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Perceptions of Residential Elders Following Facilitated Advance Care Planning

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PERCEPTIONS OF RESIDENTIAL ELDERS FOLLOWING FACILITATED
ADVANCE CARE PLANNING

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Dedication

This is dedicated to my son, Blake.

Blake,

Thank you for being the reason for me to go back to school and pursue higher education. I know this has been a struggle for both of us, and I appreciate your support throughout this process over the past four years. I also could not have done the Doctor of Nursing Practice program or this dissertation without you grounding me with real life comments. For instance, one comment you made was, "Well, you chose to do this", and you walked away. On another occasion I asked you if you thought this whole process was worth it, and you replied, "It will be!"

Thank you for loving me through this,

Mom

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Abstract

The purpose of this project was to explore the perceptions of residential elders following a facilitated advance care planning (ACP) conversation. While literature is available regarding ACP and advance directives (ADs), there is minimal knowledge of first hand experiences from those who complete ACP and live in a residential or retirement community. Five residents of a retirement community who participated in facilitated ACP conversations also participated in a focus group interview to explore their perceptions of facilitators of and barriers to ACP and completing an AD. The interview was audio recorded and transcribed verbatim. Then the transcript was reviewed for accuracy and field notes were added to preserved nuances observed during the focus group. The transcription was analyzed for themes to determine residents' perceptions of their ACP experience. All of the residents had previously participated in some form of ACP prior to the facilitated conversation, and of interest all made changes to their documentation following the conversation. The facilitators for ACP included: future preparedness; having something in writing; feeling of comfort; communication; family involvement; advancing age; knowledge of future death; lack of fear about death; wanting to have a peaceful death; previous experience with loss of a loved one; preventing burden to families by planning ahead; and Christian faith. The barrier for ACP was uncertainty in illness. All participants agreed it was a barrier to their ACP decision-making. Implications for practice are limited to similar residential populations in a select Midwestern city. Suggestions include encouraging residents to: participate in facilitated ACP conversations, revisit the document annually, integrate ACP into an annual visit, and encourage advocate and family involvement in the ACP process.

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Please note: some of the appendices have been changed from the original documents to these current documents to protect the identity of the hosting institution and other members of this project.

CHAPTER 1

INTRODUCTION

Several decades of interest have produced only modest change in the end-of-life care in the US, while decision-making at the end-of-life care has not progressed in tandem with advances in medical sciences (Rushton, Kaylor & Christopher, 2012). The ability of medical science to sustain life in the era before the past few decades was very limited. As a result, the discrepancy between available treatment and appropriate treatment has been debated in the literature, the media, and the legislature. While substantial improvements have occurred in shared decision-making and awareness of patient autonomy, one consistent barrier to improving the quality of end-of-life care is the inconsistent use of advance directives (ADs) aimed at preserving patient autonomy. Many authors suggest placing a greater emphasis on advance care planning (ACP) than on AD completion rate alone (Hammes & Briggs, 2011; Hammes, Rooney, Gundrum, 2010). The purpose of this project evaluation is to explore facilitators of and barriers to ACP in a residential elder population.

Use of Advance Directives

An AD, as defined by the federal Patient Self-Determination Act of 1991, is "a written instruction, such as a living will or durable power of attorney for health care, recognized under state law, relating to the provision of health care when the individual is incapacitated" (Centers for Medicare & Medicaid Services [CMS], 2013). The true rate of completion for ADs across the US remains unknown, but the estimates of completed ADs in existing studies range from 18-36% (U.S. Department of Health and Human

Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy [USDHHS], 2008, p. 13). As patients move through the continuum of care and progress toward end of life, the number of completed ADs generally increases (Jones, Moss, & Harris-Kojetin, 2011). Often, when elders are admitted to a facility for independent or skilled nursing care, the proportion of those with an AD document is expected to be slightly higher (Lu & Johantgen, 2010). However, even among hospice and terminally ill patients, the number of completed ADs is only about 70% (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2009).

When community-dwelling elder couples relocate to a residential facility, each elder often appoints his or her significant other to be his or her designated health care advocate. Unfortunately, residents' care needs change, and ADs are frequently not updated to reflect the ongoing wishes of the resident, changes in health status, or the abilities of the advocate as the advocate's health deteriorates (American Academy of Nursing, 2010). This is of particular concern for residential elders whose advocate suffers from multiple comorbidities or known life-limiting diseases (Lu & Johantgen, 2010; Teno, et al., 2007).

Progress towards Advance Care Planning

The American Geriatrics Society [AGS] predicts that the population of adults ages 65 and older will increase about 15 million by 2021(AGS, 2011). As the US health care system prepares for this increasing population of older adults, the need for functional, comprehensive, and documented ADs will increase. As a result, multiple initiatives now exist to increase AD completion rates, particularly in residential elder populations who are known to be vulnerable (Jones, et al., 2011).

However, multiple authors conclude that increasing the number of ADs may not necessarily increase the usability of the documented AD (Andershed & Harstäde, 2007; Angus, Barnato, Linde-Zwirble, Weissfeld, Watson, Rickert, & Rubenfeld, 2004; Duke, Yarbrough, & Pang, 2009; Hammes, Rooney, & Gundrum, 2010; Jones, et al., 2011; Kwak, Allen, & Haley, 2011; Schwartz, et al., 2002; Teno, et al., 2007; Ulrich, 1999; Wendler & Rid, 2011). In fact, the last decade has shown a movement away from focusing on the AD document, in lieu of directing attention toward the conversation associated with document interpretation (Teno, et al., 2007; Zhang, et al., 2009). This important conversation ideally includes the person's appointed advocate and is more accurately described as ACP. Specifically, ACP entails the "process of assisting individuals to understand, reflect upon, and communicate future medical treatment preferences, including end-of-life care" (Hammes & Briggs, 2011, p. 212). Several nationally organized approaches to structured conversation include, but are not limited to, *Five Wishes*, *Respecting Choices®,* and *Physician Orders for Life-Sustaining Treatments* (*POLST*) (Gittler, 2011; Hammes, Rooney, Gundrum, Hickman, & Hager, 2012; Hickman, et al. 2009).

In 2011, a coalition was formed in an area of Michigan with the intention of increasing communication about and support for ACP. The coalition initially included several retirement communities, a primary care provider office, a local cancer and hematology center, and a community support center known as "Gilda's Club." The coalition elected to adopt the *Respecting Choices®* model for ACP. The *Respecting Choices®* model is designed to initiate a conversation about the importance of ADs with healthy elders and to create a process for perpetual documents to meet the needs of adults

as they age and their health care needs change. The three stages of the *Respecting*

Choices® model include *First Steps*®, for generally well adults; *Next Steps*®, for adults

diagnosed with chronic or life-limiting diseases; and *Last Steps*®, for those with a life

expectancy of less than one year (Hammes & Briggs, 2011). The staged planning process

is intended to meet the ongoing needs of the adult with chronic and/or life-limiting

diseases (Hammes, et al., 2012; Hickman, et al., 2009).

Background

The initiative for ACP started over twenty years ago in the national legislature.

The effort was predicated by a number of court cases pleading for a patient's right to

choose whether to receive medical treatment (Ulrich, 1999). Two of the more publicized

cases were *Karen Ann Quinlan v. State of New Jersey* and *Nancy Cruzan v. Director,*

Missouri Department of Health (70 N.J. 10 (1976) 355 A.2d 647; 497 U.S. 261, 110 S.

Ct. 2841, 111 L. Ed. 2d 224, 1990 U.S., respectively). Both cases engendered significant

press and publicity that argued over a patient's right to die. Subsequently, the Patient

Self-Determination Act of 1990 (PSDA) passed through the United States Legislature

and was enacted in 1991 (H.R. Res. 101st Cong. H. R. 4449 (1990). The PSDA provided

the legal right for patients to determine which, if any, treatment options they preferred. It

also allowed patients to appoint an advocate who would make decisions on their behalves

in the event they were unable to do so (Duke, et al., 2009; Ulrich, 1999). The primary

intention of the PSDA was to prevent cases similar to Quinlan's or Cruzan's from

reoccurring by increasing the availability and utility of AD documents (Ulrich).

Unfortunately, the AD documents that followed were often vague and left the

interpretation of the document to the advocate (Andershed & Harstäde, 2007; Kirchhoff,

Hammes, Kehl, Briggs, & Brown, 2010). Further discrepancies arose when AD documents did not itemize treatment decisions for specific medical interventions (Teno, et al., 2007). As an unintended outcome, the burden of life-sustaining decision making often was left to the advocate (Andershed & Harstäde, 2007; Wendler & Rid, 2011). In fact, when Andershed and Harstäde explored survivor burden, they reported advocates felt ill-prepared to make these decisions. The results were often guilt, shame, and feelings of not having done enough even when the advocate felt further treatment was futile (Andershed & Harstäde).

Current Advance Care Planning Intervention

Multiple stakeholders in the local area agreed to move away from the AD document and toward an ACP conversation. An ACP initiative now exists using the *Respecting Choices®* model in the local Michigan area. The original initiative was developed as a quality improvement project to enhance the overall outcomes and preserve residents' wishes related to end-of-life care. To accomplish this, a retirement community (RC) provided a facilitated ACP discussion with participating residents using this model over a six-month period.

This project will extend the original effort to include an additional evaluation component of residents' perceptions of facilitated ACP. Residents of a RC who participated in facilitated ACP discussions and agreed to be a part of the project participated in a focus group. The aim of this focus group was to explore residents' perceptions of facilitators of and barriers to ACP completion. The focus group format was chosen because it is an effective and efficient way to collect participants' perceptions of their experience (Krueger & Casey, 2009; Morgan, 1997). The focus group interview

was also designed to promote discussion among members of the group without forcing the group to come to a consensus (Krueger & Casey).

Summary

In spite of comparatively low completion rates of ADs across the US, the need for ACP and corresponding documentation increases as the size of older adult populations and number of care options grow. Existing models for ACP initiatives need to be evaluated for utility across settings. This project evaluated a previously initiated ACP project at a RC in Michigan. This evaluation project used a focus group to obtain perceptions of residents who participated in the facilitated ACP process. Ultimate outcomes are to report on residents' perceptions and experiences with the ACP process, to improve the quality and utility of the documented advance care plan, to preserve the wishes of the residents, and to decrease the burden involved in the decision-making process for residents.

CHAPTER 2

INTEGRATIVE LITERATURE REVIEW

The purpose of this chapter is to explore the literature relative to the perceptions of elders who resided at residential facilities and participated in facilitated advance care planning (ACP). For this integrative literature review to be comprehensive, multiple databases were searched from 1990 to 2014 including the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, Cochrane Collaboration, ProQuest Medical Library, MedLine, EBSCO host, and Google Scholar. Key search terms included "advance directive" (AD); "ACP"; "elder"; "older adult"; "retirement community"; and "residential elder". Additionally, the reference lists of retrieved materials were reviewed for inclusion. Finally, a medical librarian was consulted to ensure completeness of the literature search.

To structure the search and subsequent analysis, the integrative method developed by Whittemore and Knafl (2005) was used. This approach utilizes five distinct steps for reviewing and analyzing a body of literature. The first step was to clearly identify the problem (Whittemore & Knafl). In this case, the perception of residential elders following facilitated ACP conversations was the problem of interest. The second step of the method was to search the literature using key words accomplished through a systematic search. The third step was to evaluate the data using established criteria (Whittemore & Knafl). To accomplish this, studies were evaluated for inclusion in a logical and consistent manner based on the focus of the topic, methodology, population, sample criteria, results, and conclusions. With regard to this literature review, both

quantitative and qualitative methods were included. Methodologies varied and included

meta-analyses, random controlled trials, cross-sectional studies, focus group interviews,

and expert opinions. Whittemore and Knafl's fourth step was to analyze and separate the

data into a table with categories derived from the literature relative to ACP. The created

table clarified categories of information related to ACP and served as a ready reference.

Lastly, the final step was the presentation of data in a succinct and comprehensive

manner with special attention to support for the conclusions in each section as they

related and contributed to the understanding of ACP in residential elders (Whittemore &

Knafl).

