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# A Retrospective Study Describing Documentation of Advance Care Planning in a Long Term Care Setting

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A Retrospective Study Describing Documentation of  
Advance Care Planning in a  
Long Term Care Setting

A thesis submitted in partial fulfillment  
Of the requirements for the degree of  
Master of Science in Nursing

By

Nathan J. Linder

B.S.N. Cedarville University, 2010

2013

Cedarville University

## **Abstract**

**Problem:** Increased life expectancy and aging baby boomers will increase the population of those 65 years of age and older to nearly 20% of the United States population by 2030. It is estimated that 40-70% of this population will need long term care during their lifetime, and by 2020, 40% of patients in long term care will die there. As patients age, advance care planning (ACP) and advance directives (AD) should be completed to make their wishes known to healthcare providers and family. Despite legal requirements for completion at entry to healthcare settings, less than 95% of hospitalized patients and 50% of long term care patients have an AD or ACP.

**Significance:** Advance care planning increases patients' quality of life, may decrease stress and ease decision making at end of life for patients and families. There is little research on the completion levels of ACP in long term care.

**Purpose:** The primary purpose of this retrospective study is to describe the level of ACP documentation in a long term care setting. A secondary purpose is to describe potential relationships between demographic, past medical history (PMH) and ACP variables

**Design:** Retrospective descriptive chart review

**Results:** More than 76% of patients at the facility were over the age of 65. Less than 43% of patients had an AD listed in their chart, and less than 31% of patients had an AD completed prior to admission at the long term care facility. At admission to the facility, only 7 of 29 (12.7%) patients that came from the hospital had an AD or ACP documented. Seven patients at the facility were listed as Hospice patients, and only three of seven (42.8%) had ACP documented. Only 33% of patients had an ACP meeting at the facility listed in their chart. Of ACP meetings that occurred, there was a high level of patient and family involvement in end of life decision making. A correlation was found

between Alzheimer's disease and ACP completion, as well as Medicaid insurance and ACP completion.

*Keywords: Long Term Care, Advance Directive, Advance Care Planning, Nursing Home, Geriatrics, End of Life, Quality of Life, Hospice*

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## Chapter 1

### Introduction

The baby boomer population in America is rapidly aging and comprises around 78 million people (CDC, 2009). Over the last 70 years the life expectancy for Americans has increased from an average of 60 years to nearly 79 years (U.S. Social Security Administration, 2013). This increased life expectancy can be attributed to the advent of antibiotics, medical technologies, Cardio-Pulmonary Resuscitation (CPR), mechanical ventilation, improved disease management, public health initiatives, and improved sanitation standards (Van Leuven, 2012; U.S Department of Health and Human Services, 2008). As Americans grow older, many are challenged with an increased chronic disease burden (Van Leuven, 2012; U.S DHHS, 2008). An increased chronic disease burden and continued normal aging changes can result in decreased functional ability and independence. Currently, those that are 65 years and older have a 40-70% chance of needing a long term care (LTC) facility during their remaining years (U.S. DHHS, 2013a; Medicare, 2012). Long term care facilities exist to support those who are unable to be independent through providing appropriate care that seeks to maintain quality of life (QoL) (Medicare, 2012). The promotion of QoL through the delivery of appropriate care is the purpose of Advance Care Planning (ACP). Advance Care Planning is an essential aspect of care for promoting QoL in LTC residents.

Advance care planning is the discussion and documentation of the discussion between the individual, significant other, family, clinician and other healthcare providers to determine the individual's knowledge of his or her disease process, wishes for care at end of life, and a decision maker to act on behalf of the individual if he or she loses the capacity to make decisions on his or her own (Colville & Kennedy, 2012; Chrash, Mulich

& Patton, 2011; Jones, Moss & Harris-Kojetin, 2011; Jeong, Higgins, & McMillan 2009; Henry et al, 2008; U.S. DHHS, 2008). It also serves to provide the individual with autonomous decision making, the right to self determination, and enabling an individual to communicate his or her healthcare decisions with loved ones going forward towards end of life (Blackford, Strickland & Morris, 2007).

End of life (EoL) is not well defined but includes the diagnosis of a terminal disease and the days, weeks or months leading up to an individual's death (NIH, 2004). Oxford Handbook of Palliative Care (Watson, 2005) defines EoL as the last part of a person's life where it is clear there is a progressive state of decline. When EoL is near, advance care planning can make the individual's preferences for care known to loved ones and healthcare staff, potentially making the last days less stressful.

Advance care planning should occur before a health crisis arises when the individual is of sound mind in order to prevent the individual from not being able to communicate his or her wishes (Chan & Pang, 2010). The primary care setting is the ideal setting for ACP to take place because primary care providers have better understanding of the individual's conditions, his or her desires and wishes for care, have established a trusting relationship with the individual, have the opportunity to talk on multiple occasions, and the primary care setting is a peaceful care setting compared to an acute health crisis visit to a hospital (Kahana, Dan, Kahana & Kercher, 2004; Maxfield, Pohl & Colling, 2003). Research has demonstrated that ACP discussions lower stress and anxiety, and that providers and family members better understand individual's desires for care (National Cancer Institute, 2013; Colville & Kennedy, 2012; Chrash et al, 2011; Jeong et al, 2010; Blackford et al, 2007; Kass-Bartlemes & Hughes 2003).

Despite the legal requirements for healthcare facilities, the Agency for Healthcare Research and Quality (AHRQ) reports fewer than 50% of severely or terminally ill individuals have any kind of Advance Directive (AD) or ACP documented in their charts (Chrash et al, 2011; Kass-Bartlemes & Hughes, 2003). Salmond and David (2005) found that 95% of hospitalized patients had not discussed EoL issues. There has been little to no research conducted on the level of ACP and AD completion and meetings in long term care to date.

The primary purpose of this retrospective study is to describe the level of ACP documentation in a long term care setting. A secondary purpose is to describe potential relationships between demographic, PMH and ACP variables.

