

5-2014

Factors that Impact Couples' Discussions of Advanced Directive Contents

Margaret I. Nerison
St. Catherine University

Recommended Citation

Nerison, Margaret I., "Factors that Impact Couples' Discussions of Advanced Directive Contents" (2014). *Master of Social Work Clinical Research Papers*. Paper 366.
http://sophia.stkate.edu/msw_papers/366

This Clinical research paper is brought to you for free and open access by the School of Social Work at SOPHIA. It has been accepted for inclusion in Master of Social Work Clinical Research Papers by an authorized administrator of SOPHIA. For more information, please contact ejasch@stkate.edu.

Factors that Impact Couples' Discussions of Advanced Directive Contents

By

Margaret I. Nerison, BSW

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catharine University and the University of St. Thomas
St. Paul, Minnesota
in Partial Fulfillment of the Requirements for the Degree of

Master of Social Work

Committee Members
Katharine Hill, Ph.D., MSW, MPP, LISW (Chair)
Molly Matteson, LICSW
Doretta Stark, MA, LICSW, emertius

The Clinical Research Project is a graduation requirement for MSW students at St. Catharine 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 the findings of the study.

This project is neither a Master's thesis nor a dissertation.

Factors that Impact Couples' Discussions of Advanced Directive Contents
By Margaret. I. Nerison

Research Chair: Katharine Hill, Ph.D., MSW, MPP, LISW

Committee Members: Molly Matteson, LICSW; Doretta Stark, MA, LICSW, emertius

An advanced directive is a document used to communicate end-of-life treatment desires when a patient is incapacitated or determined to be incapable of making their own decisions. This study was conducted using secondary data analysis of data collected from a 2010 survey by the National Center for Family and Marriage Research. The sample utilized in this study included married and cohabitating couples between 45 and 64 years of age. This research analyzed the accuracy of couples' perceptions of their partner's end-of-life treatment wishes. Characteristics among those who have advanced directives in place were distinguished. Individuals are better able to predict their spouses' end-of-life treatment wishes when they themselves were in poor health. Factors that contributed to a slightly higher percentage rate of participant's ability to distinguish their spouse's end-of-life treatment wishes included having a spouse appointed as durable power of attorney for health care and having discussed end-of-life treatment wishes with a spouse. Participants who reported dissatisfaction with their spouses' listening were found to have slightly lower percentage rates of ability to predict their spouses' end-of-life treatment wishes. These findings reveal that many Americans do not actually know the level of care their spouses would like to receive at the end of their lives. The findings suggest a need for social workers to assess if there is a disconnect between couples when it comes to understanding one another's advanced directive contents. A disconnect in this vital communication may leave individuals receiving care they do not want, or not receiving care they would prefer.

Acknowledgements

I would like to thank my research committee chair, Katharine Hill, for the support and guidance throughout this entire project. She offered so much insight into the research process and was always available for my millions of questions. I also wish to thank Molly Matteson, one of my committee members. Molly's positivity is an inspiration to me. She was a great cheerleader for me whenever I approached her with a new piece of my project and had great insight into the topic. Doretta Stark, another committee member, offered so much knowledge on the topic and challenged me to expand the depth of my literature review. She was so encouraging throughout the process. Also, David Chapman was instrumental to the completion of this project. He spent hours working with me, as well as my data, to help me find the best way to analyze and organize it. "Thank you" does not seem to express how grateful I am for their help.

I would like to thank my boyfriend, Jack Dee, for the emotional support throughout my graduate school experience. He talked me through late night panic attacks and helped me through the hardest aspects of this past year. My parents, Mike and Anne Nerison, have never doubted me in my educational endeavors. They have supported me through good times and bad, and have pushed me to become the person I am now. I will always be grateful for their amazing encouragement. I also want to thank my advanced standing one-year family. We have been with each other throughout our graduate school experience, and it would not have been the same without them.

In 1991, the Patient Self-Determination Act was enacted. One of the requirements in the act is that hospitals, nursing homes, home health agencies, and other health care institutions inform residents or patients of their right to complete advanced directives and keep a copy of the advanced directive in the patient's medical file. These health care institutions are also required to offer information and assistance for patients or residents to complete advanced directives (Engel et al., 1997; Giger, Davidhizar, & Fordham, 2006). An advanced directive is a document used to communicate end-of-life treatment desires when a patient is unable to make their own decisions. Living wills and durable power of attorneys for health care are included in an advanced directive. A living will is a document that specifies which life-sustaining treatment options are determined acceptable or unacceptable by the author. A durable power of attorney for health care (DPAHC) is an individual appointed by the patient who makes health care decisions on their behalf should they become unable to make their own decisions.

In Minnesota, an advanced directive is referred to as a "health care directive" (Minnesota Statutes, 2013). Minnesota Statutes (2013) Chapter 145C.02 states,

"A principal with the capacity to do so may execute a health care directive. A health care directive may include one or more health care instructions to direct health care providers, others assisting with health care, family members, and a health care agent. A health care directive may include a health care power of attorney to appoint a health care agent to make health care decisions for the principal when the principal, in the judgment of the principal's attending physician, lacks decision-making capacity, unless otherwise specified in the health care directive."

“Decision making capacity” was defined as “the ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision.” (Minnesota Statutes, 2013).

Despite the wide availability of information on advanced directives, very few people have completed advanced directives. A survey of all inpatient admissions in a hospital over the course of a year revealed that only 11% of inpatients had an advanced directive upon admission (Gross, 1998). There is a higher prevalence of completed advanced directives among individuals residing in nursing homes, enrolled in home health, or enrolled in hospice which is speculated to be caused by the prevalence of chronic illnesses in these care settings (Jones, Moss, & Harris-Kojetin, 2011, as cited by Waldrop & Meeker, 2012)

In the absence of advanced directives, an individual may receive end-of-life care that is against their wishes. Even if an individual has an advanced directive in place, it may not always be on file in that person’s medical records. A study conducted by Duke, Thompson, and Hastie (2007) found that only 40% of advanced directives were included in medical records. Families also face many barriers in communicating their end-of-life wishes and discussing their feelings regarding their prognosis, as evidenced in many studies (Coyne & Smith, 1991; Goldsmith & Domann-Schulz, 2013; Moorman, 2010; Song, 2012) which will be outlined in the literature review.

The purpose of this research paper is to determine the accuracy in married couples’ perceptions of their spouse’s end-of-life treatment wishes. With the advancement of medical technology capable of prolonging life, it has become more important for individuals to have discussions concerning end-of-life treatment. This study will be conducted using secondary data analysis of data collected from a 2010 survey by the National Center for Family and Marriage

Research. The sample utilized in this study included married and cohabitating couples between 45 and 64 years of age. This research analyzed the accuracy of couples' perceptions of their partner's end-of-life treatment wishes and distinguished characteristics among those who have completed advanced directives. This paper will include a literature review, which will outline the broader advanced directive topic, as well as how couples communicate due to the lack of literature on couples' communication regarding advanced directives. The methodology will be described, as well as the results. Finally, strengths and limitations of the proposal will be discussed.

There has been a multitude of research studies on the topics of both advanced directives and communication between significant others. However, there is little research on how couples communicate about their end-of-life treatment preferences. It is important for communication about advanced directives to be studied as it is becoming increasingly relevant within the medical community because of the advancement of medical technology and the continued low numbers of individuals with advanced directives. Findings of this study could allow health care professionals, including social workers, to better address the topic of advanced directives with their patients.

Literature Review

Advanced Directives

Ethical Debate. There are multiple ethical debates surrounding advanced directives. Buford (2008) outlined the two major objections to advanced directives. One suggestion against advanced directives is that medical and therapeutic interventions may continue to progress after the creation of the advanced directive, thereby changing the prognosis of the disease or illness (Buchanan, 1988 as cited in Buford, 2008). For example, if a patient were to be unable to

communicate and had stated in their advanced directives they do not wish to have breathing tubes used to sustain life, and if future technology had created a new alternative to breathing tubes, the person may not receive the new breathing alternative. The most argued ethical questions regarding advanced directives is whether the individual who created the advanced directive is the same person who will be receiving, or not receiving, the treatment (Dresser, 1986 as cited by Buford, 2008). This was termed “psychological continuity”. Individuals who argue against the validity of advanced directives often suggest the competent and functional author of the advanced directive is no longer the same person once they are in an incapacitated state (Buford, 2008).

Buford (2008) did point out some models in support of advanced directives, which address the ethical questions described above. The Guardian Model suggests that the author of the advanced directive, who is no longer the same person as the individual who is ill in the sense of psychological continuity as previously described, acts as a guardian through the advanced directive. The guardian can then make the decisions in the treatment process as depicted by the advanced directives. The author, as a guardian, can make the decision to withhold treatment much like that of a next-of-kin making the decision. The Proxy Model suggests that the advanced directive should be considered a guide, rather than a strict set of rules, for the way in which the patient would like their condition to be treated, which would address the issue of advances in medical technology changing the prognosis of a condition after an advanced directive is created (Buford, 2008).

