

# Assessing Adult Attitudes Toward End-of-life Issues And Advanced Directives After Implementing An Educational Intervention In A

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ASSESSING ADULT ATTITUDES TOWARD END-OF-LIFE ISSUES  
AND ADVANCED DIRECTIVES AFTER IMPLEMENTING AN EDUCATIONAL  
INTERVENTION IN A WORKPLACE SETTING

by

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A doctoral thesis submitted in partial fulfillment of the requirements  
for the degree of Doctor of Nursing Practice  
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## ABSTRACT

Nursing, medicine, the legislature, and the general public have endorsed advanced directives as a means to protect the rights of the patient; however, people tend not to execute advanced directives. A lack of advanced directives execution fails to meet the needs of dying patients. This can lead to family, nurses, and the health care team making decisions and attempting to meet the needs of the patient without knowledge of what the patient would or would not want during the last days of his/her life. It is currently unknown why so few people execute advanced directives. To fill this research gap, the researcher investigated if an education intervention program would increase end-of-life discussions and the execution of advanced directives. The purpose of this study was to determine the effectiveness of education interventions among individuals to increase end-of-life discussions and advanced directive execution rates. By studying a heterogeneous sample of adult Americans in an occupational health setting, the researcher implemented a descriptive design using quantitative data and qualitative data. The researcher began the first data collection session using a demographic questionnaire. The researcher assessed initial participant knowledge using a pre-program questionnaire and implemented the educational component of the program by using the *Five Wishes* document as an intervention tool. At that time, program effectiveness was assessed using a program evaluation questionnaire. In addition, participants were invited to a second session during which a focus group was conducted. The focus group was designed with a semi-structured interview schedule and functioned to elicit additional program feedback in a small structured setting. Post-program data assessing changes in participant knowledge

were collected through an additional questionnaire that was completed by participants at their convenience over the course of a week following the educational presentation. SPSS chi-square statistical analysis was used to measure data. The researcher looked for demographic trends and patterns of participation as well as effectiveness of the program's educational element. Limitations of the study, as well as implications for nursing professionals and health care providers that will improve patient outcomes are presented.

This doctoral thesis is dedicated to my family, who has supported me throughout this endeavor.

*“If we stand tall, it is because we stand on the backs of our ancestors”*

## ACKNOWLEDGMENTS

“Oh give thanks to the Lord! Call upon His name; make known His deeds among the people! Sing to Him, sing Psalms to Him; talk of His wondrous works” (Psalm 105: 1-2)! To my almighty, all knowing, merciful God, thank you for your many blessings. It has truly been your wondrous works which have kept and sustained me throughout this endeavor. To my loving husband Patrick, thank you for being my rock. Your love and support meant a great deal to me. You are my heart and soul, and I love you. To my beautiful children Amani, Asante’, and Amir, thank you for the hugs, kisses, and constant “I love you’s!” To my mother Carol, thank you for instilling in me the virtues of a God-fearing woman. You have always given me the drive to excel, and I am a woman of God today because of the foundation you gave me. I love you mom! To my dad Billie, thank you for always believing in me. To my brother Byron, thank you for being my bodyguard; every little sister needs one. I love you! To my doctoral advisor and thesis chair Dr. Susan Chase, thank you for your guidance and leadership. It truly has been a blessing working with you. Your support and wisdom has been greatly appreciated. Your sweet, compassionate spirit and inspiration has been a blessing. To my committee members Dr. Elizabeth Rash and Dr. Carolyn Ramsey, thank you for your support. Dr. Elizabeth Rash, thank you for your encouragement and push to succeed since the beginning of this endeavor. Thank you for believing in us. Dr. Carolyn Ramsey, thank you for your expert advice. I am so glad I had the opportunity to work with you. To my dearest family and friends, thank you for your love, prayers, and support! To God be the glory . . . I made it!

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## CHAPTER I: INTRODUCTION

More than two million people in the United States die each year (U.S. Census Bureau, 2009) leaving family members to make end-of-life decisions on their behalf. Managing responsibility for a dying family member's medical treatment can be both stressful and challenging and have profound effects on family members (McSteen & Peden-McAlpine, 2006). Care of the dying is not only a concern for family members however; it is emerging as a major concern among the health care team (American Association of Colleges of Nursing, 2009).

Despite the observable impact of end-of-life decision making on both families and the health care team in addition to increased societal awareness of end-of-life issues, few people have made the effort to indicate their end-of-life wishes prior to becoming medically incapacitated and unable to make decisions for themselves. An advanced directive is a legal document expressing a person's end-of-life wishes. Through an advanced directive, a person can provide clear instructions regarding his or her end-of-life decisions, relieving family members and the health care team of the responsibility of making those decisions (Sessanna & Jezewski, 2008).

In 2006, researchers found that only 29% of Americans had advanced directives (The Pew Research Center for the People & the Press). In a 2007 study comparing participants who had executed advanced directives to those who had not executed advanced

directives, researchers found a ratio of 2 to 5 respectively (Harris Interactive). Among the chronically ill patients in both studies, the majority had no advanced directives.

## **Background of the Problem**

Although individuals are living longer, they are not necessarily living better (Gerst & Burr, 2008). This social condition, encouraged by advances in medical technology, affords physicians the opportunity to delay death for many patients. However, if patients become incapacitated or seriously ill, they may lose their ability to participate in decisions about their own medical treatments.

If advanced directives exist, then they must be used to direct the care of the incapacitated patients. However, if patients' desires concerning end-of-life care are not known through advanced directives, family members must make the difficult and complicated end-of-life decisions without guidance (Kass-Bartelmes & Hughes, 2009). The role of the family in this situation is to make decisions for the incapacitated patient based on the family's best understanding of what the patient would want, not based on what family members would want for themselves. The health care team often experiences the struggle family members encounter when faced with making end-of-life decisions (McSteen & Peden-McAlpine, 2006).

There are three forms of advanced directives: (a) living will, (b) durable power of attorney for health care, and (c) oral statements. Regardless of the form of the advanced directive however, its purpose is to provide clear and concise guidance for the delivery of healthcare to patients during their most vulnerable time when they may be critically ill and unable to make their own medical decisions.

The federal Patient Self-Determination Act (PSDA) of 1990 and individual state legislation governing advanced directives have been in effect for 19 years (Jezewski, Meeker, Sessanna, & Finnell, 2007). The PSDA requires all health care institutions that receive federal funds to educate patients about their rights to determine their care at the end of the lives in accordance with individual governing state laws (Jezewski et al., 2007). Despite federal and state legislation, the number of persons completing advanced directives has not significantly increased since its inception (Sessanna & Jezewski, 2008), and currently less than 50% of severely or terminally ill patients have an advanced directive (Kass-Bartelmes & Hughes, 2009).

## **Problem**

A patient may have an advanced directive upon admission to a health care facility, or the document can be completed on admission during the advanced care planning process. Advanced care planning is an interactive process between a mentally competent patient, his or her family, and a health care provider. Advanced care planning for end-of-life care is a process of communication for the purpose of making decisions about future medical care by clarifying treatment preferences and developing individualized goals of care. It involves educating patients about their illness with discussions of diagnosis, prognosis, expected course of illness, and likely outcomes of different treatments as well as the patients' goals, expectations, values, beliefs, and fears.

Because discussions concerning end-of-life issues can be uncomfortable and emotional, they often are avoided. Barriers to advanced care planning have been identified and include poor communication with health care providers and lack of knowledge regarding the necessity for legalizing one's health care wishes (Feeg &

Elebiary, 2005). However, when an individual is educated about advanced directives and has the opportunity to execute an advanced directive, he or she will engage in a discussion regarding end-of-life issues and may execute an advanced directive (Beckstrand, Callister, & Kirchhoff, 2006). More educational interventions need to be employed to break down perceived barriers to the execution of advanced directives.

### **Significance**

When it comes to making end-of-life decisions, most individuals assume that when the time arrives for making such decisions, their family and health care team members will make choices for them (Kass-Bartelmes & Hughes, 2009). However, family and health-care-team views and decisions may not mirror those of the patient leading to the potential of delivering undesired life-sustaining treatment to individuals who are incapacitated.

When individuals assess their own values regarding quality of life and make decisions about both how they wish to live and the type of care they desire at the end of their lives, the potential for undesired care is prevented (Hampson & Emanuel, 2005). Advanced directives can protect incapacitated patients from unwanted interventions and limit care to that which maintains their values regarding nutrition and hydration, while protecting their autonomy (Hampson & Emanuel, 2005). Advanced directives give patients a voice in decisions about their medical care whether or not they can express those decisions consciously (Gerst & Burr, 2008). Through advanced directives, patients not only can provide clear instructions for their preferred plan of care, but they can relieve family members from the responsibility of making end-of-life decisions (Gerst & Burr, 2008).



The topic of advanced directives and the lack of execution of advanced directives have personal significance for the researcher, an advanced practice nurse with 11 years of clinical experience in an acute care setting and 6 years in an occupational setting. In the last 6 years of employment, while the researcher worked in an occupational health care setting, she has witnessed a lack of discussion of end-of-life care and advanced directives. Despite the opportunity inherent in the clinical setting, no education regarding end-of-life care or advanced directives has been provided to the hundreds of employees at this occupational site. The lack of discussion on site and the low execution rate of advanced directives raised the researcher's sensitivity to the ethical complexities of this situation prompting the researcher to question current practices and seek working solutions. The researcher understands that the value of advanced directives cannot be realized if they are not executed and that poor execution rates can be increased through educational programs implemented by nursing staff. The opportunity to effect positive social change is significant.

## **Objectives**

The aim of this study is to develop an understanding of factors that may affect an individual's willingness to participate in end-of-life discussions and execute an advanced directive. This information may be useful when educating individuals about end-of-life issues and advanced directives. The researcher will take into account that any discussion about one's own death might arouse an emotional reaction. These reactions may or may not affect one's ability to discuss end-of-life issues and execute an advanced directive. These reactions may include anxiety, fear, anger, or conflict. These reactions may influence a participant's willingness to participate in end-of-life discussions or to execute

or not execute an advanced directive. Research may help to develop a better understanding of end-of-life issues with a goal of increasing the rate of execution of advanced directives through a workplace-delivered advanced directive education program.

### **Research Questions**

The following research questions guided this study:

1. When assessing adult attitudes toward end-of-life issues and the execution of advanced directive in the occupational work setting, what responses are generated?
2. Are barriers to completing advanced directives uncovered?
3. Is there a difference in responses after the education intervention?

### **Definitions**

In this study, the following definitions were used when pertaining to the indicated terms:

1. Advanced directive: A person's oral and/or written instructions concerning his or her future medical care in the event that the person becomes unable to speak for him or herself (Zerwekh, 2006).
2. Durable power of attorney for health care: A legal instrument that grants another person the authority to act as another person's legal representative and to make binding legal decisions on that person's behalf (Zerwekh, 2006).
3. End-of-life decisions: The act or process of deciding what actions or means of care will be taken when life can no longer be sustained naturally (Zerwekh, 2006).

4. *Five Wishes*: A living will document used to educate people about end-of-life decision making and provide a method for completing an advanced directive (Aging with Dignity, 2009).
5. Incapacitated patient: A person who is legally incapable of making health care decisions (Zerwekh, 2006).
6. Living will: A legal form that documents a person's wishes regarding life-prolonging treatments (Zerwekh, 2006).

### **Assumptions**

Two assumptions guided this study:

1. Research participants will describe their educational experience to the researcher as they are perceived.
2. Participation in the focus group will prompt participants to share more in-depth descriptions of their perceptions than they would if interviewed individually.

### **Summary**

The 21<sup>st</sup> century promises a new era of healthy living and longevity fostered by improved lifestyles and effective advances in medicine including pharmaceutical and technological advances in diagnosis and treatment. However, the increasingly aggressive health care workplace created by unforeseen traumatic events, emerging infectious and pandemic diseases, drug resistant pathogens, and natural disasters will add unknown variables to future legal and ethical life-and-death medical decisions. In the face of these many challenges, advanced directives have the potential to provide useful guidance and

direction to family and the health care team faced with making end-of-life decisions for incapacitated patients.

The execution of an advanced directive communicates a patient's preferences for end-of-life medical procedures. Having an advance directive in place may reduce the risk that the family or health care team will needlessly suffer the stress and anxiety often associated with making presumptions regarding appropriate treatment for incapacitated patients. However, research has found that the execution of advanced directives remains low. Increasing the awareness and education of end-of-life issues and advanced directives is the key.

When an advanced directive is formulated and documented, it increases the chance that a patient will receive the care he or she desires when that patient cannot voice his or her wishes. This will allow the health care team to provide care in which the patient can die at peace and with dignity. This study implements and evaluates a literature-based program and will address the critical need for research investigating the effect education has on individuals and their willingness to participate in discussions regarding end-of-life care and executing advanced directives.

## CHAPTER II: LITERATURE REVIEW

A review of current literature related to advanced directives and end-of-life care was conducted searching databases: CINAHL, PubMed, and the University of Central Florida Library database. Search terms included: *end-of-life care*, *advanced directives*, *palliative care*, *living wills*, *durable power of attorney*, and *health care proxy*. The researcher based article selection on publication dates (1999-2009) and study locations (United States). Several research studies conducted more than 10 years prior to this current study were included to demonstrate patterns of social reactions to end-of-life issues and advanced directive execution over time and the failure of related programs to evolve significantly. Topics of research included in this section focus on historical implications of end-of-life discussions and barriers to end-of-life discussions and advanced directive execution.

### Overview

More than two million people in the United States die each year (U.S. Census Bureau, 2009). Because people tend not to execute advanced directives (Feeg & Elebiary, 2005), the majority of people dying annually die without having left instructions for their end-of-life care. Some estimates have suggested that only 15 to 25% of American adults have executed advanced directives (Sessanna & Jezewski, 2008). Others suggest that that

average does not exceed 20% (Scherer, Jezewski, Graves, Wu, & Bu, 2006). Rates of advanced directive execution remain low despite efforts by health care professionals, the legislature, and the general public who have endorsed advanced directives as a means to protect the rights of dying patients (Feeg & Elebiary, 2005).

The PSDA of 1990 constituted a legislative mandate intended to increase participation in advanced directive discussion and execution (Schlegel & Shannon, 2000). The act mandated that health care facilities and health care providers ask patients about advanced directives and integrate those communicated end-of-life wishes into patients' medical plan of care (Schlegel & Shannon, 2000). Research has indicated that although a small percentage of people admitted to health care facilities already have executed advanced directives, the majority of people have not, making the potential for impact significant (Jezewski et al., 2007). This condition has been underscored by the realization that of the millions of deaths occurring annually in the US, 80% percent occur in hospitals (Beckstrand et al., 2006).

Because advanced care planning has been identified as an interactive process between a mentally competent patient, his or her family, and a health care provider, the time afforded during hospital admission offers a valuable opportunity to execute an advanced directive (Goodwin, Kiehl, & Peterson, 2002). However, although the PSDA mandated that health care facilities and health care providers ask patients if they have an advanced directive and provide patients with advanced directive information, the act did not mandate that health care facilities and health care providers offer an opportunity for patients to complete an advanced directive (Schlegel & Shannon, 2000). As a result, a significant increase in the execution of advanced directives has not been realized as

intended by the enactment of the PSDA of 1990 and its implementation in 1991 (Jezewski et al., 2007).

