

University of Nevada, Reno

Advanced Care Planning in Community Dwelling Older Adults

A thesis submitted for partial fulfillment of the
requirements for the degree of Masters in Nursing

by

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Abstract

There are a growing number of older Americans. This means an increased proportion of people at the end of life. Advanced care planning is significant because it has been shown to decrease costs at the end of life and increased quality of life (Sabino, 2010). Advanced directives such as living wills and durable power of attorney for health care have been used as markers of advance care planning but rates are generally low.

The purpose of this cross-sectional study was to identify the rates of different types of advanced care planning completed by community dwelling older adults including advanced directives and determine if relationships exist between age, sex, health and primary care provider type and completion or discussion of advanced directives. Participants were recruited via convenience and/or snowball sampling from three local communities that provide programs for those over 50. Survey data was analyzed using logistics regression to test associations with level of significance set at $< \text{or} = 0.05$.

A total of 177 surveys were collected. Rates of advance directive completion for this survey mirrored those of the national average (Predit, 2014). Many people have spoken to their family about advanced care planning (66.7%, $n = 118$) but doctors were not in the top four responses (19%, $n = 35$). Those conversations that did occur with the primary care provider were mainly started by the patient (54.3%, $n = 19$) and tended to last less than 5 minutes (42.9%, $n = 15$). The data also found a correlation between those who have not talked to anyone about advanced care planning and those who were not married (OR = 352.5, $p < 0.0001$). Further it found that men were less likely to talk with friends (OR = 0.341, $p = 0.015$) and family (OR = 0.298, $p = 0.0009$) about advanced

care planning. This study gives important insight into advance care planning discussions and reveals those individuals who are less likely to complete advance care planning discussions

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A special thanks to my mentor and dear friend Mary Becherer, RN, MSN. Without her help I would not have been able to complete this research. She has been a champion and cheerleader for me both personally and professionally. I am constantly inspired by the passion she has for the profession and life in general.

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Table of Contents

Abstract	i
Acknowledgements	iii
List of Tables	vi
List of Figures	vii
Chapter One: Introduction	1
Background and Significance	1
Problem Statement	2
Conceptual Framework	2
Purpose and Research Questions	3
Conceptual Definitions	4
Assumptions	6
Limitations	6
Chapter One Summary	6
Chapter Two: Literature Review	7
Dying in the United States	7
Benefits of Advanced Directives	8
Provider Discussion About End of Life Care	8
Rates of Completion	9
Increasing Rates of Advance Directives	10
Chapter Two Summary	10
Chapter Three: Methodology	12
Research Design	12
Sample	12
Procedure	13
Data Collection	13
Research Instruments	13
Data Analysis	14
Funding	14

Chapter Three Summary	15
Chapter Four: Results	16
Sample Description	16
Findings Question 1	21
Findings Question 2	21
Findings Question 3	21
Additional Findings	22
Chapter Five: Discussion	23
Conceptual Framework	25
Limitations	27
Nursing Implications	28
Implications for Further Research	29
Conclusion	29
References	31
Appendices	37
Appendix A: Community Survey Facility Agreement Form	38
Appendix B: Survey Information Letter	40
Appendix C: Advanced Care Planning Survey	42
Appendix D: Request for Permission Letter	47
Appendix E: Example Survey Participation Opportunity Flyer	49

List of Tables

Table 1: Demographic Data	17
Table 2: Advanced Care Planning	19
Table 3: Advanced Care Planning Conversation with Primary Care Provider.....	20

List of Figures

Figure 1: Conceptual framework for advance directive completion	5
Figure 2: Relationship of study findings to literature findings	26

Chapter One

Introduction

The call for patient autonomy in healthcare decisions has been ongoing since the late 1960's. Improvements in medical technology can prolong life, but may negatively affect the quality of life, especially in the elderly. While patients have the right to refuse care, they must make their wishes known in order to do so. Advanced directives are a legally binding option for patients to document their wishes for end of life care in the event they are incapacitated. Patients who have advanced directives are more likely than those who do not to receive care that is consistent with their wishes at the end of life (Silvera, Kim, & Langa, 2010).

Background and Significance

End of life care for older adults is significant because three out of every four deaths that occur in the US are of people over the age of 65 (Sahyoun, Lentzer, Hoyert, & Robinson, 2001). Currently, more than one in every eight Americans is classified as an older adult and in 2020 there will be 55 million people in the United States who are older than 65 (Administration on Aging, 2011).

This increase in the aging population will create issues in healthcare both ethically and financially. Moral distress in nurses has been linked to futile and inadequate care leading to burnout and exhaustion (Pier, Dewitt, Steeman, Vlerick, Benoit, & Van Den Noortgate, 2011). The providers who help counsel patients on difficult decisions for end of life care have little to no training on this topic (Davison, 2012). Also, quality of care at end of life varies widely based on geographic region leading to increased disparities (Curtis & Vincent, 2010).

Care at the end of life is expensive. Medicare patient costs increased 26% in the last 180 days of life and had higher rates of intensive care hospital admissions (Unroe et al., 2011). In the last six months of life patients were much more likely to see 10 or more doctors, many of which are specialists, leading to increased patient costs (Goodman, Esty, Fisher & Chang, 2011).

Advanced directives and living wills have been hailed as a solution to the ethical and financial crisis that happens at the end of life (Sabino, 2010). Advanced directives provide instruction to the healthcare team and family thereby reducing ethical dilemmas. Further, advanced directives have shown to decrease costs at the end of life (Nicholas, Langa, Iwashyna, & Weir, 2011).

