

JUST LET HER EAT THE DARN COOKIES: TO WHAT EXTENT
WILL EDUCATION ABOUT THE NATURE AND CONSEQUENCES
OF ADVANCED MEDICAL TECHNOLOGY INFLUENCE A
PERSON'S END-OF-LIFE CARE CHOICES

by

Mary Joan Midgley Speer

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Approved by:

1.

Dr. Lisa R. Merriweather

Dr. Sandra L. Dika

Dr. Rosemarie Tong

Dr. William P. Brandon

ABSTRACT

MARY JOAN MIDGLEY SPEER, *Just Let Her Eat the Darn Cookies*: To what extent will education about the nature and consequences of advanced medical technology influence a person's end-of-life care choices? (Under the direction of DR. LISA MERRIWEATHER)

The purpose of the study was to determine the extent to which education about the nature and consequences of advanced medical technology influenced beliefs and shaped perceptions about the end-of-life care choices adults might make. The research questions were: to what extent is spirituality related to pre-intervention beliefs and preferences about end-of-life care; to what extent does participation in a brief transformational education program change adults' preferences about end-of-life care, overall and by program delivery type; to what extent does participation in a brief transformational education program change adults' beliefs about the artificial means to extend life, overall and by program delivery type? Rather than being separate conditions of therapeutic interventions, caring and curing are mutually supportive. Bringing care and cure together more effectively supports the patient's need physiologically, emotionally and spiritually.

A short educational program was developed to help individuals understand the impact of cardiopulmonary resuscitation, mechanical ventilation, feeding tube placement, dialysis and rounds of pharmaceutical interventions at the end-of-life. A pre and post survey was given to each participant to assess their perceptions: For the entire sample, preferences for end of life care changed slightly with an orientation toward comfort over treatment interventions to cure. For the entire sample beliefs about the use of artificial means to extend life did not significantly change.

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TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION	1
1.1 Physiology of the Persistent Vegetative State	3
1.2 Women of the Movement to Advance End-of-Life Care	5
1.3 Statement of Problem	7
1.4 Research Questions	11
1.5 Theoretical Framework	12
1.6 Research Design	12
1.7 Significance of Study	13
CHAPTER 2: LITERATURE REVIEW	15
2.1 Purpose of Study	15
2.2 Nature of End-of-Life Care	15
2.3 Caring Versus Curing	16
2.4 Frailty, Futility and Existential Suffering	18
2.5 Studies on End-of-Life Care	24
2.6 Provider's Perceptions on End-of-Life Care	25
2.7 Patient and Family Perceptions on End-of-Life Care	29
2.8 Studies on Education on End-of-Life Care	30
2.9 Conceptual Frameworks	33
CHAPTER 3: RESEARCH METHODOLOGY	38
3.1 Research Design	39
3.2 Research Questions	41
3.3 Sampling and Participants	41
3.4 Data Collection and Instrumentation	44

3.5 Preferences for End-of-Life Care	44
3.6 Beliefs about Dying	45
3.7 Spirituality	45
3.8 Demographic Characteristics	45
3.9 Intervention / Treatment	48
3.10 Data Analysis	51
CHAPTER 4: RESULTS	52
4.1 Descriptive Analysis	53
4.2 Inferential Analysis	56
4.3 Wilcoxon Signed Rank Test	57
CHAPTER 5: DISCUSSION	60
5.1 Connection Between Bioethics, Existential Suffering and Transformational Learning	60
5.2 Preferences for End-of-Life Care	62
5.3 Beliefs About Use of Artificial Means	66
5.4 Limitations	67
5.5 Recommendations	68
5.6 Conclusion	69
REFERENCES	71
APPENDIX A: INFORMED CONSENT	76
APPENDIX B: LETTER OF INTRODUCTION	78
APPENDIX C: PRE – TEST	79
APPENDIX D: END-OF-LIFE CHOICES INTERVENTION	83

APPENDIX E: POST-TEST

85

CHAPTER 1: INTRODUCTION

The title of this dissertation *“Let Her Eat the Darn Cookies”* came to be after I attended a talk given by Dr. Atul Gawande. He related the case of an elderly woman who had been put on dietary restrictions, but all she really wanted to do was eat some cookies. She frequently managed to get into the kitchen and take cookies. When the staff asked for Dr. Gawande’s advice on how to deal with the matter, his response was “let her eat the darn cookies”! This work is couched in the conviction that at the end of one’s life what is truly important is that one dies as they wish, in comfort and peace.

In November of 1959, Dr. Bernard Lown performed a treatment intervention that changed the delivery of health care. The treatment was delivered by a large, heavy device that was plugged into the wall and transferred wall current to a patient whose heart was not beating. The current delivered could be set from 0 to 750 volts. Dr. Lown had the patient anesthetized, set the voltage at 400, and placed two silver-plated electrical paddles on the chest of the patient. The anesthesiologist rendered the patient anesthetized, everyone in the room stepped back, and Dr. Lown pushed the discharge button and delivered 400 volts of electricity into the patient’s heart. After several seconds, the physician assessed the patient’s heart rhythm using a simple stethoscope and the sound he heard was the slow rhythmic beating of a human heart (Colby, 2006).

On May 20th, 1962, Dr. Hughes Day opened the first unit specifically designed to treat patients with heart disease and called it a Coronary Care Unit (CCU). In the CCU, innovations newly reported in the literature were performed: electrical shock to a fibrillating

heart from outside the chest, the new concept of closed chest massage or cardio-pulmonary resuscitation (CPR), and the new electronic monitoring of patients (Colby, 2006).

In 1970, Dr. Robert Potter returned home from a five year tour of duty with the Kansas National Guard. On his return to the practice of medicine, Dr. Potter experienced many miracles due to the relentless and amazing technological advances that had occurred in the hospital setting during his absence. On one occasion, Dr. Potter restored a regular heartbeat to a patient after an event of ventricular fibrillation, but the patient did not regain consciousness. He lay in a bed eyes open, but unaware of his surroundings for three years, at which time he was taken off life support and rendered lifeless. Dr. Potter admitted feeling “guilty for having created the situation with my almost successful technology” (Colby, 2006, p. 66). Dr. Potter began to see and think more about a “dark side” to this growing technology (Colby, 2006, p. 66). Advances in medical technology have saved many lives and diminished much suffering, but left many with no cognitive awareness of their surroundings.

In light of the preceding information, the researcher’s healthcare experience, and the knowledge that the current healthcare delivery system is not sustainable (Callahan, 2009; Emanuel, 2014; & Fleck, 2009), the researcher demonstrated how a transformational learning education program can influence an individual’s preferences and beliefs about end-of-life care. A short program helped individuals understand that cardiopulmonary resuscitation, mechanical ventilation, feeding tube placement, dialysis, and rounds of pharmaceutical interventions at the end-of-life may not serve patients well as they near death.

This researcher’s believes advanced medical technology at the end of one’s life causes pain and suffering, not comfort and peace. Interventions to spare individuals needless suffering while preserving individual choices and autonomy is the goal of the care

versus cure model. This work is an inquiry intended to lay an empirical groundwork through fact finding, education, reflection and discourse. Further, this work is an effort to affect change through the use of transformational learning programs that enhance knowledge and understanding to ease the challenges and dilemmas of delivering end-of-life care.

Physiology of the Persistent Vegetative State

Dr. Potter's patient exhibited the condition termed Persistent Vegetative State (PVS). PVS was defined in 1972 by Drs. Plum and Jennett in the British medical journal, *The Lancet*. Cases existed before 1972 but the number of cases was increasing due to advancing medical technology. The advancing technology changed not only how doctors thought about consciousness, but how they defined death (Colby, 2006).

The human brain is often likened to a mushroom, with the cerebral hemispheres being the top of the mushroom and the brainstem being the stem. Cognition and consciousness occur in the cerebral hemispheres. The brainstem contains what medical textbooks call the body's "vegetative functions"—breathing, digesting food, producing urine and some basic reflexes. The term "brain death" refers to the loss of all brain function. The heart and lungs continue to function, but only with mechanical ventilation support of these functions that the brain can no longer support (Mayfield Clinic and Spine Institute, 2013).

Brain death can occur following traumatic brain injury, a stroke caused by a ruptured blood vessel or clot in a vessel in the brain, or if the heart has stopped and the brain goes without oxygen and other nutrients it needs to survive for a long period of time. Some physicians and ethicists prefer not to use the term 'life support' to describe the ventilator and other equipment that can maintain blood flow and breathing in a patient who has been

declared brain dead. They say it is somewhat deceiving to use the term 'life support' with a more appropriate term for this physiologic state being 'organ support' (Rubin, 2014).

Brain-stem reflexes are often the last to go. These reflexes include the dilation of pupils and coughing or gagging when the vocal chords are tickled. When there is no evidence of higher brain function or brain-stem reflexes, and when other factors that could mimic brain death, such as drugs or low blood pressure, have been ruled out, the need for a formal brain-death evaluation is indicated. A person who has been declared brain-dead cannot be revived. Brain death is death (Senelick, 2012).

Patients in a vegetative state are not brain dead; they retain relatively normal brainstem function. The brainstem can survive significantly longer without oxygen than the upper cognitive part of the brain. The cerebral hemispheres of the brain begin to suffer irreparable damage after four to six minutes without oxygen. Patients in a vegetative state are unconscious. They may appear awake, but are unaware of their presence in time or place. Their eyes may move around a room, they may smile, grimace, make noise, and cough. While these actions may appear to indicate consciousness, they are not. Patients in PVS have no ability to think or feel, and have no consciousness of their surroundings (Laureys, Owen, & Schiff, 2004).

Women of the Movement to Advance End-of-Life Care

Dr. Potter's fear of there being 'a dark side' to technology came to fruition. On April 15, 1975 at 2:00 am, the parents of Karen Ann Quinlan received a phone call telling them that their daughter, Karen Ann, was brought to the hospital. She was unconscious, and not long after her arrival at the hospital her coma was diagnosed as being . Her condition was deemed a persistent vegetative state from which she would not recover. As time went on, her body began to take on distinctive patterns. Karen would thrash wildly at times, she would blindly resist treatments and the machines she was attached to, yet all the while unable to communicate and respond to voices of her loved ones. After making the painstaking decision to have Karen removed from life support, the Quinlan's discovered that in order to carry out this personal wish, they needed to petition the court. In 1976, the New Jersey Supreme Court ruled the mechanical ventilation device, the respirator, could be removed. Eighteen days after the order was rendered, the tube was removed. After much negotiation between the Quinlan's, the hospital staff and the New Jersey Supreme Court, Karen Ann was weaned from the respirator that supplied oxygen to her brain. It took five days to wean her from the respirator, but Karen Ann kept breathing. While the respirator was removed, the feeding tube remained in her abdomen. She was moved to nursing home in June 1976. Instead of the photos of Karen resting quietly and calmly with no ill effects, Karen Ann's body was being contorted inward in a kind of fetal position. All her joints were flexed and despite attempts by physical therapy to straighten out her bent form, her limbs quickly retracted after therapy sessions. In spite of frequent turning, there was no way to prevent pressure sores on her body. Karen Ann was unable to respond to her family in any way. She was to breathe on her own for another nine years before dying on June 11, 1985 of pneumonia (McFadden, 1985).

On January 11, 1983, Nancy Cruzan lost control of her car. She was thrown from the vehicle and landed along the side of the road lying in water. Paramedics found her without respiratory or cardiac function. Nancy was without oxygen for twelve to fourteen minutes. CPR was performed; she was resuscitated and transported to a hospital. After three weeks in a coma, she too was diagnosed as being in a persistent vegetative state (PVS). Surgeons inserted a feeding tube to sustain her nutritional needs. In October 1983, Nancy Cruzan was transferred to a state hospital. Attempts at rehabilitation failed. It became clear that she had no chance of regaining her cognitive functioning or her ability to think or feel. Her parents, who had been appointed as her guardians, asked the hospital to remove her feeding tube. The hospital refused to grant the request without court approval (Colby, 2006).

The Cruzan's judicial journey went from the Missouri trial court, to the Missouri Supreme Court, to the United States Supreme Court, then finally back to the Missouri Supreme Court. In the end, witnesses satisfied the Missouri courts that such clear and convincing evidence of her wishes did exist and her feeding tube was removed. Cruzan died two weeks later. Her epitaph read, *Departed*, January 11, 1983; *At Peace*, December 26, 1990 (Colby, 2006).

In the aftermath of the Cruzan case, the federal government passed the Patient Self Determination Act. The Act became federal law in 1990. It requires written information be provided concerning an individual's right to make decisions concerning medical care, the right to accept or refuse medical treatment, and the right to formulate advance directive (Ulrich, 1998).

The Patient Self Determination Act (1990) would be put to the test with the Terri Schiavo case. Schiavo was 26 years old when she collapsed on Feb. 25, 1990. An autopsy revealed no reason as to why she had lost consciousness. Whatever the cause, her brain was deprived of oxygen long enough to leave her in a persistent vegetative state. She could

breathe without mechanical assistance, but needed medically assisted nutrition and hydration procedures to survive. Doctors concluded that she was incapable of thought or emotion (Eisenberg, 2005).

The judicial journey of the Schiavo case began on May 11, 1998 when her husband went to probate court and argued for the passage of “Terri’s Law” (Bousquet, 2003). “Terri’s Law,” is a one-page bill passed by the Florida Legislature and signed into law by Governor Jeb Bush in less than 24 hours. Schiavo’s husband argued that Terri’s feeding tube should be removed. On February 11, 2000, the judge in the case rendered his opinion that Terri Schiavo’s feeding tube could be removed. The parents of the victim did not agree with the opinion handed down. The Florida Appeals Court heard the case on four different occasions. In October, 2002 Schiavo’s husband took his case to the Florida Supreme Court to review “Terri’s Law”. Following the refusal of the Florida Supreme Court to hear the case, it was sent to the United States Supreme Court on January 24, 2005. The court refused to review the law. On March 25, 2005, after a nearly seven year foray into the judicial system, Terri Schiavo’s feeding tube was removed. On March 31, 2005, more than fifteen years after her collapse, Terri Schiavo was pronounced dead (Eisenberg, 2005).

