Barriers And Facilitators To The Completion Of Advance Directives In Healthy, Non-Healthcare Employed Adults Aged 45-65.

By

Michael Lawrence Dion
A.D.N. (Sacramento City College) 2000
B.S.N. (California State University Chico) 2012
THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

In

Nursing Science & Healthcare Leadership

In the

OFFICE OF GRADUATE STUDIES

of the

UNIVERSITY OF CALIFORNIA

DAVIS

Approved:

Debra Bakerjian, Ph.D., A.P.R.N., F.A.A.N., F.A.A.N.P., Chair

Jann Murray – Garcia, M.D., M.P.H., Committee Member

Deborah Ward, Ph.D., R.N., F.A.A.N., Committee Member

Committee in Charge

2016

Table of Contents

Table of Contents

Acknowledgements

I would like to thank my wife Nicole and my children Kyle and Natalie for their support and patience during my absence in pursuing a master's degree. Without your support and understanding, I would not have been successful. The three of you are a welcome respite from the rigors of the day. Nicole, I derive so much enjoyment being married to you. Your drive and enthusiasm for life make me want to strive to be better as well. This process would not have been possible without your support.

I would also like to thank my mother Maureen. You are one of the smartest people I know. You are the reason for my drive and my work ethic. With out your wisdom, and dedication to your family, I would not be who I am today. You live life by doing and not complaining. I'll never forget your words to me as I am lamenting my being 30 before I graduate from nursing school, "Mike, you will be thirty anyway." For these wise words and so many others, I am forever grateful and I dedicate the work of this degree to you.

Abstract

Background: The Patient Self-Determination Act -- passed in 1991 -- requires staff in health care facilities -- such as skilled nursing facilities, hospitals, home health services and primary care offices -- to ask patients about advanced directives. Despite this, actual completions of advance directives in America remain low.

Objective: To determine the barriers and facilitators to the completion of advance directives in healthy, non-health care employed individuals aged 45-65. It is believed healthy individuals in this age group both desire the advance directive, and have strong opinions regarding their end of life preferences.

Methods: This study used a cross sectional survey design to study the barriers and facilitators to the completion of advanced directives in healthy adults aged 45-65 who are not employed in healthcare. A 16 item survey was developed to collect demographic data, ascertain participants' general knowledge of advance directives, and determine the desire of this age group for end of life treatments.

Findings: The findings for this age group were consistent with the literature. Individuals in this age group desired an advance directive, and considered it an important document, and felt the discussion is best started with a health care provider.

Chapter 1: Introduction

There is a need for the facilitation of advance directive discussions for end of life care preferences with health care providers and their patients. These discussions best serve the patient when they happen early and often. This ensures that the patient has had an opportunity to make their end of life care wishes known to family, friends, and to their healthcare providers. Studies suggest that earlier intervention regarding end of life care should happen over the course of multiple visits in order to be effective (Shickedanz et al., 2009). “The most successful interventions incorporated direct patient – healthcare professional interactions over multiple visits.” (Bravo, Dubois, and Wagneur, 2008). Even in the case of chronic disease, early discussions of advance directives have been shown to be effective in allowing a patient and their family to openly discuss his or her wishes regarding end of life issues (Johnson et al., 2012).

Advance directives do guide care and are followed in most cases if the patient wishes are clearly laid out and discussed with the patient, surrogate decision maker, family, and/or physician (Hammes & Rooney, 1998). During a health care collaborative and educational push for advance care directives in one Wisconsin setting, those with advanced directives had their wishes for end of life care followed 85% of the time (Hammes & Rooney, 1998). This retrospective study conducted a review of all charts of 504 patients known to have an advance directive prior to their death. The La Crosse Advance Directive Study (LADS) started a community-wide collaborative advance directive drive titled "Respecting your choices" in 1991. The median age of those in this retrospective study was 81 years old, and more than half of those were women (Hammes & Rooney, 1998). There were no data regarding younger participants with advance directives included in this study. The sample study did indicate that individuals younger than 18 years of age were eliminated due to their inability to complete an advance directive (Hammes & Rooney, 1998). The LADS study noted that the time between death and advance directive completion was 1.2 years (Hammes & Rooney, 1998). The end of life preferences of those with advance directives in this study was consistently followed in the majority of cases. Prior to this educational program, only 15% of the people in La Crosse, Wisconsin had an advance directive. Following the study, a total of 540 decedents were in included in the study with almost 85% having advance directives followed at the end of life (Schwartz et al., 2002). This finding helps to illustrate the usefulness of an extensive advance directive program and is important because the push and education for the advance directives start the conversation and eventually makes the discussion easier. The absence of an advance directive and lack of discussion and communication also increases the probability that individual wishes may not be followed.

In America, there are approximately 37.9 million people over the age of 65. By 2020, this number is expected to grow to well over 55 million (Hinders, 2012). This demographic shift presents challenges to the health care system. Many senior citizens over the age of 65 have at least one chronic health problem and many individuals with multiple health problems have average hospital stays in this age group of 5.5 days (Hinders, 2012). The lack of significant advance care planning needs to be addressed because of the financial and emotional costs associated with unnecessary and unwanted medical care at the end of life (Carr & Khodyakov, 2007). In a 2005 study, it was found that of hospitalized patients over the age of 80, 63% received non – palliative care treatments despite the fact that only 30% of those patients wanted that care (Plonk & Arnold, 2005).

Failing to have end of life discussions, lead to increased burdens on the healthcare system for expensive, unwanted treatments (Ko & Lee, 2014). This unwanted care is very expensive in an already expensive healthcare system. In 2014, 18% of the U.S. gross national product was spent on healthcare (Dyess et al., 2014). Medicare spending in the U.S. accounted for $554 billion; of this $544 billion, $170 billion was spent in the last six months of life (Dyess et al., 2014). The Institute of Medicine, in their 2014 report "Dying in America" found more than 90% of those surveyed thought advance directives were important. Yet fewer than 30% of Americans have an advance directive (Institute of Medicine [IOM], 2014). When utilized, advance directives are very effective in maintaining individual patient wishes (Schwartz et al., 2002), and can have a significant impact in lowering hospital costs, and decreasing the number of days in the hospital by 50% (Johnson et al., 2012).