## Chapter 2

### Review of Literature

It is estimated that by 2030, nearly 20% of the population of the United States will be over the age of 65 (Vincent & Velkoff, 2010). These individuals have an increased life expectancy for many reasons including advances in healthcare and increased responsibility for self care (Van Leuven, 2012; Administration on Aging, 2011; U.S. DHHS, 2008). Additionally, 63% of individuals 65 years of age and older report receiving the influenza vaccine, 59% report receiving the pneumococcal vaccine and around 30% report engaging in regular physical activity (AoA, 2011). Fewer individuals 65 years of age and older report smoking or excessive alcohol use, and up to 97% of individuals report seeing the same healthcare provider regularly (AoA, 2011). As a result of these medical advancements and self care behaviors, individuals can expect to increase their life expectancies.

As a result of their increased life expectancies, the likelihood of developing multiple chronic diseases increases with age. Between 2009 and 2010, 45% of adults aged 65 years and older had been diagnosed with at least two chronic conditions (Freid, Bernstein & Bush, 2012). These chronic conditions can lead to disability, including functional and cognitive decline (AoA, 2011). The most common debilitating chronic conditions cited in persons 65 and older are heart disease (28.2%), cancer (22.2%), respiratory diseases (8.8%), cerebrovascular diseases (6.6%), Alzheimer's/dementia (4.2%), diabetes (2.9%), and other causes and comorbidities combined (24.9%) (CDC, 2011a). These conditions often create a need to transition living arrangements to a LTC facility.

**Long term care facilities.** Long term care facilities are for individuals whose healthcare and personal needs exceed what can be provided at home, but individuals whose healthcare and personal needs no longer require hospital care. Long term care facilities assist individuals in meeting various health and personal care needs (U.S. DHHS, 2013b; Medicare, 2012). Long term care facilities provide services ranging from assisted living, where individuals receive assistance with activities of daily living (ADLs) including dressing, medication administration, bathing or going to the bathroom, to skilled nursing, where individuals receive assistance with wound care management, rehabilitation, or dementia care (Assisted Living Federation of America, 2011; Medicare 2013).

Over the past few decades, the population of individuals utilizing LTC facilities has increased. In 2008, 21 million individuals utilized a LTC facility for temporary or permanent residence, and it is estimated that by 2013 20% (nearly 8.5 million) of individuals 65 years of age and older would require the services of a LTC facility (U.S. DHHS, 2013c; U.S. DHHS, 2013d). Most admissions to LTC facilities are for temporary therapies. However, the National Nursing Home Survey (2009) found that there were nearly 1.5 million individuals permanently residing in LTC facilities, of which 1.3 million individuals were 65 years of age or older. It is estimated that by 2020, 40% of individuals 65 years of age and older residing in LTC facilities will die there (Benz, 2012). Although the majority of individuals utilizing LTC are considered temporary residents, a large number are dying while in LTC facilities. Therefore, LTC facilities should regularly assess the provision of care and the promotion of QoL.

**Quality of life.** Quality of life is difficult to define because it is based on preferences and subjective factors that are important to each individual. Quality of life is

improved when individuals are involved in their plans of care and can choose their treatments. In assessing QoL, it is important to assess for overall life satisfaction, what is important, what future accomplishments are desired, individual values, religious preferences, perceived levels of health, levels of independence and function, social interactions and outlooks on life (Pike, Evangelista, Doering, Eastwood, Lewis & Child, 2012; CDC, 2011b; EPERC, 2006; WHO, 1997). More specifically, health related quality of life (HRQoL) considers physical health, psychological well-being, and views on current health status and leading a fulfilling life (Pike et al, 2012; Kamphuis et al, 2002; Bowling, 1999). Quality of life in LTC includes the emotional and physical health, functional status, comfort and security, social function, and self-worth of the individual (Sloane et al, 2005; Kane et al, 2003; NIH, 2002). Adler & McKinley (2006) conducted a survey of nursing home residents and found four categories that contribute to QoL: caring and showing concern for others, spiritual health, making environments familiar and similar to home, and providing privacy. Long term care facilities can provide appropriate care by promoting all aspects of QoL including emotional and physical health care, increased functional abilities, providing comfort, security, a familiar environment, social interaction, religious consideration, respect, dignity and the ability to make decisions for care.

**Advance directives.** A first step in determining patient wishes is the completion of an Advance Directive (AD). The Patient Self Determination Act (PSDA) of 1991 requires LTC facilities, hospitals, and home health care services to assess on admission if individuals have an AD in place and a designated person to make decisions on the individual's behalf if he or she becomes incapacitated (Van Leuven, 2012; Jones, Moss & Harris-Kojetin, 2011). The Joint Commission requires LTC facilities and hospitals to

determine if an individual has an AD, and if not, provide resources to complete them (Van Leuven, 2012; Chrash et al, 2011; Joint Commission, 2009). Advance directives are the documents that pre-state an individual's wishes for care in the event he or she is unable to express his or her wishes. Some of the most common components of ADs are a living will and a health care power of attorney. Living wills communicate the individual's wishes when he/she cannot make or express those decisions in a terminally ill case, and a health care power of attorney is someone appointed by the individual trusted to carry out the individual's wishes if he/she become incapacitated (National Cancer Institute, 2013). The appointed health care power of attorney is only allowed to make healthcare related decisions. These documents result from ACP discussions and outline the individual's wishes at the end of life, and communicate the care he or she receives or wishes to refuse (Caring Connections, 2013; Chrash et al, 2011; Chan & Pang, 2010). Advance Care Planning is more than formulating AD documents: it is a process to provide appropriate care and involve individuals in their plan of care. The healthcare system has become complicated and offers many different innovations and life sustaining treatment options. Long term care facilities strive to provide continuity of care and a stable environment for individuals, making LTC facilities a setting for ACP discussions (Chan & Pang, 2010).

Despite the legal requirements for healthcare facilities, the AHRQ reports fewer than 50% of severely or terminally ill individuals have any kind of AD or ACP documented in their charts (Chrash et al, 2011; Kass-Bartlemes & Hughes, 2003). Salmond and David (2005) found that 95% of hospitalized patients had not discussed EoL issues. In 2009, 27% of deaths in people age 65 years and older occurred in a LTC facility, and it is estimated by 2020 that 40% of deaths in the United States will occur in LTC facilities (Federal Interagency Forum on Aging-Related Statistics, 2012; Benz,

2012). With increased numbers of individuals over the age of 65 dying in LTC facilities, it is important to promote effective ACP to provide the best QoL for individuals in their remaining years.