Problem Statement

Several studies show that completion rates of advanced directives increase when primary care providers discuss advanced care planning with their patients (Lawrence, 2009; Ramsaroop, Reid & Adelman, 2007). However, questions remain as to what extent older adults are talking about advanced care planning, including completion of an advance directive. Further, the relationships between these conversations, as well as demographic variables, with the rate of advanced directive completion or provider discussion have not been thoroughly studied.

Conceptual Framework

This study was guided by the health belief model as the conceptual framework. Developed in the 1950's by Hochbaum, Kegels and Rosenstock the health belief model was originally intended to explain the underuse of preventative health programs at the time. This conceptual framework is most often used to explain and predict behavior

related to preventative health. It suggests that individuals will only engage in preventative health behaviors, such as advanced care planning, if they feel they are susceptible to the disease process, in this case death and dying. Other factors that influence preventative health behaviors, according to the health belief model are: the seriousness of the consequences if health prevention is not done; if the prevention will be beneficial to reducing the effects of the disease process; and/or if the benefits outweigh the barriers or the cost (Strecher & Rosenstock, 1997).

Cues to action are another part of the health belief model. Cues to action are events or circumstances that spur the patient into action. For example, the unpleasant death of a loved one may influence those who witnessed it to complete an advanced directive. Other variables are also significant in the health belief model. Factors such as social status, demographic variables and education level all play a role in the understanding of the consequences of the disease and the importance of health promotion (Strecher & Rosenstock, 1997). The impact of demographics on advanced care planning will be explored in this study.

While there is no way to prevent death, planning for end of life has many of the same advantages of other preventative health services. Advance care planning decreases costs, decreases patient and family anxiety around death and increases quality of life.

Purpose and Research Questions

The purpose of the study was to identify the rates of different types of advanced care planning completed by community dwelling older adults including advanced directives and who was initiating these discussions. Specific research questions included:

1. What is the rate of advanced care planning completion for community-

dwelling people over 50?

2. Who are people over 50 talking to about advanced care planning?
3. Is there a relationship between primary care provider type, age, health perception, race, marital status, or gender and the completion of advanced directives? (Figure 1).

Conceptual Definitions

For the purpose of this study, the following terms were defined:

1. Advanced directive completion means completion of advanced directive paperwork such as a living will, durable power of attorney, and/or do not resuscitate orders.
2. Advanced care planning is used as a broader term that includes living will durable power of attorney as well as organ donation, burial pre-plans, and last will and testament.
3. Primary care provider is defined as the medical personnel primarily responsible for overseeing care of the person.
4. Health perception is defined in this study as an individual's interpretation of wellness and illness.
5. Older adult is defined as anyone over 50 years of age.
6. Community dwelling is defined as those who do not live in an assisted living facility or retirement home but rather, independently in a house, apartment or other dwelling.

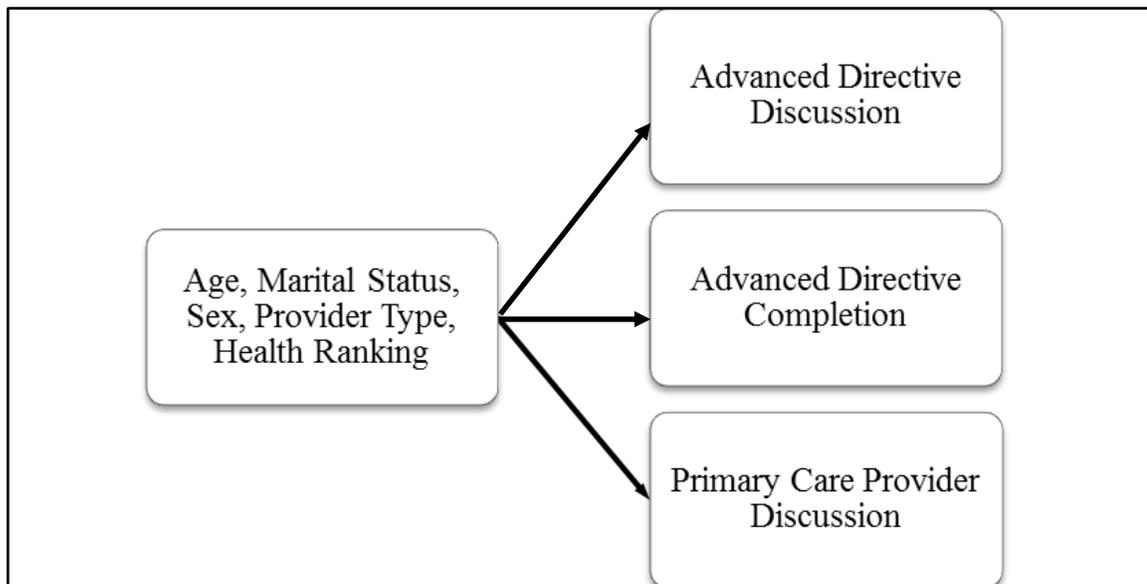


Figure 1. Research framework for advance directive completion.

Assumptions

The assumptions made by this research study were as follows:

1. Older adults are thinking about end of life.
2. Respondents know what a serious chronic illness is.
3. Respondents will answer honestly.

Limitations

The major study limitations are as follows:

1. Convenience and snowball sampling will limit the generalizability of the study to other older populations.
2. Data was collected by self-report which may lead to biased responses.
3. Subject matter of end of life may limit number of respondents due to the sensitive nature of the topic.
4. Data purity may be compromised due to discussion of responses from participants.