The Patient Self-Determination Act of 1991 requires staff in health care facilities and agencies to ask about and give information regarding advance directives (Van Leuven, 2012). Despite this law, advance directives are not consistently addressed or filled out. Actual numbers of completed advance directives in America vary between studies, from 15% - 20% (Schwartz et al., 2002), to between 18% and 36% ("U.S. Department of Health and Human Services," 2008). Without these advance directives, the patient, and his or her family often experience a long journey as an inpatient. Hospital admissions are often filled with procedures that utilize aggressive measures to keep people alive, even though they might not want the treatments being offered (Hinders, 2012, Schwartz et al., 2002).

The 2014 IOM report "Dying in America" outlined some important key findings supporting the need for earlier and detailed discussions, as well as for more education regarding advance directives. The key parts of the IOM report supported findings in the literature that education and communication are required to facilitate the completion of advance directives, with health care professionals leading the way. The IOM also concurs with present literature findings that support patients' desire for better understanding of advance directives, as well as patients' desire to have an advance directive (Institute of Medicine [IOM], 2014).

Terminology in Advance Care Planning

In many healthcare settings and in the community, "living will" and "durable power of attorney for health care" are often mistakenly thought to have the same meaning. An advance directive or living will is a legal document. This document allows an individual to make provision for healthcare decisions in the event that that person becomes unable to make decisions on his or her own (The National Institute on Aging, n.d.). The National Institute on Aging notes that some states do not always legally recognize the living will for medical care. The advance directive, however, has "absolute legal clout" in health care decision making when the patient is unable to make decisions for themselves (The National Institute on Aging, n.d).

The durable power of attorney (DPOA) empowers one individual of the patient's choosing to act as a "proxy", "surrogate", or "health care agent". This agent makes health care decisions as dictated by the advance directive or living will when the patient lacks the capacity to do so on his or her own. Often, the living will or advance directive is seen as a written guide that that the DOPA can follow when the patient is unable (The National Institute on Aging, n.d).

Palliative care and hospice care are two different terms that often confused, and used interchangeably as well. Palliative care --defined by the World Health Organization-- is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness. Good palliative care happens through the prevention and relief of suffering using early identification, assessment, and treatment of pain. Physical, psychosocial and spiritual issues are also addressed during palliative care (The World Health Organization, n.d., para. 1). Palliative care can be utilized at any stage of the illness, not just the late stages.

Conversely, hospice care is defined as the care provided for someone that is terminally ill and focused on comfort, not a cure. While palliative in nature, the disease process has moved into hospice care because further curative treatment is no longer desired, nor is it beneficial.

Treatment options in palliative care are not limited and can range from aggressive/curative to conservative. Palliative treatments can begin at any time while hospice usually begins when the patient has less than six months to live ("Differences in Palliative vs. Hospice Care," n.d). Distinctions between palliative care and hospice care are important. Hospice care is specific and time-limited, due to the progression of the terminal illness, while palliative care is not. Palliative care may be started at the very first sign of disease emergence. Palliative care can help both the clinician and the patient open a dialogue regarding the wishes of the patient over the course of the relationship, leading to the completion of the advance directive. The goal of a curative outcome may be met, but goals of care need discussion, and a dialogue started with the health care team. Unfortunately, these early goals of care discussions are slow to occur, if at all (IOM Dying in America).

The discussion of the use of advance directives has been carried on for many years from a hospital and policy perspective. Despite these discussions, a small percentage of the general public has an advance directive (Van Leuven, 2012). It is unclear why. What is known is that patients are more likely to complete advance directives following repeated, early consultations with palliative care (Van Leuven, 2012). Allowing a complete and thorough discussion about end of life care makes the discussion of death easier in both the early and late stages of advanced disease (Pereira et al., 2011).

Nursing has a unique position in the completion of advance directives. From offering culturally competent care (Mezey et al., 2000), to patient advocacy and education regarding patient rights in end of life care (Hinders, 2012), it is often the nurse that will be engaged in multiple different roles in their constant interactions with patients and families (Hinders, 2012). Nurses are some of most trusted health care clinicians and are in a special place to have honest end of life discussions, as well as be an advocate for the patient and the family, both before illness starts and the end of life (Nogler, 2014). The American Nurses Association Position Statement views nursing as an essential component to successful end of life care planning, and stressed that this planning should begin earlier, not later, in a patient's life (Nogler, 2014). Most importantly, according to Mezey, the Patient Self Determination act of 1991 states that, "nurses will and must play a primary role in the implementation of the law" (Mezey et al., 2000).

This study seeks to assess the attitudes of, and desire for, advance directives among a sample of individuals younger than 65, who are free of significant or unmanageable health problems, and who can provide for their own activities of daily living (ADLs), and instrumental activities of daily living (IADLs). IADLs defined, is the ability to attend to a higher level of functionality greater than ADLs, tasks such as the ability to pay bills, shop for groceries, and driving.

Chapter 2: Review of the Literature

A search of the literature was conducted to investigate whether studies have been completed regarding the effectiveness of advance directives in healthy individuals less than sixty-five years of age. Utilizing Google Scholar and OVID Medline search engines, the following search terms were used: the case for completion of early advance directives, the barriers and facilitators to the completion of advance directives in the younger age groups, completion of advance directives in healthy adults aged 45-65, the use of advance directives in the young, and completion of advance directives in younger, healthy, outpatient populations. Upon review of the literature, distinct themes emerged regarding the need for increased awareness and discussion about advance directives in the general public. These distinct barriers to the completion of advance directives included poor communication, timing of exposure to advanced directives, psychological importance of advance directives, and education, culture, and socioeconomic status.