**Advance care planning.** Advance care planning is defined as the discussion and documentation of the discussion between the individual, significant other, family, clinician and other specialty providers to determine the individual's knowledge of his or her disease process, desires for care at end of life, and a decision maker to act on behalf of the individual if he or she loses the capacity to make decisions on his or her own (Colville & Kennedy, 2012; Chrash, Mulich & Patton, 2011; Jones, Moss & Harris-Kojetin, 2011; Jeong, Higgins, & McMillan 2009; Henry et al, 2008; U.S. DHHS, 2008). Also, advance care planning helps respect and promote autonomy, right to self determination, and enables individuals to communicate their decisions for healthcare in the present and the future (Blackford, Strickland & Morris, 2007). Advance care planning makes an individual's care preferences known, respects his or her desires and autonomy, and should occur before a health crisis arises, potentially inhibiting the individual from being able to communicate his or her wishes (Chan & Pang, 2010). The primary care setting is the ideal setting for ACP to take place because primary care providers have better understanding of the individual's conditions, his or her desires for care, have greater rapport in making these decisions, and is not a stressful care setting such as during an admission to a hospital (Kahana, Dan, Kahana & Kercher, 2004; Maxfield, Pohl & Colling, 2003).

Advance care planning is an ongoing process of meetings that should take place at initial disease diagnosis and continue until the individual is no longer able to participate in his or her decision planning (Colville & Kennedy, 2012; Jones, et al, 2011; Jeong,

Higgins & McMillan, 2010; Henry, Seymour & Ryder, 2008). Advance care planning strives to link across care settings, from primary care to the LTC facility. Advance care planning is not about withholding treatment or pain and symptom management; the goal is to make the individual's wishes for care known and help he or she define what care he or she wants (Chan & Pang, 2010; Jeong et al, 2010). The ACP conversation is intended to improve QoL by fostering a relationship for honoring wishes and preventing unwanted medical interventions and hospitalizations.

The benefits of ACP include promotion of patient autonomy, increased QoL, and improved communication for those involved in the plan of care. At the initiation of ACP discussions, strong emotions and stress may arise between the individual, family members and healthcare providers (Goldman, 2011; Chan & Pang, 2010; Jeong et al, 2010). However, in the long run, ACP decreases conflict, burden of decision making, and stress among those involved.

Research has demonstrated that ACP discussions lower stress and anxiety and healthcare providers and family members better understand the individual's wishes because decisions for care have already been established (National Cancer Institute, 2013; Colville & Kennedy, 2012; Chrash et al, 2011; Jeong et al, 2010; Blackford et al, 2007; Kass-Bartlemes & Hughes 2003). Advance care planning is important to make known that unwanted care is not administered or that care is not withheld that the individual may have desired (Jeong, et al, 2010; Blackford et al, 2007). Through ACP, an individual can be content in knowing that his or her wishes are documented and the plan of care will be carried out if the individual is unable to verbalize his or her choices.

The need for ACP was illustrated in the case of Terri Schiavo during the 1990's and early 2000's. In this case the debate was over who had guardianship of Terri and the

legal authority to make terminal medical decisions between her husband and parents.

Terri's husband argued that her wishes were to never remain in a vegetative state with no hope for recovery, and Terri's parent's argued that she would want to be kept alive (Soylent Communications, 2012; CNN Justice, 2005). If Terri had completed an AD and included her husband and parents in the ACP process, many years of emotional, physical and psychological trauma may have been avoided (Soylent Communications, 2012; CNN Justice, 2005).

Advance care planning discussions are improved when the individual has an established, trusting relationship with primary care providers, and a good understanding about his or her disease process and prognosis (Blackford et al, 2007). Advance care planning discussions should include a discussion of values, religion, goals of care, and an opportunity for the individual to express concerns (Blackford et al, 2007). Advance care planning discussions should also include what types of treatment the individual desires, ranging from feeding tubes, mechanical ventilation, CPR, dialysis, hospitalization, or antibiotic therapy (Van Leuven, 2012; Jones et al, 2011; Jeong et al, 2009; Blackford et al, 2007). It is beneficial to include in the ACP discussion professionals from various disciplines to offer advice in their specific area of expertise to better guide the ACP decisions. It is important to readdress the ACP and AD documents every time an individual makes a facility change or has a change in condition to keep abreast of his or her wishes, to comply with the PSDA of 1991, and to comply with the Joint Commission requirements for accreditation (Colville & Kennedy, 2012; Van Leuven, 2012; Jeong et al, 2010; Joint Commission, 2009; Blackford et al, 2007). Documentation of ACP should be noted in the chart in addition to the AD that results, to demonstrate these discussions occurred and the wishes for care were made known by the individual (Blackford, 2007).

Copies of the ACP and AD should be given to family members involved in the individual's care (Jeong et al, 2010; Blackford, 2007). In addition, these ACP documents should be communicated across facilities and various care providers involved.

The growing population of individuals 65 years of age and older are developing chronic diseases that often end with a transition to a LTC facility. In providing appropriate care and promoting QoL, LTC facilities should initiate and regularly engage individuals and their families in ACP. Research clearly identifies who should be included in ACP meetings, what should be discussed, how often meetings should be conducted, legislative requirements for LTC facilities to assess for AD and ACP and that ACP is more than an AD or code status in a chart. However, a review of the literature has not demonstrated research that has focused on the documentation of these conversations in long term care. Therefore, the purpose of this retrospective study was to describe the level of ACP documentation in a long term care setting. A secondary purpose was to describe potential relationships between demographic, PMH and ACP variables.

### **Theoretical Framework**

An environment for effective ACP is necessary, so that the care a patient desires is the care received. Caring for patients means showing compassion and support as well as meeting their physical, emotional, spiritual and psychological needs (Finkelman & Kenner, 2013; Ranheim, Kärner, Arman, Rehnsfeldt, & Berterö, 2010). The action of caring is central to the provision of healthcare and promotes QoL, establishes rapport, and encourages active participation in the plan of care (Finkelman & Kenner, 2013).

