FACTORS INFLUENCING THE COMPLETION OF ADVANCE DIRECTIVES

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Advance directives (ADs) were created to empower patients and give them choices regarding their end-of-life care, but completion rates for ADs are rather low. The current study explored the factors influencing advance directive (AD) completion in an Eastern Kentucky college community. A total of 197 participants took part in the quantitative analysis and 39 participants were interviewed in the qualitative analysis. Using a socio-demographic questionnaire, the Lester Attitude Toward Death Scale and the Advance Directive Attitude Survey, the effects of the independent variables of age, education, health, attitudes toward death and attitudes toward ADs on AD completion were examined. Positive relationships were found between the variables of age, education, and attitudes toward ADs and actual AD completion rates. In-depth interviews found that personal or professional experience with death was closely related to age and served as the primary motivating factor for AD completion along with the
need to avoid burdening loved ones, gain control one’s own care, and accommodate family situations. Barriers to AD completion were identified including lack of knowledge regarding ADs, misunderstandings and fears pertaining to end-of-life care, procrastination and surrogate selection. The modernist theoretical concept of sequestration of death was used to analyze the findings. The sequestration of death in American culture was found to contribute to a lack of knowledge regarding death and an absence of death-related social norms. However, death is an unavoidable event that all of the study participants have discussed and considered. Attitudes toward ADs were rather positive and few participants reported fearing death. Despite positive findings, major changes in the treatment of death in American culture must take place before real improvements can be made in AD completion and end-of-life care communication.

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AN INTRODUCTION TO ADVANCE DIRECTIVES

All of us must die eventually. Our lives are like water spilled out on the ground, which cannot be gathered up again.
- 2 Samuel, 14:14a, New Living Translation Bible

From the moment we are born, our bodies begin the inexorable journey toward death. In early life our brain cells undergo apoptosis in which redundant neurons are destroyed, and as we age our sensory abilities decline (Blank 2001). Though an assortment of factors including advancements in medical technology, nutrition, and safety regulations may serve to prolong human life and compensate for diminished sensory capacities, death is an inextricable aspect of life, and because of this, death is woven into the fabric of our culture, a culture that often attempts to control nature and give it a sense of order and predictability (Kaufman 2005). In modernity this control and order provides members of society with a sense of ontological security, and in part this security is dependent on the sequestration of death and illness from social life (Giddens 1991). Modern American medical culture, which aids in the sequestration of death, frequently attempts to control death through newly developed technologies that may add hours, days, months or sometimes years to one’s life, but the use of these life-prolonging advances may not be desired by every patient (Kaufman 2005).

Advances in medical technology developed during the twentieth century provided doctors with countless weapons with which to combat death and prolong life and also elevated the occupation of physician to a near god-like status (Burnham 1982). However, as the twentieth century progressed, individuals outside of the medical field made attempts to usurp some of medicine’s power in order to gain more control over their own deaths. In this power struggle,
advance directives (ADs) were born (King 1996). Advance directives consist of documents that allow people to state their wishes regarding their end-of-life (EOL) care, especially their preferences regarding the use of life support technology to prolong their lives, and allow people to appoint a surrogate to make health care decisions for them that are compatible with their preferences. ADs can be particularly useful in the event that an individual becomes incapacitated and is no longer able to state her or his wishes regarding treatment (King 1996). Despite their benefits AD completion rates remain low ranging from 15-25% (Salmond and David 2005), and some people doubt the effectiveness of the current AD forms. The sequestration of death and the bureaucratization of medicine in modernity likely play a role in the low completion rates of ADs. However, death is unavoidable meaning that many Americans have experiences with death and dying, and these experiences may help pull death out of sequestration. The intent of this study is to explore attitudes toward advance directives and to examine the factors that influence advance directive completion.

The Birth of Advance Directives

“I don’t want to be kept alive dead.”

- Quote from the oldest son of Amanda (pseudonym), a current study participant

The fight to control death and prolong life through the use of nonhuman medical technologies sparked a number of ethical and legal debates. Though advances in medical technology were not able to cure every patient, these advances allowed the lives of many terminally ill patients to be prolonged (King 1996). However, just because a human life can be prolonged with the aid of medical technology doesn’t necessarily mean that the life should be prolonged (King 1996). While some embraced the new medical technology, others witnessed patients being kept alive by machines, suspended in a gray zone of unconsciousness, and feared
that without proper protection, they too could one day meet a similar fate (Kaufman 2005). The tension between the desire to save a life at all costs and to allow a person to die with dignity sparked several popular court battles and ultimately led to the creation of ADs.

The Karen Ann Quinlan case is one such example. In 1975 Karen slipped into a coma when she fell asleep after consuming a mixture alcohol and drugs, and after several months in a comatose state with a poor prognosis, Karen’s family fought to have her removed from a respirator (King 1996). Prior to her coma, Karen had made comments to friends and family indicating that she would not want to live in a persistent comatose state, and her family requested that Karen’s wishes be followed and she be removed from the respirator and allowed to die while the hospital sought to preserve Karen’s life at all costs (King 1996). Finally, in 1976 the New Jersey Supreme Court ruled that Karen could be removed from the respirator and allowed to die, but ironically after being removed from the ventilator, Karen continued to breathe on her own until she died in 1985 (King 1996).

A multitude of cases followed, including the Nancy Beth Cruzan, Baby Jane Doe and Terri Schiavo cases, in which the legal system was called upon to settle disputes between family members or between family members and medical facilities regarding the removal of comatose patients from life support technology (Leming and Dickinson 2007). It should be noted that in many of these court decisions the patients’ wishes regarding their medical treatment were not recorded in writing. Insight into these patients’ wishes was derived from bits of conversation that family members recalled having with the patients regarding life support or the previous cases including comments like, “I do not want to end up like Karen Quinlan” (King 1996). In the 1990 case *Cruzan v. Director*, the U. S. Supreme Court upheld an individual’s right to refuse life-prolonging treatment, and Justice Sandra Day O’Connor expressed a preference for written
ADs over oral communications because written directives provided greater evidence of one’s wishes (Yates and Glick 1997).

The need for written documents allowing people to express their preferences regarding the use of respirators, feeding tubes, artificial hydration, and other life-prolonging medical technology became increasingly apparent after the Cruzan decision. Model documents, called advance directives, were drafted by legal professionals and patient advocacy groups to allow people to state their medical preferences in writing. These model documents influenced lawmakers and ultimately resulted in the adoption of advance directive forms and end-of-life (EOL) care policies by state legislators (King 1996). Early federal acts regarding EOL decision making included the Commissioner’s Model Health-Care Consent Act of 1982, the Uniform Rights of the Terminally Ill Act of 1985, and the Uniform Rights of the Terminally Ill Act of 1989, all of which attempted to legislate EOL care (King 1996). As early as 1976 California passed their Natural Death Act, which created a one-page living will that allowed patients to refuse treatment (Luptak 2004), and in 1978 North Carolina passed their Right to a Natural Death Act giving patients the freedom to determine their EOL care to a certain extent (Connell and Mallory 2007). By 1983 a total of 14 states had laws governing EOL care decision-making, and by 1998 the total number of states with such laws had increased to 47 (Darr 1999). Currently all 50 States have legislation governing EOL care decision-making issues, including advance directives (National Hospice and Palliative Care Organization [NHPCO] 2006). The adoption of AD policies by all 50 States is due in large part to legislation, such as the Uniform Health-Care Decisions Act developed by the National Conference of Commissioners on Uniform State Laws, which promoted patient rights in medical decision making and was enacted in 1993, as well as the Patient Self-Determination Act of 1991 (Darr 1999).
The Federal Patient Self-Determination Act (PSDA), which was part of the Omnibus Budget Reconciliation Act of 1990, went into effect on December 1, 1991 with the intention of giving patients increased rights including the right to complete advance directives (Duke, Thompson and Hastie 2007; Baker 2002; Darr 1999). However, the PSDA initially sparked a firestorm of controversy with organizations such as the American Hospital Association, the American Bar Association, the American Medical Association, and the Catholic Church, who viewed the PSDA as a threat to their interests in protecting life and avoiding undue harm to patients in opposition, and right to die groups, who promoted patient autonomy, in support of the Act (Baker 2002). Opposition to the PSDA and ADs in general was often caused by fear that ADs would be used to curb the rising expenses triggered by the increased use of life-sustaining treatment and on-going court battles regarding the use and termination of life-sustaining treatment (Baker 2002). Eventually a number of groups that initially opposed the PSDA, including the American Medical Association, the American Bar Association, and American Hospital Association, agreed to endorse the act (Baker 2002).

The purpose of the PSDA was to allow individuals to engage in autonomous decision making regarding preferences for end-of-life (EOL) care in the event that they become incapacitated and are unable to voice their wishes regarding life support, artificial nutrition and hydration, and organ donation (Duke et al. 2007). Under the PSDA, all hospitals, skilled nursing facilities, home health agencies, providers of home healthcare, and hospices that receive federal funds from Medicare and Medicaid are mandated to ask all adult patients if they have advance directives (Black 2007). If a patient does not have an advance directive, these facilities are required to ask if that patient would like to complete one (Black 2007). These health care facilities are also required to have written policies and procedures regarding advance directives
Such written policies and procedures should convey information about the patient’s rights under state law regarding advance directives, notify patients of any limitations on these patient rights, and ensure patients that the facility will comply with State law concerning advance directives (DHHS 1995).

The PSDA also states the appropriate time when patients should receive advance directive information, such as upon admission to a hospital or nursing home, and under the PSDA medical facilities must provide education for staff regarding the facility’s advance directive policies (DHHS 1995). Medical facilities must also develop policies regarding community education programs about advance directives, and the PSDA states that written materials may also be created by medical facilities, and these materials “should define what constitutes an advance directive, emphasizing that an advance directive is designed to enhance an incapacitated individual’s control over medical treatment, and describe applicable State law concerning advance directives” (DHHS 1995). The PSDA outlined a number of requirements for medical facilities pertaining to advance directives on the federal level, but each State, including Kentucky, is responsible for legislating advance directives making advance directive policies and formats different for each state (Jezewski and Meeker 2005).

**Kentucky Advance Directives**

Researcher: “How did you feel about that, about filling out those forms [advance directives] and sharing that information with your loved ones?”

Georgia: “I felt really good because I knew that if something happened to me during surgery, they would make sure that I had the kind of end of life that I really wanted.”

- Exert from interview with Georgia (pseudonym), a current study participant

The current study will focus on Kentucky’s advance directives, which consist of two documents- the power of attorney and the living will. Powers of attorney allow the grantor, or
the person creating the advance directive, to appoint a trustworthy attorney-in-fact who will make decisions for the grantor, and the attorney-in-fact is given the power to make decisions regarding both medical and financial affairs (Sublett 2005). Powers of attorney documents are recognized in the court of law (Leming and Dickinson 2007), and they must be prepared with legal assistance, such as that provided by a private attorney or a legal aid worker (Sublett 2005). 

*Durable* powers of attorney become effective immediately when signed by a grantor (Sublett 2005).

The Kentucky Living Will Directive Act of 1994 was passed to ensure that citizens have the right to make decisions regarding their own medical care, including the right to accept or refuse treatments that extend life, like a breathing machine or a feeding tube (Office of the Attorney General 2013). Living wills pertain primarily to end-of-life care decisions, and the concept for living wills was developed by advocacy groups that feared the misuse of medical technology, such as ventilators and feeding tubes, to prolong the lives of people who were actively dying and had no true quality of life (Darr 1999). Unlike power of attorney forms, the Kentucky living will does not require legal assistance to complete though they can be completed with an attorney, and living will forms can be obtained from various sources including Internet sites, doctor’s offices, nursing homes, hospitals, and hospices. Living wills can also be revoked or revised at any time reflecting changes in the grantor’s health care preferences, and guidelines exist regarding the appropriate method of living will revocation (NHPCO 2006).

The Kentucky living will (see Appendix C) allows the grantor to state preferences in 3 major categories. The grantor can indicate if he/she does or does not want life-prolonging treatment to be withheld or withdrawn allowing the grantor to die naturally (NHPCO 2006). The grantor can also state if he/she does or does not authorize the withholding or withdrawal of
artificial food, water or other forms of nourishment or fluids. However, the grantor can simply give the surrogate the discretion to decide if artificial nourishment and fluids should be removed or withheld as long as the decision is made in the best interest of the grantor (NHPCO 2006). Finally, the grantor can state if he or she wishes to donate all or any part of his or her body upon death for organ donation or medical research (NHPCO 2006).

The final portion of the living will document requires the date, signature, and address of the grantor as well as the signatures of witnesses or a notary public. Witnesses cannot include the appointed healthcare surrogate(s), anyone related to the grantor by blood, marriage or adoption, anyone entitled to the grantor’s estate, the grantor’s attending physician, an employee of the healthcare facility where the grantor resides unless this employee is a notary public, or someone directly financially responsible for the grantor’s medical care (NHPCO 2006). The current Kentucky living will packet available on the Attorney General website lists these requirements for witnesses in both the instructions section and on signature page (Office of the Attorney General 2013).

Grantors can also attach directions for their healthcare if these directions are not addressed explicitly in the living will document. However, adding directions to living wills may not improve communication of a patient’s end-of-life care wishes. While advance directives are documents that individuals use to convey their preferences regarding end-of-life (EOL) medical treatment, and to guide decision making regarding medical treatment, the effectiveness of advance directives may be “countered by bureaucratic safeguards” (King 1996: 111). The living will formats approved by state legislators address a limited number of issues, such as tube feeding, respirators, and organ donation, and cannot possibly cover the wide range of medical decisions that patients and their family members may face. Living will formats created by non-
governmental agencies may allow patients to express a wider range of preferences and even include a signature line for the patient’s physician stating that she or he has seen the living will, but these forms may not be approved by state legislators.

Because the PSDA defines an advance directive as a “written instruction, such as a living will or power of attorney, recognized under state law (whether statutory or as recognized by the courts of the State), relating to the provision of health care when the individual is incapacitated” (Department of Health and Human Services 1995), the State-approved living wills are favored by health care facilities to the exclusion of the more detailed living wills that have not been approved by the State (King 1996). Not only are living wills limited by legislation, hospital administrators often adopt a very rigid interpretation of the State-approved forms while disregarding attached requests or non-State-approved living wills out of fear that a court may rule against the hospital for not meticulously adhering to the living will if litigation ensues (King 1996). Detailed comments from patients regarding EOL care usually help physicians and family members to better understand the context in which patients make certain healthcare choices and help decision-makers gain a better understanding of the patients’ values and beliefs, but the medical decision-maker’s need for detail is often at odds with the medical administrator’s need for legal safeguards (King 1996). Also, because living wills vary from State to State, a living will from one State may not be recognized by medical facilities in another State (NHPCO 2006).

Difficult Choices

“I try to tell patients when we talk about things that are that severe is that you’re not picking between bad and good decisions. You’re just making choices. You don’t have a good decision basically. You’ve got a decision and whichever one you do is right, but you can’t think of them as good and bad because they’re not going to be. There are problems with both of them.”

- Exert from interview with Dr. Campbell (pseudonym), a current study participant
The Kentucky living will, like most living wills, allows patients to appoint a health care surrogate, or someone to make decisions for the patient in the event that the patient becomes incapacitated. The role of the surrogate is to uphold and protect the patient’s wishes, and the surrogate is expected to follow the patient’s wishes as stated in the living will because this is the responsibility bestowed upon a person when he or she is appointed to be a healthcare surrogate (May, Aulisio and DeVita 2000). It is recommended that patients communicate their health care preferences stated in their living wills and even the reasons behind these preferences with their surrogates, and surrogates who are not comfortable with the patients’ preferences, such as refusing life-sustaining treatment, should resign from their role as a surrogate (King 1996).

According to Kentucky law, if a patient becomes incapacitated and is unable to make decisions regarding medical care, intestate succession goes into effect in selecting another person to make decisions for the patient. Intestate succession begins with a court-appointed guardian and then moves to the surrogate or attorney-in-fact if a guardian is not named. If the patient does not have a surrogate or guardian, the patient’s spouse, then a majority of the patient’s adult children who are available to make decisions, then the patient’s parents, and finally, a majority of the patient’s next nearest living relatives who are able to make decisions (Office of the Attorney General: KRS 311.631).

The powers of the health care surrogate have been outlined by the Kentucky legislator. According to KRS 311.629, a surrogate is obligated to act in accordance with the patient’s desires as stated in the advance directive, but the surrogate must also consider recommendations made by the patient’s physician (Office of the Attorney General: KRS 311.629). For a surrogate to request the withholding or withdrawal of artificial nutrition and hydration, physicians must rule that the patient’s death will most likely be imminent regardless of the use of artificial
support, the patient is in a permanently unconscious state, the patient’s body is no longer physically able to take in artificial means of nutrition, or when the burden of artificial nutrition or hydration outweigh the benefits of such treatment (Office of the Attorney General: KRS 311.629). In the event that the patient is pregnant, artificial nutrition and hydration must be provided to the patient unless the “procedures will not maintain the woman in a way to permit the continuing development and live birth of the unborn child, will be physically harmful to the woman or prolong severe pain which cannot be alleviated by medication” (Office of the Attorney General: KRS 311.629). The act states that physicians can make decisions for patients with those patients’ surrogates refuse to make decisions (Office of the Attorney General: KRS 311.629). While the above Kentucky legislative act encourages surrogates and physicians to comply with requests made in advance directives, the act does not state that advance directives must be followed explicitly in all circumstances.

The Kentucky living will allows people to designate their wishes regarding the use of artificial hydration and nutrition. Artificial nutrition and hydration support can be used for a short period of time to help people, such as stroke patients, regain their strength and their ability to eat and drink on their own, or they may be used for longer periods of time to help patients who are unlikely to regain their ability to eat or drink, such as patients with severe dementia or patients in a persistent vegetative state (Dunn 2001). Artificial hydration is most often delivered intravenously, and the insertion point, the point in which the IV catheter enters the veins, must be changed every 3-5 days (Dunn 2001). Patients receiving artificial hydration via IV for a prolonged period of time may experience discomfort, irritation, and even infection at the insertion site, and some patients have to be restrained because they attempt to pull out their IV lines (Dunn 2001).
Artificial feeding can take several different forms. Patients may receive *nasogastric* (NG) feeding in which a feeding tube is inserted in the nose, *total parenteral nutrition* (TPN) in which an IV is used to deliver liquid nutrients directly to the bloodstream, and *percutaneous endoscopic gastrostomy* (PEG) where a tube is surgically placed in the stomach wall into which liquid nutrients, such as supplemental drinks like Ensure, can be poured or pumped (Dunn 2001). Patients receiving tube feeding may be at increased risk for pneumonia, bed sores, stiff limbs, ulcers, and infection, and again, patients may need to be restrained to prevent them from attempting to remove the feeding tube (Dunn 2001). Also, social isolation may increase for patients receiving artificial nutrition because they no longer eat meals with others nor do they need to be hand fed by a caregiver (Dunn 2001).

The Kentucky living will contains a section for people to mark their preferences regarding the use “life-prolonging treatment” such as the use of mechanical ventilators, which are sometimes referred to as respirators. Mechanical ventilators work by forcing air directly into a patient’s lungs via a tube that is inserted down the trachea (Dunn 2001). The tube inserted into a patient’s lungs is uncomfortable, and the patient’s hands may need to be tied down to prevent the patient from removing the tube (Dunn 2001). It is standard practice for physicians to place mechanical ventilators in patients who have trouble breathing due to illness or injury, such as severe brain injury (Kaufman 2005). A ventilator will most likely be placed in a patient presenting with serious breathing problems unless the patient or an advocate of the patient, such as a family member, makes it clearly known to medical staff that a mechanical ventilator is not wanted (Kaufman 2005). Once a ventilator has been placed and the patient shows no signs of improvement or continues to get worse, the physician, patient, and family members may decide to remove the tube and allow the patient to die (Dunn 2001). Antibiotics can also be viewed as
life-prolonging treatment, and though the living will does not specify life-prolonging treatments, physicians, patients, and family members may discuss the pros and cons of withholding antibiotics for patients at the end of their lives, particularly those suffering from poor quality of life with Alzheimer’s disease or recurrent pneumonia (Dunn 2001). Life-prolonging treatment can include a number of medications and complex equipment, such as kidney dialysis, medications to raise blood pressure, respirator use, and antibiotics (Dunn 2001), but the basic Kentucky living will lumps these diverse treatments into a single category and does not discuss these treatments separately making it difficult for one to consider and voice his or her preferences for each of these treatments.

Next, the Kentucky living will allows people to state their preferences regarding anatomical gifts. The most current version of the Kentucky living will contains detailed options regarding organ and tissue donation, and allows one to even write in specific organs or tissues not listed on the form (Office of the Attorney General 2013). However, these specific organ and tissue donation options were only recently added to the Kentucky living will, and previous versions contained vague wording that did not distinguish between simply donating one’s organs or tissues and donating one’s entire body (Office of the Attorney General 2013). Organ and tissue donation may help the donor’s family cope with the loss of the donor because they know that other lives have been saved by the donor’s death, and one organ donor could save at least seven people by donating two lungs, a liver, a heart, a pancreas, and two kidneys to different recipients, and many more recipients’ lives could be improved by tissue donation (May et al. 2000). At least fifty people’s lives could be saved or greatly improved by tissue donation (Kentucky Organ Donor Affiliate [KODA] 2013). Though organ and tissue donation has benefits for both the donor’s family and the recipients’ families, a lack of knowledge about organ
and tissue donation can create unnecessary concerns, such as the fear that doctors will cut up the patient’s body to the point where an open-casket funeral would be impossible, and these concerns may cause families members to object to organ or tissue donation. In 2006 Kentucky passed legislation that created an electronic organ donor registry and enacted First Person Consent laws to protect the wishes of organ and tissue donors and to prevent family or physicians from overriding these wishes (KODA 2013). However, the KODA website recommends that donors discuss their wishes regarding organ and tissue donation with their family members to avoid potential conflicts in the event that a donor becomes brain dead and is able to have his or her organs and tissues retrieved (KODA 2013).

The emergence of life-support technology has saved patients who previously would have died, but some of these patients survived with brain damage (Perkins 2007). Cardiopulmonary resuscitation (CPR) was developed in the 1960s as a method for rescuing victims of sudden, unexpected, or accidental death, such as heart attack or drowning, but it was not initially used in certain cases, such as with patients diagnosed with an irreversible terminal illness in which case death would not be unexpected (Dunn 2001). Today, however, CPR has become common practice for patients of all conditions unless a patient has Do Not Resuscitate (DNR) orders (Dunn 2001), though some DNR patients do in fact accidentally receive CPR. Patients who do not wish to receive CPR are “No Codes” while patients requesting CPR are “Full Codes” in their medical charts and will receive CPR if they code- their heart stops pumping blood or they stop breathing (Dunn 2001). With the use of cardiopulmonary resuscitation (CPR), the average survival rate for hospital patients is 15.2%, but survival rates are more successful for patients who are generally in good health (Dunn 2001). Patients who have multiple medical problems, are totally dependent on others for their care, or have a terminal illness have a less than 2%
survival rate for CPR. Besides the low survival rate, several other burdens of CPR have been identified. First, the amount of pressure needed to perform chest compressions may result in fractured ribs, which can then puncture the patient’s lung, and once a person is resuscitated, he/she may be found to have suffered brain damage from oxygen deprivation (Dunn 2001). This brain damage may be subtle resulting in minor personality changes or may result in a permanent loss of consciousness thus causing the “survivor” to remain on life support for the rest of his or her life (Dunn 2001).

While CPR is not stated as an option on the Kentucky living will, CPR is often the beginning of a chain reaction in which patients, especially older or ill patients, who are resuscitated by CPR may be left unable to make medical decisions for themselves and may require life support measures, such as artificial hydration and feeding and respirator support. CPR was also addressed by several of the informants in the current study as an important factor in end-of-life care planning. Of course, surrogates and attorneys-in-fact appointed by the patient may be asked to make other decisions that are not explicitly addressed in the living will farther complicating the EOL care decision-making process.

The end-of-life medical care decisions described above are often complicated and require some knowledge of medical conditions and treatments afforded by technological advances. Though the decisions outlined in the living will seem simple on the surface, does the average American possess the knowledge to make truly informed decisions regarding their EOL care? EOL medical care has become increasingly technological and complex (Kaufman 2005), and though individuals have greater access to medical information via the Internet, journals, television, etc., this plethora of diverse and often contradictory information can be exasperating rather than empowering to individuals who lack a medical background (Giddens 1991). While
the overabundance of information regarding EOL care can be overwhelming, the lack of knowledge pertaining to death caused by society’s sequestration of death can be equally problematic. Medical facilities serve to hide death from public view, and death has become a highly technical matter in modern societies (Giddens 1991). Because of this, fewer Americans have direct experience with death today than in previous generations, and many Americans do not know what death actually looks like (i.e. Kaufman 2005). The complex nature of end-of-life care coupled with lack of knowledge and experience with death may negatively influence advance directive completion rates but also make ADs increasingly necessary.

LITERATURE REVIEW

It is estimated that only 20% of the United States’ population have completed advance directives in spite of the passage of the PSDA, which requires health care institutions to make patients aware of their right to have advance directives (Duke et al. 2007). Despite its merits, some claim that the PSDA is rather anemic and has done little to improve patient rights (Yates and Glick 1997).

Advance directives, such as the living will and power of attorney form, are generally concise documents that allow one to name another individual to make decisions in one’s place, and the living will specifically enables one to state his or her preferences regarding three end-of-life (EOL) care choices. However, ADs can become a complex and confusing documents to those making important decisions regarding their end-of-life care. First, ADs are written in “legalese” using terms such as grantor, surrogate and anatomical gift in the living will that can intimidate people who read the document. Also, as one can see in the description of living wills provided above, a series of rules and guidelines govern the processes of selecting the surrogate(s) and witnesses as well as requesting the withdrawal or withholding of artificial nutrition and
hydration. While ADs were devised as a way to give individuals greater control over their health care, they are covered with the fingerprints of legal professionals.

Not only are the terms used in living wills confusing, but the readability of the documents must also be taken into consideration. In general, documents that are in small font, lack white space, contain too much information, have text that is continuous rather than broken down into sections, contain medical jargon, and use large, multi-syllabic words are difficult to read, or in other words, have low readability (Case Management Advisor 2008). Though most health care documents are written above the 10\textsuperscript{th} grade reading level, the average American adult reads at the 8\textsuperscript{th} or 9\textsuperscript{th} grade level, and one out of five Americans reads at or below the 5\textsuperscript{th} grade level (Rathbun, Thornton, and Fox 2008). Rathbun, Thornton, and Fox (2008) suggested that a computer-based readability calculator be used to assess the readability of healthcare materials before disseminating them to the public, pretesting reading materials and using feedback from pretests to improve readability of the material, and consider updating information to improve readability (Rathbun et al. 2008). While power of attorney forms are generally prepared by attorneys, living wills can be accessed in a variety of ways, such as online, and may not always be completed with professional assistance making it crucial for living wills to be “user friendly.”

Another barrier to living will completion is that the choices afforded by the current living will forms may not adequately meet the needs of patients. Most living wills are designed to address medical treatment for patients with terminal illnesses, but many patients, especially elderly patients, are more likely to suffer from chronic illnesses and various forms of dementia, which can contribute to their death (Quadagno 2005). Abbo, Sobatka, and Meltzer (2008) created a modified version of the Illinois living will containing both conditional and unconditional options. The unconditional option allowed the patient to request that life-
sustaining therapy (LST) be withheld regardless of the underlying condition while the conditional options allowed patients to request a trial of LST that can be discontinued if the trial is not beneficial and recovery is unlikely, to request LST (i.e. artificial hydration and nutrition, CPR, and mechanical ventilation) be limited in the event of advanced dementia or terminal illness for which there is no chance of recovery (Abbo et al. 2008). A total of 72 patients at the University of Chicago clinic were given both the modified living will with the conditional and unconditional options and the basic state-approved living will, and 86% of the 72 participants preferred the modified version (Abbo et al. 2008). Of the 72 participants, 21 indicated a desire to complete a living will, and 18 of those 21 participants completed the modified version of the living will, which was legally accepted under Illinois Common Law (Abbo et al. 2008). All 18 patients completing the modified version requested a trial of LST in the event of critical illness (Abbo et al. 2008). A majority also requested no LST in the event of terminal illness or advanced dementia, and none of the 18 patients selected the unconditional option of no LST regardless of medical condition (Abbo et al. 2008). The study indicated that by modifying living wills to include a greater number of illnesses and conditions and allowing patients to request a trial run of LST, the documents may be more appealing to patients because of their wider applicability and range of options.

Though advance directives are an effective way to voice wishes regarding specific medical care, there is still room for improvement regarding quality of life care. In a study conducted by Teno, Gruneir, Schwartz, Nanda, and Wettle (2007) advance directives were found to reduce the use of unwanted life-prolonging treatment, increase hospice use, and increase the likelihood that the patient will die at home rather than in a hospital. However, patients with advance directives still suffered from inadequate pain management and a lack of emotional
support (Teno et al. 2007). Interviews with senior citizens found that quality of life issues, rather than focus on specific treatments, tended to be of greater concern for the seniors (Rosenfeld, Wenger, and Kagawa-Singer (2000). Altering the format of advance directives to allow patients to state wishes regarding quality of life issues including pain management and emotional support could provide greater comfort to patients and allow care givers to better understand the needs of the patients.

Health care providers and social workers within hospitals and nursing homes are in a good position to educate patients on advance directives, but a number of factors limit the ability of health care and social workers to discuss advance directives with their patients. In a study conducted by Duke, Thompson, and Hastie (2007), most of the patients interviewed learned of advance directives from the media, pastoral services, the workplace, and attorneys, and a very small number of participants learned of advance directives from healthcare providers. Steps must be taken to ensure that health care workers have a strong understanding of the rules that govern advance directives, and then health care workers must be encouraged to openly discuss and share information with their patients.

In a study conducted by Nolan and Bruder (1997), it was found that while a majority of patients possessed knowledge of advance directives, the patients also possessed a number of fears regarding how advance directives would be used to determine their end-of-life treatment. First, while 96% of the patients surveyed by the researchers reported that they had choices about the type of end-of-life treatment they wanted to receive, half of these participants reported that they did not know enough about medicine to make informed decisions regarding medical treatment preferences (Nolan and Bruder 1997). Because of a lack of knowledge, patients were fearful that completing advance directives would automatically require them to become organ
donors, would cause them to receive less aggressive care at the end-of-life, or would be used to deny the patients any form of care (Nolan and Bruder 1997). Rather than viewing advance directives as a way to voice their end-of-life care preferences, many study participants feared that advance directives would be used to deny them wanted treatment resulting in their demise.

Community efforts can be made to educate people about advance directives, alleviate fears, such as those mentioned in the paragraph above, and improve completion rates. In one Idaho community a booth was set up at a health fair for community members to receive information about living wills, and medical social workers assisted community members one-on-one with their directives and answered questions (Later and King 2007). The community members who completed living wills at the health fair were given the opportunity to complete a small, laminated pocket version that explained the basic content of their directive and also stated the location their complete living will. Community members had the opportunity to attend an hour long advance directive symposium where an oncologist, an attorney, and a risk manager at the local medical center presented at the symposium. The health fair provided community members with a non-threatening way to discuss advance directives in an interactive manner with professionals who could answer their questions and address their fears (Later and King 2007). Because research has indicated that many people are not aware of the availability of advance directives or had just never thought about end-of-life care planning (Jezewski and Meeker 2005), community education efforts could create greater awareness, make advance directives more accessible, and could also encourage people to start thinking about end-of-life care planning.

Fear of death in general and the desire to avoid death and death-related topics may deter people from completing their advance directives, and simply educating people about advance directives is not enough to remedy this basic human fear. One participant in a study conducted
by Jezewski and Meeker (2005) described what he or she believed to be the reason why many people do not complete ADs: “They're avoiding them [advance directives] because of the fact that death is a thing that you don't talk about very often because we don't want to get dead” (p. 323). Procrastination was closely related to avoidance and denial. Many participants claimed that they need not worry about competing advance directives immediately because they will have ample time in the future to fill out the forms (Duke et al. 2007; Jezewski and Meeker 2005). Also, many participants expressed interest in doing advance planning, but put it off stating that they didn’t have time or just hadn’t gotten around to it yet (Jezewski and Meeker 2005). Participants cited America’s denial of death as a cultural barrier to AD conversation and completion and believed that avoidance of the topic of death made learning about end-of-life care options and ADs more difficult (Jezewski and Meeker 2005).

Indeed, American society has a somewhat impractical and perverse relationship with death. According to Giddens (1991), death is sequestered within medical institutions and is under the control of technology and bureaucratic processes in modern society. In her work *On Death and Dying*, Kübler-Ross (1969) noted that most deaths once took place in the home with the dying person surrounded by friends and family, but today death has been removed from the home and is hidden behind the foreboding brick walls of the hospital. In fact, Kaufman (2005) speculated that most Americans have forgotten what death looks like. While the average American citizen has little first-hand experience with death, people are bombarded with images of fictional death on television crime shows and dramas, in movies, in music, and in video games, and even “nonfiction” deaths reported on the evening news seem to be distant events that have little significance to most people (Gibson 2007). Death entertains Americans but Americans are less willing to entertain thoughts of their own death.
Not only must people consider their own end-of-life care when completing advance directives, they are often required to select a health care surrogate or proxy to advocate on their behalf. Selecting a surrogate is a process that should extend beyond writing the surrogate’s name on an advance directive form and should include open dialogue between the person preparing the advance directive and that person’s surrogate. Research indicates that many surrogates have a limited understanding of the patients’ wishes regarding end-of-life care, but this problem can be resolved with ongoing communication between the people selecting their surrogates and the surrogates themselves (Carr and Khodyakov 2007). Many people select surrogates who are close family members, and in an analysis of 476 advance directives on file at the Mayo Clinic, it was found that a majority of patients (41.7%) selected their spouse to be their surrogate while other patients designated a child (16.6%), a close relative (i.e. parent or sibling) (5.5%), or friend (1.2%) while 35% of the ADs analyzed designated no proxy (Nishimura, Mueller, Evenson, Downer, Bowron, Thieke, Wrobleski, and Crowley 2007). The inability to identify a surrogate has been identified as a barrier to AD completion (Jezewski and Meeker, 2005). While married people were more likely to name a spouse, and couples with children were likely to name a child, the surrogate selections made by unmarried childless individuals were rather heterogeneous (Carr and Khodyakov 2007). While 33% of unmarried childless individuals studied by Carr and Khodyakov (2007) named a sibling or other relative, 16% choose a friend or coworker, and a smaller amount choose a non-marital romantic partner, ex-spouse, or professional, such as clergy. In most cultures, females are assigned the role of caregiver, and it was not surprising that female surrogates were preferred over male surrogates (Cramer, Tuokko, and Evans 2001). Because surrogates are appointed to act as the patient’s spokesperson when the patient is
incapacitated, surrogates must have a clear understanding of the patient’s wishes in order to ensure the patient’s wishes are followed.

Though living wills promote patient autonomy, end-of-life medical decisions are not made in a vacuum. Patients must trust that their healthcare surrogates, physicians, and healthcare facilities will honor the wishes stated in their advance directives (Darr 1999). Health care surrogates and physicians will generally honor a living will provided that the document is made available to them because this document expresses the treatment preferences of the dying individual (Darr 1999). However, there is no legislation or court-developed case law to give advance directives legal status, and living wills may not be followed for a number of reasons (Darr 1999). Often, the patient’s wishes are not followed because the grantor failed to share the documents with the appropriate people, or living will documents got left behind at the nursing facility when nursing home patients are transferred from the nursing home to the hospital (Darr 1999).

In a study of elderly patients hospitalized for acute illness, it was found that in 75% of cases physicians failed to consult the patients’ living wills or talk with the designated healthcare surrogate (Darr 1999). At times, physicians or family members may also believe that the patient’s wishes regarding treatment are inappropriate and should be overridden. Physicians may feel obligated to override a patient’s end-of-life care requests if the requests conflict with family requests, hospital policy or the physician’s own standard practice procedures (Perkins 2005). When family members wish to override a patient’s advance directives, they may use threats of legal repercussions to persuade a physician to violate a patient’s directives. The fear of lawsuits is real and can be a powerful motivating force for physicians who are reminded of the adage “dead patients can’t sue, but live families can” (May et al. 2000: 333). When individuals learn
that the wishes stated in their living wills can be overridden, they question their need to invest

time in completing living will documents that have no legal teeth (Leming and Dickinson 2007).