Prevalence. It is estimated that the number of individuals in the United States with completed advanced directives is somewhere between 5-15% (Jones, Moss & Harris-Kojetin, 2011, as cited by Waldrop & Meeker, 2012). There was a study conducted by Gross (1998) in

which a questionnaire was distributed to all patients admitted to a local hospital for one year.

Gross (1998) found that almost all elderly patients stated they did not want prolonged life if there was not much chance for a good quality of life, yet only 11% had advanced directives. A separate study found that 22% of the outpatients surveyed had formed opinions on treatment they would want to receive at the end of their lives, but none of the patients had actually written them down or completed advanced directives to ensure their wishes were known (Sam & Singer, 1993). In a retrospective study by Guo and colleagues (2010), individuals with Metastatic Spinal Cord Compression seldom had completed advanced directives, even with a median survival time of 3-6 months. Living wills were in place among only 23% of patients, while 31% had a health care proxy.

As previously mentioned, Jones, Moss, and Harris-Kojetin (2011, as cited by Waldrop & Meeker, 2012) found that there was a higher prevalence of advanced directives among patients enrolled in hospice and home health and residents of nursing homes. In a chart-review by VanLueven (2012) of 272 nursing home residents requiring a skilled nursing level of care, it was found that 90.44% of residents entered skilled care after a hospitalization, yet had not completed an advanced directive. The ages of the residents analyzed ranged from 35 to 100 years old. The reasons for skilled nursing ranged from acute rehabilitation to long-term care. After experiencing a steady decline in health status, 21.32% of residents authored advanced directives. The shortest amount of time between admission to the skilled nursing unit and implementing an advanced directive was four years, with the longest amount of time being 17 years (VanLueven, 2012).

Duke, Thompson, and Hastie (2007) broke down the contents of advanced directives completed among 47 inpatients in two Texas acute care hospitals. Living wills and DPAHC

were in place among 64% of individuals with advanced directives. Individuals with DPAHC alone made up only 4% of the sample population, and individuals with only a living will in place constituted 32% of the sample population. Further exploration found that only 40% of advanced directives could be found in the patients' medical records.

Patient Factors Regarding Advanced Directive Use.

Demographic factors. Individuals most likely to have a completed advanced directive are Caucasian females with a college education (Gilber, Counsell, Guin, O'Neill, & Briggs, 2001, as cited by Duke, Thompson & Hastie, 2007). Patients' ethnicity seems to play a role in advanced directives (Blackhall et al., 1995; DeSpelder & Strickland, 1999; Gilber et al., 2001 as cited in Duke, Thompson, & Hastie, 2011; Mitty, 2001). For example, some Hispanic individuals value hierarchy, which in turn suggests they prescribe to the old saying "doctor knows best". These patients and their families prefer to have a doctor make end-of-life decisions for them. This would decrease the likelihood of certain Hispanic individuals creating advance directives (Mitty, 2001). DeSpelder and Strickland (1999) suggested a distrust of the health care system is present among many African-Americans. These individuals may see an advanced directive as legalized neglect. Additionally, a study by Blackhall, Murphy, Frank, Michel, and Azen (1995) found that African-Americans who participated in their study, which utilized both qualitative and quantitative data, believed that limiting treatment for end-of-life put a barrier between the patient and God's will.

Reasons for advanced directives. A qualitative study conducted by Duke and colleagues (2007) determined 36% of patients implemented an advanced directive while they were experiencing health issues. As previously discussed, a study by VanLueven (2012) found 21.32% of the nursing home residents implemented advanced directives after experiencing a

decline in their health. It should be noted that 70% of participants who had advanced directives in the study by Duke and colleagues (2007) reported their health status did not impact their decision to complete advanced directives.

It is not uncommon for an individual contemplating end-of-life to utilize their religious beliefs. Of individuals with advanced directives, 45% reported their religion played a role in their decision (Duke, Thompson, & Hastie, 2007). The desire to have control over their fate was cited as a reason for completing advanced directives in 17% of participants. Participants cited the single most influential factor in the formation of their advanced directives as not wanting to burden their family (Duke, Thompson & Hastie, 2007). The fear of burdening family members appears to be supported in the literature. In those without completed advanced directives, familial stress after the decision to end life-sustaining treatments was high immediately after the death, and remained high even six months after the death (Wilson, 2000).

Barriers to completion of advanced directives. A program review by Berrio and Levesque (1996) identified common barriers to completion of advanced directives. Among the barriers listed were being uninformed about advanced directives, unclear wording on advanced directives, and the process of completing them. The belief that the individual had plenty of time to think about end-of-life treatment decisions was another factor identified (Berrio & Levesque, 1996; Butterworth, 2003). A discussion guide outlining barriers to completion of advanced directives identified additional obstacles. Uneasiness associated with conversations surrounding end-of-life issues by both health care providers and patients and their families prevents many discussions about advanced directives (Butterworth, 2003). Overestimation of the success of CPR is also a factor that prevents the completion of advanced directives. Individuals commonly are not aware of the negative consequences associated with the procedure, which has a survival

to hospital discharge rate between 22% and 41% (Butterworth, 2003; Deep, Green, Griffith & Wilson, 2007; Schonwetter, Walker, Kramer & Robinson, 1993).

Patient knowledge of advanced directives. VanLueven (2012) observed hospital admission processes and observed patient being asked if they had advanced directives in place as required by the Patient Self-Determination Act. However, the PSDA also requires education on advanced directives. VanLuevan (2012) observed zero attempts to educate or discuss with patients the importance of advanced directives. Sam and Singer (1993) found outpatients had positive attitudes towards advanced directives, but a limited knowledge concerning them. Only 16% of participants knew what living wills were, and 11% knew about DPAHC. Further, in a study by Jacobson, Battin, Francis, Green, and Kasworm (1994) in which a majority of participants were white males, 90% of participants reported they were aware of living wills. Only one-third of those individuals could explain living wills satisfactorily and only 10% had completed living wills. Participants were also asked about DPAHC. Only one-third of participants were aware of a DPAHC, and only half of those people could describe a DPAHC. Less than 10% of those participants who were familiar with DPAHC had completed one. Patients with advanced directives did not know what their advanced directives stated (Janssen et al., 1994).

Badzek, Hines, and Moss (1998) surveyed hemodialysis patients. When asked if they were educated on their condition, 75% reported they were well informed. However, only 14% could correctly answer questions concerning their diagnosis (Badzek, Hines, & Moss, 1998). This displays the lack of knowledge among many patients that may impact their decisions on whether to create advanced directives. In a study conducted by Schonwetter and colleagues (1993) it was determined that elderly patients overestimated their chances of surviving and the

expected quality of life following CPR. This could be due to mixed messages and unrealistic optimism from health care professionals (Butterworth, 2003). After education, the preference for receiving CPR decreased (Schonwetter et al., 1993).

Health Care Provider Factors.

Health care provider knowledge and education on advanced directives and end-of-life care. Health care professionals are instrumental in educating patients and their families as they are the group that recognizes the need for advanced directives in patients (Crego & Lipp, 1998; as cited in Conelius, 2008). Crego and Lipp (1998; as cited in Conelius, 2008) surveyed a group of nurses and found over 50% of the nurses did not have a solid understanding of advanced directives. Additionally, 67% of the nurses interviewed felt that nurses were the most likely health care provider to analyze the need to implement advanced directives and initiate advanced care planning. In their qualitative study which surveyed 55 medical residents, Ury, Berkman, Weber, Pignotti, and Leipzig (2003) found that medical residents rate the amount of teaching they receive regarding end-of-life care lower than the rest of their medical education. When asked to rate the quality of the teaching they receive regarding end-of-life care, medical residents also rated it lower than the rest of their medical education. In another survey of medical residents, Sullivan, Lakoma, and Block (2003; as cited in Deep, Green, Griffith, & Wilson, 2007) reported medical residents are rarely observed having discussions with patients regarding DNR orders. They also admitted receiving little feedback concerning their performance of such a task (Sullivan, Lakoma, & Block, 2003; as cited in Deep et al., 2007). One-third of medical residents rated their skill in discussing end-of-life issues with their patients as low (Deep et al., 2007).