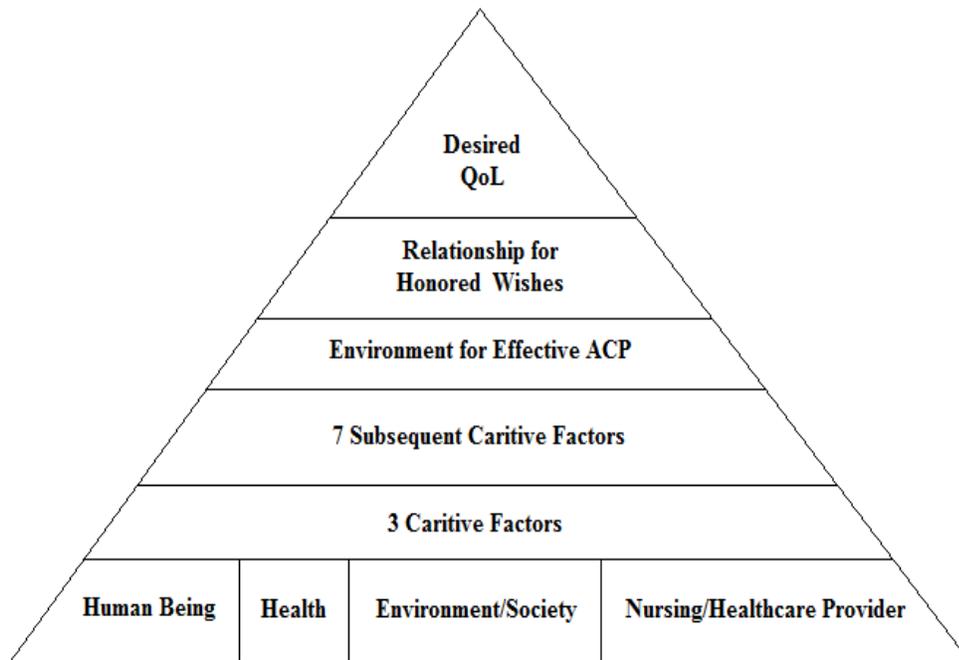
Dr. Jean Watson first authored her Philosophy and Theory of Transpersonal Caring for nursing in 1979 (Watson, 1979). Watson's theory is based on the caring factors of nursing compared to the curing factors of medicine (Butts & Rich, 2011). Four

major themes are present in her theory: human being, health, environment/society, and nursing (Current Nursing, 2012). These four themes shape Watson's definition of caring and how to provide a holistic caring intervention.

Watson's definition of caring is based on her first three principals of her ten caritative factors (CF): altruism (CF 1), encourage faith and hope (CF 2), and being sensitive to self and those being cared for (CF 3) (Current Nursing, 2012; Butts & Rich, 2011; Watson Caring Science Institute, nd; Watson, 1985). The next seven factors stem from the first three: development of helping – trusting – caring – relationships (CF 4); acceptance of positive and negative feelings (CF 5); scientific problem solving for caring decision making (CF 6); teaching and learning that is appropriate to needs (CF 7); fostering a healing environment for physical, emotional and spiritual needs (CF 8); assist with basic physical, emotional and spiritual needs (CF 9); and allowing mystery and miracles to happen (CF 10). Many of these caritative factors can be linked to the promotion of ACP for the individual's benefit.

Advance care planning is not about promoting the clinician or facility; rather, the impetus for these discussions is the promotion of the individual and his or her plan of care wishes for that time when unable to communicate (CF 1). Effective ACP helps promote autonomy, involvement in the plan of care and QoL in the individual by honoring his or her values and wishes, meeting his or her religious needs, and involving those loved ones in the plan of care (CF 2, CF 9). Advance care planning involves respecting the individual's religious beliefs and values in creating a plan of care for end of life (CF 3, CF 9). Advance care planning helps develop a trust between clinicians, nurses, the individual, and significant loved ones by nurturing conversations to talk about appropriate plan of care and desired wishes in the event of incapacitation (CF 4).

Advance care planning takes into consideration the individual's thoughts and feelings on the plan of care, noting that it is ok to refuse care he or she does not wish to receive (such as CPR, dialysis, mechanical ventilation, feeding tubes or hospitalizations) or include care to promote QoL (CF 5). It also helps foster an environment to discuss emotional topics about end of life (CF 5, CF 9). Advance care planning helps promote understanding of plan of care, disease process, his or her specific prognosis and wishes to better shape decision making ability of the individual (CF 6, CF 7). One of the main goals of ACP is to promote discussion of the desired plan of care that honors and respects the dignity of the individual when treatment occurs (CF 1, CF 8). The foundation of caring is meeting basic needs, and effective ACP helps promote which actions are essential in promoting QoL and planning for end of life wishes (CF 9). Religious preferences and considerations are a part of appropriate caring, and effective ACP allows for the religious beliefs of the person to help guide plan of care (CF 3, CF 9). Watson's caritive factors provide a firm theoretical basis for this study because in effective ACP, appropriate care is achieved. The figure below illustrates Watson's Philosophy and Theory of Transpersonal Caring for nursing as found in the context of effective ACP.



Watson described the human as a “valued person ... to be cared for, respected, nurtured, understood, and assisted” (Watson, 1985). Additionally, humans have intrinsic value as they are uniquely created in the image of God. Humans have five interrelated dimensions: physical, intellectual, emotional, spiritual and social. Appropriate care includes acknowledging and treating all of these dimensions.

Health is a dynamic state that reflects one’s ability to alter demands and manage resources to achieve balance within and across the five dimensions. The World Health Organization (WHO, 1948) defines health as “a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity.” Merriam-Webster (2013) defines health as the condition of the spirit, mind, and body, and the general physical condition of the body. Health is the overall assessment of physical, mental and

social well-being, the ability to complete daily living, and the absence of illnesses; caring is exhibited by the culture of the profession (Current Nursing, 2012).