Chapter One Summary

This chapter introduced the problem, background and significance of advanced care planning. It highlighted the conceptual framework that was used in this study. Also, it reviewed the purpose, research questions, operational definitions, assumptions, limitations of this study. The next chapter will be a more in depth review of the literature pertinent to advanced directives.

Chapter Two

Literature Review

This literature review is aimed at giving the reader a more in-depth understanding of the research surrounding advanced directives. It will look into the dying experience near the end of life for older Americans and will outline the benefits of advance directives. Next rates of provider discussion about advanced care planning and reasons for these rates will be discussed. Finally, rates of completion of advanced directives will be presented as well as interventions to increase these rates.

Dying in the United States

Seventy percent of deaths occur in those who are 65 and older (American Psychological Association, 2014). These are mostly from chronic diseases such as heart disease, cancer, and chronic lower respiratory disease (Centers for Disease Control, 2013). This means that dying for older adults is typically not a sudden event and often-times happens after a long trajectory of illness. The impact of the prolonged dying process on advanced care planning is that older adults have time to think about and discuss their wishes for end of life care.

When it comes to end of life care in America, great disparities arise in regards to how people want to die and what actually happens (American Hospital Association, 2007). A small minority of elderly at the end of life request life-prolonging care, yet the norm in many cases is to opt for this aggressive treatment (Heyland et al., 2013). This leads to a multitude of other issues. More than 25 percent of healthcare costs are spent in the last year of life, however, these higher costs equate to a decreased quality of life (Hamlet, Hobgood, Dobbs, Rula, & Pope, 2010). Untreated pain and unwanted treatment

are commonly associated with care near the end of life (Seaman, 2013).

Benefits of Advanced Directives

Advanced care planning has been shown to decrease patient depression and increase their sense of control over end of life decisions. Advanced directives can help caregivers by reducing caregiver stress, anxiety, and depression. Further, they have been shown to improve the overall care at the end of life (Detering, Hancock, Reade, & Silvester, 2010; Maxfield, Pohl, & Colling, 2003; Spelhoff & Elliott, 2012).

There is also a financial interest in addressing issues in end of life care. Interventions to help patients decide what end of life care they desire lead to decreased costs at end of life (Hamlet, Hobgood, Hamar, Dobbs, Rula, & Pope, 2010). Research consistently shows reduced cost associated with advanced care planning, advanced directives and palliative care (Halpern & Emanuel, 2012; Morrison et al., 2011).

Provider Discussion About End of Life Care

Rates of aggressive treatment in the last 30 days of life are also reduced when physicians talk to their patients about end of life care (Mack et al., 2012). However, the literature shows that providers are uncomfortable talking with patients about advanced directives. Primary care physicians spend only a short amount of time talking about advanced directives with their patients and spend most of the time speaking rather than listening. Most of the discussion revolves around irreversible scenarios. In these discussions, vague language tended to be utilized and the topic of patient's personal values was avoided (Tulsky, Fischer, Rose & Arnold, 1998). Patients want to be involved in this discussion but are not. Physicians do not typically involve the elderly in the care planning process. This leaves the patients feeling left out of their own care

(Ekdahl, Andersson, Wirehn, & Friedrichsen, 2011).

Discussions should not be put off until the patient is ill. Initiating the conversation early and revisiting it often in the primary care setting has been shown to be a key to success in ensuring patients' wishes are known and followed (Bloomer, Tan, & Lee, 2010; Ramsaroop, Reid, & Adelman, 2007; Tung et al., 2013).

Only a small portion of patients had talked to their doctors or healthcare providers in regards to end of life choices (McCarthy et al., 2008). Further, the literature highlights the need for providers to initiate discussions about advanced directives because the patients do not feel comfortable bringing up the subject. Talking with patients about advanced care planning allows the provider to better associate themselves with their patient's end of life desires (Sessanna & Jezewski, 2008). Increased interaction with the primary care provider resulted in increased rates of advanced directive completion and improved end of life care (Lawrence, 2009; Wu, Lorenz, & Chodosh, 2008).

Rates of Completion

Advanced care planning, advanced directives, and living wills are not widely used. Estimates range from 5-15% of the US adult population having completed advanced directives. These rates have been shown to increase as age increases and overall health declines. Caucasian patients were more likely than African American patients to have completed an advanced directive. Lower literacy rates were associated with decreased rates of advanced directives (AARP, 2008; Johnson, Zhao, Newby, Granger & Granger, 2012; Tung et al., 2013; Waite et al., 2013).

Low completion rates may be due to misunderstanding what the document is about and how it is used. Forms in most states are filled with legal jargon and vague

terms causing incorrect completion. There is also evidence to show that these documents are disregarded in times of medical crisis (Johnson, Zhao, Newby, Granger & Granger, 2012; Sudore & Fried, 2010; Weiner & Tilly, 2003).

Increasing Rates of Advanced Directives

Increasing the rates of advanced directive completion is important. They are used as a tool to identify end of life wishes and start the discussion regarding end of life care. Several studies have shown that by simply asking the patient about advanced directives, their chance of completing one increases. Focusing on the positive impact of advanced directives has shown to be an effective strategy to aid in completion rates (Payne, Prentice-Dunn & Allen, 2010; Ramsaroop, Reid, & Adelman, 2007). There is a weak evidence base to support one educational intervention over another for increased advanced directive completion (Durbin, Fish, Bachman, & Smith, 2010).