### **Historical Implications**

Two very public cases of medical care decision making for incapacitated patients brought end-of-life issues to the forefront in 1970s America: the cases of Karen Ann Quinlan and Nancy Cruzan. During this decade, the capacities of modern medicine and technology were becoming evident (Jezewski et al., 2007). The country was beginning to understand that although modern medicine could not always cure or reverse an illness or catastrophic injury, it could sustain life. It was with this new understanding and the publicity given to the Quinlan and Cruzan cases that the term *right-to-die* (Hampson & Emanuel, 2005) emerged to capture the complexities of this sensitive and social issue.

The case of Karen Ann Quinlan was the first documented right-to-die case in the US (Whetstine, 2006). Whetstine (2006) described Quinlan as a 21-year-old female who ceased breathing while at a party. Upon arrival at the emergency room, she was unresponsive to deep pain stimuli, and her pupils were non-reactive. She was placed on a mechanical ventilator. One year later, she was ventilator-dependent in a persistent vegetative state and receiving nutrition via a feeding tube. Quinlan's parents eventually requested that the ventilator be discontinued; however, her physician refused, and a series of court cases ensued.

In response to the cases brought before the New Jersey Supreme Court, the Court established a precedent for a person's right to refuse medical care (Hampson & Emanuel, 2005). Hampson and Emanuel (2005) reported that although the Court felt that end-of-life decision making should be decided in a hospital setting rather than a court room, the

Court granted Quinlan's family the right to withdraw the ventilator. The Court, however, did make it clear that it did not support the court room as a venue for every end-of-life dispute case. The case was taken to the U.S. Supreme Court; however, the Court refused to hear the case resulting in the standing judgment of the New Jersey Supreme Court that the ventilator be removed. The ventilator eventually was withdrawn, and Quinlan continued to breathe on her own and was kept alive for more than 9 years with artificial nutrition and hydration.

Following the public exposure of the Quinlan case in 1976 and throughout the 1980s, the United States engaged in extensive discussions concerning end-of-life care through a series of state court decisions lead by California, Florida, Massachusetts, and New Jersey (Hampson & Emanuel, 2005). Whetstine (2006) reported that eventually, the nation came to an agreement. First, there was a general consensus that competent patients have the exclusive right to refuse or terminate life-sustaining care, even if the wishes of the patient conflict with the wishes of family members and/or the health care team. Second, the courts established that life-sustaining treatments that can be refused include not only the ventilator but also blood transfusions, renal dialysis, chemotherapy, and artificial nutrition and hydration. Third, there was a general consensus that the stated end-of-life care preferences communicated in living wills or other advanced directive documents of mentally incompetent patients are enforceable in decisions involving the refusal or termination of medical care.

In 1990, the nation revisited the concepts of end-of-life care and the right to die. In this case, Nancy Cruzan, a 31-year-old woman, suffered severe brain damage as the result of a motor vehicle accident (Hampson & Emanuel, 2005). Hampson and Emanuel



(2005) reported that after many years with no recovery in brain function, Cruzan's family sought to have her artificial feeding and hydration terminated. However, Cruzan's home state of Missouri was a *right-to-life state*, one which required that clear and convincing evidence be demonstrated before life-sustaining treatment would be removed. When the Missouri courts refused to grant Cruzan's family the right to discontinue life-sustaining treatment, the family appealed to the U.S. Supreme Court.

The U.S. Supreme Court ruling on the Cruzan case was that individual states did have the right to regulate standards of evidence (Annas, 2005; Hampson & Emanuel, 2005). Thus, as Hampson and Emanuel (2005) indicated, Missouri was found to have the capacity to determine eligibility for removal of life-sustaining treatments and the case was returned to the state level where the Cruzan family again faced the burden of demonstrating clear and convincing evidence. Although providing such evidence without written document of a patient's wishes may have been considered challenging, a family member who claimed to have had a conversation about end-of-life care with Cruzan prior to the accident testified that Cruzan would not want to be kept alive in a persistent vegetative state with artificial nutrition and hydration. The testimony by the family member satisfied the Court's evidentiary requirement, and the Court ruled that the artificial nutrition and hydration be discontinued. In light of the national attention brought to existing state requirements for high levels of evidence for right-to-die approval, the Cruzan case fostered a heightened awareness of the importance of executing an advanced directive.

Nearly 10 years later, in 1998, the end-of-life case of Terri Schiavo became the focus of an intense national debate. Terri Schiavo, a 26-year-old woman, suffered a

cardiac arrest and lapsed into a persistent vegetative state, receiving nutrition and hydration via a feeding tube (American Society for Healthcare Risk Management, 2006; Annas, 2005; Whetstine, 2006). Annas (2005) reported that during the first 3 years after being diagnosed, Schiavo underwent aggressive rehabilitation. When her condition did not improve, her husband requested removal of the artificial nutrition and hydration. Schiavo's parents disagreed, claiming that their daughter would not refuse treatment and disputed that she was in a persistent vegetative stage.

For over 7 years, the case was heard in numerous Florida courts, which repeatedly upheld her husband Michael's request for removal of life-sustaining support (American Society for Healthcare Risk Management, 2006; Annas, 2005; Whetstine, 2006). Whetstine (2006) reported that eventually, the courts granted permission for Schiavo to be taken off life support. In essence, the lengthy battle hinged on what medical treatments Schiavo would have wanted for herself and whether or not her husband's right as legal guardian put him in a position to make those decisions for her. In part as a result of the prolonged court battle, Schiavo's death came nearly 15 years after she had suffered her cardiac arrest.

### **Advantages of Advanced Directives**

Several benefits to executing advanced directives have been identified. One identified benefit is that patients would not incur unwanted medical procedures and life-sustaining treatments (Dasta, MacLaughlin, Mody, & Piech, 2005). Dasta et al. (2005) have indicated that with fewer unwanted medical procedures conducted, health care facilities could save millions of dollars in expenses annually. Dasta et al. indicated, for example, that the average cost of care per day in an intensive care unit is \$3,946. When

mechanical ventilation is included in that care, the cost rises to \$4,796 per day, an increase of almost 18%.

In addition, the execution of advanced directives benefits the families of dying patients (Ramsey, 2009). Ramsey (2009) has indicated that when patients do not provide direction for their end-of-life care, conflicts may arise among family members attempting to make appropriate care choices for their loved ones. In addition, when patients do provide direction for their end-of-life care, families may be spared unnecessary stress and emotional strain associated with the responsibility of making end-of-life decisions for their incapacitated family members.

Gerst and Burr (2008) indicated that execution of advanced directives also has been found to benefit health care professionals who may avoid involvement in patients' end-of-life decision making. Many times, when patients enter the emergency department or intensive care unit, they do so without an advanced directive and without family members who are knowledgeable about their end-of-life care preferences. In these circumstances, health care professionals may be forced to make decisions on the patients' behalf.

Despite the identified benefits of executing advanced directives and the awareness of end-of-life issues brought to the nation's attention through, most recently, the Terri Schiavo case, execution of advanced directives has continued to be low (Whetstine, 2005). Whetstine (2005) reported that legislative mandates developed to increase the public's execution of advanced directives have failed to make a significant impact. Endorsement by health care professional has been insufficient to garner change. This

social condition best can be explained by examining barriers to advanced care planning and the communication of end-of-life preferences.

## **Barriers**

Despite the general agreement that advanced care planning and communicating end-of-life preferences with family and health care teams is desirable, barriers to execution of advanced directives have been identified (Lustbader, 2001). Lustbader (2001) has indicated that these barriers to communication are both health care team related and patient related and include patient demographics as well as conditions related to patients' and health care professionals' knowledge about advanced directives, engagement in end-of-life discussions, perceived responsibility for initiating end-of-life discussions and for end-of life decision making, and timing of end-of-life discussions.

## **Demographics.**

A study of 210 community dwelling adults found an advanced directive execution rate of 18.1% among study participants (Havens, 2000). Havens (2000) indicated that the executors of advance directives in this population were found to be older than non-executors as well as more educated. In addition to age and educational level, cultural differences and ethnic variation have been identified as factors in the execution of advanced directives (Hickman, 2002; Hornung et al., 1998).

In a survey of 1,193 older adult nursing home residents, Hornung et al. (1998) found a distinction between residents' ethnicities and their participation in the execution of advanced directives. The diverse population consisted of 385 European Americans, 364 African Americans, 288 Asian Americans, and 156 Hispanics. Their research

indicated that European Americans had a higher percentage of advanced directive execution than did any other ethnic group.

### **Knowledge.**

Other literature has suggested that the level of patient knowledge regarding end-of-life care decision making and advanced directives may be a barrier to advanced directive execution. Studies have indicated that advanced directives may be perceived as complicated because the information that people received is too general or too specific and the terminology is vague and confusing (Beckstrand et al., 2006; Norton & Talerico, 2000). In addition, general lack of understanding of end-of-life issues also has been indicated as a barrier to advanced directive execution (Hanson, Daris, & Garrett, 1997). Conversely, rates of advanced directive execution among nursing home residents in Havens's (2000) study indicated that those who executed advanced directives were more knowledgeable about advanced directives and terminal illnesses because of personal experiences with relatives or friends.

The connection between knowledge and the discussion of advanced directives also has been indicated with health care professionals. Physicians and nurses have been found to be uncomfortable counseling patients about end-of-life decisions because they lack knowledge of the legal guidelines and clinical applications of the advanced care planning process (Schlegel & Shannon, 2000). Schlegel and Shannon (2000) have indicated that in addition, these health care professionals often lack practical experience and hold misconceptions regarding the emotional distress associated with the discussion of advanced directives. In still other cases, health care professionals simply lack basic

education about advanced directives fostered by lack of community involvement and awareness for coalition building (Hickman, 2002).

### **Engagement.**

Engagement in end-of-life discussions also has been found to be a factor in the execution of advanced directives (Hanson et al., 1997; Havens, 2000). One reason for the lack of engagement in end-of-life discussions may be connected to poor support from health care professionals as indicated by low advanced directive execution rates found among health care staff and their families (Orlander, 1999). Orlander (1999) reported that of those invited to participate in the researcher's study of older adults in an assisted living facility ( $n = 730$ ), 553 residents responded. Of the 76% of survey respondents, 18% indicated that they had executed an advanced directive. Orlander determined that health care workers do not appear to complete advanced directives at a rate any higher than that of the general population.

Studies also have indicated that patient procrastination may contribute to lack of engagement in advanced directive discussion (Llovera et al., 1999; Lowery, 2008; Phipps et al., 2003). Fearfulness of receiving less aggressive care (Nolan & Bruder, 2000) or of being denied care (Gilligan & Jensen, 1995) if end-of-life wishes were discussed with family and the health care team also have been identified as factors contributing to lack of engagement in end-of-life discussions.

Other studies have suggested that in particular hospitalized patients were too anxious about their immediate stressors to be able to calmly consider executing an advanced directive (Schlegel & Shannon, 2000). Other patients believed that they never would be in a position where they needed an advance directive (Llovera et al., 1999;

Phipps et al., 2003). Still others avoided participation in end-of-life care discussion because they perceived aggressive education on advanced directives as coercive and uncaring (Nolan & Bruder, 2000).

### **Responsibility.**

Perception of responsibility for initiating end-of-life discussions or for making end-of-life decisions has been found to be a factor in the execution of advanced directives. In some cases, health care professionals felt that patients should be responsible for initiating end-of-life discussions (Hickman, 2002). Pan (2002) has indicated that often however, patients who do want to discuss end-of-life issues with their health care team wait for the health care team to initiate the discussion because they feel that it is the responsibility of the health care team to do so. In other cases, patients preferred or expected their family to make end-of-life decisions for them (Llovera et al., 1999; Lowery, 2008; Phipps et al., 2003).

### **Timing.**

Timing related to end-of-life discussions also has been found to be a factor in the execution of advanced directives. Studies have shown that physicians are more likely to have conversations about end-of-life care with their patients when clinical situations dictate. That is, some physicians believe that end-of-life discussions are not necessary unless a patient has a specific and identified terminal illness (Hickman, 2002; Lowery, 2008). In general, however, these conversations rarely occur despite the clinical condition of the patient (Lowery, 2008). When patient perspectives regarding timing of end-of-life discussions were examined, a survey indicated that patients felt that end-of-life

discussions should take place earlier rather than later in the medical care plan and prior to any life threatening disease (Pan, 2002).

Other studies have indicated that limitation of time posed a barrier to end-of-life discussion and execution of advanced directives. When a group of interns ( $n = 56$ ) and their patients ( $n = 56$ ) discussed methods through which health care providers should introduce end-of-life discussions, their audio taped discussions indicated that the average length of discussions was 5.6 minutes (Tulsky, Fisher, Rose, & Arnold, 1998). Of this time, the health care professional spoke two thirds of the time (Tulsky et al., 1998).

Further, the patients found that the minimal time spent discussing end-of-life issues with health care providers was not sufficient for them to voice concerns, ask questions, or actively participate in the conversation (Tulsky et al, 1998). The patients expressed that the minimal time investment on behalf of the health care professionals did not encourage them to execute an advanced directive (Tulsky et al, 1998). In other cases, health care professionals confirmed such patient perspectives indicating that their work demands imposed limitations on time available for them to engage patients in end-of-life discussions (Schlegel & Shannon, 2000).

Similarly, Hanson et al. (1997) found that barriers precluded the completion of advanced directives. The researchers study asked 461 families that recently experienced the death of a loved for recommendations to improve end-of-life decision-making. Of the participant comments, 91% emphasized better communication and access to a physician's and or nurses' time.



## Summary

The research revealed that patient demographics, particularly age, race, and level of education; and conditions related to patients' and health care professionals' knowledge about advanced directives, engagement in end-of-life discussions, perceived responsibility for initiating end-of-life discussions and for end-of life decision making, and timing of end-of-life discussions had a significant impact on the execution of advanced directives. The research also revealed that the execution of advanced directives can foster positive outcomes for patients who may be spared unwanted life-prolonging procedures. Family members and/or the health care team may benefit from guidance provided by an advanced directive rather than having to make difficult end-of-life decisions for an incapacitated patient with no end-of-life care instructions.

Advanced directives allow patients to communicate their end-of-life wishes to their family and health care team when they are incapacitated and unable to do so. With such communicative significance, advanced directives must be viewed as a tool to aid the patient, the patient's family members, and the patient's health care providers in making decisions regarding end-of-life care. The literature, however, revealed that although many benefits of advanced directives are recognized, the practice of educating people and patients about the importance of executing advanced directives has not been fully realized. There is a need to continue educating the public and the health care team of the importance of advanced directives and their execution as a communicative tool of end-of-life health care preferences.

## CHAPTER III: METHODOLOGY

### Overview

To best answer the research question in this descriptive study, the researcher chose to use a mixed methods design using both quantitative and qualitative research. Quantitative and qualitative approaches are based on the belief that a human experience can be communicated to others by rating that experience on a Likert-type scale or through describing the experience with words or artistic expressions (Polit & Beck, 2008). This study, although primarily quantitative in nature, presents insightful qualitative data which describes in detail the events and experiences shared by the participants.