Barriers: Communication

The most common barriers found involved poor communication between the physician and the patient with respect to the initiation of end of life planning discussions and education. In one study, the majority of patients in the outpatient setting felt that the provider was the one responsible to start the discussion regarding advance directives (Carr & Khodyakov, 2007). Interestingly, another study found many providers felt the discussion to be too sensitive to discuss (Emmanuel et al., 1991). When asked about their discomfort with the topic of end of life planning, patients rejected this as a reason for not completing the advance directive, instead citing provider failure to even discuss the topic of end of life care with the patient (Emmanuel et al., 1991). In one study of 1195 respondents, Pollack (2010) found that 61% of adults wanting advance directives felt the barrier to the completion of advance directives was clinician reluctance to discuss advance care planning. Patients have preferences regarding end of life care, and want to discuss these preferences with their provider (Pollack, Morhaim, & Williams, 2010). Interestingly, even in the case of chronic disease, providers are reluctant to discuss end of life planning with their patient, despite their patient wanting this very discussion to take place (Nogler, 2014). As noted earlier, completion of advance directives in America is very low. This is due in part because not having an advance directive can be directly attributed to the lack of communication between the patient and provider (Schwartz et al,. 2002)

Steinhauser (2000) cited instances where providers felt inadequately trained to have end of life care discussions with their patients. "Whether such discomfort is caused by feelings of failure, a desire for professional distance, or inexperience, it can adversely affect care" (Steinhauser et al., 2000, p. 8). Clinicians also feel inadequately prepared to have such sensitive topic such as end of life care discussions. This is especially true in cases where a patient has a chronic illness and the outcome of their illness cannot be predicted (Nogler, 2014).

Barriers: Timing of Exposure to Advance Directives

Often the conversations surrounding end of life planning are very complex and can be too time consuming for one office visit (Schwartz et al., 2002). As Van Leuven stated above, it is the repeated visits for palliative care that create a safe place where sensitive end of life discussions can occur. Providing patients and their families with only passive information such as pamphlets or reading material about advance directives does very little to facilitate the completion of advance directives (Tamayo-Valazquez et al., 2009). Patients and their agents often require a great deal more time from the doctor to have specific information in order to make an informed decision about end of life care (Schwartz et al., 2002). If left to the patient to make these decisions without the input of individuals trained in end of life care, these conversations never happen leaving the patient and their proxy without an advance directive, and more anxious than before (Nogler, 2014). When a patient does have an advance directive, this does not ensure increased communication between the primary doctor and the patient because the primary doctor is often not aware that the patient has an advance directive unless this same physician was part of the discussion in creating the advance directive (Rurup et al.,2005).

Psychological Importance of Advance Directives

Having either an advance directive, or someone that is supposed to know the patient’s wishes, does not ensure communication between the patient and that designated individual regarding end of life preferences has happened (Zaide et al., 2013). When communication of patient wishes to his or her designated proxy does not happen, the family may not be aware of patient wishes and therefore cannot speak to specific treatments based on patient desires, leaving specific end of life preferences incomplete (Carr & Khodyakov, 2007). Unfortunately, when wishes were not clear, patients felt disregarded, family members were confused and concerned that their loved one was suffering, and providers felt as though they were not providing good care (Steinhauser et al., 2000).

Further complicating the completion of advance directive is that often the patient's first exposure to advance directives is when they enter the hospital (Carr & Khodyakov, 2007). Admission to the hospital is often an extremely stressful time and the family is too overwhelmed to make informed decisions in order to complete the advance directive (Steinhauser et al., 2000). Despite this, some physicians still feel that advance directives are unnecessary for young, healthy patients (Rurup et al., 2005), and should only be discussed at the time of poor health and old age (Emmanuel et al.,1991).

Advance directives often involve multiple sensitive subjects regarding the spiritual, psychosocial, religious, medical, family, and cultural dynamics related to end of life care (Schwartz et al., 2002). These types of discussions, as noted before, are usually time consuming and require input from family and spiritual leaders, as well a medical representative (Schwartz et al., 2002). Providers are not always clear as to the specific educational limitations, socioeconomic factors, and cultural and spiritual differences of their patients (Johnson et al., 2012). Without clear understanding of these different complexities, further significant barriers exist in allowing for advance directives to be completed. To add to this problem, standard forms for advance directives fail to address the specific complexities mentioned above (Zager & Yancey, 2011), and allow for the expression of different cultural, educational or socioeconomic differences in diverse patient populations.

Barriers: Education, Culture and Socioeconomic Status

Interestingly, the level of education and socioeconomic status has more of an effect on the completion rates of an advance directive than does race (Mazey et al., 2000). The IOM also found that those that have advance directives tend to be white, of higher income, and over the age of 65 with one or more chronic illnesses (Institute of Medicine [IOM], 2014). Being less educated and poor correlated with lower literacy rates, hence lower completion rates with advance directives (Freer et al., 2006). This is important because according to Hinders, 40% of Americans read at or below an 8th grade level. This is problematic when the forms for advance directives are written for those reading at a 12th grade level (Hinders, 2012). For these individuals, an advance directive program might require specific tailoring to meet the specific needs of less educated and poorer individuals (Freer et al., 2006).

Lower levels of education also correlated with a feeling of vulnerability of those individuals with respect to their healthcare interactions (Mazey et al., 2000). Often these patients view advance directives as something that actually compromises their already difficult access to healthcare (Mazey et al., 2000). This is an important finding to take into consideration when discussing the cultural implications contributing to the lack of completion of advance directives. For instance, in the black community, rates of advance directives are further reduced some data suggest, by pre-existing levels of distrust already felt by this community towards the healthcare system (Ko & Lee, 2014). When it comes to planning for end of life care, some in this cultural group would rather seek the council of a spiritual advisor or a family member, rather than trust the healthcare system (Zager & Yancey, 2011).

Some data suggest Hispanic patients were more likely to leave the decisions regarding end of life care up to the family members rather than discuss with a healthcare professional because of the inherent dislike of discussions regarding end of life planning (Ko & Lee, 2014). Typically though, Hispanic patients did not discuss their preferences with anyone further complicating the completions rates in the Hispanic community (Zaide et al., 2013). In the Hispanic community it is often the case that the family prefers that their loved one does not know the extent, or the seriousness of the illness that he or she is facing. Healthcare decisions are left to the spouse or the adult children (Ko & Lee, 2014).

Some research suggests that some Native American patients do not like to put anything negative in writing due to the belief that writing about such negative things such as death will ensure that death will happen. This type of belief is not addressed by a healthcare system that requires forms to be filled out for the completion of an advance directive (Zager & Yancey, 2011).

Whites and Asians are more likely to have a surrogate decision maker(s) much like those patients in the black community, though like Blacks and Hispanics, Asians were more likely to have utilized family based decision making (Zaide et al., 2013). Troubling to the improvement in rates of advance directive completion, across all non-white cultural groups, all groups were more likely to have lower completion rates of advance directives then did whites (Zager & Yancey, 2011).