Environment is the context in which the caring activity occurs. It is defined as the shared set of values, beliefs, norms, role expectations and social structures that produces a patterned, common way of life. For the present study the environment is a LTC facility. The LTC facility is where individuals can go when they no longer can care for themselves or need healthcare interventions after an acute hospital admission. This environment is a structured one: meals, rehabilitation appointments, medication administration, wound care, social activities, outings, and other actions occur at specific times.

Healthcare is an intellectual, interactive, caring process, the goal of which is to assist individuals, families and communities in attaining, maintaining and regaining health. Nurses work in healthcare to enhance resources and alter demands by promoting a healthful balance within and across the five dimensions. "The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or peaceful death) that he would perform unaided if he had the necessary strength, will, or knowledge" (Henderson, 1966, p. 15). To that end, nurses employ a systematic problem-solving approach in providing client-centered care. The scope of nursing includes, but is not limited to, education, administration, clinical practice and research. Nursing is more than caring for illness: it is the promotion of health, prevention of illness, and restoring health status all while providing holistic care that reaches all aspects of a person (Current Nursing, 2012).

Watson's definition of caring is based on her 10 Caritive Factors: altruism (CF 1), encourage faith and hope (CF 2), and being sensitive to self and those being cared for

(CF 3); development of helping – trusting – caring – relationships (CF 4); acceptance of positive and negative feelings (CF 5); scientific problem solving for caring decision making (CF 6); teaching and learning that is appropriate to needs (CF 7); fostering a healing environment for physical, emotional and spiritual needs (CF 8); assist with basic physical, emotional and spiritual needs (CF 9); and allowing mystery and miracles to happen (CF 10) (Watson, 1985).

Effective ACP is the level of discussion and documentation between the individual, family, significant other, clinician and other specialties to determine the individual's wishes for care at end of life (Colville & Kennedy, 2012; Chrash, Mulich & Patton, 2011; Jones, Moss & Harris-Kojetin, 2011; Jeong, Higgins, & McMillan 2009; Henry et al, 2008; U.S. DHHS, 2008). Advance care planning strives to increase the individual's autonomy, self determination, and QoL, while decreasing incidence of unwanted care, negative emotions and stress among family, especially during end of life. Through effective ACP, and individual's wishes are taken into consideration.

An individual's wishes are honored when the plan that he or she put forth is implemented in the event the individual is no longer able to make decisions on his or her own accord. The wishes stem from effective ACP discussion and a review of what is important to the individual in relation to care, religious preferences, cultural practices, and personal preferences. Implementing a plan of care in accordance to the individual's wishes maximizes QoL. Quality of life includes those things an individual perceives to be important and is maximized when an individual is active in his or her plan of care (Pike et al, 2012; CDC, 2011b; EPERC, 2006; WHO, 1997).

## **Chapter 3**

### **Methods**

#### **Research design**

A retrospective descriptive study was conducted. The medical charts of temporary and permanent residents in a long term care facility were reviewed to assess for the presence and extent of prior and current ACP documentation.

#### **Setting**

The setting was a Long Term Care facility in the Midwest with approximately 55 residents.

#### **Participants**

Inclusion criteria for this study were the following: temporary or permanent resident of the LTC facility and being either male or female. All races and ethnicities were included. If a resident at the LTC facility was a minor, the respective chart was excluded.

#### **Data collection**

Data collection commenced in early July, 2013, and included a review of all the charts of current residents at the LTC facility. The charts were assessed for inclusion criteria. Then, if the inclusion criteria were met, information was collected from the chart using the data collection tools (see Appendix A and B). For this study, data was collected without patient identifiers and kept secured and confidential.

#### **Data analysis**

The sample was characterized by using descriptive statistics (means, standard deviations, frequencies, and percentages) for demographic and clinical data. Descriptive statistics were also used to analyze ACP documentation.

**Ethical considerations**

Before data collection began, IRB approval was obtained from Cedarville University and institutional approval for this study was granted by the LTC facility.

## Chapter 4

### Results

The results of this research study were obtained so as to mitigate the loss of participants through being discharged by the facility, either by resident passage, transfers to higher or lower levels of care or discharge to home. A patient census list was created on the initial day of data collection, and only patients present at the LTC facility on the census at that time were included in the chart audit if the inclusion criteria were met.

Data was analyzed using SPSS version 21.0 (IBM Corporation, 2012).

### Sample Characteristics

Data was obtained from 55 patient charts at the LTC facility. No patient charts were excluded from this study. Demographic data collection included age, gender, race, PMH, type of insurance, length of stay (LOS), and the individual's prior place of residence before admission to the LTC facility. Appendix A contains the demographic data collection tool.

Collected data was analyzed and demonstrated that the majority of the residents were aged 75 years and older (76.4%), Caucasian (89.1%) and female (72.7%). The mean age for the sample was 79.5 years old, and the standard deviation was 12.3. There was a high report of heart disease (80.0%), Alzheimer's/dementia (49.1%), diabetes (40.0%), and cerebrovascular disease (40.0%) in the sample. Additionally, 94.5% of the sample had other disease comorbidities that did not fall into the most common disease categories listed. Forty nine patients (89.1%) were Caucasian, four patients (7.3%) were African American, and one patient (1.8%) was Asian. One patient chart (1.8%) did not document his or her race.

Medicare Part A and Part B were the two most commonly reported insurance types (70.9% and 61.8% respectively), followed by Medicaid (54.5%) and Private insurance (23.6%). Six patients (10.9%) had a LOS of 0-30 days, five patients (9.1%) had a LOS of 31-90 days, 7 patients (12.7%) had a LOS of 91-180 days, 5 patients (9.1%) had a LOS of 181-365 days, and 31 patients (58.2%) had a LOS equal to or greater than 366 days. The mean LOS was more than four years, with a standard deviation of 6.29 years.

More than half of the sample (29 patients, 52.7%) were admitted to the LTC facility after an acute admission to the hospital, eight patients (14.5%) were admitted from home, 14 patients (25.5%) were from other medical facilities such as other nursing homes, county homes, inpatient rehabs, inpatient hospice, foster/group homes, home with home health, or assisted living facilities. The remaining four patients (7.3%) did not have a prior location to admission at the LTC facility listed on their charts.