The quantitative aspect of this study was realized using quantitative data collection tools. The qualitative aspect of this study was realized using a qualitative data collection tool. The study sought to better understand participant experiences and attitudes surrounding the execution of advanced directives. This study evaluated the effects of an advanced directive education program delivered in a workplace environment.

### Setting and Sample

The setting for this study, an occupational health clinic operated by Johns Hopkins Occupational Health Center, was located in a soft drink bottling facility locate

in a southern U.S. state. Three shifts of approximately 489 people operated the facility. A private conference room at the occupational health clinic was reserved for implementing questionnaires and for conducting advanced directive education and focus group sessions.

Convenience sampling was used to recruit 78 participants. The researcher selected a sample based on inclusion and exclusion criteria which consisted of characteristics of the target population: individuals who were 18 years of age or older and who were employed either full-time or part-time at the bottling facility. Because a high school diploma was required for employment at bottling facility, it was assumed that all participants were able to read and speak English on a high school level. Employees of all job functions were invited to participate: sales representatives, account managers, merchandisers, warehouse loaders, gate checkers, forklift drivers, bulk drivers, bay deliver drivers, transport drivers, customer service representatives, human resource representatives, information technologists, and yard workers. Employees' family members and temporary employees were not eligible to participate. Based on these criteria, participants varied in gender, age, religious, ethnic, educational, occupational, and socioeconomic backgrounds. The focus group was conducted with only one researcher and five of the consenting participants who participated in the questionnaire portion of the study.

### **Data Collection**

Prior to program participation and data collection, written permission was obtained from each participant using a consent form (see Appendix A). Data were collected using both quantitative and qualitative tools. Quantitative data were collected using a demographic questionnaire, a pre-program questionnaire, a post-program

questionnaire, and a program evaluation form. Qualitative data were collected using a focus group. Data collection was conducted during a 2-week period.

### **Ethical Consideration**

Because human subjects were involved in this study, the researcher sought approval to conduct the study through appropriate administrative channels at the occupational site (see Appendix B). The researcher sought Institutional Review Board (IRB) approval (see Appendix C) and provided approval documentation to the administration. The informed consent was given to each participant and explained.

Participation in the study was voluntary. The researcher kept the consent forms, audiotapes, transcripts, and computer files in a locked box in a secured area at the University of Central Florida College Of Nursing. In addition, all audiotapes were destroyed at the completion of the study. The researcher informed each participant of his or her right to terminate their participation at any time without penalty, prejudice, or loss of benefits to which the participant was entitled. Participants were not required to answer any question with which they were not comfortable.

The researcher ensured that no participant was exposed to hurt, harm, or danger with the exception of potential emotional distress caused by discussing end-of-life issues. During the interview, participants were free to discontinue participation in the discussion or to leave. On-site counseling was available through the employee assistance program at the occupational health clinic for any participant who exemplified any emotional distress. Confidentiality was maintained. The researcher randomly assigned numbers to participants upon their entry into the program. Participants drew numbers from a container and identified themselves on the data collection tools only by that number.

After the elements of the study and informed consent were reviewed, the researcher and each participant signed two copies of the informed consent. The participant was given one copy of the informed consent, and the researcher retained the other copy of the informed consent. Consents were completed prior to beginning questionnaires and focus groups. The option to give consent verbally was available for any participant who refused to sign a consent form but who desired to participate in the study. No informed consent was required for participants who wished to participate only in the educational portion of the program.

Those employees who wished only to participate in the educational portion of the program received a program packet containing only the educational component of the program and thus did not complete any data collection questionnaires. The researcher did not start data collection until approval was obtained from the University of Central Florida and Johns Hopkins Occupation Health Center Institutional Review Boards. At all times, the researcher upheld the ethical responsibility of maintaining professional standards of nursing conduct.

## **Instruments**

Instruments for data collection included a demographic questionnaire, a pre-program questionnaire, a post-program questionnaire, a program evaluation form, and a focus group. The Advanced Directives Program Demographic Data Questionnaire (see Appendix D) was designed to elicit from the participants demographic information that the researcher used to identify trends or patterns of participation. The Advanced Directives Program Pre-Program Questionnaire (see Appendix E), was designed to assess initial participant knowledge regarding advanced directives. The Advanced Directives

Program Post-Program Questionnaire (see Appendix F), which was administered after the educational component of the program was complete, was used to assess changes in participant knowledge. The Advanced Directives Program Evaluation Questionnaire (see Appendix G) was used to assess program effectiveness.

The focus group was designed using the Advanced Directives Program Focus Group Sample Questions (see Appendix H), a semi-structured interview schedule consisting of 10 questions that helped facilitate group discussion. The researcher conducted the focus group and encouraged participants to elaborate on their feelings and attitudes toward end-of-life discussion and/or the execution of advanced directives. The focus group functioned to elicit additional program feedback and as an evaluative tool for the effectiveness of the program's educational component. The interview schedule guided, rather than controlled, the research process. The researcher provided an hour and a half for the focused group interview.

#### **Intervention tool.**

The *Five Wishes* document (Aging with Dignity, 2009), a guide for understanding the purpose and value of executing advanced directives (see Appendix I), was used in this study's program. The document was used in the educational component of the program as an intervention tool, the purpose of which was to increase the discussion of end-of-life care and the execution of advanced directives. Regarding end-of-life care, the document addressed:

Who you want to make health care decisions for you when you can't make them;

The kind of medical treatment you want or don't want; How comfortable you

want to be; How you want people to treat you; What you want your loved ones to know. (Aging with Dignity, 2009, p. 2)

The document included a legally recognized living will which may be registered with certified advanced directive registries nationwide (see Appendix I) as well as a supplemental quick reference fact sheet. Use of the *Five Wishes* document (Aging with Dignity, 2009) as an intervention tool allowed the researcher to determine if education was a contributing factor to any noted increase in the discussion of end-of-life care and/or execution of advanced directives among study participants.

The researcher used a presenter's version of the document, *Sharing the Gift: A Guide to Presenting Five Wishes* (Aging with Dignity, 2009) while reviewing the document with study participants. The presenter's version included an overview of the history of advanced directives and the *Five Wishes* document; definitions of terms; tips for presenting information and prompting successful discussion; and a timeline for guiding discussion. The presentation for participants followed the *Five Wishes* discussion outline:

1. Oral Presentation (10 minutes)
  - a. Present details of Wish 1: Discussion of the concepts of a health care agent
  - b. Present details of Wish 2: Discussion of the concepts of a living will
2. Open Discussion for questions (10 minutes)
3. Oral Presentation (15 minutes)
  - a. Present details of Wish 3: Discussion of comfort measures

- b. Present details of Wish 4: Discussion of “How you want people to treat you”
  - c. Present details of Wish 5: Discussion of “What you would want your loved ones to know”
4. Open floor for questions and answers (10 minutes)

### **Data Analysis**

Data analysis was conducted in order to better understand participant experiences and attitudes surrounding the execution of advanced directives. In addition, data analysis was used to evaluate the effects of a workplace-delivered advanced directive education program. During data analysis, the researcher assessed for normal distribution, skewness, and outliers of data collected in the study. Also, the researcher remained mindful of potential sample bias.

#### **Quantitative.**

The demographic data collected using the quantitative Advanced Directive Program Demographic Data Questionnaire; the participant knowledge data collected using the Advanced Directive Pre-Program Questionnaire and the Advanced Directive Post-Program Questionnaire; and the program evaluation data collected using the Advanced Directive Program Evaluation Questionnaire were described and synthesized using descriptive statistics. Descriptive statistical analysis was appropriate in this study because it allowed the researcher to systematically categorize, interpret, and communicate the collected measures. This process allowed the researcher to summarize sample characteristics, describe key research variables, and document methodological features.



The data were analyzed using SPSS frequency distribution and paired *t* test with a summary of the variables used in the study. The data file was verified for accuracy prior to analyzing data. The frequency distribution informed the researcher of the values of each variable and the number of subjects with each value. The resulting demographic characteristics of the sample are illustrated graphically in table format in the findings sections.

### **Qualitative.**

Additional participant data collected using the Advanced Directive Program Focus Group Sample Questions were described and synthesized using content analysis. Morse and Field (1995) indicated that content analysis is based on symbolic interaction theory which focuses on human behavior, specifically the meaning of events to a group of people in a natural or every day setting. The focus of content analysis is the understanding how a group of people, through their social interactions, define their reality. For the researcher studying social interaction, meaning guides behavior, and situation precedes action. Thus, the meaning of the situation is created by the group and leads to action and consequences of action.

Content analysis has been identified as an approach to theory development based on a study of human conduct (Chenitz & Swanson, 1986). Further, this method of analysis has been identified as a logical procedure for collecting, categorizing, and analyzing empirical data from nursing practice as a means of identifying behavioral patterns and emergent themes. Therefore, the use of content analysis in nursing research is appropriate as understanding patient and family behaviors regarding advanced directives may guide nursing actions and interventions. In this study, content analysis was

used to investigate individuals' decision-making processes when deciding whether or not to participate in end-of-life discussions and/or the execution of an advanced directive.

Data collected from the focus group were analyzed as it was processed. First, the researcher read the transcription of the focus group session and compared it with the original audiotape for accuracy. The researcher then read the transcript in its entirety to gain a sense of continuity. Next, the researcher assigned codes to emerging themes, concepts, and categories that arose from the data. Symbols were used to clarify participant words and phrases, and a research consultant evaluated transcripts for coding consistency. Finally, by comparing identified patterns in the coded data, the researcher noted emerging themes.

## **Procedures**

The researcher accomplished the study's objectives following pre-determined procedures. The study was conducted in two sessions: Session 2 occurred 2 weeks after Session 1. The study procedures included 13 steps:

Prior to beginning the study:

1. Obtain permission – The researcher obtained permission to conduct the study from both the university and data collection site prior to beginning data collection.
2. Recruit participants – The researcher recruited participants from the data collection site. The researcher publicized the study via announcements in communication flyers and inserts in payroll envelopes. The participants contacted the researcher using the provided telephone contact number.

Participants were not provided incentives to participate.

Session 1:

3. Conduct participant intake - Direct random assignment of numbers to participants and distribute program packets. Those who agreed to sign informed consents received a full program packet including the educational component of the program as well as the data collection questionnaires. Those who did not wish to sign informed consents received a program packet containing only the educational component of the program.
4. Obtain informed consent – The researcher obtained written consent from each agreeing participant.
5. Implement Advanced Directives Program Demographic Data Questionnaire – The researcher directed consenting participants to complete the Advanced Directives Data Demographic Data Questionnaire.
6. Implement Advanced Directives Pre-Program Questionnaire – The researcher directed consenting participants to complete the Advanced Directives Pre-Program Questionnaire.
7. Implement educational program intervention - The researcher used the *Five Wishes* document to educate participants about end-of-life care and advanced directives for end-of-life decision making. The presentation followed a schedule: a 10-minute researcher-lead informational segment followed by a 10-minute open discussion and a 15-minute researcher-lead informational segment followed by a 10-minute open discussion. The researcher then informed participants that completed *Five Wishes* living wills may be submitted to certified advanced directive registries. The researcher

emphasized that living will documents did not need to be returned to the researcher. Finally, the researcher provided her contact number for participants in case they had additional questions or concerns at a later time. The researcher also provided the contact number for Aging with Dignity for those who needed to talk with someone other than the researcher.

8. Excuse non-consenting employees – The researcher thanked those employees who wished to participate only in the educational component of the program and excused them.
9. Discuss Advanced Directives Post-Program Questionnaire – The researcher directed consenting participants to complete the Advanced Directives Post-Program Questionnaire any time during the next 7 days and return it to the researcher. The questionnaires were returned to a secure and marked receptacle provided at the facility.
10. Invite participants to focus group – The researcher invited the participants to take part in the focus group. The researcher discussed the purpose of the focus group and the potential benefits that the researcher might gain from their engagement and participation.
11. Implement the Advanced Directives Program Evaluation Questionnaire - The researcher directed consenting participant to complete the Advanced Directives Program Evaluation Questionnaire.

Prior to Session 2:

12. Data entry – The researcher completed computer data entry of all data gathered from participant questionnaires. The entered data were converted

into an SPSS data file which was verified for accuracy prior to the completion of any data analysis.

Session 2:

13. Implement focus group – The researcher conducted a focus group using the Advanced Directives Focus Group Sample Questions and recording equipment.
14. Record field notes – At the end of the focus group, the researcher recorded field notes in order to help the researcher separate preconceived ideas from the research process itself.

Following Session 2:

15. Transcription – The researcher employed a professional transcriptionist to transcribe the focus group audiotapes verbatim.
16. Data analysis – Qualitative data were analyzed for themes. The researcher analyzed and disseminated data and findings accordingly.
17. Reporting – The researcher shared the study results with the research group and occupational worksite. The researcher prepared a final report discussing study findings and implications for future study.

### **Plan Summary**

The findings of the literature synthesis revealed that a person's attitude regarding end-of-life issues have a significant impact on the execution of advanced directives.

Advanced directives are viewed as a tool to aide a patient, his or her family members, and health care providers in making end-of-life decisions. If a person's desires concerning end-of-life care are not known, family members and/or the health care team become

responsible for making end-of-life decisions without patient guidance. Making these decisions can be difficult, complicated, and stressful.

The researcher conducted a study regarding attitudes toward the discussion of end-of-life care and the execution of advanced directives based on a work place setting educational intervention. The researcher studied a heterogeneous sample of adults in an occupational work setting using a mixed methods design using both a quantitative and qualitative measures. The researcher used four quantitative data-gathering tools and one qualitative data-gathering tool to evaluate the effectiveness of the intervention tool, the *Five Wishes* document.

Use of the focus group afforded the researcher the opportunity to gather more detailed participant information than could be gathered from questionnaires alone. Face-to-face meetings provided participants a forum in which they could share information about what they thought or felt about end-of-life issues and the execution of advanced directives as well as why they thought or felt the way they do. Although for some participants, self-disclosure may be difficult or uncomfortable, the potential for depth of disclosure among the participant group as a whole was significant and supported the use of focus groups to gather data. The researcher provided participants the opportunity to evaluate the program as a means of gathering suggestions for future use and for clarifying the research experience. The researcher planned to share with colleagues the information collected from the evaluation forms.

The researcher reduced threats to validity by using accepted statistical analysis software. The researcher reduced threats to reliability by verifying the computer data file before conducting any analyses of the quantitative data, by checking the audiotape

transcription against the original focus group audio tape, by employing a research consultant to check data coding accuracy before conducting any analyses of the qualitative data, and by maintaining awareness of researcher bias. Neutrality was maintained by clarification and validation of emerging themes. Trustworthiness was maintained throughout the study.

## CHAPTER IV: RESEARCH FINDINGS

### Introduction

This chapter presents the results of this study which investigated adult attitudes toward end-of-life issues and the execution of advanced directives. The purpose of this mixed method descriptive study was to determine the effectiveness of education interventions among individuals in a workplace setting for increasing end-of-life discussions and advanced directive execution rates. Procedures for data analysis are identified, findings are described, and themes and exemplars are presented. The major findings from both the quantitative and qualitative analyses are discussed. The quantitative data were collected using the demographic, and pre- and post-program questionnaires. Those data were analyzed and synthesized using statistical procedures. The qualitative data were collected from 5 focus-group participants. Those data were analyzed and synthesized by the researcher.