The Patient Self Determination Act is intended to inquire about advance directives. It was also intended to provide education about rights and choices in end of life decisions. Because of the multiple complexities regarding barriers to completion rates as discussed above, it has devolved into little more than the recording of a yes or no answer regarding the presence of an advance directive (Van Leuven, 2012).

What is known is merely asking the patient if they have an advance directive, as well as giving the patient the opportunity to complete an advance directive form, does nothing to determine patient and family knowledge base regarding that advance directive (Johnson et al., 2012). It is also well understood that merely handing documents and informative pamphlets to a patient to read and fill out does not increase the completion rates of advance directives (Tamayo-Valazquez et al., 2009 , Bravo, Dubois, & Wagneur, 2008).

Facilitators: Effectiveness of Palliative Care

Effective end of life care planning is complicated and must take into consideration patient preferences, including, religious and cultural beliefs, socioeconomic status, and educational levels. (Schickendanz et al., 2009). As noted earlier, Steinhauser (2000) indicated that primary care providers feel inadequate to have these sensitive discussions with their patients due to the lack training required to skillfully initiate these discussions. Additionally, research also indicates that it is helpful for primary care and other specific specialties such as cardiology that may not be trained in palliative care to make use of referral services to palliative care (Evangelista et al., 2012). Unfortunately the purpose of palliative care is poorly understood in the medical community and delayed for fear that it represents that the provider is giving up on the patient too soon (Zaide et al., 2013).

Research suggests that early end of life discussions over multiple visits have proven to be considerably more effective in the completion rates for advance directives (Bravo, Dubois, Wagneur, 2008). Further, the completion rates are improved when the patient, proxy, and family have an opportunity to have an open dialogue with which to ask questions, and obtain clarification with experts in the field of advanced care planning (Tamayo-Valazquez et al., 2009). This would include utilizing strategies to educate and support physicians on how to initiate and have end of life discussions in a timely manner with their patients (Raijmakers et al., 2013).

Two different studies found it is unrealistic for the physicians to have a one-time lengthy discussion regarding advance care planning (Schickedanz et al., 2009), but rather discussions over multiple visits, with a physician or team that plans thoughtful interaction with the patient to help guide decision making (Johnson et al., 2012). The completion of the advance directive should be included in overall health maintenance and completed before the patient becomes burdened by either acute or chronic illness (Hinders, 2012. Pereira et al., 2011). Physicians, nurse, and social workers trained to collaborate in advance care planning can have a meaningful effect on the completion of advance directives, and take on some of the complexities of end of life planning when the primary physician is unable to do so (Dyess, Tappen, & Hennekens, 2014).

Facilitators: Nursing as a Discussion

Nurses, more than any other member of the healthcare team have a unique opportunity to act as a liaison between the family and the healthcare team regarding end of life discussions (Hinders, 2012). This is especially true if the patient is in the hospital or long term care facility. This is because it is the nurse that often develops a relationship with the patient and their family during the inpatient period. Because end of life care preferences are often very personal discussions, these discussions require participation from a member of the healthcare team that knows the patient, and sometimes the patient's family intimately (Nogler, 2014). Often, this member of the healthcare team is the nurse. Given this fact, additional facilitators to the completion of advance directives might involve the utilization of nursing governance to create written nursing policies and protocols that would empower nursing to take a more active role to help inpatients complete advance directives (Mezey et al., 2000).

Chapter 3: Method

It is important to note that with any healthcare directive, decision, or procedure, the needs and desires of the patient must be the priority. If healthcare is to be patient centered then end of life care must be as well. Patient centered care dictates that if a patient does not want to discuss end of life care, or have an advance directive, then the wishes of the patient must be respected in these instances as well. The job of healthcare providers is to provide information and education in an easy to understand and neutral format. It is only then that the health care system can be truly patient centered.

Design

This study used a cross sectional survey design to study the barriers and/or facilitators to the completion of advanced directives in healthy adults aged 45-65, who were not employed in healthcare. Not being employed in healthcare was deemed important since many healthcare professionals are already familiar with advance directives. This study focused instead on advanced directives for the general public .

Sample

The initial contacts for the study were chosen through convenience sampling, followed by snowball sampling. These initial contacts, while known by the PI, could participate in the study only if they met the eligibility requirements. The inclusion criteria included healthy non-healthcare employed individuals, aged 45-65, who were cognitively and emotionally able to complete a sixteen question survey (appendix B). The initial contacts were given an informational recruitment flyer by email and in person (Appendix A) directing participants to an online survey utilizing Survey Monkey©. This survey sought to ascertain the barriers and facilitators to the completion of advance directives in healthy individuals not involved in health care. The survey was opened in mid-November 2014 and closed January 1, 2015.

Additional study participants were recruited through snowball sampling. The initial use of convenience sampling was utilized in order to obtain a better cross section of the community to provide maximum variation sample. The PI did not meet with any of the study participants after the initial contacts were recruited.

Protection of Human Subjects

An application for approval for this study was submitted for analysis and approval to the Internal Review Board (IRB) for the University of California Davis to further ensure protection of human subjects. The study was started only after approval by the IRB was granted in the Fall of 2014. Participation in this study was voluntary and the participants were given the option to withdraw from the study at any time. Risk to the participants is assumed to be minimal, though the topic of death and dying can invoke a strong emotional response. Consent regarding the material in the survey was assumed by completion of the survey. Only completed surveys were included in the final data analysis.

Procedure

A 16 item survey was developed based on information found in the literature review. The survey was designed to capture the knowledge of the general public on advance directives. One hundred surveys were sent out with 40 participants responding. Answers were collected with the results of all surveys being collated by Survey Monkey©.

Instrument

The survey was designed to ascertain the level of understanding, and the interest of this particular age group in having an advance directive. The belief on the part of the principle investigator is that this age group would discuss, and complete, the advance directive while healthy if given the opportunity. It should be noted that reliability and validity were not established for this survey. Face validity however, was conducted immediately following the construction and approval of the survey by the thesis chair.