Statement of Problem

It cannot be said with certainty when the evolution of Bioethics as a distinct field of study dealing with moral conduct as it relates to medicine began; but it can be said with certainty, that in the initial stages, the catalyst for the creation of Bioethics as an interdisciplinary field of study was the extraordinary advances in American medicine. New medicines, dialysis machines, organ transplantation, mechanical ventilation support systems, medically delivered nutrition, ICU’s and lifesaving surgeries made possible a level of medical care never before attainable. With each new development, new ethical dilemmas were created. Modern Bioethics is not simply concerned with experimentation on human

subjects and humane medical treatment. From its inception Bioethics has been concerned with the delivery of just, compassionate care in keeping with the fundamental principles of Bioethics. (Garrett, Jotterand & Ralston, 2013).

Ethics guidelines do not provide a formula for making correct decisions. They aim to guide reflection, judgement and action in providing good care near the end-of-life. They provide an ethical framework for making decisions under conditions that are challenging and sometimes psychologically distressing. They clarify the rights and responsibilities of each participant in the decision-making process. They can help ensure that decisions are made with appropriate knowledge, deliberation, transparency and fairness, safeguarding vulnerable patients. The Ethics guidelines protect against under treatment by means such as denial of pain medication, physical therapy and general comfort measures on the one hand, and over treatment by subjecting individuals to interventions that would cause suffering and prolong life regardless of cognition and consciousness on the other hand. For most patients consequences of over treatment include pain and symptoms that result in suffering, helplessness and loss of self, diminished ability to do things that have meaning and give pleasure, and financial cost and stress imposed on patient and families (Berlinger, Jennings & Wolf, 2013). Over treatment, as described above, is in no small measure the “dark side” of technology experienced by those facing the end- of-life; exactly what Dr. Potter feared. This study focused on four technologies: cardiopulmonary resuscitation, mechanical ventilation, feeding tube insertion and kidney dialysis. While certainly not the costliest of treatment options, they are the most prevalent used to treat critically ill and dying patients. Because of the advances in medical technology, discussions must occur about the difference between curing and caring and the effects of over treatment on end-of-life care delivery. Daniel Callahan (2009) asserts that the introduction of new technology has failed to generate effective improvement in treatment of disease. The influence of technological,

pharmaceutical, and private insurance interests on Congress has inhibited any legislative efforts to control healthcare costs or to assess the effectiveness of new treatments. On March 23, 2010, President Obama signed comprehensive health reform, the Patient Protection and Affordable Care Act (2010) into law to put in place measures to control healthcare costs.

Callahan (2009) argues there is no moral obligation or imperative to continually improve the general health of populations already at historic high levels. But we can and should work to improve the general health of populations that are at risk of declining into chronic conditions due to the disparities they face. Callahan asserts “what might be of immense value to us as individuals may not be compatible with an equitable health care system, aiming for a common good, not just the private good” (p. 3).

Callahan (2009) argues

The medical model that needs change encompasses a combination of values: that suffering of any kind, but mainly biological suffering, is an inherent evil; that death is intrinsically wrong and should be the main enemy of medicine; that the anti-ageism movement of recent decades is de facto acting as if old age were a biological anachronism, to be transcended even if not quite eliminated; and that endless medical progress should be pursued...medical technology’s economic harms can exceed its benefits. Learning how to manage medical technology, which constantly extends the frontiers of medicine but requires economic limits, will be a vital first step toward a sustainable health care system. (pp.7-9)

The organizational and management scheme that presently dominates reform efforts is to just make the system work. The pursuit of such efforts is similar to the problem that plagues

end-of-life care, that of embracing hope and treatment that is likely to fail, while refusing to accept the obvious fact that the patient is dying. On the “institutional glide path”(Colby, 2006, p. 114), the mantra is do not give up, provide one more round of chemotherapy and radiation, one more superfluous invasive therapy and one more meaningless round of testing just to be sure there is no cure.

It is essential that health care professionals, who have primary responsibility for the care of the patient, support informed decision making. Informed decision making results from an evaluation that yields the following information: the concerns of the patient, diagnosis, prognosis, treatment options, their likely benefits, burdens, and the likely effects of each option. The capacity to understand the current diagnosis, prognosis, treatment options and treatment recommendation is essential for informed decision-making. A patient has decision-making capacity when the patient has the ability to: understand one’s condition and treatment options, deliberate in accordance with one’s own values and goals to make a decision regarding treatment options, and the ability to communicate one’s decision (Berlinger, Jennings & Wolf, 2013). The competent patient has the autonomy to make informed decisions; the health care provider has the responsibility to carry out the patient’s wishes for end-of-life care.

There are, according to Beauchamp and Childress (2009), five central virtues that are widely acknowledged in biomedical ethics. They are the virtues of compassion, discernment, trustworthiness, integrity, and conscientiousness. These virtues help focus on the character of healthcare professionals. Compassion combines an attitude of active regard for another’s welfare with an imaginative awareness and an emotional response of sympathy, tenderness, and discomfort at another’s misfortune and suffering. Discernment brings sensitive insight, astute judgement, and understanding to the process of decision making. Trust is a confident belief in and reliance on the moral character and competence of

another person. Trust also involves respect of all those in the process. Integrity means soundness, wholeness and integration of moral character. Problems in maintaining integrity sometime arise from moral demands that require persons to sacrifice in a way that causes them to abandon their personal goals and projects. To compromise below the threshold of integrity is simply to lose it. Conscientiousness is the motivation to do what is right, because it is right, trying diligently to determine what is right, intending to do what is right and exerting an appropriate level to do so. (pp. 38-44)

Research Questions

The purpose of this study is to understand the extent to which a brief transformational education program can change perceptions and beliefs on end-of-life care choices, as well as the impact of the spiritual beliefs on those preferences.

Three related research questions were explored:

1. To what extent is spirituality related to pre-intervention beliefs and preferences about end-of-life care?
2. To what extent does participation in a brief transformational education program change adults' perceptions about preferences for end-of-life care, overall and by delivery type?
3. To what extent does participation in a brief transformational education program change adults' beliefs about the use of artificial means to extend life, overall and by program type?

The Null Hypothesis can be stated as:

H_0 there is no difference within population's survey scores or between population's survey scores before or after end-of-life education has been delivered.

H_a there is a difference within population's survey scores and between population survey scores both before and after end-of-life education has been delivered.

Theoretical Framework

Transformational Learning Theory serves as the theoretical framework for this study and can be defined as the “process of using a prior interpretation to construe a new or revised interpretation of the meaning of one’s experience in order to guide future action” (Mezirow, 2000, p.132). There are four main components of the transformational learning process: experience, critical reflection, reflective discourse and action (Merriam, Caffarella & Baumgartner, 2007).

Moral learning goes on constantly, if not always consciously. A goal of moral learning is truth seeking, a willingness to think deeply about differing positions and arguments and to be convinced by evidence and argument.

Research Design

The researcher used a one group pre-test, post-test design to determine the extent to which participation in an hour long program influences an adult’s understanding of end-of-life care choices, as well as perceptions about their own end-of-life care choices. For those that could not attend a presentation a mailing with all information contained in the presentation was sent out. This type of design is pre-experimental and can provide tentative evidence of the effectiveness of treatment by examining differences in scores on the dependent variables of interest prior to and after the intervention.

Assumptions:

- Individuals were representative of groups of which they are members.
- Individuals understood the presentation.
- Individuals were reflective and answered truthfully.

The study will be conducted under the following conditions:

- An educational program was presented at designated sites.
- A packet of material was mailed to professional colleagues and family members.

- Pre-tests and post tests were used in both venues.

The study was limited to:

- Those who had the capacity to understand the information.
- Those over eighteen years of age.

Significance of Study

This study is significant because it fosters discourse surrounding end-of-life care choices. Our propensity for technology and fear of death restrain effective discourse from taking place on these issues and converge to dampen real discussions on the benefits of delivering comfort care and the risks of delivering curative interventions from coming to pass. Callahan (2009) explores the uncomfortable truth that “while we are not immortal, we often like to pretend we are. The denial of death is not serving us well” (p. 151). This study is also significant because it helps to develop effective transformational education programs. Finally it contributes to the revisions of futility policies and the enhancement of adherence to Ethics Committee recommendations.

Summary

The purpose of this study, using Transformational Learning Theory, is to inform individuals of the advantages and disadvantages of the use of advanced medical technology when one is facing end-of-life care choices. Callahan (2009) likens medical technology to “an unruly and untamed, but beloved beast” (p. 37). Advanced medical technology has increased the medical communities ability to diagnosis and treat but, it can cause discomfort and suffering at the end-of-life. This chapter reviewed the condition of being in a persistent vegetative state (PVS), the role of the conditions of young women and their family’s efforts in advancing end- of-life care legislation and the emergence of the field of Bioethics resulting from the development of advanced medical technology.

In Chapter 2 I reviewed literature on caring versus curing, the nature of end-of-life care, the nature of frailty, futile treatment, ones that have no chance of being efficacious and existential suffering. Included in this chapter is a discussion of Transformational Learning Theory and Moral Learning.

CHAPTER 2: LITERATURE REVIEW

*Living is not the good, but living well.
The wise man therefore lives as long as he should, not as
long as he can.
He will always think of life in terms of quality, not quantity.
Seneca*

This chapter reviews literature on caring versus curing, the nature of end-of-life care the nature of frailty, futile treatment, ones that have no chance of being efficacious and existential suffering. Included in this chapter is a discussion of Transformational Learning Theory and Moral Learning.

Purpose of Study

The purpose of this study was to determine the extent to which education about the nature and consequences of advanced medical technology influences beliefs and shapes perceptions about the end-of-life care choices adults in a large city in the southeastern United States might make.

Nature of End-of-Life Care

How Americans live and die has changed dramatically in the past century. In 1900, an American life expectancy was an average of forty-seven years. Disability and illness were common at every age. Death was often sudden and the cause was often acute illness such as pneumonia, tuberculosis, diarrhea, vomiting and traumatic injury. The time from onset of a serious illness to death was measured in days or weeks, not years. Families were responsible for most of the cost of care. For the most part, the primary caregivers were the mothers, wives and daughters of the person needing care. The last days of one's life were usually spent at home with family attending to their needs of their loved one (Lynn & Adamson, 2003).

Now most Americans are healthier in every phase of life and live in good health into old age. In 2000, the average life expectancy for Americans was 77 years of age for women and 73 years of age for men. Improved public health and medical treatments have lowered the death rate from acute causes such as childbirth and infections. Currently, the most common causes of death are heart disease, cancer, stroke, chronic respiratory disease, diabetes and injuries, in particular, hip fractures. The last years of one's life for a large part of the population include dementia and frailty. Most Americans face life's end in hospitals or nursing homes not at home with family. Americans will usually spend two or more of their last years frail enough to need help with their care. In the next thirty years, the number of older Americans will continue to grow. In 2000, 4.2 million Americans were 85 or older. The prospect of substantial and sustained disability looms large for the aging population, as nearly 9 million Americans will be over 85 by 2030 (Lynn & Adamson, 2003).

Caring Versus Curing

There are two primary approaches to healthcare for end-of-life: caring and curing. According to Lynn (2004), the goal of medicine is to manage symptoms, coordinate a plan of care and ensure treatment interventions that reflect the preferences of patients. Empathetic care is achieved when there is balance between the benefits and risks of medical care and the individual and their families are supported. The following section speaks to the definitions of caring and curing as conceptual issues in healthcare.

Peter Kotzian (2003) defines caring

“as all other medical services, encompassing all medical ...activities without a direct impact on physiological health and the extension of life, but aiming at improvements of subjective quality of life, psychological well-being ...showing the patient that his

personal problems, perceived needs and wishes are taken seriously by the personnel of the HCS [healthcare systems]. A caring model results in more satisfaction of individuals and families with the healthcare system. There are three major functions of a caring model: easing of symptoms, enhanced autonomy and alleviation of anxiety. Healthcare providers meet the functions of care through responsiveness, which requires providers to take responsibility for attending to and meeting the needs of their patients. Responsiveness is a major factor in patient satisfaction.

(p. 69)

Virginia Held (2006) provides additional ways of understanding how healthcare providers meet the major functions of a caring model. She uses the term essence of care to describe how providers fulfill the functions of a caring model. Essence of care values emotions rather than rejecting them and holds persons as relational, rather than as self-sufficient independent individuals. To value patients' emotions is to understand and accept what they are experiencing. Relational care involves deeper and more meaningful interactions that extend beyond simply caring for the patient's physical state of health and understanding beliefs and values. Held sees "care" as a deeply fundamental ethical value that must be incorporated into the delivery of healthcare. When health cannot be restored, there is no limit to alleviating pain and suffering through a caring model. The research studies show differences between curing and caring need to be understood by healthcare practitioners, patients and families.

Curtis and Rubenfeld (2001) provide additional context for understanding the concept of curing. They define cure as the use of excessive treatments and resources to provide life-

sustaining medical care. To cure is the assumption that using advanced medical technologies in the delivery of medical care results in the highest quality of care being delivered. Cure does not wholistically assess the risks and benefits of the treatment intervention. A wholistic assessment would include knowledge of the state of the patient's bodily reserves which is a determinant of health. A body's reserves are those body systems such as the immune, neurologic, and endocrine that gives the body the capacity to respond to illness. When such reserves are diminished, "cure" is no longer effective in restoring health (Curtis & Rubenfeld, 2001).

Frailty, Futility and Existential Suffering

Cure requires understanding the concepts of frailty, chronic condition, and futility according to Lynn (2004). *Frailty* is the fragility of multiple body systems as their reserves diminish with age and disease. Frailty may already be a major path through the end-of-life, but seldom not recognized. Therefore, persons in a general state of decline are often labeled with "heart failure" or some other specific manifestation of their more general decline as opposed to their overall state of frailty. In a sense, fatal chronic conditions are those that occur when the rest of the body's systems have substantial reserves but one of its systems has greatly diminished capacity. In contrast, frailty is a fatal chronic condition in which all of the body's systems have little reserve and small upsets can cause cascading health problems.