People who have health care insurance were more likely to have a completed advanced directive. Healthcare insurance is the third strongest predictor of having a completed advanced directive after age and college education (Yang, Hardwick, Tiano, & Pettis, 2010)

Chapter Two Summary

Most of the literature is focused on advanced care planning in an intensive care or nursing home setting. There is little published data on advanced care planning in community dwelling older adults. Of Americans who are older than 65 years, 95.9% live in a community setting (Administration on Aging, 2011). There is a lack of research on whether or not providers are speaking to their patients about advanced directives and who these patients share this information with. It is known that primary care provider

involvement increases the likelihood of having a completed advanced directive.

However, there is no convincing evidence in the literature that the type of healthcare provider affects the rate of advanced directive completion.

Chapter Three

Methodology

The purpose of this study was to build on the current literature regarding advanced directive completion rates in community dwelling older adults, who these older adults are talking to about advanced directives, and correlate demographic data with advanced directive completion.

Research Design

To assess current rates of advanced care planning discussion and completion in community dwelling older adults, a descriptive, cross sectional, survey design was utilized. Multiple community settings of adults 50 years or older were approached by the PI via email and in person for permission to obtain data. Three main sites were used. The first was Osher Center for Lifelong Learning which is a continuing education college for those over 50 in the Reno area. The other sites were the Reno Senior Center as well as Sierra Manor, a low income senior housing apartment complex run by the Volunteers of America. Written consent was obtained from the settings and fliers were posted advertising the study with a brief description of the impact. Further participants were obtained from co-workers and contacts of the principal investigator.

Sample

A power analysis was conducted and a sample size of at least 143 subjects was needed to have a significance level of 0.05. To be eligible to participate in the study, participants needed to be 50 years or older with willingness to complete the survey and living in a community dwelling. Those who lived in a nursing home or assisted living facility were excluded. The study protocol was approved by the Institutional Review

Board of the University of Nevada, Reno prior to data collection. Informed consent letters were attached to each survey and the participants who completed and returned the survey were assumed to have consented to be study participants. A total of 177 surveys were obtained for this study.

Procedure

After permission was obtained (Appendix A), fliers were hung advertising the study in communities around Reno where people 50 years or older tend to live (Appendix E). Participants that showed an interest were approached by the PI and given a survey packet that included an overview of the study's purpose and how data would be used (Appendix B), the survey (Appendix C) and a return envelope with postage pre-paid. Participants were asked to fill out the survey at their convenience and mail it back or return it to the principal investigator, if completed while she was present.

Data Collection

The study was conducted from September 2013 until December 2013. A self-administered survey was distributed by the principle investigator to all study participants. Sampling was through a combination of convenience and snowball methodology. Participants were asked to complete the survey and either to hand it in to the PI or mail it by December 31st, 2013. The average time to complete the survey was five minutes.

Research Instrument

The survey was adapted from the American Association of Retired Persons (AARP) North Carolina End of Life Care Survey. This tool has been used to assess the attitudes of older adults regarding various end of life decisions. Approval from AARP was obtained to use and modify the original survey if needed (Appendix D). The original

survey contained 41 questions and was edited to 12 questions. These modifications were made to focus on demographic questions and questions pertinent to advanced directives. Additional modifications included changing the font of the text to 14 point Calibri font and printing it in black ink on white paper to enhance legibility (see Appendix C). Reliability could not be established based on the nominal nature of the data. Based on the prior use of the AARP survey in North Carolina as well as a similar survey in Massachusetts also by AARP, the survey was determined to have face validity.

Data Analysis

All data was entered by the principal investigator into IBM SPSS for Windows (Version 22) Software. Frequency tables were run on all data. Inconsistencies in the data were examined, verified or corrected as necessary. Logistics regression tests were conducted by using SAS 9.3 software on the data to see if relationships existed between variables of primary care provider type, age, sex, health ranking and primary provider discussion of advance directives or completion of advance directives (Figure 1). Multiple linear logistic regression models were applied to test the association between primary care provider type and demographic variable and the completion of advanced directives. Level of significance is set at p value ≤ 0.05 . In order to yield more robust data, the marital status demographic was divided into married and not married, where not married included all other marital statuses besides married.

Funding

A research grant was received from Sigma Theta Tau, Nu Iota Chapter. This grant covered research materials, postage to mail back the surveys, and the SPSS software purchase.

Chapter Three Summary

This study used a descriptive, cross sectional design. The purpose of this study was to build on the current literature regarding advanced directive completion rates in community dwelling older adults, investigate who these older adults are talking to about advanced directives, and correlate demographic data with advanced directive completion and primary care provider type. The target population was community dwelling adults in the Reno area who were 50 years of age or older. Convenience and snowball sampling lead to 177 participants. IRB approval was obtained from the University of Nevada, Reno. Participants were asked to complete a survey. Data analysis was completed using SPSS 22 and SAS 9.3.

Chapter Four

Results

Sample Description

Approximately 275 surveys were handed out to interested participants over the three month survey period. Return rate was 64% with a total of 177 surveys returned by the survey deadline. Surveys were received back in person or by mail. All surveys were eligible for inclusion.

The majority of the respondents were women (65%, $n = 115$) and between 60 and 74 years of age (48%, $n = 85$). Over half of the respondents were married (52.5%, $n = 93$) with the next greatest number of respondents equally divided among divorced (18.6%, $n = 33$) and widowed (18.6%, $n = 33$). The majority of the participants reported their primary care provider was a physician (78.5%, $n = 139$). Next most frequently identified primary care providers were nurse practitioners (13%, $n = 23$). Table 1 presents the demographic data of the study participants.