When the Whittemore and Knafl (2005) model was used, no primary articles were

found that focused solely on the perception of ACP following a formal facilitated process

among elders living in a residential facility. However, two related studies exist: one by

Hall and Jenson (2014), and a second by Shaffer, Keenan, Zwirchitz, and Tierschel

(2012). Hall and Jenson examined the completion of the Physician Orders for Life

Sustaining Treatment (POLST) form by residents of a Midwestern Assisted Living

Facility (ALF). The investigators' first outcome measure was the number of patients who

completed a POLST form, and the second outcome measure was satisfaction with the

facilitated communication technique. Satisfaction was measured using an established

tool, the Quality of Patient-Clinician Communication About End-of-Life Care, adapted

from a previous study of patients with AIDS (Hall & Jenson). The Cronbach α

coefficient for the communication tool was internally consistent for patients and health

care advocates at .87 and .88 respectively. On the questionnaire, four questions asked

about the clarity of the facilitated conversation, and the final question asked about

satisfaction with the interview using a five point Likert scale with five being the most satisfied (Hall & Jenson). The responses of eight residents and nine health care agents included in the findings expressed a positive experience with the facilitated conversations with satisfaction scores of 90% for both residents and agents (Hall & Jenson).

In the second study of elders in a residential setting, Shaffer et al. (2012) used focus group interviews gathered from assisted living facility residents in order to elicit their perspectives on end-of-life discussions and experiences. The Shaffer et al. researchers compared residents' perceptions to those of family members and staff of assisted living facilities. The authors explored the goals and values of the residents, families, and staff and assessed approaches to facilitate end-of-life conversations.

The methodology researchers in the Shaffer et al. (2012) study employed was multiple focus groups from three assisted living facilities. Groups were comprised of sixteen residents divided into three resident focus groups; five family members divided into two family-only focus groups; and eleven staff members divided into two focus groups. The population of the assisted living facilities consisted of primarily Caucasian adults with fewer than four minority residents per facility. Limited demographic data were reported for the participating residents; however, all participating residents were Caucasian with both genders represented (Shaffer et al., 2012). Thematic analysis outcomes from resident focus groups included the meaning of end-of-life; encounters with death and dying; not wanting life prolonged; conversations about end-of-life; making end of life decisions; and information desired about end-of-life decision making (Shaffer et al.). Likewise, themes identified from family member focus groups included the meaning of end-of-life; care processes; conversations about end-of-life; making

health care decisions; and information needed about health status and care (Shaffer et al.).

In contrast, themes that emerged from staff member focus groups logically included care

coordination; staff roles in end-of-life care; working with family; conversations about end

of life; and end of life educational needs (Shaffer et al.). Conclusions drawn by the

authors described suggestions to structure end-of-life informational opportunities

separately for residents, family members, and staff members. The authors also discussed

the importance of organizational culture supporting a palliative care philosophy to

enhance discussions about end of life.

While no other directly related materials were retrieved describing facilitated

ACP in residential elders, further review of the literature revealed several supportive

themes relative to ACP in elder populations. To develop further understanding of ACP,

the retrieved studies were divided into thematic categories as recommended by

Whittemore and Knafl (2005). In particular, categories were developed to identify and

explore known facilitators of and barriers to ACP so that future implications could

eventually be applied to facilitated ACP conversations. Categories include the history of

ADs; the cultural shift from ADs to ACP conversations; goals of ACP; facilitators of

ACP; barriers to ACP; and recommendations to promote ACP in the future.

History of Advance Directives

Early support for ADs was foreshadowed in 1986 when federal legislation

requiring emergency treatment for all persons went into effect. This legislation, known

as the Emergency Medical Treatment and Labor Act (EMTALA), ensured emergency

medical care for individuals regardless of their ability to pay for services (Siegel, 2008).

Because of this requirement to treat in emergent situations, the patient care priority was

to save life, maintain life, or mitigate harm when a person was unable to express his or

her own wishes (Siegel). Therefore, the default for medical care was to save life at all

costs, unless documentation was available that the patient would not want specific

treatment (Kwak et al., 2011). In summary, this law provided assurance of emergent

medical treatment for patients and families in emergent situations, but failed to direct

caregivers away from possibly unwanted medical interventions.

In the nationally publicized cases of Karen Quinlan in 1975 and Nancy Cruzan in

1990, emergent life-sustaining treatment consistent with EMTALA was provided,

resulting in tragic outcomes. At their young ages, Quinlan and Cruzan did not have ADs,

and this combined with EMTALA regulations resulted in prolonged and arguably futile

care, as well as legal and ethical burdens for the families, and a prolonged and repeated

public debate about these burdens in each case (Ulrich, 1999). Following these

publicized cases, federal legislation was passed in 1990 to provide a legal mechanism for

patients to express legally enforceable wanted and unwanted care. The Patient Self

Determination Act of 1990 (PSDA) went into effect in 1991 and allowed patients to name

a surrogate decision-maker by assigning a durable power of attorney for health care and

to specify parameters for medical treatment, including unwanted care (H.R. Res. 101st

Cong. H. R. 4449 (1990); Hunsaker & Mann, 2013). The focus of the PSDA was to

preserve patient autonomy, even if the patient was incapacitated at the time when medical

decision-making was required (Ulrich). However, legal requirements for facilitating and

honoring the PSDA remains limited to facilities that accept Medicare and Medicaid

funds, limiting its benefit to some Americans, especially the young, who may not have

considered medical options should they experience serious illness (Centers for Medicare and Medicaid Services [CMS], 2013).

Another effort to increase the prevalence of AD documents has been provided by CMS, an accrediting body in health care. CMS has designed a quality survey measure to assess the presence of an AD document in a patient's medical record (CMS, 2013). Unfortunately, the unintended consequence of this initiative was simply focusing on the presence or absence of an AD and did not focus on the functionality of the document (Ulrich, 1999). Five years following the act, Rein et al. (1996) reported limited patient knowledge of AD, even when the facility was charged to provide patients with AD information as required by the PSDA. The continued lack of ADs and the failure of the PSDA was again noted in 2005 during Terri Schaivo's publicized case (*In re Guardianship of Schiavo*, 792 So.2d 551, 554 (Fla. 2d DCA 2001); Quill, 2005).

Many authors continue to report low AD completion rates (Jones et al., 2011; United States Census Bureau [USCB], 2010; USDHHS, 2008; Van Leuven, 2012). In particular, Jones et al. (2011) reported variability in ADs across health care settings. In this study, investigators reported only 28% of home health residents had an AD, compared to 65% of residents in skilled nursing facilities (Jones et al.). In contrast, 88% of Medicare approved hospice patients were reported to have an AD (Jones et al.). Lu and Johantgen (2010) explored ADs in the hospice setting, noting when ADs were in place, they were usually limited to a Do Not Resuscitate (DNR) order. In other studies, patients who have completed AD documents shared similar characteristics such as a lengthy health decline, multiple hospitalizations, and chronic life-limiting diseases (Lu &

Johantgen; Ramsaroop, Reid, & Adelman, 2007; Van Leuven). Often, patients were also older than 85 years and were residents of a skilled nursing facility (Jones, et al.; USCB).

Of concern, the USCB (2010) projected an increase in older adult populations and an anticipated decrease in the health status of elders, creating an urgent demand to communicate end-of-life preferences (Jones et al., 2011). Following many initiatives to increase AD completion rates, multiple authors concluded increased completion rates were not correlated with improvement in consistency of medical care provided and/or medical care wanted at the end of life (Teno et al., 2007; USDHHS, 2008). Alternatively, ACP conversations between the patient and the health care advocate have shown increased consistency with medical care wanted and medical care delivered in other studies (Hammes et al., 2010; Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2012; Teno et al., 2007).

Cultural Shift to Advance Care Planning Conversations

As the process of ACP becomes more commonplace, numerous standardized approaches have evolved to facilitate intentional ACP conversations, including several well-established approaches from *POLST*, *Five Wishes*, and *Respecting Choices®* (Hickman et al., 2009; Gittler, 2011; Hammes et al.,2012, respectively). ACP conversations are aimed towards ascertaining patient preferences for end-of-life care; encompassing opportunities for an individual to talk about previous experiences; sharing values, beliefs, and treatment goals; and using hypothetical situations to help clarify beliefs (USDHHS, 2008).

Multiple authors describe how ACP conversations can be complex, dynamic, and emotionally charged (Hospice and Palliative Nurses Association [HPNA], 2011; Kwak et

al., 2011; McMahan, Knight, Fried, & Sudore, 2013). Successful ACP conversations may be further compromised by lingering uncertainty associated with life-limiting illness or previous disagreements between the patient and the advocate or the patient and family (Bomba, 2005; Emanuel, Danis, Pearlman, & Singer, 1995; Hammes & Briggs, 2011; Kwak, Kramer, Lang, & Ledger, 2012). Kwak et al. (2011) remarked on the essential element of fluidity as a necessity in the ACP process. Other authors suggest ACP should also involve planned, progressive ongoing conversations between patients, their advocate(s), and a facilitator (Emanuel et al., 1995; Kuehlmeyer, Borasio, & Jox, 2012; Rushton, Kaylor, & Christopher, 2012; Silvester & Detering, 2011; Storey & Sherwen, 2013). Furthermore, common recommendations for ACP include reviewing ADs on an annual basis, discussing AD updates at wellness visits with patients and their provider, and revisiting ADs at any entry into the health care system (Ali, 1999; Bomba, 2005; Emanuel et al.). Storey and Sherwen, in fact, noted more frequent exposure to ACP provides support for the advocate and the patient as it reaffirms the intention of the patient's wishes in the written document.

Kuehlmeyer et al. (2012) concluded that the utility of the AD document is dependent on the clear interpretation of the items in the written plan. Unfortunately, all treatment options cannot be explicitly stated in the AD document, alluding to concerns with document interpretation (Briggs, Kirchhoff, Hammes, Song, & Colvin, 2004; Gittler, 2011). Briggs et al. explored the utility of a multifaceted conversation including beliefs, values, morals, and hypothetical situations to affirm patients' and advocates' thinking processes. Many authors define the success of ACP by comparing documented wishes for treatment with actual treatment rendered at the end of life (Detering, Hancock,

Reade, & Silvester, 2010; Hammes et al., 2010; Hammes et al., 2012; Hickman et al., 2011; Teno et al., 2007). While numerous authors described the success of ACP that supported patient wishes, patients with an AD attained through facilitated ACP historically had a significantly higher percentage of care congruent with their wishes (Detering et al.; Hammes et al, 2010; Hammes et al., 2011; Hickman et al., 2011; Teno et al., 2007). Additionally, when advance care plans were followed, there was increased patient, advocate, and family satisfaction and decreased stress, anxiety, and depression in surviving family members and advocates (Andershed & Harstäde, 2007; Detering et al.; Kelly, Rid, & Wendler, 2012; Kwak et al., 2011; Wendler & Rid, 2011).

Detering et al. (2010) interviewed advocates who described feelings of peace and comfort following their advocate roles and expressed the value of having had conversations with patients about acceptable treatment outcomes and goals. In several studies, families and advocates of decedents who participated in the ACP process were more likely to report a peaceful death for their loved one (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; USDHHS, 2008; Wendler & Rid, 2011). Other authors discussed a decrease in resource utilization when the patient's wishes were known and followed (Bischoff et al., 2013; Hickman et al., 2011; Silveira, Kim, & Langa, 2010; Teno et al., 2007).

In anticipation of the growing number of older adults, Angus et al. (2004) examined the concept of either expanding intensive care units and rationing care at the end of life, or increasing ACP and enhancing end of life care in alternative settings such as long term care facilities. Zhang et al. (2009) also studied elders and noted higher health care expenditures occurred when patients were given more aggressive treatment

and wishes were unknown. Zhang et al. also hypothesized that higher costs are linked

with a lower quality death. Cumulatively, authors reported consistent use of ACP

conversations, like *Respecting Choices®*, were associated with lower health care

expenditures in the final week of life (Angus et al.; Giovanni, 2012; Hickman et al.,

2011; Jennings & Morrissey, 2010; Kirchhoff et al., 2012; Teno et al., 2007; Wholihan &

Pace, 2012; Zhang et al.). This is consistent with Teno et al. (2007), who reported the

majority of American citizens wanted to die peacefully in their homes and not in the

acute care setting with multiple machines maintaining life.