Of those invited to participate in this study, 79 participants completed the education program. One participant failed to complete a post-program questionnaire. Therefore, the total number of completed pre- and post-program questionnaires ( $n = 78$ ) was one less than the total number of participants. No participants exemplified any emotional distress; therefore, no participants were referred for counseling that had available through the employee assistance program at the occupational health clinic. No participants refused to sign a consent form, and no verbal consents were captured on



audiotape. Seven participants wished to participate only in the educational portion of the program, thus no informed consent was required for those participants.

## **Quantitative Findings**

This section presents a summary of the sample demographics of the 78 adults who participated in the education program and completed the Demographic Data Questionnaire, Pre-Program Questionnaire, and Post-Program Questionnaire. The major findings from statistical analysis are also presented. Correlations were calculated between the pre- and post-program questionnaires. Frequency distribution, independent *t* tests, paired *t* tests, and Pearson correlation coefficients were used to test relationships between the independent variables (age, gender, ethnicity, and religion) and select dependent variables (knowledge, likelihood to consider executing an advanced directive, and likelihood to discuss end-of-life solutions, loved-ones making decisions, and advanced directives are important). Given the conditions in the quantitative design (pre- and post-program questionnaire), paired *t* tests were conducted in order to examine if there was a significant within-group difference between pre- and post-program questionnaire data on independent variables.

Table 1 provides a demographic profile of the 78 participants who participated in the quantitative portion of the study. Of the total participants, an overwhelming majority were male (92%). The group's ethnicities varied; however, the three most common ethnic backgrounds demonstrated relatively close percentages. Most of the participants either were married and either were drivers, salespeople, or warehouse workers. More participants indicated no religious affiliation than any other affiliation, and the majority of participants indicated that they had a high school diploma.

Table 1. Demographic Characteristics of Study Participants.

Characteristic	n	%
<b>Gender</b>		
Female	6	8
Male	72	92
<b>Ethnicity</b>		
African American	22	28
European American	23	30
Latin American	17	22
Native American	4	5
Other	12	15
<b>Marital status</b>		
Single	30	38
Married	42	54
Separated	3	4
Divorced	3	4
<b>Occupation</b>		
Driver	27	35
Management	8	10
Production	7	9
Sales	19	24
Technician	1	1
Warehouse	16	21
<b>Religion</b>		
Baptist	14	18
Catholic	17	22
No religion	26	33
Other	21	27
<b>Education</b>		
No high school	2	3
High school	53	68
Associate's degree	14	18
Bachelor's degree	8	10
Graduate degree	1	1

Note. *N* = 78.

In order to determine program effectiveness in encouraging people to communicate about advanced directives, data were collected via the pre- and post-program questionnaires. The pre-program questionnaire was designed to assess initial participants' knowledge regarding advanced directives, and the post-program questionnaire was used to assess changes in participants' knowledge. The pre- and post-program questionnaire items were answered on 5-point Likert-type scale: 1 (*strongly agree*), 2 (*somewhat agree*), 3 (*neither agree nor disagree*), 4 (*somewhat disagree*), 5 (*strongly disagree*). Figures 1 through 5 provide descriptive statistics of participant responses to the pre- and post-program questionnaire items.

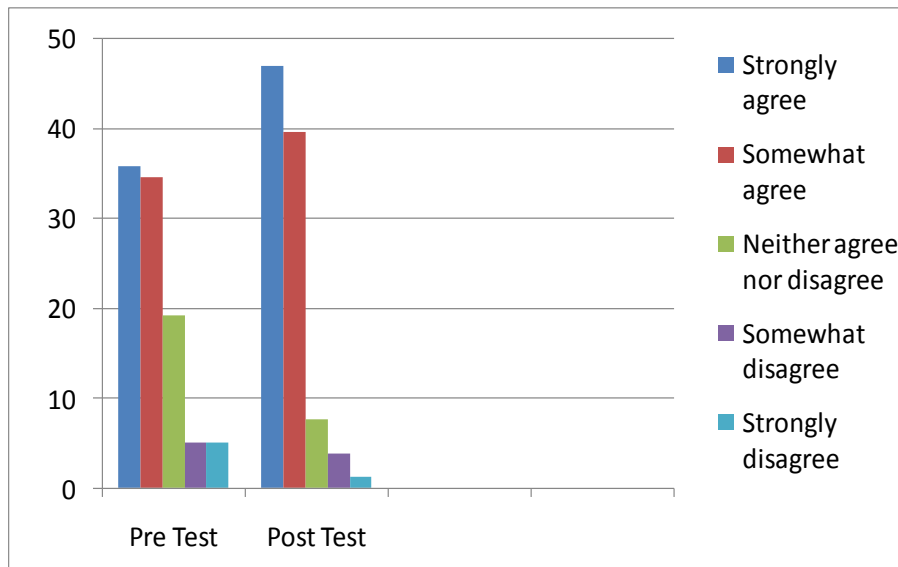


Figure 1. Pre- and post-program questionnaire Question 1: I am knowledgeable regarding end-of-life decision making and advanced directives.

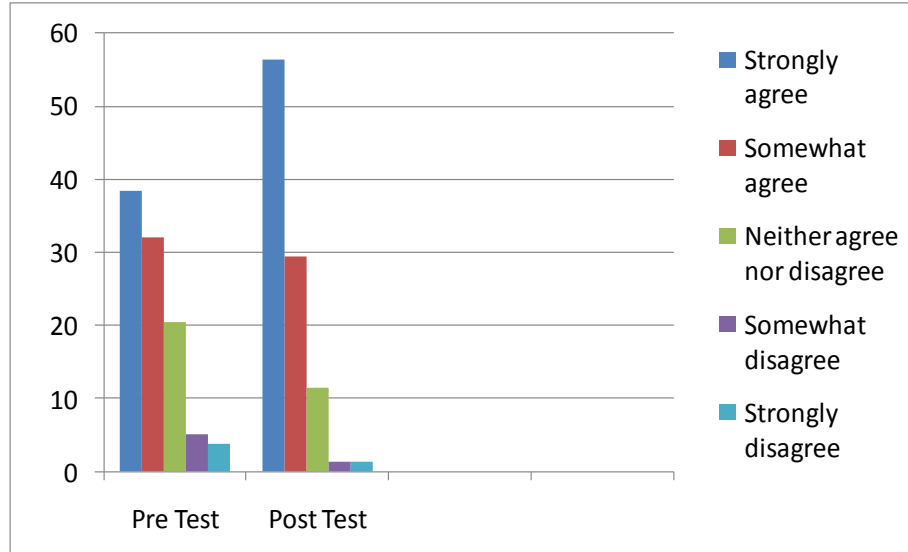


Figure 2. Pre- and post-program questionnaire Question 2: I am likely to consider completing an advanced directive.

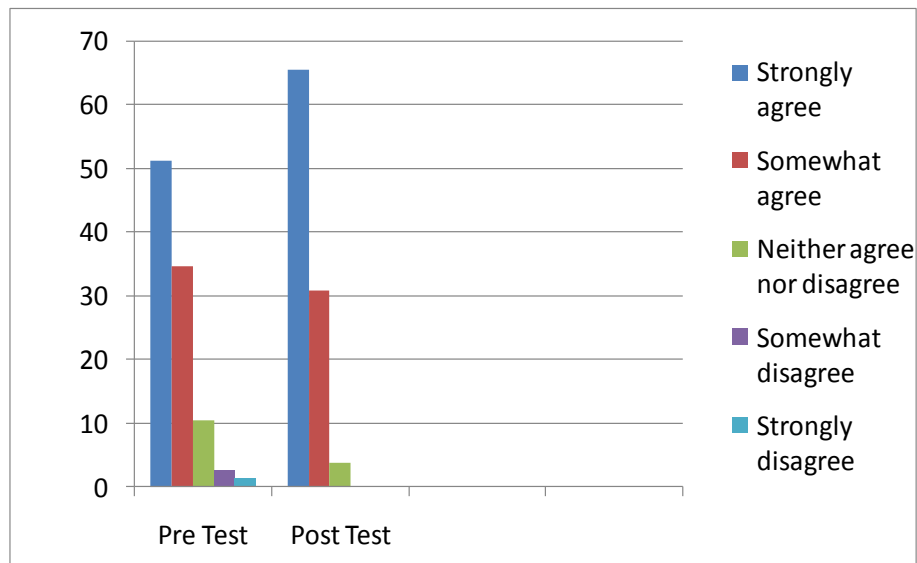


Figure 3. Pre- and post-program questionnaire Question 3: I am likely to discuss end-of-life care solutions with family, friends, and health care providers.

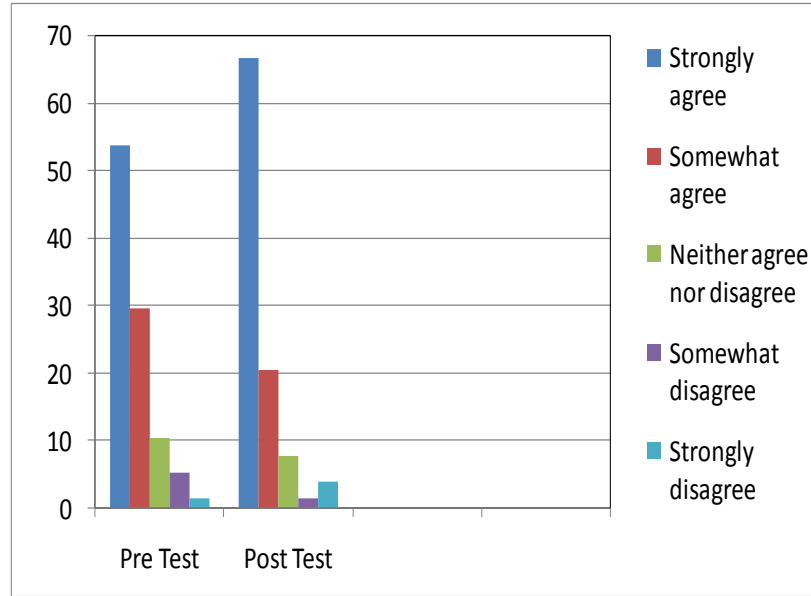


Figure 4. Pre- and post-program questionnaire Question 4: If I were in a coma and a medical decision had to be on my behalf, I would be comfortable with a loved-one making a decision for me.

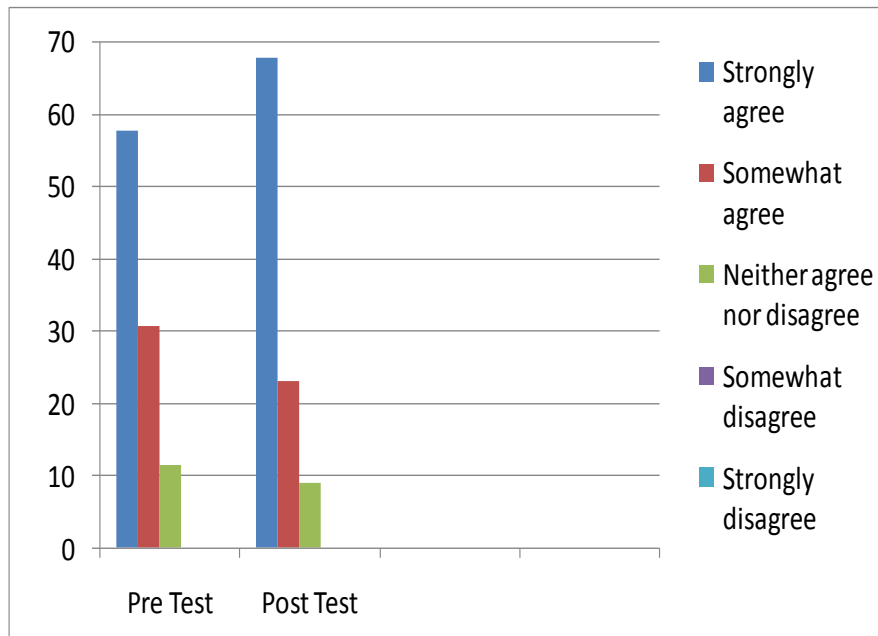


Figure 5. Pre- and post-program questionnaire Question 5: I believe that advanced directives are important for a dying person who cannot make decisions for him or herself.

### **Paired samples *t* test.**

Table 2 provides additional descriptive statistics of the participants' responses to the pre- and post-program questionnaire items including mean scores. The pre-program questionnaire measured a lack of knowledge and understanding of end-of-life planning and advanced directives. The post-program questionnaire measured the increase in knowledge and understanding of end-of-life planning and advanced directives. Results indicated a high mean score on the pre-questionnaire but a decrease in the mean scores on the post-questionnaire. The decrease was statistically significant for Questions 1 through 3. There was a significant change ( $p < .05$ ) regarding pre- and post-program questionnaire items (dependent variables) knowledge, likely to consider executing an advanced directive, and likely to discuss end-of-life solutions. There was no significant difference from pre- to post-program questionnaire items (dependent variables) regarding *loved-ones making decisions* and *advanced directives are important*.

The researcher used the paired samples *t* test to compare the means of the pre-program questionnaire scores to the post-program questionnaire scores. A paired samples *t* test was calculated to compare the mean pre-program questionnaire knowledge score to the mean post-program questionnaire knowledge score. The mean on the pre-program questionnaire was 2.09 ( $SD = 1.11$ ), and the mean on the post-program questionnaire was 1.72 ( $SD = .87$ ). Thus, a significant increase from pre-program questionnaire to post-program questionnaire knowledge was found:  $t(77) = 2.146$ ,  $p < .05$ .

A paired samples *t* test was calculated to compare the mean pre-program questionnaire likely to consider executing an advanced directive score to the post-program questionnaire likely to consider executing an advanced directive score. The

mean on the pre-program questionnaire was 2.04 ( $SD = 1.07$ ), and the mean on the post-program questionnaire was 1.62 ( $SD = .841$ ). A significant increase from pre- to post-program questionnaire likely to consider executing an advanced directive was found:  $t(77) = 2.584, p < .05$ .

A paired samples  $t$  test was calculated to compare the mean pre-program questionnaire likely to discuss end-of-life solutions score to the post-program questionnaire likely to discuss end-of-life solutions score. The mean on the pre-program questionnaire was 1.68 ( $SD = .860$ ), and the mean post-program questionnaire was 1.38 ( $SD = .564$ ). A significant increase from pre-questionnaire to post-questionnaire likely to discuss end-of-life solutions was found:  $t(77) = 2.433, p < .05$ .

A paired samples  $t$  test was calculated to compare the mean pre-program questionnaire loved-ones making decisions score to the post-program questionnaire loved-ones making decisions score. The mean on the pre-program questionnaire was 1.71 ( $SD = .107$ ), and the mean post-program questionnaire was 1.55 ( $SD = .110$ ). No significant difference from pre- to post-program questionnaire was found:  $t(77) = .973, p > .05$ .

Another paired samples  $t$  test was calculated to compare the mean pre-program questionnaire advanced directives are important score to the post-program questionnaire advanced directives are important score. The mean of the pre-program questionnaire was 1.54 ( $SD = .653$ ), and the mean post-program questionnaire score was 1.41 ( $SD = .653$ ). No significant difference from the pre- to post-program questionnaire was found:  $t(77) = 1.134, p > .05$ .