The first eight questions collected basic demographic data including age, income level, health insurance status, educational level, relationship status, and whether the respondents had children in the home under the age of 18. Three questions followed a simple yes or no pattern, with an additional four more questions in a Likert-scale format. Responses to the Likert questions rated the importance of specific issues about advance directives with responses being scored from extremely important (1), to not important at all (5). The purpose of these questions was to assess both the knowledge level regarding advance directives, as well as some of the most important things to include in the advance directive. The last question in the survey consisted of an open-ended question inviting participants to further explain what, if anything, they would like to learn about advance directives.

Chapter 4: Results

Sample Demographics

The sample demographics for this survey are presented in Table 1. Thirty eight participants (n=38) answered the first eight demographic questions; two participants skipped the first eight questions. Three yes/no format questions had 33 responses (n=33) with 7 participants choosing to skip the questions completely.

Table 1

Survey Sample Demographics

Characteristic	N	%
Gender		
Male	15	39.5%
Female	23	60.5%
Age		
45 to 54	16	42.1%
55 to 65	22	57.9%
Ethnicity		
White/Caucasian	35	92.1%
Hispanic or Latino	2	5.3%
Black or African American	1	2.6%
Marital Status		
Married	29	76.3%
Divorced	2	5.3%
Separated	1	2.6%
In a Domestic Partnership/Civil Union	1	2.6%
Single (Never Married)	4	10.5%
Prefer Not to Answer	1	2.6%
Parental Status		
Children Under 18	12	31.6%
No Children Under 18	25	65.8%
Prefer Not to Answer	1	2.6%
Health Insurance Coverage		
Yes	37	97.4%
No	1	2.6%
Annual Income		
\$30,000 to \$59,999	3	7.9%
\$60,000 to \$119,999	26	68.4%
\$120,000 to \$179,999	5	13.2%
\$180,000 or more	3	7.9%
Prefer Not to Answer	1	2.6%
Education		
High School Degree or GED	1	2.6%
Some College (No Degree)	4	10.5%
Associate Degree	4	10.5%
Bachelor Degree	12	31.6%
Graduate Degree	17	44.7%

The majority of those who completed the survey were mostly Caucasian females, married, and middle class with a large percentage being highly educated. It is also important to note that the majority of those in this study have health insurance. Age ranges were about even in the particular age group surveyed.

Table 2 ***Reasons for Not Having an Advance Directive***

Reason	Strongly Disagree #/%	Disagree #/%	Neither Agree nor Disagree #/%	Agree #/%	Strongly Agree #/%	Total
I don't know what they are.	7 44%	3 19%	3 19%	2 13%	1 6%	16
I don't think I need one.	8 47%	6 35%	0 0%	1 6%	2 12%	17
I don't want one.	8 50%	6 38%	0 0%	1 6%	1 6%	16
It's too costly.	5 33%	2 13%	4 27%	3 20%	1 7%	15
I don't know what is involved to complete an advance directive.	3 19%	0 0%	2 13%	5 31%	6 38%	16
My family would not follow it.	11 65%	4 24%	1 6%	1 0%	1 6%	17
Doctors and Nurses will not take care of me if I have one.	9 53%	5 29%	1 6%	1 6%	1 6%	17
I don't know what will happen to me if I have one.	9 53%	1 6%	5 29%	1 6%	1 6%	17
Not applicable, because I have an advance directive.	14 82%	0 0%	2 12%	0 0%	1 6%	17
I find this topic too uncomfortable to discuss.	11 65%	3 18%	2 12%	0 0%	1 6%	17

The majority of respondents (80%) cited lack of understanding, and not knowing what an advance directive is as the main reason for not having completed an advance directive. In addition, many in this study (73%) cited the physician/ provider not discussing advance directives as an additional reason for not having an advance directive completed.

T**able 3** ***Method in Which Study Individuals Heard About or Obtained Advance Directive:***

Method	Strongly Disagree #/%	Disagree #/%	Neither Agree nor Disagree #/%	Agree #/%	Strongly Agree #/%	Total
Prepared it on your own?	3 20%	2 13%	1 7%	3 20%	6 40%	15
Researched it on the internet?	5 33%	1 7%	7 47%	2 13%	0 0%	15
Ask for help from a legal professional?	2 13%	1 6%	2 13%	5 31%	6 38%	16
Ask for advice or discuss it with a medical provider?	5 33%	2 13%	5 33%	2 13%	1 7%	15
Store it with a legal professional?	3 20%	2 13%	1 7%	3 20%	6 40%	15
Store it at home?	0 0%	0 0%	0 0%	5 31%	11 69%	16
Advise friends and family about your wishes?	1 7%	0 0%	0 0%	3 20%	11 73%	15
Not applicable, I don’t have one.	4 80%	0 0%	1 20%	0 0%	0 0%	5

The majority of those in this study discussed advance directives with their loved ones, prepared it on their own, or utilized the help of a professional to get their advance directive completed

Table 4. *Desired Respondent Advance Direction Inclusions*

Measure	**Extremely important**	**Very important**	**Important**	**Not very important**	**Not important at all**	**N/A**	**Total**
Use of artificial means for life support (ex: breathing machine/ ventilators (a tube inserted in your lung to help you breathe)	19 59%	6 19%	3 9%	2 6%	2 6%	0 0%	32
Use of tube feeding for nourishment to keep you alive	18 56%	5 16%	3 9%	2 6%	4 13%	0 0%	32
Performance of cardio pulmonary resuscitation (CPR) because your heart stops	22 69%	4 13%	5 16%	0 0%	1 3%	0 0%	32
Treatment for infections during end of life care	14 45%	5 16%	6 19%	3 10%	3 10%	0 0%	31
Use of intravenous fluids nutrition during end of life care	18 56%	5 16%	5 16%	1 3%	3 9%	0 0%	32
Dying at home without pain/ discomfort	19 58%	9 27%	3 9%	1 3%	1 3%	0 0%	33
Dying in the hospital without pain/ discomfort	17 55%	8 26%	4 13%	0 0%	1 3%	1 3%	31
How important do you think it is for someone to have an advance directive?	21 66%	7 22%	3 9%	0 0%	0 0%	1 3%	32

Many in this study felt that advance directives were extremely important. X% of the sample wanted the majority of life sustaining treatments offered in the hospital even though the same number wanted to die at home without pain.