<div align="center">**Structured Facilitated Advance Care Planning**</div>

In effort to improve ADs, ACP conversations have been gaining recognition as a

means to promote patient autonomy while decreasing ambiguity interpreting the AD

document. Because ACP goals are focused on the patient, care is only truly patient-

centered when the goals of care are known and followed (Briggs et al., 2004; Hammes &

Briggs, 2011; Waldrop & Meeker, 2012). Secondary goals for ACP also focus on the

advocate and family, providers, and the health care system as a whole. The patient-

centered ACP process is structured to ultimately benefit the patient by creating increased

consistency among facilitators and enhancing patient desired external outcomes (Song,

Kirchhoff, Douglas, Ward, & Hammes, 2005; Waldrop & Meeker).

Some goals derived from structured facilitated ACP conversations are specific to

the advocate. Several authors describe ACP as ongoing, clear communication about the

patient's treatment preferences (Bischoff et al., 2013; Bomba, 2005; Briggs et al., 2004;

Detering et al., 2010; Emanuel et al., 1995; Gittler, 2011; Hickman et al., 2011; HPNA,

2011; Kuehlmeyer et al., 2012; Kwak et al., 2011; Romer & Hammes, 2004; Schwartz et

al., 2002; Schwartz et al., 2003). An additional goal of ACP is increased probability of

the advocate upholding the plan (Briggs et al.; Hammes et al., 2010; Song et al., 2005).

One important goal is reduced trauma and ambivalence related to advocate decision-

making (Andershed & Harstäde, 2007; Detering et al.; Hammes & Briggs, 2011; Wendler

& Rid, 2011). Examples of reduced trauma and ambivalence may include decreased

feelings of guilt, shame, or feelings that not enough was done (Andershed & Harstäde).

Collaborative goals for both patients and advocates include increased satisfaction with

the ACP process (Briggs et al.; Detering et al.; McMahan et al., 2013; Schwartz et al.,

2002; Wendler & Rid, 2011). Another goal for the advocate is increased satisfaction

when care provided was congruent with patient wishes (Andershed & Harstäde; Detering

et al.; Hammes & Briggs; Wendler & Rid). In separate studies, authors defined the

ultimate goal was helping the advocate to be able to make appropriate changes to an ACP

document intuitively based on the values and outcomes for a quality of life important to

the patient (Bischoff et al.; Briggs et al.; Hammes et al, 2010; Kelly et al., 2012;

Kirchhoff et al., 2012; Kuehlmeyer et al., McMahan et al., 2013; Romer & Hammes;

Wendler & Rid).

Goals specific to health care providers must also center on care consistent with

patients' wishes (Angus et al., 2004; Baughman et al., 2012b; Cohen & Nirenberg, 2011;

DeLaGarza, Andersen, Mach, & Bennett, 2001). A completed AD includes the

appointed advocate, allowing care providers to engage in decision-making with the

appropriate person whenever questions arise when patients cannot advocate for

themselves (USDHHS, 2008). When health care providers have clear direction and can

act on behalf of the patient's known and documented wishes, this aligns with the goals of

all stakeholders (USDHHS). A final goal is to reduce the burden for health care

providers due to less ambiguity regarding patients' wishes (Angus et al.; Van Leuven,

2012).

Three of the goals for the health care system as a whole are to provide safe care to

patients, provide quality care to patients, and deliver cost-effective care. These goals are

described as the triple aim of health care and were established by the Institute of

Healthcare Improvement (IHI) as a means to improve the overall quality of health and

health care in the US (Berwick, Nolan, & Whittington, 2008). These overarching health

care goals are consistent with the goals for patient-centered ACP.

Facilitators of Advance Care Planning

Some common denominators exist for those who are interested and those who

complete the facilitated end of life interview and subsequent documentation. Possible

triggers for initially participating in the ACP process include perceived decline in health

or the personal loss such as the death of a close relative (Baughman et al., 2012a; Carr,

2012; Crisp, 2007). Also, the addition of optional ACP to the admission process for

independent or long-term care facilities may trigger the use of the ACP process

(Schwartz et al., 2002).

Similar and separate triggers exist for revisiting the ACP process (Lu &

Johantgen, 2010). The patient may experience a change in health status or decide to

change treatment goals (Briggs et al., 2004; Lu & Johantgen). At this point, it is

important to first clarify values and beliefs of the patient, and then share new treatment

goals with the advocate present (Bomba, 2005; Kirchhoff et al., 2012; Kwak et al., 2011;

McMahan et al., 2013; Rushton et al., 2012; USDHHS, 2008). Increased AD completion

rates have also been reported among those with increased health care provider visits (Sessanna & Jezewski, 2008).

Finally, a trigger for providers to initiate or revise ADs using the ACP process is having a tool or questionnaire available to initiate and direct end-of-life discussions (Hickman et al., 2009). Bomba (2005) reported providers who offer and honor ACP documents build trust with their patients. Multiple studies indicate that the patients' wishes can only be followed if they are known, so encouraging patients to have facilitated ACP conversations increases the likelihood their plan will be followed (Bischoff et al., 2013; Briggs et al., 2004; Detering et al., 2010; Hammes et al., 2010; Hammes et al., 2012; Hickman et al., 2009; Jones et al., 2011; Newton, Clark, & Ahlquist, 2009; Romer & Hammes, 2004; Schwartz et al., 2002; Teno et al., 2007; USDHHS, 2008; Waldrop & Meeker, 2012).

Barriers to Advance Care Planning

Unfortunately, the number of barriers to ACP outweighs the numbers of facilitators. Any of the following barriers could potentially prevent a patient from either completing the ACP process or creating the AD document. Barriers involved reluctance of providers, patients, families, and advocates to engage in difficult conversations and system barriers for health care and legislature (Weiner & Cole, 2004; Schwartz et al., 2002; Baughman et al., 2012; in der Schmitten et al., 2012; Giovanni, 2012; respectively)

Health care providers who may not personally feel comfortable with the conversation are reluctant to have ACP conversations with patients (Crisp, 2007; ELNEC, 2013; Emanuel et al., 1995, Giovanni, 2012; Hinders, 2012; HPNA, 2011; Kwak et al., 2011; Mahon et al., 2011). Emanuel et al. and Ramsaroop et al. (2007)

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reported providers may feel there is not enough time to have ACP conversations, and providers may not start the conversations. Multiple authors reported providers may fail to identify the changes in a patient's condition due to the slow decline in health status, especially when the patient suffers from multiple comorbid diseases and medical care is fragmented (Kwak et al., 2011; Schonfeld, Stevens, Lampman, & Lyons, 2012; Storey & Sherwen, 2013; Travis et al., 2002; Weiner & Cole, 2004). Finally, the current culture for some providers does not allow the provider to approach this topic without feelings of appearing to advocate for treatment denial (Kwak et al., 2011; Mahon et al.; USDHHS, 2008; Weiner & Cole).

Many authors reported reluctance as a patient barrier to participate in ACP (Salmond & David, 2005; Schwartz et al., 2002; Sessanna & Jezewski, 2008). The most prominent patient barrier reported by numerous authors is the reluctance to discuss dying with another person, as the discussion may be perceived as uncomfortable for the patient (Briggs et al., 2004; Crisp, 2007; ELNEC, 2013; Hinders, 2012; Sessanna & Jezewski, 2008). The patient may feel he or she is too young and/or healthy to think about dying, and put off the conversation (Kahana, Dan, Kahana, & Kercher 2004; Kwak et al., 2012; Salmond & David, 2005; Sessanna & Jezewski, 2008). Fried et al. (2012) noted contentment with current state of health as a barrier to ACP conversations; therefore, patients may feel like having an AD would have a negative effect on their treatment outcomes. Kwak et al. reported lack of interest, knowledge, or time to complete the ACP process as patient barriers. Another barrier patients may have is an erroneous belief about delegating an advocate as equivocal to having participated in ACP (Fried et al., 2011; Schwartz et al., 2002). Finally, a patient may also defer the conversation because

culturally he or she is not the primary decision-maker and would like to maintain his or her dependence, or because culturally he or she is the primary decision-maker and would like to maintain his or her independence (Moorman, 2011; Travis et al., 2002).

Similarities exist between patient and advocate/family ACP barriers. There may be a lack of communication within the family, which causes dissension among family members, and prohibits ACP conversations (Baughman et al., 2012a; Kwak et al., 2012; Travis et al., 2002). Also, family dynamics may prevent the conversation from being productive (Kwak et al., 2012; Schwartz et al., 2002; Travis et al.). Sessanna and Jezewski (2008) discussed the presence of familial fear, which prevents discussion about end-of-life care. Baughman et al. (2012a) and Kwak et al. (2012) agree families may not have information or resources to help the patient create an AD. Specific barriers related to advocate involvement include not knowing who has been delegated and not being comfortable having end of life conversations with the patient (Hammes & Briggs, 2011; Travis et al.). Finally, advocates may defer treatment decisions due to the lack of communication between the provider and themselves (Salmond & David, 2005; Travis et al.).

Currently, our national health care culture favors treatment and cure in lieu of ACP conversations, palliative care, and hospice care (Angus et al., 2009; ELNEC, 2013; HPNA, 2011; Jennings & Morrissey, 2011; Travis et al., 2002; Wholihan & Pace, 2012). According to SUPPORT study authors, the majority of Americans do not want to have extensive end of life treatment when poor health outcomes are anticipated (Teno et al., 2007). Authors note that the majority of Americans want to spend the end of their lives at home (Institute of Medicine [IOM], 1997; Teno et al., 2007). However, there is a

disconnect between the substantial number of Americans who spend the end of their lives in an acute health care setting compared to those who do not (IOM; Rushton et al., 2012; Teno et al., 2007; Teno et al., 2011; USDHHS, 2008).

Legislative barriers to ACP include misconception and inconsistent payment for ACP. The misconception about the Affordable Care Act (2009) was the idea of a "death panel" (Giovanni, 2012). This stemmed from language in the bill which would reimburse providers for having ACP conversations with patients; however, the language was misinterpreted and subsequently removed (Giovanni). ACP conversations can be time-consuming and emotionally charged due to the sensitive nature (USDHHS, 2008). For providers to consistently have ACP conversations with patients and their advocates, financial compensation should match the necessary time and skills (American Academy of Nursing, 2010; Giovanni).

Recommendations to Promote Advance Care Planning

Numerous action items need to be accomplished to promote ACP in the future. According to Marchand, Fowler, and Kokanovic (2006), three characteristics are necessary to promote ACP in the future: commitment, cohesiveness, and goals. Commitment to using ACP manifests in a number of ways (Marchand et al.). The members of an organization's leadership team need to support the ACP process and be on the team in order to promote ACP (Ali, 1999; Hammes & Briggs, 2011). Another commitment from the institution promoting ACP is a financial commitment to the process (Hammes & Briggs). This financial commitment requires educating employees to conduct facilitated conversations as well as paying employees to facilitate the conversations (Hammes & Briggs; Marchand et al.).

The second characteristic, cohesiveness, focuses on having interdisciplinary teams collaborate towards a common purpose (Marchand et al., 2006). Usually the teams involve leadership members of an organization, the trained facilitators, the health information management members (to ensure appropriate storage and retrieval of the documents), and the patients and advocates who are at the center of the conversation (Hammes & Briggs, 2011).

The final characteristic is focusing on the goals of ACP (Marchand et al., 2006). One of the goals of ACP is to create a culture of communication among patients, advocates, and providers (Emanuel et al., 1995; ELNEC, 2013; Fried et al., 2012; Newton et al., 2009; Ramsaroop et al., 2007; Schwartz et al., 2002; USDHHS, 2008). Another recommendation is to change the culture of ADs from completing documents to having ongoing conversations about the plans supporting the documents (HPNA, 2011; Kuehlmeyer et al., 2012; Rushton et al., 2012; Storey & Sherwen, 2013; USDHHS). This culture change requires educating the public through purposeful initiatives (Hammes & Briggs, 2011; USDHHS).