More than three quarters of the sample stated they did not have a serious illness (76.8%, $n = 136$). Interestingly, one participant reported she did not feel like she had a serious illness, even though she had hypertension and diabetes, because they were controlled. Most people viewed their health as excellent, very good or good (85.9%, $n = 152$).

Table 1

Demographic data ($N = 177$)

	Variable	<i>n</i>	%
Age	50-59	28	15.8
	60-74	85	48
	75 or older	59	33.3
	No answer	5	2.8
Marital Status	Married	93	52.5
	Divorced	33	18.6
	Widowed	33	18.6
	Single	9	5.1
	Living with a Partner	3	1.7
	Separated	1	0.6
	No Answer	5	2.8
Sex	Female	115	65
	Male	56	31.6
	No Answer	6	3.4
Provider Type	MD	139	78.5
	DO	7	4
	NP/APN	23	13
	None	4	2.3

	Unsure	1	0.6
	No Answer	3	1.7
Health Ranking	Excellent Health	47	26.6
	Very Good Health	49	27.7
	Good Health	56	31.6
	Fair Health	20	11.3
	Poor Health	4	2.3
	No Answer	1	0.6
Serious Chronic Illness	No	136	76.8
	Yes	41	23.2

Table 2

Advanced Care Planning ($N = 177$)

	Variable	<i>n</i>	%
Advanced Directives	Living Will	126	71.2
	Last Will and Testament	120	67.8
	POA	118	66.7
	Organ Donation	86	48.6
	DNR Order	85	48
	Funeral/Burial Plans	58	32.8
End of Life Discussion	Family	118	66.7
	Spouse/Partner	98	55.4
	Lawyer	56	31.6
	Friends	48	27.1
	Doctor	35	19.8
	Estate Planner	29	16.4
	No One	13	7.3
	Clergy	9	5.1
	Funeral Director	8	4.5
	Mental Health Professional	5	2.8
	Disease-Specific Organizations	2	1.1

Table 3

Advanced Care Planning Conversation with Primary Care Provider ($N = 35$)

	Variable	<i>n</i>	%
Conversation Initiation	Patient	19	54.3
	Doctor	9	25.7
	Family/Spouse	5	14.3
	No Answer	2	5.7
Conversation Length	Less than 5 minutes	15	42.9
	5-10 minutes	8	22.9
	10-15 minutes	4	11.4
	More than 15 minutes	8	22.9

Findings Question 1

What is the rate of advanced care planning for community dwelling older adults? Most people had advanced directives like a living will (71.2%, $n = 126$) or durable power of attorney for healthcare (66.7%, $n = 118$). More people said they had a last will and testament than power of attorney (67.8%, $n = 120$). Almost half stated they had a DNR order (48.6%, $n = 86$) or wished to be considered for organ donation (48.6%, $n = 86$). Only 32.8% ($n = 58$) had burial pre-plans.

Findings Question 2

Who are people over 50 talking to about advanced care planning? The majority of the participants have talked to family (66.7%, $n = 118$) or their spouse about advanced care planning (55.4%, $n = 98$). More people reported having talked to friends (27.1%, $n = 48$) than to doctors about advanced directives and only 19% ($n = 35$), had a discussion with their doctors about advanced directives. Ultimately 7.3% ($n = 13$) of respondents stated they had talked to no one about wishes near the end of their life.

Findings Question 3

Is there a relationship between primary care provider type, age, health perception, race, marital status, or gender and the completion of advanced directives? No significant relationship was found between the demographic variables, age, gender, marital status, or health, and completion of advanced care planning. Also, no significant relationship was present between demographic data and discussion with a primary care provider about advanced directives. Males were less likely to talk to family ($OR = 0.298$, $p = 0.0009$) and to friends ($OR = 0.341$, $p = 0.015$) about care near end of the life. There was a relationship between those who were not married and those who

talked to no one about their wishes at the end of life. Married individuals were significantly more likely to talk to their spouse or partner ($OR = 352.5, p < 0.0001$), and significantly less likely to not discuss advanced care planning ($OR = 0.043, p = 0.004$).

Additional Findings

Most people initiated the conversation with their primary care provider themselves (54.3%, $n = 19$). Only 25.7% of people ($n = 9$) said their doctor started the advanced care planning conversation. Most respondents reported that these conversations were less than five minutes in length (42.9%, $n = 15$).

Overall respondents reported a positive health perception. This does match the overall national trend where 78% of white respondents in a national survey stated their health was good to excellent (Federal Interagency Forum on Aging-Related Statistics, 2012).

Chapter Five

Discussion

This study revealed rates of advanced directive and advanced care planning completion for adults over 50 years old living in three community dwellings in Reno, Nevada. It further indicated who these older adults are talking to about advanced care planning. It also attempted to correlate advanced care planning with provider type and demographic data including age, sex, marital status, and overall health.

Despite having disproportionate response rates of age demographics, rates of advanced directive completion mirror those rates nation-wide (Preidt, 2014). However, rates of DNR orders for this study were higher than the national average (AARP, 2008). On a national average, women outnumber men as age increases thus the gender data is consistent with the national trend (Administration on Aging, 2011).