Chronic conditions cannot be extricated from the delivery of care at end-of-life. Work done by Wolff, Starfield and Anderson (2002) has shown that as much as 45% of the general population and 88% of the population aged 65 years and older have one chronic condition or more and that more than 78% percent of all US health care expenditures are related to the treatment of chronic conditions. The prevalence of chronic conditions continues to increase. By 2020 an estimated 157 million Americans (nearly 50% of the

population) are projected to have at least one chronic condition. Therefore, it is not surprising that considerable attention has been directed toward designing treatment protocols to prevent or inhibit the progression of specific chronic conditions such as diabetes, asthma, or stroke. Sophisticated pharmacological therapies, disease management programs, and patient education efforts have been developed in an attempt to prevent progression of specific chronic conditions and to improve ongoing disease management. However, with rare exceptions, nearly all of these initiatives have focused on a single chronic condition (Wolff, Starfield & Anderson (2002).

Wolff, Starfield, and Anderson (2002) indicate that chronic conditions cluster, and that persons with one chronic condition are more likely to have other conditions. The figure below shows spending on behalf of people with multiple chronic conditions increases with the addition of each condition (Medical Expenditure Panel Survey, 1998). While current health care financing and delivery systems are designed primarily to treat acute conditions, 78% of health spending is devoted to people with chronic conditions.

Moreover, persons with multiple chronic conditions may have more rapid declines in health status and a greater likelihood of being frail. In terms of medical treatment, poor coordination of clinical services may predispose persons with multiple chronic conditions to errors of both omission and commission, such as adverse drug-drug interactions. Wolff, Starfield and Anderson (2002) found that individuals with chronic conditions were less likely to receive important routine outpatient medical treatments that were unrelated to their chronic condition. Contraindicated medical care may be especially problematic among the elderly population, as seniors are at greater risk for having multiple chronic conditions and may be more susceptible to complications of treatment as a result of physical frailty, complicated drug regimens, and poor coordination of care (Wolff, Starfield, & Anderson, 2002).

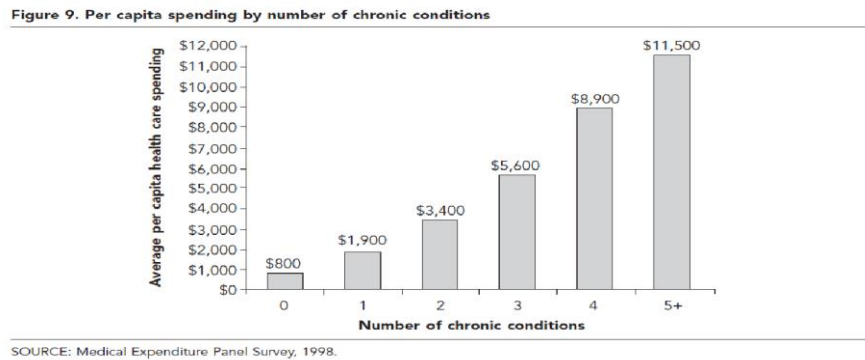


Figure 1: Image

Quality medical care for people with chronic conditions requires a new orientation toward prevention of chronic disease and provision of ongoing medical care and care management to maintain their health status and functioning. Specific focus should be applied to people with multiple chronic conditions. Anderson and Horvath (2004) define chronic conditions as those conditions that last a year or more and require ongoing medical attention and/or limit activities of daily living. Individuals with chronic conditions are in need of education to aid them in understanding their disease in order for them to make responsible health care decisions regarding their chronic condition as well as their end-of-life care.

In contrast, *futility* is a fatal chronic condition in which all of the body's systems have little reserve and small upsets result in cascading health problems. Schneiderman, Jecker, Jonsen (1990) describe futility as "any effort to achieve a result that is possible, but that reasoning or experience suggests is highly improbable and cannot be systematically produced" (p. 951). If a person is living with one or more fatal illnesses, very often the suffering imposed by treatment more than outweighs the possible advantage of success with treatment (Lynn, 2004). Curing is acceptable when focused on treating an acute illness in a healthy person. However, for individuals with advanced chronic diseases experiencing pain and suffering, a focus on cure and restoration of health may not be acceptable.

Existential suffering is complex, intense, inherently deep, broad, nuanced and a very personal experience. It is the pain of meaninglessness, disconnection from one's usual relationships and life and the loss of intactness of self (Cassell, 1991). Yalom (1980) holds that there are four basic domains that result in existential suffering.

Yalom (1980) posits

these domains are significant for the care of those facing end-of-life.

Freedom means that one always has the ability choose. The question of *meaning* and *meaninglessness*, where, e.g., relationships, spirituality, and even religion may (but do not have to) give meaning. *Existential isolation*, which refers to the fact that in certain situations, one can feel alone—even in the company of others—particularly prior to one's own death. *Death*, which is the source of a universal anxiety but also reflects life and makes the remaining life more intense and authentic. (p. 471)

Healthcare providers are generally more comfortable treating physical symptoms and are not particularly adept at dealing with existential suffering. Existential suffering, particularly at the end-of-life, does not necessarily involve physical pain (Strang et al., 2004). The concerns mentioned are those of treating pain and meeting all other needs that will enhance the comfort of the patient. Rather than being separate conditions of therapeutic interventions, caring and curing are mutually supportive and equally indispensable aspects of tending to the needs of the sick (Kottow, 2001). According to Glouberman and Mintzberg (2001), “We need to bring care and cure together more effectively to coordinate patient's services in hospitals and communities (p. 20). This literature suggests that when caring and curing are both considered, the quality of healthcare delivered is heightened and existential suffering is decreased.

Lynn and Adamson (2003) offer a model that illustrates how understandings of care and cure impact the delivery of healthcare for persons with serious illness. Physicians, nurses, administrators and allied healthcare workers should understand the influence of the models below on the patient's well-being during the end-of-life.

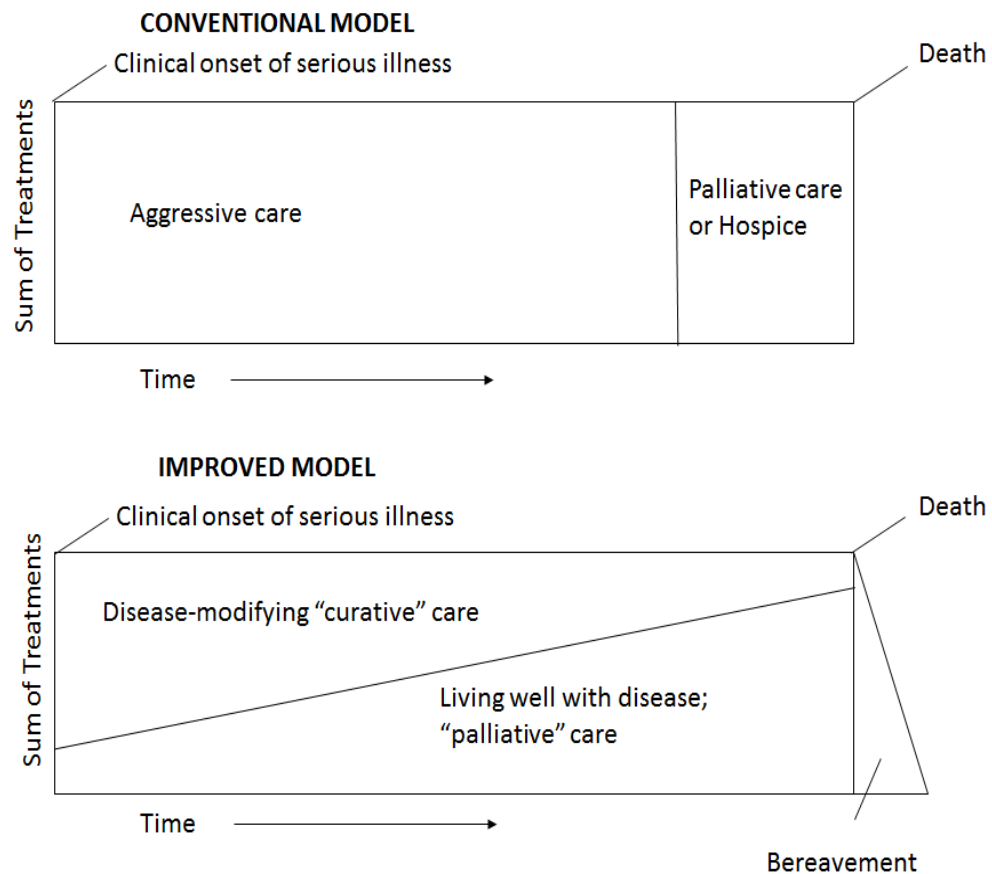


Figure 4- Appropriate care near end of life. Source: Lynn and Adamson

Figure 2

The diagrams illustrate how a curing and caring model differ. In the Conventional Model (curing) treatment continues until one is close to death. Only then does the implementation of comfort measures become paramount. In the Improved Model (caring) delivering palliative care enables the patient to experience a sense of well-being beginning at the outset of the delivery of care, with attempts to cure being diminished significantly over time. Palliative care is defined by the World Health Organization (1998) as an

approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 1998). Much work has been done and continues to be done in the quest to establish, as the means of treating individuals at the end-of-life, an improved model of care delivery.

In his book *Being Mortal*, Atul Gawande (2014) expresses his feeling on the state of the cure versus care issues in the healthcare delivery system.

Technological society has forgotten what scholars call the ‘dying role’ and its importance to people as life approaches its end. People want to pass on wisdoms, settle relationships, be peaceful spiritually, and ensure those that are left behind will be okay. This role is most important for both the dying and surviving. The way we deny people this role, out of obtuseness and neglect, is cause for everlasting shame. Over and over healthcare practitioners inflict deep gouges at the end of people’s lives and then stand oblivious to the harm done. (p. 249)

The quote by Gawande and information provided by others (Held, 2006; Johnson, 2008; Kotzian, 2003; Lynn, 2004) indicates that the population is aging and becoming frail. A “care” model delivering compassionate care results in comfort measures whereas a conventional model seeking to cure results in pain and suffering. A “care” model needs to be implemented throughout the healthcare delivery system.

End-of-life care is an area of healthcare that could be improved. Many individuals end up going to the emergency room and being admitted to the hospital in the last few months of life landing on what Colby (2006) calls the “institution glide path” (p. xii). Most Americans say they want to die at home, free from the burdens of machines and pain, in the

midst of their loved ones. Colby points out that one's actual fate is generally much different. Most individuals die in institutions, either the hospital or long term care facility, being encumbered by ventilator tubes, feeding tubes and restraints, isolated, and in pain Colby, (2006). One way of staying off the "institution glide path" would be to cut in half the number of emergency room visits and hospitalizations in the last two months of life by following the Medicare guidelines on hospital readmission rates. The Medicare readmission policy holds hospitals accountable for admissions prior to thirty days from discharge. High rates of readmission within 30 days of discharge from the hospitals may result from quality indicators not being met such as complications from treatments gotten during a hospital stay, inadequate treatment rendered, inadequate care coordination and follow up care in the community and unexpected worsening of disease after discharge from the hospital. Hospital readmissions may cause undue suffering to patients and their families and may lead to significant increase in health care spending if delivery of quality care given is not demonstrated (Kaiser Family Foundation, 2013).

Studies on End-of-Life Care

Lynn (2004) states now that many Americans live into old age before becoming seriously burdened with chronic illness. Issues of *frailty*, *futility* and *suffering* become central in creating a plan of care. Individuals hope to live as well as possible, even with serious illness. Lynn argues, "it matters to the individuals and those caring for them to ease symptoms, enhance autonomy, avoid bankruptcy, alleviate depression, and otherwise relieve what suffering can be relieved. We must reach beyond the folly of focusing only on prevention and cure" (p. 28). This section describes providers' perceptions, family perceptions and studies on education about the end-of-life care.

Provider's Perceptions on End-of-Life Care

The literature indicates that providers have mixed perceptions about end-of-life and what it means to wholistically treat the patient. In a study by Strang et al. (2004) chaplains and physicians who were trained to treat persons at the end-of-life participated in a study to examine their perceptions on treating suffering at the end-of-life. The aim of the study was to let chaplains, physicians in palliative care and pain specialists respond to the question: How would you define the concept of existential pain? According to Murata and Morita (2006), existential suffering is “pain caused by extinction of the being and the meaning of the self” (p. 279).

A combined qualitative and quantitative analysis of the question was conducted. (Strang et al., 2004) The results of the study suggest

chaplains described existential pain more often in terms of guilt, isolation and religious questions, while physicians focused significantly on death anxiety. Of the palliative physicians and healthcare providers who are pain specialists, 99% and 78% respectively had treated patients with existential pain. Physicians emphasized “the importance of actively including the existential components because untreated anxiety about dying, questions about meaning and existential isolation have a great significance for quality of life in the final phase of life”. (p. 247)

It is important to note again that these are healthcare providers are specially trained in caring for patients at the end of their lives. Their focus was not just on physical pain.

In a study by Breaden et al. (2012) the aim was to examine healthcare professionals’ (nurses, doctors and allied health workers) experiences of working with a patient’s refractory suffering, together with their clinical management plan of care. “Refractory

suffering is pain that is not relieved by ordinary medical, surgical, and nursing measures. The pain is often chronic and persistent and can be psychogenic in nature” (p. 897). A qualitative research design involving semi-structured interviews with seventeen experienced palliative care physicians participating; thirteen with face to face interviews 4 by an online questionnaire was used to collect data. Common across all the participants’ responses was the overarching theme of “negotiating uncertain terrain” (p. 899). As experienced clinicians trained to control symptoms and provide comfort, existential suffering took them into areas with which they were relatively unfamiliar. In an attempt to provide competent care, clinicians negotiated areas of uncertainty with no clear directions and few expert guidelines. The authors identified four areas where change was needed. Changing the approach from “fixing” to “being with,” maintaining perspective, negotiating boundaries and living the paradoxes.