Summary

While a number of authors have written about the numerous facets of successful ACP, currently no published articles use a focus group interview to examine facilitators of and barriers to ACP in a residential elder facility. Implementing ACP initiatives has shown to be successful in some health care systems, suggesting that the culture of end-of-life planning can be changed throughout the US. Programs with successful implementation have common themes regarding facilitators of and barriers to the programs including family and advocate involvement during the ACP process, revisiting

ACP documents at planned intervals, and encouraging providers to discuss ACP with patients or residents. It is important to identify components so that ACP initiatives do not repeat preventable mistakes. The aim of this project provides an analysis of the facilitators and barriers affecting a select group of residential elders and describes their perceptions related to a facilitated ACP process.

CHAPTER 3

CONCEPTUAL FRAMEWORK

The purpose of this chapter is to describe the conceptual underpinning of this

evaluation project. While many models exist for the purpose of improving the advance

care planning (ACP) process, this project will use a conceptual model specifically

designed for ACP authored by Pearlman, Cole, Patrick, Starks, and Cain (1995).

Pearlman developed concepts from the Transtheoretical Model of Change and the Health

Belief Model to create an integrated model for ACP (See Appendix A for Pearlman's

ACP Model). This chapter develops components of Pearlman's ACP Model by

including: a description to illustrate ACP, components of the Transtheoretical Model of

Change, with the Health Belief Model as the conceptual underpinning. Overall,

Pearlman's ACP Model describes critical elements in ACP and further integrates areas

that may lead an individual to participate in ACP.

Pearlman's Advance Care Planning Model

Pearlman's ACP Model was first published in 1995 to increase understanding of

the complexity of ACP. The model is separated into three main sections: *person*,

behavior, and *outcomes* (Pearlman, et al. 1995). These sections are all influenced by

cultural, institutional, social, and *interpersonal* factors with overarching environmental

aspects (Pearlman, et al.). The concept of *person* embodies beliefs about benefits of

engagement as well as self-efficacy. Ideally, these beliefs lead to the decision to

participate in ACP. Participating in ACP is further enabled through the individual's

ability to process information, which encompasses values and knowledge (Pearlman, et al.).

The *behavior* section of this model describes the documented and communicated preferences of persons with stakeholders, including the individual, their advocate, and their provider (Pearlman, et al., 1995). Participating in this behavior is the act of ACP. This essential component includes communication among stakeholders and the finalization of documentation.

The third section of the model describes *outcomes*. The outcomes are divided into immediate outcomes and possible future outcomes. Immediate outcomes include shared understanding; proper distribution of any documented plan to all stakeholders; enhanced autonomy and well-being for the individual; and, ideally, a decreased burden on the designated advocate (Pearlman, et al., 1995). Possible future outcomes depend on the need to use the documented plan and involve the designated advocate at such time when mental or physical incapacity occurs. Anticipated outcomes for this model include a decreased burden on the advocate, continued health care congruent with an individual's wishes, and a decrease in health care expenses with provided care being congruent with the individual's wishes while at the same time minimizing unwanted care (Pearlman, et al.). These three sections are all interdependent for a successful ACP process.

Transtheoretical Model of Change

In addition to the three sections, there are five stages of behavior change that influence an individual's decision to participate in or continue ACP. The Transtheoretical Model of Change is centered on the various stages a person may encounter while participating in a behavior change. This model is separated into five

stages: *precontemplation*, *contemplation*, *preparation*, *action*, and *maintenance* (Prochaska & Velicer, 1997). The first stage, *precontemplation*, is defined as a state of awareness, but implies a minimal possibility for change within the next six months. Those who fit this demographic typically lack sufficient information to move to the next stage of change. The individual in this stage may not have been exposed to enough information to engage in a given change, or he or she may avoid available information (Prochaska & Velicer).

The next stage is *contemplation*. Individuals in this stage are likely to accept and participate in the experience of health status change within the next six months. In this stage, the individual actually weighs the positive effects against the negative effects of the anticipated change. Vacillation between the positive and negative effects of the change can lead to a conclusion about the benefits of change, and therefore, lead to the next stage of the model. However, this stage can become permanent if no conclusions are made (Prochaska & Velicer, 1997).

When a person has decided to move to the next stage of the model, *preparation*, it is likely he or she will act or change within the next month (Prochaska & Velicer, 1997). This group is highly motivated for change, and its members are most likely to engage in action-oriented programs, specifically ACP conversations. Next, the *action* stage follows the *preparation* stage. This stage embraces the new modifications of participating in programs (Prochaska & Velicer). This stage is generally easier to monitor than the other stages, as there are observable behaviors and actions within the *action* stage.

Lastly, the *maintenance* stage incorporates some overt behaviors, but these behaviors are less likely to be observed. Prochaska and Velicer (1997) explain this

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decrease in observed behaviors is likely due to the lower need for observable actions. Yet the actions an individual takes in the *maintenance* stage are directed towards a specific change in needs.

Using the Transtheoretical Model of Change within Pearlman's ACP Model offers insight to the utility in practice. In the model by Pearlman, et al. (1995), each of the five stages of change is applicable to part of the ACP process. *Precontemplation*, the first stage, is an elevated awareness of the benefits of ACP. For example, an individual or couple may verbalize the possibility of a tragic accident or change in health in the future (Pearlman, et al.). *Contemplation*, the second stage, is the information gathering stage. The individual may also be looking for support via ACP so the end result is achieved and the documents are completed (Pearlman, et al.).

Preparation, the third stage, is the identification of personal, spiritual, and/or religious values as they relate to ACP. In this stage, an individual identifies what is important for end of life planning (Pearlman, et al.). *Action*, the fourth stage, is the active participation in ACP facilitation conversations. This stage usually results in the procurement of a document that delineates the individual's end-of-life medical care preferences and priorities (Pearlman, et al.). *Maintenance*, the final stage, is the review and revision of the document as needed. This final stage also includes the distribution of the document to those who may need access, such as medical providers, advocate(s), and local institutions where the individual is likely to seek medical care (Pearlman, et al.).

Health Belief Model

The Health Belief Model was one of the first models to predict individual engagement in health behaviors (Kuhns & McEwen, 2011). The Health Belief Model is

comprised of three sections and four concepts (Rosenstock, 1974). The three sections include *individual perception, modifying factors,* and *likelihood of action* (Rosenstock). *Individual perception* can be separated into perceived susceptibility and perceived severity of the disease, while the second section, *modifying factors*, accounts for individual variability including demographic, sociopsychologic, and structural variables (Rosenstock). Finally, *likelihood of action* correlates to whether or not the individual participates in the health behavior activity (Rosenstock).

The Health Belief Model includes four main concepts related to ACP that are integrated into Pearlman's ACP Model. The first concept is *perceived threats or susceptibility*. This concept addresses whether or not the individual perceives inability to make his or her own medical decisions as a threat (Pearlman, et al. 1995). The next concept is *perceived benefits*, such as preserved autonomy and proactive involvement with the advocate (Pearlman, et al.). *Perceived barriers* may incorporate family disagreements and other family dynamics that would prevent the facilitation of ACP (Pearlman, et al.). Lastly, *self-efficacy* engages the individual to believe he or she is able to take action (Pearlman, et al.). Self-efficacy connects all of the other models, as it is most likely to determine if the individual will take imminent action.

Summary

Pearlman's ACP Model functions as a collaborative model to better understand the components involved with facilitating ACP outcomes. It accounts for the positive, negative, internal, and external factors associated with ACP. This model also facilitates understanding for those who are not currently interested in participating with advance

care facilitation, as well as providing insight as to what may encourage individuals to participate in the future.

CHAPTER 4

METHODOLOGY

The purpose of this chapter is to describe the qualitative approach selected for this quality improvement evaluation project. The following includes an assessment of the site and population. In addition, this chapter includes the selected methodology, the plan for data collection, and the approach to analysis. Finally, this chapter presents information regarding participant confidentiality.

Retirement Community Description

The retirement community (RC) which hosted this project is a not-for-profit retirement community in Michigan. The RC is accredited by the Commission on Accreditation of Rehabilitation Facilities-Continuing Care Accreditation Commission to provide care to residential elders. The care options at this RC vary and include independent living, assisted living, rehabilitation, and skilled nursing care. Throughout the continuum of care at this RC, the average age is 85 years, with about three female residents to every male resident. The dominant ethnic group is Caucasian which comprise the dominant ethnic group for this area of Michigan well (Retrieved on September 30, 2013, from www.quickfacts.census.gov). This area in Michigan is a large metropolitan area located near the lakeshore of Lake Michigan. The population in Grand Rapids, Michigan, was estimated around 190,000 in 2012, with 11.1% of the population being 65 years or older (Retrieved on September 30, 2013, from www.quickfacts.census.gov).

Project Overview

Residents at this RC were invited to attend informational meetings about ACP between July 2012 and December 2012. Those who were interested in having a facilitated discussion about ACP scheduled a meeting with one of six facilitators. Only four of the six facilitators completed ACP facilitations. Facilitators for ACP, including this author, were educated using the *Respecting Choices®* curriculum. This curriculum includes six online modules followed by an eight-hour in-person class with time allotted for practicing facilitations with feedback.

A total of thirty residents participated in the facilitated ACP discussions. Those thirty residents were free of known cognitive decline or known mentally-limiting diseases, such as dementia, at the time of the facilitated ACP interviews. The mental clarity of the residents was corroborated by the agency staff and author as there were no clinical findings suggesting memory loss or confusion of the residents during the interviews. Of the 30 residents who participated in the facilitated conversation quality improvement pilot project, six ACP interviews were facilitated by the author and were excluded as potential participants. The other 24 residents were deemed eligible for the focus group interview. Unfortunately, due to the demographics of this population, attrition due to illness and death resulted in only 19 eligible residents. Among the 19 possible residents, there were five married couples.

Recruitment of Subjects for Focus Group Interview

Using the above listed criteria, all eligible residents were invited to participate. An invitation letter discussing the focus group interview was created (Seidman, 2006). (See Appendix B for Invitation.) The letter also contained a self-addressed stamped

envelope as well as the author's phone number for the resident to confirm or deny

participation (Seidman). The invitation letter gave the resident a date by which the letter

had to be returned or a call had to be made to the author in order to participate. Residents

who did not return their letter or call to confirm participation by the given date did not

participate in the study. The participation goal of this focus group interview was five to

nine residents. One phone call occurred the week prior to the interview to ensure

participant availability and answer any logistical questions (Krueger & Casey, 2009).

Focus Group Interview Description

A focus group interview was chosen as the method for data collection as it is an

effective way to obtain qualitative evaluation data in a small setting (Creswell, 2007;

Krueger & Casey, 2009; Morgan, 1997; Seidman, 2006). It was also an efficient way to

collect opinion-focused answers to open-ended questions (Creswell; Morgan). Focus

group interviews are preferable to individual interviews when interaction among

members may enrich the data (Morgan). It was also appropriate to ask questions to a

group when the interviewees are similar to each other and are able to cooperate together

(Creswell). The open-ended questions allow for greater depth of responses. The

moderator was charged with informing the participants that reaching a consensus was not

necessary for this type of project, there was no right answer, and all responses were valid

(Creswell; Krueger & Casey; Morgan). The moderator was also charged with including

contributions from all of the group members (Krueger & Casey; Morgan). With a focus

group interview, the researcher was the moderator, listener, observer, and analyst

(Krueger & Casey).

Potential limitations of the focus group interview could result from the size, the participants, the interviewer, the location, or the recording. Krueger and Casey (2009) recommend three groups of five to ten participants each. This was not feasible considering the small number of eligible participants. Because one group of five participants was about a 26% selection rate, it was deemed appropriate. The potential limitations with the participants included one participant dominating the interview or minimal or unequal participation of other participants (Krueger & Casey; Morgan, 1997). The interviewer could also limit the potential data collected by asking leading questions, not allowing enough time on one or more questions, or not establishing trust by the moderator (Creswell, 2007). The opposite could also be true, in that too much time allotted to one question could decrease the available time to respond to another question (Creswell). Potential limitations with the facility included possible interruptions, extraneous noises, or an uncomfortable setting (Krueger & Casey).

The setting in which the interview took place was a critical component to the success of the interview. Administrators of the RC generously offered the use of a private meeting room located on their campus. The recommendation was to have the interview in an easily accessible but private area (Krueger & Casey, 2009). Light refreshments were provided for the participants for the duration of the interview.