Vig, Taylor, Starks, Hopley, and Fryer-Edwards (2006) described five methods that
surrogates planned to use when making end-of-life care decisions for older, chronically ill family
members. First, a majority (66%) of surrogates interviewed stated they would use conversations
they had with the patient about end-of-life care as the basis for making decisions, but only a
small number of these conversations were deep and extensive enough to fully convey the
patient’s preferences to the surrogate (Vig et al. 2006). A small number (10%) of surrogates
relied solely on the patient’s advance directives and did not feel that conversation was necessary
(Vig et al. 2006). A slightly larger group of surrogates (16%) reported that they would rely on
the values and life experiences they shared with the patient to guide their decisions (Vig et al.
2006). Some of these surrogates claimed that they would “just know” what the patient wanted if
a situation presented itself because they had lived closely with the patient for a number of years
(Vig et al. 2006). Twenty-eight percent of surrogates reported that they would rely on their own
beliefs, values and preferences, including the desire to prolong the patient’s life despite the
possible suffering this prolongation may cause (Vig et al. 2006). Finally, some (18%) of
surrogates reported that they would seek input from others in their social network including
family members, clergy, and physicians who might possess special knowledge that could be
employed to guide the surrogate’s decisions (Vig et al. 2006). A number of surrogates claimed
that they would rely on more than one of these five methods when they were required to make
decisions for dying loved ones (Vig et al. 2006). This study implies that surrogates are often
unable to isolate their own feelings and preferences from those of the patient, and many
surrogates find making end-of-life care decisions extremely difficult requiring them to seek assistance from a number of resources (Vig et al. 2006).

End-of-life care decision-making can indeed be difficult for surrogates, and Kaufman (2005) speculates that part of this difficulty arises from the fact that surrogates are not equipped with adequate medical knowledge to make informed decisions for patients. From a medical anthropological view, physicians, nurses and other medical staff are natives in hospitals while patients and families are foreigners (Kaufman 2005). The natives, or physicians and nurses, possess a special knowledge of the inner workings of the hospital that patients and family members lack. Therefore, when physicians ask the patient’s family members to make major decisions regarding the patient’s care, such as inserting a respirator because the patient can no longer breathe on his or her own, family members are faced with a great deal of stress as they attempt to make life-and-death decisions in the foreign territory of a hospital with inadequate knowledge of the situation.

Just as a number of factors impact the likelihood of surrogates complying with a patient’s advance directives, there are myriad factors that influence compliance among medical staff. Scherer, Jezewski, Graves, Wu, and Bu (2006) found that physicians and nurses were often unaware of the key guidelines governing advance directives. Yates and Glick (1997) report that physicians may not fully understand State law regarding patient refusal of and physician removal of treatment as well as the stance that medical associations and ethics groups take on issues regarding the removal of life-prolonging treatment. Also, physicians may dislike advance directives like living wills because they are vague documents that cannot account for specific medical conditions and treatment options, and physicians with negative attitudes toward advance
directives may spend little time discussing these documents with their patients (Yates and Glick 1997).

In a study of nursing programs in North Carolina, Connell and Mallory (2007) found that the majority of nursing programs surveyed provided nursing students with few classes in which advance directives were discussed, and a bulk of the information about advance directives was presented via textbooks and lectures rather than more hands-on methods like conferences and role playing. Such teaching methods were believed to prevent students from adequately retaining information about advance directives, building on this information throughout their education, and later applying the information to work situations (Connell and Mallory 2007). Improved education for medical staff regarding advance directives could allow staff to be more effective at educating patients about directives and could enhance communication between patients and staff concerning the patients’ end-of-life care wishes.

Physicians’ experiences with and attitudes toward death may also serve as a barrier to effective end-of-life care planning with patients. Death talks are conversations between physicians and their patients regarding the patients’ terminal illnesses, and these talks may guide patients with writing advance directives. Death talks are social engagements involving meaning-making humans, are complicated and involve opportunities for growth and personal insight (Moon 2008). However, a number of factors have been found to prevent death talks. Physicians are trained to save lives rather than focus on planning for death, and they operate in a health care system in which life-saving and life-sustaining therapies are emphasized and live in a death-aversive society (Moon 2008). Also, physicians may lack the skills to cope with patient death and the array of emotions (i.e. guilt, anger, remorse, and anxiety) experienced by the patients, their families, and the physicians themselves that accompany the dying process (Moon 2008).
Black (2007) reported that healthcare providers who had experience working with patients with terminal illnesses were more likely to disclose information about advance directives to patients and the patients’ loved ones. Even though physicians’ personal experiences with death and dying can be used to increase death-talks with patients and the patients’ family, steps must be taken to help the physicians interpret their death and dying experiences and internalize the meanings they derive from them (Moon 2008). To help physicians derive meaning from their experiences, Moon (2008) suggests that physicians engage in rational discourse with other physicians to help them understand how their experiences shape their views of death and dying. Another suggestion is that physicians write subjective statements about their death-related experiences to help them identify their personal standpoints, prejudices, and biases, keeping personal narratives of death-related experiences as a means of providing physicians with a means of introspection. Also, engaging in a mentoring process with other physicians can encourage rational and critical discourse and help physicians explore deeper meanings in life and death (Moon 2008). While the suggestions listed above could provide physicians with a greater understanding of how their own attitudes and experiences related to death and dying influence how they interact with dying patients, it seems unlikely that most medical facilities, which focus primarily on saving lives and avoiding death, will readily adopt these practices.

At times medical staff who have little training in communicating about death and end-of-life care planning are required to present patients with advance directives, and the method of presentation could influence completion rates of advance directives among patients. Simply distributing living will information to patients does not guarantee that patients will read the material. Salmond and David (2005) found that only 82% of the 80 patients they surveyed reported receiving information on living wills despite the fact that the hospital gave everyone
living will information upon admission. Less than 50% of the patients who reported that they had received information on living wills could describe the purpose of the documents (Salmond and David 2005). Social workers in nursing homes studied by Forbes-Thompson and Gessert (2005) asked patients about advance directives, such as living wills, only during the in-take process and only then to determine if the new patients had pre-existing directives, and the topic of advance directives was not pursued or discussed after the in-take process. Yates and Glick (1997) found a greater living will completion rates in medical facilities in which medical staff actively encouraged patients to learn about living wills and followed up with patients after in-take to discuss living wills. Darr (1999) found that when hospitals gave patients living will information several days prior to admission they had higher completion rates than hospitals that gave patients information the day of admission. Patients were much more likely to read the information regarding living wills when it was made available to them before hospitalization (Darr 1999). Direct mail campaigns have also been used to educate patients on the issues regarding living wills, and these campaigns were found to increase completion rates. Healthcare providers can openly address living wills with their patients and offer gentle reminders to patients who have not completed the directives (Darr 1999).

The need exists for a more effective method of educating people on the topic of living wills. The research in the paragraph above indicates that simply giving patients information on advance directives, and living wills in particular, is not enough to ensure increased completion rates or improved understanding. However, giving patients time to read and process information and encouraging patients to discuss advance directives with staff who are informed and willing to spend time with patients can improve understanding and increase completion rates.
The sequestration of death in modern American society may be to blame for the lack of communication regarding advance directives (ADs). Research has shown that physicians and nurses receive little instruction on ADs, including AD policies, and they also receive scant instruction on how to communicate with patients and family members about death and end-of-life care planning (i.e. Moon 2008; Connell and Mallory 2007; Dickinson and Field 2002). Medical schools and healthcare facilities are heavily focused on curative treatment and are unlikely to encourage physicians to explore their thoughts and feelings on death and use their insights to help them engage in death talks as Moon (2008) suggests. The bureaucratic nature of medical facilities influence the implementation of AD laws, and may help bury the topic of ADs and death behind cold administrative processes that fail to foster communication about ADs between patients and staff (i.e. Forbes-Thompson and Gessert 2005). Completion of ADs may increase when death is allowed to come out of hiding and end-of-life care is able to be discussed openly by patients, their family members and medical staff (Darr 1999; Yates and Glick 1997).

In the paragraphs above, a multitude of factors have been identified that can hinder or help advance directive completion and compliance. Advance directives were described as somewhat complicated medical and legal documents that are often difficult to read and may not be readily discussed in medical facilities or in society at large. Being made aware of the complexity of advance directives, it is not surprising to learn that only a small percentage of Americans actually possess advance directives.

Various researchers have identified many characteristics of those Americans who have completed advance directives. People who are functionally dependent were more likely to have living wills, and this is most likely due to the facts that these people have been given the opportunity to complete living wills by a healthcare facility and that functionally dependent
people may be more accepting of their inevitable death and wish to avoid leaving the burden of decision making regarding end-of-life care to loved ones (Duke et al. 2007). Advance directive completion rates were also higher among Caucasians, females, college-educated people, people with private insurance, and people with yearly incomes over $22,000 (Duke et al. 2007). Teno et al. (2007) and Orlander (1999) also found that older patients were more likely to complete living wills than younger patients. Orlander (1999) found that as people age they tend to feel more vulnerable to health risks through personal health experiences or the health experiences of others, and this vulnerability served as a motivating force behind their AD completion. Overall, it was found that patients who were older, had higher levels of educational attainment, were Caucasian, had increased activities of daily living limitations, and had chronic health conditions were more likely to complete ADs (McGuire, Rao, Anderson, and Ford 2007).

Positive attitudes toward advance directives were also found to play an important role in promoting completion. Douglas and Brown (2002) used Nolan and Bruder’s (1997) Advance Directive Attitude Survey (ADAS) to measure hospitalized patients’ attitudes toward ADs and found that patients with more positive attitudes toward ADs had higher AD completion rates than those with negative attitudes toward ADs. Patients with more positive attitudes toward ADs desired to control their medical care and believed that ADs would allow them to do so (Douglas and Brown 2002). However, patients with negative attitudes toward ADs tend to not fully understand the content and implementation of ADs (Eisemann and Richter 1999), or these patients feared that ADs would be used deny wanted treatment (Douglas and Brown 2002). Douglas and Brown (2002) reported that individuals with negative attitudes toward end-of-life care planning were 90% less likely to complete ADs. Negative attitudes toward ADs may be closely related to racial discrimination and cultural values as described below.
The issue of race and ethnicity is an important factor when analyzing advance directives. Controlling for socio-economic factors, racial and ethnic minorities are less likely to complete advance directives than Caucasians, and this may be due to racial and ethnic disparities in health care as well as a lack of trust that many minorities may have in the health care system (Baker 2002). African Americans expressed fear that they would receive subpar treatment if they had an advance directive, and this may indicate a fear that policies regarding advance directives might not protect their rights but might actually jeopardize them (Baker 2002). Minority patients with advance directives were more likely to request ongoing life-prolonging treatment than Caucasian patients, and again, this most likely indicates a lack of trust in the medical system along with the concern that physicians may not use all possible measures in an to attempt to restore their health before treatment is terminated (Baker 2002). In light of these facts, it is imperative that advance directive forms and policies become more sensitive to cultural differences in the United States.

Differences in cultural values must also be taken into consideration. While the idea of patient autonomy may appeal to most white, educated adults who value autonomy, it may not appeal to groups like Latinos who tend favor family-based decision-making, to Koreans who often find autonomy to be isolating and cumbersome, or to African Americans who fear that advance directives legitimize patient neglect (Giger, Davidhizar, and Fordham 2006). To appeal to a wide range of Americans, advance directives must be flexible enough to accommodate the needs of a diverse population, and social workers, nurses, and physicians must develop cultural understanding and sensitivity (Giger et al. 2006).

Ultimately, death, as both a social and individual dilemma, is a portentous beast that has yet to be captured and abolished by humans, but this has not prevented Americans from seeking numerous ways to restrain death and reduce its unpleasant sting. For example, death has been
hidden within medical institutions, bureaucratized, and combated with ventilators, feeding tubes, and intravenous hydration that allow humans who are unable to breathe, eat, or drink on their own to live. However, as the American institution of healthcare gained the power to prolong human life indefinitely with technology, humans began to fight for autonomy and control over the use of such powerful technology.

Advance directives are one example of how humans have gained greater independence and power over technology. Advance directives, particularly living wills, tend to be problematic documents that can pull death out of sequestration by forcing people to acknowledge death and make provisions for their own dying process- a process that can evoke numerous fears and concerns. Also, advance directives are implemented in the increasingly rational and bureaucratic culture of the medical field, in which the individualistic nature of patients’ wishes may be at odds with medical facilities’ needs for efficiency, calculability and predictability and can be overridden without legal repercussions. The current study seeks to identify factors that influence advance directive completion, including attitudes toward ADs, and motivations and barriers to AD completion, in a small university community in Eastern Kentucky.
The modern age witnessed rapid development in medicine creating the need for advance directives (ADs) while simultaneously removing the traditional social structures that once guided decision making and sequestering death and illness behind the doors of medical institutions. In short, modernist theorists argue that while the advances that have taken place in modernity give individuals a wide range of choices, such as the ability to express end-of-life care decisions in ADs, it neglects to offer individuals moral guidance in their decision-making process (Mellor and Shilling 1993; Giddens 1991). Also, death is frequently hidden making it both easy to ignore and difficult for which to plan and prepare. As the rationality brought about by the Enlightenment spread causing Western society to witness the “gradual assimilation of all cognitive values to scientific ones,” the traditions, rites and rituals that guided social behavior in pre-modern societies were weakened and in some cases eliminated (Gaukroger 2005: 1).

Gaukroger (2005) cites evidence that the growth of science did not directly cause the decline of religious influence in modern society, and as religion became historicized and relativized it became subjected to criticism that caused religion to lose its status as a dominant source of inspiration for humanity. Instead Western culture turned to science as the means of solving the world’s problems (Gaukroger 2005).

One consequence of the proliferation of science and rationality is that doubt has become pervasive (Giddens 1991). Modern institutions help fill the void by providing individuals with routines that order daily life and protect humanity from the chaos that lurks on the other side of order and wreaks havoc with one’s sense of ontological security. To protect this shared concept of the reality of people and things that is vital to the normal functioning of society, certain human
conditions, such as death and dying, are sequestered (Giddens 1991). However, death is a universal phenomenon and cannot be completely avoided. The sequestration of death within medical institutions, which are heavily rationalized and bureaucratized, may allow society to function normally by avoiding frequent existential crises, but it does little to help individuals plan for, discuss, and seriously consider their own dying and death process (Giddens 1991).

CHARACTERISTICS OF MODERNITY

Modernity developed alongside the rise of rationalization and the desacralization of social life. Because of this modernity has been described as a post-traditional order in which the traditions, most of which were religious, that guided social behavior by providing moral frameworks have been essentially replaced by an order based on the principles of science in which humans have greater control over their lives but lack moral frameworks to guide their behavior (Mellor and Shilling 1993; Giddens 1991). Individuals have increasingly focused inward, developing a self-reflexive guide to help them make decisions, and the concept of self-identity has become ever more important for individuals (Giddens 1991). Even death, which is an experience that all living things must encounter, has moved from an event of public to private significance, and this privatization of death fragments and individualizes the meaning of death so that it seems less like an unavoidable, universal constant (Mellor and Shilling 1993). When individuals do encounter death, they lack the social rituals that once connected them to their society and gave meaning to death leaving them with the lonely task of constructing and maintaining their own values and meanings to guide them through the death experience (Mellor and Shilling 1993).

Rationalization, Bureaucratization and McDonaldization

While physician care in bureaucracies is often humane, such behavior seems to occur despite bureaucratic structure rather than because of it.
Where individuals once turned to their communal traditions or religion for answers, they now turn to a rationalized system of experts. In this system, modern expertise is oriented toward continual internal improvement or effectiveness, and knowledge has become increasingly limited and specialized with experts being required to undergo lengthy training and specialization (Giddens 1991). The intense focus that specialists have on issues in their field can cause issues outside of their narrow focus to blur to the extent that specialists neglect to see the full consequences of their actions beyond their narrow focus (Giddens 1991). Unintended and unforeseen outcomes that cannot be controlled or contained are more likely in narrowly focused expert systems (Giddens 1991).

Another potential negative characteristic of modernity and its expert systems is the uncertainty they create for individuals in need. Numerous systems of experts exist representing different sources of authority, and even within the same field, such as in the medical field, experts may possess divergent opinions regarding diagnoses and the courses of actions a patient should take (Giddens 1991). Where religion and tradition once served as an overarching authority that provided individuals with answers to questions, expert systems are regularly changing and may contain conflicting information leaving the individual with a sense of uncertainty and doubt (Giddens 1991). In fact, doubt is pervasive in modernity due to its reflexive nature. In science even the most reliable and beloved principles are never proven but are always open to revision or elimination if new information emerges that disproves the principles (Giddens 1991). At the same time that expert systems cause individuals to feel uncertain, they also require individuals to possess a great deal of trust in the goods and services of strangers who provide everything from cars, food, and clothing to medicine and therapies and
who frequently have little to no direct contact with the individuals they serve (Giddens 1991). Expert systems depend on this trust, but it is impersonal and it lacks the moral rewards that once stemmed from the personalized trust that characterized pre-modern societies (Giddens 1991).

Modernity’s highly rationalized nature has been addressed by a number of researchers, and nearly one hundred years before Giddens wrote about society in high modernity, Max Weber wrote about the rise of formal rationality and the growing popularity of bureaucratization. Milovanovic (2003) defines rationality as “following some criteria of decision [making] which is applicable to all like cases” meaning that rationality essentially equals generality and possesses a high level of predictability (p. 51). Kalberg (1980) categorizes Weber’s descriptions of rationality into four types, one of which is formal rationality. Formal rationality consists of means-ends rational patterns of action that are not based merely on practical self-interests…but on “universally applied rules, laws, and regulations” (Kalberg 1980: 1158). Formal rationality has come to dominate many spheres of society, especially the economic, scientific and legal realms.

Of Weber’s four types of rationality, formal rationality was the most recent form to develop arising in the West during the industrial revolution (Ritzer and Goodman 2004) with roots in the Enlightenment’s mechanical world view and emphasis on reason (Koch 1993). The universal regulations and standards adopted by formal rational systems gave societies in the West “a freedom to inquire, to dispute, to experiment, a belief in the possibilities of improvement, a concern for the practical rather than the abstract, a rationalism which defied mandarin codes, religious dogma, and traditional folklore” (Kennedy 1987: 30). This afforded the West the ability to industrialize, develop an advanced capitalist state, and become a leading world power early in the nineteenth century (Cockerham, Abel, and Lüschen 1993).
Giddens (1991) wrote that in high modernity, administrative control has become intensified and impacts the lives of everyone, and administrative control in modern society is most effectively achieved through a bureaucratic structure. Bureaucracy developed as a highly effective means of administration within the formal rational system. According to Weber (1958), a bureaucracy has a clearly defined area of purpose, responsibility and activity, and management of offices within a bureaucracy is based on written documents or “files.” Within bureaucracies exists a hierarchy of offices and positions filled by qualified officials, and there are clear and calculable rules that officials, or office holders, must follow. The officials within bureaucracies are subject to strict supervision and discipline, which is enacted in a top-down order with people higher up in the bureaucratic structure supervising and punishing those below them (Weber 1958). Individuals within a bureaucracy are deemed expendable and can easily be replaced by someone else with the proper training and qualifications (Weber 1958).

Regarding training, Weber (1958) stated that educational institutions are “dominated and influenced by the need for the kind of education that produces a system of special examinations and the trained experts that is increasingly indispensable for modern bureaucracy” (p. 240). Not only does this increased demand for education and special exams limit the number of employees available for official positions and allow their monopolization by those with such training, they also indicate that a worker is an acceptable employee within the bureaucracy. According to Weber (1958), “bureaucracy rests upon expert training, a functional specialization of work, and an attitude set for habitual and virtuoso-like mastery of single yet methodically integrated functions” (p. 229). This training entitles the employee to the “respectable” wage of a fixed salary paid in money and work-related benefits (Weber 1958). However, Weber believed that
such highly trained and specialized employees were “specialists without spirit” acting without regard to their personal values (Koch 1993).

Upon being hired, the employee enters a “free contractual relationship” in which the worker’s position is his or her sole vocation thus severing ties that existed between one’s private life and career position in previous systems of administration, and the worker moves along fixed career lines where promotions are based on seniority and/or good performance. The office holder also enjoys a distinct social esteem based on his or her official position (Weber 1958). These characteristics of Weber’s ideal type bureaucracy seek to promote efficiency, calculability and predictability within an institution, which serves the needs of a capitalist economy.

Ritzer’s concept of McDonaldization is considered an “extension and amplification” of Max Weber’s concept of formal rationality (Ritzer 2004: 25). Ritzer uses the popular fast food restaurant McDonald’s to build on Weber’s theory of formal rationalization and to illustrate how the principles of formal rationalization and bureaucratization have come to dominate numerous aspects of human life. Ritzer (2004) defines McDonaldization as “the process by which the principles of the fast-food restaurant are coming to dominate more and more sectors of American society as well as the rest of the world” (p. 1). McDonald’s is considered a leader in the fast-food world in terms of adopting and operating under the formal rational concepts first described by Weber, and since its inception, many other sectors of society have emulated McDonald’s model (Ritzer 2004).

McDonald’s model includes the principles of efficiency, calculability, predictability, and control through nonhuman technology. McDonald’s offers efficiency, or the “optimum means to a given end” (p. 43), by streamlining production through a variety of methods including assembly lines, limited ingredients in the food, and limited items on the menu, and this quest for
efficiency seeks to save customers and McDonald’s time and money and increasing the company’s profit (Ritzer 2004). The second goal of McDonald’s is *calculability*, or the process of “calculating, counting, [and] quantifying” (p. 66), and calculability allows the restaurant to easily calculate how many items it will need to produce a specified number of food products, how many food products are sold, how long it takes to make a product, and how quickly customers can be served (Ritzer 2004). McDonald’s also emphasizes *predictability*, which means that products and services are the same at every McDonald’s, and this predictability was achieved through “discipline, order, systematization, formalization, routine, consistency, and methodical operation” (Ritzer 2004: 86). Finally, human error, which can jeopardize the efficiency and predictability of McDonald’s, is reduced by *control through nonhuman technology* which includes employee protocols and premeasured ingredients, nearly fool-proof computerized ordering systems, scripts that employees are required to recite to customers, clearly defined lines in which customers must wait to order food, and menus that limit customers’ options (Ritzer 2004).

While the rationalization of McDonald’s ultimately leads to the positive outcomes of faster service, lower prices, and greater profits, rationalization inevitably suffers from what Ritzer calls the *irrationality of rationality* (Ritzer 2004). While McDonald’s highly rational system serves to benefit customers by saving them time and providing them with a needed service (i.e. inexpensive food quickly prepared and served), customers and employees are often dehumanized by the rational processes. For example, customers are corralled into lines, forced to select from a limited menu, and employees and customers both are “trained” to follow a script during their brief interactions to promote optimum efficiency. The principle of predictability can create mind-numbing experiences for customers and staff alike. Also, the quality of the food is
all too often sacrificed for quantity (Ritzer 2004). Despite the inevitable irrationalities that are created by a formal rational system, Weber (1958) believed that the modern state was totally dependent on formal rationality and its bureaucratic administration, and more currently Ritzer (2004) contends that the process of McDonaldization is rapidly gaining popularity.

**Institutions and Ontological Security**

Modern institutions, most of which have become bureaucratized and even McDonaldized, play a key role in society by providing the routines that organize daily life and protect a shared sense of ontological security. A basic sense trust normally develops in infants from their interactions with caregivers, and this trust gives humans a sense of hope which is an essential component in developing ontological security (Giddens 1991). Ontological security consists of socially agreed upon, shared cognitive frames of meaning that, when combined with underlying emotional commitment based on trust, hope, and courage, generate faith in the “coherence of everyday life” (Giddens 1991: 38). This ontological security is “a sense of the shared- but unproven and unprovable- framework of reality” that is “simultaneously sturdy and fragile” (Giddens 1991: 36). Daily routines, which are most often centered around institutions frequently lack moral meaning and can come to be experienced as empty practices, but they can also provide a sense of normalcy and permanency that serve to protect ontological security (Giddens 1991). Death, including the death of a loved one or thoughts of one’s own death, has the ability to shatter ontological security and create existential dilemmas for humans.

Most individuals can comprehend and accept the concept of biological death, but subjective death in which one is aware of the concept that he or she will cease to exist, is more troubling (Giddens 1991). As traditions and religion lost much of their control over society, self-identity and a focus on the physical body rather than the soul increasingly gained importance,
and self-identities came to be adopted and represented as solid attributes that people possess (Willmott 2000). Also, one’s self-identity is perceived to be an on-going project, and death leaves the project of the self incomplete and shatters the personal meaning individuals spent their lives working to create (Giddens 1991). In modernity, the death of the body seems especially troubling not only because of the increased focus on the body and individual self-identity but also because “modernity has deprived increasing numbers of people the means of containing [death] in an overarching, existentially meaningful ritual structure” (Mellor and Shilling 1991: 427).

Modern institutions help shield humans from the existential problems caused by death by attempting to remove, or sequester, death from the daily lives of individuals. Modernity emphasizes human control, and currently many aspects of nature have become subordinated to humans (Giddens 1991). However, death, which represents the total loss of human control, is still a very real and unavoidable aspect of human existence despite medical advances that lengthen the lifespan and exert a great deal of influence over the dying process. In fact, the nature of the lifespan itself has been altered over the course of modernity. In modernity the lifespan has become separated from the larger social context of traditional rites and rituals, the externalities of kinship and geographic ties, and the life cycle of the generations causing the lifespan to become influenced by the lifestyle one selects and the behaviors associated with that lifestyle (Giddens 1991). Because nature has become subjected to constant human intervention, even nature fails to serve as an external reference. Though humans are reflexive and use the larger social environment to shape their self-identity, a sense of internal referentiality is fundamental to modernity. Humans lack an internal referentiality regarding death since one cannot easily die a little and then come back to report the experience to the living, and many of
the traditions and religious ideas that provided guidance and comfort in the face of death have been eroded by modernity’s rationality. In light of these challenges, it is no wonder that the issue of death has been pushed to the sidelines of human experience by society’s need to preserve ontological security (Giddens 1991).

*The Sequestration of Death*

“…hospitals can be seen as the institutional expression of the modern desire to sequester corporeal evidence of sickness and death away from the public gaze.”

*Mellor and Shilling, Modernity, Self-Identity and the Sequestration of Death, 1993*

The existential questions that are dredged up by basic life experiences that much of Western culture finds troubling, particularly madness, criminality, sexuality, nature, and sickness and death, are repressed or excluded from social life by the process of sequestration. Giddens (1991) believes that the sequestration of experience is the “outcome of a culture in which the moral and aesthetic domains are held to be dissolved by the expansion of technical knowledge…[and] internally referential systems lose contact with extrinsic criteria” (p. 165).

According to Giddens (1991) organizations can directly sequester experience, such as a hospital sequestering death, or sequestration can be dependent more on the general features of the internally referential systems of modern society. Regardless of how sequestration takes place, its primary goal is to maintain daily routines established by modern systems that sustain ontological security (Giddens 1991). When one’s routine becomes disrupted, the sequestered experience may seep back into the individual’s conscious creating an existential crisis with which the individual lacks the psychological and social resources to cope (Giddens 1991). Death is a sequestered experience, and medical culture and medical institutions have assisted with the
sequestration of death by hiding it within their facilities, making it a highly technical matter, and subjecting it to bureaucratic procedures and administrative control.

The way American society, specifically the medical community, treats illness and the dying process has changed dramatically over the course of the twentieth century as the medical field has come to embrace formal rationalism, bureaucratization and McDonaldization. Before the advent of antibiotics, which began to be commonly used in medicine in the 1930s and 1940s, a number of people died from pneumonia, post-operative infections, tuberculosis and a variety of other ailments that can easily be treated or cured with common antibiotics today (Kaufman 1993). The prominent goal of medicine could be summarized in the French motto, “To cure sometimes, to help often, to comfort and console always” (Kaufman 1993: 43). The dearth of diagnostic and curative measures available at that time made the task of curing patients extremely difficult, but despite the lack of effective treatment, physicians could offer patients and their families comfort and consolation (Kaufman 1993). Physicians had a weak grasp on death’s reigns, and though medicine provided some hope for patients, the prospect of death still loomed on the horizon.

Because of medicine’s limited ability to cure patients and thwart death, death was more highly visible before the second half of the twentieth century. Deaths often took place in the home where the dying were surrounded by familiar people and furnishings, and children, rather than being excluded from the dying person’s bedside, were involved in visiting with the dying and assisting with preparations (Kübler-Ross 1969). Many families, especially in rural areas that lacked funeral homes, had to prepare the bodies for burial, build the coffin, and dig the grave (Luptake 2004; Crissman 1994). A number of religious and non-religious rituals guided social behavior during the death and mourning process. For example, certain practices such as opening
a window and covering mirrors in the room where a person’s death had just occurred were observed for many generations (Crissman 1994), and numerous cultures had prescribed periods of mourning that dictated many aspects of social life including dress and behavior (Leming and Dickinson 2007). While most civilizations, including Western civilization, viewed death as undesirable and dreaded, death was also viewed as part of the normal human experience (Kübler-Ross 1969).

However, as medical technology became increasingly advanced, and more individuals had access to medical treatment, a greater number of deaths took place behind curtains and heavy metal doors in medical facilities. The passage of the Burton-Hill Act in 1947 provided federal funds for the construction of hospitals making hospitals more prevalent, and the creation of Medicare and Medicaid in the 1960s and growth in private sector medical insurance enabled Americans to seek medical treatment in hospitals (Sloane 1994). These acts also allowed more patients to die away from home with nearly half of all deaths taking place in the hospital by 1960 (Sloane 1994).

As dying and death became increasingly institutionalized, some argued that in American culture death was becoming a more taboo topic than sex. Geoffrey Gorer (1955) observed that during the twentieth century, there seemed to have been an “unremarked shift in prudery; whereas copulation has become more and more ‘mentionable,’ particularly in the Anglo-Saxon societies, death has become more and more ‘unmentionable’ as a natural process” (p. 50).

Regarding the undesirable aspects of death and decay, Gorer (1955) stated, “The ugly facts are relentlessly hidden; the art of the embalmers is an art of complete denial” (p. 51). Evidence of this denial of death in American society can be seen in a variety of areas, including using euphemisms in which death is replaced with passed on or departed, referring to death as resting
or sleeping, and relying on professionals to treat dying patients, prepare dead bodies for funerals, and bury the dead (Leming and Dickinson 2006).

Even the funeral industry, which is dependent on death for business, presents the embalmed and make-up clad dead in ornate caskets covered with expensive floral arrangements to conceal the inevitable decay the body will experience and give the illusion that the deceased is simply slumbering (Mitford 2000). Mitford (2000) also found that the American funeral industry was able to grossly overcharge their customers because few Americans openly inquired about and compared funeral costs prior to the death of a loved one thus allowing them to be taken advantage of by funeral directors when planning for that loved one’s funeral. Death was transformed from a family or local affair to a sequestered experience handled by highly trained professionals including medical personnel and funeral directors (Kübler-Ross 1969). In these ways the sequestration of death took place not only in the ways individuals perceived and discussed death but also in how large-scale institutions managed death and dying. During death’s sequestration death became rationalized and bureaucratized and in a sense sanitized so that even the very natural process of dying, death and decay became separated from nature (Mellor and Shilling 1993).

The process by which the medical field came to adopt formal rationality and its bureaucratic means of administration was a gradual process. In fact, Weber (1958) implied that medicine was not bureaucratized when he stated that the special examination could also be found outside of bureaucratic structures in the “free professions of medicine and law and in the guild organized trades” (p. 240). Medicine may have been a rather free profession in the past, but this freedom did not last as the profession faced a number of legal reprimands from courts and control by outside parties such as insurance companies and the U. S. Congress. Physicians in the
early twentieth century generally practiced alone or in small group practices, and because specialization was extremely uncommon, most physicians were general practitioners who engaged in a wide array of medical practices (Kaufman 1993). Group practice began to increase after 1910 when physicians started practicing in hospital settings with more frequency and during WWI and WWII when a number of physicians found themselves working together in military field hospitals (Madison and Conrad 1988). Blue Cross and Blue Shield were created in the 1930s enabling a number of Americans to obtain private health insurance to pay for medical treatments (Sloane 1994). Also, the passage of the Burton-Hill Act in the 1940s granted patients increased access to hospitals, and the enactment of the federal Medicare and Medicaid programs in the 1960s increased the government’s oversight role in healthcare and while simultaneously increasing the number of patients who could afford to seek healthcare (Sloane 1994).

One prime example of increased administrative control in healthcare is the adoption of Diagnostic Related Groups (DRGs) by Medicare in 1983. DRGs is a reimbursement program that requires physicians to classify each of their cases into one of 467 groups based on diagnoses that are then linked to specific treatments (Kaufman 2005). Under DRGs, physician activity is restricted by administrators who oversee billing and reimbursements for “products” such as bypass surgeries and transplants, and physicians are rewarded for quickly diagnosing, treating and discharging patients (Kaufman 2005). Over time the power and freedom of physicians have come under a system of checks and balances established by legal rulings, the government (Chapman 1978) and even third party payers like insurance companies (Mechanic 1977).

This growth in turn resulted in drastic changes in the administration of medical facilities. Prior to World War II hospital directors were either physicians or nurses who were experts trained in medical care, but as medical care became increasingly more complex and hospitals
grew in size and employed additional staff including technicians to operate the new technology, the demand for trained, nonmedical professionals to oversee the administration of medical facilities escalated (Sills 1976). Sills (1976) reported that these nonmedical bureaucrats sought to maintain and legitimate their authority by forming coalitions with either physicians or nurses in an attempt to prevent physicians and nurses from forming their own coalitions and jeopardizing the power of administrators. Medical education also changed, slowly evolving from an apprenticeship system to a standardized system where students were trained in hospital clinics (Sloane 1994). Specialization and sub-specialization within medicine grew rapidly (Sloane 1994) with specialists being labeled as experts, possessing vast knowledge in a limited area of health care (Stein 2006).

As medicine underwent the transformation from individual physicians independently performing an array of procedures including delivering babies, pulling teeth and comforting elderly patients near death to physicians operating within a specific area of medicine in a specific facility under the supervision of administrators, insurance companies, and government agencies, medicine became increasingly bureaucratized. The bureaucratization of medicine not only consists of changes in medical policies and practices but also shapes the daily activities of those who practice medicine and the patients receiving medical treatment. Bureaucratic structures in medicine promote detached doctor-patient relationships and rewards physicians who assume larger workloads, serve as managers and researchers and adopt the bureaucratic values of efficiency and calculability (Mechanic 1977).

Inevitably, the bureaucratization of medicine threatens the intimacy that is often needed for doctors and patients to openly discuss the health of the patient as well as personal issues like dying and wishes regarding end-of-life care. Kaufman (2005) interviewed a young physician
who “characterized the first year of her residency in internal medicine as a period of learning to be disciplined by the bureaucracy to be a cog in the system. Patients were merely an epiphenomenon…the objects acted on to ensure the smooth running of the institution” (p. 14).

In fact the very term patient implies the passive role that humans entering into the care of medical professionals are expected to adopt (Chambliss 1996). Norwood (2006) reported how the hospital’s bureaucratic organization compartmentalizes human beings and disease by placing patients with various illnesses in different floors and departments according to their diseases. In hospitals patients are frequently dehumanized in the sense that they no longer have control over their bodies but must surrender their bodies to medicine, which objectifies patients and views their bodies in terms of internal physiology rather than the experiences and emotions of the patient (Norwood 2006). Kaufman (2005) observed that the hospital is a place of well-ordered, bureaucratic logic disconnected from the human emotions that accompany illness and death where professionals strive to navigate patients through a structured system of medical algorithms and professional relations. If patients are objects to be acted on by a host of staff operating within a bureaucratic structure, how much power, if any, does the patient have in relation to this structure?

In his book The Asymmetric Society, Coleman (1982) writes about the creation of corporate actors stating that changes in the thirteenth century made it necessary for the law to consider entities other than natural persons- these entities were corporate actors. Today, hospitals, nursing homes and insurance companies are but a few examples of corporate actors, and the differences between individual and corporate actors contribute to what Coleman (1982) named the “asymmetric society.” These differences include the fact that while individual actors have clear rights and obligations to society, a cloud of ambiguity surrounds the rights and
obligations that corporate actors have to society (Coleman 1982). Also, most often corporate actors have far greater resources, power and control in society than individuals, but the liability of corporate actors is much more limited in comparison to the liability that individuals have for their actions (Coleman 1982). The asymmetry between individuals and corporations has the effect of diminishing the personal responsibility of the medical provider and spreading that responsibility throughout the entire system (Mechanic 1977). Because of this diluted responsibility, patients who are victims of negligence or malpractice must battle the entire bureaucratic structure, equipped with its own team of lawyers, public relations department, and abundance of financial wealth, rather than battling a single practitioner for compensation (Mechanic 1977). Charles Rosenberg, a professor in the history of science at Harvard University, described the hospital as “a technological and bureaucratic brontosaurus with an enormous appetite, an inadequate heart, and a minute social brain” (cited in Sloane 1994: 89). This description of the hospital conjures up images of a small, fragile patient attempting to fight an enormous, powerful dinosaur— the hospital.

