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The Experiences of Older Adults Who Have Completed Advance Directives

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The Experiences of Older Adults Who Have Completed Advance Directives

Submitted by Lisa Watts

May, 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

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Abstract

This project is a qualitative research study used to explore the experiences of older adults who have written advance directives. Advance directives are an often underutilized tool used by individuals to outline plans for end-of-life care, in the anticipation that the individual may not be able to verbalize his or her decisions when the time comes for choices to be made regarding care. The experiences of individuals who have written an advance directive may help clinical social workers when working with clients who are considering writing an advance directive. For the purpose of this study, six participants were recruited for a focus group in a Midwestern city using flyers posted at the focus group location. Participants were required to be at least 65 years old and have completed a form of an advance directive. The focus group found that participants had a positive experience writing an advance directive and that family members, namely children, were involved in the decision making process. Respondents agreed that they wrote advance directives to decrease potential burden to family members and had certain wishes that they wanted carried-out in the case that they become unable to verbalize them. Overall, focus group respondents agreed with literature review findings, but spoke of themes in a more personal and individual manner. Further research should be conducted with multiple focus groups in a larger geographic area with more varied demographics. Also, further research comparing similar individuals without an advance directive may help identify barriers to completion of directives.

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Introduction

The Advance Healthcare Directives (AD) is a tool used by individuals to make plans for end-of-life events, in the anticipation that an individual will not be able to make these decisions for his or herself when the time comes for choices to be made regarding care (Conelius, 2010). However, this tool is underutilized as a way to prevent unwanted medical treatments and procedures. Though ADs may be helpful tools in maintaining patient autonomy at the end-of-life, only 29% of the United States population has completed an advance directive (Eckstein & Mullener, 2010). In 1990, only 15% of the population had a completed advance directive. So, the rate of completing end-of-life planning has increased, but the AD is still underused.

Death can be an uncomfortable topic of discussion that is avoided at times because of the sensitivity toward illness and dying (Pockett, Walker & Dave, 2010). Because of this, ADs help to facilitate this conversation and ensure that an individual maintains autonomy regarding decisions even in the event that they are unable to communicate their needs and desires at the end of life. ADs can alleviate the pressures and confusion that a family may face in the event of needing to make decisions for an incapacitated family member (Besirevic, 2010).

ADs come in a variety of formats, and offer many options for end of life care planning. An AD typically outlines instructions for acceptable and unacceptable treatments, including CPR orders, intubation, antibiotics, and methods of liquid and food nourishment to the body. Some ADs go beyond the typical healthcare orders to outline specific desires for a variety of circumstances, such as hospitalizations for treatments, and allow people to designate a legal decision maker in place of themselves if they become

unable to vocalize their wishes for care in the case of being incapacitated at that time (Moorman, 2011). In the United States, individuals have the right to make end-of-life choices and have his or her health care providers honor these choices, and an AD is a helpful tool in ensuring that these choices are honored in the event that an individual will not be able to communicate their wishes at the end of life. In the event that an individual has an AD and is unable to vocalize his or her wishes, health care providers are obligated to act according to written directions (Moorman, 2011). It can be critical for an individual to have an advance directive at the end of life in order to communicate his or her needs to healthcare providers.

An AD may also include parameters regarding pain and symptom management, and can provide support to the individual and his or her family in other healthcare decisions, including an individual's preferences for potential hospice care and palliative treatment (Blank, 2011). An AD can be the gateway to keeping autonomy during the end of life, and is a tool to promote empowerment for an individual who may perceive death and dying with hopelessness (Blank, 2011).

Decision making at the end of life may be one of the most emotionally and ethically charged issues because of the differences in opinion regarding the treatment of the dying. There are many differing opinions regarding the ethics of withholding or withdrawing life-sustaining treatment. There is a possible misunderstood view that allowing a person to die when treatments are available may be seen as cruel and even as assisted suicide (Blank, 2011).

This study will explore experiences of individuals who have created advance directives. These experiences may serve as a tool to facilitate the conversation between

social workers and individuals that may benefit from having an advance directive. Since ADs are helpful in communicating wishes to family members and healthcare providers, they can be a powerful tool in maintaining autonomy during the end of life. The experiences of individuals who have completed advance directives may empower social workers to engage clients in end-of-life planning and give individuals the courage to write an advance directive.

Literature Review

This review of the literature explores aspects of advance directives, including history, different types of advance directives, values around the end of life, decision making for individuals and families, barriers to completing advance directives, AD stigma, cultural influences on creating an AD, consequences of not completing an AD, and the social work role related to ADs.

History of Advance Directives

With the ever-changing advances in medicine and the growing number of the elder population, the choices of end-of-life care have become more perplexing than ever before. With the growing number of treatment options for the ill and elderly, healthcare continues to become more complicated to navigate for individuals and the families faced with making decisions for next-of-kin. In response to the overwhelming options and the desire of individuals to maintain autonomy during the end of their life, the advance directive was created (Sabatino, 2010).

The first advance directive was proposed in 1967 by the Euthanasia Society of America as a tool to prevent medical treatment without patient consent. In 1976, this was developed into the advance directive in order to include individuals and their physician in

the advance planning of life-sustaining treatment (Sabatino, 2010) Advance directives were made more common and sophisticated in the 1970s as a means to provide specific legal instructions surrounding the withdrawal or the withholding of life-sustaining treatment or interventions in the case that an individual is unable to communicate his or her wishes. Over the next decade, the use of advance directives gained popularity, and forty-one states had adopted the use of ADs by 1990 (Sabatino, 2010). These advance directives were created to maintain patient wishes and protect physicians and facilities in maintaining individual wishes (Sabatino, 2010).

The Patient Self Determination Act of 1990, or PSDA, indicates that facilities that receive payment from Medicare or Medicaid must advise patients of their right to have and create an advance directive (Larson & Eaton, 1997). The PSDA requires facilities to give patients information on their rights regarding advance directives (Larson & Eaton, 1997). This act was created in order to give individuals the opportunity to discuss plans and write an advance directive when admitted to a hospital or long term care setting (Rich, Gruber-Baldini, Quinn, & Zimmerman, 2009). In 2008, Congress included end-of-life planning in the physical examination for newly-enrolled Medicare beneficiaries. In 2009, Congress debated including Medicare coverage for advance care consultation, but this provision was not included in the final draft of health care reform (Sabatino, 2010). These advance care consultations would have reimbursed physicians for facilitating a discussion regarding end-of-life care with a patient every five years. This concept has been misconstrued as “death panels,” due to the fear that these consultations would encourage seniors to end their life prematurely. However, the purpose of the proposed consultations was to provide Medicare coverage for advance care consultations to

individuals who wish to pursue end-of-life planning. Such planning is not currently a Medicare benefit (Snow, Grever, & Childs, 2009). So, even with the strides made in making the advance directive accessible, it is still an underutilized tool fraught with misunderstanding.