The interview was scheduled for mid-afternoon for an hour. The room was set up for the participants and moderator to sit at one table. Another table was in the room for the professional recorder and transcriptionist. Participants had the opportunity to leave the interview at any time and were given an information sheet prior to the recorded interview. While it was likely that some participants knew each other, they had the

opportunity to choose an alternate name for identity confidentiality (Seidman, 2006).

Each participant was given the opportunity to say his or her name for the

transcriptionist's reference as well as for a sound check for the professional recorder.

Focus Group Interview Questionnaire

At the start of the interview, the moderator introduced the topic and then

addressed the participants as the experts for the interview (Seidman, 2006). Using the

theoretical frameworks described in the previous chapter and recommendations for

questions by Krueger and Casey (2009), five questions for the focus group interview

were constructed. Theoretical framework and rationale follow for each question. The

questionnaire established for the project was followed, and prompts were only used as

needed (Krueger & Casey, 2009). Following the conclusion of the interview, the

moderator thanked the participants for their time (Krueger & Casey). Information was

provided to the participants about how the data collected would be used at the RC and for

dissemination through the dissertation.

Question 1

"Think back a minute, and tell us who you are and your experiences with advance

care planning prior to the *First Steps*® session." Further probing questions if needed

were: "Can you talk about any experiences you have had prior to *First Steps*®

facilitation?"; "When you worked with advance directives in the past, tell me how it

went."; "Maybe you can tell about a time when you acted as an advocate for someone

else." This question aligns with the stages of the Transtheoretical Model of Change by

giving insight to the primary investigator regarding which stage of change the

participants were in prior to ACP facilitation (Pearlman et al., 1995). This question also

addressed the first concept in Pearlman's ACP Model by describing the participants as individual persons (Pearlman et al.). Krueger and Casey (2009) recommended an opening question which is easy to answer and allows for an understanding of the pre-intervention attitudes and behaviors of the residents.

Question 2

"Thinking back, please take a minute to tell me about your experience with the *First Steps*® facilitated conversation." Further probing questions if needed were: "What were you thinking or feeling during your interview?"; "Your advance care planning conversation could have been with one of the three facilitators."; "What do you believe prompted you to participate in advance care planning?"; and "What value did you find with *First Steps*® planning as it relates to you in your life?".   This question queried the concept of *behavior* in Pearlman's ACP Model (Pearlman et al., 1995). The participants in the focus group interview had all participated in the ACP facilitation, and therefore all had acted on the concept of *behavior*. It also ensured that each of the participants were in the *action* stage of the Transtheoretical Model of Change at some time. Krueger and Casey (2009) described this as an introductory question, as it introduces the topic of facilitated ACP.

Question 3

"Given what you have just told me about your *First Steps*® interviews, how do you see advance care planning helping you or not?" Further probing questions if needed were: "How was this helpful or not helpful?"; "What parts of your advance care planning were more or less clear after the facilitation interview?"; and "If you needed to give your advocate a new copy of the document (advance directive, advance care plan, living will,

Durable Power of Attorney), tell me, how did it go sharing your advance care planning document with your advocate or family members?" This question addresses the immediate and future-focused outcomes in Pearlman's ACP Model (Pearlman et al., 1995). It may also inform movement to the *maintenance* stage of the Transtheoretical Model of Change (Prochaska & Velicer, 1997). Krueger and Casey (2009) described this type of question as a key question where probes and pauses are more likely to be used. This was the question around which the evaluation project is based.

Question 4

"If you were the facilitator, what else would you have covered in your *First Steps*® facilitation interview?" Further probing questions if needed were: "How was the length of time spent on each of the sections?"; "Which parts did you feel rushed through?"; and "Tell me about the sections you felt were too long." This question addressed possible or perceived voids in the facilitation process, which was still part of the evaluation of the *behavior* concept of Pearlman's ACP Model (1995). Krueger and Casey (2009) discussed the need for a transition question, in which the participants learn about each other's views.

Question 5

"All things considered, if you could change one thing about advance care planning at this retirement community, what would it be?" Further probing questions if needed were: "How should advance care planning be presented to residents in independent or assisted living?"; "What should be avoided during advance care planning conversations?"; and "What was most effective for getting you to participate in facilitated advance care planning?" This question was directed towards future planning for other

residents, and directly relates to the *maintenance* stage of the Transtheoretical Model of Change (Prochaska & Velicer, 1997). This was also consistent with future outcomes in Pearlman's ACP Model (Pearlman et al., 1995). Another attribute of this question was to understand the culture of this retirement community, which will be important for dissemination at this RC. *Culture* and *institution* are two of the four environmental factors associated with the *person*, the *behaviors* and the *outcomes* of Pearlman's ACP Model (Pearlman et al.). Krueger and Casey (2009) discussed the utility of closure at the end of the interview prior to the moderator giving a final synopsis. Closure ensured crucial aspects have been discussed throughout the entire focus group interview (Krueger & Casey).

Data Collection Method

Interview data was collected on ALESIS HD 24 professional recording equipment as a .wav file. The professional recorder took the original .wav file to his studio for mixing and saved it to an encrypted flash drive. Upon completion of the professional mix, it was personally obtained by the moderator and immediately rendered to the transcriptionist as a .wav file on the encrypted flash drive. Both the digital audio file and the electronic transcription of the interview were collected from the transcriptionist by the moderator and immediately brought to Grand Valley State University's Information Technology Center for secure uploading to the N-Drive. Any physical transfer of data from one location to another was managed by the moderator. All data were to be kept secure following transcription and stored in a locked storage cabinet. The data files are password protected within the N-Drive and on the encrypted flash drive in a locked storage cabinet.

Data Analysis: Analyzing for Themes

Data were reported as perceptions of facilitators of and barriers to residential elders following facilitated ACP discussions. Perceptions were reported in themes, and themes were created in a stepwise manner after reading and rereading the transcripts. Recurring words and phrases were noted along with their context. A qualitative expert agreed to review the transcripts for themes. The emphasis was on the interaction between members of the group and the moderator, and the code development and thematic classification were created based on those interactions (Guest, MacQueen, & Namey, 2012). This approach is inclusive of all transcribed text, allowing for the development of categories and overarching themes (Guest et al.). All prospective themes were verified by the qualitative expert to ensure completeness of analyzed themes.

Human Subject Consideration

Due to the nature of a focus group with participants who all reside in one retirement community, it was expected that the participants knew one another. This posed a slight risk for the participants, as private information shared among the participants could possibly be revealed to the public by other participants. Preventative efforts discouraged this action prior to holding the group interview. One preventative effort was to have the participants know that this was a group interview where they would be asked to share experiences and opinions. Another preventative effort was to inform the participants of this possible risk. The final preventative effort was the act of receiving verbal consent to participate from the focus group interview participants. Participants had the opportunity to exit the focus group interview at any time if they felt uncomfortable about participating. Other efforts were taken to ensure the privacy of the

location, the security of the data during transfer, and the anonymity of the participants. The Human Research Review Committee at Grand Valley State University deemed this project as exempt from review as it is an evaluation project and is not a research study.

Summary

This chapter included a description of the methodology used for this project based on Pearlman's ACP Model framework. Subject recruitment and the focus group interview approach were also discussed as they related to the residential elder population. The focus group interview format proved to be an ideal methodology for this population because of the interaction among group members and potentially increased data richness. Additionally, questions used for the focus group interview were presented with rationale parallel to Pearlman's ACP Model. Finally, human subject considerations to ensure safety and privacy of the participants were described.

CHAPTER 5

RESULTS

The purpose of this chapter is to share the results of this study vis-á-vis the focus group interview. First is the description of the focus group participants. Next are the details of the focus group and data collection. Then are the details of the transcription analysis. Finally, findings from the focus group are reported as themes for each question and then related to concepts within Pearlman's Advance Care Planning (ACP) Model (Pearlman et al., 1995).

Participants

A total of thirty residents participated in the retirement community's (RC) original ACP pilot project. Six were eliminated because their facilitation was provided by the author. Five of the remaining residents were lost to attrition due to either death or mental incapacity. At the onset of this project, nineteen were eligible to participate and sent invitations to the focus group. Of the nineteen who were sent an invitation, nine responded by phone and none responded via post mail. Four residents declined wanting to participate, and five residents agreed to participate. Three residents were female and two were male. There was one couple who participated in this focus group interview together. Two participants previously experienced the death of their spouse, and the final participant was still married. Demographic data was purposefully not collected in effort to protect the participants from being identified.

Focus Group Interview

The focus group was held in a predetermined room and was provided free from charge by the RC. It was a known location to all residents, and all were able to get to the location independently. The room was prepared prior to the residents' arrival with refreshments and microphones for each of the residents and the moderator. Each person was positioned behind a microphone to ensure that his or her voice was individually recorded, distinguishable, and captured. Both the recorder and transcriptionist were present for the entire interview. The recording equipment used was ALESIS HD 24. The recording was then prepared by the professional recorder to filter extraneous noise and to ensure that independent voices were distinguishable. It was transferred to a password-protected flash drive as a .wav file. The data were then delivered to the professional transcriptionist, who created a Word document from the .wav file and also saved the transcription to the password-protected flash drive. The data files were uploaded to Grand Valley State University's secure N-Drive as per protocol. The staff at the RC were offered a copy of the data files, but they declined a copy of the data.

The focus group lasted approximately one hour and five minutes. All five participants were vocal throughout the interview, and no one person seemed to dominate the conversation. Residents were asked a series of five predetermined questions designed to elicit conversation among the residents. Some questions and topics arose where the group reached a consensus, while the group did not reach a consensus on other topics.

Transcription Analysis

Initially, the transcription was reviewed for accuracy. The transcription was then reviewed again for accuracy and to ensure that all personal identifiers were removed.

Then field notes were added to enhance the narrative and to add breadth to the interview. The interview transcripts were shared with an experienced qualitative researcher for analysis. The transcripts were read multiple times by the author and an experienced researcher to determine themes deduced from the interview as well as categories based on concepts in Pearlman's ACP Model (Pearlman et al., 1995). A common finding was that Pearlman's ACP Model was helpful in understanding the ACP process from the residents' perspective. Employing Krueger and Casey's (2009) method of analysis, themes were created based on repeated words and phrases used by the residents, strength and emotion portrayed through responses, and specific and detailed responses to questions by the residents. Deduced themes were ultimately corroborated by Dr. Ruth Ann Brintnall, dissertation chair to this author.

Question 1

The first question was asked to learn about the experiences the residents may have had prior to the *First Steps*® facilitation. All of the residents had a working knowledge about end-of-life planning documents, and each had previous experience creating their documents with an attorney. One resident stated, "We had our first will in 1965." The usual forms expressed were a trust or a will. All of the residents had participated in end-of-life planning at least ten or more years prior to living at [the] RC. End-of-life preparation was explicitly stated by another resident, "We had made out our will, our wills and trusts about ten years before we came here [RC]." Some residents found they were lacking the health care advocate or health care power of attorney prior to the *First Steps*® facilitation. An additional resident stated, "… found out one thing that I was surprised about, I guess I assumed that they [care providers] would ask your husband or

wife first. Nope." Themes which emerged for advanced planning were future preparedness and belief in the need to have something in writing. A highly sought-after stakeholder for these documents was an attorney. No resident mentioned consulting a health care professional regarding the health care power of attorney prior to the *First Steps®* facilitation.

Elements of Pearlman's ACP Model include *beliefs about benefits and self-efficiency*, *decision to do ACP*, and *communication among stakeholders* (Pearlman et al., 1995). Discussion among the residents regarding *benefits and self-efficiency* were highly motivated by the *communication among stakeholders*, namely, attorneys. The *decision to do ACP* was then often related to the conversations the residents had with their attorneys. Residents' dialogue produced themes that related to three of Pearlman's ACP Model's concepts in relationship to ACP prior to *First Steps®* facilitation.

Question 2

The next question asked about the specific *First Steps®* facilitation. Four of the five residents remembered the conversation with an educated facilitator, while one participant did not remember having this type of conversation with any of the three possible facilitators. The overwhelming feeling about *First Steps®* was that it is a "good" program, and "We had a good experience working on this." The facilitated conversation was educational to those who had misconceptions regarding their current advance directive (AD). One resident stated, "… when we came here [RC], they [RC staff] had us name our advocates and things like that." Of those who participated in the facilitated ACP sessions, all made changes to their documents or created new documents. One of the themes about the facilitated conversation was a feeling of comfort.