Chapter 5: Discussion

The study performed found education and communication is needed to effectively facilitate the completion of early advance directives. This finding is indeed consistent with the literature review in that there is a desire for advance directives among those people in this survey, but there was confusion on when and how to start. In the last question of the survey, 14 of 16 participant responses centered on the lack of education and understanding about what an advance directive is, to why one is needed in the first place. It was expected that advance directives as a discussion topic would be a difficult conversation to have, but in this study population the majority of those did not validate this presupposition. Many of those in the study wanted to have advance care discussions but felt that it was the clinician's responsibility to start the conversation.

In this study, 81% of survey respondents did not really have any idea what an advance directive was but they did feel that they needed, or would like to have one completed. More importantly, 88% of those who answered this question were not sure what would happen to them if they had an advance directive, which ironically, is one specific purpose of advance care planning.

The literature review specifically mentioned a desire among patients older than 65 to have the discussion of advance directives with their doctor. This was also the case in 67% of those individuals that took this survey. It was essential to determine whether or not the topic of end of life care was the major reason that patients were not seeking information on advance directives from their care providers. Only 13% of those surveyed in this study reported that the topic of advance directives was too uncomfortable to discuss. This finding supports both the notion that patients want education about advance directives, and desire end of life planning. This finding also agrees with the recommendations from the IOM. The IOM report states the need for public engagement and education on this topic, as well the reimbursement of those care providers spending time and effort to have end of life discussions with their patients (IOM, 2014).

This study also supported the idea that when faced with the offer to do everything to extend an individual's life, participants would say they want everything done to save their lives. The survey did not further explore if the desire to have everything done would change should respondents remain on life support and be unable to return to full functioning.

The overwhelming majority, 95%, of those that answered question 13 thought the advance directive document was an important document. The desire for education and communication about the advance directive and end of life care is clearly present in this study population, supporting the idea that earlier and frequent discussions about advance directives would be beneficial. This finding is also consistent with the findings in the literature review of those over the age of 65 (IOM, 2014).

Limitations

There are significant limitations to this study. First, the small sample size of 38 individuals who agreed to complete the survey was far fewer than the desired 100. A small sample size decreases the diversity of those taking the survey, potentially failing to detect meaningful difference between this study and the existing literature. Of the 38 individuals that took the survey, some individuals chose to answer some of the questions and not others. Why this happened is not understood.

This small sample size provided for further limitations in the following ways.

The majority of those individuals surveyed were Caucasian (92%), with only 8% of those surveyed being both black and Hispanic or Latino. American Indians and Asians and Pacific Islanders were completely absent from this study. The majority of individuals surveyed (97%) had health insurance. More than 88% of those surveyed made more than $60,000 per year. Those at the lower end of the socioeconomic scale, as well as non-whites, were poorly represented in this study. Therefore, a larger more comprehensive study of the community is needed to adequately determine the true opinions of advance directives in the general population.

Another limitation is the inclusion criteria. The age and health status of the individual is entirely based on the honor system. There is no way to determine if the age inclusion, and/or health status requirement were true of the individuals taking the survey. Further larger studies might benefit from face to face interaction with the study population in different settings within the community. This may provide a broader range of respondents in terms of ethnicity, socioeconomic level, and education level. This is important because, when having sensitive discussions regarding end of life care, all members of the community need to be considered for a successful conversation about advance directives.

Another limitation involved the structure of question 13. From extremely Important to not very important, a list of treatments was offered to the respondents, ranging from life support and cardiopulmonary resuscitation, to the use of intravenous fluids and tube feeds. Predictably, a large percentage of those that took the survey stated that they wanted all treatments offered. It is unknown from these survey respondents if these opinions would change if they were in either a persistent vegetative state, had a terminal illness, were facing progressive dementia, or would permanently require tube feedings or breathing help from a machine even if they were not in a vegetative state. The study in the New England Journal of Medicine noted in the literature review found that those outpatients surveyed overwhelmingly did not want life sustaining treatments if any of the above scenarios were present (Emmanuel et al., 1991). Unfortunately, this question was never asked within the survey questions. Earlier studies support the idea that, should a patient wind up in a persistent vegetative state, a large majority of those polled stated they would not want to live under these specific circumstances (Emanuel et al., 1991). Therefore, determining the desire for life sustaining treatments if the individual cannot return to full functioning should have been asked in this study.

Conclusion

This study attempted to examine the barriers and facilitators of advance directive planning among healthy, non-healthcare employed individuals aged 45-65. The goal was to obtain an understanding about what healthy, younger individuals desire regarding advance directives. Discussions about advance care planning largely take place with members of the population older than 65 (Emanuel et al.,1991). Even though the topic of death is difficult, the majority of patients in this study wanted the right to make their own informed decisions as to what treatments and procedures are desired. Participants in this study expressed their desire for more education with their healthcare team, initiated by their physician or provider. Respondents indicated confusion as to how advance directives are to be obtained, but more importantly, if their wishes will be followed should an advance directive be completed.

Moving forward, it is recommended that educational workshops be conducted on end of life care planning as they would be very beneficial to the healthcare consumer. Moreover, these discussions workshops would be most effective if they happened through palliative care professionals, as they are the most knowledgeable regarding end of life care planning (IOM, 2014). As supported by the IOM recommendations, reimbursement for this planning is an issue that does need to be addressed. Whether this payment is through the hospital or third party insurance is still to be determined. Currently, many hospitals are holding these types of workshops for their own employees through palliative care as directed by the patients' primary care team. Could these types of workshops be extended to the outpatient population as well? Should this be possible, it is important these workshops clarify specific desires in the prolongation of life and what that might mean for the individual. These discussions would be ongoing and long term with the understanding that goals change over time and might need to be discussed at least once per year. Patient centered care starts with a relationship between the patient and his or her healthcare team, and must be continued throughout life and during the dying process.

References

Advance Directives and Advance Care Planning: Report to Congress. (2008). Retrieved from http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf

Bravo, G., Dubois, M., & Wagneur, B. (2008). Assessing the effectiveness of interventions to promote advance directives among older adults: A systematic review and multi-level analysis. *Social Science & Medicine*, *67*, 1122-1132. Retrieved from www.elsevier.com/locate/socscimed

Carr, D., & Khodyakov, D. (2007). End-of-life Care Planning Among Young-Old Adults: An Assessmenr of Psychosocial Influences. *Journal of Gerontology*, *Vol. 62B*(2), S135-S141.