Table 2. Pre- and Post-program Questionnaire Response Values.

Questionnaire item	<i>M</i> (pre) <sup>a</sup>	<i>M</i> (post) <sup>b</sup>	<i>p</i> value
I am knowledgeable regarding end-of-life decision making and advanced directives.	2.09	1.72	.035
I am likely to consider completing an advanced directive.	2.04	1.62	.012
I am likely to discuss end-of-life care solutions with family, friends, and health care providers.	1.68	1.38	.017
If I were in a coma and a medical decision had to be made on my behalf, I would be comfortable with a loved-one making a decision for me.	1.71	1.55	.334
I believe that advanced directives are important for a dying person who cannot make decisions for him or herself.	1.54	1.41	.260

*N* = 78.

<sup>a</sup>Mean score for pre-program questionnaire responses.

<sup>b</sup>Mean score for post-program questionnaire responses.

*p* < .05

A Pearson correlation was calculated to examine the relationship among variables to determine if one variable affected another variable. The relationships between participants' age, ethnicity, and religion with regard to knowledge and likely to consider executing an advanced directive were analyzed. Table 3 reveals the Pearson correlation among age, ethnicity, and religion.

A weak correlation among all three variables (age, ethnicity, religion) was found although it was not significant (*p* > .05). Age, ethnicity, and religion were not related to participants' knowledge or likelihood of considering the execution of an advanced directive. Given that the significant level greatly exceeded .05, it is clear there were no significant relationship among these variables.



Table 3. Pearson Correlation of Dependent and Select Independent Variables.

Dependent & independent variables	$\chi^2$	<i>df</i>	<i>p</i> value
Knowledge			
Age	4.583	8	.801
Ethnicity	14.374	16	.571
Religion	15.451	12	.218
Consideration of advance directive			
Age	9.108	8	.333
Ethnicity	15.214	16	.509
Religion	8.673	12	.731

*N* = 78.

*p* < .05

When participants were asked if they had discussed end-of-life solutions with their healthcare provider, 10.3% (*n* = 8) of participants answered yes, and 89.7% (*n* = 70) answered no. Of the 10.3% that answered yes, 50% (*n* = 4) were in the 18-34 age group, and 50% (*n* = 4) were in the 35-60 age group. No participants were in the 60 and older age group. With regard to ethnic background, of those who discussed end-of-life solutions with a health care provider, 25% were African American, 25% were European American, 25% were Latin American, 12.5% were Native American, and 12.5% were other.

Prior to the education intervention program, no participants had executed an advanced directive. At the conclusion of the study, 26.9% (*n* = 21) of the participants had executed an advanced directive; 73.1% (*n* = 57) did not execute the advanced directive. Of those participants who executed an advanced directive, 38.1% (*n* = 8) were African

American, 33.3% ( $n = 7$ ) were European American, 14.3% ( $n = 3$ ) were Latin American, and 14.3% ( $n = 3$ ) were other. No Native Americans executed an advanced directive.

Data also revealed that when asked if there were barriers to discussing end-of-life solutions, 34.6% of participants answered yes, and 65.4% answered no. Of the 78 participants, 44.4% of the 18-34 age group and 56.6% of the 35-60 age group answered yes, while 56.9% of the 18-34 age group, 41.2% of the 35-60 age group, and 2.0% of the more than 60 age group answered no.

### **Summary of Quantitative Findings**

A variety of statistical procedures was employed to analyze key demographic variables and their relationships to end-of-life care and advanced directives. From the results obtained in Table 2 of pre- and post-program questionnaire mean scores, a significant relationship between implementing an educational intervention, and end-of-life care and advanced directives was discovered. The finding is especially significant given the samples size ( $N = 78$ ). The quantitative findings confirm the net data from the qualitative results that follow below.

### **Qualitative Findings**

This section presents the results of this study that sought to better understand participant experiences and attitudes surrounding the execution of advanced directives. Thematic findings that emerged from the focus group portion of this study are identified, described, and summarized. In addition, the Program Evaluation Questionnaire evaluated the effects of an advanced directive education program delivered in a workplace environment. The intention of the qualitative portion of this study was to provide a range

of experiences in order to capture the realities faced by participants in discussing end-of-life care and advanced directive planning. The following questions formed the basis of the qualitative portion of this study:

Research Question 1. When assessing adult attitudes toward end-of-life issues and the execution of advanced directives in the occupational work setting, what responses are generated?

Research Question 2. Are barriers to completing advanced directives uncovered?

Research Question 3. Did the participation increase end-of-life discussions and/or the execution of advanced directives?

**Focus group.**

Participants were encouraged to answer questions which they felt comfortable answering. Their answers were categorized by themes and illustrated by quotes from the transcribed focus group. The focus group was analyzed through content analysis and the resulting theoretical model is described. Direct quotes from focus group participants are used as exemplars to illustrate concepts of the theoretical model. The findings are organized based upon the model concepts.

Data was analyzed one day after it was collected. Once the audiotape was transcribed, the transcript was read and compared with the audiotape to assess for accuracy. The researcher first read the transcript holistically to gain a sense of the continuity in the data. Then, the researcher read the transcript critically focusing on themes that might be present in the data. The researcher noted recurring concepts and assigned codes to emerging themes and categories that arose from the data. From the

data, the researcher established a theoretical model: the Jones model of end-of-life education intervention.

### **Theoretical model.**

The theoretical model that evolved from the data is illustrated in Figure 6. The Jones model focuses on the concepts involved in the transition from lack of knowledge to communication. Those concepts include *lack of knowledge, education, acceptance, and communication/execution* of an advanced directive. One can move from one stage to another progressively. One can also begin at any stage.

Research participants demonstrated a transition from lack of knowledge, with minimal to no understanding of end-of-life care and advanced directive planning, to an educated state represented by the ability to participate in end-of-life care discussions and practices. Participation in discussion included communication with family, friends, and the healthcare team. Participation in practices was demonstrated by the execution of an advanced directive. That participants moved through education to communication and execution of advanced directives demonstrated that they had gained acceptance of the concept.

### ***Lack of knowledge***

Most of the participants verbalized a lack of knowledge regarding end-of-life care and advanced directives. Of the participants, 80% ( $n = 4$ ) verbalized a lack of knowledge. Although the majority of the participants verbalized a lack of education and was oblivious to end-of-life care and advanced directives, the group remained engaged and appeared eager to hear what the researcher would say about end-of-life care and

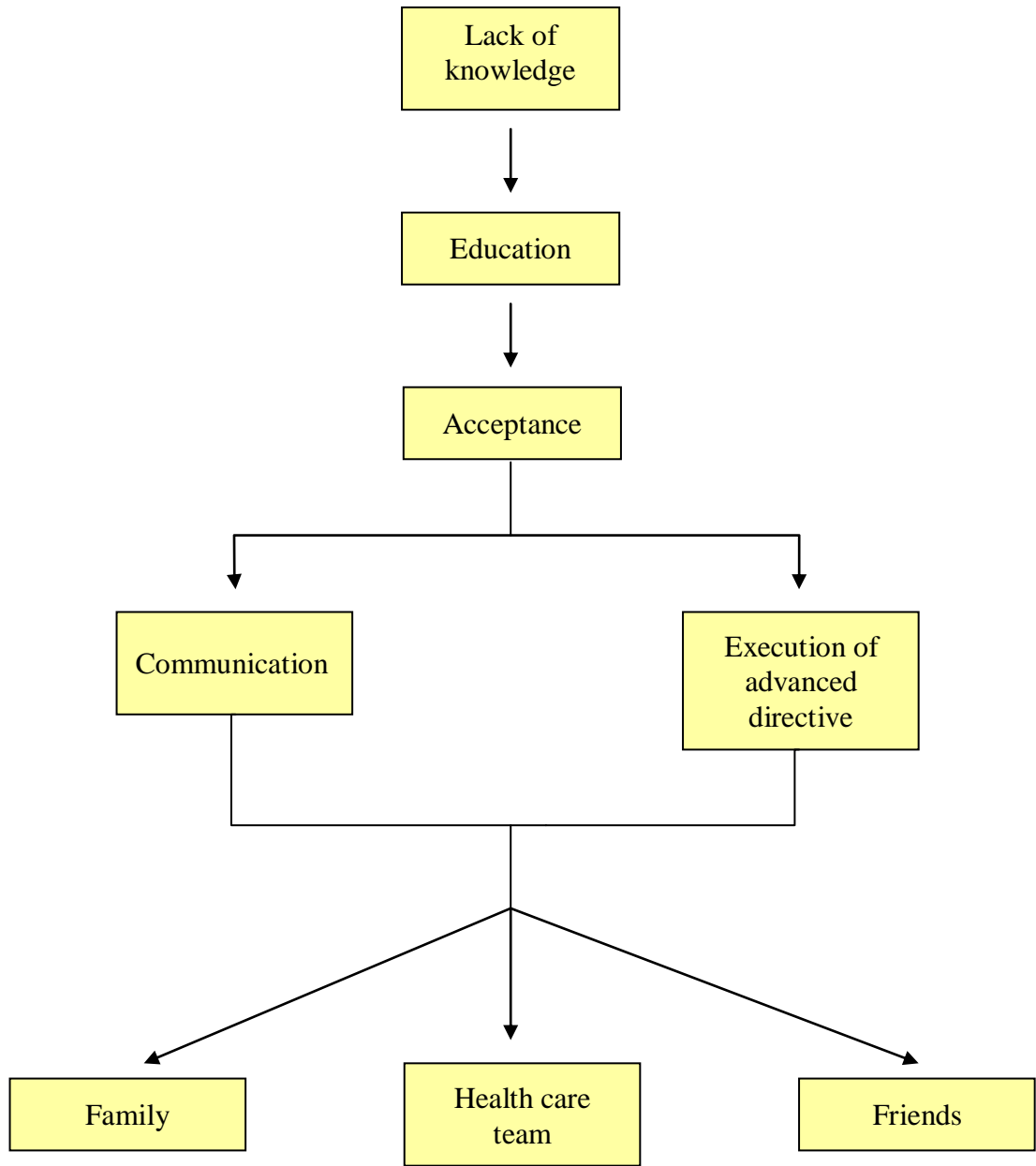


Figure 6. The Jones model of end-of-life education intervention. Created by Marchina T. Jones at the University of Florida (2010).

advanced directives. No one verbalized a lack of interest in the focus, nor did anyone leave the focus group.

Several of the participants made statements regarding a lack of knowledge:

- “I am not planning to die today, so I don’t see a rush.”
- “[End-of-life care is] something I feel I don’t I need to worry about right now.”
- “I thought you had to be sick to have a living will.”
- “What you don’t know won’t hurt you.”
- “You think it is something just for old people, not young people.”
- “It’s a turn off when the hospital asks me if I have a living will. I only go in for my colonoscopy!”
- “I didn’t know a living had anything to do with my hospital stay. I thought it was for my money, house, and car.”
- “Why don’t they teach us this stuff when we fill out our beneficiary for our work insurance?”

Although the focus group demonstrated an overall lack of knowledge of end-of-life care and advanced directives, one participant expressed having knowledge of end-of-life care and advanced directives. The participant explained, “My mother had a massive stroke. She had a living will; that was my first time learning about it. It was easier to guide my decision.” Despite this participant’s knowledge, the participant had not executed an advanced directive prior to the research program.

### ***Education.***

The *Five Wishes* document was reviewed and discussed in detail with participants during the education phase of the study. When participants realized they had a lack of knowledge regarding end-of-life care and advanced directives, they began asking questions and discussing end-of-life care with one another. The participants asked/stated:

- “Do I have to make all these decisions right now about what’s going to happen to me if something happened?”
- “Why won’t the doctors sit down and mention this stuff with you during your physicals?”
- “If my grandmother had not set up a living will, it would have been a nightmare. I mean, it really does help in the long run.”
- “If I don’t have something in writing, someone is going to make the wrong decision for me.”
- “Not having a will can also work against you too. When my ex-my mother-in-law was so sick, I was the only one at the hospital with her. I hated the woman. I hated her with a passion. The doctors kept coming to me saying ‘we can do this or we can do that.’ I was thinking in the back of my head, let her go. [Group laughs] So, if she didn’t have something in writing, I was making the wrong decision for that woman.”

After continued discussion, 100% ( $n = 5$ ) of the group participants felt that education was an important factor to better understand end-of-life care and advanced directives. A participant stated, “They [hospital staff] are asking more about living wills, but what is being done so people can get to do it and understand the importance of it?”

Participants felt they are being asked if they have an advanced directive, but that education is needed in order to gain an understanding of its purpose.

*Acceptance.*

Prior to participant acceptance, there was minimal engagement among participants and between participants and the researcher. At the beginning of the focus group, participants were very quiet and made very little conversation with each other. The researcher not only noticed that there was a lack of communication among participants, but there was a lack of interaction between the participants and the researcher as well. The researcher observed participants fondling their clothes, tapping their feet, looking at the floor, looking at the ceiling, and avoiding eye contact with other participants and researcher. During this time, the researcher did most of the speaking but continued to encourage the participants to verbalize their thoughts and feelings regarding end-of-life care and advanced directives.

It was not until the researcher began discussing personal experiences with end-of-life planning and advanced directives that participants began to talk among each other and with the researcher. Dialogue slowly developed between the participants, and eventually the participants reached acceptance. Acceptance was determined to be agreement, either through verbal expression or actions and conduct, with discussing the reality of end-of-life care and advanced directives.

Each participant reached different levels of acceptance and did so at different rates; however, every participant verbalized an understanding of the importance of end-of-life care and advanced directives. Participants stated:



- “If our doctors and nurses would actually take the time to actually sit with the patient and discuss that on a personal level, one-on-one. I think it would probably hit home with a lot more people.”
- “I don’t want any miscommunication. It is really important to communicate. If I was on life support, would I really want my mom to be at the hospital for weeks looking at me with this machine just pumping air into me? Do I really want that? Do I want her to suffer through that? What type of decision do I want to be made? The directive will save your loved ones from pain, and you will have done what you want done for yourself.”
- “I don’t want to end up like Terri Schiavo. You know it hit home in the media, it really made people think. You should make all the decisions you want for yourself now with a will. You cannot assume someone else is going to know exactly what you would want. My husband would react on emotions, so I have to make sure I put it in writing what I would want.”
- “The topic made me understand that this is my life and I should be the one to make decisions about what I would or would not want, not my family.”

***Communication and execution of an advanced directive.***

Once participants moved from a lack of knowledge to acceptance, communication among participants and the researcher became more open. Participants were able to begin discussing end-of-life care with each other. Of the participants, 80% ( $n = 4$ ) executed an advanced directive. One participant stated, “Make all of the decisions you can right now about what you want to happen for you. Tomorrow is not promised. Now is the time.”

### Program evaluation.

The Program Evaluation Questionnaire was completed by 78 participants. A majority of the participants answered strongly agree and agree to a majority of the questions. Table 4 illustrates the answers from the Program Evaluation Questionnaire.

Table 4. Participant Evaluation Questionnaire Responses.