Specifically, one resident stated, "We had a nice informal discussion." The facilitated

ACP conversation appeared to give those who participated a greater understanding

regarding decisions made for health care at end of life. For instance, this resident stated,

"It got to the point of quality of life." More than half of the residents changed their

health care power of attorney due to the facilitated conversation. One resident

commented, "… we took ourselves off as patient advocates for each other, husband and

wife, and gave those over to our daughters." Also, the conversations cleared

misconceptions about the designated advocate's role. Residents stated this conversation

encouraged family involvement and communication, which was perceived as a positive

factor and was a theme throughout the responses for this question.

Themes evolved from question two are similar to the *behavior* concepts in

Pearlman's ACP Model: *communication among stakeholders* and *documentation of*

preferences (Pearlman et al., 1995). The stakeholders changed from those discussed in

the first question of resident and attorney to resident and *First Steps®* facilitator in the

second question. The communication clarified misconceptions about what residents'

previous ADs represented, and what they did not. The residents documented different

preferences on their subsequent AD. These *behavior* concepts had a direct effect on an

outcome concept of *shared understanding*. The facilitated conversation increased *shared*

understanding among the stakeholders. Question two responses centered around the

behavior and *outcome* sections of Pearlman's ACP Model (Pearlman et al., 1995).

Question 3

The third item queried the helpful and non-helpful parts of facilitated ACP. This

question aimed to answer the question investigated by this project: what are the perceived

facilitators of and barriers to ACP with residential elders? Residents had a predominantly

positive outlook on ACP and listed numerous reasons to participate. Residents also noted

one barrier to ACP, and one resident had not yet finalized an AD document for these

reasons. This finding was incongruent to the findings of the integrative literature review

that found more barriers to ACP than facilitators. Common themes expressed by all

residents were age, knowledge of future death, lack of fear about death, wanting to have a

peaceful death, previous experience with loss of a loved one, preventing burdening

families by planning ahead, and Christian faith. Other facilitators for ACP noted by some

residents were also included. Finally, the barrier to completing ACP documents was

discussed.

A facilitator theme for ACP was the advanced age of the participating residents.

Aging was directly related to their knowledge of future death. One resident stated, "It's

reasonable to think in terms of knowing that life is limited." This theme was mutually

agreed upon by others in the group with nodding gestures. The realization of future death

was a facilitator for ACP. This theme is closely related to the concept of *working

memory* within the *human info processing* section in Pearlman's ACP Model (Pearlman

et al., 1995).

The next theme was lack of fear of death as a facilitator for ACP. One resident was a

World War II veteran and expressed lack of fear of dying, even at a young age. Some of

the other residents also agreed they lack the fear of death that was present earlier in their

life. One resident, while discussing the change in death perception, stated, "They look at

death differently when they are younger. You know, than we do." Two residents

specifically stated they had no fear of death, which was talked about as a positive

facilitator for ACP completion. Lack of fear of death is not explicitly stated within Pearlman's ACP Model, but it could be considered part of the *values* of the *person*. This value could change the behavior of *documentation of preferences* (Pearlman et al., 1995).

Another theme mentioned by the residents was a previous experience with the loss of a loved one. Two residents talked about the death of their spouse, and how the death impacted their decision to participate in ACP. Other residents talked about the dying process as it related to their parents. Perceptions of both positive and negative death experiences influenced the residents' wishes for their future deaths. All of the residents noted previous positive experiences with hospice care, and how they would all like to use hospice services at the end of their lives. This theme is also not explicitly noted within Pearlman's ACP Model; however, it could also be considered part of the *person* section in either *beliefs about benefits and self-efficiency* or *human info processing* (Pearlman et al., 1995).

An additional theme mentioned by the residents was having a plan in place to decrease the burden placed on family members. One resident stated, "Plans don't always work out… but I like to have plans for the future." Another resident talked about having a *First Steps*® conversation with a son present. She talked about not wanting to have to burden someone with removing life-saving or life-maintaining treatment. She noted her family as having an understanding of her acceptable quality of life by stating, "This is up for my children to discover, their mother's quality of life." Her quote referenced her children's understanding of what kinds of decisions she would want if she were unable to make her own decisions. Another resident talked about changing the named advocates on both his and his wife's AD to specifically name their daughters. This was done to

prevent not having a decision-capable advocate. While the reasons to decrease familial

burden vary, all residents agreed it was appropriate to participate in ACP for the purpose

of decreasing familial burden. This is a theme which is explicitly stated within

Pearlman's ACP Model within the *outcomes* section (Pearlman et al., 1995). This theme

aligns with the concept of *decreased burden on proxy/family* (Pearlman et al., 1995).

The last theme that all the residents agreed upon was that Christian faith is a positive

facilitator for ACP. Faith was referenced more than twenty times throughout the focus

group as having influenced both life decisions and ACP decisions. Some residents grew

up in Christian faith while one did not become a Christian until adulthood. All the

residents talked about how faith decreased their fear of death. Since faith was such an

integral part of their lives, it would also be integral in death. This theme of faith is

congruent with the concept of *values* within Pearlman's ACP Model (Pearlman et al.,

1995). Residents emphasized the importance of this theme disproportionate to the

amount of space Pearlman gives *values* in his model.

Residents mentioned other people as having a positive effect on ACP; these include

spouse, family, and clergy, as well as legal and medical professionals. The two residents

who had lost their spouses talked about working on their own advance care plans

following their spouses' death. Family was mentioned a number of times in relationship

to changing the named health care power of attorney. Clergy were mentioned as an ACP

facilitator to decision-making. An attorney was referenced as having said, "You never

know, something might happen." Finally, a medical professional was noted as having

been in support of withdrawing life support to allow natural death for the spouse of one

resident. This resident did not want someone to have to withdraw life support for her,

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which was a positive facilitator for ACP. This theme of people having influence on ACP decision-making is consistent with Pearlman's ACP Model concept of *communication among stakeholders* (Pearlman et al., 1995). The focus group interview helped the residents identify other stakeholders who were influential in their decision-making process. Alternative reasons for participating in ACP mentioned by residents were education about ACP, a college education, maturity, personal organization, and illness.

Barriers preventing the completion of an ACP document, such as an AD, were all related to the theme of uncertainty in illness. Some residents discussed not knowing what will happen to them as a barrier to finishing the document. Having uncertainty in illness progression or uncertainty about death were reasons for some ACP conversations to occur, but as one resident stated, "I don't know if I want to put resuscitation yet, or not." Later, she went on to reference uncertainty in illness by stating, "That's why we didn't sign it at first." She also stated, "There is a difference between existing and living. I want to live, but I don't want to just exist." No residents verbalized living as equivocal to being alive in a persistent vegetative state. Another resident, who has been living with a chronic and debilitating disease for a number of years, stated, "It was hard for us to write down directives of what we wanted because there are so many unknowns with health care." In referencing her husband's death, she also went on to say, "I realized it was nothing we could have put on paper, to write down directives, because there is no way of knowing what your needs will be at the end of life… So, we left ours unanswered that way." Even after facilitated conversations regarding ACP, of the five residents present, only two felt their completed AD document reflected their current wishes. Three of the five residents still had some reservations about the document. Two of those three had a

completed document with hand-written changes, while the other resident did not have any documentation completed. Relative to the stages of behavioral change, a person may not progress out of the *contemplation* stage if he or she is unable to come to a decision regarding what he or she would want in the ACP document (Prochaska & Velicer, 1997).

Question 4

The fourth question brought the residents back to the ACP conversation by inviting them to give examples of alternative things to cover in ACP. Generally speaking, those who remembered the facilitated conversation were pleased with the content already embedded into the script. Residents emphasized the importance of having family present for the conversation, especially when a family member is also the designated advocate. One resident noted that during a conversation to assist another individual with decision-making, it is important for the interviewer to remain neutral and to "accept the expression the person is stating." Both of these suggestions are relevant to ACP facilitations, and both are part of the education and training provided when learning how to facilitate an interview using the *Respecting Choices*® curriculum (Hammes & Briggs, 2011).

A suggestion for improving the interview included adding a section to discuss the nature of disease progression so the resident would be able to make a more informed decision. Because the residents had only participated in *First Steps*® planning conversations, they were unaware of content covered within a *Next Steps*® conversation. A *Next Steps*® conversation specifically covers disease progression as it relates to the individual. The *Next Steps*® conversation may only be completed with a medically educated individual and is outside of the scope of this project.

Question 5

The last question was specific to ACP at this RC and invited the residents to give a recommendation about changing the ACP process within the institution. There were no consistent agreements reached on this topic, and there were no disagreements with any of the recommendations. The first recommendation was to start the ACP conversation with stories of previous experiences. This parallels the *First Steps®* facilitation, which also starts with personal stories about ACP. The next recommendation was to keep the conversation simple, specifically stated by one resident, "simplify, simplify, simplify." The next recommendation was to make a facilitated ACP conversation "an automatic thing when [new residents] come to" this RC. This resident likened it to being as essential as "getting their storage room and finding out where their keys go." The final recommendation was to remind residents that participation in ACP is voluntary.

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Summary

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Following the conclusion of the focus group, residents were thanked for their time and the experiences they shared. They were all reminded to take the information sheets provided and to call or write with questions or comments they might have. Overall, the focus group conversation produced twenty-three pages of typed transcription. Participants only required redirection one time. The general tone of the focus group became more comfortable as the focus group proceeded. In general, all group members came to a consensus about having had a good life and expressed the desire to have a good death. They also felt mental incapacitation was equal to death. Residents agreed there is a difference between existing and living. All participants were residents of a faith-based retirement community and had similar ethnicities, so it was expected they would find

some common ground while having various perspectives regarding ACP. The common

facilitating themes linked to ACP throughout the interview were future preparedness,

having something in writing, feeling of comfort, communication, family involvement,

advancing age, knowledge of future death, lack of fear about death, previous experience

with loss of a loved one, preventing burdening families by planning ahead, and Christian

faith. Participants were troubled the most by uncertainty of illness as a barrier to

completing ACP. Residents perceived ACP as a complex process which requires

consideration of multiple components and stakeholders to be successful. The benefit of

this focus group to the residents was defining the value of the ACP process in their life.

CHAPTER 6

DISCUSSION

The purpose of this chapter is to relate the findings of this project to clinical

application. Strengths and limitations of this project will be discussed first, followed by

implications for nursing practice. Then, roles of doctoral nursing practice and doctor of

nursing practice (DNP) essentials will be discussed as I enacted the roles and as the

essentials relate to this project.

Strengths

The greatest strength of this project was giving a voice to residents of a retirement

community who had participated in facilitated advance care planning (ACP)

conversations. Focus group methodology is one of the preferred ways to collect

information about experiences and perceptions (Krueger & Casey, 2009). It is a well-

known way to collect qualitative data (Morgan, 1997). This project was well suited for

qualitative data collection because the purpose was to gather perceptions of residential

elders regarding the facilitators of and barriers to ACP. The focus group interview

elicited productive and beneficial conversation among group members, which may not

have been produced with individual interviews. Another strength of this project was

directed conversation and interaction among group members, which validated some

themes. Some consistent agreements were reached among the group members, which

strengthened the analysis for themes. No one person dominated the interview, and

moderator redirection was minimal. There was good involvement from all members,

which is also considered a strength for focus group interviews (Krueger & Casey, 2009).

Limitations

Some limitations exist which could have been avoided if this project had been completed a year prior. A lag existed between the pilot project the retirement community (RC) and the focus group interview for this project. This interval of one-and-a-half to two years limited the number of eligible participants. Attrition in this aging population from death or mental incapacity was an unavoidable limitation. Another limitation was only having one focus group of only five residents. An increase in resident participation or an additional focus group may have increased data richness.

The narrow demographic profile of participants interviewed could be viewed as another limitation. All residents interviewed in this project were of similar racial and religious backgrounds. This project, therefore, cannot be directly translated to other residential populations who do not share these traits, specifically with regards to beliefs of other religious groups.