According to Breaden et al. (2012) having been trained to manage and control symptoms, clinicians realized the limits of their training in dealing with existential suffering. There needed to be a change in perspective and a commitment to “being with” the suffering persons. This study identified the wisdom of taking time to think, of waiting for patients, family and staff to work through all they needed to and checking that all that needed to be done was being done. Negotiating and maintaining boundaries entailed recognizing the difference between therapeutic and personal relationships. Living the paradoxes was riddled with complexity. The clinicians had to “stay with” the patient providing comfort, while knowing they had no ability to cure. The clinicians had to acknowledge their own distress, while providing compassion and care. The clinicians also had to accept realistic limits while doing everything possible to ease existential suffering. The study identified several aspects relating to existential suffering. The terrain of suffering is uncertain and largely unexplored. Breaden et al. advise “Guides are needed in this

challenging area, guides who are courageous, who are prepared to undertake a pilgrimage alongside the suffering person, and who can provide a human connection in a dark place” (p. 900).

A study by Ferrand et al. (2003) evaluated the perceptions of caregivers involved in the process of deciding when to withhold or withdraw life-supporting treatments. Over the last decade decisions to forego life-sustaining treatment have become commonplace in intensive care units. Each caregiver was asked to complete a questionnaire. Univariate analysis was used to compare variables of interest; multiple logistic regression analysis was performed to examine relationships between caregiver characteristics and their perception on decisions to forego life-sustaining treatments (DFLST). The results of this study indicated the following: nursing staff were dissatisfied with the DFLST process, there were differences between nursing staff and physicians with the physicians being satisfied with the procedures, and “fear of litigation clearly had an unfavorable influence on the quality of DFLST procedures” (p. 1315).

The findings of the above studies are clear. Health care providers and chaplains understand and accept the importance of actively including the components of existential suffering in their care of patients because untreated anxiety about dying, questions about meaning and existential isolation have a great significance for quality of life in the final phase of life. However, the term existential suffering is ambiguous and provoking for healthcare providers. Health care providers need educational opportunities to better understand the concepts of existential suffering and refractory pain in order to have effective communication around end-of-life care choices with patients and their families. Traversing the uncertain terrain of suffering when the cause of suffering and resolution of that suffering appears impossible is confusing and causes anxiety for all involved in the patients care. It is heart wrenching for all involved in the patients care when there are few

guides as to what to do and when all attempts at palliative care fail and a person continues to suffer. Caregivers believed that decision making should be collaborative but frequently felt unprepared to provide many key components of good care for the dying. Current educational practices and institutional culture in the delivery of care do not support adequate end-of-life care.

Patient and Family Perceptions on End-of-Life Care

End-of-life care is a complex, sensitive area which presents many challenges for healthcare providers, patients and families. Steihauser et al. (2000) studied the factors of importance at end-of-life by patients, families and their care providers. The study was done to determine what was integral to the success of improving care. The study was a cross-sectional, stratified random national survey. There were 1462 dying patients in the study. Dying patients face complex and unique challenges that threaten their physical, emotional and spiritual integrity. This study of dying patients concluded that “although pain and symptom management are important, communication with one’s physician, preparation for death, and the opportunity to achieve a sense of completion are the most important factors [at the end of one’s life]” (p. 2476).

Heyland, et al., (2006) studied what mattered most in end-of-life care. The primary purpose of the study was to describe what seriously ill patients in hospitals and their family members considered to be the key elements of quality end-of-life care. This is a quantitative study for which a cross-sectional survey was designed. A face to face questionnaire was administered to 440 patients with serious illness and 160 family members of those patients. They identified these elements of care as being most important when determining a patient’s advance care choices. The elements included: trusting one’s doctor, not being kept alive on life support when there is little hope for a meaningful recovery, effective communication between care providers, patients and their families, being able to complete things and prepare for life’s end. The authors also noted that patient and family preferences may change as death approaches and suggested this may be influenced by deficiencies in care being given as life’s end nears.

Say et al. (2005) examined patients’ preferences for involvement in medical decision making. Increasing emphasis is being placed on involving patients in making decisions

about their care. Shared decision making is the model in which doctors and patients exchange information regarding treatment, risks and benefits of interventions, then deliberate and decide the treatment moving forward together. This study reviewed quantitative, qualitative and a mixed method studies from 1975-2003 using online databases. The conclusions of this study noted that “in the context of socio-political change patient involvement in decision making has become an important issue for healthcare professionals and an understanding of and responsiveness to individual patient’s preferences is important in improving the quality of care provided” (p. 112). Involving patients in decision making improves quality, positively impacts health outcomes and improves concordance between healthcare providers, patients and families, while increasing patient satisfaction.

Studies on Education on End-of-Life Care

There are many studies on end-of-life care education. Connors, Lynn et al. (1995) did early, foundational work on end- of- life care treatment. The SUPPORT study brought into focus the state of end-of-life care and the need to educate healthcare providers, patients and families on the need to transition from a Conventional Model (Curing) to an Improved Model (Caring).

In 1989 over a four year period, a group of researchers conducted the largest study of death and dying ever done in the United States. Dr. Joanne Lynn was the principal researcher responsible for the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, called by its acronym SUPPORT which enrolled 9,105 seriously ill patients from five teaching hospitals around the country. The initial goal of the project was to better understand how decisions were made for the seriously ill patients to provide better information about what treatment could accomplish, and then to provide better support for the decision makers.

The study had two phases: an investigative phase, then an interventional phase. The results of the investigative phase of SUPPORT were disquieting. The reason for this disquiet was because half of patients facing their life's end suffered pain that went untreated before they died. Living wills, when found at all, were vague and they did not include do-not-resuscitate (DNR) orders; consequently, patients often died after prolonged stay in Intensive Care Units (ICU). Doctors and families simply had no idea what the patient's preferred. Some five thousand of the original subjects recruited for the study died during the investigational phase of the study. The results of this study left many issues to be dealt with in future research such as, what types of educational programs should shape preferences and beliefs about end-of-life care.

The interventional phase of the study was carried out from 1992-1994. Dr. Lynn and her fellow researchers sought remedies to address the results of the investigative phase of SUPPORT. They divided the study participants into two groups. The control group received no additional services or counseling to help them make informed decisions. The physicians in the intervention group received estimates of the likelihood of 6-month survival, estimated outcomes of cardiopulmonary resuscitation (CPR) and estimated functional disability at 2 months. A specially trained nurse had multiple contacts with the patient, family, physician, and hospital staff to elicit preferences, improve understanding of outcomes, encourage attention to pain control, and facilitate advance care planning and patient-physician communication.

The phase I observation of SUPPORT confirmed substantial shortcomings in care for seriously ill hospitalized adults while the phase II intervention failed to improve care or patient outcomes with the interventions. The significant interventions, however, made no difference in how decisions were made in the intervention group nor changed the basic patterns of care the intervention group received. The failure of the interventions to change

behaviors was complicated. The conclusion was that although there were many layers to the failure of the interventions, all were produced in one way or another by medical technology. In order to enhance the care given to the dying patient, a commitment must be made by patients, families and the medical community to be forward thinking and dedicated to improving the quality of care as one dies. Enhancing opportunities for more patient-physician communication, although advocated as the major method for improving patient outcomes, may be inadequate to change established practices. The SUPPORT study conducted by Dr. Lynn and her colleagues (2004) showed that focusing only on prevention and cure has been the preferred model of healthcare in the past and continues to be the case today. Dr. Lynn stated, “our priorities should reflect an effort to maximize comfort and capabilities as well as length of life” (p. 42).

The Duke Study on Culture and End-of-Life Care Johnson, Kuchibhatla and Tulsky (2008) sought to determine how knowledge, social support, beliefs about spirituality, death and dying, advance care planning, and mistrust of the healthcare system influence attitudes toward end-of-life care decisions made by adults. Cultural beliefs are essential to perceptions of illness. Understanding how culture impacts end-of-life care choices may aid in reducing disparities in health care outcomes. The study suggested that cultural values, beliefs and family practices may have significant relevance at the end-of-life. This study was a cross-sectional survey of 205 adults over sixty-five years of age who participated in a phone interview. The results of the Duke Study have implications for the design of healthcare delivery models and development of programs, which provide culturally-sensitive end-of-life care to a growing population of diverse adults. The results of the study also have implications for developing policies and programs that may improve end-of-life care. The challenge for healthcare providers revealed by this study and others is to develop,

evaluate and present programs which serve a broad range of individuals with differing cultural beliefs, values, and preferences.

A study by Sullivan et al. (2003) was done to assess the status of medical education in end-of-life care and identify opportunities for improvement. A telephone survey was conducted with medical students, residents and faculty at 62 accredited United States medical schools. Packets of information were sent soliciting potential participants. A twenty five minute telephone survey was conducted with those willing to be part of the project. Assessed in the conversations were attitudes, quantity and quality of education, preparation to provide and teach care, and perceived care for the dying patient. The results of the study indicated that students and residents in the United States feel unprepared to provide and faculty and residents unprepared to teach key components of good care for the dying. Current educational practices and institutional culture in U.S. medical schools do not support adequate end-of-life care and attention to both curricular and cultural change are needed to improve end-of-life care education.

Conceptual Frameworks

The process of transformational learning is generally initiated by a disorienting dilemma, is considered irreversible and is never neutral. The disorienting dilemma leading to a search for new meaning often evolves from loss and knowing there is a need to go forward. The crisis fosters a deep exploration of meaning of one's life. Transformational learning is generally irreversible, profound and occurs in unexpected ways. Accumulative transformational learnings, over extended periods, gradually lead one to embrace a changing worldview. That transformational learning is never neutral is explicated by Paulo Freire (2011) in his work, *Pedagogy of the Oppressed*. "There is no such thing as a neutral educational process...it becomes the practice of freedom, the means by which men and

women deal critically and creatively with reality and discover how to participate in the transformation of their world” (p.34).

The components of the transformational learning process as described by Merriam, Caffarella and Baumgartner (2007) are experience, critical reflection, reflective discourse and action. *Experiences* for the adult learner functions in several ways. Adult learners are important resources for learning for themselves and others.

The adult learner needs to make sense of his or her life’s experiences as a reason for engaging in a learning experience. Adults use experience in learning to reintegrate or transform meanings and values. However, adults past experiences can become barriers to transformational learning. According to Mezirow, (1997), a defining condition of being human is that we have to understand the meaning of our experience. In contemporary societies we must learn to make our own interpretations rather than act on purposes, beliefs, judgements, and feelings of others. Facilitating such understanding is the major goal of adult education.

The total of life experience, the composition of that experience, the development issues adults face, as well as how aging affects memory are the foundations of how adults learn. Adults are a complex mix of experiences that defines their world. The experiences selectively shape and delimit expectations, perceptions, cognition and feelings. When circumstances permit, transformative learners move toward a frame of reference that is more inclusive, discriminating, self-reflective, and integrative of experience (Mezirow, 1997).

Critical reflection posits Cranton, (2002) “is the means by which we work through beliefs and assumptions, assessing their validity in the light of new experience or knowledge, considering their sources and examining underlying premises” (p. 65). Reflection enables us to recognize the distortions in our beliefs and examine the

assumptions on which our beliefs are built. Reflection is to seek an understanding of how and why we have perceived, thought, felt and acted. Acting on what is already known is not reflection it is simply taking action. The most significant learning experiences in adulthood involve critical reflection. It is the learning that takes place after one assess the problems that are posed and one's orientation to perceiving, knowing, believing, feeling and action on the dilemmas one faces Mezirow, (1990).

Reflective discourse as studied by Merriam, Cafferella and Baumgartner, (2007) “involves an effort to set aside bias, prejudice and personal concerns and to be objective in presenting and assessing reason and reviewing the evidence and arguments... to arrive at a consensus” (p. 255). Transformational theory holds that moral values are legitimized by agreement through discourse. The claim is that if everyone could participate in a discourse, under the ideal conditions of discourse, there would be universal rational consensus concerning those values. Transformational theory holds that moral values are legitimized by agreement through discourse (Mezirow, 1990).

Action is taken according to Apte (2009) when a person's perceptions change enabling them to see things differently and act differently in the world. Ways that health educators can encourage conversations about change when people are in a reflective phase are to accept that the person may not be ready for change at the time and to present information that may be reflected on at a later time. In order to minimize the risk of resistance to acceptance of the information presented; exploration of the issues, a person's current perceptions, and an acknowledgement that change may not occur must be conveyed.

According to Knowles (1984) “to develop the capacity to form opinions independently and clarify beliefs... Information, no matter how accessible, is useless—and perhaps even dangerous—without sagacity to understand one's own belief structure and the capacity to develop well-informed substantial opinions” (p. 165). I suggest this challenge is

further complicated when an individual is faced with making choices about care at the end-of-life, while experiencing existential suffering.

Encouraging the acquisition of information on critical educational issues necessitates the identification and understanding of the information. To foster such developments the adult learner must actively engage in a number of transformational learning strategies requiring the examination of values and beliefs, context and experience and competing worldviews. The goal of this project is to equip the learners to understand, contemplate and enhance their ability to challenge long standing misperceptions on curing versus caring as one makes end-of-life care decisions.

Moral Learning

Noddings (2002) explicates the components of moral learning. The first component of moral learning is modeling. Modeling is putting one's self forward as an example of how being moral can be achieved. Reflection is essential in assessing one's competence and ability to model. Dialogue is a fundamental component of moral learning. Dialogue is not just conversation. Participants in the process of moral education both speak and listen. Dialogue is central to moral education because it always implies the question and permits discourse in a safe setting. Programs of moral education concentrate on helping others develop moral reasoning. Noddings states "immortal conversations" are more deeply concerned with content than with process. Matters of birth, death, cruelty, pain, misfortune, love and good fortune are of interest to people and get far too little attention (p. 136).

Brookfield (1998) posits the following pattern on which an episode of moral learning, within the context of adult life, enters a person's mind. This condition of moral learning is prompted by an "unexpected occurrence which occasions reflection on the discrepancy between the assumptions, rules and criteria informing our moral commitments and actions and our experience of reality" (p. 285). Moral learning and transformational

learning are inextricably intertwined. Both are critical if education on end-of-life choices is to promote the use of a caring model not a curing model. This end will be achieved when, through deliberative discourse, significant conclusions about one's end-of-life care are reached.