Health care provider attitudes towards advanced directives. Despite the difference between Do Not Resuscitate orders and advanced directives, looking at research regarding DNR orders point out barriers to advising a patient to complete advanced directives. Beliefs that a patient was not going to die in the near future was cited 56% of the time as a reason for not writing a DNR order when a patient had expressed such desires (Karnik, 2002). Another commonly cited excuse in the survey of health care providers conducted by Karnik (2002) was the health care provider did not have adequate time to write the order. In a survey of 55 medical residents, many reported they often disagreed with the patient's decision to receive resuscitation efforts. One-third of residents reported feeling unhappy with their discussions regarding DNR orders and the results of such conversations (Deep et al., 2007). Sixty percent of the medical residents surveyed held the belief that less than half of their patients fully understood the process and results of CPR. They often believed that patients overestimated the chance of survival (Deep et al., 2007). As previously discussed, Schonwetter and colleagues (1993) found that patients often overestimate the survival rate of CPR and their willingness to receive CPR decreased after being educated about the procedure and its consequences. Nearly a quarter of medical residents reported regretting performing CPR on more than half of their patients. These "over-treated" deaths were believed to be filled with more suffering for the patients involved (Deep et al., 2007).

Interventions. As described previously, there is a severe lack of use of advanced directives among today's health care recipients. There seems to be a number of studies conducted in efforts of pinpointing ways to increase the use of advanced directives. Molloy and colleagues (1997) implemented an educational program in a nursing home. After the conclusion of the study, 64% of competent residents completed advanced directives. The families of 72% of

incompetent residents completed advanced directives by the end of the study as well. Culgari, Miller and Sobal (1995, as cited by Conelius, 2008) conducted an experiment using two hospitals and their patients with planned admissions. One hospital administered advanced directive education prior to a patient's admission. The other hospital did not provide any form of education prior to admission. Fifty-four percent of planned admission patients completed advanced directives when they were provided an education prior to their admission. Those patients also reported they preferred receiving the advanced directive information from their family practitioner during an office visit compared to a doctor in a hospital with whom they did not have a familiarity (Culgari, Miller, & Sobal, 1995, as cited by Conelius, 2008).

There are many issues surrounding the topic of advanced directives. Studies have revealed that many people are uneducated on advanced directives, a minority of the population have completed advanced directives, and many times, there is confusion about the treatment preferences laid out in the advanced directive (Jacobson et al., 1994, as cited by Conelius, 2008). The focus of this research will be on couples' communication regarding their advanced directives. If a spouse is named as decision maker, but has not had a discussion about their partners' treatment wishes, there is the potential that the patient will receive unwanted care.

Communication

There seems to be little research regarding couples' communication regarding their end-of-life preferences and advanced directives. A broader sense of communication between couples will be discussed, as well as their communication surrounding the topic of illness and preventative health care. Social work's role in facilitating discussions regarding advanced directives and planning for end-of-life care will also be highlighted.

Aspects of Communication. According to Goldsmith and Homann-Scholz (2013), open communication is a popular idea in American culture. In a survey of Americans, open communication was voted the preferred method of communication in close relationships (Goldsmith & Homann-Scholz, 2013). Conversations that reflect closeness and support are deemed open communication (Katriel & Philipsen, 1981). Demand-withdraw was another identified style of communication within couples (Laurenceau, Barrett, & Rovine, 2005). This was found to be associated with low rates of satisfaction in marriage. Demand-withdraw refers to the occurrence of one individual wanting to talk about an issue, and their partner's avoidance of the topic. This is also associated with lower levels of intimacy within the marriage.

Self-disclosure is a key aspect of communication. Laurenceau and colleagues (2005) found that in married couples, when an individual self-discloses, their spouse responds with self-disclosure. This, among other findings, were determined after multiple married couples kept a 42-day diary regarding their interactions of 10 minutes or more each day. Self-disclosure contributes to the feeling of intimacy and closeness within a marriage. Intimacy is achieved by self-disclosure and perceived partner responsiveness. Husbands tended to rate the relationship's intimacy level higher when they self-disclosed. Wives, however, required high-perceived partner responsiveness in the form of understanding, acceptance, caring, and validation before they felt their intimacy with their husband was at a high level. Having felt that they were heard and accepted by their partner allowed the self-discloser to continue sharing information (Laurenceau et al., 2005).

Influence on others is a form of communication found to be present in marital relationships (Manne et al., 2012). Manne and colleagues (2012) studied the decision-making process for couples regarding their decision whether or not to undergo colorectal cancer

screenings. Couples in this study were either compliant or noncompliant with screenings. This study was completed through interviewing the couples regarding factors that impacted their decisions. They found three direct partner effects. Leadership was one direct partner effect identified during the interview by couples that were current on their screenings. Oftentimes, when one spouse was screened for cancer, their partner did as well. Some identified that they were able to see that the procedures were not as troublesome as they had originally perceived them to be. Persuasion was also a direct partner effect. Spousal encouragement was found to be an important factor in screenings for colorectal cancer. Manne and colleagues (2012) pointed out a limitation of the study, in that a partner may have worded it "encouragement" rather than "nagging" because of the presence of their spouse. Partnership was the factor that appeared to have the greatest impact on whether an individual would get a colorectal cancer screening. This was displayed through participants reporting they completed screening for their spouse.

Communication about Illness and End-of-Life. Moorman (2010) found that many couples never have conversations about decision-making at the end of life. Even when couples have such discussions, Coyne and Smith (1991) found there are many barriers to completely understanding the patient's wishes. Such barriers included patients not wanting to tell their loved one their preferences in fear of upsetting them with their choices, or not wanting to cause stress for their spouse (Coyne & Smith, 1991). When couples were able to communicate openly about their treatment wishes with their surrogates at the end of their lives, 79% reported feeling "extremely well understood" after these conversations (Moorman, 2010). However, Shalowitz, Garrett-Mayer, and Wendler (2006, as cited by Moorman, 2010) identified that DPAHC surrogates who had discussions about what they wanted for care at the end of their lives with the

patient scored the same at perceiving what the patient wanted as surrogates who did not have the conversation.

Keeping discussions about illness and end-of-life to a minimum was seen as a method for remaining optimistic and positive among families with a parent who died from lung cancer according to Caughlin (2011, as cited in Goldsmith and Domann-Schulz, 2013). Too much discussion about the illness was seen by families as “dwelling” on the issue. Families reported they believed open communication was important and showed that the patient was coming to terms with their diagnosis, but too much discussion meant the patient was not coping properly. Caughlin, Mikcuki-Enyart, Middleton, Stone and Brown (2011, as cited in Goldsmith & Domann-Schulz, 2013) reported that after interviewing adult children whose parent perished from lung cancer, they found families often avoided the subject of cancer during their loved one's illness. They chose not to discuss the diagnosis, prognosis, decision-making, death, or the many difficult emotions that come with a cancer diagnosis. The reasons cited included remaining positive and hopeful, not believing they were capable of facilitating such discussions, and believing it was against family norms to discuss the illness. Song (2012) also determined that cancer patients and their spouses found discussing symptoms and prognosis difficult topics to discuss.

Moorman (2010) determined that if an individual discussed their end-of-life wishes with anyone outside of their marriage, when a spouse communicated their end-of-life wishes to the individual, the spouse would have a greater feeling of being understood. This was attributed to the scenario of a wife talking to her daughter about her end-of-life wishes, and her daughter responding with certain expressions, like compassion. The wife would feel validated and understood, so when her husband wants to discuss his end-of-life wishes as well, the wife is able

to use the expressions that helped her feel understood; hence the spouse's greater feeling of being understood. Increased relational quality was associated with perceptions that an individual's end-of-life wishes were well understood (Moorman, 2010). Open communication regarding recovery from illness and prognosis facilitated individual and relational well-being according to a study by Joekes, Maes, & Warrens, 2007. A study by Goldsmith and Domann-Scholz (2013) stated,

“Openness sometimes referred to a single big talk in which a couple acknowledged mortality, talked about their life together, or set the record straight for past regrets. Big talks were prompted by a health crisis but focused on what the threat to life meant for self and relationship.” (Goldsmith & Domann-Scholz, 2013, p 276).

“Big talks” often occurred prior to a high-stakes surgery and were described by the couples as “emotionally-charged” and significant. Couples reported they did not discuss the topic again following the “big talk”, due to avoidance and feeling it was not necessary (Goldsmith & Domann-Scholz, 2013).

Facilitating communication between couples about end-of-life treatment options and advanced directives is an important role for social work. Communication between couples regarding treatment wishes increases a patient's self-determination and can enhance coping by facilitating social support. Osman and Perlin (1994, as cited by Luptak, 2004) suggested that social workers are great assets in advanced directive planning as a result of their education and experience working with different populations. In discussion of the study by Osman and Perlin (1994), Luptak (2004) stated,

“With their expertise in family and group dynamics, value assessment, and conflict resolution, social workers should be well equipped to help patients and families make decisions and to support them in articulating treatment preferences to the care team.”