Older adults are talking with their family and friends about advanced care planning. They are not as frequently talking to their doctors. The discussion with the primary care provider has been linked increased rates of advance directive completion (Lawrence, 2009; Ramsaroop, Reid & Adelman, 2007). Prior research showed a similar trend where up to 76% of doctors were unaware that their patients had a completed advance directive (Kass-Bartelmes & Huges, 2004). Women were more likely to talk with friends and family about advanced care planning. This is supported by earlier studies that found that men are passive, rather than active, participants in their own healthcare (Sloan, Gough, & Conner, 2010). Married individuals were more likely to have talked to their spouse about end of life care.

Survey participants tended to rate their health better than those on a national

scale (CDC, 2013). This might be attributed to the fact that surveys were gathered from those who were able to leave their homes. People who are still community dwelling but are home bound may have a decreased perception of health, thus making the data more consistent with the national average.

This survey found that health was unrelated to primary care provider discussion of advance directives. It was also found that primary care providers, regardless of the type, were not talking to most of their patients about advanced directives, despite strong evidence that doing so will increase the rate of completion. Also significant was the fact that the demographic variables did not impact the advanced care planning discussion with the doctor.

Figure 2 highlights the similarities and differences between this research and the previously explored literature. In this figure the independent variables of age, sex, health, and marital status utilized in the study are connected to the dependent variables of primary care provider discussion, advanced directive discussion and advanced directive completion. This figure illustrates that significant relationships exist between sex and marital status and advance directive completion in this study. As stated above, those who are male and those who are not married are much more likely to talk to no one about advanced care planning.

Other studies have indicated relationships between age, sex and health ranking and advanced directive completion and primary care provider discussion. In these studies, the older the patient and the increase in chronic conditions the more likely are to have advanced directives. Females were also more likely than males to have advanced directives. That may be because, as shown in this study, females talk more

about advanced care planning than their male counterparts.

Conceptual Framework

The health behavior model suggests that individuals will only engage in preventative health behaviors, such as advanced care planning, if they feel they are susceptible to the disease process. Overall, this population viewed itself as healthy; therefore, there is a decreased perceived need for advanced directives.

Other factors that influence preventative health behaviors according to the health belief model are the seriousness of the consequences if health prevention is not done, the overall benefit of reducing the effects of the disease process, and ensuring that the benefits outweigh the barriers (Strecher, & Rosenstock, 1997). Older adults do not realize the consequences of not having an advanced directive. Many people do not know the ramifications of life sustaining interventions at the end of life such as CPR, artificial nutrition, and mechanical ventilation. If providers had honest discussions regarding these consequences rates of advance directive completion might increase. Speaking in real numbers helps families make informed decisions about the care their loved one will receive. However, most providers lack the knowledge of this information. Providers tend to overestimate the actual rates of survival and underestimate the loss of function (Seaman, 2013).