While these powerful dinosaurs do treat patients and meet their healthcare needs, medical facilities, such as hospitals have evolved from charitable organizations to businesses in which increasing profits often have priority over the quality of care patients receive (Sloane 1994). In fact, Sloane (1994) reported that newly constructed hospitals are being modeled after shopping malls and emphasize the role of patients as consumers of healthcare. Kaufman (2005) found that finances often controlled many aspects of healthcare, and physicians and nurses felt restrained by the corporate cost-saving practices of the hospitals in which they practiced. For example, the number of nurses employed was reduced, and physicians reported that they felt like “expendable commodities at the service of the bureaucracy and [were] thrust into unwanted negotiations with
hospital administrators and managed care companies about how fast they can discharge patients and how few procedures (and which ones) they can prescribe” (Kaufman 2005: 13). Physicians and nurses also reported that their work was “under constant surveillance by utilization review committees, risk management departments, and those whose job is to watch the bottom line” (Kaufman 2005: 13). Reimbursements from Medicare also greatly influenced the end-of-life care received by elderly patients. For example, to reduce spending nursing homes send patients to hospitals when they are dying to prevent paying for intensive treatment, and in turn hospitals work to stabilize the patients and quickly discharge them to avoid paying for palliative care (Kaufman 2005). This focus on the financial aspects of medical care allows medical facilities to calculate and quantify their success, but undoubtedly it also detracts from the quality of patient care as well as from the relationship between medical staff and patients.

Out-patient surgery is one example of how the desire for efficiency, predictability and calculability has led to McDonaldization in medical practice. Despite the inconveniences associated with recovering from surgery at home, such as lack of medical support during the recovery period, many patients preferred the efficiency, predictability and control they believed out-patient surgery afforded them (Mottram 2011). Out-patient surgery was preferred by patients because it saved time and allowed them to meet the demands of their busy lives (Mottram 2011). Out-patient surgery typically has very rigid timelines allowing patients to feel more in control of their situation because barring any unforeseen complications, it is rather predictable and can be compared to an assembly line in which the patient enters as a raw material and emerges as a completed “healed” product (Mottram 2011). Patients in Mottram’s (2011) study did allude to the irrationalities associated with rationality when they discussed the dehumanizing experiences of feeling like they were on a conveyor belt and being rushed to go
home despite being in physical pain. Out-patient surgery patients felt like their individual needs were not being met by medical staff, but medical staff found out-patient surgery to be efficient because it reduced the need for staff to provide human support to patients following surgery (Mottram 2011). Patients and healthcare providers could simply interact via telephone though this level of contact, while advantageous to healthcare providers desiring to save time, rarely provided patients with adequate support (Mottram 2011).

*Death in a Bureaucratic System*

Kaufman (2005) argues that the bureaucratic nature of healthcare, especially hospitals, plays a significant role in how hospital staff members discuss death and dying and how the dying process is shaped. She states, “The contemporary hospital, with its remarkable tools and complicated ways of organizing health professional’s work and moving patients and families through the system, is on the cutting edge of culture-making. Its systems, techniques, and logic shape the forms of dying that occur there” (Kaufman 2005: 28). In fact, Kaufman (2005) stated that death is usually not discussed by medical staff until the patient is actively dying, and staff members are trained to treat until there is no response to the treatment, at which point death is taking place. Kaufman (2005) contrasts this current treatment of death to that of the 1960s in which, again, death was not readily discussed but patients were allowed to linger in the hospital receiving comfort care for weeks or even months while they died. Several days before the actual death would take place, nurses would usually identify that the patient was near death and would institute a deathwatch placing the patient under increased supervision and shielding the family from the more unpleasant aspects of the dying process (Kaufman 2005).

The driving forces behind the current treatment of death, according to Kaufman (2005), involve administrative and technological advances. Diagnostic Related Groups (DRGs) require
medical staff to diagnose patients and then administer the appropriate treatments based on their diagnoses, and dying patients must receive a diagnosis and treatment since dying is not billable (Kaufman 2005). Quantitative laboratory reports and output from machines are relied upon more heavily by medical staff than holistic observations of the patient, and this advanced technology can more accurately pinpoint when treatments are no longer working and the body is succumbing to death at which point treatments are stopped and an abbreviated deathwatch consisting of hours rather than days is instituted (Kaufman 2005). In a study of nursing homes, Oliver, Porock, and Oliver (2006) found that long-term care is heavily guided by state regulations that require long-term care facilities to focus on rehabilitation, maintenance, and prevention. Rather than placing an emphasis on quality end-of-life care in which the patient, his or her family, and staff members are allowed to openly discuss the patient’s wishes regarding the dying process, state regulations push dying into the background (Oliver et al. 2006).

An ever-increasing number of nonhuman technologies can be implemented to control the dying process and prolong life. These technologies include the introduction of the mechanical ventilator and open heart surgery in the 1950s and kidney dialysis, cardiopulmonary resuscitation (CPR), bypass surgery, and radiation and chemotherapy in the 1960s (King 1996). Computer systems are now being used to calculate a patient’s chances of survival, and the results from the computer program in turn influence how medical staff treats the patient (Ritzer 2004). Improved medical technology has allowed the creation of long-term care wards dedicated to the care of comatose patients on respirators who linger in a “gray zone” suspended between life and death for months and even years (Kaufman 2005). These technological advances can increase the quantity of a patient’s life without necessarily improving the life’s quality, and one can argue that this is a prime example of the irrationality of rationality (Ritzer 2004). Also, while medical
personnel seem to have greater control over death, bureaucratic processes and nonhuman technologies exert greater control over the medical personnel who treat dying patients (Kaufman 2005). Often, those with the least control over medical care are the patients themselves, but advance directives, which allow patients to state their preferences regarding the use of certain medical procedures at the end of one’s life, may allow patients to regain some control over their end-of-life care (Ritzer 2004).

*Advance Directives- Cure for Bureaucracy or Bureaucratic Cure?*

Advance directives can be used to guide medical care at the end of one’s life, but King (1996) argues that the effectiveness of advance directives is often “countered by bureaucratic safeguards” (p. 111). As discussed in the previous chapter, the Patient Self-Determination Act (PSDA) was created with the purpose of increasing the public’s awareness and use of advance directives. While the PSDA sought an administratively simple means of fulfilling its purpose, health care institutions that were required under the PSDA to provide patients with information about advance directives have bureaucratized the process (King 1996).

Shortly after the passage of the PSDA, the Health Care Financing Administration published its “interim final rule” on the PSDA in early 1992, and while this rule basically echoed what was said in the PSDA, its lengthy preamble emphasized the freedom given to health care facilities in defining their own policies and practices under the PSDA (Sabatino 1993). For example, providers are not given specifics regarding how they should inquire if patients have advance directives (ADs) or how they should document patients’ ADs, and even though the PSDA requires facilities to provide community education, it does not provide any examples of what this education might entail (Sabatino 1993). Also, while the PSDA prohibits discrimination of patients on the basis of their possession of ADs, a major goal of the Act is to promote the
completion of ADs. However, many providers incorrectly interpret the PSDA’s discrimination policy as a mandate to remain neutral and not encourage patients to exercise their rights by completing ADs (Sabatino 1993). Legislators who created the PSDA may have been purposefully vague in their instructions because they believed the health care providers were in the best position to develop specific instructions pertaining to the PSDA, but health care providers, who must operate under State and federal regulation, including the PSDA, felt they needed more detailed instructions from the act’s creators to ensure they were in full compliance (Sabatino 1993). Sabatino (1993) believes that the PSDA has not achieved its fullest potential because, “The regulatory process seldom if ever generates enthusiasm or a sense of collaboration and exploration among those regulated. Too often it generates defensive attitudes and minimal, mechanistic compliance” (p. 16).

It is unlikely that ADs are doomed simply because they were created and carried out within highly regulated and bureaucratized environments, but the odds do seem stacked against ADs. The sequestration of death has attempted to remove the issue of death and dying from daily life by placing it within the confines of modern medicine, which is highly technical, rationalized, bureaucratized and professionalized (Mellor and Shilling 1993; Giddens 1991). Advances in modern medicine have given individuals greater choices regarding their end-of-life (EOL) care and treatment, but modernity has eroded the traditions and moral frameworks that once guided such choices making EOL care decisions particularly difficult for many. ADs force individuals to ponder the unpleasant topic of their own death, and they often require people to discuss their EOL care decisions with loved ones who may not wish to be reminded of death. ADs require people to make decisions regarding their EOL care despite the fact that many people are not experts within the complex, technical and specialized world of EOL medical care and few
people have first-hand experience with death. ADs are regulated by lawmakers and very often administered by staff within highly bureaucratized medical facilities. These very personal documents can become cold and impersonal when handled in such a manner, and EOL medical care can become cold and impersonal when provided by highly rational, technical and bureaucratic medical institutions. Under these circumstances it is not surprising that AD completion rates hover around 20% (i.e. Salmond and David 2005). The current study attempt to better understand the attitudes people inside and outside of the medical community harbor toward advance directives and to identify factors that influence advance directive completion rates.
HYPOTHESES AND RESEARCH QUESTIONS

Quantitative Hypotheses

The current study consisted of both quantitative and a qualitative inquiries. Based on the findings of the studies discussed above, the researcher developed five hypotheses to be tested in the quantitative portion of the current study. The hypotheses were tested using data obtained from a self-administered survey packet (see Appendix A).

It was hypothesized that:

1. **Participants with higher levels of education will have higher advance directive (AD) completion rates than participants with lower levels of education.**

   Previous studies obtained similar findings (i.e. Duke, et al. 2007), and though an explanation behind these findings was not provided by the previous studies found by the researcher, the researcher speculated that the positive correlation between education and AD completion was due to several factors. The sequestration of death makes AD completion challenging because information regarding ADs and end-of-life (EOL) care is not widely discussed among the general population, most medical professionals are not adequately educated regarding ADs and EOL care issues, and to complete a legitimate AD that will be recognized by a medical facility, individuals often have some knowledge of and experience with legal and bureaucratic processes. The researcher believed that those with higher levels of education may be more likely to research ADs making them more familiar their EOL care choices, be more comfortable broaching the topic of ADs with medical and legal professionals, and may have more experience with legal and bureaucratic processes. Higher levels of education have also been correlated with higher income (i.e. Marra, Lynd, Harvard, and Grubisic 2011), and those
with higher incomes often have greater access to healthcare and attorneys, both of which are popular avenues to AD completion.

2. **Older participants will have higher advance directive completion rates than younger participants.**

   A number of other researchers (i.e. Teno, et al. 2007; Orlander 1999), reported that older adults were more likely to complete ADs. Orlander (1999) found that as people aged they felt more vulnerable to health risks, and this sense of vulnerability was caused by their personal experiences or the experiences of those around them. This sense of vulnerability motivated people to complete ADs (Orlander 1999). Older adults may have more experience with healthcare situations in which they are asked about ADs increasing their opportunities to complete ADs (Douglas and Brown 2002). Experience with the deaths of loved ones and cohorts generally increases with age, and the researcher speculated that exposure to death tends to pull death out of sequestration and force people to consider death in general as well as their own mortality. Such exposure to death may also be another motivating factor for AD completion.

3. **Participants with poorer health will be more likely to have ADs than participants in good health.**

   The variable of health status was believed to be similar to the variable of age for several reasons. First, those in poorer health may feel more vulnerable to health risks, and their poor health may have forced them to consider and plan for their own death thus forcing death out of sequestration. People who are functionally dependent due to medical problems were more likely to have ADs due to increased exposure to medical situations in which they were asked about ADs, and their health status may make them more accepting of their inevitable death and
motivate them to create directives to avoid placing unnecessary burdens on loved ones (Duke, et al. 2007). Similar to age, people with poor health may pull death out of sequestration and encourage serious contemplation of death, and similar to the variable of education level, the increased exposure to the increasingly bureaucratic healthcare system that generally accompanies poor health may also increase comfort and familiarity with the bureaucratic process of obtaining and completing ADs.

4. **Participants with more favorable attitudes toward death will be more likely to have completed advance directives than participants with more negative attitudes.**

The researcher speculated that people who possess negative attitudes toward death will be more likely to avoid considering and preparing for their own deaths. Modernist theorists, such as Mellor and Shilling (1994) and Giddens (1991), argue that death is sequestered in modern American culture in order to protect humanity’s sense of ontological security making the reality of death easier to deny today. Death is indeed an unpleasant and threatening reality that is frequently hidden, but attitudes toward death vary greatly among individuals (Lester 1991). The researcher believed that people who have negative attitudes toward death may wish to avoid thoughts of death, particularly their own death, and will avoid making preparations for their own deaths, such as completing ADs. Similarly, the researcher speculated that participants who have more positive attitudes toward death will be more likely to contemplate their own death and be more willing to complete ADs. It is believed that the current atmosphere of death denial in American culture facilitates the avoidance of end-of-life care preparation, but other factors, which the researcher will explore in the qualitative chapter, may actually encourage AD completion.
5. Participants with more positive attitudes toward advance directives will have higher AD completion rates than participants with more negative attitudes toward advance directives.

The researcher believed that participants with positive attitudes toward advance directives would be more likely to actively seek and complete ADs. Nolan and Bruder (1997) found that patients with negative perceptions of ADs often feared that ADs would be misused to deny them treatment that could save their lives, and this negative perception stemmed from a lack of knowledge of medical choices that would be available to them. Racial and ethnic minorities were also more likely to distrust the healthcare system and to report negative attitudes toward ADs, including fears that their ADs would be used to deny them desired treatment, and they were less likely to complete ADs (Baker 2002). Also, Douglas and Brown (2002) reported that people with negative attitudes toward end-of-life care planning were 90% less likely to have ADs. People who hold positive attitudes toward ADs were more likely to believe that ADs would afford them the opportunity to express their EOL care wishes, provide their family and physician with guidance in EOL care decision-making, and reduce financial burden for loved ones (Nolan and Bruder 1997). Because of these previous findings, the researcher believed that participants with negative attitudes toward ADs would avoid obtaining ADs while those with positive attitudes toward ADs would be more likely to complete ADs.

Qualitative Research Questions

To obtain a more in-depth understanding of advance directives, a qualitative study was conducted in conjunction with the quantitative study mentioned above. A list of interview questions were used during the interviews (see Appendix B), and these interview questions were guided by the following five research questions:
1. What attitudes do community members possess regarding advance directives? What factors influence these attitudes?

2. How do professionals who work with advance directives (i.e. nurses, physicians, social workers, lawyers) view their roles?

3. What do people perceive to be factors that encourage advance directive completion?

4. What do people perceive to be barriers to advance directive completion?

5. What can be done in this community to improve knowledge and communication about advance directives?

The modernist theoretical concept of sequestration of death within the medical field as well as the domestication of death served as the lenses through which the data were examined. At times during the interviews, the topic of death denial, the bureaucratization and professionalization of medicine and how these factors impact end-of-life care issues like advance directives was openly addressed, especially by medical professionals. However, in the vast majority of cases, these theoretical issues lurked quietly under the surface. While many participants provided evidence of death sequestration, they also reported having personal experiences with death, talking about death with family members, and discussing their end-of-life care wishes with loved ones. The quantitative and qualitative chapters that follow reveal the findings in detail.
Chapter 3: Methodology

Primary data were collected to test the hypotheses and answer the research questions. The quantitative data were gathered using a self-administered survey packet. The quantitative data were analyzed using the MicroCase statistical program. It also contained an Interview Willingness Form which, combined with purposive and snowball sampling, was used to recruit participants for the qualitative portion of the study. The qualitative data consisted of in-depth interviews regarding issues pertaining to advance directives. The interviews were tape recorded, transcribed and analyzed. Appendix A contains the items given to those who participated in the quantitative portion of the study, and Appendix B contains the informed consent letters given to interview participants as well as lists of the approximate questions asked to interview participants.

QUANTITATIVE RESEARCH

Materials

Socio-demographic data were obtained through the brief socio-demographic questionnaire (see Appendix A). This questionnaire asked participants to indicate their age (numerical age in years), sex (select from the choices “Male” or “Female”), race/ethnicity (select from the choices “African American,” “Caucasian,” “Hispanic,” “Multiracial,” or “Other,” and participants selecting “Other” were asked to write their race/ethnicity). Participants were also asked to rate their level of health and were given the options of “Excellent,” “Good,” “Fair,” and “Poor,” and to indicate their highest level of education completed from a list consisting of the options (1) “Below High School,” (2) “High School,” (3) “Some College,” (4) “Associate’s Degree,” (5) “Bachelor’s Degree,” (6) “Master’s Degree,” and (7) “Doctorate.” Participants
were also asked if they had advance directives and were given the options “Yes,” “No,” and “Don’t Know.” If participants indicated that they had advance directives, they were then asked to indicate through which agency, if any, they completed their advance directives. Participants could select from a list consisting of (1) “Primary health care provider,” (2) “Hospital,” (3) “Hospice,” (4) “Lawyer,” (5) “On my own with help from no agency,” and (6) “Other.” Participants selecting “Other” were asked to write the agency they used to complete their advance directives. Finally, participants were asked if they considered themselves to be from the Appalachian region. The researcher initially believed there would be differences regarding advance directives between participants from the Appalachian region and those from outside of the region, but no significant regional differences were found in the quantitative portion of the study.

Several variables in the socio-demographic questionnaire were collapsed during the analysis of the quantitative data. Health, which was measured using the 4 categories “Excellent,” “Good,” “Fair,” and “Poor,” and labeled as variable Health1 was collapsed due to the small number of participants with fair health. “Excellent” and “Good” health were collapsed into one category labeled “Good” while “Fair” and “Poor” health were collapsed into one category named “Poor” creating a second health variable Health2. Education, which contained the 7 categories (1) “Below High School,” (2) “High School,” (3) “Some College,” (4) “Associate’s Degree,” (5) “Bachelor’s Degree,” (6) “Master’s Degree,” and (7) “Doctorate” and labeled Education1, was collapsed to reduce the large number of cells with frequencies under 5 during a chi-square test. This new variable, which was labeled Education2, was created when the “Below High School” and “High School” categories were collapsed to create a single category labeled “High School,” and the categories “Some College” and “Associate’s Degree”
were collapsed to create a new category named “Some College.” Thus the new \textit{Education2} variable contained the 5 categories (1) “High School,” (2) “Some College,” (3) “Bachelor’s Degree,” (4) “Master’s Degree,” and (5) “Doctorate.” The variable \textit{AD status} was also modified with the “No” and “Don’t Know” categories being collapsed into a single “No” category making the AD status variable dichotomous. This was done because participants who did not know if they had ADs most likely did not have them and were not familiar enough with the term to accurately report their own AD status.

To measure the participants’ attitudes toward death, the Lester Attitude Toward Death Scale (LATDS) was used (see Appendix A). The LATDS is a Thurstone-type scale consisting of 21 items to which the respondents were asked to select “Agree” or “Disagree.” Statements regarding attitudes toward death were scaled on an equal interval scale ranging from 1 (most favorable) to 11 (least favorable) based on judges’ ratings that indicated the degree of favorability toward death (Lester 1991). The judges’ scale values for each item were provided by Lester, and as the LATDS scale progresses (moves from items 1 to 21), the items become increasingly more negative toward death. To illustrate this, the statements ranged from “What we call death is only the birth of the soul into a new and delightful life” (Item 1; value =1.29) to “Death is the worst thing that could possibly happen to me” (Item 21; value = 10.76) (Lester 1991). When participants answered “Agree” for an item, they were given the numerical scale value created by the judges while an answer of “Disagree” received a score of zero, and the scores for the 21 items were totaled to create an overall LATDS score. The range of possible scores for this scale was zero to 131.78 with higher scores indicating a more negative attitude toward death.
The LATDS was tested for test-retest reliability and concurrent validity. Lester obtained a Spearman rank order correlation of 0.70 for the attitude toward death score from a sample of eighty students given the LATDS six weeks apart, which indicated a relatively strong test-retest validity (Lester 1991). Also, when tested for concurrent validity, the researcher found that the LATDS was a valid measure of the fear of death in general as well as fear of one’s own death (Lester 1991). The masculine wording that was originally used in items 9, 14, 18 and 19 were changed to gender neutral wording for the purpose of this study. For example, the words “man” or “men” in the original survey were changed to “person” or “people” in the current survey thus changing Item 9, which states, “Death makes all men equal,” in the original scale, to “Death makes all people equal,” in the current scale. The only other alteration to the LATDS made by the researcher in the current study was to enlarge the font and place the questions and possible responses (“Agree” or “Disagree”) in a table format with rows and columns in order to make the scale more user friendly.

The Advance Directive Attitude Survey (ADAS) was developed by Nolan and Bruder (1997) to measure patient’s attitudes toward advance directives (see Appendix A). The survey contains 17 items and uses a four-point Likert scale to determine the extent to which respondents view advance directives as positive or negative. The possible responses included (1) “Strongly Disagree”), (2) “Disagree”, (3) “Agree,” and (4) “Strongly Agree,” and the point values for these responses ranged from 1 to 4 with “Strongly Disagree” being given 1 point and “Strongly Agree” having the value of 4 points. Higher scores were associated with a more positive attitude toward advance directives (Nolan and Bruder 1997). Thirteen items were positively worded (i.e. “My family wants me to have an AD”), but items 7, 9, 13, and 16 negatively worded (i.e. “I am not old enough to have an AD”) and were reversed scored (Nolan and Bruder 1997). The survey
covers four subject areas that include 1) opportunity for treatment choices, 2) impact of advance directives on families, 3) effect of an advance directive on treatment, and 4) perception of illness (Nolan and Bruder 1997). The possible scores for this survey range from 17 to 68, and Nolan and Bruder (1997) reported that their newly-designed ADAS had a coefficient alpha of 0.74, which is above the 0.70 coefficient that is considered adequate for new scales. The researcher contacted Dr. Nolan to obtain a copy of the ADAS, and this survey was used by the researcher with Dr. Nolan’s permission.

Finally, an Interview Willingness Form was used to recruit interview participants for the qualitative portion of this study (see Appendix A). This form stated “To obtain more in depth information regarding the survey items you just completed, I would like to conduct interviews with interested participants.” Participants who checked “Yes” to indicate their willingness to participate in an interview were asked to provide their telephone number and/or e-mail address so the researcher could contact the participants to schedule an interview. They were also asked to indicate a preferred time of day to be called by the researcher if they did not use e-mail. The Interview Willingness Form also reminded participants that they had the right to withdraw their participation in the interview at any time.

Sample

Survey participants were recruited from seven sociology classes at the local university, at the local senior citizen center, a local once-monthly senior citizen’s gathering, and two local churches. Nearly one third of the participants were recruited from introductory sociology classes at the local university. The researcher chose the introductory to sociology classes because these classes usually contain students from a variety of academic majors and diverse backgrounds. The two local senior groups consisted of senior citizens who were retired and mobile, and the
majority of these seniors were female and Caucasian. The two local churches represented two popular mainline Protestant denominations.

In each case, the researcher first obtained permission to administer the surveys and then attended the gathering (i.e. class, senior meeting, or worship service) where she explained the study, distributed the materials to interested participants and then collected the completed materials. In the classroom, it was explained both verbally and in the informed consent letter (see Appendix A) that participating in the study would not affect the students’ grades, and professors were encouraged to leave the room during the time that the surveys were being completed. In five of the seven classes surveyed, the professors stepped out of the room while the surveys were being distributed, completed, and returned.

Prior to administering the surveys, a consent form was given to each of the participants (see Appendix A). In the consent form the participants were told that their participation was voluntary and they could discontinue their participation in the study at any time. Participants were also told that their responses would be kept confidential and anonymous. The participants were given a copy of the consent form labeled “Participant Copy” to keep, which included the researcher’s contact information in the event that participants had questions or concerns regarding the study. The researcher also collected an identical copy of the consent form labeled “Researcher Copy” containing the participant’s signature.

Each survey packet distributed to the participants included the “Participant Copy” and “Researcher Copy” of the consent form, a demographic questionnaire, the Lester Attitude Toward Death Scale (LATDS) and the Advance Directive Attitude Survey (ADAS), and the Interview Willingness Form (see Appendix A). To avoid any possible ordering effects, the order of the LATDS and the ADAS was alternated in the survey packs so the LATDS preceded the
ADAS in every other survey pack created by the researcher. The socio-demographic questionnaire, LATDS and ADAS were stapled together to create a survey packet. Finally, an unattached Interview Willingness Form was given to participants. In the early stages of data collection, the researcher used a 12-point font to type the documents distributed to the participants, but after receiving feedback from a church congregation where a large number of older participants were present, the researcher developed large-print versions of each of the documents included in the pack. From that point on, all items distributed to participants were the large-print versions.

Participants were not given a specific amount of time in which to complete the surveys and were told to work at a pace that was comfortable for them. On average, participants took five to ten minutes to complete the survey packets. The items in the survey packet were printed on paper and answered using a pencil or pen. When participants had questions about the meaning of specific survey items, the researcher attempted to clarify the item. Participants who expressed difficulty responding to items were encouraged to select the most appropriate response, and the researcher encouraged participants to include written explanations beside any survey items that the participants had difficulty answering. Once the participants completed the surveys, the researcher collected the consent forms, survey packs, and Interview Willingness Forms, which were placed in three separate envelopes that were labeled accordingly. Envelopes were used to separate the consent forms and Interview Willingness Forms, which contained the names of participants, from the surveys in an attempt to maintain anonymity.

Once participants had turned in their consent forms, surveys, and Interview Willingness Forms, they were offered a document containing information on advance directives and contact information for grief counseling programs available in the area (see Appendix A). Receipt of this
informative document was not contingent upon completing the survey. The researcher offered it to any member of the group from which the researcher recruited (i.e. classroom, senior citizen meeting, church) that expressed interest regardless of their completion of the survey.

Sample Characteristics

A total of 204 participants signed and returned their informed consent letters to the researcher. However, seven surveys contained missing data and were therefore excluded from the study resulting in an actual total of 197 completed surveys. The survey sample of 197 participants was predominately young, Caucasian and female as shown in Tables 1, 2 and 3 below. Although age ranged from 18 to 86, age was concentrated near the younger end of this range with the mean age being 34 and the median age being 22 years (a total of 39 participants reported being 19 years of age) with a standard deviation of 20.95 years (see Table 3). The concentration of ages near the younger end of the range may be due in part to the sampling that was done in college classrooms. It was more difficult to find large groups of older adults than large groups of young adults. Nearly twice as many females participated in the study than males with a total of 134 (68%) females and 63 (32%) males completing the survey.

As shown in Table 2, the vast majority (93.4%) of participants was Caucasian, six were African American, and one was Hispanic. Two participants selected the multi-racial option. Four participants selected the Other category listing their race/ethnicity as being Appalachian (N = 1), Native American (N = 1), Persian American (N = 1), and Scots-Irish-German American Indian (N = 1) (see Table 3). According to the 2010 Census data, the county in which the study took place was 96.2% Caucasian, 1.8% African American, and 1.4% Hispanic, and persons reporting they were multiracial were 1.0% (U. S. Census Bureau n.d.). Therefore, the racial/ethnic makeup of the study sample was predominately Caucasian and was similar to the
county’s recent Census racial profile. Because the demographic questionnaire did not capture much racial/ethnic diversity, race was not used as an independent variable.

Table 1. Sex of Participants

<table>
<thead>
<tr>
<th>Sex</th>
<th>f</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>134</td>
<td>68</td>
</tr>
<tr>
<td>Male</td>
<td>63</td>
<td>32</td>
</tr>
<tr>
<td>Total</td>
<td>197</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 2. Race/Ethnicity of Participants

<table>
<thead>
<tr>
<th>Race</th>
<th>f</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>184</td>
<td>93.4</td>
</tr>
<tr>
<td>African American</td>
<td>6</td>
<td>3.0</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>0.5</td>
</tr>
<tr>
<td>Multi-Racial</td>
<td>2</td>
<td>1.0</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>2.0</td>
</tr>
<tr>
<td>Total</td>
<td>197</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 3. Age Distribution of Participants

<table>
<thead>
<tr>
<th>Age (in years)</th>
<th>f</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>117</td>
<td>59.4</td>
</tr>
<tr>
<td>25-34</td>
<td>18</td>
<td>9.1</td>
</tr>
<tr>
<td>35-44</td>
<td>9</td>
<td>4.6</td>
</tr>
<tr>
<td>45-54</td>
<td>8</td>
<td>4.1</td>
</tr>
<tr>
<td>55-64</td>
<td>12</td>
<td>6.1</td>
</tr>
<tr>
<td>65-74</td>
<td>23</td>
<td>11.7</td>
</tr>
<tr>
<td>75-94</td>
<td>10</td>
<td>5.1</td>
</tr>
<tr>
<td>Total</td>
<td>197</td>
<td>100</td>
</tr>
</tbody>
</table>
QUALITATIVE RESEARCH

To develop a more thorough understanding of factors influencing living will completion, the researcher also devised a qualitative portion of the study in which interviews were conducted. Interview participants were recruited using two methods. “Community members” were recruited via the Interview Willingness Form, and “professionals” were invited to participate in an interview based on their profession. The terms “community member” and “professional” are simply used here to distinguish between those whose professions involve end-of-life care issues (the professionals) and those whose professions do not (the community members). Most of the professionals interviewed were members of the community in which the study took place, and most of the community members were professionals in some other field unrelated to the topic under study or were students at the local university. Pseudonyms were given to all of the interview participants in an attempt to protect their identity and create a more conducive environment for sharing personal and potentially sensitive information. All interview participants were notified of this in their informed consent letter and verbally by the researcher prior to beginning the interview.

First, community members were recruited using the Interview Willingness Form that was administered to all survey participants. Participants who indicated their interest in an interview were contacted by the researcher, and interviews were scheduled with participants who continued to express their desire to participate in an interview. A total of 43 participants indicated their interest in taking part in an interview by submitting Interview Willingness Forms. Seven of the 43 participants who completed and submitted the Interview Willingness Form to the researcher initially agreed to an interview via email or telephone but subsequently failed to participate in the interview. Five of these participants were unable to participate due to
scheduling problems while the remaining two did not offer an explanation. Fifteen of these 43 participants did not respond to the researcher’s follow-up emails or calls or did not provide the researcher with working phone numbers or e-mail addresses thus preventing the researcher from contacting them. In sum, 21 participants recruited via the quantitative portion of the study were actually interviewed (see Table 4 for a summary of interview participants).

Secondly, a combination of purposive and snowball sampling was used to obtain interviews with local physicians, nurses, lawyers, social workers and other professionals who have experience with end-of-life care planning resulting in 18 additional participants. The researcher obtained the names of potential professional interview participants via discussions with her thesis committee and the Institutional Review Board chair at the local hospital, and the researcher also used her status as a hospice volunteer to gain access to professionals in hospice and palliative care. The researcher also asked professionals who had participated in the survey if they would like to recommend another professional whom they believed would be a valuable source for the current study. This use of snowball sampling provided several participants from the medical and social work fields. The researcher focused on recruiting professionals who were likely to have knowledge and experience with advance directives and end-of-life care.

Three physicians (one hospice physician, one palliative care physician, and one internal medicine hospitalist) were interviewed. Two physician assistants, one with a background in geriatrics and one with a background in nephrology were interviewed. Seven medical social workers were also interviewed. Two of these seven social workers worked for the local hospice, one was a palliative care social worker, one was the social service director at a local nursing home, one was the director of social work at the local hospital, and two social workers worked for a large hospital located in north eastern Kentucky. Three lawyers, one of whom worked for
the local county attorney’s office, were interviewed, and one professor in the physician assistant program at a large Kentucky university was interviewed. Overall, five nurses were interviewed. However, one Intensive Care Unit (ICU) nurse and one palliative care nurse were purposely recruited because of their occupational backgrounds while three other nurses (one oncology unit nurse, and two university students with backgrounds in nursing) were recruited via the Interview Willingness Form that was part of the survey. The researcher did not know these participants were nurses when they were recruited but asked questions pertaining to their nursing background during the interview after learning about their nursing experience. These latter nurses were counted among those recruited via the Interview Willingness Form.

Table 4. Name, Status, Recruitment Method, AD Status, Sex, Age/Years of Experience of Interview Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Interview Status</th>
<th>Recruitment Method</th>
<th>AD?</th>
<th>Sex</th>
<th>Age/ Yrs Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Greg</td>
<td>Attorney</td>
<td>Contacted by Researcher</td>
<td>M</td>
<td>36 yrs experience</td>
<td></td>
</tr>
<tr>
<td>2 Steven</td>
<td>Attorney</td>
<td>Contacted by Researcher</td>
<td>M</td>
<td>20 yrs experience</td>
<td></td>
</tr>
<tr>
<td>3 Adam</td>
<td>Attorney</td>
<td>Contacted by Researcher</td>
<td>M</td>
<td>10 yrs experience</td>
<td></td>
</tr>
<tr>
<td>4 Dr. Campbell</td>
<td>Physician (Internal Medicine)</td>
<td>Referred by a physician</td>
<td>M</td>
<td>16 yrs experience</td>
<td></td>
</tr>
<tr>
<td>5 Dr. Thompson</td>
<td>Physician (Palliative Care)</td>
<td>Referred by hospice social workers</td>
<td>F</td>
<td>23 yrs experience</td>
<td></td>
</tr>
<tr>
<td>6 Dr. Friedman</td>
<td>Physician (Hospice)</td>
<td>Referred by Dr. Thompson</td>
<td>M</td>
<td>48 yrs experience</td>
<td></td>
</tr>
<tr>
<td>7 Joan</td>
<td>Nurse (Oncology Ward)</td>
<td>Survey- Church</td>
<td>No</td>
<td>F 55 yrs old /31 yrs experience</td>
<td></td>
</tr>
<tr>
<td>8 Laura</td>
<td>Former Nurse</td>
<td>Survey- Class</td>
<td>Yes</td>
<td>F 43 yrs old/ 21 yrs experience</td>
<td></td>
</tr>
<tr>
<td>9 Leslie</td>
<td>Nursing Student</td>
<td>Survey-Class</td>
<td>Yes</td>
<td>F 24 yrs old/ 5 yrs experience</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Name</td>
<td>Occupation</td>
<td>Contacted by</td>
<td>Gender</td>
<td>Age</td>
</tr>
<tr>
<td>---</td>
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<td>-------------------------------</td>
<td>------------------------</td>
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<td>-------</td>
</tr>
<tr>
<td>10</td>
<td>Clare</td>
<td>Nurse (ICU)</td>
<td>Researcher</td>
<td>F</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Molly</td>
<td>Nurse (Palliative Care)</td>
<td>Researcher, Dr. Thompson</td>
<td>F</td>
<td>41 yrs experience</td>
</tr>
<tr>
<td>12</td>
<td>Judith*</td>
<td>Hospice Social Worker</td>
<td>Researcher</td>
<td>F</td>
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<tr>
<td>13</td>
<td>Linda*</td>
<td>Hospice Social Worker</td>
<td>Researcher</td>
<td>F</td>
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<td>14</td>
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<td>Molly</td>
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<td>Robert</td>
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</tr>
<tr>
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<td>Charlie</td>
<td>Hospital Social Worker</td>
<td>Greg</td>
<td>M</td>
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<tr>
<td>17</td>
<td>Tina*</td>
<td>Hospital Social Worker</td>
<td>Professor</td>
<td>F</td>
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<tr>
<td>18</td>
<td>Mindy*</td>
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<td>Professor</td>
<td>F</td>
<td></td>
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<tr>
<td>19</td>
<td>Janet*</td>
<td>Physician Assistant (nephrology)</td>
<td>Professor</td>
<td>F</td>
<td></td>
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<tr>
<td>20</td>
<td>Andrew*</td>
<td>Physician Assistant (gerontology)</td>
<td>Professor</td>
<td>M</td>
<td></td>
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<tr>
<td>21</td>
<td>Ruth</td>
<td>Physician Assistant Professor</td>
<td>Janet and Andrew</td>
<td>F</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Rachel</td>
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<td>Survey- Class</td>
<td>No</td>
<td>F</td>
</tr>
<tr>
<td>23</td>
<td>Michael</td>
<td>Community member- Student</td>
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</tr>
<tr>
<td>24</td>
<td>Daniel</td>
<td>Community Member- Student</td>
<td>Survey-Class</td>
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<td>M</td>
</tr>
<tr>
<td>25</td>
<td>Scott</td>
<td>Community Member- Student</td>
<td>Survey-Class</td>
<td>No</td>
<td>M</td>
</tr>
<tr>
<td>26</td>
<td>Alex</td>
<td>Community Member- Bank Teller</td>
<td>Survey-Church</td>
<td>No</td>
<td>M</td>
</tr>
<tr>
<td>27</td>
<td>Theresa</td>
<td>Community Member- Retired Food Service Worker</td>
<td>Survey-Church</td>
<td>No</td>
<td>F</td>
</tr>
<tr>
<td>28</td>
<td>Susan</td>
<td>Community Member- Retired therapist</td>
<td>Survey-Church</td>
<td>No</td>
<td>F</td>
</tr>
<tr>
<td>No.</td>
<td>Name</td>
<td>Occupation</td>
<td>Survey Location</td>
<td>Participated</td>
<td>Gender</td>
</tr>
<tr>
<td>-----</td>
<td>---------</td>
<td>-------------------------------------</td>
<td>-----------------</td>
<td>-------------</td>
<td>--------</td>
</tr>
<tr>
<td>29</td>
<td>Deb</td>
<td>Community Member- Retired Administrative Assistant</td>
<td>Survey-Church</td>
<td>Yes</td>
<td>F</td>
</tr>
<tr>
<td>30</td>
<td>Amanda</td>
<td>Community Member- Administrator</td>
<td>Survey-Church</td>
<td>Yes</td>
<td>F</td>
</tr>
<tr>
<td>31</td>
<td>Georgia</td>
<td>Community Member- Professor</td>
<td>Survey-Church</td>
<td>Yes</td>
<td>F</td>
</tr>
<tr>
<td>32</td>
<td>Helen</td>
<td>Community Member- Retired (former EMT)</td>
<td>Survey-Church</td>
<td>Yes</td>
<td>F</td>
</tr>
<tr>
<td>33</td>
<td>Donald</td>
<td>Community Member- Retired Professor</td>
<td>Survey-Church</td>
<td>Yes</td>
<td>M</td>
</tr>
<tr>
<td>34</td>
<td>George</td>
<td>Community Member- Retired Professor</td>
<td>Survey-Church</td>
<td>Yes</td>
<td>M</td>
</tr>
<tr>
<td>35</td>
<td>Barbara</td>
<td>Community Member- Retired Teacher</td>
<td>Survey-Church</td>
<td>Yes</td>
<td>F</td>
</tr>
<tr>
<td>36</td>
<td>Shirley</td>
<td>Community Member- Retired (former EMT)</td>
<td>Survey-Church</td>
<td>Yes</td>
<td>F</td>
</tr>
<tr>
<td>37</td>
<td>Duncan*</td>
<td>Community Member- Retired Radiology Tech</td>
<td>Survey-Senior Center</td>
<td>Yes</td>
<td>M</td>
</tr>
<tr>
<td>38</td>
<td>Emogene*</td>
<td>Community Member- Retired Teacher</td>
<td>Survey-Senior Center</td>
<td>Yes</td>
<td>F</td>
</tr>
<tr>
<td>39</td>
<td>Daisy</td>
<td>Community Member- Retired Teacher</td>
<td>Survey-Monthly Senior Group</td>
<td>Yes</td>
<td>F</td>
</tr>
</tbody>
</table>

*The following participants were interviewed as pairs:

1. Judith and Linda
2. Tina and Mindy
3. Janet and Andrew
4. Duncan and Emogene

Three community member participants recruited using the Interview Willingness Form indicated that they had medical backgrounds during the course of the interview. Two of these
participants had served as Emergency Medical Technicians (EMTs) and another participant had worked as a radiology technician. They were retired and were interviewed using the same types of questions asked to non-professional community members. These participants claimed that their medical backgrounds influenced their personal attitudes toward death and end-of-life care.