As research suggests couples and families tend to avoid topics of mortality and end-of-life, it is important for social workers to facilitate such discussions. Although research has found couples avoid conversations regarding end-of-life when it is approaching, it is important to research whether couples discuss advanced directives and their future care plans. Discussions regarding end-of-life should include advanced directives and the types of treatments they would want at the end of their life.

Conceptual Framework

This study was influenced by the Life Model developed by Germain and Gitterman (1980) and Crisis Theory developed by Taplin (1971, as cited in Slaikeu, 1990). These theories will be reviewed and applied to advanced directives individually.

The Life Model of Social Work Practice (Germain & Gitterman, 1980) outlined how crisis events, such as learning of a new illness or approaching death, can illicit defense responses in an individual (Germain & Gitterman, 1980). Some of these defenses include denial, regression, rationalization and projection. One of the criteria for a crisis as determined by Germain and Gitterman (1980) is the necessity of coping skills, which means common methods of handling stressors are no longer appropriate. Crises have a time-limit; an individual may experience crisis level stressors at the initial determination of a terminal prognosis, for example. The crisis state would last a short time, followed by high levels of stress.

Crisis theory, as described by Slaikeu (1990) has a cognitive component (Taplin, 1971, as cited in Slaikeu, 1990). This may address the situation of some individuals recognizing the need

for an advanced directive, while others use defense mechanisms to postpone the implementation of an advanced directive (Germain & Gitterman, 1980). Taplin (1971, as cited by Slaikou, 1990) suggests there is a cognitive component of whether a person identifies an experience as a crisis. In order for someone to experience an event as a crisis, it would not fit into the frame of their expectations for their life (Taplin, 1971, as cited by Slaikou, 1990).

Defense mechanisms would prevent a family from discussing important treatment decisions. Denial is a coping skill that is common among individuals and their families when it comes to the need for advanced directives and discussing end-of-life wishes. A study by Berrio and Levesque (1996) and an informational brochure by Butterworth (2003) identified that individuals often feel as though they have an abundance of time left to make their end-of-life treatment decisions. Because of this denial, terminally ill individuals may choose to postpone the completion of advanced directives and not participate in important discussions with their families regarding the types of care they would want to receive. After the crisis state has abated, these individuals would still experience high levels of stress. They may still avoid talking about the subject of death with their families while they continue through a difficult transition. Rationalization may also be a defense mechanism utilized by individuals who are facing end-of-life decisions. Individuals and their families may claim they are simply remaining optimistic and hopeful regarding their prognosis, and therefore are not discussing what care the patient wishes to receive should they become unable to make decisions. By putting up the front of remaining optimistic, they may receive encouragement for their behaviors from family, friends, and even healthcare providers, which would perpetuate the avoidance of the topic.

The cognitive component of crisis theory allows one to view the other side of crisis situations. Some individuals may perceive medical diagnoses as a natural part of life. They may

also be oriented with the ideas of life and death and recognize the inevitability of death. This means they may acknowledge the importance of completing an advanced directive, because the notion they will need it in the future does not compete with their preexisting assumptions. For example, a man who recognizes a long line of heart disease in his family, who has been diagnosed with heart disease himself, may not enter a crisis mode compared to a person who did not foresee themselves ever receiving such a diagnosis. The man in the example may recognize the need for an advanced directive in case of a heart attack, whereas the person who was not anticipating a diagnosis may deny that there could come a point where an advanced directive would be necessary.

Methods

Study Purpose and Design

This study used secondary data from a survey utilized by the National Center for Family and Marriage Research (2010). The original study was funded by the United States Department of Health and Human Services and Bowling Green State University. It was conducted by Dennis, McCready, DiSogra, and Rodkin. The survey was designed and disseminated in a manner that aimed to increase participants' interest levels and foster more thoughtful responses (NCFMR, 2010). This study analyzed data for the purpose of furthering knowledge regarding couples' communication about end-of-life treatment decisions in efforts to promote self-determination among aged and terminally ill populations.

Data Collection Instrument Development and Categories of Questions

The National Center for Family and Marriage Research (2010) developed the Married and Cohabiting Couples, 2010 Questionnaire. The questionnaire provided questions to prescreened couples regarding relationship quality, how the relationship started and health care

choices. Questions aimed at gathering information surrounding relationship quality included scaling questions about relationship satisfaction, whether the relationship has changed for the better or worse, and quality of spouse's listening. How the relationship started was measured through questions focused on past relationships and factors contributing to decisions for or against living together prior to marriage. Questions focused on health care decisions included whether the participant had a DPAHC or advanced directive, who was the designee, and who had copies. Also, participants were asked to rate the level of medical intervention they would wish to receive at the end of their life, as well as predict what their spouse would want (NCFMR, 2010).

Sampling Method and Data Collection Process

Knowledge Networks was used to administer the survey as Knowledge Networks had an online pool of potential research participants representative of the United States population. Knowledge Networks utilized a combination of random-digit dialing and address based sampling to recruit a research panel. After recruitment onto the panel, contact was made with participants through email. If panelists did not have access to the Internet, they were provided with it. Knowledge Networks collected demographic information, such as age, gender, race, income, and education, on panelists upon recruitment. Knowledge Networks also provided ongoing monetary incentives to facilitate survey completion (NCFMR, 2011).

Data collection began on July 26, 2010 and ended on October 13, 2010. By the end of data collection, 1504 participants completed the Married and Cohabiting Couples, 2010 Questionnaire (NCFMR, 2010). Participants were between the ages of 18 and 64 and were in heterosexual relationships. Couples had to either live together or be married to each other in order to participate. In married couples, the survey was administered online to the men first. Men were asked to complete the survey first, as they have lower completion rates for surveys

than women. Of the 1500 men asked to participate in the survey, 1060 completed the survey. Surveys were then administered to the men who completed the surveys' wives. Of the 1060 surveys dispersed to the women, 752 completed the survey. This resulted in the 1504 participants, which made up 752 couples. Knowledge Networks did not have enough cohabitating partners in their database for the study. Knowledge Networks collected the sample by using partners who were both panelists in Knowledge Networks, panelists and their partners who were not affiliated with Knowledge Networks, and couples not involved with Knowledge Networks at all. As with married couples, men were administered the survey first, then their female partners. Surveys were administered to 646 participants, making up 323 couples. For both married and partnered couples, completion of the survey was a sign of agreement to the Informed Consent at the beginning of the questionnaire (NCFMR, 2011).

Measures for Protection of Human Subjects

In efforts to protect participants from possible harm, a Letter of Informed Consent preceded the survey. The Letter of Informed consent outlined the purpose of the study and what types of questions participants could expect. The voluntary and anonymous nature of the study, as well as withdrawal from the study was also discussed. The Letter of Informed Consent identified potential risks and benefits, and participants were instructed to clear their Internet browser history upon completion of the survey to ensure confidentiality. Completion of the survey meant the participants agreed to the Letter of Informed Consent.

Strengths and Limitations to Secondary Analysis of Married and Cohabiting Couples, 2010 Data

Utilization of the Married and Cohabiting Couples, 2010 had many strengths. A major strength of using the questionnaire was the diversity of the sample as participants were drawn

from a pool of research panelists representative of the United States population. Additionally, the strength and validity of the questionnaire was an asset. There also seemed to be limited research that could address couples' communication regarding health care decisions. Secondary data analysis also allowed for practical use of resources, as it was time-efficient and cost-effective. Limitations of using secondary analysis of the Married and Cohabiting Couples, 2010 data revolved around the sequence of questionnaire administration. As men were given the survey first, the questions may have inspired discussion between the couple, altering the wives' responses. An additional limitation focused on previous literature. Much of the literature reviewed in preparation for this study considered DPAHC to be a type of advanced directive. However in this study, DPAHC was considered separate from an advanced directive. To preserve the validity of the data, operational definitions could not be redefined to fit this research study (Monette, Sullivan, & DeJong, 2011). Lastly, a limitation of secondary data analysis revolved around errors made in the study of origin. This study could not have a way of knowing if there were mistakes during the coding of the data (Connelly, 2010).

Secondary Analysis

Due to the wide range of ages in this study, analysis only focused on participants ages 45 through 64. Only couples with both individuals over the age of 45 were included. This occurred by sorting the data prior to analysis. The limited age range was in hopes of finding couples who have been married longer, increasing the chance they had discussed care options as a couple. Additionally, it seemed that younger individuals may not have contemplated their own end-of-life as much as older individuals. Only married couples were included in this study. Sorting data before analysis made this possible. Lastly, only participants with a spouse who also completed the survey that was included in the study of origin's data analysis were included. This

was for the purpose of ensuring that all participants had a spouses' response to compare their answers to. Household numbers without matches were manually removed from the data set.