Types of Advance Directives

There are several varieties of advance directives available to individuals who wish to create one. A common document available is a health care directive, which varies in format state-by-state. In Minnesota it is called the Minnesota Health Care Directive document which appoints a proxy decision maker, or durable power of attorney, in the case of an individual becoming unable to dictate decisions independently. The health care directive outlines decisions and restrictions that a proxy may be allowed to make for the incapacitated individual. This form also has blank space for an individual to outline treatments that they may or may not want in the event of becoming incapacitated. The directive also has options of outlining desires regarding tissue donation. Once the form is completed, it is signed by two separate witnesses who are not appointed proxies, or a notary of the public, and then this advance directive becomes a legal document that health care providers are obligated to follow. This form is available online at http://www.mnaging.org/pdf/HCD_LegalForm_fillsav.pdf, and does not require the approval of a physician to become an active document in an individual's medical chart. (Hammes, Rooney, & Gundrum, 2010). However, the statutory form is not required in Minnesota. Any document that meets the requirement of the statute is valid, and most other state documents are valid in Minnesota.

A more standardized and brief form of an advance directive is a document called a Provider Order for Life-Sustaining Treatment, or POLST, which is also varies state-to-state like the Minnesota Health Care Directive document (Sabatino, 2010). This form is usually completed upon admission to a healthcare facility that implements the POLST form, and may include a discussion between the individual and a nurse or social worker of the facility. In the case that an individual is unable to make decisions upon admission to the facility, the discussion will occur with a surrogate or family member of the patient. This document addresses the patient's wishes in regards to CPR, goals of treatment, antibiotics, intubation, and nutrition and hydration to the body. This form is then reviewed and signed by the attending physician, becomes a physician's order, and becomes a part of the medical chart (Muramoto, 2011). This form can be particularly helpful, as since it becomes a doctor's order, it follows an individual to different facilities and settings in which an individual may receive care (Sabatino, 2010). In the event of an emergency that an individual has an accessible POLST, the emergency medical staff must honor wishes documented on a POLST, whereas other advance directives are not physician orders, and will not be consulted or followed by EMTs for first responders (J. Wright, personal communication, 2011). A POLST form can help enhance an existing advance directive, or can stand in place of one altogether. However, a POLST is only used in end-of-life situations, and is based on current patient conditions and not for advance planning of unknown conditions. According to research on the POLST tool, it has become a useful document in preventing patients from being undesirably resuscitated and encourages individuals to make choices regarding treatment goals (Sabatino, 2010). A copy of the Minnesota POLST form can be found at www.polstm.org.

The Five Wishes advance directive was created by the Aging and Dignity organization in 1997, and has been a nationally marketed AD. This form was created in order to make a easy-to-use, non-legalistic instrument for individuals to outline end-of-life choices that would have flexibility and relevance across many states (Sabatino, 2010). This AD meets legal requirements in 40 states, and is referred to as the “advance directive with a heart and soul” (Eckstein & Mullener, 2010). In the Twin Cities metro area, an advance directive referred to as the Honoring Choices directive was adopted by hospitals and clinics metro-wide in 2011 (Twin Cities Medical Society, 2011).

Advance Directive Issues

Value of Advance Directives

Documented ADs have been encouraged by some medical professionals for approximately twenty years in order to promote individual autonomy and ensure respect of end-of-life choices in healthcare settings (Levi & Green, 2010). According to an article published by the U.S. Department of Health and Human Services in 2006, the promotion and implementation of ADs has failed, and only a limited amount of individuals are choosing to complete a healthcare directive. However, in a study reported by Hammes, Rooney, and Gundrum, in April 1996, 85% of all deaths in the study’s target population in Wisconsin had an advance directive (Hammes, Rooney & Gundrum, 2010). Due to a progressive advance directive program called Respecting Choices at the Gunderson Lutheran Hospital, 96% of adults in La Crosse, Wisconsin die with a written advance directive, the highest rate in the country (Shapiro, 2009). The Respecting Choices program allows for each hospital patient to receive individual end-of-life care discussions with medical personnel. The cost of care for an individual in the last two years of their

life at the Gunderson Lutheran Hospital is an average of \$18,000. The national average is about \$26,000 per individual (Shapiro, 2009).

ADs are encouraged by health care professionals because they can help to ensure that healthcare staff provides end-of-life care that matches what an individual wishes and prefers. It is essential that end-of-life issues are discussed with both a person's family and those who are providing care (Gjerberg, Forde, & Bjorndal, 2011). These conversations can prevent unnecessary hospitalizations and treatments that an individual would not desire if they were able to communicate their wishes. The use of a formal advance directive may be used to facilitate a discussion of end-of-life choices with family and healthcare providers and to communicate wishes. Also, that appointing of a health care proxy is one of the most important and effective aspects of an AD, and the discussion regarding the individual who will fill this role is a vital part of creating the directive.

While advance directives are useful, there is controversy over the effectiveness of ADs in outlining wishes to healthcare professionals and family members regarding the type of care that an individual wishes to receive (Castillo et al., 2011). It is arguable that advance directives may not be doable in theory, as there is no perfect death that advance directives may plan for, and circumstances are completely unpredictable. Some barriers to an AD being understood by professionals and family includes readability of the document, proxy restrictions, a shortfall in the steps needed to make the document legal (Castillo, et al., 2011).

Decision Making

Asking family members to make end-of-life decisions once an individual is unable to make his or her own choices is an ethical dilemma. There may be a belief by

individuals and their families that family members know and are more aware of an individual's desires regarding their healthcare than professionals. However, according to research, family may not always be a reliable source of information regarding these desires, and an individual may not always communicate directly about their care desires (Haddard, 2004). The use of a written advance directive can alleviate the stress of family members making choices based solely on intuition. An advance directive will outline an individual's wishes, and this can help families make difficult choices. An AD can help take the guessing out of making choices for another individual, and give a clear guideline for what is acceptable treatment (Huddard, 2004).