Summary

The literature has validated that the American healthcare system is complex, expensive and not meeting the needs, effectively, of those desirous of compassionate care. Attempts to cure disease processes with little to no hope of efficaciously resolving their condition are generally not in the best interest of the patient (Callahan, 2009; Cassell, 1991; Emmanuel, 2014). A study by Sullivan et al. (2003) has shown that current educational practices and institutional culture in U.S. medical schools do not support adequate end-of-life care. Attention to both curricular and cultural change is needed to improve end-of-life care education. A study by Steinhauser et al. (2000) found that health care providers are unable to provide a context for delivering compassionate care helping patients to resolve their existential angst as they approach death.

Transformational learning strategies require the examination of values, beliefs, context, experience and competing worldviews. The goal of this project is to equip the learners to understand, analyze and improve their ability to challenge long standing misperceptions on curing versus caring as one makes end-of-life care decisions. We need to break down the barriers between care and cure. When caring and curing are both considered, the quality of healthcare delivered is heightened and suffering is

CHAPTER 3: RESEARCH METHODOLOGY

Modern bioethics is not simply concerned with experimentation on human subjects and humane medical treatment. From its inception it has been concerned with the participation of patients and communities in decisions about socio-economic issues of access and distribution of scarce resources (Garrett, Jotterand, & Ralston, 2013). It cannot be said with certainty when the evolution of bioethics as a distinct field of study dealing with moral conduct as it relates to medicine began; however, it is clear that the catalyst for the creation of bioethics as an interdisciplinary field of study was the extraordinary advances in American medical technology. New medicines, dialysis machines, organ transplantation, mechanical ventilation support systems, medically delivered nutrition, intensive care units (ICU's) and lifesaving surgeries made possible a level of medical care never before attainable. With each new development, new ethical dilemmas were created, along with the idea of a "dark side" to this growing technology (Colby, 2006).

Ethics guidelines aim to guide reflection, judgement and action in providing good care near the end-of-life and, in particular, to provide an ethical framework for making decisions under conditions that are challenging and sometimes psychologically distressing (Beauchamp & Childress, 2009). They can help ensure that decisions are made with appropriate knowledge, deliberation, transparency and fairness, safeguarding vulnerable patients. The ethics guidelines protect against under-treatment, denial of pain medication, physical therapy and general comfort measures. The immediate consequences of under-treatment are pain and discomfort. When treating to cure is replaced by treating to comfort, the consequences are beneficial. The ethics guidelines also protect against over-treatment that would cause individuals suffering and prolong life regardless of cognition or

consciousness. For most patients, consequences of over-treatment include pain and symptoms that result in suffering, helplessness and loss of self, diminished ability to do things that have meaning and give pleasure, and financial cost and stress imposed on patients and their families (Berlinger, Jennings, & Wolf, 2013). Over-treatment as described above is in no small measure, “the dark side” of technology, experienced by those facing the end-of-life.

The purpose of this study, conducted in a large city in the southeastern United States, is to determine the extent to which a brief educational program about the nature and consequences of advanced medical technology changes beliefs about end-of-life care choices and shapes perceptions about those choices among adults. If the United States is to have a sustainable health care delivery system functioning in a just society, the need is great to provide: basic care for more patients, inform individuals on making choices that will provide them death with dignity and promote discourse as to whether human life should be prolonged without consideration given to quality of life.

Research Design

The researcher used a one group pre-test, post-test design to determine the extent to which exposure to transformational material, influences an adult’s understanding about end-of-life care choices, as well as to be aware of how patients’ perceptions may affect their own end-of-life care choices. This type of design is pre-experimental and can provide tentative evidence of the effectiveness of treatment by examining differences in scores on the dependent variables of interest prior to and after the intervention. The transformational education program, designed by the researcher, consists of a forty-minute presentation followed by a twenty-minute question session. For those who could not attend the presentation, written materials were prepared and mailed to them. These were professional

colleagues and family members who reside out of town. Further details on the program are provided later in the chapter.

Situations for which the one group pre-test, post-test design is appropriate are those that require the behavior to be measured (learning) when that behavior is not likely to change without intervention (treatment). This design can have several sources of experimental invalidity due to the lack of a control group. The validity of the proposed study is strengthened due to the short time frame of the study which controls for threats of history and maturation. Due to the short time between the pre-and post-test, one hour, there arguably is not sufficient time for reflection and discourse. However, because it is anticipated that participants will have a low to moderate level of knowledge about end-of-life choices prior to treatment, this is not a strong threat to validity in the researcher's opinion. Instrumentation threats are controlled in this study through the use of identical pre-and post-tests for all participants.

Research Questions

The purpose of this study is to understand the extent to which a brief transformational education program on end-of-life care choices can change beliefs and perceptions. Transformational learning hinges on reflection and discourse in order to effect lasting change. Three related research questions were explored:

1. To what extent is spirituality related to pre-intervention beliefs and preferences about end-of-life care?
2. To what extent does participation in a brief transformational education program change adults' preferences about end-of-life care, overall and by delivery type?
3. To what extent does participation in a brief transformational education program change adults' beliefs about the use of artificial means to extend life, overall and by delivery type?

Transformational Learning Theory, (Mezirow, 2000) serves as the theoretical framework for this study and can be defined as the “process of using a prior interpretation to construe a new or revised interpretation of the meaning of one's experience in order to guide future action” (p.132). There are four main components of the transformational learning process: experience, critical reflection, reflective discourse and action. The process is most often set in motion by a disorienting dilemma (Merriam, Caffarella & Baumgartner, 2007).

Sampling and Participants

To recruit a representative volunteer sample, the researcher sent a letter requesting agreement to host the program to the appropriate representatives at 6 proposed sites. The sites were chosen to represent a diversity of age, race/ethnicity, socio-economic status, religion, and level of educational attainment. Eligibility for participation in the program included being at least 18 years of age with no known cognitive impairment or dementia. To

recruit a representative volunteer sample, the researcher sent a letter requesting agreement to host the program to the appropriate representatives at 6 proposed sites. The sites were chosen to represent a diversity of age, race/ethnicity, and level of educational attainment. The chosen sites included a program for individuals with disabilities, the Emergency Medical Services Paramedic Training Program, a church-affiliated Bible Study Group and a Bereavement Ministry group from a local church. The program for adults with disabilities included members of the disability community comprised of various professional, racial, ethnic and gender backgrounds as well as varying education and age levels. The Emergency Medical Services Paramedic Program participants were mostly under the age of 40, making them younger than the participants at the other sites. This group had racial, ethnic, gender and educational diversity. The Bible Study Group consisted of white women between the ages of 34 to 50, all with bachelor's degrees or higher. The Bereavement Ministry Church Group consisted of black women between the ages of 41 to 60. They all had bachelor's degrees or higher. The mail groups consisted of professional colleagues and family, and friends. The professional colleagues were of racial, ethnic and gender diversity, all having technical degrees or higher. The family members and friends were predominately white, with both males and females, aging from twenty-five to seventy. All had a technical degrees or higher. Invitations to members of the communities identified were announced at church services or organizational events, as well as email (Appendix B).

Eligibility for participation in the program included age (at least 18 years of age) and no known cognitive dissonance or dementia. The ideal number of participants for each session was 15-20 to permit adequate opportunity for participant questions and discourse, while the final number per site was between 6 and 30. Participants completed an informed consent form indicating their consent to participate in the study. They attended the entire program session, or completed a reflective reading of the information in the packet sent via

mail. The researcher assumes that the individuals were representative of the groups from which they are members, individuals understood the presentation / reading materials, and that individuals were reflective and answered truthfully.

The final total number of participants consisted of 106 adults, 18 years of age or older, who volunteered to participate in the end-of-life care choices program at 4 different sites in a large city in the Southeastern United States. Two groups, family and professional colleagues, received a mailed packet. The sample selected was a diverse group of individuals including 5 ethnic backgrounds, ranging in age from 18 to 70, with an identified marital status of being single, married, widowed or divorced. Education ranged from high school graduate through post graduate /professional degrees, while health ranged from excellent to poor. Specific demographic differences among the sites, is evidenced below.

Table 1: Demographic characteristics of participants, total and by intervention

Variable		Mail	Program	Total	% of Total
Ethnicity	White	40	45	85	80%
	African American	2	15	17	16%
	Asian	0	1	1	1%
	Hispanic	0	2	2	2%
	American Indian	0	1	1	1%
Gender	Male	23	30	53	50%
	Female	19	34	53	50%
Age	18 to 25	0	23	23	23%
	26 to 30	5	5	10	9%
	31 to 40	10	10	20	20%
	41 to 50	8	15	23	22%
	51 to 60	7	9	16	15%
	61 to 70	12	2	14	13%
Marital Status	Married	30	25	55	51%
	Single never married	7	35	42	40%
	Widowed	2	1	3	3%
	Divorced	3	3	6	6%
Education	High School	2	2	4	4%
	Some College	14	22	36	34%
	College	17	29	46	43%
	Post Graduate / Professional	9	11	20	19%
Health	Excellent	12	11	23	22%
	Very Good	24	37	61	58%
	Good	4	14	18	16%
	Fair	2	1	3	3%
	Poor	0	1	1	1%

Data Collection and Instrumentation

Program participants completed pre- and post-tests as part of their participation in the program. Total time for the onsite program delivery was 60 minutes, while a similar amount of time was anticipated for individuals who participated via the mailed information packet. The questionnaires were pre-coded in pairs with a four-digit code to identify the venue, participant number, and test (pre or post).

The instrument for this study incorporated demographic items and three sections of questions developed for the Duke Study on Culture and End-of-Life Care, Duke University School of Medicine; Johnson, Kuchibhatla & Tulsky, (2008). The Duke study sought to determine how knowledge, social support, beliefs about spirituality, death and dying, advance care planning, and mistrust of the healthcare system influence attitudes toward end-of-life care decisions made by adults. The researcher chose 21 items, 7 on preference, 7 on beliefs and 7 on spirituality, as well as 7 items to gather demographic information (Appendix D).

Preferences for End-of-Life Care

Seven statements about wanting to live as long as possible were examined. In this section the respondent chose whether they wanted to live as long as possible; if they had an incurable, terminal condition, if they were on life support, if their brain was not functioning, if they had a feeding tube and if they were in severe pain. The respondents chose: whether they wanted to be comfortable or live as long as possible, be at home or in the hospital, and if they wanted to stay at home, would they consider being taken to an Emergency Room when in crisis.

Beliefs about Dying

Seven statements regarding beliefs about dying and being comfortable with talking about death were examined. The respondents were asked if they were dying would they want to be told and would they want to tell their family. Did they believe dying was a normal part of life? Did they agree or disagree that artificial means to extend life are short term, expensive and should be avoided? Did they know what kind of treatment they wanted when dying and did they tell their families about their end-of-life care choices?

Spirituality

Seven statements regarding spiritual beliefs about suffering and death were examined to determine if the study participants believed the following. God determines whether I live or die. Pain and suffering is sometimes part of God's plan. God sometimes wants us to suffer while we are dying. Those who believe in God would want everything done to keep them alive even if they had a disease like cancer that could not be cured. Accepting that you are going to die means you do not have faith. Those who believe in God do not need hospice.

Demographic Characteristics

Six of the demographic items only appear on the pre-test instrument. Participants were requested to self-report race/ethnicity, gender, age, current marital status, highest level of education completed, and general health. The race/ethnicity categories included African American, Asian American, Latino/Hispanic, and Caucasian. Age (in years) was reported in the following eight ranges: 18-25, 26-30, 31-40, 41-50, 51-60, 61-70, 71-80, and over 81. Marital status was identified as single, never married, married, separated, divorced or widowed. Participants were asked to report the highest level of education completed: less than high school, high school graduate, some college or technical training and post graduate or professional degree. Health was assessed as being from excellent to poor on a 5 point

scale. The seventh demographic item; preference of place for dying (home, hospital, nursing home or other) appears on both the pre-test and post-test.

The description of the three scales is shown in Table 2. All of the items are rated on a five-point Likert Scale from Strongly Agree (5) to Strongly Disagree (1). Cronbach's Alpha was used for each of the three scales to demonstrate the reliability of the questions. In previous research, Johnson et al., (2008), and similar levels of internal consistency were found in the current study.

Table 2. Instrumentation, scoring, and internal consistency for three scales

Scale / Variable	Score Range	Score Meaning	Example Item	Cronbach's Alpha
Preferences for end-of-life care	7 - 35	<p>Scores approaching 35 indicate desire for comfort care</p> <p>Scores approaching 7 indicate desire for use of all treatment options</p>	<p>Pain free, comfortable, able to interact with family and friends, be at home</p> <p>Initiate CPR, use of ventilator, feeding tube, dialysis and remain in hospital</p>	0.75

Beliefs about dying and advanced care planning	7 - 35	Scores approaching 35 indicate a sense of peace about dying Scores approaching 7 indicate a desire to live as long as possible, no matter the consequences	Comfortable with talking to family and physicians about dying, the care preferred, Advanced Care Plan in place, Fear dying and have no plan of care in place to prohibit the use of all treatment measures	0.72
Spirituality	7 - 35	Scores approaching 35 indicate a trust in an ability to make well-reasoned decisions Score approaching 7 indicate conflict with Comfort Care measures	A belief in using all measures available to achieve a meaningful life while in the dying process Desire to live as long as possible in any condition	0.62

AARP North Carolina End-of-life Care Survey

Spirituality was included in this study to understand possible relationship to beliefs and preferences prior to the intervention (research question 1). The nature of the program intervention did not address spirituality nor assume there would be any changes in spirituality as a result of the brief program. While initially it was assumed that the entire end-of-life care preferences scale would be used to examine research question 3, the researcher determined that one's spiritual beliefs could not be expected to change due to the nature of the intervention. This decision is discussed in more detail in chapter 4.

Intervention/Treatment

The program consists of an informational session provided by the facilitator, including a PowerPoint, a video and a question-and-answer session. The program agenda and information sources for each component are shown in Table 3.