The first variable analyzed from the Married and Cohabiting Couples, 2010 survey was whether or not the participant had an advanced directive in place. The corresponding question in Married and Cohabiting Couples, 2010 was #D4, "Do you have a living will or advance directive? These are written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow unable to communicate." This variable was analyzed using a frequency distribution and displayed in a bar chart.

The second research question analyzed was "Of participants who reported having an advanced directive, how many reported discussing its contents with their spouse?" In Married and Cohabiting Couples, 2010, the question that addressed this question was #D8, "Have you discussed with anyone plans about the types of medical treatment you want or don't want if you become seriously ill in the future? With whom did you have that discussion?" This variable was measured with a frequency distribution. The frequency distribution was transformed into a bar chart to display the data.

The research question, "How many participants had a DPAHC?" was analyzed third using the Married and Cohabiting Couples, 2010 question #D1, "Have you made any legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself? This is sometimes called a durable power of attorney for health care." This variable was displayed in a bar chart after analysis using a frequency distribution.

The fourth analysis answered the descriptive question of "Of participants who reported having a DPAHC, how many appointed their spouse as DPAHC?" The questions in Married and Cohabiting Couples, 2010 that corresponded with this question included #D1, "Have you made

any legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself? This is sometimes called a durable power of attorney for health care.” and #D2, “Who is that person?” This variable was analyzed with a frequency distribution, and displayed in a bar chart.

Research questions five through ten utilized the same methodology. Questions #D10 and #D11 in *Married and Cohabiting Couples, 2010* followed the prompt, “Now we have some questions about the kind of decisions you might make when considering your own health at the end of life. Suppose *you* had a serious illness today with very low chances of survival”. Question #D10 asked, “What if you were mentally intact, but in severe and constant physical pain? Please select the number that best represents the level of treatment you would like” followed by a likert scale from 0 (stop all life-prolonging treatment) and 10 (continue all treatment). Question #D11 asked, “What if you had minimal physical pain, but had limited ability to speak, walk, or recognize others? Please select the number that best represents the level of treatment you would like.” A likert scale of 0 through 10 was again provided for answers. Participants were then asked to apply the same scenarios to their spouses in questions #D12 and #D13 and predict what level of treatment their spouse would like to receive.

Responses to questions #D10, #D11, #D12, and #D13 were recoded to increase validity. Original responses ranged from 0-10, with 0 meaning “no treatment” and 10 meaning “as much treatment as possible”. New categories were developed with 0 continuing to represent “no treatment”. Numbers 1 through 4 represent “limited treatment”. 5 represents “undecided” or “depending on the situation”. 6 through 9 represented “moderate treatment”. 10 continued to represent “as much treatment as possible”. Participants’ recoded responses to #D10 and #D11 were then matched to their spouses’ recoded responses to #D12 and #D13. Accurate perceptions

were counted and divided by the total number of participants to determine the percentage of couples who were able to accurately predict what their spouse would prefer for their end-of-life treatment wishes.

The fifth research question, "How many participants could correctly identify their spouse's treatment wishes?" was answered after comparing data corresponding with questions #D10 through #D13 in Married and Cohabiting Couples, 2010 for both spouses.

The sixth research question was, "Is there an association between appointing the participant's spouse as DPAHC and the spouse's correct predictions?" Participants' responses to The Married and Cohabiting Couples, 2010 question #D2, as mentioned above, were used to filter data for this research question to only include couples where at least one person had their spouse appointed as DPAHC.

The seventh research question was, "Is there an association between participants feeling their spouses don't listen and spouses' correct predictions?" Participants' responses to The Married and Cohabiting Couples, 2010 question #A5, "How satisfied are you with how well your spouse/partner listens to you?" were used to filter data for this research question to only include couples with at least one person who reported their spouse does not listen to them.

Research question eight, "Is there an association between avoiding discussions about difficult topics and spouses' correct predictions?" was answered after participants' responses to Married and Cohabiting Couples, 2010 question #A10, "My spouse/partner and I avoid discussing unpleasant or difficult topics" were filtered to only include couples with at least one person who responded either "Agree" or "Strongly Agree".

Research question nine, "Is there an association between participant reported declining health and spousal correct predictions?" This research question was analyzed by filtering for

“Fair” and “Poor” responses to Married and Cohabiting Couples, 2010 question #A1 “In general, would you say your health is” followed by the options “Excellent, Very Good, Good, Fair, Poor”.

The final research question, “Is there an association between the participant discussing their treatment wishes with their spouse and their spouse’s correct predictions?” The Married and Cohabiting Couples, 2010 question #D8 was utilized to only include couples with at least one person who reported having such discussions with their spouse.

Findings

A frequency distribution was used to answer the first research question, “How many participants have completed an advanced directive?”. Table 1 (below) is a frequency distribution that displays the number of participants who either did (yes) or did not (no) have an advance directive in place.

Table 1. *Number of Participants with Advance Directives*

		Do you have a living will or advance directive?			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	263	35.6	36.0	36.0
	No	468	63.3	64.0	100.0
	Total	731	98.9	100.0	
Missing	Refused	8	1.1		
Total		739	100.0		

Table 1 shows that there were a total of 731 responses to the survey question; eight participants chose not to respond to this survey question. The table reveals that 263, or 36% of the participants, had a completed advanced directive. The frequency distribution also shows that 468, or 64%, did not have an advanced directive. The bar chart below, Figure 1, displays

participant responses for this research question.

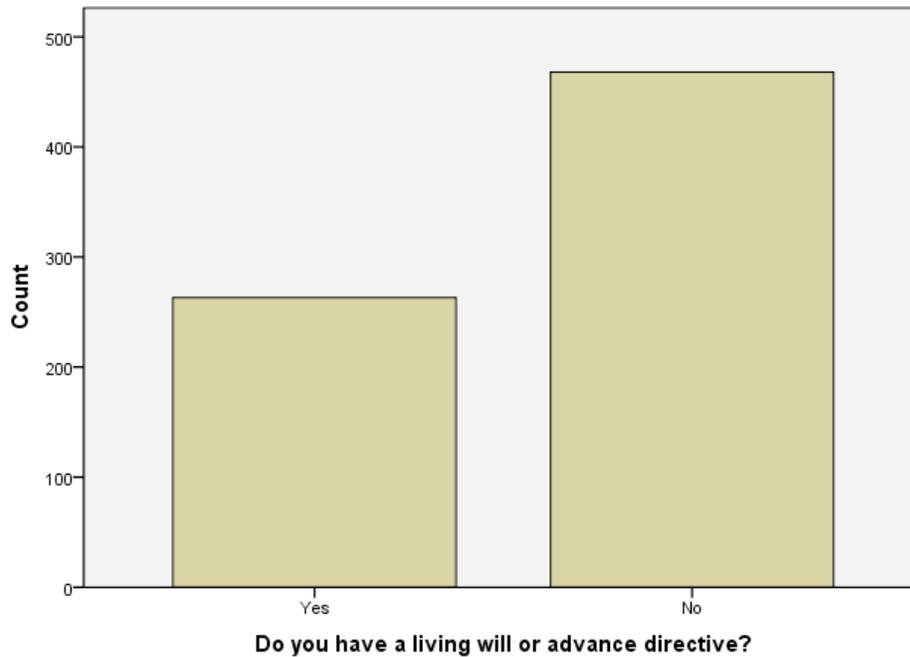


Figure 1. *Number of Participants with or without Advanced Directives*

This bar chart shows that participants' responses to whether or not they had an advanced directive were not evenly distributed. The difference in whether or not participants had advanced directives shows that many more participants did not have advanced directives in place.

The second research question, ““Of participants who reported having an advanced directive, how many reported discussing its contents with their spouse?”” was analyzed with a frequency distribution (see Table 2, below). The frequency distribution displays participants that have an advanced directive and have also discussed their end-of-life treatment wishes with their spouse (yes) and those that have not had such discussions (no).

[Spouse/partner] with whom did you have that discussion

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	15	5.6	6.3	6.3
	Yes	224	83.0	93.7	100.0
	Total	239	88.5	100.0	
Missing	System	31	11.5		
Total		270	100.0		

Table 2. *Participants with an advanced directive that have discussed their end-of-life treatment wishes with their spouse*

Table 2 shows there were 239 participants with an advanced directive who responded to this survey question. There were 31 participants with an advanced directive who chose not to respond to this research question. There were 15 participants, 6.3%, who responded that they had not discussed their end-of-life treatment wishes with their spouse. There were 224 participants, 93.7%, who reported discussing their end-of-life wishes with their spouse. The bar chart below (Figure 2) displays participants' responses to this research question.