Creating an advance directive can give an individual a sense of control during a time in which he/she may have little control over his or her circumstances. According to the National Association of Social Work Code of Ethics, "social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals. Social workers may limit clients' right to self-determination when, in the social workers' professional judgment, clients' actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others" (NASW, 1996). The creation or the unwillingness to create an advance directive indicates the right of clients to exercise their self-determination. The end of life can be a terrifying notion for many individuals, and the act of making plans for this time in life can be soothing. An AD can also create a way for people to cope with the fear of death in knowing that there will still be some personal control over their circumstance. When an individual is given the freedom to make a choice for themselves, it can be a therapeutic

way to process the fear of death and illness. It is also a way for an individual to consult with his or her medical professionals and his or her families (Doka, 2005).

Consequences when an Advance Directive is not Completed

Family Involvement

Without the use of an advance directive, decision making falls on the next-of-kin, and family is left with making choices when an individual is unable to do so for him/herself. It is not uncommon for family to have disagreements over treatments and choices, and it can be difficult for healthcare staff to determine who has the final word in making these choices. An individual must discuss his or her wishes and work through disagreements with family members while he/she are still able to communicate their desires in order for his or her wishes to be honored during times of heightened stress among family (Haddard, 2004). Without the support of the individual who is unable to communicate prior to end-of-life, the family must make life-altering decisions without knowledge of preferences, and then experience the consequences of these actions (Haddard, 2004). The research concludes that family members may have a difficult time making health care decisions, and often times are unsure of what an individual's preferences for end-of-life care are. With this, families may have a difficult time distinguishing what the individual would want from family members' own emotional desires regarding withdrawing or withholding treatment (Lind et. al., 2011).

When faced with the end of life, dying individuals may feel pressure from their families regarding concerns about family obligations, which can cause stress in the individual during a time of illness or end of life. This obligation to family may create conflict between what an individual wants for him/herself and what an individual wants

in order to protect his or her family. Because of this, an individual may want to protect his or her family from death regardless of his or her own best interest (Caldwell & Freeman, 2009). In order for an individual to feel comfortable in his or her choices and face the end of his or her life, an individual's family must accept death and allow for an individual to let go (Kubler-Ross, 1969).

Some individuals who create an advance directive appoint an alternative decision maker, or proxy, which is often times a family member. This proxy can make medical decisions for an individual when her/she becomes incapable. It is not uncommon for families to disagree on choices that should be made, even with this proxy. The disagreements among family members can cause conflict and the disputes can complicate grief of the family when an individual has reached the end of his or her life (Doka, 2005).

Not all decisions that create discourse with families are to ultimately end life. It is also possible that decisions are made to prolong life with treatments, and families can disagree on the potential for the individual to suffer needlessly. Research suggests that family discord tends to result in more aggressive life-sustaining treatment for patients. This can impact the patient's quality of life, prolong potential suffering, and prevent palliative care from occurring (Winter & Parks, 2008). When an individual lacks decision making ability, the next of kin does have the legal right to be involved in making healthcare choices for the individual, but are also obligated to make choices that are in the best interest of the individual, and should not be based on their personal wishes (Gjerberg, Forde & Bjorndal, 2011). However, the ultimate decision is left to the physician and healthcare providers, who must ultimately act in what they believe to be

the best interests of the patient if the patient or legally-appointed proxy is not available to decide.

Barriers to Completing an Advance Directive

Death vs. Life

A controversy regarding end-of-life choices is the line drawn between life and death. This is a decision that those creating advance directives are ultimately faced with making. Advance directives outline the choice to pursue a treatment option or let nature take its course regarding a medical complication. These choices either encourage treatment or allow natural death. If an advance directive exists, it will outline an individual's choice to either request CPR or to request a do-not-resuscitate (DNR) order in the case that an individual stops breathing and loses a pulse (Savulescu, 2006). This can be a challenging choice for individuals to make. Though typically individuals do not wish to die, there are circumstances when someone may want a DNR order, particularly later in life. CPR does not guarantee life and may cause a painful death and leave an elderly individual with severe physical complications or brain death (Savulescu, 2006). An individual may choose natural death, or DNR, in order to have a comfortable death.

Controversies

A controversy regarding the choices that individuals make in using an advance directive is the choice to live and the choice to allow death. However, it is argued that advance directives may also encourage a killing versus "let die" approach to end-of-life choices (Savulescu, 2006). Savulescu suggests that not giving a patient a potentially life-saving treatment, regardless of the risk or potential complications, is not in a patient's best interest, regardless of the wishes they have outlined (Savulescu, 2008). However, the

law does allow for a patient or his or her legally appointed proxy to refuse a potentially lifesaving or life sustaining treatment, and a physician must abide by these wishes (Savulescu, 2008).

Another issue created by advance directives whether an individual's wishes are still relevant once an individual experiences terminal disease, especially if an AD is written far in advance prior to the illness (Sharman et. al., 2008). It is possible that an individual who has written an advance directive has changed his or her mind regarding treatments and choices, but has not updated his or her wishes on the documented advance directive.

It is also be argued that advance directives are irrelevant during the end-of-life because an individual is not the same person that he/she was when the advance directive was written. In this case, it is possible that a person is different when he/she are of sound mind and health than when he/she become terminally ill (Buford, 2008). In the worst case scenario, an individual will not receive the care that he/she wished for during the end of life even though an advance directive is in place. Because of this possible scenario, individuals must update advance directive documents and inform surrogate decision makers of any changes that may influence the course of their end-of-life. Advance care planning does not need to be a two-step procedure of planning and then dying. It should instead be an ongoing process of planning. The process of making medical decisions is a practice that has the ability to encompass a patient's changing life from health to disease and death (Muramoto, 2011). Advance directives are not set in stone and can be changed and altered as a person becomes more aware of how he/she may react to illness. Because of the many barriers to creating an AD, the experiences of individuals who have created

advance directives is a tool to understanding why an individual chooses to plan for end-of-life choices. The experiences will serve as a way to gain knowledge both of what prevents individuals from creating an AD, and also what promotes the creation of an AD.

Stigma

It is common for there to be some misunderstanding regarding advance directives. There is also sometimes a negative stigma regarding the use of such a tool. One such stigma is that advance directives aid in the use of assisted suicide when an individual may have a treatable diagnosis but has indicated that he/she does not wish to receive certain treatments. There is a misconception that ADs promote assisted suicide by withholding treatments. However, advance directives are not used to promote untimely death of an individual (Caldwell & Freeman, 2009).

With the advances in medicine and treatments, it is almost possible to prolong life indefinitely. However, with unnaturally prolonged life usually comes poor quality of life and reliance on medical technology (Blank, 2011). End of life planning will continue to become more difficult due to changes in how individuals age; advances in medicine; and the increase in the rate of chronic disease among the elderly. An individual may create an advance directive that mandates for all possible treatments and life saving treatments in order to preserve his or her life, and a family and healthcare provider may feel obligated to follow these wishes. An individual may suffer brain death or suffer from a chronic illness that necessitates intubations, tube feedings, and intravenous medications. Though this individual is alive, they also may be otherwise unresponsive or unaware of his or her surroundings, which can go on for years at a time. There is the stigma that some advance directives promote keeping individuals alive by artificial means for prolonged time.