Table 3: Agenda and description for program sessions at local sites

Program element	Time	Description	Information source
Overview	5 minutes	Intertwined Evolution of Medical Technology and Bioethics	Garrett, Jotterand & Ralston, 2013
Case Review	5 minutes	Cases of Dax Cowart and Terri Schiavo	Jonsen, Siegler & Winslade 2010 Colby, 2006
Information Sharing	20 minutes	Cardiopulmonary Resuscitation Mechanical Ventilation Feeding Tubes Kidney Dialysis	American Heart Association American Thoracic Society American Society of Gastroenterologists Hart & Evans, 1987
Legislative Milestones	8 minutes	Women of the Movement	Speer, 2013
Case Review	2 minutes	Case of Brittany Maynard	Castro, 2015
Question and Answer	20 minutes	Interactive session of answering questions	Participants in the program

The program begins with a historical description of how the evolution of advanced medical technology and the field of bioethics were intertwined. The case of Dax Cowart speaks to issues of the denial of an individual's autonomy or right to choose his or her own treatment. The case of Terri Schiavo speaks to the issues of what constitutes quality of life and who gets to make that decision when an individual is incapable of doing so.

Descriptions of medical treatments that will prolong life when an individual is critically ill are a key component of the program session and informational materials. Those treatments include the following four procedures.

Cardiopulmonary resuscitation is the use of chest compressions and artificial ventilation to maintain circulatory flow and oxygenation during cardiac arrest.

Mechanical ventilation is the use of a machine that makes it easier for patients to breathe until they are able to breathe completely on their own.

Feeding tubes are designed to offer nutrients to patients that are sick or have swallowing complications. Feeding tubes offer liquid nutritional supplements to patients that can't take in food or drink by mouth.

Dialysis is a treatment that assists with some of the functions done by healthy kidneys. It is needed when kidneys can no longer take care of the body's needs.

The advantages and disadvantages of using each of these medical technologies as well as the expected outcomes of each are also addressed in the program and informational materials.

There were significant legislative milestones that were met to achieve the Patient Self Determination Act, (1990). The individuals and their families that participated in lawsuits to achieve the necessary legislative protections of one's rights will be reviewed. The participants were encouraged to question the knowledge put forward with intensity. An alternative intervention was developed for individuals who could not attend one of the program sessions. The intervention was a mailed packet consisting of an informed consent form; a pre-test and post-test; and information on four treatment interventions including cardio-pulmonary resuscitation, mechanical ventilation, feeding tube insertion and dialysis. Suggestions for viewing material on cases with significant ethical issues were also provided. In light of the preceding information, the researchers' healthcare experience and the knowledge that the current healthcare delivery system is not sustainable, Callahan, (2009), Emanuel, (2014), & Fleck, (2009) the researcher intends to demonstrate how a brief transformational learning education program can influence an individual's preferences and

beliefs about end-of-life care. Caring for and providing comfort, not curing, demand the examination of the factors and practices leading to the excessive use of ineffective treatment and interventions that expose the “dark side” of technology. The need is great to provide basic care for more patients and inform individuals on making choices that will provide them death with dignity. Caring for and providing comfort, not curing, demand the examination of the factors and practices leading to the excessive use of ineffective treatment interventions. These factors are:

- the availability of medical technology,
- unraveling the intertwined issues of futility,
- the necessity for the delivery of care grounded in compassion, discernment, trustworthiness, integrity, and conscientiousness.

Data Analysis

The pre- and post-tests were coded to identify location and test type. Numbers were used only to match the pre- and post-tests and no identifying information was collected from the participants. Participant responses were entered into an SPSS database by the researcher, and all analysis was conducted using SPSS 21.0. The researcher employed descriptive statistics, including frequencies, means, and standard deviations, to explore the demographic characteristics of the participants and the dependent variables in the three research questions. A non-parametric statistical test Wilcoxon Signed Rank (WSR) test) was used for the analyses of research questions 2 and 3, taking into account the nature of the data. Research question 1 was evaluated using bivariate correlation among the three scales. Statistical significance for all tests was evaluated at the $\alpha < .05$ level.

Summary

This study used a one group pre-post-test design, with the program material exactly the same pre-post-test. Some participants, colleagues and family, could not attend in person

and read the material, sent by mail at their convenience, to determine the extent to which participation in a brief program influences the beliefs and perceptions of an adult learner about end-of-life care choices. The program was developed by the researcher (sources identified and credited in Table 3), and the instrumentation for the study was developed from existing measures developed by faculty at Duke University to assess beliefs and preferences about end-of-life care. The proposed analysis plan included descriptive statistics to evaluate and describe the sample characteristics, while correlation and nonparametric statistics were proposed to examine the three research questions. Participants were volunteers who either attended the program at one of 4 different sites or received the mailed packet and returned the pre- and post-tests (44 returned).

CHAPTER 4: RESULTS

Beliefs and preferences regarding end-of-life care are central to perceptions of illness and care choices made at the end of one's life. Understanding how these beliefs and preferences impact the treatment received during the terminal phase of illness is essential in determining if an individual will choose comfort care or a quest for a cure. The purpose of this study is to determine the extent to which education about the nature and consequences of advanced medical technology influences beliefs and shapes perceptions about the end-of-life care choices adults make in a large city in the southeastern United States make.

The following research questions were explored.

1. To what extent is spirituality related to pre-intervention beliefs and preferences about end-of-life care?
2. To what extent does participation in a brief transformational education program change adults' preferences about end-of-life care, overall and by program delivery type?
3. To what extent does participation in a brief transformational education program change adults' beliefs about the use of artificial means to extend life, overall and by program delivery type?

The program delivery type was either a presentation and Q&A session led by the researcher (four sites, n=63), or a mailed packet of information (n=43). The packet of information included a pre-test, information on the risks and benefits of treatment intervention and a post-test. The treatment interventions listed in the packet explained the risks and benefits of cardio pulmonary resuscitation (CPR), mechanical ventilation, feeding tube placement and kidney dialysis, as outlined in Chapter 3.

The Null Hypothesis was stated as:

H_0 there is no difference within population's survey scores or between population's survey scores before or after end-of-life education has been delivered.

H_a there is a difference within population's survey scores and between population survey scores both before and after end-of-life education has been delivered.

Descriptive Analysis

Prior to conducting the analyses for the research questions, the researcher explored the descriptive statistics for the dependent variables of interest. Data were examined separately for the pre-test (Table 2), post-test (Table 3), and then compared to note differences pre-post (Table 4).

Table 2 Descriptive statistics for dependent variables on the pre-test, total and by program type						
		N	Min	Max	Mean	SD
Beliefs	Total	106	13.00	35.00	27.72	3.83
	Presentation	63	13.00	35.00	26.62	3.78
	Mail	43	20.00	35.00	29.33	3.35
Preferences	Total	106	14.00	35.00	30.02	4.10
	Presentation	63	14.00	35.00	29.67	4.24
	Mail	43	23.00	35.00	30.53	3.89
Artificial Means	Total	106	1.00	5.00	3.35	1.14
	Presentation	63	1.00	5.00	3.22	1.13
	Mail	43	2.00	5.00	3.53	1.14
Spirituality	Total	106	19.00	35.00	25.84	3.98
	Presentation	63	19.00	35.00	25.37	3.99
	Mail	43	19.00	33.00	26.53	3.92

The pre-test data display several characteristics worth noting. For all three preferences and beliefs variables (beliefs, preferences, artificial means), the mail intervention mean score was slightly higher than the presentation mean score. Standard deviations for the mail intervention group were lower than the presentation intervention group for all except the artificial means variable.

Table 3 Descriptive statistics for dependent variables on the post-test, total and by program type						
		N	Min	Max	Mean	SD
Beliefs	Total	106	19.00	35.00	27.94	3.57
	Presentation	63	21.00	35.00	27.21	3.36
	Mail	43	19.00	35.00	29.02	3.63
Preferences	Total	106	16.00	35.00	30.54	4.30
	Presentation	63	16.00	35.00	30.41	4.39
	Mail	43	19.00	35.00	30.72	4.22
Artificial Means	Total	106	1.00	5.00	3.42	1.13
	Presentation	63	1.00	5.00	3.30	1.06
	Mail	43	1.00	5.00	3.60	1.22

As with the pre-test results, the mail intervention group had significantly higher mean scores on all dependent variables on the post-test. Standard deviations were similar, with the mail group having slightly higher variation in scores on beliefs and use of artificial means, and lower variation in preferences.

To view mean differences from pre to post-test by group easily, the researcher calculated change in mean scores, shown in Table 4. Overall and by program group, all of the mean scores moved in the positive, intended direction except for the beliefs score among the mail

intervention group. This change was slightly negative (-0.31), but when comparing to the post-test standard deviation (3.63), it is negligible.

Table 4 Descriptive statistics for dependent variables, pre-test-post-test change					
		N	Pre test	Post test	Δ
Beliefs	Total	106	27.72	27.94	0.22
	Presentation	63	26.62	27.21	0.59
	Mail	43	29.33	29.02	-0.31
Preferences	Total	106	30.02	30.54	0.52
	Presentation	63	29.67	30.41	0.74
	Mail	43	30.53	30.72	0.19
Artificial Means	Total	106	3.35	3.42	0.07
	Presentation	63	3.22	3.30	0.08
	Mail	43	3.53	3.60	0.07

The descriptive examination of the data supported the researcher's decision to examine each of the research questions for the program overall, as well as by program intervention type.

These analyses also revealed that the data are not normally distributed. This guided the researcher's decisions related to the analysis of research questions 2 and 3.

Inferential Analyses

Research question 1: *To what extent is spirituality related to pre-intervention beliefs and preferences about end-of-life care?*

To understand the relationship between spirituality and beliefs and preferences prior to the intervention, the researcher conducted bivariate correlations between each of the variable pairs. The correlations are shown in Table 5.

Table 5 Bivariate correlations of pre-test spirituality, beliefs, and preferences			
		Beliefs	Preferences
Spirituality	Total (n=106)	0.03	0.09
	Presentation (n=63)	-0.15	0.04
	Mail (n=43)	0.20	0.13
Beliefs	Total (n=106)	--	0.40*
	Presentation (n=63)	--	0.40***
	Mail (n=43)	--	0.36*

* $p < .05$, *** $p < .001$

Contrary to expectations, spirituality was not significantly correlated with preferences or beliefs prior to the intervention, for the entire sample and for each program intervention separately. Beliefs and preferences, however, were significant and moderately correlated at $p < .05$ for the entire group and for both the program intervention group the mail intervention group separately.

Research question 2: *To what extent does participation in a brief transformational education program change adults' preferences about end-of-life care, overall and by delivery type?*

Wilcoxon Signed Rank Test

To understand whether preferences for end-of-life care choices changed after the brief program session, the researcher used a Wilcoxon signed rank (WSR) test to compare the scale scores pre- and post-intervention. The WSR test was used rather than a paired t-test due to the non-normality of the data. Mean ranks indicated that the preferences for end-of-life care changed positively in the direction toward the care orientation from pre- to post-test for the entire sample and for each program intervention type separately. The WSR test showed that this change was statistically significant for the entire sample ($Z=2.44$, $p=0.02$) and for the program intervention ($Z=2.25$, $p=0.03$), but not for the mail intervention ($Z=1.07$, $p=0.28$).

Research question 3: *To what extent does a brief, transformational education program change beliefs about the use of artificial means to extend life?*

The researcher again used a Wilcoxon Signed Rank (WSR) test to understand whether beliefs about the use of artificial means to extend life changed as a result of the intervention. In this case, the WSR test was used due to the ordinal nature of the data (five point scale). The mean ranks indicated that beliefs about the use of artificial means changed positively in the direction toward the care orientation from pre- to post- test for the entire sample and for the program intervention, but mean ranks did not show any difference for the mail intervention. The WSR test results indicated that observed changes in mean ranks were not statistically significant for the entire sample ($Z=0.70$, $p=0.49$), or either of the intervention types (presentation $Z=0.30$, $p=0.77$; mail $Z=0.75$, $p=0.45$).

The Z scores for research questions 2 and 3 are summarized in Table 6.

Table 6 Wilcoxon signed rank tests (Z) to determine changes in preferences and beliefs as a result of program participation, by program delivery type		
	Preferences	Use of artificial means to extend life
Total (n=106)	2.44	0.70
Presentation (n=63)	2.25	0.30
Mail (n=43)	1.07	0.75

* $p < .05$

Summary

One hundred and six individuals participated in the study. Though there was little racial and ethnic diversity, participants were predominately white. The sample was diverse in terms of age, gender, marital status, education spiritual views. Overall the sample was in very good health. Data was gathered on: the significance of spirituality in participant's lives before receiving information on end-of-life care, preferences for treatment options at the end-of-life before and after receiving information on end-of-life care and beliefs about using artificial means to extend life as long as possible before and after receiving information on end-of-life care. Presentations were made in person to four groups; a packet of information was mailed to two groups.

In reference to Research Question 1, data suggested there was no significant correlation between spirituality and to pre-intervention beliefs and preferences about end-of-life care.

In reference to Research Question 2 to what extent does participation in a brief transformational education program change adults' preferences about end-of-life care? For the entire sample the intervention data showed a moderate change in preference for end-of-life care toward a comfort over cure care orientation from pre to post-test. Participants in the program intervention reported slight, but statistically significant changes in preferences,

while participants in the mail intervention did not indicate statistically significant change in preferences for end-of-life.

In reference to Research Question 3, beliefs about the use of artificial means to extend life; there was no significant change in beliefs about the use of artificial means to extend life overall or by program type.

Chapter Five offers an interpretation of the results reported in Chapter Four and makes connections to existing literature. It also highlights limitations of the study and makes recommendation for future end-of-life care educational programs.

CHAPTER 5: DISCUSSION

“You have also reminded all of us that it [healthcare reform] concerns more than material things; that what we face is above all a moral issue; that at stake are not just the details of policy, but fundamental principles of social justice and the character of our country....And while I will not see the victory, I was able to look forward and know that we will--yes we will—fulfill the promise of health care in America as a right and not a privilege...”

Ted Kennedy Letter to Barack Obama

September 3rd, 2009

This chapter will interpret the data in the previous chapter. The findings will be compared against existing literature. This chapter presents conclusions, followed by practical recommendations for the delivery of care and suggestions for continued research. This study examined the extent to which education about the nature and consequences of advanced medical technology influences beliefs and shapes perceptions about the end-of-life care choices made by adults.

Connection Between Bioethics, Existential Suffering and Transformational Learning

That there is a connection between bioethics, existential suffering and transformational learning has become apparent to me. What has also become apparent is the need to have the connection articulated, understood and shared with all those with whom I am able to interact.