Figure 2. *Participants who reported discussing end-of-life treatment wishes with their spouse*

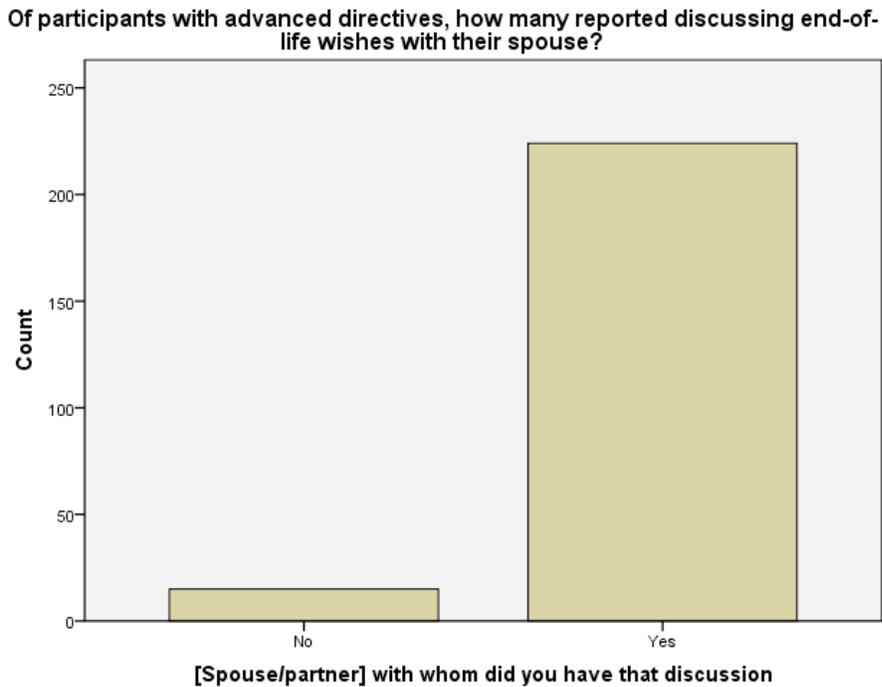


Figure 2 shows that participants' responses to this research question were unevenly distributed. The bar chart displays that a vast majority of participants that had an advanced directive had discussed their end-of-life wishes with their spouse.

The third research question, "How many participants have a DPAHC?" was analyzed with a frequency distribution (see Table 3, below). The frequency distribution displays participants that have a DPAHC (yes) or do not have a DPAHC (no).

Legal arrangements for someone to make decisions about medical care					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	268	36.3	36.5	36.5
	No	467	63.2	63.5	100.0
	Total	735	99.5	100.0	
Missing	Refused	4	.5		

Legal arrangements for someone to make decisions about medical care					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	268	36.3	36.5	36.5
	No	467	63.2	63.5	100.0
	Total	735	99.5	100.0	
Missing	Refused	4	.5		
Total		739	100.0		

Table 3. *Participants with or without a DPAHC*

Table 3 shows there were 735 participants who responded to this survey, with 4 participants who chose not to answer the survey question. Participants who responded that they did have a DPAHC in place numbered 268, or 36.5%. The table also reveals that 467 participants, or 63.5%, did not have a DPAHC. The bar chart below, Figure 3, displays the responses to this research question.

Figure 3. *Participants with or without DPAHC*

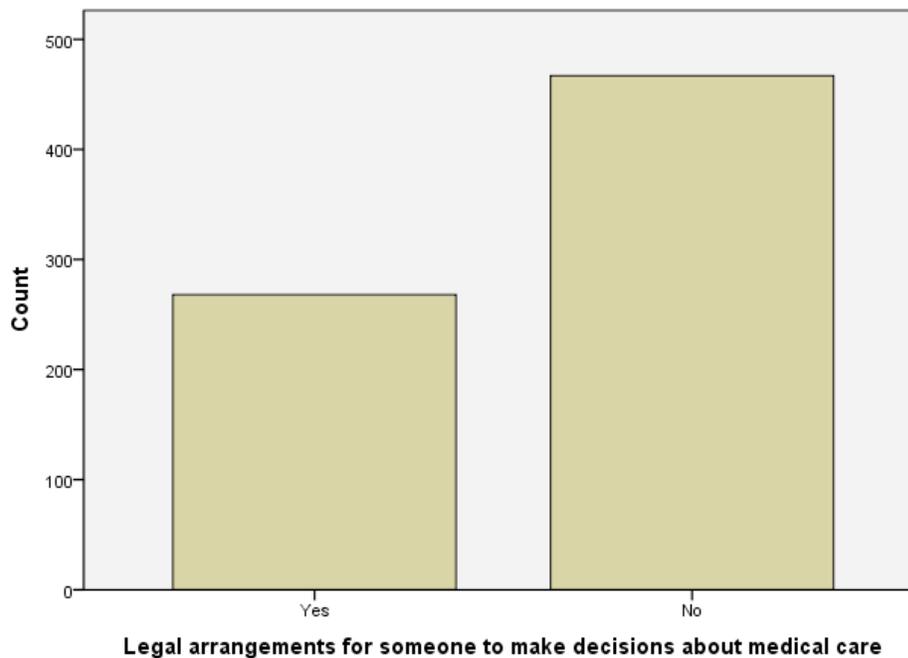


Figure 3 shows that participants' responses as to whether or not they have a DPAHC were not

evenly distributed. The bar chart displays that most participants did not have a DPAHC in place.

Research question number 4 asked how many participants with a DPAHC in place had appointed their spouse as DPAHC. Table 4 (below) is a frequency distribution for how many participants had appointed their spouse as DPAHC.

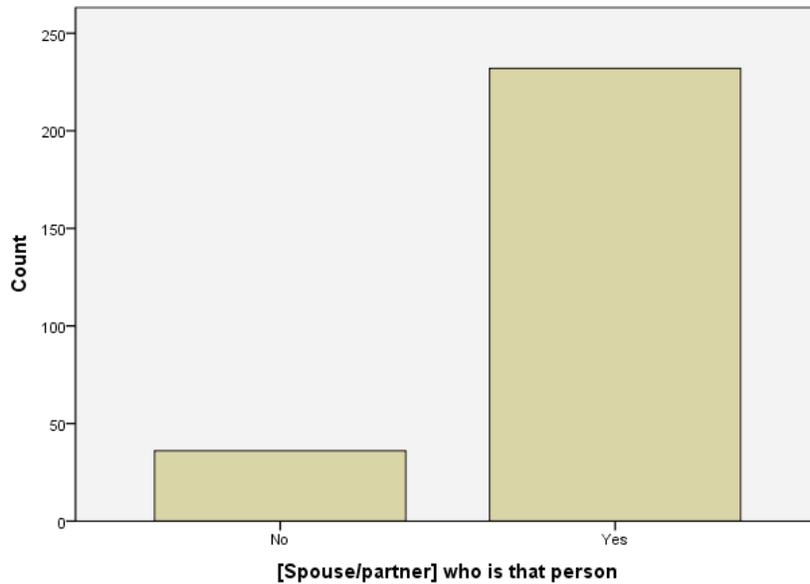
		[Spouse/partner] who is that person			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	36	4.9	13.4	13.4
	Yes	232	31.4	86.6	100.0
	Total	268	36.3	100.0	
Missing	System	471	63.7		
Total		739	100.0		

Table 4. *Participants Who Appointed Their Spouse as DPAHC*

Table 4 reveals that of 268 participants who responded to this question. Participants who did not respond numbered 471, with 467 who had previously responded as not having a DPAHC in place. The frequency distribution reveals that 232 participants, or 86.6%, appointed their spouse as DPAHC. There were 36 participants, or 13.3% that did not appoint their spouse as DPAHC.

Figure 4 is a bar chart that displays responses to this research question.

Figure 4. *Participants who Appointed Their Spouse as DPAHC*



The bar chart (Figure 4) shows the distribution of responses to the question if participants appointed their spouse as DPAHC. As the bar chart displays, a majority of participants had appointed their spouse as their DPAHC.

The fifth research question was “How many participants could correctly identify their spouse’s treatment wishes?” After comparing couples’ responses to #D10 and #D12 (scenario of mentally intact but severe physical pain), it was found that 37.6 percent of participants could accurately predict their spouse’s end-of-life treatment wishes. Responses to #D11 and #D13 (scenario of limited physical pain but also minimal mental capacity) were compared among couples. 39.8 percent of participants were able to accurately identify their spouse’s end-of-life treatment wishes.

The sixth research question, “Is there an association between appointing the participant’s spouse as DPAHC and the spouse’s correct predictions?” had 296 participants. In comparisons of spouses’ responses to questions #D10 and #D12, 44.3% of participants were able to accurately

identify their spouse's end-of-life treatment wishes in the scenario of being mentally intact, but in constant physical pain. In the scenario of limited physical pain, but minimal mental capacity (#D11 and #D13) 45.6% of participants were able to correctly predict their spouse's end-of-life treatment wishes.