Evaluation item	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I am likely to recommend others for participation in this program.	40.0	51.4	7.2	0.0	1.4
I am likely to suggest that a co-worker or loved-one participate in this type of program.	42.8	45.7	8.7	1.4	1.4
I would agree to recommend this program to a coworker or loved-one.	50.0	40.0	7.2	1.4	1.4
This program has increased the likelihood that I would discuss end-of-life issues with others.	47.1	45.7	7.2	0.0	0.0
This program has increased the likelihood that I would complete an advanced directive.	45.7	42.8	10.1	0.0	1.4

*N* = 78. Responses given in percentages.

In addition to responding to the questions posed on the evaluation, participants also offered comments on the program and program concepts. Participants voiced concern about barriers as identified by their specific comments: “difficult topic,” “I don’t like to talk about death,” and “I am afraid.” Other participants said:

- “Having someone come in and talk to us was a good idea. The timing was perfect.”
- “I don’t think my family knows what I want if something happened to me. I feel the timing of the program is too short.”
- “It made me more aware of the importance of having an advanced directive. Timing was good because we were able to talk in a relax environment.”
- “I was able to learn about this difficult decision. Timing was adequate.”
- “It gives more insight on what to do. The timing was right.”
- “This is a topic we don’t think about enough. It brought awareness and attention. The timing was short.”
- “I think this would open peoples’ eyes about death and wills.”
- “It’s a good program, but I did not like the group discussion.”
- “This program gave me insight to an issue and a way to complete something I was previously unaware of.”
- “Very informative, but I needed just a little more information. Program too short, I need a little more information.”
- “I don’t want to discuss anything regarding death while at work!”
- “It makes you think ahead. The program was useful. I felt it was too short.”

Participants continued to ask questions after the completion of both the education session and the program evaluation. Several questions included:

- “What made you choose this place to talk about living wills?”
- “What will you do with this information?”

- “Will you share this stuff with management? They need to put this in the benefits enrollment.”

### **Summary of Qualitative Findings**

The qualitative results of the study were discussed. A detailed explanation of the theoretical model was presented, and results of the program evaluation were described.

The qualitative results suggest an overall increase in end-of-life discussions and advanced directive execution rates.

## CHAPTER V: DISCUSSION

This chapter presents the researcher's interpretation of findings from the previous chapter, an overall summary of the study, and a section detailing the researcher's response to the study. Implications for nursing practice and recommendations for future research are discussed.

### **Interpretation of Findings**

Data analysis from the quantitative portion of this study revealed that end-of-life discussions are not being discussed with health care providers. Analysis also identified that there was a significant relationship between implementing an educational intervention and end-of-life care and advanced directives. The implication of this finding is significant as it yields empirical evidence to suggest that an education intervention program in a workplace setting significantly increases end-of-life discussions and advanced directive execution rates.

Results obtained from the qualitative portion of this study lead to the development of the Jones model of end-of-life education intervention. Concepts of the model included lack of knowledge, education, acceptance, and communication/execution of an advanced directive. The researcher determined that these concepts were not mutually exclusive. One can move from one stage to another progressively or one can begin at secondary stages. Participants reacted individually during the focus group. There were no normal ways to react or respond.

Participant feedback indicated that education, especially in the workplace, was helpful and often essential for understanding the concepts associated with end-of-life care and the execution of advanced directives:

- “There should be a series.”
- “This is needed during benefits enrollment.”
- “The program could have been longer.”
- “This was a good place to talk about this type of subject.”
- “I am more aware of advanced directives.”
- “Good topic, but let’s not discuss this too early in the morning.”

### **Summary of the Research Study**

The Jones model of end-of-life education intervention was conceptualized to illuminate how participants transitioned from a lack of knowledge regarding end-of-life care and advanced directive planning to the ability to communicate with others and to the execution of an advanced directive. Lack of knowledge, education, acceptance, and communication/execution of an advanced directive emerged as concepts of the theoretical model. Lack of knowledge was described as the lack of understanding about end-of-life care and advanced directives. When the researcher presented the *Five Wishes* document to participants during the educational portion of the study, lack of knowledge was replaced with education. When the participants felt comfortable with their level of understanding of end-of-life care and advanced directives, they transitioned to acceptance of the importance of end-of-life care and advanced directives. One participant stated, “I did not realize how important advanced directives are. My mother won’t know what I

want. I need to write it.” When acceptance was reached, participants were able to communicate the importance of end-of-life care and advanced directives and the execution of advanced directives.

### **Determining study trustworthiness.**

Trustworthiness and validity as they are known in the positivistic paradigm are quite different when naturalistic inquiry is imposed (Lincoln & Guba, 1985). Lincoln and Guba (1985) discussed trustworthiness of qualitative research through the use of truth-value, applicability, consistency, and neutrality. Trustworthiness was maintained throughout this study through the implementation of these techniques for reducing threats to the validity to the study. Trustworthiness through truth-value, applicability, consistency, and neutrality were controlled throughout the study by the researcher’s control of the study environment, equivalence of subjects, and extraneous variables.

### ***Truth-value.***

Truth-value is the accuracy and believability of the study’s findings. It is the credibility of the research, which is related to internal validity in empirical research (Polit & Beck, 2008). Validity refers to the extent to which study’s findings accurately depict psychological and social processes that people use to make sense of their world (Morse & Field, 1995). In qualitative research, multiple realities are measured (Chenitz & Swanson, 1986). Sandolwski (1986) found that a qualitative inquiry is credible when it is able to present an accurate account of a human experience. The researcher recognized multiple realities in this study as well to ensure credibility of the research.

Lincoln and Guba (1985) described truth-value as the ability to establish confidence in the truth of the research findings for the participants and the context in

which the investigation was carried out. Truth-value in this study was maintained by collecting subjective data from participants in a natural setting. Data were gathered through open-ended questions. For example, participants were asked, “How has, or might discussing end-of-life decision making before a traumatic event or illness impact the way you deal with end-of-life decision making?” This opened-ended question opened a flow of dialogue among participants. One participant answered, “The thought of someone having to choose rather to pull or not pull the plug for me scares me to death!” Another participant stated, “You never think you will have to make these kinds of decisions, so I guess you have to be prepared. I will let my family know what I want because I don’t want them struggling with what to do . . .”

The researcher was able to obtain direct quotes from research participants and gather other verbal data. This allowed the researcher to better understand the participants in a natural setting as they discussed end-of-life care and advanced directives. The researcher also prevented research biases by recruiting a community health nurse consultant to review the transcript and validate the coding accuracy. There was a general consistency in coding noted between the consultant and researcher.

### **Applicability.**

Lincoln and Guba (1985) described applicability as the ability to determine the extent to which the findings of the naturalistic inquiry have compared with another context. Applicability was needed in order to be able to integrate the research findings into nurses’ knowledge base and apply the findings to nursing practice. These findings contributed to nursing theory development. In the positivistic paradigm, applicability would be equated with external validity. Applicability is transferability of the study’s



findings to contexts other than the study setting (Morse & Field, 1995). Transferability of the research results of a naturalistic inquiry is dependent upon the degree of similarity between the sending and receiving contexts (Polit & Beck, 2008). For this study, applicability was determined by the degree of sampling that was achieved. The researcher recruited participants of different ages, genders, ethnicities, religions, educational levels, and occupations.

### **Consistency.**

Lincoln and Guba (1985) described consistency as the ability to determine whether or not the findings of a naturalistic inquiry could be repeated if the inquiry were replicated with the same or similar participants in the same or similar circumstances. In the positivistic paradigm, consistency would be equated with reliability in qualitative research. Consistency was addressed through the iterative process of data collection and data analysis. The ability of the researcher to maintain consistency in data collection was critical throughout the study, and the researcher achieved this by using the focus group questions. When the focus group was completed, a transcriptionist transcribed the audiotape. The transcript was analyzed to assure consistency with the audio tape recording. Through consistency, another researcher could clearly follow the research study and arrive at the same or comparable conclusions.

### **Neutrality.**

Neutrality is described as the ability to establish the degree to which research findings of a naturalistic inquiry are determined by the participants themselves; it includes the condition of inquiry without biases, interests, or perspectives of the researcher (Lincoln & Guba, 1985). The researcher recorded field notes immediately

after the focus group was completed and thus made herself aware of her own biases. This allowed the researcher to separate her preconceived idealizations from the research process and thus maintain neutrality within the study. The researcher also provided adequate time for the focus group and thus maintained neutrality with participants. Neutrality also was maintained by clarification and validation of emerging themes and concepts with participants in the study as data was collected and analyzed.

### **Researcher's Response**

The researcher was skeptical about how management and employees would react to the study. However, when the researcher introduced herself and the study topic to management and staff members at the occupational worksite, they appeared to be excited about the research. The management team made statements to the researcher about their willingness to help in any way they could to aid in the completion of the study as they felt the topic of the study would be important to discuss in an occupational setting. The Human Resource department was delighted to know that employees would be able to learn about end-of-life care and advanced directives at the workplace setting. Participants provided feedback too. This combined support helped the researcher assume an authoritative role during the implementation of the study.

During the focus group, the researcher was anxious and nervous and thus wanted to rush the focus group process. The researcher felt employees would find it difficult to talk about end-of-life issues, but as the focus group progressed, employees opened a line of communication and talked about end-of-life care and advanced directives. And although the researcher allowed the interview to flow on its own accord, the researcher

did play a critical role in ensuring that lines of communication remained open and thus felt valuable to the process.

All of the participants in the focus group verbalized how discussing the end-of-life issues in a workplace setting made it easier to open up and discuss the topic, and most participants appeared happy to talk with the researcher. This was demonstrated by warm smiles, handshakes, pats on the back, words of appreciation, and thank you's received. One participant indicated to the researcher that her voice was very calming and that it made the topic easier to talk about. The positive feedback from the participants gave the researcher confidence.

When data saturation was reached, the researcher felt a sense of closure. Because the participants appeared to be receptive to the information shared throughout the focus group, the researcher made an effort to make sure no participant left the focus group with an unanswered question. Even so, the researcher continued to receive calls from employees with questions regarding end-of-life care and request for copies of the *Five Wishes* document. For the reaction of the participants, the researcher felt gratitude for being allowed the opportunity to talk about end-of-life care issues and advanced directives with this people and in a setting where the topics previously had not been discussed.

### **Limitations**

Although the findings of this study are positive and compelling, a number of limitations are worthy of consideration. The information that was gathered from the study was obtained from one occupational setting in one geographical location. This limited sample and setting may not be representative of the general public and, therefore, does

not allow for generalization of findings. However, convenience sampling may provide insight that maybe used to generate new ideas and theories for future study.

The demographic data revealed a high percentage (33%) of religious affiliations identified as other. The researcher could have listed a wider variety of religious affiliations, including Protestant, to capture a more accurate interpretation of religious backgrounds of the participants. Also, 15.4% of the sample answered other for ethnicity. The researcher could have listed a wider ethnic variety to capture a more accurate interpretation of the ethnicities of the group.

Another limitation of this study is that currently, there is no documented evidence of the reliability or validity of the *Five Wishes* document as an intervention tool. However, since its development in 1997, 15,000 supporting organizations have distributed more than 14 million copies of the document (Aging with Dignity, 2009). Supported by the United Health Foundation, the document currently is available in 23 languages and “meets the legal requirements in 42 states and is useful in all 50” (Aging with Dignity, ¶ 2).

### **Implication for Practice and Education**

Advanced directives indicates a person’s wishes concerning end-of-life care. Information regarding a person’s end-of-life wishes could be communicated to family members and significant others through an advanced directive. Family members could alleviate some conflicts by discussing ahead of time the type of care they might want and under what circumstances they might want that care. It is crucial for people to communicate their wishes to loved ones to prevent miscommunication. Despite this, research has indicated that the execution of advanced directives remain low, ranging from

15 - 25% (Sessanna & Jezewski, 2008). Healthcare members should become knowledgeable of the laws governing advanced directives for their state and policies of their healthcare facility so they may provide appropriate information to patients, families and the community.

This study revealed that only 10.3 % of participants discussed end-of-life care and advanced directives with a health care provider. Previous research has revealed that advanced directive execution rates are low. This research study revealed an increase in both end-of-life discussions and advanced directive execution rate. It is the healthcare provider's responsibility to promote an opportunity for education. Healthcare providers must allow patients to ask questions regarding end-of-life care and be given the opportunity to have questions answered. The lack of education and low execution rates can be burdensome to both families and the health care team. Dealing with the impending death of a family member can be a major burden to handle. This can cause family to possibly become abusive, domineering, insensitive, and even violate hospital policies and rules. If staff members become too exhausted, another nurse, charge nurse, nurse supervisor, or ethicist should be contacted to intervene immediately. Intervention needs to be quick and efficient, which has been found to be difficult. It becomes a burden to family members and the healthcare team caring for a patient when it takes an inordinate amount of time for intervention. Educating not only patients, but the general public including the healthcare team members about end-of-life care and advanced directives can make the process less painful. It is the researcher's intent that results from this study may enhance adults' self-awareness and understanding of the importance of end-of-life

planning and advanced directives, and encourage health care providers to implement advanced directive programs in community settings.

### **Recommendations for Future Research**

Recommendations for future study include using various occupational worksites, a larger sample size, and an evaluation of the implementation of the Jones model of end-of-life education intervention in the occupational setting. Data collection from multiple occupational settings in a different geographic location may allow for a more ethnically diverse sample. The development of a culture-specific instrument from the concepts and themes of this study and the testing of the instrument to determine its psychometric properties would add to the understanding of how individuals moved toward being able to communicate end-of-life planning with others. Evaluating the implementation of the Jones model by health care providers in other types of clinical settings would add to the state of the science.

### **Conclusion**

The American Nurses Association has taken a position of encouraging nurses to be familiar with the strengths and limitations of Advanced Care Planning, and help ensure that patients have an advanced directive (Beckstrand et al., 2006). This study has indicated that educating people about end-of-life care options may lead to an increase in the execution of advanced directives. Thus, it is critical that the implementation of this education program be continued in other workplace settings.

## APPENDIX A: INFORMED CONSENT

## Informed Consent

IRB Approval Date: April 1, 2010  
Principle Investigator: Marchina T. Jones

Dear Research Participant,

This informed consent is an invitation to participate in a research study that I am conducting entitled *Assessing Adult Attitudes Toward End of Life Issues and the Execution of Advanced Directives*. An advanced directive, which may include a living will or health care surrogate, is designed to communicate end-of-life wishes for incapacitated patients. Elements of the study and your participatory expectations follow.

### *The Study*

Your participation in this study will consist of two sessions which include an educational presentation by the principle investigator and completion of four short questionnaires. Participants will be invited to attend a second session which offers the opportunity to participate in a focus group discussion. The focus group session will allow participants to share their impressions. The group will be conducted in a private area and audio-taped. A participant number will be randomly assigned to you at the beginning of the interview process in order to conceal your identity, and all of the data collected will be kept confidential. The results of the study will be reported as group findings, and your name will not appear in any results.

### *Participation*

Your participation in this study is voluntary, and you will not receive any monetary compensation for your participation. You may withdraw your participation from this study at any time and for any reason up to the time of data analysis without penalty, prejudice, or loss of benefits to which you are otherwise entitled. If you choose to withdraw from the study prior to data analysis, your information will be destroyed. You have the right to ask questions and be answered to your satisfaction.

