patients is frightening.

7. Withholding or terminating artificial feeding equates to starving the patient.
8. If a patient talks about fear of death, nurses should reassure the patient that he shouldn’t worry.  
9. It is possible for nurses to help patients prepare for death. 
10. Use of sufficient narcotics to keep a patient pain free can cause heart and breathing to stop. 
11. People should be kept alive as long as possible.

Demographic information:
1. Age
2. Gender
3. Education: Number of years of education? Degrees?
4. Number of years employed as licensed nurse?
5. RN or LVN?
6. How long have you worked in long term care?
7. How many years of experience do you have working in acute care?
8. Where did you receive your nursing training/education?
9. During your training, did you have any classes on death and dying?
APPENDIX F

Preferred Intensity of Care Form

Bruceville Terrace
CHW

Preferred intensity of Care

It is the wishes of _____________________ that the following

Intensity of care be complied with:

I WANT I DO NOT WANT PROCEDURE
__________________________________________________________
Cardiopulmonary Resuscitation (CPR) intervention given by a
person, machine, via drugs when the heart and/or lungs stop
working, with the transport to hospital.

Transfer to Acute Hospital.

Artificial Nutrition / Hydration from a nasogastric, gastrostomy
or endostomy tube.

Antibiotics - to treat infection (Pneumonia, etc).

IV Fluids

Oxygen

Organ / Eye / Tissues Donation

Other:

☐ I DO NOT WISH ANY OF THE ABOVE

I WISH:

☐ Caring & supportive nursing & medical care to relieve pain & suffering including narcotics to relieve pain,
including the use of Oxygen.

☐ Food & Fluids to be offered as long as I am conscious to take them by mouth.

Comments:

I understand that I can change my mind at any time and the facility will assist me in notifying my physician of my
choices when or if there are changes.

Resident:

Date:

Responsible Party for Healthcare Relationship to Resident Date

Attending Physician

Date

Durable Power of Attorney for Healthcare ☐ YES ☐ NO

RESIDENT ROOM NO. PHYSICIAN MR #
REFERENCES


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