Methods

Before engaging in the interview, participants were given two consent forms containing identical information (see Appendix B). One consent form was labeled “Researcher Copy,” which was collected by the researcher, and the second consent form was labeled “Participant Copy” and was given to the participants to keep. Both copies of the informed consent letter included the telephone numbers for the researcher, the chair of the researcher’s thesis committee, and the local hospital’s Institutional Review Board, and participants were encouraged to call any of these numbers if they had additional questions or concerns about the study. The informed consent letter also contained a line asking participants if they wanted to review the researcher’s write up of their interview to ensure its accuracy though only three participants wished to do so. Participants were told that their involvement in the interviews was voluntary, and they could end the interviews at any time.

The researcher employed several measures to protect the interview participants. Each participant was given a pseudonym in order to protect his or her identity. The participant’s actual name was not linked in any way to the participants’ transcribed interviews, and the tapes containing the interviews were labeled using the pseudonym. Pseudonyms were also used to refer to any other people (i.e. physicians, professors, family members, etc.) referenced during the interview, and the names of certain communities or states were changed when the information could potentially be used to identify the participant. The interviews were conducted in a variety
of locations, including offices, lounges, private homes, churches, and libraries. The researcher asked her participants for their permission to tape record the interview, and all of the participants consented. Lists of questions were used to guide the interviews (see Appendix B).

The lists of questions varied depending on the participant. However, the questions could be broken down into several categories. Professionals were first asked background questions about their education, years of experience in their fields, and trainings on advance directives. Next they were asked questions pertaining to their current experiences with advance directives including the processes they use to broach the topic and complete the forms as well as how clients or patients and their family members react to this process. Then professionals were asked to identify barriers to advance directive completion and provide suggestions for overcoming these barriers. Finally, professionals were asked to identify any unique characteristics of the Eastern Kentucky region that could influence advance directive completion rates.

Community members were first asked introductory questions to help the researcher get to know the participant better and to help the participant feel at ease about the interview. These questions covered a range of topics including the age, geographical and occupational background, and family composition of the participants. Next, community members were asked advance directive questions including if they currently have advance directives. Participants with advance directives were asked questions regarding their advance directives including what motivated them to obtain advance directives and what they did with their advance directives after they completed them. Participants without advance directives were asked what deterred them from obtaining the documents, if they plan to complete advance directives in the future, and what they know about the forms. Community members were then asked death-related questions such as their experiences with death and dying, fears and concerns about death, and how they think
American culture deals with death. Next, community members were asked to identify barriers to completion and provide suggestions to improve completion rates. Finally, participants were asked if they could identify any unique characteristics of the Eastern Kentucky region like those asked of professionals. At the end of each interview the researcher allowed the participant to share any additional relevant information that was not addressed by the interview questions.

The interview questions were not asked in the order they appeared on the list but in the order that seemed least disruptive to the flow of the interview. At times the researcher asked pertinent questions not located on the list or skipped questions on the list that seemed inappropriate to the interview situation. When necessary, probes were used to encourage participants to elaborate on their responses, and participants were encouraged to share personal anecdotes.

To better capture the nature of the interview, field notes were taken. The researcher attempted to limit the recording of field notes during the interviews often taking field notes immediately following the study. The field notes included references to any nonverbal gestures made by the participants, the condition of the interview environment (i.e. noisy, too warm, comfortable, etc.), the physical appearance of the participant, the emotional/mental state of the researcher, and any other important pieces of information not captured on tape. While transcribing the interviews, the researcher indicated changes in voice, laughter, crying and other sounds captured on tape that accompanied the participants’ words.

Sample

Overall, 35 interviews were conducted, and 39 participants were interviewed (see Figure 1 above). While most of the interviews consisted of the interviewer and one participant, four interviews consisted of two participants. These four interviews were with the following pairs:
Judith and Linda, Janet and Andrew, Tina and Mindy, and Duncan and Emogene. A total of twenty-four females and fifteen males participated in the interviews. All of the interview participants were Caucasian, and their ages ranged from eighteen to eighty two years. An analysis of the quantitative and qualitative data will follow in the next two chapters.
Chapter 4: Quantitative Study

As stated in the preceding chapter, the current study consisted of both quantitative and qualitative data. Both types of data were used to identify the factors that influence advance directive (AD) completion in the community in which the study took place. This chapter will address the results of the quantitative study.

After the completed surveys were collected from the 197 participants, the data were entered into the MicroCase statistical program. Analysis of the socio-demographic data, Advance Directive Attitude Survey scores, and Lester Attitude Toward Death Scale scores were then performed. The results are discussed in detail below. Please note that the .05 level was used as the cutoff for statistical significance for all statistical tests described in the current study.

SOCIO-DEMOGRAPHIC DATA AND ADVANCE DIRECTIVE STATUS

First, advance directive (AD) completion status (i.e. whether participants completed an advance directive) was examined. Of the 197 people surveyed, an overwhelming 54.8% of them reported having no advance directives. The remaining participants were nearly equally divided between those who had advance directives (22.8%) and those who did not know if they had advance directives (22.3%). The “Don’t Know” and “No” categories were then collapsed into a single new “No” category. This was done because the “Don’t Know” category most likely consisted of participants who did not know what advance directives were and had most likely not completed the documents. The participants who answered “Don’t Know” were young with an average age of 19.73 years. After collapsing the “No” and “Don’t Know” categories, the newly created “No” category comprised roughly 77% of the participants (see Table 5 below). The
percentage of participants with advance directives is similar to the percentages discussed in Duke, Thompson and Hastie’s (2007) study.

Table 5. AD Status of Participants

<table>
<thead>
<tr>
<th>Status</th>
<th>f</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>45</td>
<td>22.8</td>
</tr>
<tr>
<td>No</td>
<td>152</td>
<td>77.2</td>
</tr>
<tr>
<td>Total</td>
<td>197</td>
<td>100</td>
</tr>
</tbody>
</table>

Participants were also asked to indicate the location or agency with which their advance directives were completed. Legal, rather than medical, agencies tended to be the more popular route for completing advance directives with close to half (44.4%) of the 45 participants with ADs stating that they completed these documents through a lawyer. A slightly smaller percentage of those with ADs completed them with a healthcare provider, hospital or hospice (see Table 6 below). These three medical agencies were then collapsed into a single “Medical” category containing 17 participants (37.8%). Several other participants stated they completed their advance directives themselves with no aid from any agency.

Table 6. Location of AD Completion

<table>
<thead>
<tr>
<th>Location</th>
<th>f</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare</td>
<td>5</td>
<td>11.1</td>
</tr>
<tr>
<td>Provider</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>11</td>
<td>24.4</td>
</tr>
<tr>
<td>Hospice</td>
<td>1</td>
<td>2.2</td>
</tr>
<tr>
<td>Lawyer</td>
<td>20</td>
<td>44.4</td>
</tr>
<tr>
<td>Self</td>
<td>8</td>
<td>17.8</td>
</tr>
<tr>
<td>Total</td>
<td>45</td>
<td>100</td>
</tr>
</tbody>
</table>

Initially three participants selected the “Other” option, reporting that they used an agency other than the ones listed above to complete their advance directives. These participants were
asked to list the agency through which they completed their ADs. Two of the three participants stated that they completed their advance directives at a senior citizens meeting, which was facilitated by the local Legal Aid service, and the third participant stated that he/she completed a standard AD received in the mail. Because the two participants who completed their advance directives with the senior group received assistance from Legal Aid, and the third participant completed the standard AD with no aid from a lawyer or medical agency, these three responses were reclassified. The two participants who received assistance from Legal Aid were reclassified as using a lawyer, and the third participant was reclassified as completing his or her advance directive on his or her own.

Several trends were observed between the agencies used to complete ADs and other independent variables. First, the relationship between sex and AD location was explored using the newly created “Medical” variable, but the relationship was not found to be statistically significant. However, it is interesting to note that all 11 of the participants who completed their ADs at the hospital were female. Age did appear to play a role in the location in which ADs were completed, and using an ANOVA, it was found that the differences among the means yield an $F(4, 40) = 5.65$, which is statistically significant at the .001 level (see Tables 7 and 8 below). With an eta-squared of .32, 32% of the variability in the agencies used to complete ADs can be explained by age. When the relationship between education and location of AD completion was examined, it was observed that people with higher levels of education were more likely to complete their ADs with a lawyer, but more than 20% of the expected frequencies were less than 5 when a chi-square test was attempted. The same problem was encountered when the relationship between health and Agency used to complete ADs was examined with only 6 participants with ADs being in poor health.
Table 7. Mean Age of Participants (in years) by Agency Used to Complete ADs (using collapsed “Medical” category)

<table>
<thead>
<tr>
<th>Agency</th>
<th>Mean</th>
<th>SD</th>
<th>(N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>40.29</td>
<td>23.12</td>
<td>(17)</td>
</tr>
<tr>
<td>Lawyer</td>
<td>68.10</td>
<td>10.57</td>
<td>(20)</td>
</tr>
<tr>
<td>Self</td>
<td>61.10</td>
<td>26.09</td>
<td>(8)</td>
</tr>
</tbody>
</table>

Table 8. Analysis of Variance of Age by Agency Used to Complete ADs

<table>
<thead>
<tr>
<th>Source</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Sum of Square</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between</td>
<td>7345.60</td>
<td>2</td>
<td>3672.80</td>
<td>9.99</td>
<td>0.001</td>
</tr>
<tr>
<td>Within</td>
<td>15439.20</td>
<td>42</td>
<td>367.60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>22784.800</td>
<td>44</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Participants were also asked to indicate their highest level of education obtained. The educational levels on the demographic questionnaire consisted of (1) “Below High School,” (2) “High School,” (3) “Some College,” (4) “Associate’s Degree,” (5) “Bachelor’s Degree,” (6) “Master’s Degree,” and (7) “Doctorate.” However, due to the low number of participants in several of the categories, the first four categories were collapsed into two categories. The “Below High School” and “High School” categories were collapsed into a new “High School” category, and the “Some College” and “Associate’s Degree” categories were collapsed into a new category named “Some College”. The education levels of participants with ADs were varied with 25 having a Bachelor’s degree or higher and 20 having some college or below (see Table 9 below). While the education levels for those with no advance directives were still varied, the majority of participants with no ADs were concentrated on the lower education levels with 129 of the 152 participants with no ADs being in the “High School” and “Some College” categories. A significant relationship appears to exist between education and AD completion.
with a chi square of 39.42, 4 degrees of freedom, and a significance level of .001. One’s level of education does appear to influence AD completion with participants with higher levels of education being more likely to have ADs. With a Cramer’s $V$ of .45, the relationship between education and AD status is moderate.

Table 9. Highest Education Level of Participants by AD Status

<table>
<thead>
<tr>
<th>Status</th>
<th>High School</th>
<th>Some College</th>
<th>Bachelor’s</th>
<th>Master’s</th>
<th>Doctorate</th>
<th>(N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>30.8</td>
<td>11.8</td>
<td>28.6</td>
<td>61.9</td>
<td>61.5</td>
<td>(45)</td>
</tr>
<tr>
<td>No</td>
<td>69.2</td>
<td>88.2</td>
<td>71.4</td>
<td>38.1</td>
<td>38.5</td>
<td>(152)</td>
</tr>
<tr>
<td>Total (%)</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>(100)</td>
</tr>
<tr>
<td>(N)</td>
<td>(13)</td>
<td>(136)</td>
<td>(14)</td>
<td>(21)</td>
<td>(13)</td>
<td>(197)</td>
</tr>
</tbody>
</table>

$x^2 = 39.42; df = 4; p < .001$

$V = .45$

Age was also found to have an impact on AD completion status. The ages of those with ADs ranged from 18 to 86 years. The ages of those without advance directives ranged from 18 to 78 years of age (see Table 10 below). The difference between the mean ages for those with advance directives and those without ADs was rather large. A difference of 28.77 years existed between the mean age for the group with advance directives and the group with no advance directives with the no ADs group having the younger mean age. A $t$ test indicated that the difference between the mean age for the group with ADs and the group without ADs was statistically significant with $t = 9.89, df = 195, p < .001$ (see Table 11 below). The eta-squared of .33 is moderately strong indicating that the errors in estimating advance directive status are reduced by 33% by using the participants’ age. It is important to note that education and age
were positively correlated \( (r = .61, p < 0.01) \), and this may be due in part to older participants having more time to obtain higher levels of education.

Table 10. Mean Age of Participants (in years) by AD Status

<table>
<thead>
<tr>
<th>AD Status</th>
<th>Mean</th>
<th>SD</th>
<th>( (N) )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>56.40</td>
<td>22.76</td>
<td>(45)</td>
</tr>
<tr>
<td>No</td>
<td>27.63</td>
<td>15.12</td>
<td>(152)</td>
</tr>
</tbody>
</table>

Table 11. \( t \) Test of AD Status by Age

<table>
<thead>
<tr>
<th>Source</th>
<th>Sum of Squares</th>
<th>( df )</th>
<th>Mean Sum of Square</th>
<th>( t )</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between</td>
<td>28748.85</td>
<td>1</td>
<td>28748.85</td>
<td>9.89</td>
<td>0.001</td>
</tr>
<tr>
<td>Within</td>
<td>57286.43</td>
<td>195</td>
<td>293.78</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>86035.28</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Item 13 on the Advance Directive Attitude Survey (ADAS) stated, “I am not old enough to have an advance directive.” This item was reversed scored with the response of “Strongly Agree” receiving 1 point, “Agree” 2 points, “Disagree” 3 points, and “Strongly Disagree” 4 points. The more points the respondent had, the more positive his or her attitude toward advance directives. Younger participants tended to have lower scores for Item 13, and the differences between the mean age for each of the four possible responses was statistically significant with \( F = 9.69, df = 3, p < .001 \) (see Tables 12 and 13 below). Though anyone over the age of eighteen years can obtain an advance directive, many of the younger participants believed they were too young to have an advance directive. Responses to Item 13 may indicate that many people, especially young people, associate advance directives with advanced age and may reduce the likelihood of younger adults obtaining advance directives.
Table 12. Mean Age of Participants (in years) by Score for ADAS Item 13

<table>
<thead>
<tr>
<th>Score</th>
<th>Mean</th>
<th>SD</th>
<th>(N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (SA)</td>
<td>30.43</td>
<td>21.06</td>
<td>(14)</td>
</tr>
<tr>
<td>2 (A)</td>
<td>21.48</td>
<td>6.95</td>
<td>(44)</td>
</tr>
<tr>
<td>3 (D)</td>
<td>36.04</td>
<td>21.97</td>
<td>(80)</td>
</tr>
<tr>
<td>4 (SD)</td>
<td>42.08</td>
<td>22.29</td>
<td>(59)</td>
</tr>
</tbody>
</table>

Table 13. Analysis of Variance of Age by Score for ADAS Item 13

<table>
<thead>
<tr>
<th>Source</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Sum of Square</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between</td>
<td>11259.41</td>
<td>3</td>
<td>3753.14</td>
<td>9.687</td>
<td>0.001</td>
</tr>
<tr>
<td>Within</td>
<td>74775.87</td>
<td>193</td>
<td>387.44</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>86035.28</td>
<td>196</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

There did not appear to be a relationship between sex and advance directive completion status (see Table 14 below for details). Because of the large number of female participants, both AD status groups contained a larger proportion of females. A chi-square test of independence was performed to determine if sex and advance directive status were independent, and the chi-square test did not yield significant results thus indicating that the sex of participants was not related to AD completion in the current study though Duke, Thompson and Hastie’s (2007) study found that females were more likely to have ADs than males.
Table 14. AD Status by Sex

<table>
<thead>
<tr>
<th>AD Status</th>
<th>Female (%)</th>
<th>Male (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>23.1</td>
<td>22.2</td>
</tr>
<tr>
<td>No</td>
<td>76.9</td>
<td>77.8</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>(N)</td>
<td>(134)</td>
<td>(63)</td>
</tr>
</tbody>
</table>

$\chi^2 = .02, df=1, p > .05$

Participants were asked to rate their current health status as either “Excellent,” “Good,” “Fair,” or “Poor.” However, due to low numbers in the “Excellent” and “Poor” categories, the “Excellent” and “Good” health categories were collapsed into one category labeled “Good” while “Fair” and “Poor” health categories were collapsed into one category named “Poor”. A total of 90.9% ($N = 179$) of the participants fell into the collapsed “Good” category while only 9.7% ($N = 18$) were represented in the “Poor” category. Overall, the health of participants was good despite advance directive status with a majority of the participants with ADs as well as those with no ADs reporting to be in good health (see Table 15 below). Previous studies have linked poor health with the increased likelihood of having advance directives (i.e. Duke, et al. 2007). However, this study did not find a significant relationship between health and AD completion with $\chi^2 = 1.24, df = 1, p > .05$. 
Table 15. Health of Participants by AD Completion

<table>
<thead>
<tr>
<th>Health Status</th>
<th>Good (%)</th>
<th>Poor (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>21.8</td>
<td>33.3</td>
</tr>
<tr>
<td>No</td>
<td>78.2</td>
<td>66.7</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>(N)</td>
<td>(179)</td>
<td>(18)</td>
</tr>
</tbody>
</table>

$\chi^2 = 1.24; df = 1; p > .05$

Items 15 and 16 on the ADAS referred directly to the issue of health and advance directives. Item 15 stated, “It is better to make an advance directive when you are healthy.” Nearly 92% of participants responded with “Agree” or “Strongly Agree” to this item. Experts working with advance directives do agree that ADs are best completed when people are in good health and able to make sound decisions regarding their end-of-life care. Item 16 stated, “I am not sick enough to have an advance directive,” to which 66% of participants answered “Agree” or “Strongly Agree.” When the mean responses for Item 16 of those in good health and those in poor health were compared, no significant difference was found between the two means though those in poor health were more likely to answer “Disagree” to this item.

ADAS AND LATDS ANALYSIS

Scores for the Advance Directive Attitude Survey (ADAS) items were totaled for each participant to create a total ADAS score. The possible range of total scores for this scale was 17 to 68. The actual ADAS total scores obtained in the study ranged from 42 to 68 with higher scores indicating a more positive attitude toward advance directives. The mean score was 54.92
\(SD = 6.08\), and the median score was 55. Overall the survey participants appeared to have rather positive attitudes toward ADs.

Five independent variables were examined to determine if they were related to ADAS total scores. Though a relationship did not appear to exist between the sex or health of the participants and their ADAS total scores, relationships did appear to exist between ADAS total scores and age, education and AD status (see Table 16 below). The correlation coefficient for ADAS total score and age was .40, which was statistically significant at the .01 level with older participants having more positive attitudes toward ADs as indicated by their higher total scores on the ADAS. The correlation coefficient for ADAS total score and education was .34, which was significant at the .01 level indicating that as the education levels of participants increased their ADAS total scores tended to increase as well. Recall that the age and educational attainment of participants in the current study were positively correlated. The correlation coefficient for AD status and ADAS total score was .32 with a significance level of .01, and this indicated that higher ADAS total scores were correlated with possession of an advance directive.

Table 16. Correlations Among ADAS total Scores and Five Independent Variables
(listwise deletion, \(N = 197\))

<table>
<thead>
<tr>
<th>Variables</th>
<th>ADAS</th>
<th>Age</th>
<th>Education</th>
<th>Sex</th>
<th>Health</th>
<th>AD Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADAS</td>
<td>--</td>
<td>.40**</td>
<td>.34**</td>
<td>.10</td>
<td>.09</td>
<td>.32**</td>
</tr>
<tr>
<td>Age</td>
<td>--</td>
<td>.63**</td>
<td>.03</td>
<td>.17**</td>
<td>.58**</td>
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</tr>
<tr>
<td>Education</td>
<td>--</td>
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<td>.04</td>
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<td>Sex</td>
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<td>AD Status</td>
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</table>

\(**p < .01\)
The two independent variables of health and sex were examined to determine if they influence ADAS total scores. The health of participants did not appear to influence their ADAS total scores. The group of participants in good health had a mean ADAS total score ($M = 54.91$, $SD = 6.12$) that was slightly lower than the mean ADAS total score for the group in poor health ($M = 55.06$, $SD = 5.80$). A $t$ test did not reveal a significant difference between these two means. Also, the sex of participants did not appear to influence ADAS total scores ($t = .10$, $df = 195$, $p > .05$). The mean ADAS total score for men ($M = 54.06$, $SD = 6.16$) and for women ($M = 55.33$, $SD = 5.86$) were nearly identical, and a $t$ test ($t = 1.37$, $df = 195$, $p > .05$) revealed that this difference between male and female ADAS total scores was not statistically significant.

Lester Attitude Toward Death Scale (LATDS) scores ranged from 11.85 to 104.37 with higher scores indicating an increased fear of death. The range of possible total scores spanned 0 to 131.78 for this scale. The mean score was 56.13 with a standard deviation of 18.2 and the median score was 55. The survey evoked the greatest number of questions from participants, and yielded the largest number of written responses from participants.

As with the ADAS total scores, correlations were performed to determine if relationships existed between the LATDS total scores and the independent variables age and education (see Table 17 below). A relationship was found between the age of participants and their LATDS total scores. A correlation produced a coefficient of -.20, and though this coefficient is rather small, it was statistically significant at the .01 level. The LATDS measured fear of death with lower scores indicating less fear, and as age increased, the LATDS total scores tended to decrease. A similar relationship was found to exist between education level and LATDS total scores, which produced a correlation coefficient of -.19 and was significant at the .01 level. As highest education level obtained increased, fear of death was found to decrease, but the effect
size of this correlation coefficient is somewhat small. Also, recall that age and education are positively correlated.

Table 17. Correlations among LATDS Total Scores and Two Independent Variables (listwise deletion, N = 197)

<table>
<thead>
<tr>
<th>Variables</th>
<th>LATDS</th>
<th>Age</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>LATDS</td>
<td>--</td>
<td>-.20**</td>
<td>-.19**</td>
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<tr>
<td>Age</td>
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<td>.63**</td>
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<tr>
<td>Education</td>
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</table>

**p < .01

The independent variables of sex, health and AD status were also studied to determine if their influence on LATDS total scores. First, a t test was performed to determine if a significant difference existed between the mean LATDS total scores for females ($M = 56.80, SD = 18.57$) and males ($M = 54.72, SD = 17.47$), and the t test revealed that sex did not influence LATDS total scores ($t = .74, df = 195, p > .05$). Next, health was examined. The group of participants in good health had a mean LATDS total score of 55.95 ($SD = 18.13$), and the group of participants in poor health had a marginally higher score of 58 ($SD = 19.40$) indicating a slightly increased fear of death. However, a t test did not reveal a statistically significant difference between these two means ($t = .46, df = 195, p > .05$). Finally, the advance directive status of participants was examined. Though the group of participants with advance directives had a lower mean LATDS scores than the group who did not have ADs, a t test comparing the mean total scores for the LATDS by AD status did not yield significant results with $t = 1.64, df = 195, p > .05$. The independent variables of health, sex and AD status did not significantly impact the LATDS total scores in the current study.

Next, a correlation was performed to determine if a relationship existed between ADAS total scores and LATDS total scores. The correlation produced a coefficient of -1.18, which was
significant at the .01 level. As ADAS scores increased, LATDS scores decreased. Therefore, as
attitudes toward advance directives as measured by the ADAS became more positive, fear of
death as measured by the LATDS decreased.

The study took place in an Eastern Kentucky community, an area classified as part of the
Appalachian region. Participants were asked if they considered themselves to be from Eastern
Kentucky region in order to explore possible geographical influences on the findings. Of the 197
study participants, over half of the participants (69%) indicated that they were from Eastern
Kentucky. The mean age of those from the region of Eastern Kentucky was higher than the
mean age for those not from the region. This difference could be due to the fact that many of the
older participants were residents of the region who were recruited predominately through church
groups while most of the younger participants were university students, some of whom came to
the university from outside of the region. Also, residents from the Eastern Kentucky region were
more likely to have ADs and tended to have higher ADAS total score. However, these two
differences were more likely due to age with older participants regardless of region having
higher AD completion rates, and a positive correlation was found to exist between AD status and
ADAS total scores. Overall, there were few differences between those from Eastern Kentucky
and those who were not. While the Eastern Kentucky region has a unique history and culture
worthy of consideration when social research of any kind is being conducted in the region,
regional differences did not appear to play a significant role in the variables examined by the
quantitative portion of the current study.

The Socio-demographic Questionnaire, Advance Directive Attitude Scale (ADAS), and
Lester Attitude Toward Death Scale (LATDS) did shed light on the topic of advance directives.
However, the scope of these instruments is limited. To obtain greater insight into factors
influencing advance directive completion, in-depth interviews were conducted. Their results are discussed in the following chapter.
Chapter 5: Qualitative Study

In-depth interviews were conducted in conjunction with the Socio-demographic questionnaire, the Advance Directive Attitude Survey, and the Lester Attitude Toward Death Scale. The interviews were guided by the five research questions listed above, and provided additional information on advance directives (ADs) including how professionals broach the topic of ADs with clients or patients, how community members obtain their ADs, what factors motivate or prevent people from acquiring the documents, and suggestions for improving access to ADs. Data provided by interview participants also helped illuminate the quantitative findings discussed above.

The modernist theoretical concept of death sequestration was used to guide the analysis of the interview material. Using this theoretical perspective, the researcher looked for evidence of death being hidden in current American culture and the effect this sequestration of death had on how participants discussed and planned for their end-of-life (EOL) medical treatment. Factors that motivated participants to complete ADs were also explored. The belief that death has become increasingly hidden in American society thereby preventing many people from obtaining first-hand experience with death was echoed by multiple participants. Themes pertaining to death denial within American culture and among individuals emerged during the interviews. Age played an important role in attitudes toward death with younger people being more likely to avoid discussing and planning for death.

PARTICIPANTS

A total of 39 people participated in the interviews. All of the participants were living in Eastern Kentucky as residents or students between April 2008 and April 2009 when the
interviews were conducted. The participants, however, represented diverse geographical backgrounds including different regions of Kentucky, the nation, and other nations. The ages of the participants ranged widely from 18 years to 82 years. All interview participants were Caucasian.

Participants came from a variety of occupational and educational backgrounds. For the purpose of this study, participants were divided into two categories: professionals and community members. The professionals consisted of nurses, medical social workers, physician assistants, physicians, a professor in a physician assistant program, and attorneys who worked closely with advance directives in their occupations. A total of 18 professionals participated in the interviews. Community members were the participants recruited via the quantitative survey who did not work as nurses, medical social workers, physician assistants, physicians, or attorneys. Community members represented a range of occupational and educational backgrounds including college professors, retired teachers, college students, and service sector workers. A total of 21 community members took part in the interviews. Pseudonyms were used for all of the participants to ensure anonymity, and participants were informed of this prior to the commencement of their interview.

Community members were asked if they had advance directives (ADs). Thirteen community members reported having ADs while eight community members did not have ADs. Participants with ADs were asked to describe what motivated them to complete their ADs and where they obtained the documents. Participants without ADs were asked to name the factors preventing them from obtaining their ADs and if they knew where they could obtain ADs if they wanted to complete the documents.
Professionals were asked to describe their roles in helping patients/clients with ADs. Professionals were also asked to describe their training and education regarding death, dying, and bereavement, and end-of-life care planning. Because of their occupations, it was believed that these professionals had unique insights into the factors that motivate or prevent people from completing ADs. Below, the professionals describe how they broach the topic of ADs with their patients or clients.

PROFESSIONALS

Initiating Dialogue

The Socio-demographic questionnaire used in the quantitative portion of the current study indicated that a number of participants with ADs (n = 45) obtained their advance directives (ADs) from legal (44.4%) or medical (37.8%) professionals. Because ADs are legal documents concerning medical decisions, conversations about ADs are frequently initiated in medical and legal settings. However, how is the topic of ADs broached and whose role is it to bring up the topic of end-of-life care planning? Also, examining the roles and duties of these professionals provides insight into the bureaucratic processes involved in AD completion.

In the medical and legal setting, conversation about advance directives may be initiated by the patient/client or by the medical or legal professional. The interviews revealed that very few patients/clients initiated conversations about ADs with the professionals involved in the study. Below Dr. Campbell gives his response to the question of whether very many patients initiate conversation about ADs:

Uh…some, sure…but even in the ER I’ve had people bring that up, or I’ve had family members bring that up and that happens more, there might be someone who has severe Alzheimer’s who might be in the hospital for whatever reason and their family members accompany them and they will bring it up often. You know, I guess typically people who are in those situations have thought about it more than people who aren’t. So sure they do,
but … what percent of the time do they bring it up? Well, it’s not very much, maybe ten percent of the time.

The low rate of patient/client-initiated conversations about ADs seemed to be common among the professionals interviewed. According to Dr. Campbell, those who initiated conversation, whether patients for family members of the patient, tended to be dealing with dementia of some sort, which often has a slow onset thus allowing time for end-of-life care planning.

At times, professionals were required to initiate conversations about ADs with patients as part of their professional role. For example the social workers who were interviewed worked with hospice, palliative care, local hospitals, and a local nursing home and were required to ask patients about ADs during an intake process. Attorneys frequently brought up ADs when they were preparing last will and testaments for their clients. Therefore, the professionals often broached the topic first as part of their professional role thus removing the patient’s/client’s need to do so.

Programs like hospice and palliative care tended to create a very open environment for end-of-life (EOL) care discussion and planning. Hospice is focused on patients who have been determined to have six months or less to live, and palliative care frequently works with patients facing terminal illnesses or chronic, life-threatening conditions (Marrelli 2005). Both programs include dialogue regarding ADs and EOL care planning in their initial meetings with their patients. These initial meetings often take place in the patients’ homes and may last up to an hour and involve a multi-disciplinary team consisting of a physician, nurse and social worker. This dialogue may continue throughout the patient-program relationship as the patient’s needs and wishes change. Below, Molly, the palliative care nurse describes the program’s goals for the initial patient visit:
I’m the palliative care patient care coordinator…and work directly with Dr. Thompson [the palliative care physician], and that is one thing that we [the palliative care nurse, social worker, and physician] do on our first visit with the patient and the family is address the ADs. Uh, we want to see what the patient wants. Sometimes the patient will have never even thought about it, which is quite amazing...like today we saw a patient who is very ill. He’s home-bound. He’s pretty much confined to one room. He’s not able to get out of that one room. And we asked if he had a living will, and [he said], “No.” Had he thought about it or what he would like? Well, he’d never given it a thought, and he’ll just have to think about it before he knows. And I guess maybe people try to put off thinking about it, and I know they’ve said several of them it’s hard to talk to the family about it because the family doesn’t want you to talk about it. But that’s one of our main goals on the first visit is to find out really what the patient is wanting and let the family hear the patient say what he wants.

For some patients, the initial interview with the palliative care team is the first time they’ve had the opportunity to discuss advance directives. Palliative care and hospice workers have time to talk with patients and their families at length and on numerous occasions about advance directives.

At two of the regional hospitals, social workers provided patients with information on living wills and facilitated completion for patients desiring a living will. According to the participants’ responses, power of attorney document completion was not facilitated by staff at both hospitals. At St. George’s hospital, the two social workers interviewed visited every patient admitted to their assigned units to ask if the patients needed anything including living wills. At St. Luke’s, the social workers were called to meet with patients who requested more information about living wills or wished to complete a living will during their intake. Nurses at both hospitals asked patients if they possessed ADs or wanted to complete a living will during the admission process. The roles of the hospital social workers included educating patients about living wills, making sure the proper steps (i.e. get paperwork filled out correctly, notarized by a qualified staff member, properly filed and documented in the chart, etc.) were taken for those
wishing to complete living wills, and ensuring that the patients who were completing living wills were mentally competent to make such decisions. If patients are admitted with ADs, the social workers at both facilities were required to review these documents and sometimes consult with the hospital’s legal department to ensure these forms were legally acceptable documents.

At any time during a patient’s care at a hospital, other staff members including nurses and physicians may also discuss EOL care with the patient, but healthcare providers typically called upon the social workers when the patient wanted to complete a living will or had questions pertaining to living wills. According to the social workers at both hospitals, their patients were asked about living wills and provided with trained social workers capable of answering their questions and assisting them with the documents.

At the local nursing home, EOL care wishes and ADs were discussed as part of the intake process. Upon admission, the patient, or the patient’s guardian if the patient is unable to make decisions, is required to sign a document stating the patient’s wishes regarding EOL care. The social service director, who is a social worker, facilitates this process and assists the patient or patient’s guardian with the process and can provide education when necessary. As with all of the other advance directives completed at the facilities discussed above, the patient or guardian can change the wishes stated in the living will by notifying a staff member who then notifies the social service director who then takes the steps necessary to change the document. The social worker at the nursing home initiates advance directive dialogue with patients or their guardians, and provides assistance with living will completion and alterations.

The socio-demographic questionnaire revealed that attorneys were another popular route for AD completion. The three attorneys who participated in the study claimed that very few clients initiated conversations about ADs, but the attorneys frequently broached the topic when
they felt it was appropriate to do so, such as when the client requested a last will and testament or some other type of estate planning, was advanced in age, or ill. Though initiating conversation about ADs is not part of an “intake” process for attorneys, they claimed that the topic was easy to broach. Attorneys frequently deal with legal documents pertaining to death, such as last will and testaments and other forms of estate planning, and they did not view advance directives any differently. One of the attorneys interviewed stated that the living will was free for clients who completed a last will and testament with his firm. For attorneys the last will and testament and ADs seemed to go side-by-side, and the attorneys claimed that conversation about ADs was easy for them to initiate.