However, this is the exception to the rule in regards to advance directives, which more typically outline the omission of treatments than the desire to have all medical treatment necessary (Blank, 2011).

Cultural influences on end-of-life choices

Ethnic groups may approach end-of-life care planning and advance directives in differing manners (Cohen et. al., 2010). Advance directives are completed most frequently by Asian/Pacific Islanders and Caucasians, less frequently by African Americans, and least often completed by Hispanic/Latino populations. (Guo et. al., 2010). There are many opinions of why there are ethnic differences in completing advance directives, including access to healthcare, cultural differences regarding appointing a proxy for healthcare decisions, fear of burdening family, and the fear of the formality of written advance directives (Cohen et. al., 2010). Caucasian individuals are more apt to discuss death and preferences for the end of life than other cultural minorities and are more likely to have a documented advance directive (Cohen et. al., 2010).

Another difference in cultural contexts related to ADs is the prevalence of healthcare available to individuals in their countries of origin or their family's country of origin. For example, complex healthcare, such as tube feeding or intubation may not exist in person's home country. Because of the lack of complex healthcare options, individuals of diverse populations may not be familiar with the many options available in the United States healthcare system, so the perception is that an AD is not necessary (Blank, 2011). Also, these populations may see symptoms, such as an individual who stops eating, as a sign of dying, but not a cause of death, and therefore have a different opinion of what is and is not a symptom that can be treated (Blank, 2011).

All individuals come to old age with a unique set of experiences and values, and the differences in culture is another aspect of the context in which we view an individual's life. Differences in life experiences, including culture, have an impact on an individual's view and opinion on the meaning of illness, suffering, and death (Blank, 2011). Healthcare providers must respect the differences that clients may face in the use of advance directives and understand the differences that culture and life experience may create in the face of making end-of-life choices. However, another explanation for the difference in the culture in completion of ADs may lie simply in the way that healthcare providers communicate with individuals regarding end-of-life choices. There is evidence that providers are more likely to discuss AD choices with white patients than with minorities, and minorities are less likely to complete ADs (Rich, Gruber-Baldini, Quinn & Zimmerman, 2009). Also, minorities are less likely than white individuals to have discussed end-of-life wishes with family and healthcare providers, which may be explained by differences in cultural views of treatment, and some spiritual beliefs that deny the certainty of death (Rich, Gruber-Baldini, Quinn & Zimmerman, 2009).

Social Work/Professional Role in End of Life Planning

Ethics

An advance directive is not a guarantee that one's wishes will be met when faced with end-of-life choices, because crises happen, and life is unpredictable. However, it is a safe way to set guidelines and make wishes known to caregivers and family (Payne, Prentice-Dunn, & Allen, 2010). With the advances in medical technology and changes in treatments for illness, the options for treatment during end-of-life care become more complicated and convoluted to those who may be faced with having to make decisions

for an individual who cannot make decisions independently. In a research study conducted by Pardon et. al., patients who were knowledgeable about their illness and were able to make choices regarding their care, which included the use of advance directives, reported a significantly higher quality of life over those who were uninformed and unable to make informed decisions regarding their care and did not have an advance directive in place (Pardon et al., 2011).

Social workers in the healthcare field work act as facilitators of communication between patients, families, and the healthcare team in regards to the end-of-life decision making process. Social workers assist individuals with navigating the complexities of end-of-life care and the needs of the individual and family during this time of heightened crisis and anxiety. These social workers work to prevent injustices of an uninformed decision regarding life sustaining treatment (Pockett, Walker, & Dave, 2010).

Social Work Role

In regards to end-of-life decision making, the National Association of Social Workers (NASW) does not take a position on the morals of the choices that an individual makes during the end of their life, but does allow for an individual to maintain autonomy regarding the care he/she wishes to receive. However, it is unethical for a social worker to participate in the discussion aiding the act of assisted suicide. (Caldwell & Freeman, 2009). A social worker may assist an individual in making his or her decisions for end-of-life care and can promote the use of an advance directive as a preventative measure protecting individual autonomy.

Healthcare professionals are finding that though newly admitted patients are given information regarding their right to complete an advance directive and incorporate it into

their medical chart, most individuals do not want to address the issue at the time of admission. Patients experience fear of being newly admitted to a hospital setting and do not feel like it is an appropriate time to make decisions that may upset their family members. These individuals may think that the discussion of end-of-life choices may make family members uncomfortable at the time of an admission (Conelius, 2010). Because of time constraints in a hospital setting, it is possible that healthcare providers have had difficulty finding the time to discuss end-of-life choices with individuals. This may be a time for a hospital social worker to step in and address the concern of the risks of not having an advance directive and the benefit of having that discussion. Even if this discussion does not lead to the creation of a documented advance directive, it is still an opportunity to have the conversation with family in order to prepare for potential sensitive decisions. Healthcare professionals, including social workers, need to assist individuals with understanding options that are available to them in order to make advance care planning (Lawrence, 2009).

As stated in the NASW Code of Ethics, a social worker should respect the inherent dignity and worth of a person (NASW, 1996). An advance directive can assist an individual retain his or her dignity and worth at the end of his or her life, and a medical social worker should be knowledgeable about advance directives and end-of-life planning. Because social workers are prevalent in healthcare settings, the knowledge of experiences of those who have already created advance directives may be beneficial to effective practice. Social workers can use the knowledge and experiences of an individual who has created an advance directive in order to promote this tool.

Conceptual Framework

The conceptual framework used in order to identify concepts of research is Erik Erikson's Stages of Psychological Development, namely integrity versus despair and the development of wisdom during the stage of old age (Erikson, Erikson, & Kivnick, 1986). The researcher will focus on the developmental stage of old age as a means of understanding and hypothesizing the need for advance directives and the psychological desire to create and outline plans for one's end of life. This developmental stage may also explain the reluctance to complete an advance directive as it speaks to the despair that one may feel in later life.