### *Risk*

There is a possibility of minimal risk with participation in this study. You may experience some anxiety while completing the questionnaires, while participating in focus group discussions, or upon reflection of your experiences with making end-of-life decisions. If you experience anxiety related to participation in this study, you will have access to counseling services provided through your employee assistance program.

### *Benefit*

The benefit involved in this research study includes providing health care professionals with valuable information related to meeting the needs of patients and their families when having to make end-of-life decisions. This information will be helpful in determining which nursing behaviors or actions provide the greatest assistance to patients and their families when faced with making end-of-life decisions and which promote the execution of advanced directives.



### *Contact Information*

Should you have questions regarding this research, you may contact the principle investigator's faculty advisor, Dr. Susan Chase, at (407) 823-6274 or myself, Marchina Jones, at (407) 656-5450. You also may contact Susan Turchin at the University of Central Florida Institutional Review Board at (407) 882-2012 should you have questions regarding your rights as a participant in this study. The Institutional Review Boards at both the University of Central Florida and Johns Hopkins Occupational Health Center has approved this research project involving human subjects. Group results will be sent to you upon your request.

### *Consent*

If you freely and voluntarily and without element of force or coercion consent to participate in the research, completion of this consent form indicates that you have read and understood this information and give your informed consent to participate. A copy of consent will be given to you, the participant, with the principle investigator's signature.

Marchina Tolbert Jones, ARNP, MSN  
Doctoral Candidate  
Principal Investigator

Should I have any questions about this research or its conduct, I may contact principal investigator Marchina Tolbert Jones at (407) 656-5450.

Committee: Dr. Susan Chase, Chair  
University of Central Florida  
College of Nursing  
Orlando, Florida

Dr. Elizabeth Rash  
University of Central Florida  
College of Nursing  
Orlando, Florida

Dr. Carolyn Ramsey  
Florida Hospital  
College of Nursing  
Orlando, Florida

Participant

I have read the information about conditions of this project and give my consent for participation.

---

Participant's Signature

Date

Please provide the best method by which to contact you:

Phone: (    ) \_\_\_\_\_

E-mail: \_\_\_\_\_

Principle Investigator

I have explained this study and potential risks of participation to the above participant and have sought his/her understanding for informed consent.

---

Principal Investigator's Signature

Date

## APPENDIX B: LETTER OF REQUEST TO OCCUPATIONAL HEALTH CLINIC

February 12, 2010

██████████  
Southeast Business Unit Safety Manager ██████████  
██████████  
██████████

Dear Mr. ██████,

I am a doctoral student in the College of Nursing at the University of Central Florida and am conducting research under the supervision of Drs. Susan Chase, Elizabeth Rash, and Carolyn Ramsey. I am researching adult attitudes regarding end-of-life discussions and the execution of advanced directives, instructions designed to communicate end-of-life wishes for incapacitated patients. At this time, I am writing to request your assistance in gaining access to the population of interest for my study.

#### *The Study*

The study will consist of two sessions which include an educational presentation by the principal investigator and completion of four short questionnaires. Participants will be invited to attend a third session which offers the opportunity to participate in a focus group discussion. All of the meetings will be held in a private conference room located onsite at your facility. All of the data collected will be kept confidential. The study will be conducted over a 45-day period. I have enclosed the questionnaires, the educational materials, and the focus group discussion questions for your review.

#### *Participation*

Participation in this study is voluntary. Participants must be employees of your company. There will be no monetary compensation for participation, and participants may withdraw from this study at any time and for any reason up to the time of data analysis without penalty, prejudice, or loss of benefits. If a participant chooses to withdraw from the study prior to data analysis, the participant's information will be destroyed.

### *Risk*

There is a possibility of minimal risk with participation in this study. Participants may experience some anxiety while completing the questionnaires, while participating in the focus group discussions, or upon reflecting his or her experience with making end-of-life decisions. If a participant experiences anxiety related to participation in this study, the employee will have access to counseling services currently provided through your company's employee assistance program.

### *Benefit*

The benefit involved in this research study includes providing health care professional with valuable information related to meeting the needs of patients and their families when having to make end-of-life decisions. This information will be helpful in determining which nursing behaviors or actions provide the greatest assistance to patients and their families when faced with making end-of-life decisions and which promote the execution of advanced directives.

Should you have questions regarding this research, you may contact the principal investigator's faculty advisor, Dr. Susan Chase at (407) 823-6274 or myself at (407) 656-5450. Should you have questions regarding the rights of the employees in the study, you also may contact Susan Turchin at the University of Central Florida Institutional Review Board at (407) 882-2012. This research project involving human subjects only will be conducted with the prior approval of Institutional Review Boards at both the University of Central Florida and Johns Hopkins Occupational Health Center. Group results will be sent to you upon your request.

Marchina Tolbert Jones  
Doctoral Candidate  
Principal Investigator

Enclosures (6)

cc: Dr. Edward Bernacki, Director of Occupational Health and Wellness Clinics, Johns Hopkins Department of Occupational Medicine

## APPENDIX C: INSTITUTIONAL REVIEW BOARD AGREEMENT



University of Central Florida Institutional Review Board  
Office of Research & Commercialization  
12201 Research Parkway, Suite 501  
Orlando, Florida 32826-3246  
Telephone: 407-823-2901 or 407-882-2276  
[www.research.ucf.edu/compliance/irb.html](http://www.research.ucf.edu/compliance/irb.html)

### Approval of Human Research

From: UCF Institutional Review Board #1  
FWA00000351, IRB00001138  
To: Marchina L. Tolbert-Jones  
Date: April 01, 2010

Dear Researcher:

On 4/1/2010, the IRB approved the following human participant research until 3/31/2011 inclusive:

Type of Review: UCF Initial Review Submission Form  
Project Title: Assessing Adult Attitudes Toward End-of-Life Issues and the Execution of Advanced Directives  
Investigator: Marchina L. Tolbert-Jones  
IRB Number: SBE-10-06862  
Funding Agency:  
Grant Title:  
Research ID: N/A

The Continuing Review Application must be submitted 30 days prior to the expiration date for studies that were previously expedited, and 60 days prior to the expiration date for research that was previously reviewed at a convened meeting. Do not make changes to the study (i.e., protocol, methodology, consent form, personnel, site, etc.) before obtaining IRB approval. A Modification Form **cannot** be used to extend the approval period of a study. All forms may be completed and submitted online at <https://iris.research.ucf.edu>.

If continuing review approval is not granted before the expiration date of 3/31/2011, approval of this research expires on that date. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

Use of the approved, stamped consent document(s) is required. The new form supersedes all previous versions, which are now invalid for further use. Only approved investigators (or other approved key study personnel) may solicit consent for research participation. Participants or their representatives must receive a copy of the consent form(s).

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Joseph Bielitzki, DVM, UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 04/01/2010 12:25:36 PM EST

IRB Coordinator

**APPENDIX D: ADVANCED DIRECTIVES PROGRAM DEMOGRAPHIC DATA  
QUESTIONNAIRE**



## Advanced Directives Program Demographic Data Questionnaire

Please complete this questionnaire by marking on the line next to the most accurate response for each question. Begin by entering your code number below.

Code # \_\_\_\_\_

1. What gender are you?

\_\_\_\_\_ Female

\_\_\_\_\_ Male

2. Which category best describes your age?

\_\_\_\_\_ 18-34 years

\_\_\_\_\_ 35-60 years

\_\_\_\_\_ More than 60 years

3. What is your religious preference?

\_\_\_\_\_ Baptist

\_\_\_\_\_ Catholic

\_\_\_\_\_ Jewish

\_\_\_\_\_ Muslim

\_\_\_\_\_ No religious preference

\_\_\_\_\_ Other

4. What is your marital status?

Married

Lifelong partner

Single

Separated

Divorced

5. Which cultural background best describes you?

Euro-American

African American

Hispanic or Latin American

Native American

Asian American

Other (specify)

6. What is your level of education?

Did not complete high school

High school diploma

Associate degree

Bachelor degree

Graduate degree

7. Please provide your area of occupation:

\_\_\_\_\_ Sales

\_\_\_\_\_ Production

\_\_\_\_\_ Warehouse

\_\_\_\_\_ Driver

\_\_\_\_\_ Marketing

\_\_\_\_\_ Technician

\_\_\_\_\_ Management

8. Please provide your work shift:

\_\_\_\_\_ Morning (1<sup>st</sup> shift)

\_\_\_\_\_ Evening (2<sup>nd</sup> shift)

\_\_\_\_\_ Night shift (3<sup>rd</sup> shift)

## APPENDIX E: ADVANCED DIRECTIVES PRE-PROGRAM QUESTIONNAIRE

## Advanced Directives Pre-Program Questionnaire

Please complete this questionnaire by circling the most accurate response for each question. Begin by entering your code number below.

Code # \_\_\_\_\_

Date \_\_\_\_\_

1. I am knowledgeable regarding end-of-life decision making and advanced directives.

1	2	3	4	5
strongly agree	somewhat agree	neither agree nor disagree	somewhat disagree	strongly disagree

2. I am likely to consider completing an advanced directive.

1	2	3	4	5
strongly agree	somewhat agree	neither agree nor disagree	somewhat disagree	strongly disagree

3. I am likely to discuss end-of-life care solutions with family, friends, and health care providers.

1	2	3	4	5
strongly agree	somewhat agree	neither agree nor disagree	somewhat disagree	strongly disagree

4. If I were in a coma and a medical decision had to be made on my behalf, I would be comfortable with a loved-one making a decision for me.

1	2	3	4	5
strongly agree	somewhat agree	neither agree nor disagree	somewhat disagree	strongly disagree

5. I believe that advanced directives are important for a dying person who cannot make decisions for him or herself.

1	2	3	4	5
strongly agree	somewhat agree	neither agree nor disagree	somewhat disagree	strongly disagree

**Please complete this section of the questionnaire by marking on the line next to the most accurate response for each question.**

6. Have you ever had to make an end-of-life decision for someone?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

7. Is there someone you would consider to make end-of-life decisions for you?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

8. Have you discussed end-of-life decisions with your healthcare provider?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

9. Do you feel there are barriers to discussing end-of-life decision making?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

**APPENDIX F: ADVANCED DIRECTIVES POST-PROGRAM  
QUESTIONNAIRE**

## Advanced Directives Post-Program Questionnaire

Please complete this questionnaire by circling the most accurate response for each question. Begin by entering your code number below.

Code # \_\_\_\_\_

1. I am knowledgeable regarding end-of-life decision making and advanced directives.

1	2	3	4	5
strongly agree	somewhat agree	neither agree nor disagree	somewhat disagree	strongly disagree

2. I am likely to consider completing an advanced directive.

1	2	3	4	5
strongly agree	somewhat agree	neither agree nor disagree	somewhat disagree	strongly disagree

3. I am likely to discuss end-of-life care solutions with family, friends, and health care providers.

1	2	3	4	5
strongly agree	somewhat agree	neither agree nor disagree	somewhat disagree	strongly disagree

4. If I were in a coma and a medical decision had to be made on my behalf, I would be comfortable with a loved-one making a decision for me.

1	2	3	4	5
strongly agree	somewhat agree	neither agree nor disagree	somewhat disagree	strongly disagree

5. I believe that advanced directives are important for a dying person who cannot make decisions for him or herself.

1	2	3	4	5
strongly agree	somewhat agree	neither agree nor disagree	somewhat disagree	strongly disagree



**Please complete this section of the questionnaire by marking on the line next to the most accurate response for each question.**

6. Have you discussed end-of-life decisions with your family since learning about advanced directives in this program?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

7. Have you completed an advanced directive since learning about them in this program?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

8. If you did complete an advanced directive, did you fill it out completely?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

9. If you did complete an advanced directive, on what date did you complete it? (Please mark the date on the calendar.)

April						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

**APPENDIX G: ADVANCED DIRECTIVES PROGRAM EVALUATION  
QUESTIONNAIRE**

## Advanced Directives Program Evaluation Questionnaire

Please complete this section of the questionnaire by circling the most accurate response for each question.

1. I am likely to recommend others for participation in this program.

1	2	3	4	5
strongly agree	agree	neither agree nor disagree	disagree	strongly disagree

2. I am likely to suggest that a co-worker or loved-one participate in this type of program.

1	2	3	4	5
strongly agree	agree	neither agree nor disagree	disagree	strongly disagree

3. I would agree to recommend this program to a coworker or loved-one.

1	2	3	4	5
strongly agree	agree	neither agree nor disagree	disagree	strongly disagree

4. This program has increased the likelihood that I would discuss end-of-life issues with others.

1	2	3	4	5
strongly agree	agree	neither agree nor disagree	disagree	strongly disagree

5. This program has increased the likelihood that I would complete an advanced directive.

1	2	3	4	5
strongly agree	agree	neither agree nor disagree	disagree	strongly disagree

**Please complete this section of the questionnaire by providing responses for each question.**

6. What did you like about the program?

7. What didn't you like about the program?

8. Do you feel the timing of the program was adequate? Too short? Too long?

9. Would you like to see this program presented in a series?

**APPENDIX H: ADVANCED DIRECTIVES PROGRAM FOCUS GROUP  
SAMPLE QUESTIONS**

## Advanced Directives Focus Group Sample Questions

1. Have you and/or your significant other(s) discussed making end-of-life decisions for another person?
2. How did/do you and your significant other(s) deal with addressing end-of-life decisions?
3. How has, or might, discussing end-of-life decision making before a traumatic event or illness impact the way you deal with end-of-life decision making?
4. How does or might discussing end-of-life decision making before a traumatic event or illness impact the way you deal with emotions associated with the circumstances?
5. What can health care practitioners do to assist you with making end-of-life decisions?
6. What aspects of Advanced Directives, if any, are important?
7. Did participating in this work setting program help you think about these things?
8. How does it feel to discuss end-of-life decision making in this type of setting?
9. Does it make a difference discussing this issue in this type of setting?
10. What do you feel are barriers to discussing end-of-life decisions with others?

**APPENDIX I: ADVANCED DIRECTIVES PROGRAM INTERVENTIONAL  
TOOL**



# FIVE WISHES®

## MY WISH FOR:

The Person I Want to Make Care Decisions for Me When I Can't

The Kind of Medical Treatment I Want or Don't Want

How Comfortable I Want to Be

How I Want People to Treat Me

What I Want My Loved Ones to Know

print your name

birthdate



# Five Wishes

*There are many things in life that are out of our hands. This Five Wishes booklet gives you a way to control something very important—how you are treated if you get seriously ill. It is an easy-to-complete form that lets you say exactly what you want. Once it is filled out and properly signed it is valid under the laws of most states.*

## What Is Five Wishes?

Five Wishes is the first living will that talks about your personal, emotional and spiritual needs as well as your medical wishes. It lets you choose the person you want to make health care decisions for you if you are not able to make them for yourself. Five Wishes lets you say exactly how you wish to be

treated if you get seriously ill. It was written with the help of The American Bar Association's Commission on Law and Aging, and the nation's leading experts in end-of-life care. It's also easy to use. All you have to do is check a box, circle a direction, or write a few sentences.