Once these professionals engaged in dialogue about ADs with their patients or clients who did not have ADs, the reactions of the patients/clients tended to be similar. Except for a few patients/clients who either had given little to no thought about ADs or who did not wish to discuss them, most patients/clients expressed a feeling of relief for someone else having broached the topic and a desire to discuss the topic once broached. Steven, an attorney, describes the typical reaction of his clients when he brings up the topic of ADs:

> Never have I had anybody react in any manner other than, “Thank goodness that you broached the subject.” Now, they don’t say those words, but it’s almost as if they’ve been waiting for somebody else to put the music on so they can dance because they really want to talk about it, but there is no socially acceptable, um, avenue to start discussing the living will. I mean, it’s an even harder to discuss subject than the last will and testament, uh, because at least in the last will and testament, what you’re saying is, “When I’m dead and gone this is where I want my property to go. This is how I want it to be divided. I want to make sure all of my debts are paid and that nobody is left to pay my debts and I want my stuff to go in this direction.” Well, okay, that’s fine. A person can prepare a living will, um, but they can’t do that without thinking about, “Who am I going to name to carry the burden of deciding to end my life?”
The professionals involved in the study provided a socially-acceptable avenue for discussing EOL care.

For medical professionals, a number of patients expressed their wishes to learn more about end-of-life care planning. Many patients also stated that they wanted to complete ADs but had not gotten around to doing it. The medical professionals, including medical social workers, created not only a socially acceptable environment for discussing ADs but possessed the medical knowledge necessary to answer the patient’s questions. Death is an unavoidable aspect of living that often hovers just under the surface of daily life, but the act of openly discussing death is rarely considered socially appropriate. These professionals pull the dark topic of death out of hiding and expose it to the light creating an environment in which discussion of death and dying is socially acceptable.

A wealth of resources for ADs exists within certain sectors of the medical and legal communities. Patients ill enough to require hospitalization or admission to a nursing home, or a hospice/palliative care program may receive individual attention from staff readily available to assist them with their AD needs, and community members who have the need and the means to visit an attorney can obtain legally-acceptable ADs drawn up by legal professionals. However, if patients or clients do not initiate conversations, and professionals do not broach the topic, the conversation of EOL care planning often goes unsaid and the ADs go unprepared. For community members in good health who are not exposed to medical facilities that discuss ADs or to legal counsel that provides an avenue for AD completion, they may have little exposure to ADs and little assistance with completing them.

Though most people will see a physician, such as general practitioner or family physician, at some point in their lives, none of the interview participants stated that their family
physicians initiated discussion of ADs. Previous research found that EOL planning was more effective when the individual was in good health (Darr 1999). Healthy individuals may go to a physician’s office or health clinic to receive annual exams or get medical attention for minor ailments. Typically, clinics do not have medical social workers on the premise to discuss ADs leaving the task of broaching the topic of ADs to the nurses, physician assistants and physicians. The PSDA does not require doctor’s offices and health clinics to ask patients about ADs (Black 2007), and initiating the topic of ADs and EOL care in the clinic setting can be time consuming for the physician, and some argue that it might be frightening for the patient. Dr. Friedman discusses these factors below:

…and then time becomes a factor because it takes twice as long to convince someone that they don’t need an antibiotic as it does to give them one, and the same thing here, it takes much more time to help the family understand, and you’ve got a patient coming every 10 minutes and every 15 minutes or something like that, and you don’t want to be a part of that, you get behind, and then they’re all griping… You don’t have the time to do it. And people get things in their mind, “…I was just there for a sore throat, and he, uh, he wouldn’t give me medication and wouldn’t give me antibiotics, but he wanted to talk to me about death.

This quote indicates that physicians with a waiting room full of patients may simply give in to certain patient demands like a request for antibiotics that would not cure the patient’s illness because the physician, whose patients have come to expect a certain level of efficiency, lacks the time to educate the patient. Likewise, physicians, who operate in a bureaucratic structure that pressures them to increase their workloads, assume new additional roles, and adopt bureaucratic values (Mechanic 1977), have little time to discuss ADs. Also, by broaching the topic of ADs, physicians may fear that patients will become upset by a conversation about death in a facility of healing—a facility that exists in a culture of death denial. However, one might speculate that
this fear may stem more from the physician’s own attitudes toward death and lack of training regarding death than from actual patient fears (Moon 2008).

**Education and Training**

The professionals were asked about their education and training regarding advance directives. Of the three physicians interviewed, only Dr. Campbell, who had been out of medical school for 16 years, recalled learning about ADs briefly in medical school. The other two physicians had been practicing medicine for twenty or more years and had learned about ADs after medical school. Two physician assistants (PAs) were also interviewed. The younger PA had graduated from the physician assistant program four years ago and reported having lectures on the legal and medical issues surrounding end-of-life care planning. The older PA had no such training.

While the three attorneys reported learning about ADs in law school, only Adam reported having extensive educational training in preparing ADs. As part of his education, Adam was required to intern at a senior law clinic while in law school. His internship provided him with useful knowledge and experience regarding advance directives.

Three of the five nurses interviewed reported having learned about ADs as part of their nursing education, and two of these nurses had completed their nursing education within the last ten years while the third nurse was currently enrolled in nursing school. The two nurses who had not learned about ADs in school had completed their nursing education more than twenty-five years ago, and all of the nurses interviewed reported having on-the-job training pertaining to ADs.

All of the social workers stated that they had heard about ADs while in college, but they did not study them extensively. However, social workers tended to have the most extensive
formal on-the-job training. Physicians and attorneys, with the exception of Adam, tended to have little training.

Attorneys seemed to have an advantage over healthcare providers, however, because their job simply required them to have a firm grasp of the laws regarding advance directives within their State of practice, which would be an easy enough task for any attorney. On the other hand, physicians are expected to take part in a patient’s end-of-life care but receive little training in talking with patients and their families about death and advance directives. Dr. Friedman, who was on the verge of retiring at the time of his interview, received no formal education or training on how to discuss death and dying with patients and families. Dr. Thompson received some such training but stated that her medical school was rather progressive in teaching about death and dying, and Dr. Campbell’s medical school devoted only a small amount of formal education to this topic. However, the physicians interviewed indicated that formal death and dying education for physicians is improving. One participant who serves as a faculty member for the physician assistant program at a large state university stated that formal death and dying education is also improving for physician assistants.

Nurses spend a greater amount of time with patients than physicians, but even nurses are pressured to conform to the bureaucratic process of the medical facility. As Dr. Friedman lamented during his interview, “…they’ve taken…the nurse out of the patient’s room and they put her at the desk filling out forms. And I realize that some of that needs to be done. A whole lot of it needs to be done, but it has detracted…from the patient.” Attorneys and medical social workers, particularly social work directors, often had a role in preparing the documents used by their facilities. The attorneys stated that they based their forms on the AD legislation for Kentucky, and the social work directors, Charlie at St. Luke’s and Robert at Sunset Nursing
Home, consulted with attorneys to ensure their forms were in compliance with the law. In medical facilities, medical social workers tend to have a clearly defined role pertaining to ADs that puts them in an optimal position to assist patients with ADs, but the interviews show that a team approach in which nurses, physicians, physician assistants and social workers collaborate to educate the patient about his or her end-of-life care choices is often used, especially in the hospice and palliative care setting. A number of professionals stated that their education did not adequately prepare them for EOL care planning, but the on-the-job training and daily experience they received after school was effective. Every professional interviewed stated that they were comfortable broaching the topic of advance directives with patients/clients and that their comfort levels improved over time with experience.

In modernity death is hidden in the confines of medical institutions, but even within the medical field, death appears to be sequestered. Dying, death and bereavement education for medical professionals has been slow to develop, and medical staff and patients frequently do not discuss EOL planning until the patient is being admitted for surgery or is terminally ill. Bureaucratic procedures limit the time that physicians have with patients to discuss dying and EOL care, and physicians may fear a negative response from their patient when they broach such topics during a routine office visit. Based on the interviews, conversations about death in the medical field frequently seem reserved for hospitalizations, surgeries and terminal illness. However, ADs are not restricted to the medical field and may be completed with attorneys, particularly during estate planning, and via other methods including community education programs.
COMMUNITY MEMBERS

Experiences with ADs:

Advance directive completion can be accomplished using a number of routes. Overall, the community members who participated in the current study completed their ADs using attorneys, hospitals, and community groups. A small number reported that they used AD forms they obtained and completed on their own. Some participants reported having completed multiple ADs from various agencies.

Five community members, Donald, George, Amanda, Shirley, and Barbara reported that they had completed ADs with attorneys. These participants were married and had children when they completed their ADs. However, several of these participants had completed ADs with other agencies as well. Donald was the only participant to have completed his only AD with an attorney. George completed his ADs twice, once with his first wife and the second time with his second wife after divorcing his first wife, and both times were with attorneys. The first time Amanda completed her ADs she did so on her own, but she used an attorney the second time she completed them. For Shirley, the first time she completed her ADs was with the aid of an attorney. Barbara completed several advance directive documents at different times in her life, and at one point she completed an AD with an attorney. Using an attorney was a popular method utilized by participants to obtain ADs even though several of these participants used other methods to obtain ADs at other points in their lives.

Four participants, Laura, Georgia, Daisy, and Barbara, completed ADs while being hospitalized. These participants were all female and were being prepared for surgery when they were asked if they wanted to complete a living will. Laura recalled being strongly advised by hospital staff to complete a living will prior to her heart surgery, and Georgia, who was having
emergency surgery, stated that the surgical staff were “breathing down her neck” for her to quickly complete her living will and stop holding up the surgery schedule. For Laura and Georgia, the living wills they completed at the hospital were the only living wills they had. Daisy completed her first living will during one of several hospitalizations for heart surgery. Barbara completed several living wills at the hospital, and below she describes the last time she completed her living will:

I had an emergency appendectomy two years ago this month, and they brought one [living will] in for me to sign then, and I did. I guess I should have told them I already had one, but you know, it was just…it was an emergency surgery so I just signed it.

Even though Barbara had completed several pre-existing living wills at the time of her appendectomy, in the midst of her health emergency, she did not mention her pre-existing living wills and did not have a copy of her most recent AD readily available. The hospital is another place where patients, such as the four women described above, can obtain living wills, but sometimes patients are not asked about ADs until they are being admitted for surgery leaving them little time to consider and discuss their end-of-life care options or bring up pre-existing ADs.

Six participants reported completing their ADs with a community program. Daisy, Shirley, Duncan and Emogene completed their ADs through the same senior citizens’ group. For Daisy and Shirley, their ADs through the community program were their second and final ADs. Deb completed hers through a women’s education group while Helen completed her AD through a senior group hosted by the local recreation department. Helen was the director of the recreation department at the time she completed her AD and took steps to schedule a speaker to host the AD workshop held for the senior group. At these community programs, speakers
presented on the topic of advance directives and allowed community members to ask questions before giving them the opportunity to complete their own living wills.

Two participants completed their ADs on their own without assistance from any professional or agency. Amanda completed her initial living will on her own shortly after divorcing her first husband. Leslie completed her only living will on her own.

The participants with ADs used a variety of means to obtain their living wills and power of attorney documents. Community groups were the most popular route to completing ADs with attorneys and hospitals following close behind. Only two participants completed their ADs independently with no help from any agency. Several participants completed more than one AD and used different avenues to obtain their ADs each time, and this helps illustrate the complex landscape of AD completion today. Each of these participants was motivated by certain factors to complete their ADs, and these factors are discussed below.

Motivations

These thirteen participants with advance directives were asked to describe the factors that motivated them to complete their end-of-life care documents. All of these participants expressed multiple motivating factors, which were then placed into four broad categories created by the researcher. These categories consisted of avoiding burden, control of end-of-life (EOL) care, family situation, and personal/professional experience with death. Experiences with death, either in one’s profession or in one’s personal life, often served as the foundation for other motivations, especially avoiding burden and gaining control of EOL care. Control of EOL care appeared to be linked with a desire for quality of life and included not wanting futile treatment and not wanting to linger unnecessarily. Burden was often described as the burden of decision
making, the burden of guilt regarding the EOL care decisions that needed to be made, and financial burden placed on family and society for the high cost of EOL care.

Eight of the twelve participants indicated that they completed their advance directives (ADs) as a way to avoid placing a burden on others. Participants described burden as emotional and financial stating that they wished to avoid burdening family members and physicians with difficult EOL decisions that could result in conflict and feelings of guilt and doubt, and they wanted to avoid expensive futile treatments that placed a financial strain on family members and society. Laura, a nurse, wife, and mother of two young children, explains below how expressing end-of-life care wishes in an advance directive could reduce the burden of guilt:

…if you have a family, if you are married, then you should have a living will because you need to…it takes the burden off your husband, it takes the burden off your relatives because they don’t have to choose for you. You have made your choices…

Advance directives not only have the potential to reduce the burden associated with end-of-life decision making, they also have the ability to save money by expressing the patient’s desire to forego expensive futile medical treatment. Barbara, a retired teacher, said, “I would never want to bankrupt my family to keep myself alive,” referring to her desire to avoid expensive futile procedures. Four of the professionals interviewed claimed that their clients/patients list avoiding placing a burden on loved ones as a strong motivation for completing their ADs as well.

Advance directives allow one to have some control over one’s end-of-life care; powers of attorney allow one to name an attorney-in-fact while living wills allow one to name a surrogate and indicate one’s medical wishes. All of the participants stated that they completed their advance directives to avoid treatment they deemed futile or heroic and to avoid lingering in a vegetative state. Expectedly, each participant had his or her own definition of quality of life and futile treatment. For some of the participants, unwanted life-sustaining measures that did
nothing to improve the patient’s condition or quality of life contributed to an emotional and financial burden on loved ones. Duncan’s quote below echoes this sentiment:

I did not want to be hanging on like a vegetable and my family having to be worrying all the time. It’s better for me to die and get over it. And…I don’t want to put a burden on them for me to lay there like a vegetable.

In some ways, the desire to avoid burden and to gain control over EOL care were related with participants, such as Duncan, wishing to gain control over their care to avoid placing a burden on loved ones. Leslie, a twenty-three year-old nursing student, stated that she completed her living will as a way of gaining control over her end-of-life healthcare and preventing her mother from making requests for futile treatments. The participants believed that stating their EOL care wishes in advance directives could allow them to have some control over their treatment even when they were no longer able to speak or no longer possessed decision-making capacity.

Family situations were also factors that motivated four participants to complete advance directives. Two participants, Laura and Amanda, were mothers of young children at the time they prepared their advance directives, and they stated that they completed their advance directives as a way to “cover their bases” and protect their children. For example, Amanda states below that the first time she completed her living will she was more concerned about her children than about herself:

I remember when I first started worrying about getting [my advance directives] done, and uh, we had moved to Kentucky. I had three sons I was raising. Their father was in Indiana, and I had remarried…and it was one of those things that because my children, I worried about what would be done, and I had to kind of cover myself…when we did the first set [of advance directives], I was really concerned about what would happen to my kids, and I really didn’t care so much about me.

Changing family situation played a role in motivating one participant to alter his advance directives. George, a sixty-nine year old retired professor, rewrote his advance directives after
his divorce because he “had a person able to pull the plug that quite honestly wouldn’t care to pull it right now” and wanted to name his second wife, rather than his first wife, as his surrogate. Helen, an eighty-two-year old woman, stated that she completed her living will because she had never married and needed a means to express her wishes because she did not have a spouse or many living relatives to speak for her. Concern for one’s family, alterations in one’s family composition, and lack of close family members served as motivating factors for four of the interview participants.

Personal experiences with death, either in the family or work setting, also played a role in motivating participants to complete advance directives. First, four participants stated that the lingering death of a parent or spouse motivated them to complete advance directives. For these participants, the death of a loved one forced them to think about their own deaths and their own wishes regarding EOL care. While the death of a loved one is rarely easy, two of the participants indicated that their deceased loved ones had advance directives and that these ADs facilitated the EOL care decisions the participants were asked to make. However, Deb, a middle aged woman whose mother died of cancer, indicates her regret at not having known her mother’s EOL care wishes:

…well for me and for my family, if I make these ADs, how helpful that is for them. Uh, my mother passed away very young at 58 of cancer and we never spoke anything about it, and this has been many years ago, and uh, so I’ve thought about that since then because we didn’t know my mother’s wishes and at that time, I was in my 30s and I didn’t even want to discuss it with her, so it’s just so helpful for families and for your physician, you know.

Deb’s experience with the death of her mother, who did not have advance directives and had not communicated her wishes to her family, motivated her to complete a living will in order to guide her family members and physician in making end-of-life care decisions for her. Shirley and Barbara provided end-of-life care for their parents and in-laws in their own homes, and these
experiences helped them better identify and communicate their own end-of-life care wishes. Georgia witnessed the dying process and eventual death of her partner’s father, and she also assisted the family in the father’s care. This experience shaped Georgia’s own views of death, dying and EOL care. Personal experiences with dying and death can bring the subject of death into the light and create a more accepting environment in which to discuss end-of-life care and provide a realistic framework for planning for one’s own death.

Professional experiences were also cited as motivating factors for three participants. Two of these participants were nurses who were familiar with life-prolonging treatments and the typical outcomes of these treatments. For these participants, exposure to death at work allowed them to experience the burdens described above first hand. Laura, a forty three year old former nurse, captured this sentiment when she said:

I dealt a lot with death and the dying. I, you know, took care of a lot of dying people, and I learned in that process that I’ve seen some people in nursing homes also who were kept on IVs and artificial feeding tubes and all that stuff, and they no longer had a life because they were no longer conscious of anything that was going on around them. So…I think I decided early on that I did not want to be in that position because…your body may be physically alive, but you are no longer alive because you can’t participate in anything that’s going on around you. And therefore, for me personally, it’s not a life, and no, I don’t want that. I would rather be dead, ’cause your essentially dead anyway.

A third participant, Amanda, who performed administrative work for a cemetery and worked as a counselor in a crisis unit claimed that she completed her advance directives as a way to honestly communicate her wishes to her family in order to avoid conflicts like those she witnessed in her occupations:

I think it seems like the people who have the worst relationships have the hardest time and go into crazy mourning whereas if you are kind of aware…I’ve seen people fight over cemetery plots. I have seen people fight over cremains. Um, I’ve gone to court and had to testify in court over a woman who had left a will [stating] what to do with her and her husband’s
remains and the nephew didn’t do that, and I mean…I’ve seen a lot of wicked things happen, and I think the best thing is to be honest with your family.

Professional experience with death and end-of-life care decision making appeared to open several of the participants’ eyes to the importance of preparing advance directives, and these experiences certainly impacted their decisions to complete ADs.

Age and Experience

Age appears to be an underlying factor and is closely related to experience with death and dying, and older participants reported having more personal and occupational experience with death. In the previous chapter, age was found to be positively correlated with AD completion among survey participants with older participants being more likely to complete ADs. A similar trend was found among the interview participants though the sample size was far smaller. The mean age of the thirteen interview participants with ADs was 63.23 years of age ($SD = 17.04$) while the mean age of the eight interview participants without ADs was 34.88 years ($SD = 19.48$). Older participants were more likely to have experience making EOL care decisions for elderly parents, were more likely to have encountered the death of close loved ones, and they were more likely to have had hospitalizations where ADs were discussed.

Aging also appeared to be an effective catalyst for coercing participants to seriously consider their own mortality. Nearly half of the interview participants reported that aging has caused them to face death and consider their own eventual demise, and most of the younger participants indicated that they did not feel compelled to complete ADs or plan for their deaths in other ways because they were young and saw death as something far in their futures. For example, Deb, a 65 year-old resident, completed her living will 15 years ago and reported that she felt more connected to the subject matter now because of her age than she did when she completed her AD. When Theresa, a 67 year-old resident, was asked if her attitudes toward
death have changed over time, she laughingly replied, “Well, I realize it’s more imminent.” Though not addressed directly, it seemed to be more socially acceptable for older but not younger adults to consider and plan for their deaths, such as by preparing last will and testaments, making funeral arrangements and completing ADs. Aging seemed to help participants come to terms with their own mortality possibly because aging and increasing experience with death made their own mortality difficult to ignore. Also, the social acceptability of death discussions and EOL care planning that accompanies aging no doubt fostered a more hospitable environment for AD completion among older participants.

However, a number of barriers to AD completion continue to exist for many individuals. The eight participants who had not yet completed their advance directives expressed positive attitudes toward ADs, and indicated that they wished to one day complete advance directives. However, these eight participants seemed to lack the knowledge or the proper motivation to complete their advance directives. Their experiences are discussed below.

Willing but Not Ready

There were eight participants who reported not having advance directives at the time of the interview- five of which were young college students and three of which were in their fifties and sixties. Overall, these eight participants expressed positive attitudes toward advance directives and also indicated that they would like to complete advance directives at some point in their lives. When asked why they had yet to complete their ADs, they gave a range of answers that could be classified into five broad categories. First, the nature of advance directives themselves deterred people from completing the documents. Second, access to the actual documents as well as information about ADs was identified as a barrier by several participants. Third, fears or concerns about end-of-life care planning contributed to lack of AD completion.
Fourth, some people wanted to complete ADs at some point but were procrastinating. Finally, the act of naming a surrogate created a dilemma for some. The underlying issue of the unpleasant nature of death and the desire of individuals and society to avoid death appeared to limit AD completion.

*Nature of Advance Directives.* The format and content of ADs and even the terms *advance directives* and *living will* can create confusion and serve as a barrier to AD completion. The wording used to express one’s wishes in ADs is rather technical and was described by a number of participants as “legalese.” Several participants believed that the very technical and legal wording of ADs could intimidate people with lower levels of education and could make ADs difficult for the average American to understand. When reflecting on her living will, one participant described the language in the document as “cold and uncaring.” Two participants stated that not only the wording but also the structure of ADs (i.e. fill-in-the-blank options, small font, and lack of white space on the page) could make ADs appear to be cold and impersonal or difficult to read. Georgia, a professor at the local university, expressed her concerns about the living will document available on the National Hospice and Palliative Care Organization website:

> …the readability level of a document like this is very high. Uh, most Americans read at a 4th to 6th grade level, and although I appreciate the instruction box on the left-hand side, [an instruction box on the form indicates that an alternate surrogate should sign on a particular line] “alternate surrogate”…I’m not sure many people would understand what “alternate surrogate” meant. Um, even the title of the document “Designation of Healthcare Surrogate”- I don’t think people walking on the street would understand that language. So my feeling right off the top is we have to…we as a community have to make this document much easier to read and understand, and we have to make it look easy to read and understand.
Though the living will to which Georgia was referring contained instructions in a box on the left-hand side in an attempt to facilitate completion, she noticed that the wording and physical appearance of ADs may confuse individuals and create a barrier to AD completion.

Five participants complained that the current living will documents used by many institutions lack the detail necessary to allow patients to fully express their wishes. These participants stated that ADs did not have clear, specific language, and the pre-determined options stated in the living will were too limited. Three participants specifically complained that the current living will documents lacked a section to specify wishes regarding hospice or palliative care, which could play an important role in providing quality end-of-life care.

Finally, the actual titles for end-of-life care planning documents appeared to be problematic. During the interviews, several people confused living wills with last will and testaments, and professionals also indicated similar confusion among their patients/clients. One doctor complained that the terms advance directive and living will were confusing because it is difficult to determine the function of these documents by their names alone. A number of other barriers to AD completion beyond the documents themselves was identified in the interviews including difficulty accessing ADs and information pertaining to ADs.

Access. Gaining access to information about advance directives and accessing the physical documents themselves are major steps in the process of completing the end-of-life care planning documents. The eight participants who reported not having advance directives at the time of the interview were asked where they would go to obtain advance directives. Though many of these participants named facilities (i.e. lawyer’s office, courthouse or hospital) that could provide them with advance directives or at least information on how to acquire the documents, they expressed uncertainty about their responses. Of these participants, the ones who
expressed the greatest uncertainty were predominately the young, college-aged participants. The response given by Rachel, a twenty-one year old college student, when asked where she could obtain advance directives echoes the uncertainty expressed by the other four college-aged participants:

I have no idea. The thing that would come to my mind, the first thing I guess would be to call a lawyer, and I don’t know if that’s the right step or not.

Two of the older participants without living wills appeared to be somewhat more confident and accurate in naming ways they could gain access to advance directives, one of these participants, Susan, argued that accessing advance directives is still no easy task. The third older participant stated that she did not know about advance directives until her participation in the current study brought the topic to her attention.

Susan, a fifty one-year-old mental health worker who had served as her mother’s surrogate in Illinois, named a number of places where she could obtain an advance directive, but she also expressed frustration when discussing the effort needed to acquire information about the documents as well as obtain the documents themselves. Susan’s comments highlight the lack of information regarding advance directives readily available to the public:

(Researcher) I know you verbally expressed your wishes. Have you ever considered writing them down?

(Susan) I’ve really thought about it. I understand that I need to. It’s one of those things that I would have to hunt to find…it’s not something that even at retirement even though the AARP has become a pen pal of mine …nothing on that has been mailed to me…I feel the AARP could find me, and I am close personal friends with people in Saudi Arabia [referring to scam mail] you think people could find me to send me information about long term care or wills or something of that sort. But it’s not something that has come to me easily, and I would have to hunt and find. I understand I could go online and find it probably very easily by Googling in “living will” um, but I have not done that.
(Researcher) I know you mentioned online. What do you think might be some other places you could go to get the forms?

(Susan) I would probably go…I would assume that most attorneys have them. I would assume that I could go to like a hospice or someplace like that. More than likely, I was going to say, more than likely the AARP or some of those places, besides Googling I would think that there would be some specific sites that I could go to online, and honestly I don’t know beyond that. I’m sure there are more. Probably any treatment center that deals with chronic illnesses, uh, would have something like that. I know that the Agency on Aging would have some of that kind of stuff. If I stop and think seriously and put my work brain to it, I could probably figure it out, but the work brain and the personal brain probably don’t talk to each other a lot…you just don’t just trip over it easily. You have to purposefully go for it.

Susan listed a number of places where she could obtain advance directives, but she indicated that AD information is not easily obtainable.

A number of participants stated that public awareness of advance directives as well as access to advance directives themselves has improved over time. However, it is evident from the eight participants without ADs that awareness of and access to advance directives is still lacking. Most of the eight community members without advance directives seemed to lack the proper knowledge to confidently go about obtaining advance directives. A lack of knowledge regarding advance directives could prevent individuals from considering and completing advance directives.

Lack of Information. This lack of knowledge regarding advance directives was also obvious when professionals stated that they often had to educate people and about the end-of-life care documents. A number of professionals noticed that their patients/clients did not fully understand the legal policies regarding ADs. Also, patients and families did not possess enough medical knowledge about the types of end-of-life decisions involved in ADs. Insufficient information about ADs can create a barrier to AD completion among the general population while also leading to baseless fears and concerns about end-of-life care and ADs.
Below is just one example of how a lack of knowledge about laws can serve as a barrier to AD completion. A number of the professionals’ clients/patients feared that once they completed their advance directives, their decisions were set in stone and could not be altered. Dr. Campbell’s statement below provides an example of this concern:

…I think the one thing that people seem to think is once they do one [advance directive], they can’t take it back or they can’t change it, or if they’re incapacitated their surrogate person can’t, can’t change it. Of course, that’s not true.

Professionals also mentioned that patients/clients do not understand the need to appoint a surrogate or understand the state laws regarding who can make medical decisions for someone if no surrogate is appointed. For example, common law marriage does not exist in Kentucky, and some patients do not understand that intestate succession laws do not give their long-term romantic partners the end-of-life decision-making privileges equal to those of a legal spouse. Two participants also stated that some patients do not understand when an AD takes effect and fear that surrogates, once appointed, will be able to make medical decisions for the patient at any time and not just when the patient becomes terminal and unable to make his/her own decisions. Several social workers also reported seeing patients’ “do-it-yourself” ADs that were not signed or witnessed correctly. This lack of information reported by professionals was supported by several young participants who claimed that they did not understand what ADs consisted of and frequently confused them with a last will and testament.

As stated earlier, the living will allows individuals to state their preferences regarding the use of life-sustaining technology, such as a ventilator, the use of artificial nutrition or hydration, and, once the patient is declared brain dead, organ donation. Also, ADs allow one to appoint a surrogate who may be asked to make medical decisions regarding other aspects of the dying patient’s care. One would need to be knowledgeable of the medical processes involved to
confidently make the most appropriate decisions regarding one’s end-of-life care, but according to the interviews, this is not the case for most patients.

First, many people are not familiar with the processes that take place in the body as a patient is dying. Many people do not understand what happens when a patient “codes” or stops breathing, is put on a ventilator, or needs CPR. Two physician assistants discussed how a majority of Americans receive their medical information regarding coding, ventilators and CPR from fictional medical dramas rather than factual medical sources. Also, nearly all professionals discussed misunderstandings regarding artificial nutrition and hydration, especially the medical factors involved in withholding nutrition and hydration from a dying person. Below, Grace, the palliative care social worker, describes the complexities involved in helping families and patients make decisions regarding artificial nutrition and hydration:

You got some that really don’t understand it and then what little bit of knowledge they do have they make a decision that you know, “I don’t want to have my parent…starving to death. I feel like I have to…have a feeding tube placed.” Um, you know, a lot of misconceptions on what is involved with an AD and…how important it is for the particular patient to be able to make their own decision, and you know, I truly feel like it needs to be a decision that is the patient’s but it also includes the family. Um, sometimes they get a little more knowledge and they feel more comfortable with it…and so there’s a lot of misconceptions still, you know. I think we’ve educated quite a bit, but I’m sure there’s still a long way to go.

Grace illustrates the importance of educating families and patients so they can make difficult end-of-life care decisions and how misinformation can further complicate the decision-making process for patients and family members.

Misinformation regarding organ and tissue donation was also addressed by participants. Two social workers stated that many patients decide against organ donation because they believe they don’t have anything useful to donate, and the social workers have to educate the patients about how most people are able to provide useful tissue donations once dead despite being
elderly or having health problems. As consumers, Americans are encouraged to arm themselves with information when making purchases or selecting physicians in an attempt to make the best choice, and ADs should be no different. Being equipped with accurate information regarding the dying process in general as well as various medical procedures that could be employed during the dying process could allow people to be better informed when completing their ADs and can alleviate potential fears or concerns generated by misinformation and lack of information regarding end-of-life care.

Fears and Concerns. This misinformation discussed above has the potential to breed unfounded fears and concerns regarding end-of-life care. The interviews revealed fears and concerns about the AD documents in general as well as fears and concerns about specific decisions encompassed in these documents. Not only do these fears and concerns cause unnecessary anxiety regarding end-of-life care, they may also deter people from completing ADs.

General fears about ADs involved two main categories: 1) the fear that ADs could be abused by companies or the government and 2) the fear that having an AD would result in the patient receiving no treatment. A small number of community members voiced concerns regarding the first category. For example, one participant feared that health insurance companies and doctors might start requiring patients to have ADs in order to drive down medical costs associated with aggressive end-of-life care. Another participant feared that ADs could be misused to rid a society of sick or elderly members who are deemed “useless” by that society. These fears emphasize the potential for ADs to be used to the detriment of the patient.

The second category of concerns consisted of the fear that having an AD would result in the patient receiving no treatment for any medical condition, and many medical and social work
professionals as well as several community members addressed this issue. The fear that an AD would result in no treatment stems from a lack of knowledge of the policies regarding ADs. A quote from Tina, a social worker at St. George’s hospital, demonstrates the need to clarify when an AD goes into effect:

I always try to break it down really simply and say, “Okay, listen, if you leave here tomorrow, and you’re in a car wreck, and you come in the emergency room, they’re not going to go, ‘Oh, they have a living will. We’re not going to do [anything]. Everybody take your hands off.’ They’re going to treat you because at that point we don’t know what the outcome is going to be.” Um, and so that’s always I think a misconception we have to clear up with them…

Most of the professionals interviewed stated that they have to educate patients/clients regarding ADs and AD policies in order to reduce fears and anxieties that may stem from a lack of trust in our bureaucratic, business-minded healthcare system as well as a lack of information about how ADs work.

Fears and concerns about the specific directions outlined in ADs appeared to stem from inadequate knowledge about specific end-of-life care issues and about general AD policies. Decisions about artificial nutrition and hydration evoked a great deal of fear and anxiety according to a number of people interviewed. Professionals claimed that many of their patients/clients feared being unhooked from artificial nutrition or hydration prematurely and starving or dehydrating, and several community members echoed this sentiment. Also, a number of participants reported hearing that doctors allow patients who are organ and tissue donors to die so that organs and tissue can be harvested. Though none of the participants claimed they believed this statement, the belief that doctors allow donor patients to die in order to harvest the patients’ organs and tissues seems pervasive in our society. Below, Scott, a twenty-one-year-old college student, discusses his feelings toward organ donation:
…my stepmother…feels that…there’s this stereotype, and there’s this stigmatism, if you become an organ donor that you’re going to instantly die and everything’s [all of one’s organs are] going to be given away, but I don’t think that’s the case because I think both my sisters are organ donors, and I just haven’t got up the gumption to go ahead and do that. I think I’m still afraid of sort of what they’ve said.

Scott acknowledges that his stepmother’s belief about organ donation is a “stereotype” but he also claims that this stereotype has contributed to his hesitancy to become an organ donor. A number of community members stated that they did not want to be “given up on” immediately by medical professionals but at least wanted some intervention until it was determined that they were not going to survive. These community members often spoke of hope that they would survive a medical ordeal and did not want to have medical interventions withheld or removed prematurely if there was a chance of survival. However, at the same time they also mentioned that they did not want to be allowed to linger with no quality of life if they had no hope of recovering. These concerns reflect the complexity that is often involved in advance EOL care planning, especially when, unlike a terminally-ill patient, one is in good health and has no idea of how one might die.

Educating patients, clients, and family members regarding end-of-life care and advance directives was an important role played by many of the professionals interviewed. Supplying individuals and families with correct information about advance directives and end-of-life care could help eliminate fears pertaining to advance directives thus improving advance directive completion rates. However, as Janet, a former nurse and current physician assistant, describes below, just having correct information may not be enough to motivate people to complete their advance directives:

I think there’s undoubtedly more information available than there used to be, a lot of it secondary to computers. Uh, and even the less sophisticated folks out there are getting online, they like to do email, to look up things, and so I think
the information is available, but the information being available, and them accessing and putting it to good use are two different things…

What factors might contribute to this gap between having information on advance directives and actually completing the documents? For those who indicate that they wish to one day complete advance directives, procrastination caused in part by fear or denial of death may contribute to low completion rates among both young and old adults who overall have rather positive attitudes toward advance directives.

**Procrastination**. Participants without advance directives also cited procrastination as a reason for not having advanced directives. Not surprisingly, the older participants without advance directives tended to have at least given some thought to completing advance directives while younger participants devoted little if any time to thinking about end-of-life care planning. A number of the professionals interviewed also named procrastination as a barrier to end-of-life care planning that they had observed among patients. Procrastination appears to be linked to denial of death.

Item 13 of the Advance Directive Attitude Scale stated “I am not old enough to have an advance directive.” The mean ages of participants who responded to the item with “agree” (21.48 years) and “strongly agree” (30.43 years) were younger than those who answered “disagree” (36.04 years) and those who answered “strongly disagree” (42.09 years). These mean age differences were statistically significant at the .001 level. Overall, younger survey participants did not believe they were old enough to need advance directives.

The same trend was observed among young interview participants. The young interview participants with no advance directives listed their age as one of the reasons they had not completed ADs. Several young participants indicated that because they were young and had not yet started families, they did not need to worry about preparing their own advance directives
by taking care of it themselves, and 9 participants, including college students, older community members with ADs, as well as professionals discussed the difficulty of getting young adults to see the need to complete ADs and referenced the expression that the best people to send to war are young adults because they think they are immune from death. Alex, a twenty-five-year-old community member, explains why he had not yet completed advance directives:

> Well, besides the fact that I’m just lazy I guess, I don’t know, I mean…for the most part, you know, I tend to think of death or even a situation that leads to death as something far in the future for me. I know actually that that’s not necessarily true, that could happen at any moment, but I guess that’s pretty much the main reason- I keep putting it off because I keep thinking well, there’s always tomorrow.

Though the young adult participants without ADs acknowledged that they should eventually prepare their ADs because death was inevitable, they saw their deaths as being in the distant future and not something to be concerned with at the time. Indeed with the average life expectancy for Americans in 2010 being 78.7 years of age (Murphy, Xu, and Kochanek 2013), many young Americans can expect to live to old age, but of course, no young American can be sure where he or she will fall on the bell curve of life.

These young participants without ADs also acknowledged that their families and friends would think it was odd for them to be talking about end-of-life care, and Michael, an 18 year old college student, illustrates this concept while speculating on how his parents, particularly his mother, would react if he came to them with his living will:

> Uh, my mom would probably walk away crying <laughter>. No, uh, they would think it was strange, of course, for somebody my age. They would support it, of course. I would explain that everybody has to have some wishes for what they want done when it gets to that point in their life. They would support it, but they would think it was strange.

According to developmental theory, young adults are in the novice stage of development. In this stage, young adults experience opportunities to test their skills and abilities, seek to reach their
fullest potential in their lives, and often start families of their own (Levinson, Darrow, Klein, Levinson, and McKee 1978). Thoughts of death seem contradictory or counterproductive in this stage.