As described by Erikson, Erikson, and Kivnick (1986), the stage of old age is a time in an individual's life when there is an acceptance of the inalterability of one's past and the unknown of the future. At this time, an individual must balance the despair and inevitability of death with a sense of integrity and grace regarding his or her life in order to develop the insight of wisdom. With this wisdom, individuals are able to act as a teacher and guide for those who follow in reaching old age. This may serve as an insight and tool in identifying individuals who are ready to complete advance directives in later life. From this perspective, it can be argued that individuals who have created an advance directive have balanced the feelings of despair with the feelings of integrity, and are able to share this wisdom with their family and friends in the form of a plan for the care they wish to receive at the end of their lives. When an individual expresses their desires for healthcare, a sort of wisdom is passed along to his or her family and healthcare providers.

Erikson, Erikson, and Kivnick (1986) also describe the vitality of aging during the developmental stage of old age, and there was a struggle for some individuals to maintain

optimism and involvement in life during older age when he or she was faced with the inevitableness of death and sickness that may come with age. The researchers found that when an individual maintained engagement in life, there was more acceptance of death. An individual may have the ability to find death more accepting when he or she is engaging in life. This may also include the creation of an advance directive, which in an engagement in life. The researchers also state that planning for the future for life that is still to come, even though there may not be a certainty to how long this life may be, is an engagement in finding wisdom.

The concepts of Erikson's Stages of Psychological Development and old age was utilized to interview questions and used to analyze data for this study. The stages of development created insight for the researcher when hypothesizing and drawing conclusions regarding an older adult's experience in creating an advance directive. The study used the concept of an older adult confronting despair and using integrity to gain wisdom into his or her life and for the lives of others through the use of an advance directive.

Methods

Research Design

A qualitative research design was used to collect data for this study. The researcher used focus groups with individuals who have completed advance directives in order to explore the experiences that the individuals faced while planning end-of-life choices and creating advance directives. The topic of individuals and end-of-life decision making was chosen for this study due to the prevalence of misunderstanding of advance directives and the reluctance of many individuals to complete end-of-life planning. The

purpose of this study was to create a source for social workers to use when describing the experiences of creating an advance directive to clients who face the challenges of end of life planning.

Participants

The researcher sought to identify six to twelve individuals to participate in two focus groups for this study. Criteria for inclusion in this study was that a participant must be at least sixty-five years-old, had completed a form of an advance directive, was currently going through the end-of-life. The participant must have been able to attend the scheduled date and time of one of the focus groups. Potential participants for this study were obtained through the use of a flier that will be displayed in the approved agencies for this study. The potential participants were able to contact the researcher with a given telephone number that was detachable from the flier. Participants who contacted this researcher were read a telephone transcript that explained this study. Potential participants who met criteria were invited to participate in the focus group.

Protection of Human Subjects

The participants in this proposed study were protected in two different ways including (a) St. Catherine University Institutional Review Board (IRB) approval to complete this study, and (b) giving informed consent by giving each participant an informed consent letter to review and sign prior to the focus group discussion. An Expedited Review application was submitted to the IRB following the research committee approval of the research proposal.

An informed consent letter was approved by the IRB and was distributed to participants prior to the beginning of the focus group discussion. The participants

reviewed and signed this form prior to any data collection. Participants had the option of refusing to participate in the focus group upon reviewing the informed consent form. Any participants had the option of leaving the focus group at any time without penalty.

The researcher took measures to ensure the confidentiality of the participants. The participant's names were changed when reporting the data. All other identifying information was removed from the data before it was presented to others. The focus group was conducted in a private and secured setting. It is possible that focus group participants may have known each other by coincidence. In this case, participants had the option to opt out of the focus group at any time. In order to ensure confidentiality in the focus group, participants were asked to refer to themselves by only their first name or an alias of their choosing. The focus groups was audio recorded. The recorded interviews and transcripts were stored in a locked file in the researcher's home and destroyed by June 1, 2012.

All participants were be given information on the University of St. Thomas Interprofessional Center for Counseling and Legal Services, a center for free counseling, in the event that a participant required counseling services due to potential emotional distress regarding subject matter that was discussed during this research.

Data Collection

Data for this study was collected through qualitative focus groups with the individuals consent to participate in the study. Due to the qualitative nature of the study, open ended questions were chosen to allow for individual and group variations in responses. The questions were a guide for the discussion of participant's experiences and opinions. The questions were chosen based on themes in the literature review. The nature

of the focus group was for the participants to engage in conversation and elaborate on the discussion. The researcher facilitated this conversation of the participants. The researcher kept the discussion on task and encouraged participants who may be less vocal to add their opinion to the conversation. Participants had the option to decline answering any question presented to the group. The focus group was scheduled to last for approximately an hour and a half to two hours, with time allotted for participants to discuss the focus group experience and offer feedback to the researcher at the end of the discussion.

Data Analysis Plan

This researcher's focus was to see what experiences individuals had while completing advance directives. The researcher recorded the interview with an audio-recording device and the discussion was transcribed and made into a text. Once the interviews were turned into text, the discussion was reviewed using open coding. During open coding, categories of ideas were generated by reviewing the raw data in order to identify themes (Strauss & Corbin, 1990). The open coding process explored the data for evidence of themes regarding individual experiences of completing advance directives. The researcher kept notes about theories and themes that emerged in the text. The researcher used a journal in order to log impressions of the focus groups and ideas that emerged through the process of the focus group.

When the open coding was completed on the focus group discussion transcripts, the researcher organized the codes according to categories. The categories were developed using information gathered from the literature on the topic and information found in the data. The categories were reviewed to identify themes and recurring experiences presented by the participants.

Findings

This section presents the results of the study that explored the experiences of older adults who have completed advance directives. Two focus groups were planned for two agencies, one in St. Paul and one in Minneapolis. Unfortunately, no participants attended one of the groups. The second group held had six participants. The gender of the participants was evenly divided; three males and three females. All participants were at least 65 and had completed an advance directive.

The goal of this research was to identify the experiences of older adults who have written advance directives. The participants for this study were recruited through the use of a flier posted at the focus group sites and a staff member at one site assisted with encouraging individuals to participate in the study. The participants were asked to be at least 65-years-old and had completed a form of an advance directive. Demographics were not formally collected during the research, but the study included three men and three women, for a total of six participants. One participant was African American, and the rest of the group was Caucasian. The age range of the individuals varied from 66 to 87 years of age.

The data collected was analyzed for themes by the researcher. Themes were identified from the research: peace-of-mind created by writing the Advance Directive (AD), challenges posed by writing the AD, family/cultural influence on decisions, and assistance in writing the directive.

All participants reported having a basic advance directive completed. One member of the focus group was a disabled veteran, and had completed an advance directive created through a veteran's hospital. Four of the six respondents completed an

advance directive with an attorney, and not a health care provider. One respondent had a primary care physician give her the form, and one participant chose to do the AD independently because she had turned 87, and felt that age contributed to her need for a written directive.