## How Five Wishes Can Help You And Your Family

- It lets you talk with your family, friends and doctor about how you want to be treated if you become seriously ill.
- Your family members will not have to guess what you want. It protects them if you become seriously ill, because they won't have to make hard choices without knowing your wishes.
- You can know what your mom, dad, spouse, or friend wants through a Five Wishes living will. You can be there for them when they need you most. You will understand what they really want.

## How Five Wishes Began

For 12 years, a man named Jim Towey worked closely with Mother Teresa, and, for one year, he lived in a hospice she ran in Washington, DC. Inspired by this first-hand experience, Mr. Towey sought a way for patients and their families to plan ahead and to cope with serious

illness. The result is Five Wishes and the response to it has been overwhelming. It has been featured on CNN and NBC's Today Show and in the pages of *Time* and *Money* magazines. Newspapers have called Five Wishes the first "living will with a heart."

## Who Should Use Five Wishes

Five Wishes is for anyone 18 or older — married, single, parents, adult children, and friends. Over eight million Americans of all ages have already used it. Because it

works so well, lawyers, doctors, hospitals and hospices, faith communities, employers, and retiree groups are handing out this document.

## Five Wishes States

If you live in the **District of Columbia** or one of the **40 states** listed below, you can use Five Wishes and have the peace of mind to know that it substantially meets your state's requirements under the law:

Alaska	Idaho	Missouri	Rhode Island
Arizona	Illinois	Montana	South Carolina
Arkansas	Iowa	Nebraska	South Dakota
California	Louisiana	New Jersey	Tennessee
Colorado	Maine	New Mexico	Vermont
Connecticut	Maryland	New York	Virginia
Delaware	Massachusetts	North Carolina	Washington
Florida	Michigan	North Dakota	West Virginia
Georgia	Minnesota	Oklahoma	Wisconsin
Hawaii	Mississippi	Pennsylvania	Wyoming

If your state is not one of the 40 states listed here, Five Wishes does not meet the technical requirements in the statutes of your state. So some doctors in your state may be reluctant to honor Five Wishes. However, many people from states not on this list do complete Five Wishes along with their state's legal form. They find that Five Wishes helps them express all that they want and provides a helpful guide to family members, friends, care givers and doctors. Most doctors and health care professionals know they need to listen to your wishes no matter how you express them.

## How Do I Change To Five Wishes?

You may already have a living will or a durable power of attorney for health care. If you want to use Five Wishes instead, all you need to do is fill out and sign a new Five Wishes as directed. As soon as you sign it, it takes away any advance directive you had before. To make sure the right form is used, please do the following:

- Destroy all copies of your old living will or durable power of attorney for health care. Or you can write "revoked" in large letters across the copy you have. Tell your lawyer if he or she helped prepare those old forms for you. *AND*
- Tell your Health Care Agent, family members, and doctor that you have filled out the new Five Wishes. Make sure they know about your new wishes.

## The Person I Want To Make Health Care Decisions For Me When I Can't Make Them For Myself.

*If I am no longer able to make my own health care decisions, this form names the person I choose to make these choices for me. This person will be my Health Care Agent (or other term that may be used in my state, such as proxy, representative, or surrogate). This person will make my health care choices if both of these things happen:*

- My attending or treating doctor finds I am no longer able to make health care choices, AND
- Another health care professional agrees that this is true.

*If my state has a different way of finding that I am not able to make health care choices, then my state's way should be followed.*

### The Person I Choose As My Health Care Agent Is:

First Choice Name

Phone

Address

City/State/Zip

If this person is not able or willing to make these choices for me, *OR* is divorced or legally separated from me, *OR* this person has died, then these people are my next choices:

Second Choice Name

Third Choice Name

Address

Address

City/State/Zip

City/State/Zip

Phone

Phone

### Picking The Right Person To Be Your Health Care Agent

Choose someone who knows you very well, cares about you, and who can make difficult decisions. A spouse or family member may not be the best choice because they are too emotionally involved. Sometimes they **are** the best choice. You know best. Choose someone who is able to stand up for you so that your wishes are followed. Also, choose someone who is likely to be nearby so that they can help when you need them. Whether you choose a spouse, family member, or friend as your Health Care Agent, make sure you talk about these wishes and be sure that this person agrees to respect

and follow your wishes. Your Health Care Agent should be **at least 18 years or older** (in Colorado, 21 years or older) and should **not** be:

- Your health care provider, including the owner or operator of a health or residential or community care facility serving you.
- An employee or spouse of an employee of your health care provider.
- Serving as an agent or proxy for 10 or more people unless he or she is your spouse or close relative.

*I understand that my Health Care Agent can make health care decisions for me. I want my Agent to be able to do the following: (Please cross out anything you don't want your Agent to do that is listed below.)*

- Make choices for me about my medical care or services, like tests, medicine, or surgery. This care or service could be to find out what my health problem is, or how to treat it. It can also include care to keep me alive. If the treatment or care has already started, my Health Care Agent can keep it going or have it stopped.
- Interpret any instructions I have given in this form or given in other discussions, according to my Health Care Agent's understanding of my wishes and values.
- Consent to admission to an assisted living facility, hospital, hospice, or nursing home for me. My Health Care Agent can hire any kind of health care worker I may need to help me or take care of me. My Agent may also fire a health care worker, if needed.
- Make the decision to request, take away or not give medical treatments, including artificially-provided food and water, and any other treatments to keep me alive.
- See and approve release of my medical records and personal files. If I need to sign my name to get any of these files, my Health Care Agent can sign it for me.
- Move me to another state to get the care I need or to carry out my wishes.
- Authorize or refuse to authorize any medication or procedure needed to help with pain.
- Take any legal action needed to carry out my wishes.
- Donate useable organs or tissues of mine as allowed by law.
- Apply for Medicare, Medicaid, or other programs or insurance benefits for me. My Health Care Agent can see my personal files, like bank records, to find out what is needed to fill out these forms.
- Listed below are any changes, additions, or limitations on my Health Care Agent's powers.

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**If I Change My Mind About Having A Health Care Agent, I Will**

- Destroy all copies of this part of the Five Wishes form. *OR*
- Tell someone, such as my doctor or family, that I want to cancel or change my Health Care Agent. *OR*
- Write the word "Revoked" in large letters across the name of each agent whose authority I want to cancel. Sign my name on that page.

## WISH 2

### My Wish For The Kind Of Medical Treatment I Want Or Don't Want.

*I believe that my life is precious and I deserve to be treated with dignity. When the time comes that I am very sick and am not able to speak for myself, I want the following wishes, and any other directions I have given to my Health Care Agent, to be respected and followed.*

#### What You Should Keep In Mind As My Caregiver

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means that I will be drowsy or sleep more than I would otherwise.
- I do not want anything done or omitted by my doctors or nurses with the intention of taking my life.
- I want to be offered food and fluids by mouth, and kept clean and warm.

#### What "Life-Support Treatment" Means To Me

Life-support treatment means any medical procedure, device or medication to keep me alive.

Life-support treatment includes: medical devices put in me to help me breathe; food and water supplied by medical device (tube feeding); cardiopulmonary resuscitation (CPR); major surgery; blood transfusions; dialysis; antibiotics;

and anything else meant to keep me alive.

If I wish to limit the meaning of life-support treatment because of my religious or personal beliefs, I write this limitation in the space below.

I do this to make very clear what I want and under what conditions.

#### In Case Of An Emergency

If you have a medical emergency and ambulance personnel arrive, they may look to see if you have a **Do Not Resuscitate** form or bracelet. Many states require a person to have a **Do Not Resuscitate** form filled out and

signed by a doctor. This form lets ambulance personnel know that you don't want them to use life-support treatment when you are dying. Please check with your doctor to see if you need to have a **Do Not Resuscitate** form filled out.

Here is the kind of medical treatment that I want or don't want in the four situations listed below. I want my Health Care Agent, my family, my doctors and other health care providers, my friends and all others to know these directions.

**Close to death:**

If my doctor and another health care professional both decide that I am likely to die within a short period of time, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

**In A Coma And Not Expected To Wake Up Or Recover:**

If my doctor and another health care professional both decide that I am in a coma from which I am not expected to wake up or recover, and I have brain damage, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

**Permanent And Severe Brain Damage And Not Expected To Recover:**

If my doctor and another health care professional both decide that I have permanent and severe brain damage, (for example, I can open my eyes, but I can not speak or understand) and I am not expected to get better, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

**In Another Condition Under Which I Do Not Wish To Be Kept Alive:**

If there is another condition under which I do not wish to have life-support treatment, I describe it below. In this condition, I believe that the costs and burdens of life-support treatment are too much and not worth the benefits to me. Therefore, in this condition, I do not want life-support treatment. (For example, you may write "end-stage condition." That means that your health has gotten worse. You are not able to take care of yourself in any way, mentally or physically. Life-support treatment will not help you recover. Please leave the space blank if you have no other condition to describe.)

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*The next three wishes deal with my personal, spiritual and emotional wishes. They are important to me. I want to be treated with dignity near the end of my life, so I would like people to do the things written in Wishes 3, 4, and 5 when they can be done. I understand that my family, my doctors and other health care providers, my friends, and others may not be able to do these things or are not required by law to do these things. I do not expect the following wishes to place new or added legal duties on my doctors or other health care providers. I also do not expect these wishes to excuse my doctor or other health care providers from giving me the proper care asked for by law.*

## WISH 3

### **My Wish For How Comfortable I Want To Be.**

(Please cross out anything that you don't agree with.)

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means I will be drowsy or sleep more than I would otherwise.
- If I show signs of depression, nausea, shortness of breath, or hallucinations, I want my care givers to do whatever they can to help me.
- I wish to have a cool moist cloth put on my head if I have a fever.
- I want my lips and mouth kept moist to stop dryness.
- I wish to have warm baths often. I wish to be kept fresh and clean at all times.
- I wish to be massaged with warm oils as often as I can be.
- I wish to have my favorite music played when possible until my time of death.
- I wish to have personal care like shaving, nail clipping, hair brushing, and teeth brushing, as long as they do not cause me pain or discomfort.
- I wish to have religious readings and well-loved poems read aloud when I am near death.
- I wish to know about options for hospice care to provide medical, emotional and spiritual care for me and my loved ones.

## WISH 4

### **My Wish For How I Want People To Treat Me.**

(Please cross out anything that you don't agree with.)

- I wish to have people with me when possible. I want someone to be with me when it seems that death may come at any time.
- I wish to have my hand held and to be talked to when possible, even if I don't seem to respond to the voice or touch of others.
- I wish to have others by my side praying for me when possible.
- I wish to have the members of my faith community told that I am sick and asked to pray for me and visit me.
- I wish to be cared for with kindness and cheerfulness, and not sadness.
- I wish to have pictures of my loved ones in my room, near my bed.
- If I am not able to control my bowel or bladder functions, I wish for my clothes and bed linens to be kept clean, and for them to be changed as soon as they can be if they have been soiled.
- I want to die in my home, if that can be done.

8

## My Wish For What I Want My Loved Ones To Know.

(Please cross out anything that you don't agree with.)

- I wish to have my family and friends know that I love them.
- I wish to be forgiven for the times I have hurt my family, friends, and others.
- I wish to have my family, friends and others know that I forgive them for when they may have hurt me in my life.
- I wish for my family and friends to know that I do not fear death itself. I think it is not the end, but a new beginning for me.
- I wish for all of my family members to make peace with each other before my death, if they can.
- I wish for my family and friends to think about what I was like before I became seriously ill. I want them to remember me in this way after my death.
- I wish for my family and friends and caregivers to respect my wishes even if they don't agree with them.
- I wish for my family and friends to look at my dying as a time of personal growth for everyone, including me. This will help me live a meaningful life in my final days.
- I wish for my family and friends to get counseling if they have trouble with my death. I want memories of my life to give them joy and not sorrow.
- After my death, I would like my body to be (circle one): buried or cremated.
- My body or remains should be put in the following location \_\_\_\_\_.
- The following person knows my funeral wishes: \_\_\_\_\_.

If anyone asks how I want to be remembered, please say the following about me:

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If there is to be a memorial service for me, I wish for this service to include the following (list music, songs, readings or other specific requests that you have):

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(Please use the space below for any other wishes. For example, you may want to donate any or all parts of your body when you die. Please attach a separate sheet of paper if you need more space.)

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## Signing The Five Wishes Form

*Please make sure you sign your Five Wishes form in the presence of the two witnesses.*

I, \_\_\_\_\_, ask that my family, my doctors, and other health care providers, my friends, and all others, follow my wishes as communicated by my Health Care Agent (if I have one and he or she is available), or as otherwise expressed in this form. This form becomes valid when I am unable to make decisions or speak for myself. If any part of this form cannot be legally followed, I ask that all other parts of this form be followed. I also revoke any health care advance directives I have made before.

Signature: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Date: \_\_\_\_\_

### Witness Statement • (2 witnesses needed):

I, the witness, declare that the person who signed or acknowledged this form (hereafter "person") is personally known to me, that he/she signed or acknowledged this [Health Care Agent and/or Living Will form(s)] in my presence, and that he/she appears to be of sound mind and under no duress, fraud, or undue influence.

I also declare that I am over 18 years of age and am NOT:

- The individual appointed as (agent/proxy/surrogate/patient advocate/representative) by this document or his/her successor.
- The person's health care provider, including owner or operator of a health, long-term care, or other residential or community care facility serving the person,
- An employee of the person's health care provider.
- Financially responsible for the person's health care,
- An employee of a life or health insurance provider for the person,
- Related to the person by blood, marriage, or adoption, and,
- To the best of my knowledge, a creditor of the person or entitled to any part of his/her estate under a will or codicil, by operation of law.

*(Some states may have fewer rules about who may be a witness. Unless you know your state's rules, please follow the above.)*

Signature of Witness #1

Signature of Witness #2

Printed Name of Witness

Printed Name of Witness

Address

Address

Phone

Phone

### Notarization • Only required for residents of Missouri, North Carolina, South Carolina and West Virginia

- If you live in Missouri, only your signature should be notarized.
- If you live in North Carolina, South Carolina or West Virginia, you should have your signature, and the signatures of your witnesses, notarized.

STATE OF \_\_\_\_\_

COUNTY OF \_\_\_\_\_

On this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_, the said \_\_\_\_\_, \_\_\_\_\_, and \_\_\_\_\_, known to me (or satisfactorily proven) to be the person named in the foregoing instrument and witnesses, respectively, personally appeared before me, a Notary Public, within and for the State and County aforesaid, and acknowledged that they freely and voluntarily executed the same for the purposes stated therein.

My Commission Expires: \_\_\_\_\_

\_\_\_\_\_  
Notary Public

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# Advocating CHOICES®



We believe that every patient and family we serve is entitled to an individualized plan of care designed specifically to meet the needs and goals they have identified for themselves.

We empower our staff to think and act as patient advocates. This commitment is especially critical at such a challenging time of life.

For 30 years, VITAS has been a leader in the American hospice movement, helping to define the standards of care for hospice and working to ensure that terminally ill patients and their families have ready access to compassionate and effective end-of-life care.



#### WE ENCOURAGE YOU:

- Decide for yourself.
- Discuss your end-of-life wishes.
- Document so it's clear for all to see.

*At VITAS, patients and families come first.*

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