“Is there an association between participants feeling their spouse doesn't listen and spouses' correct predictions?” was the seventh research question. There were 28 participants who had designated that they were either “Somewhat Dissatisfied” or “Dissatisfied” with how well their spouse listens to them. Of the 28 participants, 39.2% could accurately predict their spouses end-of-life treatment wishes for #D10 and #D12. For #D11 and #D13, 25% of participants were able to accurately predict their spouse's end-of-life treatment wishes.

Research question eight was, “Is there an association between avoiding discussions about difficult topics and spouses' correct predictions?”. There were 78 participants who either “Strongly Agreed” or “Agreed” to the statement “My spouse/partner and I avoid discussing unpleasant or difficult topics”. Of the 78 participants, 35.9% were able to accurately predict their spouse's end-of-life treatment wishes associated with the scenario presented for survey questions #D10 and #D12. For the scenario presented in survey questions #D11 and #D13, 43.6% of participants were able to correctly predict their spouse's end-of-life treatment wishes.

“Is there an association between participant reported declining health and spousal correct predictions” was research question nine. There were 18 participants who indicated their health was either “Fair” or “Poor”. Of the 18 participants, 72.2% could accurately predict their spouse's end-of-life treatment wishes as determined by comparisons in questions #D10 and #D12. In comparisons of participants' responses to #D11 and #D13, 50% were able to correctly identify their spouse's end-of-life treatment wishes.

The final research question, "Is there an association between the participant discussing their treatment wishes with their spouse and their spouse's correct predictions?" There were 582 participants who reported discussing the types of medical treatment they wished to receive if they became seriously ill in the future with their spouse. Of the 582 participants, 41.2% were able to correctly perceive their spouse's end-of-life treatment wishes for #D10 and #D12. For #D11 and #D13, 41.1% were able to accurately predict their spouse's end-of-life treatment wishes.

Discussion

The purpose of this study was to determine factors that impact couples' discussions of their end-of-life treatment wishes. Literature suggests that couples seldom discuss their end-of-life treatment wishes (Moorman, 2011), and even when they do, there are many barriers to completely understanding their partner's wishes (Coyne & Smith, 1991). Shalowitz, Garrett-Mayer, and Wendler (2006, as cited by Moorman, 2010) found that even when an individual has had a discussion with their DPAHC regarding their treatment wishes, DPAHCs who had discussion scored just as well as DPAHCs who did not have the discussion when perceiving the individual's treatment wishes. The findings of this study tend to coincide with findings in previous studies. Participants were more able to accurately predict their spouses' end-of-life treatment wishes when at least one member of the couple reported their health was in decline.

Key Findings and Considerations

Data analysis revealed that many participants did not have an advanced directive. In this study, only 36% of the sample had an advanced directive. This study revealed a larger percentage of individuals who have advanced directives compared to other literature, such as a study by Gross (1998), which revealed that 11% of hospital inpatients had an advanced directive.

The discrepancies between these numbers may be a result of possible demographic differences of the participants in these studies. As this study solely focused on individuals aged 45 to 64, this would eliminate younger individuals who would be less likely to have completed an advanced directive that may be present in the study by Gross (1998). Additionally, the population sample of this study was reflective of the United States population, and is therefore more generalizable to the United States population than the study by Gross (1998).

The second research question analyzed was in reference to whether participants who reported that they had an advanced directive in place had discussed their end-of-life wishes with their spouse. Butterworth (2003) suggested that many individuals did not discuss advanced directives due to uneasiness surrounding the topic, however this suggestion was in reference to barriers to completing advanced directives in the first place. This study found that 93.7% of individuals who had completed an advanced directive had also discussed their end-of-life treatment wishes with their spouse. It is possible that individuals who complete advanced directives are individuals who are also more comfortable discussing their end-of-life treatment wishes.

This study found that 36.5% of the population had a DPAHC. This corresponds with a study of individuals with Metastatic Spinal Cord Compression (Guo et al., 2010). Guo and colleagues found that 31% of their participants had a "health care proxy". This study has more generalizable results due to the population being more representative of the United States population. There is still a majority of individuals who did not have a DPAHC in place (63.5%). Research question four asked whether participants who had a DPAHC had appointed their spouse as their health care agent. Data analysis revealed that 86.6% of participants with a DPAHC had appointed their spouse as the DPAHC. Although a vast majority of participants

with a DPAHC had appointed their spouse as their health care agent, previous research identified many barriers to people's understanding of their loved one's end-of-life treatment wishes (Coyne & Smith, 1991).

The sixth research question posed the question of whether having appointed a spouse as DPAHC impacted their ability to accurately predict the participant's end-of-life treatment wishes. In the scenario presented of the participant being mentally intact, but in constant physical pain, 44.3% of participants were able to accurately predict their end-of-life treatment wishes. In the scenario of the participant being in limited physical pain, but possessing minimal mental capabilities, 45.6% of participants were able to accurately predict their spouse's end-of-life treatment wishes. Although this research question did not monitor for whether the DPAHC's had in fact had a discussion regarding end-of-life treatment wishes, Moorman (2010) had found that DPAHC's who had conversations with their loved ones regarding the treatment they wished to receive in the future scored the same as DPAHC's who did not have these discussions when attempting predicting treatment wishes. Despite the already low percentage rates of 44.3% and 45.6% found in this study, they are still marginally higher than the overall sample population's ability to identify their spouses' end-of-life treatment wishes. In data analysis for the sample size as a whole, 37.6% were able to accurately predict their spouse's end-of-life treatment wishes when presented with the scenario of the spouse being mentally intact, but in constant physical pain, and 39.8% were able to accurately predict when presented with the scenario depicting limited physical pain, but limited mental abilities.

The tenth research question asked whether there was an association between participants' discussing their end-of-life treatment wishes with their spouses and their spouses' accurate predictions. It was found that in the scenario of the participant being mentally intact, but in

constant physical pain, 41.2% were able to correctly identify the participant's treatment wishes compared to 37.6% by the entire sample. In the scenario of the participant being in limited physical pain, but possessing minimal mental capabilities, 41.1% of spouses who reported having a discussion regarding end-of-life treatment wishes were able to accurately predict the participant's wishes compared to 39.8% by the entire sample. This provides some credence to Coyne and Smith's (1991) suggestion that there are barriers to completely understanding a spouse's end-of-life treatment wishes.

When participants were filtered for the reported quality of their spouses' listening, data analysis revealed the largest gap in participant ability to predict a spouse's end-of-life treatment wishes between the scenarios provided. Of couples with at least one participant reported being overall dissatisfied with the quality of their spouse's listening, only 25% of participants were able to accurately predict their spouse's treatment wishes for the scenario of limited physical pain with limited mental abilities. For the scenario presented of the spouse's constant physical pain, but being mentally intact, 39.2% of participants were able to accurately predict their spouses' treatment wishes. The gap in the accuracy percentages between scenarios findings appear to be due to chance. There does not appear to be a reason why participants would be more aware of their spouses' treatment in one scenario over another.

In data analysis of the research question that tested whether or not couples with at least one member who reported they avoid discussing difficult topics with their spouse, it was found that 35.9% were able to accurately predict their spouses' end-of-life treatment wishes when presented with the scenario of the spouse being in constant physical pain, but with mental abilities intact. This could be compared to the 37.6% accuracy rate of the overall sample population. When presented with the scenario of limited physical pain and limited mental

abilities, 43.6% were able to accurately predict their spouse's treatment wishes compared to 39.8% of the overall sample. It is interesting to note that participants who reported they or their spouse avoid discussing difficult topics were slightly more accurate in their predictions of their spouses' treatment wishes compared to the overall sample. This difference was most likely due to chance, as the difference does not appear to be significant.

Significant findings were observed in the analysis of data associated with the research question that tested the association between participant reported declining health and their spouses' ability to correctly predict their treatment wishes. It was found that 72.2% of participants were able to correctly predict their spouses' treatment wishes when provided with the scenario of the spouse being in constant physical pain, but mentally intact. This is nearly double the accuracy rate of the overall sample provided with this scenario. There was again a large gap in accuracy rates between scenarios in this research question. When provided with the scenario of the spouse being in limited physical pain, yet having limited mental abilities, 50% of participants were able to accurately predict their spouses' treatment wishes. This is still significantly higher than the overall samples' accuracy rates for this scenario: 39.8%. It is unknown why there is such a large gap in accuracy rates between scenarios. However, the results for this data analysis suggest that health status impacts couples' communication surrounding their end-of-life treatment wishes as evidenced by the higher accuracy rate in predictions. It may be that couples, when faced with the declining health of one member, have more thorough discussions of treatment wishes. Health status may also impact the frequency of these discussions. These findings should be further researched, as there were only 18 participants after filtering for at least one member of a couple reporting declining health.