Peace of Mind

The group participants spoke most frequently about having the advance directive for peace of mind. Participants discussed peace of mind related to knowing that his or her wishes will be followed in the event that she or he becomes unable to articulate his or her own healthcare choices. The peace of mind discussed during the focus group was also that the participants had the discussion with his or her family members and this would also contribute to wishes being honored because as family members were familiarized with potential decisions he or she may make. Participants discussed family involvement in discussing healthcare choices, and this also contributed to peace of mind. Group members were comforted knowing that their wishes were in writing, and that this would prevent burden to family in multiple ways.

In discussing the value of advance directives and peace-of-mind, one participant stated, *For me, it was just one of those things that I procrastinated about for a long time. And then I just felt like I needed to get something down, because I know you can change it. It's a service that's not for you, so it's peace-of-mind for those who might have to make some decisions.* Another respondent simply said, *It's peace of mind.* The attitude of the focus group was comfort in knowing that his or her wishes would be followed, and that family members were prepared to make decisions in the future that supported his or her desires.

Peace of mind was not a major theme found in the literature review. However, it is an individual perspective of the overall purpose of an advance directive, and is a facet of the value of an advance directive. Peace of mind may be defined by the knowing or ensuring that healthcare staff provide end of life care that matches what an individual wishes and prefers, and these desires are discussed with an individual's family and healthcare staff (Gjerberg, Forde, & Bjorndal, 2011). Peace of mind is comfort in knowing that wishes are documented and there is an expectation that these wishes will be honored.

One participant discussed the peace-of-mind regarding the discussion she had with her family regarding her wishes. *There is a peace-of-mind just having that discussion, but unless you get that on paper, nobody knows exactly what you want.* Another respondent added to this, stating that now that there has been a discussion regarding her wishes at the end of life, that the family does not need to worry about future events. She added that the process of writing an advance directive has helped make the family more comfortable with death and potential illness. She stated, *It's so easy to talk about death with my kids because they're all adjusted to it. Now we can fool around and have some fun.* Another respondent followed-up to this, stating that the discussion with children is valuable because it prevents family from the shock of decision making because the family has already had the discussion and, *It will prevent arguing among the children.* Focus group participants had all named family members as their health care agents, and had children involved in their lives, so the discussion of wishes with family members was of particular interest to the members of this study's focus group.

One respondent discussed the comfort in knowing that wishes will be honored at the end of life, *You just want to know that you will die in peace*. Participants supported this when asked about the value of a written directive stating, *You just have more peace o-mind*. So, participants wished for their advance directive to be used to make things as simple for themselves and for family members at the end of their life, and for individuals to die in the way that he or she has deemed desirable.

Preventing Family Member Burden

Focus group participants discussed using advance directives as a tool to protect end of life wishes. but also to prevent family members from making health care decisions that would ultimately burden the family. Group members spoke about not wanting life-prolonging treatment that would keep them in a state that would require long-term care from family members or hospital/long term care treatment for an extended period of time.

The group also discussed using advance directives to prevent family members from needing to make difficult decisions. Group participants discussed that burden to family would be lessened as the family would have an easier time making decisions. Also the directive would help the family feel more confident that they are making the correct choice. As one group member stated: *[An AD] takes the burden off the family, and is a peace-of-mind. If the family has disagreements, then it should only be subtle things because the big things will have been written down*. So, there is peace-of-mind for individuals not only that his or her wishes will be honored, but that it will decrease family responsibility for making decisions when he or she is no longer able to speak for his or herself.

Because of the discussion regarding the reasons that prompted writing an AD, participants turned to discussing the Terri Schiavo case. This was a legal battle regarding life support between family members which spanned seven years. Several members discussed that this publicity regarding differing family opinions of care and the lack of an advance directive encouraged them to think about writing an AD. The publicity of this case ultimately prompted them to write an AD and helped them understand the potential risk of burdening family members to make decisions without a written document.

Challenges

Another main theme that participants discussed was the challenge of creating an advance directive. Respondents discussed that there were aspects of writing an AD that had unique tasks, such as choosing a healthcare proxy and making the healthcare decisions represented in the directive, and what that experience was like for them.

One respondent supported that the difficulty in writing the AD was making healthcare decisions, *The challenge was really thinking through what you wanted. I kind of knew what I wanted, but then I had to really think it through and put it on paper.*

Another participant supported this statement saying, *It made me think about some things that I had never thought about before. So that was an experience itself, just thinking about those things.* Another participant followed-up, stating, *The process was interesting, because I had never thought of some things before I wrote my living will. Do I want this? Do I want that medication? It was an interesting process.* So, advance directives provoked thinking about critical health care decisions that may have been overlooked by individuals and family members. Group members did not describe the experience of

writing the advance directive as neither a particularly negative or positive experience; simply that it was a challenge to answer some questions about future choices.

A second challenge that the respondents reported was naming the healthcare proxy in the AD. One participant stated, *I have seven children, and it was hard to choose who was in charge, but in the end we chose the oldest and the only son that we have. So, it was kind of hard to say, 'Okay, we're choosing one child and not the other.* Another participant supported this statement regarding the difficulty of designating a proxy, *It was hard to decide who you trust the most. And who really wants to be involved? Who is going to take the most interest in it, and see that things are done the way you want them to be done? And fairly?* Respondents discussed the challenge of choosing a proxy based on family's geographical location, trust of the individual named the agent, time that an individual may have to devote to being a proxy, personality of the proxy, and willingness to take on the responsibility of the proxy role. The participants identified the choice of a health care proxy as the most difficult part of writing the advance directive, as it involved asking someone to fill a role that may end up being difficult or a potential burden.

Participants discussed their family involvement in making healthcare directive choices and deciding on a proxy. Some participants also discussed how culture and family history make an impact on what decisions were made within their directives. As one participant stated, *In my culture, you were always taught to take care of your elders once they couldn't take care of themselves. I'm Italian. I have no doubts that my wishes won't be held accountable. I know that they'll take care of me. I have full trust.* Other participants supported that culture was a deciding factor in helping them make particular

choices in his or her AD, but did not influence their choice whether or not to create the AD itself.

Another respondent discussed culture in the aspect of personal experience and family history, and how this impacted his healthcare choice, *In my family, I saw someone take care of a parent for about 30 years. I said that I'm not going to do that to my kids. It's not fair. I explained that I'm not one to lie around and keep bringing me back. I'd rather go and see what's happening on the other side.* Some participants agreed with this discussion, and had similar experiences that influenced the outline of care that he or she wished to receive. So, the fear of being a burden or living for a long period of time with compromised health was a common factor in this study's focus group members. Group members discussed that they wanted to prevent being a burden to family in the aspect of making decisions, but also a long-term burden in terms of requiring a child to be a caregiver. Focus group members agreed that this was part of their cultural values and personal history.