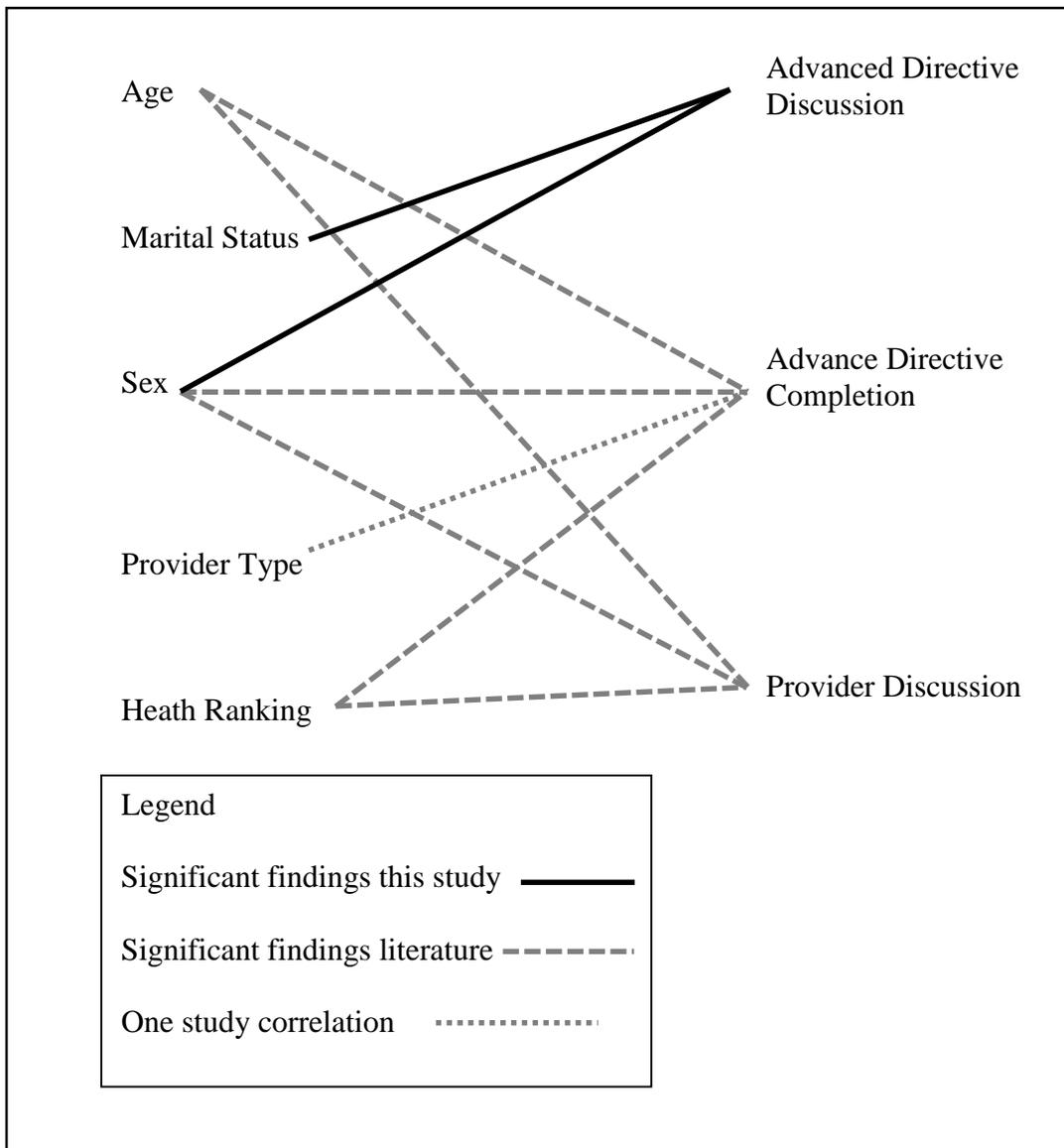


Figure 2. Relationship of study findings to literature findings. This figure illustrates the relationship between the study findings and those in the literature.

Limitations

This study had several limitations. It included people over 50 years old who lived in a one of three community-dwellings located in Reno, Nevada. Thus, anyone who was in a nursing home or assisted living facility was not included in this study. Participants had to be able to speak and read English, which may have produced results that would not be similar in a different cultural context. Because participants may not remember conversations related to advanced care planning, subject recall bias may have been a factor in this study. Although the sample was large enough to be statistically significant, the overall size was small. A larger sample size would have made the study findings more generalizable. A cross sectional design was used for this study. This allowed for only a snapshot of advanced directive completion rates rather than a longitudinal study that would trend these rates over time.

Another potential limitation of the study was the use of the AARP survey that did not have adequate reliability or validity data. Thus, it is possible that the survey did not adequately measure what it intended to measure. Further, the survey was brief. A longer survey could yield more rich data.

Convenience and snowball sampling methods were used to recruit participants. Data was not obtained about the percent of surveys from the different sites. Thus, it is unknown if the sampling methods led to disproportionate numbers of one socioeconomic class versus another. Nurse co-workers were given surveys to fill out and also distribute to friends and family. This would also lead to an underrepresentation of lower income respondents. No data was collected on socioeconomic status; therefore, the data could not be controlled for bias.

Other limitations were concerned with the respondents. There was essentially no race mix in the survey. Almost all participants stated they were white (90%). Some studies suggest that those who are not white have lower rates of advance directive completion (Wicher & Meeker, 2012). This survey was also conducted in an urban area and does not include any rural data. Literature has shown that there are differences in the health views of those who live in urban areas and those who live in rural areas (Graves, 2008). This may affect the way advance directives are viewed and utilized.

Nursing Implications

Addressing end of life care for older adults has a significant impact on nursing. Futile and painful care provided by nurses at the end of life has been linked to moral distress and burnout amongst nurses (Pier, et al., 2011). As the population ages the proportion of patients who are dying will increase. Those patients who have advance directives in place are more likely to receive care consistent with their goals and thus, less ethically challenging for the nurses taking care of them. This may help to decrease the high attrition rate from nurses at the bedside.

There are also implications for nursing education. This study showed that providers of all types are not speaking with patients about advance care planning. This may stem from a lack of education on how to discuss end of life care with patients and its importance (Davison, 2012). Further education in end of life communication is essential to prepare nurse practitioners and advanced practice registered nurses to deal with end of life communication with their patients and families. More nurse practitioners are seen as primary care providers in the outpatient setting where these discussions need to happen with patients.

Implications for Further Research

In order to make these results more generalizable, this survey should be replicated in a broader region, either state or nationwide. Completing this research would ensure that an improved snapshot of the completion rates, discussions and primary care provider involvement in advanced directives will be assessed. This import to certify that growing number of seniors will have the end of life care that they desire.

Future research should also include a more ethnically diverse sample. Some of the research shows a difference in rates of advanced directives in the non-white population. It would be beneficial to see if these rates are the same or different for discussions of advanced directives as well as conversations with the primary care provider.

Also relevant to research would be the provider viewpoint on advanced directive discussions. This would give insight into the value placed on advanced directives by healthcare professionals. It may further provide information as to why the rates of discussion are so low for these community dwelling older adults.

Conclusion

This survey indicates that regardless of demographic variables, providers of all types need to have advanced care planning conversations with their patients. This is highlighted by the study findings that most of the advanced care planning conversations is being initiated by the patient rather than by the primary care provider. Since most patients are unaware of advanced care planning and those that are aware feel that their primary care provider should be the one to approach this topic, it may go unaddressed (Petasnick, 2011).

This study also indicates those individuals who are at highest risk for not discussing advanced care planning. Men and unmarried individuals are at particularly high risk of not discussing end of life care plans. Interventions to increase advanced directive completion need to be aimed at these individuals.

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APPENDICES

APPENDIX A

COMMUNITY SURVEY FACILITY AGREEMENT FORM



University of Nevada, Reno

Community Survey Agreement

I agree to allow Kristen Lott to request participation and or conduct a community survey on advanced directives in community dwelling older adults at the below stated community from September 2013 to January 2014.