Two of the older adults without advance directives stated that they could and probably should complete their advance directives, but they had not gotten around to doing so. Joan, a nurse with thirty one years of experience in the healthcare field stated that she simply hadn’t gotten around to completing her advance directives, but she also stated that her reason for procrastination was not because the topic of death or end-of-life care frightened her. Susan, a 51 year old mental health worker, stated that even though she knew of a number of places to go in order to obtain an advance directive she had not taken the initiative to obtain information about ADs or seek out the documents themselves. A number of professionals listed procrastination as one of the main barriers to advance directive completion, and though the younger adults discussed above procrastinated because their youth gave them a sense of immunity from death, many older adults procrastinate as well. Janet, a healthcare provider with four years of experience as a physician assistant and nearly thirty years of experience as a registered nurse, describes her thoughts about procrastination:

…even those of us [who] know and understand the risks associated with not having a [living] will, uh, sometimes, as in my case, I kind of procrastinated, you know, “I’ll do that next month. I’ll go in…,” and I finally did it, but um, people tend to put things off that are not of an urgent nature or they don’t see it as an urgent nature.

Though many people may not perceive AD completion to be of an urgent nature, one could become incapacitated and need an AD at any time.

Many people find the topic of death, especially their own death, to be unpleasant and tend to avoid discussing or thinking about such a distasteful topic. Seventeen participants, including
professionals and community members, listed this fact as a reason for procrastination regarding end-of-life care planning. Though every participant acknowledged that death was inevitable, many of them also found death to be a topic that was somewhat uncomfortable to discuss or contemplate. Three professionals used the term “unrealistic” to describe those who did not want to think about or plan for their own deaths, and a number of participants described those who were being “unrealistic” because they did not want to think about or plan for their deaths as being in denial about their own deaths. Several participants indicated that this denial on the part of individuals seemed to be linked to the larger culture’s denial and avoidance of death. Most participants also indicated that American culture does not handle death well and seems to avoid or deny death.

Selecting Surrogates. Once an individual has moved beyond procrastination and is considering completing an AD, he/she is faced with the often challenging task of naming a surrogate, or a person to speak on his/her behalf in the event the AD were to go into effect. Considering the duties that surrogates are asked to perform, the task of naming a surrogate should not be taken lightly.

ADs allow an individual to select a surrogate (for the living will) or an attorney-in-fact (for the power of attorney form) to speak on behalf of that individual when the individual’s ADs go into effect (please note that for the rest of this section, the general term surrogate will be used to refer to both the surrogate named in the living will and the attorney-in-fact named in the power of attorney). This task of selecting a surrogate to make end-of-life care decisions posed no problems for some participants but created a dilemma for others. The participants with ADs reported that they had selected family members, particularly their spouses, children, or siblings. However, two of the participants with ADs could not remember who they had selected as their
surrogates. Having open communication regarding one’s end-of-life care wishes with one’s surrogate is a way to ensure that these wishes are understood and carried out by the surrogate.

Two of the attorneys interviewed stated that clients often have difficulty selecting a surrogate because surrogates may face the burden of making difficult end-of-life care decisions for the clients and because the topic of end-of-life care is often difficult for the client to bring up with the selected surrogate. Interestingly, the attorneys interviewed favored living wills that did not require one to name a surrogate because they believed that the living will was effective enough in conveying their clients’ end-of-life wishes and did not require a person to speak on behalf of the client. The attorneys believed that selecting a surrogate only complicated end-of-life planning while several other professionals and community members believed that having an AD and naming a surrogate to advocate on behalf of a dying person was more effective than the document alone.

For some of the participants without ADs, the issue of selecting a surrogate presented a challenge. Several participants stated that they did not want to offend certain family members by not selecting those family members to be their surrogate and found that having to select only one surrogate did not accommodate their close-knit family structure. Susan, who was single and lived over four hours away from her nearest family members, stated that she would have a difficult time selecting a surrogate because she had no one readily available that she could trust to make end-of-life care decisions for her.

The social workers and attorneys interviewed in this study advised their clients to not only share their ADs with the surrogates that were named in their living wills or powers of attorney but to also discuss their wishes stated in their ADs with their surrogates. However, communication about death in general and end-of-life care specifically was identified as a
problem by many of the professionals who participated in this study. This problem was related to the even more pervasive issue of death denial in our society.

_**Communication: Let’s Talk about Dying!**_ Death is an unavoidable human experience, but it is a subject matter that is often avoided in conversations because of its unpleasant nature. Below, participants share their experiences with communication about death. They describe the frequency with which death was discussed in their families during their childhood. Nearly all of the participants claimed that they have had conversations about death and end-of-life care with loved ones. Exactly who participants shared their end-of-life care wishes with was rather diverse including parents, spouses, children, siblings and friends. Also, the level of communication between participants and their loved ones varied greatly. Some participants reported having in depth conversations with loved ones about their wishes regarding their end-of-life care while other participants had little communication concerning their wishes. Overall, age and experience with death and end-of-life care planning seemed to play a significant role in determining the depth of conversations participants had with loved ones.

Community members were asked if death was discussed in their families when they were growing up. Death was an unavoidable topic that was discussed at some point in everyone’s families, but it was discussed more frequently in some families than others. Five participants stated that death was rarely discussed in their families. Two of these participants were very young when one of their parents died after which their remaining family members avoided the topic of death. Donald, a sixty nine year old retired professor with an AD, discusses the circumstances surrounding his mother’s death and his father’s subsequent reaction:

…When I was seven and my mother was forty-one, she got pregnant. She developed eclampsia and she died from it…the story I get is that my father worked on the railroad so he was on a run, and he was a couple of states away when he got the call that my mother had, when she was about eight months
pregnant had gone into a coma, and...my sister and I, I was seven and my
sister was six, and we were the ones that found her...Um, however, having
said all of that, my father was not the type of person to talk about that sort of
thing. He wasn’t good at that at all, and so when I was growing up after age
seven, we didn’t talk about death. It was kind of an unspoken topic. So there
was a sense in which we experienced it in a dramatic way, but at the same
time we did not deal with it.

The remaining three participants were over the age of sixty and believed that the topic of death
was generally avoided by families when they were growing up. Fourteen other community
members stated that death was discussed more frequently when they were growing up, and they
ranged in age from twenty-one to eighty two years. The level of communication tended to vary
from family to family and did not appear to be influenced heavily by the time period in which the
participants were born.

One common problem addressed by most of the healthcare professionals who
participated in the current study involved people not sharing their ADs with their surrogates or
other loved ones. However, the thirteen participants with ADs reported sharing their ADs with
others or discussing their end-of-life wishes in some capacity. The participants who were
married or in long term committed relationships reported sharing their wishes with their spouses
or partners. Participants with children or step-children old enough to understand the concept of
ADs and end-of-life care shared their wishes with their children or step children. Leslie, the only
college-aged participant with an AD had no spouse or children, but she had shared her living will
with her parents. Helen, who had no spouse or living parents, shared her AD with her only
living sibling. Only two participants, Duncan and Emogene Tremble, reported sharing their ADs
with their physicians, and both of these participants were of advanced age, had a history of
cardiac problems and frequently saw their physicians. Several participants reported sharing their
end-of-life wishes with their clergy. Overall, the participants with ADs felt that it was important
to share their end-of-life care wishes with the people close to them who would most likely be involved in their end-of-life care though surprisingly few participants shared their ADs with their physicians.

Most of the participants without ADs also reported having conversations about their end-of-life care wishes with loved ones with results similar to those discussed in the paragraph above. Several college age participants shared their wishes with their parents, and one college age participant did report discussing death and dying issues with his grandmother as well as his parents. The married participants discussed their preferences with their spouses. Those with children old enough to understand end-of-life care concepts shared their wishes with their children. Susan, who did not have family nearby, reported sharing her preferences with several of her close friends. One participant reported that she had not discussed her end-of-life care preferences with others until after she had participated in the quantitative portion of the current study, but after taking part in the study, she shared her wishes with her sons and her husband.

The level of communication between the participants and their loved ones seemed to be influenced by the participants’ age. Younger participants with the exception of Leslie, the only college age student with an AD, stated that they did not discuss death and end-of-life care planning frequently with family members, and on the rare occasions when it was discussed, the conversation was not in depth. Older participants reported having more in-depth conversations with loved ones about end-of-life care planning. Again, discussing death and EOL care planning seemed more socially acceptable for elderly participants.

Just as experiencing the death of a loved one served as a motivating factor for AD completion, experience also appeared to influence communication levels. Those who have experienced the dying process of a loved one were more likely to have had in depth
conversations about their wishes regarding end-of-life care. Seven participants reported experiencing the death of a loved one served as a catalyst for sharing their own end-of-life care wishes with loved ones. These conversations tended to be between the participants and other family members who were directly influenced by the death and often took place while the loved one was dying. Six of these participants were older and were directly involved in the end-of-life care of their parents or in-laws. Four of these participants had completed ADs. Alex, a twenty-five year old community member with no ADs, discusses below how his mom’s illness and subsequent death prompted his family to discuss their end-of-life care wishes in the ICU waiting room at the hospital:

...you know we just started discussing what we wanted if we were in her situation or if we were in some other similar situation um...I mean nobody ever wrote anything down, but we just kind of all discussed back and forth what we all wanted...I mean, it would have been kind of stupid to not even talk about death and end-of-life treatments and all that so I mean that aspect of it came up naturally.

As Alex indicated above, it seems pragmatic to discuss one’s end-of-life care wishes at a time when the topic is salient, such as during the death of a loved one.

Finally, certain current events also served as a trigger for AD contemplation and communication. For example, several participants mentioned the highly publicized Terri Schiavo legal case in which Terri’s husband fought to have his wife’s feeding tube removed after being in a persistent vegetative state since 1990 (Roscoe, Osman, Haley 2006). After numerous legal actions that sparked much activism, Terri’s feeding tube was removed in 2005 allowing her to die (Roscoe et al. 2006). Michael, an eighteen-year-old college student, said that he had never heard about advance directives until he started following the Terri Schiavo case on television, but Michael said that after the media frenzy over the case dwindled, he lost interest and didn’t pursue the topic of ADs farther. Similarly, Daniel, a twenty-one-year-old college student, stated
that the only exposure he had to ADs was through media coverage of the Terri Schiavo case, but Daniel was not motivated by the case to complete ADs. Susan, a fifty-one-year-old mental health worker, recalled how the coverage of the early AIDS epidemic in the United States depicting the rapid decline and suffering of AIDS victims as well as suicide parties held to end that suffering made her think about her own end-of-life care wishes. Tina and Mindy, social workers at St. George’s hospital, recalled how patients would frequently say that they didn’t want to lay in a medical facility with no quality of life like a certain family member or public figure such as Terri Schiavo did. However, Dr. Thompson, the palliative care physician, believed that cases like Terri Schiavo, Karen Ann Quinlan and Nancy Cruzan were so rare that such cases should not be used to bolster advance directive completion among young, healthy adults. Dr. Thompson explained that young, healthy adults are a poor fit for ADs compared to chronically ill patients who have a better context in which to make their end-of-life care plans. Also, these publicized events did not seem as effective in motivating participants as personal experiences with death.

Regardless of AD status, many participants stated that communication about end-of-life care was not always easy or that they weren’t always comfortable broaching the topic of their own death with loved ones. Nearly every participant identified particular family members who were very uncomfortable discussing death. For example, one participant stated that she was amazed at how her husband’s side of the family refused to discuss death and plan ahead for funerals. Few participants stated that they themselves were uncomfortable discussing death, and their attitudes toward death are discussed below.
Attitudes toward Death

Overall, the interview participants expressed somewhat positive attitudes toward death. Of the twenty-one participants who were asked about their attitudes toward death, nineteen indicated that they did not dread death, and fifteen of these participants claimed that they had become more comfortable with and accepting of the concept of their own death over time. These fifteen participants were older and indicated that their attitudes toward death had changed with them becoming less afraid of dying and more accepting of their own deaths as they aged. None of these nineteen participants expressed extremely positive attitudes toward death, however, and most of them claimed that death still caused them some anxiety because what happens to a person after his or her death is a mystery. Several participants also indicated that they feared the prospect of pain and suffering associated with the dying process.

Two participants expressed only negative attitudes toward death. These participants were both college students in their early twenties. One of these participants explained that he feared death because he feared the prospect of an afterlife where he would experience eternal damnation. The second participant stated that she loved life and wanted to live as long as possible and would want every medical treatment available to extend her life. Neither of these participants expressed positive attitudes toward death during their interviews.

Death in America: the Larger Social Context

The participants’ attitudes toward death were most likely influenced by American society’s treatment of death and dying. The vast majority of interview participants believed that American culture denies death. Five participants discussed how death has become increasingly institutionalized over time with more people now dying in medical facilities than at home. Andrew, a physician assistant, discussed how care of the dying is now predominately performed
by trained medical professionals rather than family members, and now family members are
disconnected from the consequences of the medical decisions they make for their dying loved
ones. Andrew believed that this disconnectedness makes it easier for family members to request
life-sustaining treatment that may reduce the quality of their loved ones’ lives since these family
members do not have to see the direct consequences of their decisions. Also, few Americans
know what death looks like, and as Janet, a physician assistant, says, “…people these days don’t
generally witness someone dying, and so they don’t know what to expect.” Andrew recalled a
time in which he educated a woman whose mother was dying in the nursing home where Andrew
worked about the physical reactions that take place during the dying process so this woman
would know what to expect during her mother’s dying. After her mother’s death, this woman
thanked Andrew for his honest description and said that it made her mother’s dying process a
less frightening experience to witness. Another participant stated that few Americans see dead
bodies in their natural state because current funeral practices present embalmed bodies that are
meticulously groomed.

Americans not only avoid seeing death, we also avoid discussing it. Six participants
addressed the concept of death as a taboo topic in American culture. These participants had
observed people who avoided discussing death because they believed that by talking about or
planning for their own death, they would bring on their own untimely demise. Four participants
noted that some people believe that discussing death with a patient who was dying was seen as a
loss of hope for the patient’s cure and could expedite the patient’s death. Dr. Thompson, the
palliative care physician, below, discusses this belief:

…it’s thought of as something like, [a] taboo topic. For families, I think it’s
still very much of a society where death is defied, where they just avoid
discussing death. There’s all of [these] issues about, “If you think about
death, you might be throwing away hope.” Of course, that’s ridiculous, but
that’s a big part of it, especially with cancer patients who are taking chemo that may or may not help...

Three other participants complained that American culture lacks adequate social norms for handling death and dying, and they believed this created barriers to discussing death. Fear of death, a desire to hold on to hope, and a lack of social norms appeared to contribute to a lack of communication regarding death.

Though death is frequently portrayed by the media, several participants argued that it is not portrayed in a realistic manner. Two of the medical professionals interviewed complained that medical dramas create unrealistic expectations in which everyone who is given CPR survives with no negative consequences. Two other participants observed that death is either glamorized by the media thus glossing over the harsh realities of death or it is depicted as a paranormal event in which the dead walk the earth as ghosts, vampires or zombies thus creating unnecessary fears regarding death. The participants believed that the media frequently use death to entertain its consumers rather than educate them about the realities of death.

How the medical culture approaches death in America was also addressed by participants. One of the physicians interviewed criticized the medical community’s focus on saving lives at the end rather than spending more time and money practicing preventative medicine to improve the lives of those who are not actively dying. Several participants expressed concern that physicians have too much control over the lives of dying patients- a fear that one community member expressed when she said that doctors sometimes play God. Five participants indicated that death was viewed as a failure for medical professionals, and aggressive or futile measures to save the lives of dying patients could be an attempt to avert failure. One might speculate that even within the hospital, death is hidden and avoided, especially among the medical staff trained to save lives.
Religion

According to modernist theorists (i.e. Willmott 2000; Mellor and Shilling 1993; Giddens 1991), the influence of religion in the lives of individuals has become eclipsed by scientific reasoning, but religion appeared to play a significant role in discussions about death and dying. Most of the medical professionals interviewed had observed how religion can provide comfort to dying patients, and religion appeared to have a major influence on many of the participants’ attitudes toward death. Nearly all of the participants interviewed stated that they were affiliated with the Christian faith though the researcher did not specifically ask them about their religion, and Christianity’s teachings about the afterlife provided comfort to many of the participants. In fact, fifteen participants stated that because they believed they would go to Heaven when they died, they feared death less. Shirley, a sixty six year old Christian, said that her religion made death “seem less like a death sentence” because she believed that she would experience something better in death when her life on earth became more of a burden than a joy. Several of the professionals interviewed discussed the important role of religion in the lives of their patients/clients in helping the patients/clients to more willingly accept death. Robert, the social service director at Sunset Nursing Home, stated that many of his clients chose to have Do Not Resuscitate Orders (DNRs) because they believe that when God says it is their time to die, it is their time to die, and no amount of medical intervention will undo God’s Will.

Two participants stated that their religious beliefs had no impact on their attitudes toward death because their own personal religious beliefs did not focus on the afterlife. Finally, the remaining four participants indicated that their religious beliefs fostered death-related anxiety. Three of these participants were older, well educated, and attended local Christian churches, but they questioned the existence of an afterlife, which created some anxiety and discomfort for
them because the concept of ceasing to exist seemed unpleasant to them. Daniel, a twenty-one year old college student, had previously belonged to the Pentecostal church but had stopped attending services, and this caused him to fear eternal damnation. For many participants, religion, especially the concept of an afterlife provided by one’s religion, eased death anxieties and offered comfort, but for a few, religion failed to provide comfort and even created anxiety or fear.

While dying and death are universal human experiences, every culture has a unique treatment of dying and death. These unique treatments most likely shape the attitudes that individuals within these cultures have toward dying and death. How the institutions of family and religion influence attitudes toward death were touched upon above. America’s treatment of dying and death will be discussed in greater detail below.

*Sequestration of Death*

Sequestration of death may be effective at limiting routine exposure to death and softening the blow that death takes to one’s ontological security, but death is an inevitable factor of life that cannot be ignored indefinitely. Death is hidden physically within medical institutions, and professionals are most often responsible for preparing and burying the bodies of the deceased. Death also appears to be socially sequestered in American culture where euphemisms are used to refer to death, conversations about death and dying are often avoided, and traditions and norms regarding death have dwindled. American culture’s treatment of death appears to be a barrier to AD completion by making death a difficult topic for which to plan and discuss.

The physical sequestration of death became more apparent when older participants compared their childhood experiences with death to their current experiences. With the widespread use of hospitals, nursing homes and funeral homes, people do not have as many
firsthand experiences with dying and death as they once did. Several older participants mentioned that most people today have never seen someone die, and they recalled being present for the deaths of family members when they were younger. This lack of experience with dying and death creates a dearth of knowledge regarding the dying process, and medical staff reported that they often have to educate family members of dying patients about the dying process so the family members will know what to expect when the patient expires. This lack of exposure to death was also found to create unnecessary fears and anxieties regarding EOL care treatment. Older participants also recalled how people would sit up with the dead in shifts and how they would prepare the bodies and dig the graves. The professionalization of dying and death has allowed most people to avoid a great deal of direct physical contact with death.

Participants also indicated that death was sequestered socially. Participants stated that a lack of social norms regarding death created awkward situations that people often attempted to circumvent by simply avoiding the subject of death. For example, Scott, a twenty-one year old college student recalled finding out months later that an acquaintance’s mother had died, and by that point he simply avoided discussing the topic with the acquaintance because he was afraid that the window of opportunity to say “sorry for your loss” had passed. Amanda, a fifty three year old community member, lamented the fact that we lack mourning rituals, such as the Victorian ritual that required widows to mourn for a year after their husband’s death, because many people pushed her to “move on” before she was emotionally ready after her second husband’s death. A number of participants mentioned that death seemed to be a taboo subject for many people, and even when death had to be discussed, euphemisms, such as “pass on,” were used.
Death appeared to be a widely avoided and unpleasant topic with the exception of some “safe” environments in which death could be discussed. Several participants reported that dealing with the dying process of a loved one made the topic of death easier to discuss with other family members, and attorneys reported feeling that they provided a socially acceptable avenue for discussing death and EOL care planning. Hospice and palliative care workers also indicated that their staff fostered open dialogue regarding death and dying among their patients, the patients’ family members and staff.

In fact, illness seemed to play a major role in bringing up topic of death and forcing people to think and talk about it. Most of the medical professionals interviewed reported that patients were often willing to discuss their own impending deaths but family members were not. Several medical professionals believed that family members of terminal patients overrode the patients’ ADs because the family members were not ready for their loved one, the patient, to die.

Current medical culture also appeared to deny death even though death is supposedly sequestered within medicine. A number of participants were quick to identify what they viewed as problems with medical culture and its treatment of death. Participants believed that death was perceived to be a failure for physicians, rather than a natural part of life. Participants also stated that medical care was so focused on curing and keeping patients alive that physicians had a difficult time seeing comfort measures, like palliative care, as being as legitimate as more aggressive, curative treatments. Several participants complained that physicians, particularly specialists, are quick to perform invasive procedures on frail, elderly, even terminal patients without considering what that patient’s quality of life may be like afterward. Participants discussed seeing patients go through treatments that diminished quality of life and frequently failed to improve quantity of life. Though death is not entirely ignored in medical institutions,
and some medical staff are more open to discussing death than others, death denial is prevalent enough in medical culture for most of the interview participants to have noticed it. Few participants directly acknowledged the role of bureaucratic measures, such as insurance companies only paying for hospitalizations if certain curative measures are being performed, as fostering death denial in the medical culture. Interestingly it is in this environment of death sequestration in which many people are asked about ADs.

While death is a natural, unavoidable aspect of life, it can also be unpleasant and sometimes frightening. Those who are dying may experience pain, and since there is no certainty about what actually happens to a person’s “soul” or “essence” when he or she dies, death may evoke fear and anxiety. Those left behind to mourn experience a range of emotions, many of which are unpleasant. With this in mind, it is no surprise that death is denied and avoided so frequently by our culture, a culture which seems highly focused on youth and vitality while pushing aging and death into the shadows. Sequestration of death seeks to quell our fears and anxieties regarding death by creating a culture of death denial, and in modernity one’s death is reduced from a communal event with far reaching implications to an individual event with an individual, and preventable, cause (Mellor and Shilling 1993). Advance directives seem to appeal to the highly individualized and rational nature of modernity, but they also have the ability to force death out of sequestration by requiring individuals to contemplate their own end-of-life care wishes and to share those wishes with loved ones and care providers. The interviews discussed above shed light onto the factors that hinder or facilitate AD completion, and the implications for these findings will be discussed in greater detail in the following chapter.
Chapter 6: Discussion and Conclusion

The process of completing advance directives (ADs) requires one to think about his or her death including what treatments one may or may not desire at the end of life and who should serve as one’s surrogate. Thoughts of death can generate anxiety and jeopardize one’s sense of ontological security, and modern Western culture has sequestered death within medical facilities like hospitals and nursing homes in order to protect society’s shared sense of reality (Mellor and Shilling 1993; Giddens 1991). Also, the act of completing ADs can evoke a number of emotions and can impact the lives of others, such as close family, friends and even healthcare providers. However, in modernity scientific reasoning has replaced a number of rites and rituals that once provided guidance and certainty and comfort in the face of death, and while science has contributed to myriad advances, it also fails to offer moral guidance instead of creating an atmosphere of doubt (Mellor and Shilling 1993; Giddens 1991). Issues including the sensitive nature of the subject of death, society’s sequestration of death, and the fact that ADs require one to seriously contemplate one’s own end-of-life care wishes and then discuss those wishes with loved ones make advance directives rather emotionally-charged, thought-provoking documents.

Advance directives are also simply documents, and these documents are designed by legal experts, regulated by the Patient Self-Determination Act, and often stripped to bare bones content to meet the bureaucratic needs of the medical institution rather than the needs of the patient (Sabatino 1993). The policies of medical institutions regarding ADs focus on making the process of asking patients if they have ADs or would like to complete the documents an efficient one, frequently mentioning ADs only briefly and only during the intake process (Forbes-Thompson and Gessert 2005). Medical staff, as well as patients, are often poorly educated in the area of death and end-of-life care planning, and American culture attempts to deny and defy
death at every turn (Kaufman 2005). In a time where death is habitually shaped by bureaucratic policies and technological advances that seem to make the patient an outsider to his or her own death, advance directives have the potential to restore some control to the patient, but first the patient must be properly informed and sufficiently motivated to complete the documents.

Despite these challenges to end-of-life (EOL) care planning, a total of 45 (22.8%) of participants in the current study reported having ADs, and even among those without ADs, attitudes toward ADs were rather positive. A total of 197 participants completed the quantitative portion of the study, which consisted of a set of surveys including the socio-demographic questionnaire, the Advance Directive Attitude Survey (ADAS), and the Lester Attitude Toward Death Scale (LATDS). To ensure anonymity, the participants’ names were not attached to their surveys. In addition to the surveys, 39 participants, 21 of which were recruited via the quantitative portion discussed above, took part in interviews pertaining to the topic of ADs. The remaining 18 participants were recruited using a combination of purposive and snowball sampling of local physicians, nurses, attorneys, social workers and other professionals who have experience with end-of-life care planning. The interview participants were assigned pseudonyms to protect their identities, and they were informed that they would be given pseudonyms prior to the commencement of the interview. The results of the surveys were examined in the quantitative chapter of the current study while the findings from the interviews were explored in the qualitative chapter. Both the quantitative and qualitative portions of the current study helped illuminate the issues of death and EOL care planning in general with a specific focus on AD completion. The findings and their implications are discussed below.

The researcher explored the different facilities that participants used to obtain advance directives. While the socio-demographic questionnaire simply asked participants to indicate
where they had completed their ADs, the qualitative portion revealed a much more complex landscape of AD completion than that measured by the socio-demographic questionnaire. Attorneys and medical facilities, particularly hospitals, were the primary avenues participants used for AD completion, but the interviews also indicated that community groups, such as senior citizen groups, were also popular avenues for completion. In addition, five interview participants reported having completed more than one AD, often using different facilities each time. These participants completed new ADs to accommodate their changing needs, such as after a divorce or remarriage, or as a way to update their end-of-life care wishes. The current study revealed that multiple avenues for AD completion exist, including community groups which have the ability to educate a large number of people at one time. The current study also revealed that participants sometimes complete multiple ADs using different avenues as a way to express their changing wishes. Future research could be conducted to improve the effectiveness of community groups in disseminating information about ADs and improving AD completion.

In addition to examining where participants obtain their ADs, five hypotheses were tested using the data obtained in the quantitative portion of the study. The hypotheses served to identify characteristics that, based on previous research, were thought to influence advance directive completion. The characteristics were educational attainment, age, health, attitudes toward death and attitudes toward ADs. Data regarding participants’ age, health and educational attainment were measured by the socio-demographic survey while the LATDS measured attitudes toward death and the ADAS measured attitudes toward ADs.

First, it was hypothesized that participants with higher levels of education would have higher advance directive completion rates than participants with lower levels of education. Previous studies have found that higher levels of education were related to increased knowledge
about advance directives (i.e. Moore, Danks, Ditto, Druley, Townsend and Smucker 1994) and people with higher levels of education were more likely to complete ADs (Duke, et al. 2007). This hypothesis was confirmed. However, educational attainment was positively correlated with age with older participants having more time than their younger counterparts to obtain higher levels of education. Also, while not measured in the current study, income is often positively correlated with educational attainment, and people with higher incomes are also more likely to complete ADs (Duke, et al. 2007). People with higher levels of education and income may have greater access to legal counsel and medical care, both of which are avenues to AD completion. One may also speculate that people with low levels of education and low incomes may fear that ADs will be misused to deny them wanted treatment that they cannot afford.

Second, it was hypothesized that older participants would have higher advance directive completion rates than younger participants. Numerous studies including Teno, Gruneir, Schwartz, Nanda, and Wettle (2007) and Orlander (1999) found that older patients were more likely to complete living wills than younger patients. This hypothesis was confirmed, but as indicated in the paragraph directly above, age and education were positively correlated. The relationship between age and AD completion may be due to the fact that older participants have more time to gain knowledge of ADs and have more opportunities to complete ADs, and younger participants may view ADs as something to complete in old age. For example, Item 13 of the ADAS stated, “I am not old enough to have an advance directive, and younger participants were far more likely to answer “Agree” or “Strongly Agree” to this statement.

The interviews conducted in the current study also shed light on the issue of age and its influence on AD completion rates. A majority of older participants stated that the process of aging has made them come to terms with their own mortality. A number of older participants
stated that aging has made them more accepting of the fact that they are going to die and has made them realize that their death is no longer a distant event they can ignore. Similarly, younger participants reported that they did not feel that it was necessary to plan for their deaths since they tended to view their deaths as events that would take place far off in their futures. Also, it seemed more socially acceptable for older adults, rather than younger adults, to plan for their own deaths.

The interviews revealed that older adults were more likely to have experiences with end-of-life care planning, such as serving as caregivers and healthcare surrogates for close family members like parents and in-laws. Career experiences, such as working in the medical field with dying patients or in a field where death was often encountered, such as working at a cemetery or as an emergency medical technician, emphasized the importance of end-of-life care planning and seemed to make the topic of death more difficult to deny. Experiences served to not only educate individuals about end-of-life care issues but they also motivated them to take action by completing ADs. Many younger interview participants lacked experiences serving as caregivers to dying family members and friends as well as working in death-related fields.

Older interview participants also cited obligations to family as motivating factors. Older participants stated that they did not want to place the burden of making difficult medical decisions on their children and spouses. Many younger participants were not married and did not have children, and several of them stated that they would consider completing ADs when they had family members, such as spouses or children, for whom they were responsible. Also, while older adults seem to be encouraged to prepare for their deaths by completing a last will and testament and advance directives, several younger interview participants stated that it was not as socially acceptable for them to make preparations for their own deaths. These younger
participants believed that their friends or family members would find it odd if they discussed their end-of-life care wishes with them. As mentioned above, age and educational attainment were positively correlated, and many other variables, such as experiences with death and health status, were also closely related with age.

While the sequestration of death is prevalent in American culture as a whole, it seems that special measures are taken to shelter the young from the issue of death and dying. In the past deaths often took place in the home and were far more visible to children, but today death increasingly takes place behind the doors of medical institutions making it easier to shield children from death and making the subject of death a foreign topic for children (Leming and Dickinson 2007). Parents often avoid discussing death with their children, and this may be due in part to the parents’ fear that they will inadvertently transfer their own anxieties regarding death to their children (Elias 1985). Adults may also avoid talking with children about death because they believe that children cannot cope with or comprehend such a difficult subject matter even though research in the field of child development reveals that children can comprehend the subject of death if broached in a developmentally appropriate way (Leming and Dickinson 2007). Protection from the subject of death may be one explanation for the lack of experiences with death among the young adults in the current study. It seems likely that as one ages these protections from the topic death weaken as exposure to death increases.

The third hypothesis was that participants with poorer health would be more likely to have advance directives than participants in good health. Duke et al. (2007) reported that people who were functionally dependent were more likely to have ADs, and this was most likely due to their increased exposure to ADs in long-term treatment facilities and hospitals along with their increased acceptance of their impending death. McGuire, Rao, Anderson, and Ford (2007) also
found that people with increased activities of daily living limitations and chronic illnesses were more likely to have ADs. However, this hypothesis was not confirmed in the current study. Item 4 of the socio-demographic questionnaire stated, “Rate your current health status,” and participants were given the options of “excellent,” “good,” “fair,” and “poor.” Due to low numbers in the “excellent” and “poor” categories, the “excellent” and “good” categories were collapsed into a “good” category while the “fair” and “poor” categories were collapsed into a “poor” category. The “poor” health category contained only 9.1% (N = 18) of participants with the overwhelming majority of participants (90.9% or N = 179) falling into the “good” health category.

The high number of participants in the “good” health category may be due to the fact that a large number of participants were young college students, and even the older adults who participated in the study were recruited from churches and community groups rather than from nursing homes or hospitals. Also, self-report may not be the most appropriate method for measuring health status, and a different technique for assessing health status may have yielded different results. Overall, the participants in the current study perceived themselves to be in good health.

Two items from the ADAS addressed the issue of health and AD status. Item 16 stated, “I am not sick enough to have an advance directive,” to which 66% of participants responded with “agree” or “strongly agree” indicating that ADs may be associated with poor health. Younger participants were more likely than older participants to “agree” or “strongly agree” with Item 16. Interestingly, nearly 92% agreed with Item 15 which stated, “It is better to make an advance directive when you are healthy.” While this was not measured in the current study, it is possible that while older participants did not overwhelmingly report being in poor health, they
may still view their health as having deteriorated over their lifespan causing them to see a greater need for ADs than younger, healthier participants. Future studies could better examine how the intersection of health and age impact AD completion.

Fourth, it was hypothesized that participants with more favorable attitudes toward death would be more likely to have completed advance directives than participants with more negative attitudes toward death. Though the group of participants with ADs had lower mean LATDS scores than the group who did not have ADs, indicating reduced fear of death, the difference between the means was not statistically significant, and this hypothesis was not confirmed. Previous research found that fear of death can hinder end-of-life care planning (Hamel, Guse, Hawranik, and Bond, 2002; Vandrevala, Hampson, and Chrusanthaki, 2002; Windland-Brown, 1998), and Jezewski and Meeker (2007) reported that people who felt more comfortable about death and dying were more likely to think about what kinds of treatment they may or may not want when they are near death. However, comfort with and acceptance of death may not be enough to overcome other barriers to AD completion.

Though the LATDS has been found to be a valid and reliable measurement of attitudes toward death (Lester 1991), it is limited in scope and cannot capture every attitude pertaining to death. It is possible that fear of death and the desire to avoid death does indeed influence one’s decision to complete an advance directive, and a different instrument measuring attitudes toward death, such as Hoelter’s Multidimensional Fear of Death Scale (Depaola, Griffin, Young and Neimeyer 2003), would be more appropriate for similar future studies.

Interview participants overall had somewhat positive attitudes toward death. Only one interview participant cited fear of death, or more specifically the fear of punishment in the afterlife, as the primary reason for not wanting to think about or plan for his own death. Though
a number of interview participants stated that they were not afraid of death because they believed they would have a good afterlife, they feared a painful dying process and were somewhat apprehensive about death because they had never experienced it before. No participant reported that they believed that death was pleasant, but many stated that they would prefer death over living in a great deal of pain with no quality of life. Many participants also reported that the prospect of an afterlife in heaven made the thought of being dead less dreadful, and several well-educated participants who professed to be Christians indicated that their doubts regarding the existence of an afterlife created a sense of death-related anxiety for them.

Finally, it was hypothesized that participants with ADs will have more positive attitudes toward advance directives than participants without ADs. This hypothesis was confirmed. The group of participants with ADs had a higher mean ADAS total score than the group without ADs indicating that people with ADs tend to have more positive attitudes toward them. ADAS total scores were also positively correlated with age and education. Older participants tended to have higher levels of educational attainment, were more likely to complete ADs and had more positive attitudes toward ADs. Interestingly, a small but statistically significant negative correlation was found to exist between the LATDS and ADAS total scores. As fear of death as measured by the LATDS decreased, attitudes toward advance directives as measured by the ADAS became more positive.

The five hypotheses discussed above shed light on the factors influencing advance directive completion, and five research questions guided the data collection and analysis process of the study’s qualitative component. The overarching question that shaped the remaining four questions consisted of two parts and asked, What attitudes do community members possess regarding advance directives? What factors influence these attitudes? A number of medical and
legal professionals discuss ADs and EOL care planning with patients/clients as part of their job. The researcher identified and interviewed professionals who work within the medical and legal fields and engage in interactions with patients/clients regarding ADs in an attempt to answer the question, *How do professionals who work with advance directives (i.e. nurses, physicians, social workers, lawyers) view their roles?* The interviews also attempted to answer the following two related questions: *What do people perceive to be factors that encourage advance directive completion?* *What do people perceive to be barriers to advance directive completion?* Finally, the interviewer sought answers to the question, *What can be done in this community to improve knowledge of and communication about advance directives?*

The modernist theoretical concept of sequestration of death provided the theoretical perspective used to analyze the responses to the above research questions. Weber’s theory regarding bureaucracy and Ritzer’s theory of McDonaldization, which builds on Weber’s work, were also employed to examine how the bureaucratization of medicine has shaped death and EOL care planning. Many of these questions, as well as their answers, are interrelated. The responses to the subsequent research questions helped illuminate the answers to the first, overarching question.

First, the roles of the professionals who work closely with patients and clients to complete advance directives were explored. The medical and legal professionals who were interviewed indicated that very few patients/clients initiate conversations about ADs leaving these professionals to assume the role of broaching the topic of ADs and EOL care planning. However, the act of broaching the subject of ADs varied depending on the specific professional’s occupation and affiliation. For example, some professionals, such as attorneys, were not required by law to discuss ADs with their clients, but they stated that they broached the topic of
ADs when appropriate, such as when clients were elderly or interested in estate planning. The social workers who were interviewed were required to ask patients about ADs during an intake process, and many of these social workers maintained some level of on-going conversation regarding ADs with patients after the initial intake process. The nurses who were interviewed assumed a range of roles regarding ADs with hospice and palliative care nurses being actively involved in their patients’ EOL care planning while other nurses reported being somewhat or not at all involved in assisting patients with ADs. Doctors also reported initiating conversation about ADs with patients since few patients broached the topic.