The aspect of culture and the regard to preventing family burden was also discussed as one respondent stated, *I think in my culture, we're not going to be a drain on our family and somebody else's' life, let alone our own. When it's time to go, you should go. That's not fair to family, that's not fair to the individual.* The overall consensus of this focus group was that the advance directive was created to prevent burden to family members and outline care that they wish to receive, and more importantly, avoid in the future.

Assistance

Focus group participants had completed an advance directive, but received assistance with writing the document from attorneys or family members. When asked if he or she would have preferred more assistance, the participants stated that he or she would have preferred the guidance of an individual with knowledge of healthcare. As one group member stated, *If I revisit it, it would be helpful to have someone who would be knowledgeable about healthcare issues*. So, participants of this focus group wrote advance directives without the guidance of an individual with healthcare experience or formal knowledge regarding treatments, and used his or her judgment to create the directive.

The focus group participants wrote of using his or her advance directive in order to feel at ease about future healthcare choices that may be made by family members. This ease was also found in knowing that the advance directive would prevent burden to family members in preventing long-term life-sustaining treatment and prevent arguments between family members about treatment options. These themes presented by participants were related to literature review findings, but on a more personal and individual level.

Discussion

This research set to explore experiences of individuals who have written an advance directive, and questions that were posed to the focus group were based on themes that emerged through the literature review. Some major themes that emerged from the data analysis regarding experiences writing advance directives was supported by the literature, while some of the themes that emerged through the group discussion differed from literature findings. This may be due in part to the perspective that the

literature was written. The literature included in this study was mostly written for and by professionals, and was not necessarily from the perspective of an individual who had gone through the process of writing an advance directive and from the perspective of an older adult.

The major theme from the discussion is peace of mind, which relates to the literature review of the value of an advance directive. ADs are used to promote individual autonomy and ensure respect of end-of-life choices in healthcare settings (Levi & Green, 2010). Focus group participants agreed that this was the ultimate reason to have an advance directive. The peace-of-mind is ultimately there will ultimately be respect at the end of life. This is what group members mean by peace of mind in having a directive.

Focus group members also spoke to peace of mind knowing that family members were involved in the discussion regarding care, which is related to the literature review of the value of an AD and family involvement. An individual must discuss their wishes and work through disagreements with family members while they are still able to communicate his or her desires. This helps to make sure wishes will be honored during times of heightened stress among family (Haddard, 2004). As group members stated, there was a sense of relief once this discussion was had with family members during the process of writing the directive. Participants were confident that his or her wishes would be honored by his or her family and appointed decision makers, and that this was an important aspect to writing the directive. Participants also stated that the result of this discussion with family members had made the topic of death less taboo and that family was more comfortable discussing potential illness and death now that treatment options had been discussed. The advance directive created a sense of security that family

members would be comfortable and confident in making decisions, and individuals were confident that their wishes would be followed by family members because of their involvement in the process. Because of this, individuals felt as though he or she was preventing families from having a difficult time discerning what the individual would want versus the family's own emotional desires regarding withdrawing or withholding treatment (Lind et al., 2011).

A topic of discussion among group members and family involvement was the thought that an advance directive would help with preventing family member burden, both in the physical and emotional sense. As the research suggests, family discord tends to result in more aggressive life-sustaining treatment for patients. This may impact an individual's quality of life, prolong potential suffering, and prevent palliative care from occurring (Winter & Parks, 2008). With more aggressive life-sustaining treatment, the more potential there is for an individual to be dependent on family members to provide care or draw out the dying process. Group members feared that this may happen without an advance directive, and family members would feel obligated to prolong life, ultimately prolonging care that family members would have to provide. Also, group members felt that with an advance directive, it would prevent the burden of family feeling responsible for making the decisions to prolong or end life.

Another aspect of the discussion that supported the literature review was the culture influence on decision making. Ethnic groups may approach end-of-life care planning and the writing of advance directives in differing manners (Cohen et al., 2010). Though this research group was limited in diversity based on the six respondents, the group did speak to how their culture influenced their decision making. The group

members spoke to the fact that within his or her culture, there were norms of caring for the aged, and that the advance directive was in place to ensure that family knew how to care for them. One group member, who identified himself as Italian, discussed that in his culture, younger generations were responsible for caring for the elderly. Another group member, who identified himself as African-American also discussed the cultural context of caring for the elderly, and that the advance directive would serve to assist family in making appropriate healthcare decisions. However, the group did not speak to specific cultural differences or influences on their choice in completing an advance directive.

When the group was asked about challenges in creating the advance directive, the participants all spoke to how difficult it was to appoint an alternate decision maker or a proxy. Each group member had a supportive family and children, and each group member appointed a child as a proxy. Because the group members had multiple children, it was discussed how difficult it was to choose this person without expressing favoritism to the children, and being careful to make the right choice on who would be the most appropriate proxy. However, this was not something that was discussed in the literature for this research project, though it was a strong theme throughout the focus group discussion.

Group participants reported that they did not encounter a social worker during their work completing an advance directive. However, when asked what was missing from their experience or what they would have preferred, the group members discussed the lack of medical knowledge during the writing of his or her directive. In medical settings, social workers assist individuals with navigating the complexities of end-of-life care and the needs of the individual and family during this time of heightened crisis and

anxiety. These social workers work to prevent injustices of an unknowledgeable decision regarding life sustaining treatments (Pockett, Walker, & Dave, 2010). However, the literature did not discuss the possibility that many individuals are completing advance directives before he or she is faced with needing complex medical care, so many individuals are writing advance directives without ever coming in contact with a social worker or other medical staff. As this focus group members demonstrated, they had been advised on health care directives from attorneys or completed the directive independently.

Group members spoke of writing their advance directive as a positive experience, so this focus group research did not speak to literature regarding struggles of choosing life vs. death, controversies, or stigma or writing or having an advance directive.

Strengths and Limitations

As with any research, there are various strengths and limitations to this study, including the design, the findings, and the application to other situations. One limitation for this research was low response rate to the research at one focus group site, so only one focus group was held. This limited the information that was gathered and therefore limited findings for this research. It will be beneficial for more participation in any future research. The focus group methodology may have also contributed to this low sample size. It was difficult to find suitable times or places for gathering a large number of individuals to participate in a focus group. Having low numbers or participants also limits the amount of generalization that may be done to this research and this study.