An additional limitation of this project was that one resident in the focus group was unable to recall his or her facilitated ACP conversation. This information was gathered after the start of the focus group, and an executive decision was made to keep her in the group. She was aware of ACP opportunities in the community, and she was a productive participant to the focus group. The final limitation was that the moderator had no previous experience moderating a formal focus group, and in hindsight, some comments may have benefitted from follow up questions. Even with the limitations as they were, the focus group produced interesting conversation, which reinforced the findings in the literature.

Implications for Nursing Practice

Numerous implications for nursing practice can be drawn from the project. The first should be to encourage patients to have an ACP conversation with an educated facilitator, so that confusing terminology can be clarified and a clear understanding of wishes can be determined. Currently, a grassroots effort supported by a local Michigan non-profit group offers patients or residents of any retirement community a referral to an educated facilitator for an ACP conversation free from charge. As the residents in the focus group stated, it was important for them to be encouraged to participate in ACP by a trusted individual. At times, a trigger to participate inevitably made the resident seek end-of-life planning in one form or another. End-of-life planning was not always specific to health care needs or requirements, so an educated facilitator should follow up to ensure an ACP document is complete. Residents who had made a health care power of attorney or advance directive (AD) with an attorney often did not preserve the decisions made in the original document, which is another reason to encourage residents to seek educated facilitation with their advocates.

The next implication for nursing practice is to encourage residents or patients to visit and revisit the documents at prescribed intervals (Storey & Sherwen, 2013). This repeated action not only ensures residents are able to find the document, but that they will be able to make changes as necessary. Some of the residents in the focus group changed advocates based on the changing mental capacity of their previously named advocates, while others changed advocates due to proximity of their new advocates.

Another implication for nursing practice is to better integrate ACP into an established protocol such as an admission, annual visit, or health visits for declining

health. Residents' perceived increased acceptance for ACP when it was incorporated into a previously scheduled activity. Increasing provider-led exposure to ACP would also give residents permission to talk about end-of-life wishes with family in a comfortable and less threatening environment.

The final implication for nursing practice is to encourage ACP participants to involve the advocate and family members in the planning process. Many residents in the focus group commented on the perceived decreased sense of burden to the family when the advocate and family were involved with decision-making. This is also consistent with Detering et al. (2010) findings of decedents' family members who were involved with decision-making prior to the end of life. Family involvement is also a benefit, because it allows for the correction of misunderstandings about the wishes of the resident.

Doctor of Nursing Practice Roles and Essentials

This project served as a means to integrate some parts of the DNP degree completion requirements. Within this DNP curriculum, students learn to engage in numerous roles, as well as assimilate the eight essentials for doctoral nursing education. This project did not encompass all five of the roles or all eight of the essentials in completion; however, many of the roles and essentials were required to complete this project.

The DNP roles are practitioner, advocate, clinical scholar, educator, and innovator (Dreher & Glasgow, 2011). I enacted the role of practitioner when I facilitated ACP conversations. Having completed conversations with residents who are comfortable and feel safe enough to discuss end-of-life options requires proficient communication skills. I enacted the DNP role of advocate when this project started in the retirement community

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setting. My role as advocate was to encourage new residents to participate in ACP conversations in an effort to increase the likelihood of them having their wishes followed at the end of life (Hammes et al., 2010; Kirchhoff et al., 2012). The role of advocate extends beyond the patient or resident to the institution and legislation. Ensuring residents have the resources within an institution for ACP is as important as ensuring there is a mechanism for reimbursement for the practitioner providing that service (Hammes & Briggs, 2011).

Clinical scholar was another role enacted throughout this project. This scholarly project pushed my boundaries beyond the previous scholarly work I have done. This project demonstrates my ability to coordinate a scholarly project, and it has provided direction to develop this role.

The role of educator was also evident throughout this project. The majority of the educator role included educating staff and residents of the retirement community in order to clear misconceptions and give guidance about ACP. The role of innovator in this project was more limited, as moderating focus groups and facilitating ACP conversations were well-established roles prior to this project. A DNP's role as innovator is to take feasible studies and translate them into additional patient populations or contexts, and this was demonstrated by using the focus group methodology in a residential elder population.   As the DNP degree continues to gain momentum, it is critically important to continue to develop competency with these roles to help shape the future of health care.

There are eight DNP essentials that DNP programs use for accreditation and as a basis for curriculum. The eight essentials are: (I) Scientific Underpinnings for Practice, (II) Organizational and Systems Leadership for Quality Improvement and Systems

Thinking, (III) Clinical Scholarship and Analytical Methods for Evidence-Based Practice, (IV) Information Systems/Technology and Patient Care Technology for the Improvement and Transformation of Health Care, (V) Health Care Policy for Advocacy in Health Care, (VI) Interprofessional Collaboration for Improving Patient and Population Health Outcomes, (VII) Clinical Prevention and Population Health for Improving the Nation's Health, (VIII) and Advanced Nursing Practice (American Association of Colleges of Nursing, 2006). Most of these essentials are out of the scope of this project, but were incorporated into my doctoral education through various means. Of the eight essentials, there were three essentials inherent to this project: I, III, and VI. Essential I (Scientific Underpinnings for Practice) ensured this project was rooted in evidence. Essential III (Clinical Scholarship and Analytical Methods for Evidence-Based Practice) was utilized following the focus group interview when the transcription was analyzed for themes, relationships to Pearlman's ACP Model, and clinical application (Pearlman et al., 1995). Essential VI (Interprofessional Collaboration for Improving Patient and Population Health Outcomes) was vital to the completion of this project. Successful ACP encompasses the facilitator and the resident with the designated advocate discussing wishes for health care at the end of life. Responsibilities for extend beyond the immediate stakeholders and include clinical staff for document procurement; information technology staff for document storage and retrieval; clinical staff for document interpretation; educators for facilitators; and administrative staff for collaboration with the institution(s). These responsibilities for ACP are spread throughout the local community in Michigan to ensure all ACP facets are in place. Understanding multiple roles and responsibilities ensures greater communication and flow among the

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interprofessional stakeholders. This essential interprofessional communication and collaboration is the key to any successful project.

Summary

This author explored ACP in residential elders in effort to determine facilitators of and barriers to ACP in this setting and provided a vehicle for expression for residential elders. Additionally, this project explored perceptions of experiences as they relate to ACP in a residential community setting. Future outcomes of this project align with the Triple Aim to provide safe, quality, cost effective health care in a population at risk (Berwick et al., 2008). The foremost outcome for ACP is to provide care consistent with patient wishes while improving the experience of health care. Next, ACP preserved patient autonomy and potentially reduces the burden of unwanted care in this population. While this project did not specifically address a health care need, this project clarified misunderstandings about the residents' ACP documents. The final aim of ACP is to decrease the cost of care at the end of life. This may be realized for those who completed the ACP process as unnecessary treatment is not provided to those who do not want it and only provided to those who do. Continued scholarly efforts will need to be done to ensure residents' wishes are being discussed, documented, and carried out in practice. Future health care outcomes related to ACP may be realized within this decade and as generations age.
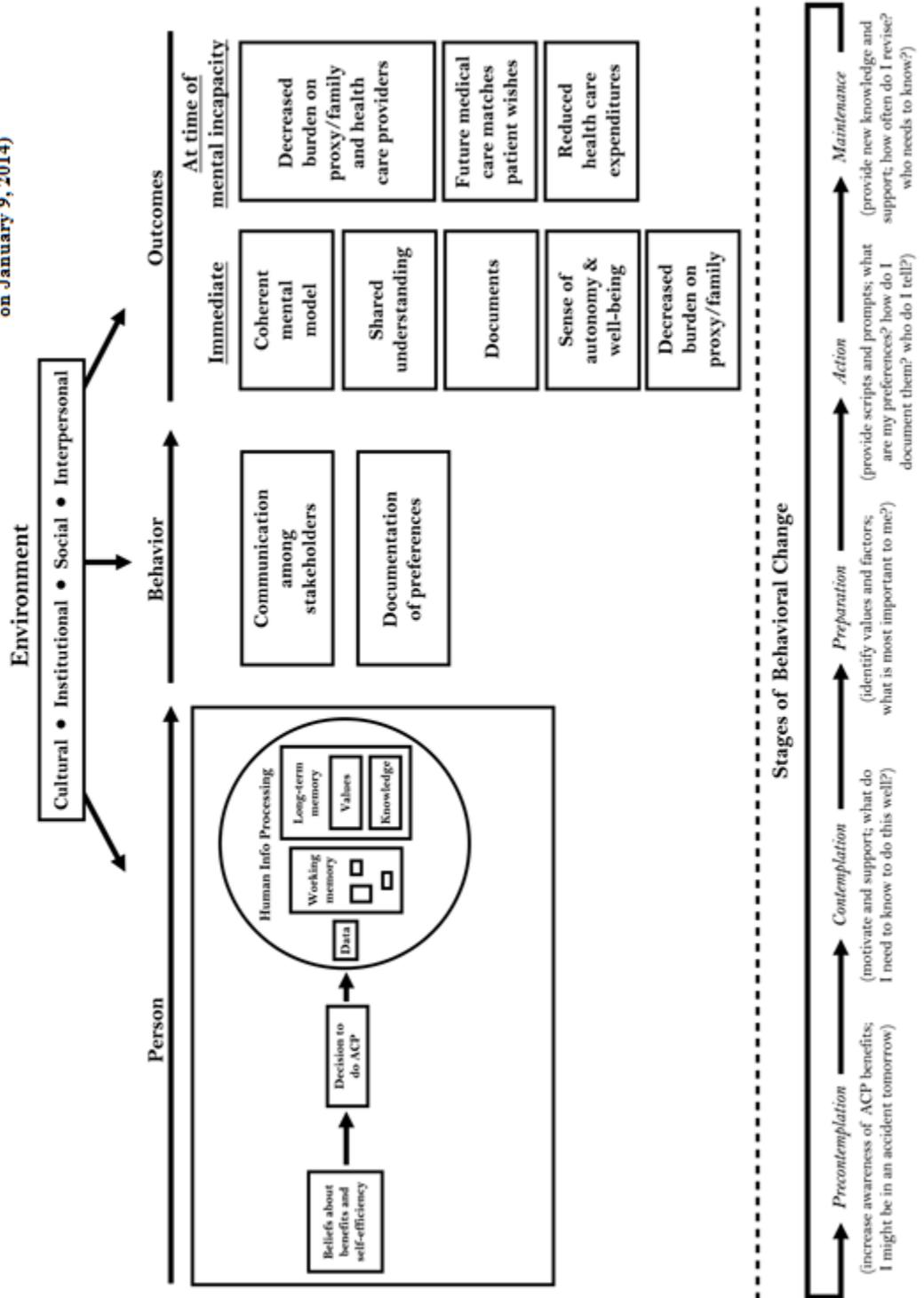
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APPENDICES

Appendix A

Pearlman's Advance Care Planning Model

Pearlman, R. A., Cole, W. G., Patrick, D. L., Starks, H. E., & Cain, K. C. (1995).

Advance care planning: Eliciting patient preferences for life-sustaining treatment.

Patient Education and Counseling, 26, 353-361.

Pearlman's Advance Care Planning Model

Environment

Cultural • Institutional • Social • Interpersonal

Person → **Behavior** → **Outcomes**

Person

Human Info Processing

Long-term memory
Values
Knowledge

Working memory

Data

Decision to do ACP

Beliefs about benefits and self-efficiency

Behavior

Communication among stakeholders

Documentation of preferences

Outcomes

Immediate

Coherent mental model

Shared understanding

Documents

Sense of autonomy & well-being

Decreased burden on proxy/family

At time of mental incapacity

Decreased burden on proxy/family and health care providers

Future medical care matches patient wishes

Reduced health care expenditures

Stages of Behavioral Change

Precontemplation
(increase awareness of ACP benefits; I might be in an accident tomorrow)

Contemplation
(motivate and support; what do I need to know to do this well?)

Preparation
(identify values and factors; what is most important to me?)

Action
(provide scripts and prompts; what are my preferences? how do I document them? who do I tell?)

Maintenance
(provide new knowledge and support; how often do I revise? who needs to know?)

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Appendix B

Invitation

Dear ***,

Thank you for taking the time to read this letter. I am Teresa Boersma, a student at Grand Valley State University. You are receiving this letter because of your previous work with an advance care planning program at this retirement community.