Once the topic of ADs was broached, a number of medical professionals indicated that they not only discussed the decisions contained in the ADs, but they also facilitated dialogue between the patient and the patient’s family members. This was particularly true to medical professionals working in hospice and palliative care. The professionals reported that most patients/clients responded positively when the professionals initiated conversations about ADs, and because discussion of death is often socially unacceptable, by broaching the topic of ADs, professionals frequently provided a socially acceptable avenue for discussing death and EOL care planning.

In addition to initiating AD dialogue with patients/clients, professionals took on the role of educator teaching patients/clients about ADs and EOL care. The sequestration of death in modernity has shielded many people from death and death-related information creating a dearth of knowledge related to death and dying. A lack of information regarding the dying process, medical care at the end of life, and advance directives was addressed by both professionals and community members. Professionals reported that patients/clients were confused about laws and policies regarding ADs, such as who can sign as a witness on an AD form, restrictions pertaining
to who can be appointed to serve as a surrogate, the ability to change one’s wishes as expressed
in one’s AD, and when ADs go into effect. The medical aspects of death and end-of-life care are
foreign terrain for many Americans, and because of this patients/clients require education as to
what happens when a person codes, or stops breathing, what the dying process is like, what
happens when one refuses artificial nutrition or hydration, and what being an organ or tissue
donor entails. Lack of knowledge can also breed fear, and professionals frequently act to relieve
fears of patients/clients who equate having an AD with receiving no treatment and fear they may
be allowed to die prematurely in order to drive down medical costs or have their organs
retrieved.

Finally, professionals assisted patients/clients in actually completing their ADs. Attorneys’ offices typed the documents, procured the proper signatures, and filed power of attorney forms at the county courthouse. While living wills could be completed at medical facilities, such as hospice or a hospital, power of attorney documents could not be and were completed through an attorney. Social workers at two hospitals in the area reported that nurses asked patients if they had ADs or wanted to complete a living will during the intake process, but social workers rather than nurses actually assisted the patients with completing their living wills. In fact, the social workers, rather than nurses, physicians or physician assistants who participated in this interview, were assigned the task of assisting the patients with their living wills, and in turn social workers were responsible for making sure living wills were distributed to the proper caregivers and placed in the proper files. Luptak (2004) reported that social workers rather than other medical or legal professionals have assumed the role of “shepherd” guiding patients through the maze of end-of-life care decision making, particularly the legal aspects of ADs, but social worker education rarely prepares them for this role. The current study found that while
social workers received little educational instruction regarding end-of-life care issues and ADs in school, they reported that they received sufficient on-the-job and continuing educational training on the topic of ADs and end-of-life care decision making.

Medical social workers play an increasingly important role in patient care as medical care becomes more professionalized and bureaucratized. The social workers who participated in the interviews appeared to have more clearly defined roles regarding advance directives than the nurses, physician assistants and physicians, but social workers were also the farthest removed from the hands-on medical care of their patients. Medical social workers abide by the policies instituted by their medical facility, such as ensuring that living wills are correctly completed by patients and placed in the proper locations and given to the proper people. The interviews also revealed that social workers help patients learn about their choices regarding end-of-life care, make decisions based on their personal desires, values and beliefs, and even communicate those wishes to their families. In these ways, medical social workers seem to bridge a gap between medical care providers, such as physicians and nurses, and hospital administrators.

The first part of the third research question asked, *What do people perceive to be factors that encourage advance directive completion?* Jezewski and Meeker (2007) found that simply knowing about the existence and function of ADs was not enough to motivate most of their study participants to complete ADs, and this also appeared to be true in the current study. The factors that encouraged, or motivated, participants to complete ADs could be classified into four broad categories. First, participants completed ADs as a way to avoid placing both financial and emotional burdens on family, and Jezewski and Meeker (2007) found the desire to avoid burdening loved ones to be a motivating factor for AD completion in their study as well. Participants completed ADs to accommodate their changing family situation, and participants
also used ADs to gain a sense of control over their end-of-life care. Finally, personal or professional experience with death spurred AD completion, as discussed in greater detail above. First-hand experience with death, either in one’s personal or professional life, exposed participants to issues related to death and dying and seemed to lay at least part of the foundation for the three other motivating factors discussed above.

Besides personal experience with death, several participants mentioned nationally publicized events that addressed the topics of ADs and end-of-life issues. Several participants reported that they first learned of ADs or really started thinking about ADs during the highly publicized Terri Schiavo case. Susan, a middle aged participant, recalled hearing about suicide parties among people infected with AIDS during the early 1980s and the Karen Quinlan case when she was younger. Though these events did cause the participants to consider ADs and end-of-life issues, none of the participants who addressed these events had ADs. Personal experience with death and end-of-life care issues seemed to act as a more powerful motivating force for AD completion than distant events related to death regardless of how widely publicized and sensationalized those events may be.

As death has become sequestered, professionalized and bureaucratized in modernity, personal experience with death and dying has become increasingly rare in American society contributing to a lack of knowledge about what the dying process entails and allowing many Americans to figuratively sweep death under the rug. However, first-hand experience with death and dying can help illuminate the process, dispelling myths and alleviating fears concerning dying. In a study conducted by Carr (2012), participants reported that witnessing either the death of a loved one who died peacefully at home, such as a hospice patient, or witnessing the death of a loved one undergoing a number of invasive, unwanted treatments motivated the participants to
complete ADs in order to control their own end-of-life care. One’s occupational experience with death may also impact attitudes toward death. Death anxiety has been found to be lower in occupations where exposure to death is high but risk of death to the employee is low, such as in the medical field versus law enforcement (Bluck, Dirk, Mackay, and Hux 2008). Bluck et al. (2008) found that experienced hospice volunteers had lower levels of death anxiety and avoidance than novice hospice volunteers with no death experience. Many of the participants who reported having experiences with death in the current study also stated that they wished to avoid placing a burden on others and wanted to control their own end-of-life care. Exposure to death, such as the dying process of a patient or family member, may have allowed the interview participants in the current study to think more realistically about their own death and consider what end-of-life care they would or would not want.

Older participants reported more exposure to death with several older participants having cared for loved ones, such as parents and in-laws, in their own homes. Older participants in the current study were more likely to have ADs, and the interviews indicated that older participants were also more likely to have had more experiences with death and dying including serving as the surrogates for loved ones. Jezewski and Meeker (2007) found that age served as a trigger for AD completion as aging participants came to terms with their own mortality. A number of older interview participants mentioned that they have come to view death as a more imminent event than they did when they were younger. It is possible that one’s aging process pulls death out of sequestration and forces one to contemplate one’s own mortality.

The second part to the third research question was, *What do people perceive to be barriers to advance directive completion?* Several barriers to AD completion were identified during the qualitative portion of the study. First, the format and wording of the documents,
particularly the living will, were identified as problematic. Secondly, the issue of access, specifically a lack of access to information about ADs and to the documents themselves, was cited as a barrier to AD completion. Procrastination was cited as another barrier to AD completion; people recognized a need to complete ADs but did not see it as an urgent matter. Finally, the act of naming a “spokes person” or surrogate to speak in one’s place also created an obstacle for some.

Most standard ADs were created by and for bureaucratic agencies rather than by and for the average patient, and because of this, they are often written at a high readability level, contain technical medical or legal wording, and appear to be cold and uncaring making them unappealing to most patients yet appealing among medical bureaucrats and legal professionals. Several participants stated that current AD documents approved by state legislators were difficult for the average American to read and comprehend. Others found ADs to offer a limited number of options and did not include options for hospice care or pain management. Finally, the name advance directive and living will tended to create some confusion and did not seem to adequately describe the function of ADs. Several hospice and palliative care workers mentioned the Five Wishes document as a more personable and user-friendly alternative to the basic state-approved living wills, which are often complex and confusing.

A lack of knowledge about ADs hindered completion, and this was closely related to age. The qualitative portion of the current study revealed that many younger people did not know what advance directives were and how they could access them. Medical and social work staff lamented the absence of knowledge regarding ADs in the general public and often had to dispel myths and quiet fears linked to end-of-life care planning. For example, professionals claimed that a number of patients/clients did not know the circumstances in which ADs go into effect, did
not understand that surrogates needed to be appointed in an AD to avoid intestate succession policies from going into effect, and were not aware that new ADs can be created to meet new needs or wishes.

Besides insufficient knowledge of the legal policies regarding ADs, professionals stated that patients/clients are not familiar enough with the technical medical aspects of dying to make informed end-of-life care decisions in their ADs, and this lack of information tended to generate a great deal of confusion and fear. The fear that ADs would be used to deny any kind of medical care to patients was prevalent. Also, the issues of artificial nutrition and hydration, what happens when a patient codes, and organ and tissue donation were identified as topics that needed the most clarification, and as discussed above, medical professionals, specifically social workers, were required to assume the role of educator in an attempt to reduce this fear and confusion and to assist patients/clients in making informed end-of-life care decisions. The PSDA’s mandate for medical facilities to educate the public about ADs seems to have fallen short, and it is likely that the sequestration of death has contributed to the scarcity of knowledge.

Possessing the correct information regarding EOL care planning may not be enough to overcome the barrier of procrastination. Many young participants did not believe that they were old enough to need ADs, and they reported that it was not socially acceptable for them to plan for death at a young age. Though many younger participants did not view their deaths as imminent, some older adults without ADs knew that they needed to complete the documents but did not perceive the matter to be urgent. Previous studies have found procrastination as the primary reason people gave for not completing ADs (i.e. Douglas and Brown 2002; High 1993). The larger theme of death, particularly American society’s fear and denial of death, seemed to
lurk under the surface of procrastination though few participants actually admitted to being afraid of death.

Selecting a surrogate and the closely related topic of communication about death and EOL care were also identified as barriers to AD completion. Though some ADs do not require one to name a surrogate to speak on one’s behalf, power of attorney documents require that an attorney-in-fact be named, and most living wills contain a section for naming a surrogate. This task was an easy one for many participants who stated that they had no difficulty naming a surrogate in their ADs or knew who they would select if they did complete ADs in the future. However, some participants found the task of naming a surrogate to be problematic because they either had too many choices for surrogate from which to select or they felt like they had no choices. For example, participants did not want to offend other family members by selecting one particular family member and desired the ability to name multiple surrogates, or they had no family members who lived close to them from which to select a surrogate. Some participants, such as Steven, an attorney, suggested that living wills should stand on their own without a surrogate, but others, such as Georgia, insisted that patients need a surrogate to act as a human advocate for the patients’ rights. While the issue of the necessity for a surrogate in the living will is debatable, the task of naming a surrogate presented a stumbling block for some participants who had not completed their ADs.

Communication

It is recommended that people with ADs communicate their EOL care wishes with their surrogates, but this task can be difficult in a society where death is sequestered. Interview participants were asked a variety of questions pertaining to communication about death and dying. First, participants reported diverse levels of communication about death in their families
with some families being more open to discussing death than others, and this diversity did not seem to be linked to the participants’ ages. Most participants could name a particular family member or group of family members who were very uncomfortable discussing death.

Age and experience did appear to play a role in the depth of conversations interview participants had with loved ones regarding end-of-life care planning. Younger participants were less likely to have had in-depth conversations with friends and family about their final care wishes. Participants also reported that experiences with the end-of-life care and death of a loved one fostered in-depth EOL care communication. These participants stated that caring for dying loved ones created a socially acceptable environment for discussing death, provided insight into the dying process, and encouraged them to consider what treatments they would or would not want at the end of their lives. These participants were older than their less experienced counterparts.

Regardless of AD status, nearly all of the community members interviewed reported sharing their end-of-life care wishes with loved ones. Married participants shared their wishes with their spouses, participants with older children often shared their wishes with their children, and some younger participants reported sharing their preferences with their parents. A few participants reported sharing their wishes with other family members including siblings and grandparents. Participants without geographically close family members discussed their wishes with close friends, and a small number of participants shared their wishes with their clergy or physicians. These findings were similar to those obtained by Carr and Khodyakov (2007).

The theory of death sequestration does not state that death is constantly hidden but that when death emerges from sequestration it causes anxiety and is quickly pushed back into hiding (Giddens 1991). Participants did state that death was not a very easy topic to broach, and that
discussing death with others often created an atmosphere of discomfort, especially for certain loved ones who seemed very uncomfortable discussing death. However, experiences involving the end-of-life care and dying process of loved ones created socially appropriate avenues for discussing one’s end-of-life care wishes and other death-related topics. Having these discussions with loved ones and completing ADs did not seem to create a great deal of discomfort but instead made participants feel a sense of relief that they had finally addressed an inevitable topic.

Participants’ Recommendations for Advance Directives

Participants were also asked to identify what can be done in this community to improve knowledge of and communication about advance directives. Their suggestions, which are addressed below, were closely related to the barriers to AD completion that were identified above. These suggestions focused primarily on altering the documents themselves, changing AD policies, and promoting awareness through education and communication.

To improve AD completion rates, participants suggested a number of changes to AD documents. Three participants identified structural issues within living will documents that could make the documents less appealing. For example, participants pointed out that many living will forms have pages containing small print and inadequate spacing between lines of words that give the pages the appearance of being cluttered and difficult to read. Five participants believed that living wills and powers of attorney forms need to use wording that people outside of the legal and medical professions can easily understand. Nine participants recommended that living wills contain more specific statements regarding wishes for end-of-life care, such as allowing one to indicate his/her preferences for palliative care, containing conditional statements pertaining to patient care, and expressing patients’ wishes in more detail than what is allowed in most current ADs. Two participants wanted ADs to allow for multiple
surrogates instead of being forced to select only one. When asked to suggest changes to AD forms, six professionals indicated that they were satisfied with the forms used by their facilities and could not think of any improvements. According to these professionals, their AD forms were custom-made to meet the needs of their facilities.

There are State and federal laws pertaining to ADs. Several participants suggested that these laws be revisited by legislators and revised to better meet the needs of people living in a rapidly changing society. Four participants also suggested a law that would prevent surrogates from overriding the patients’ wishes expressed in ADs.

Participants provided suggestions for making people more knowledgeable about ADs. First, nearly half of the participants suggested that people receive education about ADs and death starting at a young age, such as in middle school, and continuing into adulthood. While some participants suggested simply distributing educational information about ADs, others suggested that knowledgeable professionals, such as social workers, nurses or lawyers, conduct one-on-one educational sessions about ADs at events like health fairs. Four participants explicitly stated that education about the possible outcomes of end-of-life treatments, such as CPR and respirators, should be included as part of the overall AD education because these participants believed such knowledge would assist people in making informed end-of-life care decisions.

Second, participants proposed that efforts be made to promote awareness about ADs. A number of venues were suggested for AD promotion including schools, community groups including senior citizen groups, health fairs, churches, various forms of electronic media, and the American Association of Retired Persons (the AARP), which could mail informative documents about ADs to its members and publish AD information in its newsletter and magazine. Third, physician-initiated conversions about ADs to increase awareness and foster completion were
suggested. Thirteen participants believed that it should be the role of family physicians to initiate conversations about ADs with their patients. However, six other participants believed that this physician-driven approach to AD promotion would not be appropriate because the subject matter might frighten or deter patients, and it would be too time-consuming.

Third, participants emphasized the importance of communication in promoting AD awareness. Three participants recommended that measures be taken to promote communication about ADs among families and in the medical field. They did not provide details about how the promotion of communication should be performed, but they strongly believed that open and effective communication between family members or medical staff about ADs would cultivate interest in ADs and increase AD completion rates.

The participants offered a number of constructive suggestions to overcome barriers to AD completion. The suggestions provided above to improve advance directive documents, alter legislation pertaining to ADs, and increase awareness of ADs through education and communication could be a positive step in increasing AD completion rates in America if they were implemented. However, the issue of death denial in American culture would most likely continue to contribute to low completion rates unless it is openly addressed.

_Death in America_

Interview participants identified a number of barriers to open discussion of death. Participants stated that death has been removed from daily lives and moved into institutions where trained professionals use complex technology to care for the dying. Because death is now sequestered in medical institutions, most Americans do not know what the dying process looks like, and many healthcare surrogates do not have to witness the consequences of their decisions to prolong a terminally-ill loved one’s life. The topic of death is often avoided with some people
fearing that discussing death will actually lead to death or that terminal patients will lose their will to live if they discuss and plan for their own deaths. The open discussion of death is also complicated by our society’s lack of social norms for dealing with death. When death is portrayed by the media, it is often in an unrealistic manner that can generate fear or unrealistic expectations regarding medicine. Participants also stated that the medical field, where many ADs are completed and most deaths take place in America, habitually denies death by focusing on sustaining life through medical technology rather than seeing comfort care at the end of life as an equally acceptable alternative. While most participants indicated that they were comfortable discussing death and planning for their own deaths, they acknowledged that death denial in American culture was pervasive.

Medical care was also criticized for being bureaucratized. Participants expressed concern for the growing number of medical specialists who charged higher rates, sometimes failed to take the patient’s overall well-being into perspective because of their narrow specialized focus and sometimes engaged in turf wars with other specialists. Participants working in the medical field complained that bureaucratic policies frequently prevented them from providing optimal care for patients and sometimes lead to prolonged suffering for terminal patients. Advance directives developed as a way for patients to fight the medical practices that used technologies to prolong life even when quality of life has greatly diminished, but advance directives, like the medical field, have fallen under the control of bureaucratic and legal policies. Are advance directives an effective means of protecting patient rights, or have their bureaucratization left them weak and ineffective? Also, is the issue of death denial, rather than bureaucratization, the root cause of low advance directive completion rates? The answer to the latter question may be a combination of both possibilities with the bureaucratization of death being a means of death denial.
The Role of Religion

Religion, especially Christianity, played an important role in shaping many of the participants’ death attitudes. A number of participants indicated that the prospect of an afterlife made the concept of death less frightening. Professionals in the medical field reported that many of their patients/clients found comfort in religion, and at times religious beliefs regarding God’s Will prevented patients from requesting futile treatment in their ADs. For a small number of participants, their religious beliefs did not impact their attitudes regarding death. However, religion created death-related anxiety for four participants, one of whom feared eternal damnation, and three who questioned the validity of an afterlife and were troubled by the prospect of their lives ceasing to exist.

According to modernist theory, the role of religion has diminished over the course of modernity (i.e. Willmott 2000; Mellor and Shilling 1993; Giddens 1991), but many of the interview participants looked to religion, rather than science, for comfort from the sting of death. Western culture creates a negative image of death and teaches humans to fear death, but religion serves to alleviate that fear (Leming and Dickinson 2006). A study conducted by Leming (1979-1980) found that death anxiety was lowest among people who reported being very religious, and death anxiety was also rather low for participants who claimed to be not at all religious. However, participants who were somewhat religious had the highest death anxiety, and this was most likely because they were aware that they needed to do something (follow certain teachings, turn from sin, etc.) to obtain a good afterlife, but they had not fully committed to the religion in order to reap the benefits (Leming 1979-1980).

Many religions, including Christianity, include teachings about the immortality of the soul either in the form of entering into an eternal afterlife or through reincarnation into a new life
on earth (Leming and Dickinson 2006), and many of the interview participants in the current study were comforted by their beliefs in an afterlife. Science, however, focuses on the physical and biological aspects of dying and provides no evidence of a soul or afterlife. Giddens (1991) stated that in modernity subjective death was particularly difficult for humans to imagine because of the decreased religious emphasis on the soul and the increased focus on self-identity and the on-going project of creating one’s identity. Despite the fact that the current study took place in what Giddens (1991) defines as late modernity, the influence of religion and its teachings about the immortality of the soul persists for the interview participants in the current study. The influence of religion could be due to the fact that the study took place in a predominately Christian region in which a number of participants were recruited from two local churches. Nevertheless, future research could explore the relationship between religion and end-of-life issues to better determine if religion continues to be equally influential in all areas of participants’ lives in late modernity or if religion plays a significant role only when existentially troubling issues, such as death, arise.

**Sequestration or Domestication?**

Death is a natural, unavoidable event that cannot fully be sequestered. Modern philosophers argue that Western culture is currently in the “Resurrection of Death” era, which began with the dropping of the atomic bomb in 1945 and is characterized by the very real possibility of large scale death and destruction (Leming and Dickinson 2006). Giddens (1991) states that “modernity reduces the overall riskiness of certain arenas and modes of life, yet at the same time introduces new risk parameters…[including] high consequence risks,” such as “massively destructive warfare” (p. 4). Today terrorist attacks, AIDS, genocides and ethnocides, wars in the Middle East, and Latin American drug wars serve as constant reminders of death on a
large scale (Leming and Dickinson 2006). Because death cannot be fully controlled or avoided despite human attempts to repress it, death continues to bubble to the surface where it is poses existential questions, evokes reactions and counter-reactions, and is discussed and debated in what Giddens (1991) calls the “return of the repressed.”

Giddens’ work regarding sequestration of death has been criticized for overly individualizing humans, and Stanley and Wise (2011) suggest that Elias’ concept of domestic figuration could be used in conjunction with sequestration to more effectively describe human experiences with death. Elias viewed individuals as existing in figurations, which can be defined as structures and “processes involving the interweaving of people or as ‘chains of interdependence’” (Ritzer 2007: 120). The domestic figuration consists of a “network of relationships concerned with and constituting the familiar and every day and which through the persons of its members brings ‘out there’ and ‘in here’ together” (Stanley and Wise 2011: 952-3). While the domestic figuration centers on the household, it is also linked to micro-level private relations between individuals within the household as well as to macro-level extra-domestic spheres and activities (Stanley and Wise 2011).

One of the roles of domestication is to bring what is seen as “abstract,” “other,” or “out there” into the domestic figuration and make it “concrete” and “own,” and this role is particularly beneficial in the face of death (Stanley and Wise 2011). While death has become increasingly sequestered in modernity with fewer deaths occurring within the home, families still face death and grief. Certain communal rituals and customs that once helped individuals cope with death may have disappeared in modernity, but individuals continue to respond to death as part of networks of interpersonal relations that should not be discounted (Stanley and Wise 2011). Domestication of death, rather than sequestration, addresses the emotional and physical needs of
members in the domestic figuration and helps members put the ineffable character of death into familiar terms (Stanley and Wise 2011).

The qualitative component of the current study revealed that many participants addressed death and end-of-life (EOL) planning in their domestic figurations. A number of participants reported that as children death was discussed by their families, and many participants stated that they talked about death and EOL care wishes with their family members and close friends as adults. Several participants, such as Daisy, Shirley and Barbara, cared for dying loved ones in their own homes bringing the topic of death and EOL care to the forefront of their daily lives. A number of medical professionals reported observing how family members work together to make EOL care decisions for loved ones who are incapacitated, and hospice and palliative care workers encouraged patients and families to discuss EOL care wishes openly with one another. Many participants commented on experiences with death, such as attending the funerals of family members or recalling how certain loved ones died and how the family reacted to the death. Experiences with death and EOL care were instrumental in motivating many participants to complete ADs and discuss their EOL care wishes with members of their domestic sphere.

However, the sequestration of death is still prevalent in modern society. Interview participants provided many examples of sequestration of death ranging from a lack of social norms regarding death to the denial of death in countless aspects of social life. Stanley and Wise (2011) believed that domestication and sequestration of death coexisted in society, and evidence of this coexistence was found in the current study. Elias (1985) described a scene in which a dying patient in a hospital is visited by loved ones, and while the loved ones gave the patient much emotional comfort in the face of dying, the physicians and nurses treating the patient found that the presence of visitors reduced the efficiency of patient care. In fact, many medical
facilities have restricted visiting hours to limit the presence of visitors, and though this may improve efficiency of patient care, the patient’s emotional needs suffer (Elias 1985). The individuals in the current study are inhabitants of the modern, rational world, but they are also humans who have formed close relationships with loved ones. These participants, who the researcher speculates are not unlike most other Americans, must learn to navigate in this world where death is both avoided and unavoidable and where the domestic sphere, which may well be influenced by the sequestration of death, may serve as a guide. The issue of advance directive completion serves as an example of how the domestication and sequestration of death collide.

The current study sought to access the attitudes that people residing in a small, eastern Kentucky community possessed regarding advance directives. The study revealed that overall attitudes toward ADs were positive, but a number of barriers existed to AD completion. For some, aging and experiencing the deaths of others provided the push to overcome barriers, but these factors were not effective for everyone. Attitudes toward death were varied though nearly all participants reported somewhat positive attitudes toward death. While some participants reported fearing the possibility of a painful dying process and fearing death because it was something that they had never before experienced, the prospect of an afterlife in a better place provided many participants with comfort. Despite the modernist claim that the influence of religion has diminished, many participants reported that religion played an important role in how they perceived death.

The bureaucratic nature of advance directive forms did pose a barrier to AD completion, and the sequestration of death appeared to contribute to a lack of knowledge regarding end-of-life care and advance directives. A number of recommendations for improving advance directive completion were provided above. However, it is difficult to imagine how changes in education,
legislation and the AD forms themselves will contribute to real changes in AD completion as well as serious contemplation and communication about end-of-life care unless American attitudes about death are drastically altered. One can only speculate as to how the monumental task of altering the death attitudes of an entire culture will be accomplished, and it is likely that advance directives themselves serve as an indicator that the subject of death in America is becoming more open and less taboo.
References


*Advanced Practice Nursing Quarterly* 4(2): 36-40.

Appendix A- Quantitative Survey Packet

Informed Consent Letter

Dear Participant,

I am conducting a study measuring adult’s attitudes toward advance directives and issues related to death for my thesis research. Your participation in the surveys that will be administered today will make an important contribution to my study.

Your participation in this survey is voluntary, and you may end your participation at any time during the study. Also, you will not receive any rewards from the researcher for your participation. You will not be penalized if you decide not to participate in this study.

You will be asked to answer several questions about yourself, take a survey on advance directives and attitudes toward death, and read an Interview Willingness Form.

Your responses to the surveys will be anonymous. This means that your name will not be linked to your answers for the surveys. You will be asked to sign this consent form if you agree to participate in this study, but your consent form will be collected separately from the surveys in an attempt to keep your survey responses anonymous.

Also, if you are interested in participating in an interview regarding advance directives, you will be asked to sign the Interview Willingness Form and provide your contact information. However, your Interview Willingness Form will be returned in separately from the surveys to maintain anonymity of your survey answers.

Please carefully read all of the questions in the survey and give consideration to your answers so they reflect your genuine opinions and attitudes. Your opinions and attitudes are important to my study.

If you have any questions regarding this survey after leaving here today, you may email or call me. My contact information is listed below. Also, you may contact me if you would like to know the results of my study. Thank you for your time and participation.

Andrea Faulkner
MSU Graduate Student
axfaul01@morehead-st.edu
1-606-776-8142

I, ___________________________, have read this consent form and give my permission to the researcher to use my data in her study.

______________________________  __________________
Signature                        Date
Demographic Questionnaire

Please check or write the most appropriate answer for each question.

1. What is your sex? ___ Female ___ Male
2. What is your age? ___

3. What is your racial/ethnic background?
   ___ African American ___ Caucasian ___ Hispanic ___ Multiracial
   ___ Other (please specify) ________________________________

4. Rate your current health status
   ___ Excellent ___ Good ___ Fair ___ Poor

5. Do you have advance directives (i.e. a Living Will, Healthcare Surrogate Designation and/or Durable Power of Attorney)?
   _____ Yes _____ No

6. If you have advance directives, with which agency (or agencies) did you complete them?
   ___ Primary physician ___ Hospital ___ Hospice
   ___ Lawyer ___ Completed it by myself with no aid from any agency
   ___ Other (Please specify) ________________________________

7. What is the highest level of education that you have completed?
   ___ Less than High School ___ Bachelor Degree
   ___ High School ___ Master Degree
   ___ Some College ___ Doctorate Degree
   ___ Associate Degree

8. Do you consider yourself to be a resident of Eastern Kentucky?
   _____ Yes _____ No
ADVANCE DIRECTIVE ATTITUDE SURVEY

The following statements concern what you think of end of life decisions that are made in a hospital and what you think about making your own end of life wishes known. A “living will” is a paper with your end of life treatment choices in writing. A “health care power of attorney” is a person whom you choose to make health care decisions for you if you become too sick to make decisions for yourself. Both the living will and the health care power of attorney are called “advance directives”. Please indicate to what extent you agree or disagree with each statement by placing an X in the box below strongly disagree, disagree, agree, or strongly agree.

<table>
<thead>
<tr>
<th>Items</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have choices about the treatment I would receive at the end of my life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I would be given choices about the treatment I would receive at the end of my life.</td>
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<td></td>
<td></td>
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<tr>
<td>3. My doctor would include my concerns in decisions about my treatment at the end of my life.</td>
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<tr>
<td>4. If I could not make decisions, my family would be given choices about the treatment I would receive.</td>
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<tr>
<td>5. I think my family would want me to have an advance directive.</td>
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<tr>
<td>6. Making my end of life treatment wishes clear with an AD would keep my family from disagreeing over what to do if I were very sick and unable to decide for myself.</td>
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<tr>
<td>7. Having an AD would make my family feel left out of caring for me.</td>
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<td></td>
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<tr>
<td>8. Making my end of life treatment wishes clear with an advance directive would help to prevent guilt in my family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Items</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>----------------</td>
<td>-------</td>
<td>----------</td>
<td>-------------------</td>
</tr>
<tr>
<td>9. Making my end of life treatment wishes clear with an AD would have no impact on my family.</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>10. Having an AD would prevent costly medical expenses for my family.</td>
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<tr>
<td>11. Having an AD would make sure that my family knows my treatment wishes.</td>
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<tr>
<td>12. My family wants me to have an AD.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>13. I am not old enough to have an advance directive.</td>
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<tr>
<td>14. I trust one of my family or friends to make treatment decisions for me if I cannot make them myself.</td>
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<td></td>
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</tr>
<tr>
<td>15. It is better to make an advance directive when you are healthy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. I am not sick enough to have an advance directive.</td>
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<tr>
<td>17. Having an AD would make sure that I get the treatment at the end of my life that I do want.</td>
<td></td>
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</tbody>
</table>

Thank you!

Revised version of ADAS created by M. Nolan © (2003)
Lester Attitude Toward Death Scale

Please check the appropriate column for each question. If you agree with the statement, make a check in the Agree column. If you disagree, make a check in the Disagree column. Please give a response for each statement. Consider the death in each statement to mean your death at the present time.

<table>
<thead>
<tr>
<th>Question</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What we call death is only the birth of the soul into a new and delightful world.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. One should not grieve over the dead, because they are eternally happy in heaven.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Death comes to comfort us.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Death will be one of the most interesting experiences of my life.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. A peaceful death is a fitting end to a successful life.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I don’t want to die right now, but I’m glad that I will die someday.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Death is better than a painful life.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I would be willing to die to save my best friend.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Death makes all people equal.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Death is a great mystery.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Death is neither good nor bad since there is no consciousness in it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. You can’t take it with you when you die.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I would feel better about death if I knew what it was going to be like.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. It is a pity when a talented person dies, even if he/she has stopped creating.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Death is an unwanted sleep.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Death is to be feared for it brings grief.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I am afraid to die because there may be a future punishment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Nothing can be so bad that a sane person would commit suicide.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Death is the last and worst insult to people.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. I would avoid death at all costs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Death is the worst thing that could possibly happen to me.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Interview Willingness Form

To obtain more in depth information regarding the survey items you just completed, I would like to conduct interviews with interested participants.

If you are interested in participating in an interview in which I will ask you questions related to the information on the surveys you just completed, please complete the form below.

If you are not interested, do not complete this form. You may turn in your consent form, surveys, and this page to the researcher once you are finished.

Thank you for your time.

I ______________________________ am interested in participating in an interview regarding the information discussed above.

(Print Name)

My age is: ________

I am: _____ Male   _____ Female

In order to schedule an interview, the researcher may call me or email me at:

Phone number(s): __________________________________________________________

A good time to reach me by phone is: ____ Morning  _____ Afternoon  ____ Evening

Email address: ____________________________________________________________

Signature: ___________________________________  Date: __________

*Please note:
You have the right to change your mind regarding the interview. If you sign this form today, you can later decide not to participate in the interview and can simply tell me, the researcher, that you are no longer interested in being interviewed when the researcher contacts you to schedule the interview.
What are Advance Directives?

All adults have the right to voice their wishes regarding medical care, especially end-of-life medical care, through documents called advance directives. Every State in the U.S. has its own format for advance directives. You do not need a lawyer to prepare a Living Will or Healthcare Surrogate Designation form, but you do need legal assistance to complete Medical Powers of Attorney.

In Kentucky, advance directives consist of three documents:

1. Living Will
2. Medical Powers of Attorney
3. Healthcare Surrogate Designation

All three documents allow you to name a person, or healthcare surrogate, who will make medical decisions for you in the event that you become unconscious or too ill to voice your own wishes. This is especially true for end-of-life care. The Living Will also allows you to indicate your preferences regarding organ donation, the use of artificial nutrition (i.e. tube feeding) or hydration (i.e. IV fluids).

It is recommended that your physician has a copy of your advance directives in your medical file and that you share your end-of-life healthcare preferences with your healthcare surrogate as well as with friends and family members. This allows your healthcare providers and loved ones to know what kind of medical treatments and interventions you want or do not want.

Where Can I Get More Information on Advance Directives?

Healthcare institutions that receive funds from Medicare and Medicaid are required by law to make their patients aware of their right to complete advance directives. Examples of these institutions include:

- Healthcare providers
- Hospitals like St. Claire Medical Center located at 222 Medical Circle in Morehead, KY; Telephone number: 606-783-6500
- Hospices like St. Claire Hospice and Palliative Care located at 201 Lyons Ave., Morehead, KY 40351; Telephone number: 606-784-6086

Lawyers and medical social workers can also assist you in obtaining advance directive forms.

The National Hospice and Palliative Care Organization website contains information on advance directives:

http://www.caringinfo.org/AdvanceDirectives

The Attorney General for Kentucky has a website about Living Wills in Kentucky:

Grief Counseling

If you or someone you know has experienced the loss of someone close to you and would like to know more about grief counseling services, some agencies are listed below. Also, if any portion of this study caused you undue death anxiety or emotional distress, know that you can contact a counseling agency for assistance in dealing with this anxiety or distress.

- St. Claire Counseling services are available through St. Claire Regional Medical Center located at 475 Clinic Drive, Morehead, KY 40351
  Phone: 1-800-400-4544 or (606) 783-6805

- Hospice at St. Claire Regional Medical Center offers bereavement support groups. Call the number below to find out about dates and times for support group meetings. Hospice is located at 201 Lyons Avenue, Morehead, KY 40351 and can be reached by calling the number below:
  Phone: 606-784-6068

- Pathways, Incorporated has several locations in the Morehead region and offers a variety of mental health services including counseling. Call one of the numbers below to learn about available grief counseling services.
  Phone: 606-784-6068

- A number of local churches offer pastoral counseling services. If you are interested in pastoral counseling, you may consult a recent phone directory or search online for a church that closely matches your religious preferences.

- Morehead State University students and employees have access to MSU Counseling Services, which can provide information and support:
  Phone: 606-783-2123; 112 Allie Young Hall

This list is not exhaustive—other services and agencies that are not included on this list may be available to you.
Appendix B- Qualitative Materials

[Informed Consent for Community Members]

Name of Study: Factors Influencing Completion of Advance Directives

Dear Participant,

You are being invited to take part in a study about advance directives. You are being invited to take part in this research study because you indicated your willingness to participate in the interview portion of this study by signing the Interview Willingness Form when you took part in the survey portion of the advance directive study.

The person in charge of this study is Andrea Faulkner, a graduate student at Morehead State University. Andrea is being guided by a thesis committee consisting of three experienced professors in the Sociology, Social Work, and Criminology Department, Suzanne Tallichet, Ph.D., Robert Bylund, Ph.D, and Carole Olson, Ph.D.

The purpose of this research is to gather information on your experiences, perceptions, and attitudes toward advance directives. The information that you will provide will increase the researcher’s understanding of social worker’s roles in the process of completing advance directives. The goal of my research is to better understand the factors that influence advance directive completion rates as well as improvements that could be made to increase advance directive completion.

The researcher is conducting this research as part of her thesis requirement at Morehead State University, and she is receiving no funding from the university or other agencies. The results of this study will be shared with her thesis committee, and a summary of the completed thesis will be shared with St. Claire Hospice in an attempt to improve their advance directive completion rates.

This interview will take place at the time and location agreed upon by you, the participant, and the researcher, and the interview is expected to last between 30 minutes and two hours. Once the interview is ended, your participation in this study will end as well.

The interview will be tape recorded to ensure that the entire content of the interview is accurately captured by the researcher. You have the right to request that your interview not be tape recorded or that certain comments be made “off record” at which point the tape recorder will be stopped. The researcher will take notes during the interview as well in an attempt to accurately capture what is taking place during the interview.