Another limitation may be the use of qualitative research. The focus group was held open to any individual who fit the criteria for the group, and so this was a random

sample, which makes the research more true to the population. However, the group members were recruited through fliers that were posted at the focus group site, so group members were a part of the agency in some way, and may not be a true sample of seniors if they were not a part of this community.

Because the research was done in group form, there was a limit of two hours for the discussion. However, participants remarked at how long the discussion took and the desire for the group to end, so some of the discussion felt rushed. This may limit some of the research findings as participants had short answers to the questions and vocalized that they wanted the group discussion to move along faster, so it was difficult to get participants to elaborate on complex questions. For future research, individual interviews may be more appropriate for this subject as group members had individual experiences to share, and it was difficult to research the full experience due to time. Also, gathering demographic data may be an important aspect to this research, and so a multi-method approach to gathering data would be beneficial. In future research, it will be beneficial to interview more men and women, and see what gender differences exist as a barrier to complete an advance directive. Also, future research should interview individuals who have not written an advance directive and discover the reasons for not completing a directive.

Implications for Social Work Practice

According to the NASW Code of Ethics, “social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals” (NASW, 1996). The goal of an advance directive is to maintain an individual’s right to self-determination and autonomy during the end of their life. So, an

AD can be a critical key for social workers to assist individuals to promote their own self-determination and set their end of life goals.

Participants in this research did not discuss social workers having an impact on their desire to create an AD or assist in the process of creating one. Social workers need to be on the front line of assisting with promoting advance directives, and the personal experiences shared in this research group may be beneficial in understanding what the process of writing an advance directive may be for some individuals. Though there is a lot of literature available regarding professionals assisting with writing directives, there is a lack of research available regarding the human experience of the process. This research may assist medical social workers understand the challenges and personal influences on writing an advance directive.

Participants discussed the challenge of appointing a healthcare proxy, and identified this as the most difficult part of writing an advance directive. Social workers who assist with advance directives may need to understand that appointing a proxy is just as, if not more difficult than the health care decisions themselves. Social workers can assist individuals with navigating this difficult decision and help individuals understand the responsibilities that a proxy may face. Also, clinical social workers may be asked to assist with helping families decide on a proxy or support individuals in making the difficult decision to name a certain family member as a proxy over another.

Conclusion

The purpose of this qualitative study was to understand the experiences of older adults who have completed an advance directive. The information gained through this research will aid to the existing literature about advance directives and the process that

individuals go through while writing a directive. This study specifically focused on individuals who were at least 65 years of age and had already completed an advance directive. This study found that individual's experiences generally supported the literature review. Participants found peace-of-mind in writing a directive and were comforted by the potentially lessening family burden through a directive. Participants also spoke to the difficulty of appointing a proxy and the challenge that specifically naming someone posed. However, participants found that the value of having the directive and starting the discussion with family was so important in planning for their future. Social workers may find this information useful when stepping into the role of assisting individuals write an advance directive. So often clinical social workers are there to help an individual tell their story, and find meaning in the story that he or she has to tell. Often times, individuals have little control over what story he or she has and what happens in his or her life. The use of an advance directive helps an individual end the story the way he or she chooses.

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Appendix A

Interview Questions

1. What type of advance directive do you have?
2. Who assisted you with completing an advance directive?
3. Can you describe the experience you had completing an advance directive?
4. What was the biggest challenge in creating an advance directive?
5. Can you speak to the value that you see in advance directive?
6. How did you include your family in your choices?
7. What kind, if any, concerns did your family have regarding your choices?
8. What prompted you to complete an advance directive?
9. Can you describe how your culture has influenced your advance directive choices?
10. How do you see an advance directive being useful for you and your family, if it is ever needed?
11. What role do you see social workers having in promoting advance directives?
12. Is there anything else you would like to say about the experience of completing an advance directive?

Appendix B

Consent Form

The Experiences of Elderly Individuals Who Have Completed Advance Directives RESEARCH INFORMATION AND CONSENT FORM

Introduction:

You are invited to participate in a research study investigating the experiences of individuals who have completed advance directives. This study is being conducted by Lisa Watts in the Master of Social Work Program at St. Catherine University. You were selected as a possible participant in this research because you are over the age of 65 and have written an advance directive. Please read this form and ask questions before you decide whether to participate in the study.

Background Information:

The purpose of this study is to better understand the experiences of individuals who have completed an advance directive. Approximately 15-25 people are expected to participate in this research.

Procedures:

If you decide to participate, you will be asked to attend one of the scheduled focus group meetings at the Merriam Park Public Library meeting room which is reserved solely for this focus group. You will be asked to review and sign the consent form. This study will take approximately two hours over one session. The discussion will be audio recorded.

Risks and Benefits:

The study has several risks. First, it is possible that focus group participants may know each other by coincidence which may lead to a level of discomfort. The likelihood of this risk is medial, and would be coincidental. Second, you may find the discussion of advance directives sensitive. The interview questions are written for open ended response, and you have the option of not answering any questions you find uncomfortable. If you find yourself at emotional risk, you have the option to leave the group at any time without any repercussions. Information for the St. Thomas Interprofessional Center for Counseling and Legal Services for free counseling will be given to you at the end of the study in the case you require this resource.

There are no direct benefits to you for participating in this research.

Compensation:

If you participate, you will receive a \$10 gift card to Target which will be distributed at the end of the focus group.

Confidentiality:

Any information obtained in connection with this research study that could identify you will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented.

I will keep the research results in a password protected computer and/or a locked file cabinet in my private home and only I will have access to the records while I work on this project. I will finish analyzing the data by May 15, 2012. I will then destroy all original reports and identifying

information that can be linked back to you. All recorded interviews will be destroyed by June 1, 2012.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with St. Catherine University in any way. You have the options to refuse to answer any discussion questions if you choose. If you decide to participate, you are free to stop at any time without affecting these relationships, and no further data will be collected.

New Information:

If during course of this research study I learn about new findings that might influence your willingness to continue participating in the study, I will inform you of these findings.

Contacts and questions:

If you have any questions, please feel free to contact me, Lisa Watts at (651) 334-5031. You may ask questions now, or if you have any additional questions later, the faculty advisor, Sarah Ferguson at (651) 690-6296, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact John Schmitt, PhD, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739.

You may keep a copy of this form for your records.

Statement of Consent:

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time and no further data will be collected.

I consent to participate in the study. I understand the interviewer will be audio recording the focus group.

Signature of Participant

Date

Signature of Researcher

Date