### **ACP Results**

Advance Care Planning data collection included documentation and type of patient code status, involvement of hospice, next of kin or HCPoA identified in the chart, presence of an AD and type or types of AD listed, prior ACP documentation as required by the PSDA and accreditation through the Joint Commission, documentation of a family planning meeting and the elements contained in the meeting, wishes for EoL, individuals and health professionals present at the meeting, and the religious preference of the individual. Appendix B contains the ACP data collection tool. Data was analyzed in SPSS using means, standard deviations, frequencies, and percentages. See Tables 2-7 for a complete list of Advance Care Planning Data.

Data from Table 2 shows that 53 patients (96.4%) patients had a code status listed in their charts, of which 33 patients (60%) were DNRCC, 10 patients (18.2%) were Full Code, nine patients (16.4%) were DNRCCA, one patient (1.8%) was DNR, and two patients (3.6%) did not have a code status documented in their charts. Seven patients were listed as patients under Hospice services. Forty seven patients (85.5%) had a Next of Kin identified in their chart in case of emergency, and 46 patients (83.6%) had a HCPOA identified in the event of the patient no longer being able to make medical decisions for themselves.

Table 3 shows data about patient's Advance Directives completion. Less than half (43.6%) of the patients had a completed AD documented in their chart. Table 3 outlines the types of orders, such as living will, EoL wishes, DNR order and HCPOA, found on the completed ADs. Only 17 patients (30.9%) of patients had completed an AD prior to admission to the LTC facility.

Table 4 describes ACP meetings at the LTC facility. Eighteen patients (32.7%) had a documented ACP meeting while at the LTC facility. The characteristics detail what was discussed in the ACP meeting, and the involvement of the patient in the ACP meeting. Patient preferences for EOL that were outlined in the ACP meeting are listed in the table. Often it was documented in the patient charts that a meeting had occurred, but the documentation did not identify the specific goals or outcomes of care as a result of the ACP meeting. Of the 18 ACP meetings that were documented, patients were in attendance for 13 meetings, a clinician was present for 12 meetings, family was in attendance for 14 meetings, and social work was present for 14 meetings.

Table 5 compares Prior ACP Completion to Prior Location of patient before admission to the LTC facility. At the time of the study, 22 patients (40%) did not have

prior ACP documents after being discharged from a hospital, compared to only seven patients (12.7%) with prior completed ACP documents after being discharged from a hospital. Admission from other types of facilities showed equal rates of completion and non-completion at seven cases each. Four patients did not have any prior location listed, or prior ACP completed.

The second aim of the study was to describe potential relationships between demographic, PMH and ACP variables. A correlation matrix can be found in Tables 6 and 7. In Table 6, a positive, weak, significant correlation ( $r = 0.374$ ) was reported between prior ACP and Medicaid recipients. Other significant correlations were found between other insurance types and demographic data, but no other correlations between demographic data and prior ACP documentation were found. In Table 7, a positive, weak, significant correlation ( $r = 0.288$ ) was reported between prior ACP and Alzheimer's/dementia, but no other PMH diagnoses. Of the seven hospice patients, only three (42.8%) had completed AD outlining their wishes.

## Chapter 5

### Discussion

As the population ages, more individuals will utilize the LTC facility for rehabilitation purposes after hospitalizations, therapy, or long term residence. Having discussions for ACP can benefit all parties involved and make the last days less stressful and emotional, knowing that the individual's preferences were honored. Federal law and accreditation bodies mandate that AD and ACP be offered to patients upon admission to a healthcare facility if they have not already completed an AD or ACP document.

This study sample was a predominately Caucasian, female sample, which is representative of the larger geriatric female population found within the U.S. Nationally in 2011, females older than 65 comprised nearly 22.1 million people (14.2% of the general population) compared to nearly 17.1 million males (11.3% of the general population) (U.S. Census Bureau, 2011). Past medical history data was moderately consistent with the top chronic diseases in those over 65 years old (CDC, 2011a). The most common chronic conditions identified in this sample were heart disease (80%), Alzheimer's/dementia (49.1%), diabetes and cerebrovascular diseases (40% each), and respiratory diseases (34.5%). Cancer diagnoses were low (9.1%) and not consistent with national averages. Diagnoses included in the other PMH category include osteoarthritis, GERD, falls, hyperlipidemia, dysphagia and fractures.

Nearly 60% of patients had been at the LTC facility for more than a year. However, less than 50% of patients had ADs completed, nearly 70% of patients did not have ACP/AD present on admission to the facility, and less than 33% had a documented ACP meeting. These completion results are low, similarly to what Chrash and colleagues (2011) and Kass-Bartlemes and colleagues (2003) found in terminally ill patients' AD

completion rates. Salmond and David (2005) found that 95% of hospitalized patients in their study had not completed AD or ACP, which could explain why ACP completion rates in LTC patients discharged from the hospital in this study is low at 24%. This was a concerning finding, because the majority of patients came from another medical facility prior to admission at the LTC facility. By law, and for accreditation purposes, AD and ACP should occur at admission to a healthcare facility. Admission to this LTC facility was at least the second healthcare point of entry, so completion rates of AD and ACP should be higher. However, this was not the case. The present study did not reveal an association between prior place (healthcare facility) and completion of ACP.

Blackford and colleagues (2007) stated that the ACP meeting should have active patient involvement (if capable), and contain a discussion of patient values, concerns, goals for care, and wishes for end of life. In the present study, 18 ACP meetings were documented, and were found to have discussed patient goals for care in 17 of the meetings (94.4%). Wishes for EoL care were documented in seven of the meetings (38.9%). Engagement of the patient in the meeting, patient autonomy, values and concerns expressed by the patient were documented less than 28% of the time. Van Leuven (2012), Jones and colleagues (2011), Jeong and colleagues (2009), and Blackford and colleagues (2007) stated that ACP meetings should include what kind of treatment the patient wants at EoL. Of the 18 patients in the present study with documented ACP meetings, only seven patients (12.7%) had documented EoL wishes in the ACP meeting. The aforementioned researchers also write that it is beneficial for other healthcare professionals to be at the ACP meetings to offer a holistic plan of care and their respective professional expertise. This study found that patients were present in 13 of 18 meetings, family members were present in 14 meetings, a social worker was present in 14

meetings, clinicians were present in 12 meetings, nursing staff was present in three meetings, and dietary and hospice were present at two meetings each. Patient attendance at the meetings was high, at nearly 75% (n=13). Social work and family attendance was high at nearly 78% (n=14). Overall involvement of various disciplines, patients and family was high in the 18 ACP meetings that were documented.