The goals of bioethics are to relieve suffering, respect the person, their relationships, and the life they are living and supporting their dying process. Promoting well-being and respecting of one’s dignity is essential when delivering care at the end-of-life (Berlinger,

Jennings & Wolf, 2013). The development of advanced medical technologies demands the principles of Bioethics be considered when rendering care.

According to Smith (2011) “at the end-stage of life, an extricable component of adjusted care requires recognition of a fundamental right to avoid cruel and unusual suffering from terminal illness” (p. 469). “Health care providers then, must make decisions consistent with preserving the best interests of a patient’s quality of life by alleviating suffering...Imbedded, necessarily in end-of-life care are the virtues of compassion, charity and mercy” (p.470).

It is the magnitude of facing one’s death that calls for Transformational Learning Theory to be the foundation on which to build programs that educate individuals on their end-of-life care choices. Kitchenham (2010) describes transformational learning as “a deep, structural shift in basic premises of thought, feelings and actions” (p. 104). While this type of learning is complex, it demands dialogue and reflection that leads to lasting change in how one views one’s circumstances.

Being mindful of the complexity of the concepts of Bioethics, existential suffering and Transformational Learning Theory, as well as the angst surrounding one’s death, the findings of this study were those expected by the researcher, but less than those hoped for by the researcher. The research was carried out involving six groups. A brief transformational learning program was delivered in four locations: a group representing the disability community, a class of individuals training to be paramedics, women in a Bible Study group and members of the Bereavement Ministry at a local church. A packet of information including a pre-test, descriptions of medical interventions with information on the risks and benefits of each intervention and a post-test was mailed to family and friends and professional colleagues who represented the remaining two groups.

The following research questions were explored.

1. To what extent is spirituality related to pre-intervention beliefs and preferences about end-of-life care?
2. To what extent does participation in a brief transformational education program change adults' perceptions about preferences for end-of-life care, overall and by delivery type?
3. To what extent does participation in a brief transformational education program change adults' beliefs about the use of artificial means to extend life, overall and by program type?

Preferences for End-of-Life Care

According to Callahan and Lawler (2012) physicians, patients and families need to reflect deeply on care at the end-of-life. The thoughts must focus on life and death and how one understands what that means, the role of family and spirituality, and the duties of medical professionals regarding the use of advanced medical technology when delivering end-of-life care. Death is a normal of living. Dying is not simple. Society in general and the medical community in particular have rejected earlier, quicker deaths and accepted later, drawn out deaths.

People have every right to live as long as they can. In an aging population most deaths are the result of chronic disease and multiple organ failure. That being the case, more comprehensive coordination of care is needed. Care that is rendered must include an understanding of the risks and benefits, efficacy, as well as the potential pain and suffering resulting from the treatment options considered.

The questionnaire (see APPENDIX C) used in this study presented seven statements from three scales; preferences, beliefs and spirituality. A total of twenty-one questions were used to assess preferences for end-of-life care. The issue of wanting to live as long as

possible was also explored. The respondents chose whether they wanted to live as long as possible: if they had an incurable, terminal condition, if they were on life support, if their brain was not functioning, if they had a feeding tube and if they were in severe pain. The respondents chose whether they wanted to be comfortable or live as long as possible; be at home or in the hospital and if they wanted to stay at home would they consider being taken to an Emergency Room.

This study showed that there were changes in preferences for care from the pre-test to the post-test. However, the change was moderate, which suggests that while the presentation delivery impacted preferences for care more education was needed. In this study how the presentation was delivered made a difference. The presentation for this study was given in person to four groups and a packet of information was sent through the mail to two groups. The group that received the intervention in person had an opportunity to discuss the issues presented intensely with presenter. The Wilcoxon Signed Rank (WSR) test showed that this change was practically significant for the entire sample and for the program intervention, but not for the mail intervention.

This study was consistent with findings from the Support Study Connor et al. (1995), the Duke Study Johnson et al. (2008) and the Outcomes Study Lorenz et al. (2004), which indicated that more education was needed if real change in perceptions about treatment interventions is to be achieved. It is apparent that progress based on educational intervention has been made.

The Support Study Connor (1995), a foundational study, conducted in a large Midwestern medical center had dismal results. In the initial phase of this study the researchers found patients suffered pain that went untreated, physicians and families did not understand patient preferences and had no idea whether patients wanted cardiopulmonary resuscitation. Over a two-year period, researchers devoted substantial time, effort and

money to improve end-of-life decision making through personal interactions with providers, patients and families. These significant interventions made no difference in how decisions were made at the end of one's life. My study confirmed that education, particularly a short program, made no difference in what decisions would be made at the end of one's life.

The End-of-Life Care and Outcomes, Lorenz and Lynn (2004) study was done to assess the status of medical education in end-of-life care and identify opportunities for improvement. A telephone survey was conducted with medical students, residents and faculty at 62 accredited United States medical schools. The results of the study indicated that students and residents in the United States. Attention to both curricular and cultural change is needed to improve end-of-life care education. The role of medical education is teaching providers at all levels to cure. This deeply rooted tenet of medical education will not be reimagined without persistence to see change occur and the passage of time.

The Duke Study on Culture and End-of-Life Care (Johnson et al. 2008) used phone interviews to determine how knowledge, social support, beliefs about spirituality, death and dying, advance care planning, and mistrust of the healthcare system influence attitudes toward end-of-life care decisions made by adults. The study's results have implications for developing policies and programs that may improve end-of-life care. The challenge for healthcare providers in these studies and others is to design, test, and bring to fruition programs and policies that will foster and enhance a "care" model which will enable persons to die in peace and comfort according to their wishes. My study confirmed that a 60-minute session and a brief packet of materials received by mail are inadequate to promote transformational learning on a topic such as end-of-life care decisions. I recommend a program of three or more sessions with more time in each session for reflection and discourse as a foundation for educating individuals about an enhanced "care" model that will enable persons to die in peace and comfort, according to their wishes.

Berlinger et al. (2013) state that to care for a person who is facing decisions about life-sustaining treatment, or is nearing the end-of-life, means being attentive to that person wholistically. Persons who know they are facing the end-of-life may reflect on the meaning of their life as it has been lived. Some persons express the meaning of life in terms of religious faith, others with references to spirituality rather than a faith tradition. Some persons face the end-of-life with no reference to faith or spirituality.

A dying person's sense of life's meaning may change as the person faces illness and death. Some individuals reconsider long-standing values and preferences and beliefs in light of the dying process. Some individuals find meaning and comfort in practices that have not been part of their lives. Some may reject certain religious and spiritual beliefs and practices that have been long held in their lives. Others as they near the end of their lives experience feelings of estrangement or abandonment. Loved ones and healthcare professionals should consider how and when to offer spiritual care that will give the person nearing the end-of-life supportive care, comfort, and peace and demonstrate love, understanding and compassion.

In work done on patient spirituality by Post, Puchalski, and Larson (2000), the authors claim the ultimate meaning and purpose in life has clinical relevance. This phenomenon is seen particularly in the contexts of suffering, debilitation and dying. Spiritual commitment, practices and attitudes to patient well-being are emerging in clinical areas of recovery from illness, reduction of depression, mitigation of pain, adjusting to disabilities and reduction in chronic disease states. "The beneficent physician who is committed to the patient's best interest must consider how to support the patient's spirituality" (p. 579).

According to Puchalski (2002), dying should be a natural part of living. It should be a meaningful experience for a dying patient in which they find meaning in their suffering.

Yet we have systems of care that do not incorporate spirituality into the care of patients. Currently, more than half of United States medical schools have courses in spirituality and medicine and the response to these courses by practicing physicians and students has been positive. Pulchalski states, “It should be the obligation of all physicians to respond to and attempt to relieve all suffering if possible...We should have systems of care that allow people to die in peace, to die in the way they want to [die]” (p. 293). Spirituality in my study was only reviewed in an attempt to understand the context in which spirituality influenced one’s life. I did not collect data to either confirm or reject the impact of spirituality on one’s end-of-life choices as there was no correlation between spiritual beliefs and end-of-life choices.

Beliefs About the Use of Artificial Means

Life support replaces or supports a failing bodily function. In treatable or curable conditions, life support is used temporarily until the body can resume normal functioning. But, in situations where a cure is not possible, life support may prolong discomfort. A treatment may be helpful if it relieves discomfort, restores functioning, or enhances the quality of life. The same treatment can be considered harmful if it causes pain or prolongs the dying process without offering benefit. The outcome may diminish a person’s quality of life (Society of Critical Care Medicine, 2011).

Patients may consider many treatments to sustain life. In addition to cardiopulmonary resuscitation (CPR), options include mechanical ventilation, surgery, dialysis, blood transfusions, artificial nutrition and hydration, antibiotics, other medications and treatments, as well as future admissions to the hospital or to the intensive care unit. The treatment choices and the complexities increase as a patient's condition worsens. Many patients who initially choose a do-not-resuscitate (DNR) order as their body creeps toward decline choose progressively more restrictions on their treatment interventions. Although

not using an intervention and withdrawing that intervention are ethically and legally equivalent, it is better to make these decisions ahead of time. Pastoral care providers and ethics committees are resources that can offer support and guidance to patients and families making end-of-life care choices. Family physicians should feel free to provide specific advice to patients and families wrestling with these difficult decisions (Ackermann, 2000).

Seven statements regarding beliefs about dying and being comfortable with talking about death were explored from the beliefs scale. The respondents were asked if they were dying would they want to be told; would they tell their family; did they believe dying was a normal part of life; did they agree artificial means to extend life are short term, expensive and should be avoided; did they know what kind of treatment they wanted when dying and did they tell their families about their end-of-life care choices. Data were collected using a Likert scale with 5 being strongly agree to 1 being strongly disagree. The mean ranks indicated that the beliefs about the use of artificial means changed positively in the direction toward the care orientation from pre to post test for the entire sample and for the program intervention treatment, but mean ranks did not show any difference for the mail intervention treatment. The WSR test results indicated that observed changes in mean ranks were not statistically significant for the entire sample for either of the intervention types.

Limitations

The limitations of the study are stated as follows. The language of the questionnaire regarding beliefs and spirituality was misleading. The question regarding the use of artificial means was misplaced in the beliefs section. For the purposes of this study, it should have been in the preferences section. The issues surrounding the use of artificial means to extend life were not sufficiently discussed. To deal with the complexities of bioethics, existential suffering and transformational learning theory a program of four separate sessions was needed.

Recommendations

1. Attention to both curricular and cultural change is needed to improve end-of-life care education for patients, their families, physicians, nurses and allied health professionals.
2. Physicians, nurses and allied health professionals need to reflect on what existential suffering is and what it means to them. They need more time and experience dealing with patient's existential suffering. Their experiences may give healthcare providers confidence to better understand and acknowledge what a patient needs as the end-of-life nears.
3. Encourage involvement of psychosocial clinicians (psychologists and social workers) early in the end-of-life process to increase awareness that there is no realistic chance for cure.
4. Increase the quality of communication between healthcare providers and patients regarding prognosis, treatment goals and care at the end-of-life.
5. Diligently pursue, in the community's hospitals, implementation of policies and procedures that would establish a "Code Death for Dying Patients" protocol (Zitter, 2014). This protocol would involve explaining what death would look like to families. The families would be asked to wait outside of the patient room while tubes were removed and the patient was cleansed. The families would then be brought back into the room. The medical team would remain on the periphery of the room rendering care to all involved as needed.
6. For future programs I would look more closely to the use of transformational learning and moral learning as the theoretical frame on which to build the program. I would add up to four sessions to complete the program. Doing this would allow for

more time to discuss and reflect and involve more time for critical thinking about how to make an informed choice for one's end-of-life care.

Conclusion

The essential component of the study was to examine initiatives to advance the delivery of end-of-life care in which comfort and peace surround an individual throughout the dying process.

When is death acceptable? Callahan (2000) argues

is it possible to say that death is a generic evil for individual life, but that not all individual deaths are evil?... If the continued life is no more than a respirating body, or a life that has lost all potential for human flourishing, we may judge life as a lesser evil than continued life...Some will think that any life under any condition is better than no life at all, and such a position only feeds slavery to a technology that can always keep a body going just a bit longer (p. 180).

In this work, I sought to explicate that death is acceptable when further efforts to stave off dying are likely to cause pain and suffering and when the physiologic inevitability of death, without the use of extraordinary means, is obvious. In the studies I have examined and this particular study I carried out, it is clear that, while progress has been made in transforming end-life-treatment interventions from a cure model to a care model, much work needs to be done.

Dealing with suffering requires healthcare providers to move beyond the practice of extending life using means that are short term and increase suffering into the practice of acknowledging the complexity of existential suffering thereby practicing the art of medicine not just the science of medicine. I argue that challenging end-of-life care choices are best resolved through a partnership between patient, family and physician. I suggest that at the

center of the problem is that our society is one that faces the final phase of human life by choosing not to think about it.

This work was intended to lay an empirical framework for a practical intervention to solve the problem of excessive use of artificial means as one nears the end-of-life. Those who would benefit from the results of this study are those who develop curriculum for medical schools, schools of nursing and programs for allied health professionals. Healthcare leaders who make policy would benefit as would, most importantly, the sick who will suffer when curing not caring is the goal of treatment.

In this work I have set forth to intertwine the principles of Bioethics, the meaning of existential suffering and the theory of Transformational Learning. Further research on the most efficacious, effective measures to promote the delivery of compassionate care at the end-of-life is imperative if as a society we are desirous of providing a “Good Death” for those seeking peace and comfort as their life is completed through dying.

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APPENDIX A: INFORMED CONSENT



Project Purpose: To what extent will a brief transformational education program on end-of-life care choices change the beliefs and perceptions about care choices during the dying process?

The purpose of this program on end-of-life care choices is to encourage you to examine your beliefs and perceptions on these issues. The benefit of this research is that you will be aiding in the understanding of what influences end-of-life choices. This research will also aid in the development of programs to help individuals when making end-of-life decisions.

Investigator: Mary Jo Speer, RN, MA

Eligibility: Participant must be 18 years of age or older with no known cognitive dissonance. There will be no exclusion due to gender. There will be no exclusion due to race, ethnicity, or social class. All members of the particular communities studied will be invited to participate.