Please note that the information you provide will be confidential. The researcher is the only person who will have access to the interview tapes and the transcribed notes from the tape recorded interviews. While measures will be taken to maintain confidentiality, please note that there are limits to the researcher’s ability to guarantee that the information discussed in this interview will remain confidential. Also, the researcher is required by law to tell authorities if she believes that you have abused a child or you pose a danger to yourself or someone else.

Information collected during the course of this research project will be compiled and direct quotes from interviews and summaries of interview information will be included in the final thesis project. To protect your identity, the researcher will replace your name with a pseudonym, and the researcher will not include any personally identifying information in her thesis, such as your age, sex, or race.
You also have the right to view the researcher’s write up of her research to ensure that the researcher accurately captured what was said during the interview process. Please check the appropriate space below to indicate your interest in reviewing the write up.

The questions asked during this interview will be about your experience with and knowledge of advance directives as well as any suggestions that you may have to improve advance directives.

Your participation is voluntary, and the researcher will not disclose to anyone else if you did or did not participate in this study. You will not be rewarded for your participation in this interview nor will you be penalized for not participating. You also have the right to refuse to answer any questions and to discontinue your participation at any time during the course of this study with no penalty.

If you have questions or concerns regarding this study, you may ask the researcher during the interview or contact the research using the contact information listed below. You may also contact Suzanne Tallichet, chair of my thesis committee, at the number/email address listed below if you have questions or concerns about my research. If you have questions about your rights as a volunteer in this research, you may contact Mindy Erwin of the Institutional Review Board staff at St. Claire Regional Medical Center at 606-783-6600.

Thank you for your time.

Andrea Faulkner

Additional Contact: Dr. Suzanne Tallichet
Phone: 606-776-8142 Phone: 606-783-2108
Email: axfaul01@morehead-st.edu Email: s-tallic@morehead-st.edu

Please sign below if you give your consent to participate in this study and to allow your interview responses to be used in my research.

_________________________________________            _________________
Signature of Participant                      Date

__________________________________________          _________________
Printed Name of Participant                    Date

______ I want to review the researcher’s write up

I, the researcher, agree to abide by the information stated in the letter above and agree to protect the rights of my participants.

_________________________________________            _________________
Signature of Researcher                      Date
Informed Consent for Medical Professionals

Name of Study: Factors Influencing Completion of Advance Directives

Dear Participant,

You are being invited to take part in a study about advance directives. You were asked to take part in this study because your occupation involves assisting patients with end-of-life care decisions such as those discussed in advance directives.

The person in charge of this study is Andrea Faulkner, a graduate student at Morehead State University. Andrea is being guided by a thesis committee consisting of three experienced professors in the Sociology, Social Work, and Criminology Department, Suzanne Tallichet, Ph.D., Robert Bylund, Ph.D., and Carole Olson, Ph.D.

The purpose of this research is to gather information on your experiences, perceptions, and attitudes toward advance directives. The information that you will provide will increase the researcher’s understanding of different professionals’ roles in the process of completing advance directives. The goal of my research is to better understand the factors that influence advance directive completion rates as well as improvements that could be made to increase advance directive completion.

The researcher is conducting this study as part of her thesis requirement at Morehead State University, and she is receiving no funding from the university or other agencies. The results of this study will be shared with her thesis committee, and a summary of the completed thesis will be shared with St. Claire Hospice in an attempt to improve their advance directive completion rates.

This interview will take place at the time and location agreed upon by you, the participant, and the researcher, and the interview is expected to last between 30 minutes and an hour. Once the interview is ended, your participation in this study will end as well.

The interview will be tape recorded to ensure that the entire content of the interview is accurately captured by the researcher. You have the right to request that your interview not be tape recorded or that certain comments be made “off record” at which point the tape recorder will be stopped. The researcher will take notes during the interview as well in an attempt to accurately capture what is taking place during the interview.

Please note that the information you provide will be confidential. The researcher is the only person who will have access to the interview tapes and the transcribed notes from the tape recorded interviews. While measures will be taken to maintain confidentiality, please note that there are limits to the researcher’s ability to guarantee that the information discussed in this interview will remain confidential. Also, the researcher is required by law to tell authorities if she believes that you have abused a child or you pose a danger to yourself or someone else.

Information collected during the course of this research project will be compiled and direct quotes from interviews and summaries of interview information will be included in the final thesis project. To protect your identity, the researcher will replace your name with a pseudonym, and the researcher will not include any personally identifying information in her thesis, such as your age, sex, race, or name of facility in which you work.
You also have the right to view the researcher’s write up of her research to ensure that she accurately captured what was said during the interview process. Please check the appropriate space below to indicate your interest in reviewing the write up.

The questions asked during this interview will be about your experience with advance directives, your education and training on advance directives, and any suggestions that you may have to improve the implementation of advance directives.

Your participation is voluntary, and the researcher will not disclose to coworkers or supervisors if you did or did not participate in this study. You will not be rewarded for your participation in this interview nor will you be penalized for not participating. You also have the right to refuse to answer any questions and to discontinue your participation at any time during the course of this study with no penalty.

If you have questions or concerns regarding this study, you may ask the researcher during the interview or contact the researcher using the contact information listed below. You may also contact Suzanne Tallichet, chair of the researcher’s thesis committee, at the number/email address listed below if you have questions or concerns about my research. If you have questions about your rights as a volunteer in this research, you may contact Mindy Erwin of the Institutional Review Board staff at St. Claire Regional Medical Center at 606-783-6600.

Thank you for your time.

Andrea Faulkner

Phone: 606-776-8142
Email: axfaul01@morehead-st.edu

Additional Contact:
Dr. Suzanne Tallichet
Phone: 606-783-2108
Email: s-tallic@moreshead-st.edu

Please sign below if you give your consent to participate in this study and to allow your interview responses to be used in my research.

_________________________________________            _________________
Signature of Participant

Date

__________________________________________          _________________
Printed Name of Participant

Date

_____ I want to review the researcher’s write up

I, the researcher, agree to abide by the information stated in the letter above and agree to protect the rights of my participants.

_________________________________________            _________________
Signature of Researcher

Date
Dear Participant,

You are being invited to take part in a study about advance directives. You are being invited to take part in this research study because your occupation involves assisting clients with completing advance directives.

The person in charge of this study is Andrea Faulkner, a graduate student at Morehead State University. Andrea is being guided by a thesis committee consisting of three experienced professors in the Sociology, Social Work, and Criminology Department, Suzanne Tallichet, Ph.D., Robert Bylund, Ph.D, and Carole Olson, Ph.D.

The purpose of this research is to gather information on your experiences, perceptions, and attitudes toward advance directives. The information that you will provide will increase the researcher’s understanding of social worker’s roles in the process of completing advance directives. The goal of my research is to better understand the factors that influence advance directive completion rates as well as improvements that could be made to increase advance directive completion.

The researcher is conducting this research as part of her thesis requirement at Morehead State University, and she is receiving no funding from the university or other agencies. The results of this study will be shared with her thesis committee, and a summary of the completed thesis will be shared with St. Claire Hospice in an attempt to improve their advance directive completion rates.

This interview will take place at the time and location agreed upon by you, the participant, and the researcher, and the interview is expected to last between 30 minutes and an hour. Once the interview is ended, your participation in this study will end as well.

The interview will be tape recorded to ensure that the entire content of the interview is accurately captured by the researcher. You have the right to request that your interview not be tape recorded or that certain comments be made “off record” at which point the tape recorder will be stopped. The researcher will take notes during the interview as well in an attempt to accurately capture what is taking place during the interview.

Please note that the information you provide will be confidential. The researcher is the only person who will have access to the interview tapes and the transcribed notes from the tape recorded interviews. While measures will be taken to maintain confidentiality, please note that there are limits to the researcher’s ability to guarantee that the information discussed in this interview will remain confidential. Also, the researcher is required by law to tell authorities if she believes that you have abused a child or you pose a danger to yourself or someone else.

Information collected during the course of this research project will be compiled and direct quotes from interviews and summaries of interview information will be included in the final thesis project. To protect your identity, the researcher will replace your name with a pseudonym, and the researcher will not include any personally identifying information in her thesis, such as your age, sex, race, or name of facility in which you work.
You also have the right to view the researcher’s write up of her research to ensure that the researcher accurately captured what was said during the interview process. Please check the appropriate space below to indicate your interest in reviewing the write up.

The questions asked during this interview will be about your experience with advance directives, your education and training on advance directives, and any suggestions that you may have to improve the implementation of advance directives.

Your participation is voluntary, and the researcher will not disclose to coworkers or supervisors if you did or did not participate in this study. You will not be rewarded for your participation in this interview nor will you be penalized for not participating. You also have the right to refuse to answer any questions and to discontinue your participation at any time during the course of this study with no penalty.

If you have questions or concerns regarding this study, you may ask the researcher during the interview or contact the research using the contact information listed below. You may also contact Suzanne Tallichet, chair of my thesis committee, at the number/email address listed below if you have questions or concerns about my research. If you have questions about your rights as a volunteer in this research, you may contact Mindy Erwin of the Institutional Review Board staff at St. Claire Regional Medical Center at 606-783-6600.

Thank you for your time.

Andrea Faulkner

Additional Contact:
Dr. Suzanne Tallichet
Phone: 606-776-8142
Email: axfaul01@morehead-st.edu

Phone: 606-783-2108
Email: s-tallic@morehead-st.edu

Please sign below if you give your consent to participate in this study and to allow your interview responses to be used in my research.

_________________________________________            _________________
Signature of Participant                        Date

__________________________________________          _________________
Printed Name of Participant                  Date

_____ I want to review the researcher’s write up

I, the researcher, agree to abide by the information stated in the letter above and agree to protect the rights of my participants.

_________________________________________            _________________
Signature of Researcher                        Date
Interview Questions for Community Members:

1. Would you mind stating how old you are?

2. Have you lived in Morehead your whole life? (If not, where else did you live?)

3. Do you have family members in the area? (Do you have children? Grandchildren? Obtain general information about family composition…)

4. Do you have any advance directives (living wills, powers of attorney, healthcare surrogate)?

5. If yes:
   a. What type(s) of advance directives do you have?
   b. How did you first learn of advance directives?
   c. What factors motivated you to complete your advance directives?
   d. With what agency did you complete your advance directives?
   e. Who did your share your advance directives with?
   f. Currently, where are your advance directive forms? Who has copies?
   g. Did you talk with your family about your advance directives?
   h. Was your family comfortable talking about it? Did they seem okay with your decisions?
   i. How did you decide who was going to make decisions for you?
   j. How did you feel when you were completing your ADs? (Strange? Assuring? Make your nervous?)
   k. Did you share your ADs with your doctor? (Do you feel like your doctor has a good idea of what kind of treatment you would want?)

6. If no:
   a. Have you ever heard of advance directives?
   b. If no, would you like to learn more about them?
   c. If yes, what do you know about them?
   d. How did you learn about them?
e. Have you ever wanted to complete advance directives?

f. Why did you decide not to complete advance directives? (identify certain factors)

g. Do you plan to complete advance directives in the future?

h. Do you know where to go to obtain advance directive forms?

7. Are you comfortable talking about death with others?

8. Growing up, do you remember your family talking about death? Did you have any early childhood experiences with death- family deaths, illnesses?

9. Over your life span, have you noticed changes in your attitudes about death and dying? (as you matured, did your feelings change?)

10. Do you have any fears regarding your end-of-life care, such as receiving treatment you don’t want or not receiving treatment that you do want?

11. What steps, if any, can you take to reduce these fears?

12. How do you feel about EOL care choices? (Respirators, artificial nutrition and hydration, organ donation)

13. For you personally, how would you define quality of life? (Where do you draw the line and say “Enough”?)

14. Have you had experiences with loved ones or friends where you helped make end-of-life decisions? Did the dying person have advance directives? What was the situation like?

15. What would you say are some of the big moral and ethical issues that come up when people talk about EOL care? (Mention something about euthanasia.)

16. Did religion play a role in how you made EOL decisions? Does it influence your attitudes toward death?

17. Do you think there are certain unique characteristics about Eastern Kentucky that might influence EOL care and planning? (Family, religion…)

18. A lot of people do not have ADs. What do you think are some barriers to completing ADs? (What might keep people from filling them out?)

19. What can we do as a community to promote ADs and communication about EOL care planning? (As a state? As a nation?)
20. Do you think age plays a role in how people think about ADs and EOL care planning?

21. Have you noticed changes in medicine throughout your life; differences between now and when you were younger in healthcare?

22. Did you ever talk with your physician about your end-of-life wishes? (Do you feel comfortable doing this? Do you feel like your physician has time?)

23. Have you noticed medicine becoming bureaucratized?
Interview Questions for Physicians:

1. How many years have you been practicing medicine? (When did you go to medical school? Where did you go?)

2. How long have you been with Hospice and Palliative Care?

3. Have you worked in other areas of medicine?

4. Have you worked outside of this community?

5. Did you receive any education in medical school on death, dying, and bereavement?

6. If not, why do you think education in this topic wasn’t available?

7. Do you think having had some education in this area could have helped you in your job?

8. When did you first learn about advance directives?

9. What did you do before ADs came about?

10. Did you receive training on discussing advance directives with your patients?

11. Do you believe it is your duty to initiate discussion of advance directives with patients?

12. If not, whose job do you believe it is?

13. Do you feel comfortable talking with patients about advance directives? Why or why not?

14. When a patient is admitted to Hospice/Palliative Care, what is the process like? Who talks to them about ADs?

15. Talking about death with patients probably isn’t easy, especially when you first started, is there anything that you do to help you initiate these conversations and deal with your own personal feelings?

16. Are there particular subjects/topics that are more difficult to discuss with patients? What are these topics?

17. Are there certain issues addressed in the living will that are more difficult to discuss with patients?

18. Do any of your patients perceive refusing treatment as a form of suicide or euthanasia? How do you help reduce fears and confusion?
19. Do there seem to be some common fears or concerns that patients have regarding EOL care? What are some of these fears/concerns?

20. Do you think that religion or spirituality plays a role in how people deal with death and dying? How so?

21. Do your patients’ family members get involved in EOL care decision making?

22. Do you have situations where some family members’ wishes for the patient differ from the patient’s own EOL care wishes?

23. What do you do to help work out these differences?

24. What do you think are some of the obstacles that prevent patients from completing advance directives?

25. What steps need to be taken to remove or at least reduce these obstacles?

26. Have any of your patients initiated conversation with you regarding advance directives? If so, how did this make you feel, and what were these conversations like?

27. Patients are supposed to share copies of their advance directives with their physicians and have a copy placed in their medical chart. What has been your experience with this?

28. Have you experienced situations where end-of-life medical decisions were made without the aid of advance directives? What were these situations like, and could they have been improved by advance directives?

29. Are you happy with the current AD forms? If you could rewrite them or change something about the current forms, what would you do? (Do you think the wording of the form/language is appropriate or is it beyond many of your patients’ reading levels?)

30. If you could recommend changes in the current advance directive polices and format, what would you suggest?

31. Do you think advance directives are effective in communicating end-of-life medical care desires, or do you believe that some other form of communication would be more effective? If so, please explain.

32. Do you believe that there are certain characteristics of people in Eastern Kentucky that influence EOL care planning and attitudes toward EOL care planning?

33. Do you have anything else you want to add?
Interview Questions for Physician Assistants:

1. Are you originally from Morehead?
2. Could you tell me about your education?
3. Did you receive any education in medical school on death, dying, and bereavement?
4. If not, why do you think education in this topic wasn’t available?
5. Do you think having had some education in this area could have helped you in your job?
6. Could you tell me about your occupations in the medical field?
7. Could you describe what a physician assistant does?
8. In your careers, have you ever had any experience with end-of-life care planning?
9. In your careers, have you ever had any experience with living wills?
10. When did you first learn about advance directives?
11. Did you receive training on advance directives?
12. Have you ever been involved (or even observed the process) in helping a patient/the patient’s family with end-of-life care planning?
13. If you have worked in different facilities over your career, did the different facilities have different policies toward advance directives? (If so, how and why?)
14. Talking about death with patients probably isn’t easy, have you noticed ways that healthcare providers bring up the topic? Do they seem straight forward or do they seem to skirt the issue?
15. What are some common fears and concerns that patients and families seem to have regarding end-of-life care? Are there particular concerns about having a living will?
16. Have you observed situations where a patient was dying without a living will and situations where a patient was dying with a living will? Which situation seemed “better”?
17. Do you have situations where some family members’ wishes for the patient differ from the patient’s own EOL care wishes?
18. What could be done to reduce conflict between family members?
19. (If communication is defined as a problem, what are some ways that communication could be improved?)

20. What do you think are some barriers to advance directive completion?

21. Do you have any solutions to those barriers?

22. Do you think that religion or spirituality plays a role in how people deal with death and dying? How so?

23. Have you witnessed instances where patients initiated conversations with medical staff regarding advance directives? If so, how did this make you feel, and what were these conversations like?

24. Patients are supposed to share copies of their advance directives with their physicians and have a copy placed in their medical chart. What has been your experience with this? (Does this seem to happen very often?)

25. Are you happy with the current AD forms? If you could rewrite them or change something about the current forms, what would you do? (Do you think the wording of the form/language is appropriate or is it beyond many of your patients’ reading levels?)

26. If you could recommend changes in the current advance directive polices and format, what would you suggest?

27. Do you think advance directives are effective in communicating end-of-life medical care desires, or do you believe that some other form of communication would be more effective? If so, please explain.

28. Do you believe that there are certain characteristics of people in Eastern Kentucky that influence EOL care planning and attitudes toward EOL care planning?

29. Do you have anything else you want to add?
Interview Questions for Medical Social Workers:

Training/Job Experience
1. How long have you been a social worker?

2. Could you tell me about your educational background?

3. Could you tell me about the different jobs/positions you’ve held in social work as well as the different geographical regions in which you’ve practiced social work?

4. Did you learn about advance directives in any of your classes?

5. Did you ever take a “death, dying and bereavement” class?

6. Did you receive training at any of your jobs regarding advance directives, especially living wills?

Policies
7. Were you working as a social worker in the healthcare field when the Patient Self-Determination Act was passed in 1991?

8. If so, did you notice any changes that took place in your work as a result of the PSDA?

9. What types of advance directives do the social workers at St. Claire assist patients with (i.e. living wills, healthcare surrogate designation, etc.)?

10. Were these advance directive forms developed by hospital staff specifically for the hospital’s use?

11. Do you feel that any policies regulating advance directives, such as state or federal regulations, limit your ability to effectively assist patients with their advance directives?

12. If you could change any policies regarding advance directives, would you? If yes, how?

Roles/Interactions with Patients and Family
13. Could you tell me about your role in assisting patients with their advance directives?

14. Can you describe some of the ways that you come to assist patients with their advance directives?

15. Are family members often involved in discussions between you (the social worker) and the patient regarding advance directives?

16. Do you notice miscommunication/conflict between patients, health care workers, and family members regarding the patient’s end-of-life care wishes?
17. How do you think these miscommunications could have been resolved?

18. Do you often broach the topic of advance directives with patients? If so, how comfortable are you with doing this, and how do patients react?

19. Are some patients more open to discussing advance directives than others? (Please explain and provide examples)

20. Have you noticed any common features (i.e. demographic features like age, ethnicity, education, etc. or other features) that patients who are more open to discussing living wills seem to have?

Legal Issues
21. What legal action, if any, can a family member or patient take if the patient’s advance directive is not followed by medical staff?

22. What policies does the hospital have in place to help patients/family members if a physician will not abide by the patient’s advance directives due to ethical concerns (i.e. a terminal patient who requested no respirator in his living will has a respirator inserted in the ER and the physician does not believe he can ethically remove the respirator)?

23. A number of “living will” documents exist. Do you know if the hospital has guidelines regarding which forms are accepted as “valid” or does it simply depend on what the patient’s physician is willing to accept? (For example, I have a copy of the Five Wishes living will, but the Five Wishes does not meet Kentucky’s requirements under the law as an advance directive. Does St. Claire explicitly have a policy stating that my Five Wishes living will isn’t valid or does it just depend on what my treating physician will accept?)

Barriers/Suggestions
24. What are some common fears/concerns that patients and their family members tend to have regarding end-of-life care?

25. What are some common fears/concerns that patients and their family members tend to have regarding advance directives (including specific topics addressed in the living will like organ donation)?

26. Do you have suggestions for how these fears/concerns can be alleviated or reduced?

27. What might be some barriers to advance directive completion?

28. Do you have suggestions as to how these barriers can be overcome or minimized?

29. Have you been involved in efforts (i.e. handing out information or speaking to a group) to educate the community about advance directives? If so, could you describe these efforts and how the community reacted to them?
30. Do you have suggestions for how advance directive completion rates could be improved in the region served by the hospital?

31. Do you think advance directives are effective in communicating end-of-life medical care desires, or do you believe that some other form(s) of communication would be more effective? If so, please explain.

Culture
32. Do you believe that our society does a good job of preparing us to deal with death?

33. Have you noticed any characteristics of patients and their family members that seem to be unique to Eastern Kentucky? (This can pertain to medical issues as well as to more general cultural issues.)

34. Do you have any additional comments that you would like to share regarding advance directives?
Interview Questions for Nurses

1. How long have you been working in the nursing/medical field?

2. Where have you worked, and what different areas within the nursing field have you worked in?

3. When were you in nursing school?

4. Have you worked exclusively in this region or have you working in other areas of the country as well?

5. Did you learn about Advance Directives in school?

6. Did you have any classes on death and dying in school?

7. Do you recall when you first learned of Advance Directives?

8. Did you receive on-the-job training regarding Advance Directives, and did you feel this training was sufficient?

9. Could you please tell me about your work experience with Advance Directives (i.e. do you work them on a regular basis, etc.)?

10. What is your role regarding Advance Directives in your current job?

11. Do you believe it is your duty to initiate discussion of advance directives with patients?

12. If not, whose job do you believe it is?

13. How do patients/family members usually react when you discuss Advance Directives?

14. Have you noticed any fears or concerns that people generally address when they are completing their ADs or making end-of-life care decisions?

15. Do you think our culture deals well with death and dying? Why or why not?

16. Have you noticed changes in your attitudes toward Advance Directives and death over your career?

17. Have you noticed changes in your comfort level in dealing with Advance Directives and death over your career?
18. What are some of the technological and medical changes that have happened in your field over the course of your career that have altered end-of-life care?

19. What do you see as barriers to Advance Directive completion?

20. Do you have any suggestions for ways to improve knowledge about Advance Directives and improve completion rates?

21. Do you think there are any special features of this region that may influence attitudes toward Advance Directives and death and dying?

22. Do you have any additional comments that you would like to share?
Interview Questions for Attorneys

Background Questions:
1. How long have you been practicing law?
2. Have you practiced exclusively in Morehead, or have you practiced in other regions?
3. Have you assisted clients with Advance Directives (i.e. Living Wills, Medical Powers of Attorney) throughout your practice?
4. During what years were you in law school?

Education/Training:
5. Do you recall when you first learned about Advance Directives?
6. Did you learn about Advance Directives while in law school?
7. Did you receive any training on Advance Directives outside of law school?

Legislation:
8. Besides the Patient Self-Determination Act of 1991, are you aware of other federal-level legislation related to Advance Directives?
9. Besides the 1994 Kentucky Living Will Directive Act, has there been any other state-wide legislation regarding Advance Directives?
10. How did this legislation influence your practice?
11. Do you know of trials in Kentucky that involve disputes over end-of-life care that may have shaped Advance Directive policies?

Advance Directives in Your Practice:
12. How do you generally broach the topic of Advance Directives with clients?
13. When you bring up Advance Directives, how do clients react to the topic?
14. Do many of your clients seem to be familiar with the documents?
15. Do clients ever initiate discussion of Advance Directives?
16. How would you describe your role in assisting clients with Advance Directives?
17. Have you ever noticed any common features among clients who complete their Advance Directives (i.e. similar age, education level, race/ethnicity, etc.)?
18. Do clients ever voice their motivations for completing Advance Directives (i.e. not wanting to linger on life support, not wanting family to make difficult decisions, etc.)?

Advance Directive Documents:
19. Did your firm create its own living will document or did your firm adopt a pre-existing document?

20. How many different types of Powers of Attorney forms are there in Kentucky.

21. What is the range of decisions a Power of Attorney document can give an attorney-in-fact permission to make regarding care of the grantor?

22. Does a Power of Attorney form have to be drafted by an attorney?

23. If a physician goes against the patient’s Living Will or surrogate, can the surrogate or patient’s family take legal action against the physician?

24. Does a Power of Attorney have more legal standing than a Living Will?

25. After a client has their Advance Directives drawn up in your office, do you counsel them on what to do in regards to sharing their information with their physician, healthcare surrogate or attorney-in-fact, other family members, etc.? If so, what do you generally say?

26. Do clients ask questions about the medical procedures they can request/refuse in a Living Will? If so, do you try to answer them, and do you feel that you have the knowledge to answer them?

Barriers/Suggestions:
27. Have you observed any barriers that might prevent people from completing Advance Directives?

28. Do you have suggestions for how these barriers can be removed or minimized?

29. Do clients ever voice any common fears or myths when completing their Advance Directives?

30. Do you think the wording of the Living Will document is suitable for the average person, or should it be written using more common terms?

31. Do you have any suggestions to improve the Living Will document?

32. Do you believe Advance Directives “do their job”? If not, why not, and what could be done to make them more effective?

33. Do you have anything else you would like to add before ending the interview
LIVING WILL PACKET KENTUCKY

The Office of the Attorney General
Jack Conway, Attorney General
Living Wills in Kentucky

A Living Will gives you a voice in decisions about your medical care when you are unconscious or too ill to communicate. As long as you are able to express your own decisions, your Living Will will not be used and you can accept or refuse any medical treatment. But if you become seriously ill, you may lose the ability to participate in decisions about your own treatment.

You have the right to make decisions about your health care. No health care may be given to you over your objection, and necessary health care may not be stopped or withheld if you object.

The Kentucky Living Will Directive Act of 1994 was passed to ensure that citizens have the right to make decisions regarding their own medical care, including the right to accept or refuse treatment. This right to decide — to say yes or no to proposed treatment — applies to treatments that extend life, like a breathing machine or a feeding tube.

In Kentucky a Living Will allows you to leave instructions in four critical areas. You can:

- Designate a Health Care Surrogate
- Refuse or request life prolonging treatment
- Refuse or request artificial feeding or hydration (tube feeding)
- Express your wishes regarding organ donation

Everyone age 18 or older can have a Living Will. The effectiveness of a Living Will is suspended during pregnancy.

It is not necessary that you have an attorney draw up your Living Will. Kentucky law (KRS 311.625) actually specifies the form you should fill out. You probably should see an attorney if you make changes to the Living Will form. The law also prohibits relatives, heirs, health care providers or guardians from witnessing the Will. You may wish to use a Notary Public in lieu of witnesses.

The Living Will form includes two sections. The first section is the Health Care Surrogate section which allows you to designate one or more persons, such as a family member or close friend, to make health care decisions for you if you lose the ability to decide for yourself. The second section is the Living Will section in which you may make your wishes known regarding life-prolonging treatment so your Health Care Surrogate or Doctor will know what you want them to do. You can also decide whether to donate any of your organs in the event of your death.
When choosing a surrogate, remember that the person you name will have the power to make important treatment decisions, even if other people close to you might urge a different decision. Choose the person best qualified to be your health care surrogate. Also, consider picking a back-up person, in case your first choice isn’t available when needed. Be sure to tell the person that you have named them a surrogate and make sure that the person understands what’s most important to you. Your wishes should be laid out specifically in the Living Will.

If you decide to make a Living Will, be sure to talk about it with your family and your doctor. The conversation is just as important as the document.

A copy of any Living Will should be put in your medical records. Each time you are admitted for an overnight stay in a hospital or nursing home, you will be asked whether you have a Living Will. You are responsible for telling your hospital or nursing home that you have a Living Will.

If there is anything you do not understand regarding the form, you might want to discuss it with an attorney. You can also ask your doctor to explain the medical issues. When completing the form, you may complete all of the form, or only the parts you want to use.

You are not required by law to use these forms. Different forms, written the way you want, may also be used. You should consult with an attorney for advice on drafting your own forms.

You are not required to make a Living Will to receive healthcare or for any other reason. The decision to make a Living Will must be your own personal decision and should only be made after serious consideration.

For additional copies of this packet, you may download it from the Attorney General’s website at ag.ky.gov/livingwill or make photocopies of this packet.

This packet is provided to you by the Office of the Attorney General for informational purposes only.

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Copies printed with state funds.
Instructions for Completing the Kentucky Living Will Form

The Living Will form should be used to let your physician and your family know what kind of life-sustaining treatments you want to receive if you become terminally ill or permanently unconscious and are unable to make your own decisions. This form should also be used if you would like to designate someone to make those healthcare decisions for you should you become unable to express your wishes.

NOTE: You may fill out all or part of the form according to your wishes. Keep in mind that filling out this form is not required for any type of healthcare or any other reason. Filling out this form should solely be a personal decision.

1. Read over all information carefully before filling out any part of the form.

2. At the top of the form in the designated area, print your full name and birth date.

3. The first section of the form on page one relates to designating a “Health Care Surrogate.” Fill this section out if you would like to choose someone to make your healthcare decisions for you should you become unable to do so yourself. When choosing a surrogate, remember that the person you name will have the power to make important treatment decisions. Choose the person best qualified to be your health care surrogate. Also, consider picking a back-up person, in case your first choice isn’t available when needed. Be sure to tell the person that you have named them a surrogate and make sure that the person understands what’s most important to you. Do not complete this section if you do not wish to name a surrogate.

4. The next section of the form is the “Living Will Directive.” Fill out this section to identify what kinds of life-sustaining treatments you want to receive should you become terminally ill or permanently unconscious.

Life Prolonging Treatment
Under this bolded section on page one, you may designate whether or not you wish to receive treatment (such as a life support machine), and be permitted to die naturally, with only the administration of medication or treatment deemed necessary to alleviate pain. If you do not want treatment, except for pain, and would like to die naturally, check and initial the first line. If you want life-sustaining treatment, check and initial the second line. Check and initial only one line.
Nourishment and/or Fluids
Under this bolded section on page two, you may designate whether or not you wish to receive artificially provided food, water, or other artificially provided nourishment or fluids (such as a feeding tube). If you do not want to receive artificial nourishment or fluids, check and initial the first line. If you want to receive nourishment and/or fluids, check and initial the second line. Check and initial only one line.

Surrogate Determination of Best Interest
Important: This section cannot be completed if you have completed the two previous bolded sections. Under this bolded section on page two, IF you have designated a person as your surrogate in the first section, you may allow that person to make decisions for you regarding life-sustaining treatments and/or nourishment. Check and initial this line ONLY if you wish to allow your surrogate to make decisions for you and if you do not want to detail your specific life-sustaining wishes on this form.

Organ/Tissue Donation
Under this bolded section on page two, you may designate whether or not to donate your all or any part of your body upon your death. If you wish to donate all or part of your body, check and initial the first line. If you do not want to donate all or part of your body, check and initial the second line. Check and initial only one line.

5. On page three, you will sign and date the form. Sign and date the form in the presence of two witnesses over the age of 18 OR in the presence of a Notary Public.
   The following people CANNOT be a witness to or serve as a notary public:
   a) A blood relative of yours;
   b) A person who is going to inherit your property under Kentucky law;
   c) An employee of a health care facility in which you are a patient (unless the employee serves as a notary public);
   d) Your attending physician; or
   e) Any person directly financially responsible for your health care.

6. Once you have filled out the Living Will and either signed it in the presence of witnesses or in the presence of a notary public, give a copy to your personal physician and any contacts you have listed in the Living Will. A copy of any Living Will should be put in your medical records. Remember, you are responsible for telling your hospital or nursing home that you have a Living Will. Do not send your Living Will to the Office of the Attorney General.
Kentucky Living Will Directive and Health Care Surrogate
Designation of

_________________________________________
(PRINTED NAME)

___________________________
(DATE OF BIRTH)

My wishes regarding life-prolonging treatment and artificially provided nutrition and hydration to be provided to me if I no longer have decisional capacity, have a terminal condition, or become permanently unconscious have been indicated by checking and initialing the appropriate lines below.

Health Care Surrogate Designation

By checking and initialing the line below, I specifically:

☐ ______ (check box and initial line, if you desire to name a surrogate)
Designate __________________________ as my health care surrogate(s) to make health care decisions for me in accordance with this directive when I no longer have decisional capacity. If _______________________ refuses or is not able to act for me, I designate __________________________ as my health care surrogate(s).

Any prior designation is revoked.

Living Will Directive

If I do not designate a surrogate, the following are my directions to my attending physician. If I have designated a surrogate, my surrogate shall comply with my wishes as indicated below. By checking and initialing the lines below, I specifically:

Life Prolonging Treatment (check and initial only one)

☐ ______ (check box and initial line, if you desire the option below)
Direct that treatment be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical treatment deemed necessary to alleviate pain.

☐ ______ (check box and initial line, if you desire the option below)
DO NOT authorize that life-prolonging treatment be withheld or withdrawn.

Nourishment and/or Fluids (check and initial only one)

☐ ______ (check box and initial line, if you desire the option below)
Authorize the withholding or withdrawal of artificially provided food, water, or other artificially provided nourishment or fluids.
Living Will Directive — continued

☐ _______ (check box and initial line, if you desire the option below)
Do NOT authorize the withholding or withdrawal of artificially provided food,
water, or other artificially provided nourishment or fluids.

Surrogate Determination of Best Interest

NOTE: If you desire this option, DO NOT choose any of the preceding options
regarding Life Prolonging Treatment and Nourishment and/or Fluids

☐ _______ (check box and initial line, if you desire the option below)
Authorize my surrogate, as designated on the previous page, to withhold or
withdraw artificially provided nourishment or fluids, or other treatment if the
surrogate determines that withholding or withdrawing is in my best interest; but I
do not mandate that withholding or withdrawing.

Organ/Tissue/Eye Donation

I certify that I am eighteen (18) years of age or older and of sound mind, and that upon my
death, I hereby give:

Check appropriate boxes and initial the line beside that box:

☐ _______ Any needed organs, tissues, and eye/corneas
or

The following organs or tissues only (check and initial all that apply):

☐ _______ All needed organs
☐ _______ All needed tissues
☐ _______ Corneas
☐ _______ Eyes
☐ _______ Other
☐ _______ Only the specified organs/tissues as listed:

_________________________________________________________________
_________________________________________________________________

Organs that can be donated: heart, lungs, liver, pancreas, kidneys, and small bowel.

Tissues that can currently be donated: skin (outermost layer from lower trunk and
abdomen), bone, heart valves, leg veins, pericardium, vertebral bodies.

Eye donation can be the corneas (outer most layer), the sclera (shell), or the entire eye.

In the absence of my ability to give directions regarding the use of life-prolonging treatment and
artificially provided nutrition and hydration, it is my intention that this directive shall be honored by
my attending physician, my family, and any surrogate designated pursuant to this directive as the
final expression of my legal right to refuse medical or surgical treatment and I accept the
consequences of the refusal.
If I have been diagnosed as pregnant and that diagnosis is known to my attending physician, this directive shall have no force or effect during the course of my pregnancy.

I understand the full import of this directive and I am emotionally and mentally competent to make this directive.

Signed this ______ day of ____________, 20____

____________________________
(signature and address of the grantor)

Have two adults witness your signature OR have signature notarized.*
In our joint presence, the grantor, who is of sound mind and eighteen (18) years of age, or older, voluntarily dated and signed this writing or directed it to be dated and signed for the grantor.

________________________________________________________________________
(signature and address of witness)

________________________________________________________________________
(signature and address of witness)

Or

COMMONWEALTH OF KENTUCKY, ______________ County

Before me, the undersigned authority, came the grantor who is of sound mind and eighteen (18) years of age or older, and acknowledged that he/she voluntarily dated and signed this writing or directed it to be signed and dated as above.

Done this ________ day of ___________, 20____

_________________________________________      __________________
Signature of Notary Public             Date commission expires

* None of the following shall be a witness to or serve as a notary public or other person authorized to administer oaths in regard to any advance directive made under this section:
   a) A blood relative of the grantor;
   b) A beneficiary of the grantor under descent and distribution statutes of the Commonwealth;
   c) An employee of a health care facility in which the grantor is a patient, unless the employee serves as a notary public;
   d) An attending physician of the grantor; or
   e) Any person directly financially responsible for the grantor’s health care.

NOTICE: Execution of this document restricts withholding and withdrawing of some medical procedures. Consult Kentucky Revised Statutes or your attorney.

A person designated as a surrogate pursuant to an advance directive may resign at any time by giving written notice to the grantor; to the immediate successor surrogate, if any; to the attending physician; and to any health care facility which is then waiting for the surrogate to make a health care decision.