Hirschman, Corcoran, Straton, & Kapo (2010) found in their study of 165 hospice patients, nearly 65.5% had an AD. In this present study, only seven patients were receiving hospice care. Of these patients, only three (42.8%) had AD listed in their charts. These results could be because of a small hospice patient sample size, or could be because hospice employees have more complete records than what is noted in the LTC facility chart and therefore could not be gleaned from a LTC facility chart review. Regardless, hospice patient completion of ADs was anticipated to be higher due to the nature of expert ACP by hospice care.

There is little research that looks at completion rates of AD or ACP and those with Alzheimer's disease. Garand, Dew, Lingler and Dekosky (2011) studied patients that had Alzheimer's and no AD or ACP in place at initial evaluation and followed them for a period of time, monitoring their completion rates. At the end of five years, 39% of their sample had completed an advance directive. The present study found a positive, weak but significant correlation between completed ACP and Alzheimer's/Dementia diagnoses ( $r = 0.288$ ). Alzheimer's/dementia diagnoses were the second most prevalent (49.1%) behind heart disease (80%), but the only diagnosis with a significant correlation to ACP.

No literature was found that discussed ACP/AD completion as correlated to Medicaid patients. The present study found a positive, weak, but significant correlation

( $r = 0.374$ ) between Medicaid patients and Prior ACP. Thirty (nearly 55%) patients had Medicaid coverage. Half of Medicaid patients had prior ACP completed, compared with 13 out of 39 (33.3%) of Medicare part A covered patients.

**Strengths.** One of the strengths of the present study was finding an area of documentation that is not consistently being completed. This study also offered insight into a gap in literature on the documentation of ACP meetings. Another strength of this study is the high percentage of patients, families and healthcare professionals present in the ACP meetings that were documented. There were positive, weak correlations found between prior ACP and Dementia/Alzheimer's diagnoses and Medicaid patients. An additional strength is that the results also have implications for the healthcare providers and the individuals that are consumers of healthcare services to raise awareness of ACP and ACP meeting documentation, and the importance of planning for the future. A final strength was finding data that was consistent with other research, such as specific demographic data and low completion ACP documentation.

**Limitations.** Some of the limitations of this study include the inability to generalize information because of the rural setting, the research design and sample size. Because of the study setting, there is little diversity in the sample studied.

**Implications for practice.** This study aimed to describe the level of ACP documentation in a LTC facility, in accordance with the 1991 PSDA and accreditation standards set forth by the Joint Commission. As the results of the data analysis show, there is a great need for more complete documentation of patient wishes, desires and goals of care in family planning meetings and wishes of individuals at EoL. Many patient progress notes stated "Plan of Care discussed," but did not elaborate on what type of plan was discussed (medical, therapy, EoL, etc.), what was specifically was discussed, a

complete list of whom was in attendance, nor what the goals and outcomes of the meeting were. This study shows that more consistent meetings and documentation needs to occur, as well as more involvement of individuals, family and clinicians in planning for EoL.

**Recommendations for future research.** Recommendations for moving forward include a larger study across several facilities to see if the level of ACP documentation is consistent with these findings. In addition, a variety of settings (such as rural, suburban and urban) should be included to better generalize the findings. Lastly, possible relationships between education level, occupation or socioeconomic status and ACP documentation/ACP meeting occurrences should be investigated.

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## **List of Appendices**

- A. Demographic Data Collection Tool**
- B. ACP Data Collection Tool**
- C. List of Tables**

### A. Demographic Data Tool

Demographic Data Collection Tool	Data
Age	_____ Years
Gender	Male    Female
Race/Ethnicity	Caucasian African American Asian Hispanic/Latino Non-Hispanic or Latino Native Hawaiian or other Pacific Islander American Indian/Alaskan Native Not Reported Other _____
Past Medical History	Heart Disease Diabetes Cerebrovascular Disease Cancer Respiratory Disease (COPD, Influenza, PNA) Alzheimer's/Dementia Other _____
Insurance type	Medicare: A B D Medicaid Private Secondary Self-pay Other _____ Not Listed
Length of Stay	_____ Days
Place prior to admission to facility	Hospital Home Other _____ Not Listed

**B. ACP Data Collection Tool**

<b>Advance Care Planning Data Collection Tool</b>	<b>Data</b>
Code status documented in medical chart	Yes No
Type of code status	Full Code DNR-CCA DNR-CC  DNR  Not Listed
Current resident under Hospice care	Yes No
Next of Kin/Healthcare Power of Attorney identified in chart	Next of Kin Healthcare Power of Attorney  Not Present
Advance Directive	Yes No  If Yes:  Living Will End of Life Orders  DNR HCPoA Not Listed
Prior ACP documentation as required upon admission	Yes No
Documentation of ACP Meeting	Yes No
Elements of ACP Meeting present	Values of individual outlined Individual Autonomy expressed Individual's expression of concerns Goals of care Engagement of Individual in Plan of Care Wishes for care at End of Life Not Listed
Wishes for care at End of Life	Feeding Tube Mechanical Ventilation CPR Antibiotics Transfer to Hospital Other Not Listed

Persons present at ACP Meeting	Individual Family Significant Other Clinician Other Interdisciplinary Team Members: Occupational Therapy Physical Therapy Respiratory Therapy Speech Therapy Social Worker Dietician Pharmacist Religious personnel Nursing Hospice Not Listed No Meeting
Religious Preference	Atheist Buddhist Christian Hindu Judaism Muslim No Affiliation Not Listed Other _____