Conclusion

Social work practitioners need to assess if there is a disconnect between couples when it

comes to understanding one another's' end-of-life treatment wishes and intervene when necessary. In the absence of an advanced directive, the next person to make treatment decisions should one become incapacitated is legally a spouse. As this study revealed, most Americans do not actually know the level of care their spouse would like to receive at their end-of-life, even if they have had such discussions. This leaves many individuals receiving care they do not want, or not receiving care they would prefer. Continued research as to how to facilitate discussions surrounding treatment wishes would increase patient's sense of autonomy and self-determination. Social workers education should include a focus on end-of-life issues to increase comfort levels in professionals. This may help social workers approach discussions surrounding end-of-life treatment wishes more confidently and with better client outcomes.

This research would be made stronger by more statistically complex methods. For instance, a T-test could be run to reveal whether or not differences in the percentages of accurate responses were significant. Human error was also possible during this research study. Errors in data coding could have occurred during the original study, as well as during recoding in this study. Additionally, as matching spouses' answers to treatment preference questions was completed manually, there is a chance that a mistake occurred in this process. Future research could investigate methods for increasing spouses' knowledge of one another's treatment wishes.

References

- Badzek, L., Hines, S. C., & Moss, A. H. (1998). Inadequate self-care knowledge among elderly hemodialysis patients: assessing its prevalence and potential causes. *ANNA Journal*, (3), 293.
- Barnes, S. (2003). The advanced directive: A fundamental communication. *Journal of PeriAnesthesia Nursing*, 18(3), 203-205. doi:10.1016/S1089-9472(03)00088-1
- Blackhall, L. J., Frank, G., Murphy, S. T., Michel, V., Palmer, J. M., & Azen, S. P. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine*, 48(12), 1779-1789. doi:10.1016/S0277-9536(99)00077-5
- Berrio, M., & Levesque, M. (1996). Advance directives: most patients don't have one. Do yours?. *American Journal Of Nursing*, 96(8), 24-29.
- Boehmer, U., & Clark, J. A. (2001). Married couples' perspectives on prostate cancer diagnosis and treatment decision-making. *Psycho-Oncology*, 10(2), 147-155. doi:10.1002/pon.504
- Buford, C. (2008). Advancing an advance directive debate. *Bioethics*, 22(8), 423-423. doi:10.1111/j.1467-8519.2008.00667.x
- Carr, D., & Khodyakov, D. (2007). Health care proxies: whom do young old adults choose and why?(Author abstract). *The Journal Of Health And Social Behavior*, (2), 180.
- Conelius, J. (2010). A literature review: Advance directives and patients with implantable cardioverter defibrillators. *Journal of the American Academy of Nurse Practitioners*, 22(5), 250-255. doi:10.1111/j.1745-7599.2010.00499.x
- Coyne, J. C., & Smith, D. A. F. (1991). Couples coping with a myocardial infarction: A contextual perspective on wives' distress. *Journal of Personality and Social Psychology*,

61(3), 404-412. doi:10.1037/0022-3514.61.3.404

- Deep, K. S., Green, S. F., Griffith, C. H., & Wilson, J. F. (2007). Medical residents' perspectives on discussions of advanced directives: Can prior experience affect how they approach patients? *Journal of Palliative Medicine*, 10(3), 712-720. doi:10.1089/jpm.2006.0220
- DeSpelder, L. A., 1944, & Strickland, A. L. (2002). *Study guide for the last dance: Encountering death and dying*. Boston: McGraw Hill Higher Education.
- Duke, G., Thompson, S., & Hastie, M. (2007). Factors influencing completion of advanced directives in hospitalized patients. *International Journal of Palliative Nursing*, 13(1), 39-43.
- Germain, C.B., & Gitterman, A. (1980). *The life model of social work practice*. Columbia University Press, New York, New York.
- Giger, J. N., Davidhizar, R. E., & Fordham, P. (2006). Multi-cultural and multi-ethnic considerations and advanced directives: Developing cultural competency. *Journal of Cultural Diversity*, 13(1), 3.
- Goldsmith, D. J., & Domann-Scholz, K. (2013). The meanings of "Open communication" among couples coping with a cardiac event. *Journal of Communication*, 63(2), 266-286. doi:10.1111/jcom.12021
- Gross, M. D. (January 01, 1998). What do patients express as their preferences in advance directives?. *Archives of Internal Medicine*, 158, 4, 363-5.
- Guo, Y., Palmer, J. L., Bianty, J., Konzen, B., Shin, K., & Bruera, E. (2010). Advance directives and do-not-resuscitate orders in patients with cancer with metastatic spinal cord compression: Advanced care planning implications. *Journal of Palliative Medicine*, 13(5), 513-517. doi:10.1089/jpm.2009.0376

Health Care Directives. Minnesota Statutes. §145C.01-145C.16. (2013)

Jacobson, J. A., White, B. E., Battin, M. P., Francis, L. P., Green, D. J., & Kasworm, E. S. (1994). Patients' understanding and use of advance directives. *The Western Journal of Medicine, 160*(3), 232-236.

Janssen, D., Spruit, M., Schols, J., Cox, B., Nawrot, T., Curtis, J., & Wouters, E. (2012). Predicting changes in preferences for life-sustaining treatment among patients with advanced chronic organ failure. *Chest, 141*(5), 1251-1259.

Joekes, K., Maes, S., & Warrens, M. (2007). Predicting quality of life and self-management from dyadic support and overprotection after myocardial infarction. *British Journal of Health Psychology, 12*(Pt 4), 473-489. doi:10.1348/135910706X118585

Karnik, A. M. (2002). End-of-life issues and the do-not-resuscitate order: Who gives the order and what influences the decision? *Chest, 121*(3), 683-686. doi:10.1378/chest.121.3.683

Luptak, M. (2004). Social work and end-of-life care for older people: A historical perspective. *Health & Social Work, 29*(1), 7-15.

Maxfield, C. L., Pohl, J. M., Colling, K., & Butterworth, A. M. (2003). Advance Directives: A Guide for Patient Discussions. *Nurse Practitioner, 28*(5), 38-47.

Mitty, E. L. (January 01, 2001). Ethnicity and end-of-life decision-making. Reflections on Nursing Leadership / Sigma Theta Tau International, Honor Society of Nursing, 27, 1, 28-31

Molloy, D. W., Stiller, A. K., & Russo, R. (2000). Technology and educating seniors about advance directives. *Educational Gerontology, 26*(4), 357-69.
doi:10.1080/036012700407848

Moorman, S. M. (2011). The importance of feeling understood in marital conversations about end-of-life health care. *Journal Of Social & Personal Relationships*, 28(1), 100-116.

doi:10.1177/0265407510386137

National Center for Family and Marriage Research. Married and Cohabiting Couples, 2010 [United States]. ICPSR31322-v1. Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor], 2011-08-18. doi:10.3886/ICPSR31322.v1

Sam, M., & Singer, P. A. (January 01, 1993). Canadian outpatients and advance directives: poor knowledge and little experience but positive attitudes. *Cmaj : Canadian Medical Association Journal = Journal De L'association Medicale Canadienne*, 148, 9, 1497-502.

Schonwetter, R. S., Walker, R. M., Kramer, D. R., & Robinson, B. E. (January 01, 1993). Resuscitation decision making in the elderly: the value of outcome data. *Journal of General Internal Medicine*, 8, 6, 295-300.

Slaikue, K. A. (1990). *Crisis intervention: A handbook for practice and research*. Allyn and Bacon, A Pearson Education Company.

Song, L., Northouse, L. L., Zhang, L., Braun, T. M., Cimprich, B., Ronis, D. L., & Mood, D. W. (2012). Study of dyadic communication in couples managing prostate cancer: A longitudinal perspective. *Psycho-Oncology*, 21(1), 72-81. doi:10.1002/pon.1861

Ury, W., Berkman, C., Weber, C., Pignotti, M., & Leipzig, R. (n.d). Assessing medical students' training in end-of-life communication: A survey of interns at one urban teaching hospital. *Academic Medicine*, 78(5), 530-537.

Van Leuven, K. A. (2012). Advanced care planning in health service users. *Journal of Clinical Nursing*, 21(21-22), 3126-3133. doi:10.1111/j.1365-2702.2012.04190.x

Waldrop, D. P., & Meeker, M. A. (2012). Communication and advanced care planning in palliative and end-of-life care. *Nursing Outlook*, 60(6), 365-369.

doi:10.1016/j.outlook.2012.08.012

Wilson, D. M. (2000). End-of-life care preferences of Canadian senior citizens with caregiving experience. *Journal Of Advanced Nursing*, 31(6), 1416-1421.