Differences in Palliative vs. Hospice Care. (n.d.). Retrieved from http://www.stcam.com/hospice/palliative-vs-hospice/

Dyar, S., Lesperance, M., Shannon, R., Sloan, J., & Colon-Otero, G. (2012,). A Nurse Practitioner Directed Intervention Improves the Quality of Life of Patients with Metastatic Cancer: Results of a Randomized Pilot study. *Journal of Palliative Care Medicine*, *15*, 890-895. http://dx.doi.org/10.1089/jpm.2012.0014

Dyess, S. M., Tappen, R., & Hennekens, C. H. (2014). Increasing Rates of Advance Care Planning Through Interdisciplinary Collaboration. *The American Journal of Medicine*, *127*, 1142-1143. http://dx.doi.org/http://dx.doi.org/10.1016%2Fj.amjmed.2014.07.035

Dying in America Improving Quality and Honoring Individual Preferences Near the End of Life [Report Brief]. (2014). Retrieved from Institute of Medicine of the National Academies: www.iom.edu/endoflife

Evangelista, L. S., Motie, M., Lombardo, D., Ballard-Hernandez, J., Malik, S., & Liao, S. (2012). Does Preparedness Planning Improve Attitudes and Completion of Advance Directives in Patients with Symptomatic Heart Failure. *Journal of Palliative Medicine*, *15*, 1316-1320. http://dx.doi.org/10.1089/jpm.2012.0228

Emmanuel, L. L., Barry, M. J., Stoeckle, J. D., Ettelson, L. M., & Emanuel, E. J. (March 28,1991, March 28, 1991). Advance Directives for Medical Care - A Case for Greater Use. *The New England Journal of Medicine*, *324*, 889-895.

Freer, J. P., Eubanks, M., Parker, B., & Hershey, C. O. (2006). Advance Directives: Ambulatory Patients Knowledge and Perspectives . *The American Journal of Medicine*, *119*(12), 1088.e9-1088.e13. http://dx.doi.org/10.1016/j.amjmed.2006.02.028

Hinders, D. (2012). Advance Directives: Limitations to Completion. *American Journal of Hospice and Palliative Medicine, 29*(4), 286-289. doi: 10.1177/1049909111419293

Johnson, R. W., Zhao, Y., Newby, K. L., Granger, C. B., & Granger, B. B. (2012, September, 2012). Reasons for noncompletion of Advance Directives in a Cardiac Intensive Care Unit. *American Journal of Critical Care*, *21*(5), 311-319. http://dx.doi.org/http://dx.doi.org/10.4037/ajcc2012394

Kehl, K. A., Kirchhoff, K. T., Finster, M. P., & Cleary, J. F. (2008, November 7, 2008). Materials to Prepare Hospice Families foe Dying in the Home. *Journal of Palliative Care*, *11*, 696-972. http://dx.doi.org/10.1089/jpm.2008.0072

Ko, E., & Lee, J. (2014). End- of- life treatment preference among low-income older adults: A race/ethnicity comparison study. *Journal of Health Care for the Poor and Underserved, 25*(3), 1021-1033. doi: 10.1353/hpu.2014.0129

Mezey, M. D., Leitman, R., Mitty, E. L., Bottrell, M. M., & Ramsey, G. C. (2000). Why Hospital Patients Do and Do Not Execute an Advance Directive. *Nursing Outlook*, *48*, 165-171. http://dx.doi.org/10.1067/mno.2000.101772

Nogler, A. F. (2014). Hoping for the best, preparing for the worst: Strategies to promote honesty and prevent medical futility at end-of-life. *Dimensions of Critical Care Nursing, 33*(1), 22-27. doi: 10.1097/DCC.0000000000000013

Pereira, S. M., Fradique, E., Filalho, R., Cerqueira, M., Pereira, A., & Sampaio, F. (2011). Advance directives: Portuguese palliative care professionals views. *International Journal of Palliative Nursing* , *17*, 373-378. Retrieved from http://www.internurse.com/cgi-bin/go.pl/library/article.cgi?uid=85890

Plonk, W. M., & Arnold, R. M. (2005). Terminal Care: The Last Weeks of Life. *Journal of Palliative Medicine*, *8*, 1042-1054. http://dx.doi.org/10.1089/jpm.2005.8.1042

Pollack, K. M., Morhaim, D., & Williams, M. A. (2010). The public's perspectives on advance directives: Implications for state legislative and regulatory policy. *Health Policy, 96*(1), 57-63. doi: 10.1016/j.healthpol.2010.01.004

Raijmakers, N. J. H., Rietjens, J. A. C., Kouwenhoven, P. S. C., Vezzoni, C., Van Thiel, G. J. M. W., Van Delden, J. J. M., & Van Der Heide, A. (2013). Involvement of the dutch general population in advance care planning: A cross-sectional survey. *Journal of Palliative Medicine, 16*(9), 1055-1061. doi: 10.1089/jpm.2012.0555

Rurup, M. L., Onwuteaka-Philipson, B. D., Van der Heide, A., Van der Wal, G., & Deeg, D. J. (2005, September 12). Frequency and determinants of advance directives concerning end-of-life care in the Netherlands . *Social Science & Medicine*, *62*, 1552-1563. http://dx.doi.org/10.1016/j.socscimed.2005.08.010

Sahm, S., Will, R., & Hommel, G. (2005). Attitudes towards and barriers to writing advance directives amongst cancer patients, healthy controls, and medical staff. *Journal of Medical Ethics*, *31*, 437-440. http://dx.doi.org/10.1136/jme.2004.009605

Schickedanz, A. D., Schillinger, D., Lanefeld, C. S., Knight, S. J., Williams, B. A., & Sudore, R. L. (2010, Jan 1, 2010). A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients Srlf-identified Barriers. *Journal of American Geriatric Society* , *57*(1), 31-39. http://dx.doi.org/10.1111/j.1532-5415.2008.02093.x

Schwartz, C. E., Wheeler, B., Hammes, B., Basque, N., Edmonds, J., Reed, G., ... Yanko, J. (2002, July 22). Early Intervention in Planning End-of-life Care With Ambulatory Geriatric Patients . *JAMA Internal Medicine*, *162*, 1611-1618. http://dx.doi.org/10.1001/archinte.162.14.1611

Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000, May 16). In Search of a Good Death: Observations of Patients Families, and Providers. *Annals of Internal Medicine*, *132*, 825-832. http://dx.doi.org/10.7326/0003-4819-132-10-200005160-00011

Tamayo-Velazquez, M. I., Simon-Lorda, P., Villegas-Portero, R., Higueras-Callejon, C., Garcia-Guitierrez, J. F., Martinez-Pecino, F., & Maria Barrio-Cantalejo, I. (2009). Interventions to promote the use of advance directives: An overview of systematic reviews. *Patient Education and Counseling*, *80*, 10-20. http://dx.doi.org/DOI: 10.1016/j-pec.2009.09.027

Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V. (2004). Family Perspectives on End-of-Life Care at the Last Place of Care. *JAMA*, *291*, 88-93. http://dx.doi.org/10.1001/jama.291.1.88

The National Institute on Aging. (n.d.). www.nia.nih.gov/health/featured/end-of-life

The World HealthOrganization.(n.d.)http://www.who.int/cancer/palliative/definition/en/

Van Leuvan, K. A. (2012, March 13). Advanced care planning in health service users. *Journal of Clinical Nursing*, *21*, 3126-3133. http://dx.doi.org/10.1111/j.1365-2702.2012.04190.x

Zager, B. S., & Yancy, M. (2011). A Call to Improve Practice Concerning Cultural Sensitivity in Advance Directives: A Review of the Literature. *Worldviews on Evidence-Based Nursing, 8*(4), 202-211. doi: 10.1111/j.1741-6787.2011.00222.x

Zaide, G. B., Pekmezaris, R., Nouryan, C. N., Mir, T. P., Sison, C. P., Liberman, T., . . . Wolf-Klein, G. P. (2012). Ethnicity, race, and advance directives in an inpatient palliative care consultation service. *Palliative and Supportive Care, 11*(1), 5-11. doi: 10.1017/S1478951512000417

Appendix A

Research Study

Purpose of the study: to understand the level of acceptance and understanding of advanced directives in healthy, non-healthcare employed adults aged 45-65

Eligibility:

- **45-65 years of age**
- **No significant or debilitating health problems**
- **Not currently employed as a healthcare provider or employee**

What will I be asked to do?

- **Complete a short 15-20 minute survey online**
- **Surveys are accessed through surveymonkey.com**
- **No personal health information required**

For more information contact:
Michael Dion, RN, BSN
michael.dion@ucdmc.ucdavis.edu;

Your participation in this study is completely voluntary. You can decide to stop your participation at any time.
Thank You!

TO COMPLETE THE SURVEY,
COPY AND PASTE THIS URL INTO A WEB BROWSER:
www.surveymonkey.com/s/AdvanceDirectiveSurveyMikesThesis

Appendix B

Barriers and Facilitators to the completion of Advance Directives

Please answer the following questions:

1.)What is your age?
  45 to 54
  55 to 65
  Prefer not to answer

2.)What is your gender?
  Female
  Male
  Transgender
  Prefer not to answer

3.)Which of the following best describes your current relationship status?
  Married
  Widowed
  Divorced
  Separated
  In a domestic partnership or civil union
  Single, but cohabitating with significant other
  Single, never married
  Prefer not to answer

4.) Do you have any children under 18?
  Yes
  No
  Prefer not to answer

5.) Do you currently have health insurance, or not?
  Yes I do
  No, I do not
  Prefer not to answer

6.) What is the total annual income of the household in which you live?
  $0 to $29,000
  $30,000 to $59,000
  $60,000 to $119,999
  $120,000 to $179,999
  $180,000 or more
  Prefer not to answer

7.) What is the highest level of schooling you have completed?
Less than high school degree
High school degree or equivalent (e.g., GED)
Some college but no degree
Associate degree
Bachelor Degree
Graduate Degree
Doctoral Degree
Prefer not to answer

8.) What is your ethnicity?
American Indian or Alaskan Native
Asian or Pacific Islander
Black or African American
Hispanic or Latino
White / Caucasian
Other
Prefer not to answer

9.) Do you know what an advance directive is?
Yes
No

10.) Do you have an advance directive?
Yes, I have an advance directive.
I do have an advance directive, but it needs to be reviewed.
I have been meaning to complete an advance directive but I havent gotten around to it yet.
I do not have an advance directive, but I should.
No, I dont have an advance directive.
I dont have an advance directive and I dont plan on having one.

11.) To what extent do you agree with the questions below as they apply to how you heard about or obtained your advance directive. (check all that are appropriate):

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	Total
Prepared it on your own?						
Researched it on the internet?						
Ask for help from a legal professional?						
Ask for advice or						

discuss it with a medical provider?						
Store it with a legal professional?						
Store it at home?						
Advise friends and family about your wishes?						
Not applicable, I dont have one.						

12.) To what extent do you agree with the statements below for reasons for not having an advance directive? (Choose all that apply)

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Total
I dont know what they are.						
I dont think I need one.						
I dont want one.						
Its too costly.						
I dont know what is involved to complete an advance directive.						
My family would not follow it.						
Doctors and Nurses will not take care of me if I have one.						
I dont know what will happen to me if I have one.						
Not applicable, because I have an advance directive.						
I find this topic too uncomfortable to discuss.						
My doctor has never discussed advance directives with me.						
Other						

13.) Please rate the importance of including the following in an advance directive:

	Extremely important	Very important	Important	Not very important	Not important at all	N/A	Total
Use of artificial means for life support (ex: breathing machine/ ventilators (a tube inserted in your lung to help you breathe)							
Use of tube feeding for nourishment to keep you alive							
Performance of cardio pulmonary resuscitation (CPR) because your heart stops							
Treatment for infections during end of life care							
Use of intravenous fluids nutrition during end of life care							
Dying at home without pain/ discomfort							
Dying in the hospital without pain/ discomfort							
How important do you think it is for someone to have an advance directive?							

14.) Have you ever discussed advance directives with other people?
  Yes
  No

15.) What, if anything, would you like to learn about advance directives? (Free text box)

16.) Now that you have taken this survey, has this changed your thoughts on advance directives?
  Yes
  No
  Im not sure