Overall Description of Participation: If you choose to participate, you will be asked to take a pre-test regarding your present beliefs and perceptions about care choices during the dying process. You will then participate in an educational program about end-of-life care choices including; CPR, intubation, feeding tube placement and dialysis. Following the program you will be asked to complete a post test to determine if your beliefs and perceptions about care choices during the dying process have changed.

Length of Participation: Your total participation time will be not more than 60 minutes. If you decide to participate, you will be one of 100 subjects in this study.

Risks for Participants: There are no risks to participation.

Volunteer Statement: You are a volunteer. The decision to participate in this study is yours. If you decide to be in the study, you may stop at any time. You will not be treated any differently if you decide not to participate or if you stop once you have started.

Confidentiality Statement: Any information about your participation, including your identity, is completely confidential. A unique identifier will be generated for each participant, in the form of the last four digits of your phone number to match pre and post-test data. This identifier will not be recorded. Care will be taken that no individual's responses can be identified. All data will be stored in a secure database, with no personal identifier associated with the data.

Statement of Fair Treatment and Respect: UNC Charlotte wants to make sure that you are treated in a fair and respectful manner. Contact the University's Research Compliance Office (704.687.1871) if you have any questions about how you are treated as a study participant. If you have any questions about the project, please contact Mary Jo Speer, RN, MA or Lisa Merriweather PhD at 704-687-8858 or edld@uncc.edu.

Participant Consent: I have read the information in this consent form. I have had the chance to ask questions about this study, and those questions have been answered to my satisfaction. I am at least 18 years of age, and I agree to participate in this research project. I understand that I will receive a copy of this form after it has been signed by me and the Principal Investigator.

Signature of Participant

Date

Signature of Investigator

Date

APPENDIX B: LETTER OF INTRODUCTION



Greetings,

My name is Mary Jo Speer. I am a Doctoral Candidate in the Department of Educational Leadership, Community Tract, at UNCC. I am in the dissertation development phase of my quest to earn a Doctoral Degree. The purpose of my study is to determine the extent to which learning about advanced medical technology changes knowledge about end-of-life care choices and shapes perceptions about those choices.

As part of my research design I must identify participants that will permit me to collect data. Please sign the consent form. The process then is as follows; I ask you to complete a questionnaire regarding your currently held End-of-life Care choices. I have prepared information on mechanical ventilation, delivering nutrition via tube feedings, dialysis, and CPR (cardiopulmonary resuscitation) that I ask you to read and reflect on. Finally, I ask you to complete a second questionnaire based on the knowledge you have gained after reading the information provided to you. Return your responses to me in the self-addressed, stamped envelope I have provided.

My purpose in soliciting your assistance and support is twofold. I am interested in a diverse population for my study, from a population that is committed to the health and wellness of one's self and one's family physically, emotionally, and socially; while delivering knowledge that will foster 'Just Caring' practices in the delivery of health care.

Thank you for considering my request and caring that the delivery of health care is compassionate, competent, and equitable for all!

With Sincere Regards,

Mary Jo Speer, RN, MA

Ethics Advisor, Doctoral Candidate

APPENDIX C: PRE-TEST

Beliefs and Preferences about End-of-Life Care Study

Thank you for agreeing to participate in this study. I am interested in your beliefs about the kind of medical care you would want if you were seriously ill with a disease that doctors could not cure, before and after participating in a short program on end-of-life care decisions. There are no right or wrong answers; simply indicate how you think or feel at this time. Your responses are both anonymous and confidential. The codes on the two questionnaires will be used to match your responses (before and after) but will not be linked to your name or any other personally identifying information. I will not share your responses with anyone other than my dissertation committee.

Personal Information: Pre-test only.

First, a few general questions about you and your health. Check the answer that best applies to you for each question.

Race / ethnicity	<input type="checkbox"/> African American	<input type="checkbox"/> Hispanic/Latino
	<input type="checkbox"/> American Indian	<input type="checkbox"/> White
	<input type="checkbox"/> Asian American	<input type="checkbox"/> Other
Gender	<input type="checkbox"/> Female	<input type="checkbox"/> Male
Age	<input type="checkbox"/> 18-25 years	<input type="checkbox"/> 51-60 years
	<input type="checkbox"/> 26-30 years	<input type="checkbox"/> 61-70 years
	<input type="checkbox"/> 31-40 years	<input type="checkbox"/> 71-80 years
	<input type="checkbox"/> 41-50 years	<input type="checkbox"/> Over 80 years
Current marital status	<input type="checkbox"/> Single, never married	<input type="checkbox"/> Divorced
	<input type="checkbox"/> Married	<input type="checkbox"/> Widowed
	<input type="checkbox"/> Separated	<input type="checkbox"/> Other
Living Children	<input type="checkbox"/> Yes, # <input type="text"/>	<input type="checkbox"/> No
Highest level of education completed	<input type="checkbox"/> Less than high school <input type="checkbox"/> High school graduate (or GED) <input type="checkbox"/> Some college or technical training beyond high school <input type="checkbox"/> College graduate <input type="checkbox"/> Post-graduate or professional degree	
How do you rate your general health?	<input type="checkbox"/> Excellent <input type="checkbox"/> Very good <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Poor	

Preferences for Care

This section includes questions about your preferences for care if you had a serious, incurable illness. Please indicate your level of agreement with the following statements by circling the number that matches your answer, from 1=strongly agree to 5=strongly disagree.

If I had a disease that the doctors could not cure, I would want to live as long as possible...	Neither Agree nor Disagree				
	Strongly Agree	Agree	Disagree	Disagree	Strongly Disagree
... even if I had to be on life support or a breathing machine.	1	2	3	4	5
...even if my brain had stopped working	1	2	3	4	5
...even if I had to be fed through a tube	1	2	3	4	5
...even if I were in severe pain	1	2	3	4	5

If I had a disease that could not be cured...	Neither Agree nor Disagree				
	Strongly Agree	Agree	Disagree	Disagree	Strongly Disagree
...being pain free and comfortable would be more important to me than living as long as possible.	1	2	3	4	5
...being at home would be more important to me than being in the hospital.	1	2	3	4	5

If I could be taken care of at home, I would not want to go to the Emergency Room or Hospital.	1	2	3	4	5
--	---	---	---	---	---

Preference for Place of Death

If you were seriously ill with a disease like cancer that could not be cured and you could choose where to die, where would you most want to die? (check one)

- ☐ Home
☐ Hospital
☐ Nursing Home
☐ Other (write in) _____

Beliefs about Dying, Truth Telling, and Advance Care Planning

This section includes questions on your beliefs about death and dying. Please indicate your level of agreement with the following statements by circling the number that matches your answer.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I feel comfortable talking about death.	5	4	3	2	1
If I were dying, I would want the doctors to tell me.	5	4	3	2	1
If I were dying, I would tell my family.	5	4	3	2	1
Dying is a normal part of life.	5	4	3	2	1
Artificial means to extend life are short term, expensive and should be avoided	5	4	3	2	1
I have thought about the kind of medical care that I want when I am dying.	5	4	3	2	1
I have talked to my family about the kind of medical care that I want when I am dying.	5	4	3	2	1

Spirituality

Please indicate your level of agreement with the following statements by circling the number that matches your answer.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
God determines whether I live or die.	5	4	3	2	1
Pain and suffering is sometimes part of God's plan for my life.	5	4	3	2	1
God sometimes wants us to suffer while we are dying.	5	4	3	2	1
Those who believe in God do not have to plan for the kind of medical care they want when they are dying.	5	4	3	2	1
Those who believe in God would want everything done to keep them alive even if they had a disease like cancer that could not be cured.	5	4	3	2	1
Accepting that you are going to die means you do not have faith.	1	2	3	4	5

Those who believe in God do not
need hospice.

1

2

3

4

5

Thank you for your responses!

APPENDIX D: END-OF-LIFE CHOICES INTERVENTION

Curing and Caring:

Rather than being two distinct aspects of the therapeutic enterprise, caring and curing should be seen as mutually supportive and equally indispensable forms of approaching the sick.

The clinical encounter becomes damaged and ethically suspect if care is not aimed at curing the discomfort, the disease, the symptom--just as curing is harsh and less efficient if performed in a callous and careless manner. The distinction runs in the attitude, which should be one of doing good--a consequence--and doing well--a virtue. Care is the most appropriate way of encountering the living person. Even if medicine ultimately fails in keeping one alive, it will have accomplished its goal if all those involved have stood with their patients in a compassionate and trustworthy.

Cardiopulmonary Resuscitation

Cardiopulmonary resuscitation (CPR) consists of the use of chest compressions and artificial ventilation to maintain circulatory flow and oxygenation during cardiac arrest. Although survival rates and neurologic outcomes are poor for patients with cardiac arrest, early appropriate resuscitation-involving early defibrillation-and appropriate implementation of post-cardiac arrest care lead to improved survival and neurologic outcomes.

CPR should be performed immediately on any person who has become unconscious and is found to be pulseless.

The only absolute contraindication to CPR is a do-not-resuscitate (DNR) order or other advanced directive indicating a person's desire to not be resuscitated in the event of cardiac arrest. A relative contraindication to performing CPR is if a designated decision maker justifiably feels that the intervention would be medically futile.

Mechanical Ventilation

A mechanical ventilator is a machine that makes it easier for patients to breathe until they are able to breathe completely on their own. Usually, a patient is connected to the ventilator through a tube (called an endotracheal tube) that is placed in the windpipe. Despite their life- saving benefits, mechanical ventilators carry many risks. Therefore, the goal is to help patients recover as quickly as possible to get them off the ventilator at the earliest possible time.

Maintenance of Life - In some very sick patients, trying to keep the patient alive means that dying actually takes longer. A decision about continuing mechanical ventilation or not may come up if a patient is not showing any recovery or is continuing to get worse.

Some of the risks of mechanical ventilation include infections, lung damage and collapsed lungs.

Feeding tube placement:

When a decisionally incapable patient who suffers from a chronic, progressive illness develops swallowing difficulty, physicians, families, nurses and other care providers have, with increasing frequency, elected non-oral nutritional support. However, recently accumulated outcome data make dubious a reflexive decision in favor of tube feeding in this setting.

- Feeding tube placement is associated with an in-hospital mortality of 15-25, and a one-year mortality of 60.
- Co-factors associated with increased risk of mortality include: advanced age, CNS pathology (CV A, advanced dementia), cancer (except early stage Head/Neck cancer), disorientation, and low albumin.
- Aspiration occurs in up to 50 of patients being tube fed.
- For patients with advanced dementia, feeding tubes have not proven effective in prolonging life, in preventing aspiration or even in providing adequate nourishment.

Kidney Dialysis

Dialysis is a treatment that does some of the things done by healthy kidneys. It is needed when your own kidneys can no longer take care of your body's needs. You need dialysis when you develop end stage kidney failure --usually by the time you lose about 85 to 90 percent of your kidney function. When your kidneys fail, dialysis keeps your body in balance by: removing waste, salt and extra water to prevent them from building up in the body, keeping a safe level of certain chemicals in your blood, such as potassium, sodium and bicarbonate, helping to control blood pressure.

In chronic or end stage kidney failure, your kidneys do not get better and you will need dialysis for the rest of your life. If your doctor says you are a candidate, you may choose to be placed on a waiting list for a new kidney.

Usually, each hemodialysis treatment lasts about four hours and is done three times per week. Dialysis does some of the work of healthy kidneys, but it does not cure your kidney disease. You will need to have dialysis treatments for your whole life unless you are able to get a kidney transplant.

APPENDIX E: POST-TEST

Preferences for Care

This section includes questions about your preferences for care if you had a serious, incurable illness. Please indicate your level of agreement with the following statements by circling the number that matches your answer.

If I had a disease that the doctors could not cure, I would want to live as long as possible...	Neither Agree nor Disagree				
	Strongly Agree	Agree	Disagree	Disagree	Strongly Disagree
... even if I had to be on life support or a breathing machine.	1	2	3	4	5
...even if my brain had stopped working	1	2	3	4	5
...even if I had to be fed through a tube	1	2	3	4	5
...even if I were in severe pain	1	2	3	4	5

If I had a disease that could not be cured...	Neither Agree nor Disagree				
	Strongly Agree	Agree	Disagree	Disagree	Strongly Disagree
...being pain free and comfortable would be more important to me than living as long as possible.	5	4	3	2	1
...being at home would be more important to me than being in the hospital.	5	4	3	2	1
... If I could be taken care of at home, I would not want to go to the Emergency Room or Hospital.	5	4	3	2	1

Preference for Place of Death

If you were seriously ill with a disease like cancer that could not be cured and you could choose where to die, where would you most want to die? (check one)

- ☐ Home
☐ Hospital
☐ Nursing Home
☐ Other (write in) _____

Beliefs About Dying, Truth Telling, and Advance Care Planning

This section includes questions on your beliefs about death and dying. Please indicate your level of agreement with the following statements by circling the number that matches your answer.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I feel comfortable talking about death.	5	4	3	2	1
If I were dying, I would want the doctors to tell me.	5	4	3	2	1
If I were dying, I would tell my family.	5	4	3	2	1
Dying is a normal part of life.	5	4	3	2	1
Artificial means to extend life are short term, expensive and should be avoided	5	4	3	2	1
I have thought about the kind of medical care that I want when I am dying.	5	4	3	2	1
I have talked to my family about the kind of medical care that I want when I am dying.	5	4	3	2	1

Spirituality

Please indicate your level of agreement with the following statements by circling the number that matches your answer.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
God determines whether I live or die.	5	4	3	2	1
Pain and suffering is sometimes part of God's plan for my life.	5	4	3	2	1
God sometimes wants us to suffer while we are dying.	5	4	3	2	1
Those who believe in God do not have to plan for the kind of medical care they want when they are dying.	1	2	3	4	5
Those who believe in God would want everything done to keep them alive even if they had a disease like cancer that could not be cured.	1	2	3	4	5

Accepting that you are going to die means you do not have faith.	1	2	3	4	5
Those who believe in God do not need hospice.	1	2	3	4	5

Thank you for your responses!