### C. List of Tables

Table 1 Demographic Data

Characteristic	Number (%)
<b>Age</b>	
64 years and under	7(12.7)
65 years to 74 years	6(10.9)
75 years to 84 years	19(34.6)
85 years and older	23(41.8)
<b>Gender</b>	
Male	15(27.3)
Female	40(72.7)
<b>Race</b>	
Caucasian	49(89.1)
African American	4(7.3)
Asian	1(1.8)
Not Reported	1(1.8)
<b>PMH*</b>	
Heart Disease	44(80.0)
Alzheimer's/Dementia	27(49.1)
Diabetes	22(40.0)
Cerebrovascular Disease	22(40.0)
Respiratory Disease	19(34.5)
Cancer	5(9.1)
Other	52(94.5)
<b>Insurance</b>	
Medicare Part A	39(70.9)
Medicare Part B	34(61.8)
Medicaid	30(54.5)
Private	13(23.6)
Secondary	7(12.7)
Not Listed	1(1.8)
<b>Length of Stay</b>	
0-30 Days	6(10.9)
31-90 Days	5(9.1)
91-180 Days	7(12.7)
181-365 Days	5(9.1)
366 Days and longer	31(58.2)
<b>Place Prior to Admission</b>	
Hospital	29(52.7)
Home	8(14.5)
Other	14(25.5)
Not Listed	4(7.3)

\*PMH Diagnoses are not mutually exclusive

Table 2 Code Status and AD

Characteristic	Number (%)
Code in Listed in Chart	
Yes	53(96.4)
No	2(3.6)
Type of Code	
DNRCC	33(60.0)
Full	10(18.2)
DNRCCA	9(16.4)
DNR	1(1.8)
Not Listed	2(3.6)
Patient under Hospice care	
Yes	7(12.7)
No	48(87.3)
Next of Kin Identified	
Yes	47(85.5)
No	8(14.5)
HCPOA Identified	
Yes	46(83.6)
No	9(16.4)

Table 3 AD and ACP Completion

Characteristic	Number (%)
Advance Directive Present	
Yes	24(43.6)
No	31(56.4)
Type of AD in those with AD	
HCPOA	18(32.7)
Living Will	10(18.2)
End of Life Wishes	10(18.2)
DNR	6(10.9)
ACP Documents Prior to Admission	
Yes	17(30.9)
No	38(69.1)

Table 4 ACP Meeting and Characteristics

Characteristic	Number (%)
Documentation of ACP Meeting	
Yes	18(32.7)
No	37(67.3)
ACP Meeting Characteristics	
Patient Goals for Care	17(94.4)
Wishes for End of Life	7(38.9)
Engagement of Patient in Meeting	5(27.8)
Patient Autonomy	4(22.2)
Patient Values	3(16.7)
Patient Concerns	3(16.7)
Not Listed	37(67.3)
Wishes for EOL Specified in ACP Meeting	
Feeding Tube	5(27.8)
Mechanical Ventilation	5(27.8)
CPR	3(16.7)
Antibiotics	6(33.3)
Transfer to Hospital	6(33.3)
Other	8(44.4)
Not Listed	41(74.5)
People Present in ACP Meeting	
Social Work	14(77.8)
Family	14(77.8)
Patient	13(72.2)
Clinician	12(66.7)
Nursing	3(16.7)
Hospice	2(11.1)
Dietary	2(11.1)

Table 5 Prior ACP vs Place

Characteristics	Prior ACP		Total Number
	Prior Place No	Yes	
Hospital	22	7	29
Home	5	3	8
Other	7	7	14
Not Listed	4	0	4
Total Number	38	17	55

Table 6: Prior ACP and Demographic Data Correlation Matrix

	<b>Prior ACP</b>	<b>Prior Place</b>	<b>Gender</b>	<b>Race</b>	<b>Medicare A</b>	<b>Medicare B</b>	<b>Medicaid</b>	<b>Private</b>	<b>Second</b>	<b>Ins Not Listed</b>	<b>LOS</b>
<b>Prior ACP</b>	1.000										
<b>Prior Place</b>	0.111	1.000									
<b>Gender</b>	-0.12	-0.214	1.000								
<b>Race</b>	0.025	-0.242	-0.067	1.000							
<b>Medicare A</b>	0.082	0.264	-0.212	-0.147	1.000						
<b>Medicare B</b>	0.202	0.315*	-0.145	-.314*	.815**	1.000					
<b>Medicaid</b>	0.374**	0.016	0.097	-0.03	-0.022	0.184	1.000				
<b>Private</b>	-0.187	-0.28*	0.245	0.07	-.586**	-.444**	-0.18	1.000			
<b>Secondary</b>	-0.137	0.024	-0.011	0.051	0.245	0.076	-.418**	-0.212	1.000		
<b>Not Listed</b>	-0.091	-0.122	0.083	.372**	-0.212	-0.173	-0.149	-0.076	-0.052	1.000	
<b>LOS</b>	-0.152	0.096	-0.096	-0.213	0.217	.292*	.419**	-0.307*	-0.064	-0.171	1.000

\*Correlation is significant at the 0.05 level (2-tailed)    \*\*Correlation is significant at the 0.01 level (2-tailed)

Table 7: Prior ACP and PMH Correlation Matrix

	<b>Prior ACP</b>	<b>Heart Disease</b>	<b>Diabetes</b>	<b>Cerebro</b>	<b>Cancer</b>	<b>Respiratory Disease</b>	<b>Alzheimer's/ Dementia</b>	<b>Other</b>
<b>Prior ACP</b>	1.000							
<b>Heart Disease</b>	0.039	1.000						
<b>Diabetes</b>	-0.064	0.13	1.000					
<b>Cerebrovascular</b>	-0.064	-0.056	0.091	1.000				
<b>Cancer</b>	0.062	0.000	-0.258	0.000	1.000			
<b>Respiratory Disease</b>	-0.238	-0.076	-0.047	-0.125	-0.23	1.000		
<b>Alzheimer's/Dementia</b>	0.288*	-0.145	0.015	0.015	0.069	-0.178	1.000	
<b>Other</b>	0.161	-0.12	-0.131	0.033	0.076	-0.162	-0.084	1.000

\*Correlation is significant at the 0.05 level (2-tailed)