Name of Community: _____

Signature: _____ Date: _____

Name of Authorizing Person: _____

Position: _____

Phone Number: _____

Email: _____

APPENDIX B
SURVEY INFORMATION LETTER



Survey on Advanced Directives in Community Dwelling Older Adults

University of Nevada Reno, Orvis School of Nursing

The purpose of this survey is measure advanced directive completion rates in people over 50 living in the Reno area. Also this survey will investigate if primary care providers are talking to their patients about advanced directives. This information will be used to better understand how to serve our community as it grows older.

This is a confidential survey; your name will not be included or attached to the data in any way. All completed surveys will be kept at UNR in a locked file.

Survey and participation is optional. If at any time you wish to be excluded from the survey please contact Kristen Lott at the email or phone provided below.

Your consent is given by filling out and mailing back this survey in the self-addressed stamped envelope included in this packet. Please mail your survey back by **January 1st 2014**.

Thank you for taking the time to fill out this survey.

Please feel free to contact me with any questions.

Kristen Lott, RN, BSN, Principal Researcher

Kristen.courteau@gmail.com

732-513-1989

APPENDIX C
ADVANCED CARE PLANNING SURVEY

1. Advanced directives allow people to make their own health care choices known in advance of an incapacitating illness or death. Which of the following advance directives and other pre-plans have you completed (select all that you have completed)?
 - A health care proxy or durable power of attorney for health care in which you name someone to make decisions about your health care in the event you become incapacitated
 - A living will or other written instructions in which you states the kind of health care you want or don't want under certain circumstances
 - A Do Not Resuscitate ("DNR") order that authorizes emergency services personnel to honor your request for no CPR, no emergency medications, and not to place a breathing tube if your heart were to stop
 - A last will and testament that controls how your money and other property are to be distributed
 - Funeral or burial pre-plans in which you plan or purchase in advance any goods or services for yourself
 - Authorization to have your organs and/or tissues donated after you die for use by others in need of transplants

2. Who have you talked to about your wishes for care near the end of your life? (Check ALL that apply)

- Spouse/Partner
- Family
- Friends
- Clergy (for example Minister, Rabbi)
- Lawyer
- Estate Planner
- Funeral Director
- Mental Health Professional (for example Social Worker, Psychologist, or Psychiatrist)
- Disease-specific organizations (for example American Cancer Society, Alzheimer's Association, American Heart Association)
- No one

3. Have you talked with your doctor about advanced care planning?

- Yes
- No (Please skip to question # 6)

4. If yes, who initiated the conversation?

- Doctor
- Nurse
- Spouse/Partner/Family Member
- I started the conversation

5. How long did the conversation about advanced directives last?
- Less than 5 minutes
 - 5-10 minutes
 - 10-15 minutes
 - More than 15 minutes
6. What type of provider do you usually see in your primary care office?
- Medical Doctor (MD)
 - Doctor of Osteopathy (DO)
 - Nurse Practitioner/Advanced Practice Nurse (NP/APN)
 - None of the above
 - Unsure

The following are for classification purposes only and will be kept entirely confidential.

7. In general, how would you rate your own health right now?
- Excellent health
 - Very good health
 - Good health
 - Fair health
 - Poor health
8. Do you have a serious chronic illness?
- Yes
 - No

9. Are you...

- Male
- Female

10. What was your age on your last birthday? _____ (in years)

- 50-59
- 60-74
- 75 or older

11. What is your current marital status?

- Single, never married
- Married
- Living with a partner
- Separated
- Divorced
- Widowed

12. Which one or more of the following would you say is your race? (Check

ALL that apply)

- White
- Black or African American
- Asian
- American Indian or Alaskan Native
- Hispanic or Latino
- Other

APPENDIX D
REQUEST FOR PERMISSION LETTER

Kristen Courteau <kristen.courteau@gmail.com> 2/17/13

to rcummins

My name is Kristen Lott and I am a graduate student at the University of Nevada Reno in the Orvis School of Nursing. I found the AARP North Carolina End-of-Life Care Survey in my literature search and would like to use the survey in my own research on the attitudes of Nevada seniors regarding end of life care. I was wondering how I get a copy of the survey. Also, can I modify the survey or shorten it a little bit to serve my research? Finally, are there any articles besides the AARP North Carolina End-of-Life Care Survey that use this tool to research that you know of?

Thank you so much for your consideration.

Kristen Lott, RN, BSN

Cummins, Rachelle L. <RCummins@aarp.org> 2/27/13

to me, wctung

This is fine. The only request is that you cite AARP properly. You may use the instrument as you see fit for your own design. The other AARP research using this/similar survey was completed for Massachusetts and was authored by Erica L Dinger.

Rachelle L. Cummins
Research Director
AARP Research & Strategic Analysis
State Research
rcummins@AARP.org
www.AARP.org/research
[202-434-6297](tel:202-434-6297)
601 E Street, NW, B7-306
Washington, DC 20049

APPENDIX E

EXAMPLE SURVEY PARTICIPATION OPPORTUNITY FLYER

Survey Participation Opportunity
**Effect of Age, Gender and Health on Older Adult
Advanced Care Planning Discussions**



University of Nevada, Reno

The purpose of this survey is measure advanced directive completion rates in people over 50 living in the Reno area and to investigate if primary care providers are talking to their patients about advanced directives. This information will be used to better understand how to serve our community as it grows older.

If interested please see Kristen Lott on the main level
by the offices on the following dates from 11am-

1pm:

Tuesday, November 19th

Thursday, November 21st

Tuesday, November 26th

Wednesday, December 4th

Monday, December 9th