I am interested in your experience and opinions regarding your advance care planning session here. You are invited to participate in a focus group with other residents to gather information about your experience. The results of this project will help me understand your point of view on what might be helpful or not helpful for others seeking advance care planning.

Our session will be tape recorded so that I capture your comments exactly. Your personal data, such as your name, gender, and age will not be shared to keep confidentiality. The session will be about 1-1.5 hours in length. Light refreshments will be served, and the session will be scheduled at a commonly agreed upon time right here at this retirement community.

Thank you for your time,

Teresa Boersma,
Doctor of Nursing Practice student
Grand Valley State University

Appendix C

Focus Group Guide and Questionnaire

Focus Group Guide

Welcome

Thank you all again for coming this afternoon. My name is Teresa Boersma, a doctoral nursing student at Grand Valley State University. As we begin, I want to run through the format for today's discussion. As health providers, we try to provide the best care we can, but we need to understand your experience and opinions too. The purpose of today's discussion is just that. Today you are the expert!

We want to focus on your experience with end of life planning known as advance care planning, or your process of completing your advance directive. To do this we will ask you to think back and describe your experience prior to the conversation with one of the three facilitators. Then I will ask about your experience with the trained facilitator. Following those questions, I will ask about what was helpful for you to participate in advance care planning and then what were the barriers. There will be time at the end of the session for you to bring up concerns or discussion points that were not covered.

General Information

We just wanted to review a few housekeeping details on how we will proceed. I will be moderating this session. I will be keeping track of time to be able to cover the questions in about a one hour time frame. Remember we are recording so we ask you to speak into your microphone so we can capture your thoughts correctly. We want to make sure that anyone who would like to respond to a question is able to do so, please take turns talking so that we can understand all of your words. If several of you are talking at the same time, the tape will get garbled and we will miss your comments. We are interested in

every word you say. We are on a first name basis today, and in our later reports no names will be attached to comments. I just want to remind you that you can use a different first name should you wish to do so. We placed a name card in front of you and you can write the first name you would like to use during our focus group session. Now, let us all take a turn to say our names so that the professional recorder and transcriptionist can double check the recording. There are no right or wrong answers, and you do not need to come to a common answer as a group. Please feel free to share your point-of-view even if it differs from what others have said. Last, we want to remind everyone here today to respect the privacy of others and not repeat what is said in the focus group to others. Any questions before we start?

Questions

1. Think back a minute, and tell us about your experiences with advance care planning prior to the *First Steps* session.

   Probes:

   a. Can you talk about any experiences you have had prior to the *First Steps* facilitation?

   b. When you worked with Advance Directives in the past, tell me how it went.

2. Thinking back, please take a minute to tell me about your experience with the *First Steps* facilitated conversation.

   Probes:

   a. What were you thinking or feeling during your interview?

     b. What do you believe prompted you to participate in advance care

         planning?

     c. What value did you find with *First Steps* planning as it relates to you in

         your life?

3. Given what you have just told me about your *First Steps*® interviews, how do

    you see advance care planning helping you or not helping you?

    Probes:

     a. How was this helpful or not helpful?

     b. What parts of your advance care planning were more or less clear after the

         facilitation interview?

     c. If you needed to give your advocate a new copy of the document (advance

         directive, advance care plan, living will, Durable Power of Attorney), tell

         me, how did it go sharing your advance care planning document with your

         advocate or other family members?

4. If you were the facilitator, what else would you have covered in your *First Steps*

    facilitation interview?

    Probes:

     a. How was the length of time spent on each of the sections?

     b. Which parts did you feel rushed through?

     c. Tell me about the sections you felt were too long.

5. All things considered, if you could change one thing about advance care planning

    at this retirement community, what would it be?

Probes:

      a. How should advance care planning be presented to residents in

         independent living or assisted living?

      b. What should be avoided during advance care planning conversations?

      c. What was most effective for getting you to participate in facilitated

         advance care planning?

Conclusion of Focus Group

Before we close, is there anything else you would like to share with us?

Thank you all for coming this afternoon. It has been my pleasure to talk with you and learn about your experiences. Just a reminder that the information you gave today will be reported as in summary, and that you will not be tied to the comments you made. Please call or write me with any other questions you may have. Again, thank you for your time, and I wish you a great day!

Appendix D

Focus Group Information

Information to Act as a Participant in the Evaluation Project Titled:

Perceptions of Residential Elders following Facilitated Advance Care Planning

Project Leader: Teresa Boersma, BSN, RN, OCN, CHPN
Doctor of Nursing Practice (DNP) student
Ruth Ann Brintnall, PhD, AOCN, CHPN, APRN-BC
Kirkhof College of Nursing
Grand Valley State University

What is the purpose?
The purpose of this project is to examine your thoughts about advance care planning in a community residential setting following an advance care planning program. The aim of this project will focus on the conversation(s) between you and your facilitator and the conversation(s) between you and your healthcare advocate. Your thoughts will be explored using a focus group interview. The information gathered in this focus group may assist this retirement community with improving the existing advance care planning process.

Why am I being invited to participate?
You are being asked to take part in this project because you were part of an interview for your advance care planning about one and a half years ago.

How are participants selected?
You are being selected as a possible member because you are a resident at this retirement community, and you were involved with the previous project.

Who is doing this project?
Teresa Boersma, a registered nurse who is a Doctor of Nursing Practice student (DNP student) at Grand Valley State University (GVSU), is doing this project as part of her course work. She will moderate the focus group interview. Ruth Ann Brintnall, who is a registered nurse and professor at GVSU, helps to oversee this project. A professional recorder and will tape record the interview. A typist will change the tape recording into a written document for further review.

What procedures will involve me?
If you agree to participate, you will receive a follow up phone call to see when you are available to schedule the focus group. The DNP student will make final plans for the day, time, and room for the focus group interview. She will provide that information to you. The next step for you is to attend the focus group interview. This interview is expected to take about one hour.

There are no costs to you for joining this project. There is no payment to you for joining.

What are the possible risks of my participation?

There are no known risks to you from participating in this project. You will continue to receive the same care that you would normally receive at this retirement community.

There is a small chance that the privacy of your information may be lost. You should know that the DNP student will take careful steps to make this less likely. For example, when the DNP student looks at the final data, she will not use your name, gender, age, or any other identifying information in the final transcription. A specific code name will be given to you. The taped and written files will be stored in a secure data log saved on a secure flash drive and on a secure hard drive provided by GVSU. Information linking to your name and other personal information will be stored in a locked filing cabinet at GVSU in the nursing research office. Only the project leaders (Dr. Brintnall and Teresa Boersma) will have access to these data.

What are the possible benefits of my participation to me?

We cannot promise that you will receive any direct benefit as a result of you partaking in this project.

What are the possible benefits of my participation to society?

The knowledge that the DNP student gains from you may benefit other people who participate in advance care planning at this retirement community.

Who will know about my participation?

Any personal information from you that you disclose during the interview is placed into the data log will be kept as private as possible. In addition, you will not be identified by name, by your medical record information, your personal experiences, or your personal opinions in any publication of the project results.

Is my participation in the project voluntary?

Your participation in this project is completely voluntary. You do not have to participate. You may stop at any time. You will not be treated any differently if you choose to participate or choose not to participate.

How will my privacy be protected?

Your name will not be given to anyone other than those on the project team. All the information collected from you or about you will be kept private to the fullest extent allowed by law. In very rare instances, authorized university or government officials may be given access to the records for purposes of protecting your rights. I will keep your information for at least three years to follow federal law.

How will the results of this project be reported and how can I learn about the results?

The results of this project will be reported as part of a poster presentation to other students and professors in the Doctor of Nursing Practice program at Grand Valley State University. The results will also be included in a final project presentation at Grand Valley State University where the public may come to view. In the future, the DNP student may submit the results as part of an article to be published in a journal so that others can learn about this type of project and the results. At all times your personal information will not be shared, and all information is reported in summary so your personal information will not be identifiable.

Appendix E

Permission to use Pearlman's Advance Care Planning Model

Permission to use your model

Teresa Boersma ███████████████████   Jan 9 ☆

to robert.pearlman ▾

Dr. Pearlman,

I am Teresa Boersma, a Doctor of Nursing Practice student at Grand Valley State University in Michigan. The focus of my dissertation is advance care planning with ambulatory geriatric residents of a local retirement community. I am asking for permission to use your model as my theoretical framework and to have visualizations of your model in the appendices.

Thank you for your time and consideration on this. Should you have any questions, please feel free to email or call me.

Sincerely,
Teresa Boersma

███████████████

Pearlman, Robert A [REDACTED]   Jan 9 ☆ ↩ ▾

to me ▾

Teresa,

Of course you may use whatever work I have done on advance care planning for your own purposes. I presume you have reviewed my early work on "states worse than death" and the construct that links health state preferences to preferences for use of life-sustaining treatments. Let me bring to your attention three issues that you might be unfamiliar with and find helpful:

1. The following article may be difficult to find via a lit search: Pearlman RA, Cole WG, Patrick DL, Starks HE, Cain KC. Advance directives: clarifying patient preferences for life-sustaining treatment. *Patient Education and Counseling.* 1995;26:353-361.

2. The patient-centered workbook entitled "Your Life, Your Choices" was retired in VA, but is still being used elsewhere. I believe you can Google it (although there are other types of documents with the same name) and I believe it is still being used in the aging community in the State of Rhode Island.

3. A more up-to-date patient centered workbook entitled "Planning For Future Health Care Decisions...My Way" [often abbreviated to "Planning My Way"] was developed and approved in Va, but not released by the Executive Branch of the government. However, it is available (either as a hard copy or pdf) through a FOIA (Freedom of Information Act) request. The contact for requesting documents through a FOIA request is: Michael J. Wessel, MPA, VHA FOIA Office Staff Assistant, U.S. Department of Veterans Affairs, Veterans Health Administration, [REDACTED]
His phone number is [REDACTED]

Hope this information is helpful. Please send me a draft of what you produce.

Good luck!

Bob Pearlman

Teresa Boersma ███████████████████████   Mar 10 ☆ ↰ ▾

to Robert ▾

Dr. Pearlman,

I am working on the appendices for this dissertation, and I am having a difficult time with the picture of your model. Do you have a camera copy or other digital form of your model that I can use for the appendix?

Again, thank you for allowing me permission to use your work,

Teresa Boersma
GVSU Doctor of Nursing Practice student

···

Pearlman, Robert A ██████████████████   Mar 10 ☆ ↰ ▾

to me ▾

Teresa,

I'm afraid not. Sorry. Hope your dissertation defense goes well (or has gone well).

Bob

Appendix F

Permission to use Prochaska's Model

Permission to use your model `Dissertation` x

Teresa Boersma ▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓   Jan 10 ☆

to jop ▾

Dr. Prochaska,

I am Teresa Boersma, a Doctor of Nursing Practice student at Grand Valley State University in Michigan. The focus of my dissertation is advance care planning with ambulatory geriatric residents of a local retirement community. I am asking for permission to use your model as part of my theoretical framework, and to have visualizations of your model in the appendices.

Thank you for your time and consideration on this. Should you have any questions, please feel free to email or call me.

Sincerely,
Teresa Boersma

▓▓▓▓▓▓▓▓▓▓▓

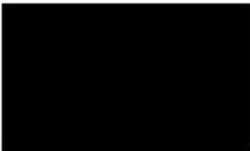**James Prochaska** ▓▓▓▓▓▓▓▓▓▓▓▓▓▓   Jan 13 ☆

to me ▾

Permission granted. Best of luck with your study.
James Prochaska

Appendix G

Permission from CEO of the retirement community

June 9, 2014

To The Grand Valley State University Human Research Review Committee:

I am writing this letter in support of Teresa Boersma's dissertation project. She is a Doctor of Nursing Practice student at Grand Valley State University. Her project will follow a quality improvement project previously completed here at ████████████████ The original quality improvement project included residents participating in facilitated advance care planning discussions with educated advance care planning facilitators. Her evaluation project will include inviting some residents to a follow up focus group interview which she will conduct. It is expected that this focus group interview will be recorded and then transcribed for later analysis. This focus group interview will gather experiences from residents about their perceptions regarding the facilitators and barriers to advance care planning.

Therefore, I give her permission to contact residents, conduct the focus group interview, and report her findings back to ████████████████

Regards,

████████████████

President/CEO

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