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**Perceptions of Persons with Dementia on What Matters in Making
Decisions about Advance Care Planning**

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Dedication

To my parents, Terry and Setsuko, for believing in me and my educational endeavors on a path uncharted in our family.

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Abstract

Perceptions of Persons with Dementia on What Matters in Making Decisions about Advance Care Planning

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With an aging Baby Boomer population, dementia in the United States is a prevalent disease. Persons with dementia (PWDs) often do not receive person-centered care at end of life because they are excluded from conversations between healthcare providers and family caregivers, and are often unable to communicate their wishes at end of life because of the severity of dementia affecting them. Engaging PWDs in advance care planning (ACP) is a strategy to increase person-centered care at the end of life for this population. However, ACP engagement rates among PWDs continue to be substellar. Thus, a secondary analysis was performed with a qualitative descriptive design in order

to describe how PWDs make decisions about engaging in ACP, as well as what facilitators and barriers exist when it comes to engaging in ACP. Findings were examined through the lens of the Ottawa Decision Support Framework. The original study had a convenience sample of seven PWDs and family caregiver dyads, as well as four health care providers, who participated in cognitive interviews about a decision aid for ACP amongst PWDs. The mean age for caregivers was 63 years old, and six of the caregivers were younger than 65 years old. All PWDs were over 65 years old, with the youngest PWD being 77 years old and a mean age of 83 years old. Content analysis of the cognitive interviews revealed PWDs' lack of knowledge about ACP concepts and process; the benefits of ACP to caregivers as surrogate decision-makers; caregivers' essential role in facilitating PWD's ACP engagement; support from family for PWDs to engage in ACP; PWDs' trust of caregivers to know and make the right decisions; the roles of caregivers; PWD's distrust of health care providers; health care providers' role in facilitating ACP; PWD's readiness to complete ACP tasks. These findings were also identified as facilitators and barriers. Findings from this study highlighted the importance of family caregivers being included in ACP conversations along with PWDs. These findings inform future research and nursing practice regarding ACP being an ongoing process that needs to occur early for PWDs.

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Chapter 1: Introduction

As the number of older adults, aged 65 years and older (Centers for Disease Control and Prevention, 2015), continues to increase in the United States, the number of people living with dementia also continues to grow (Alzheimer's Association, 2018). In fact, it is estimated that one person in the U.S. develops Alzheimer's disease, the most common cause of dementia, every 65 seconds (Alzheimer's Association, 2018). This increase in prevalence has resulted in Alzheimer's disease becoming the sixth leading cause of death in the U.S. and one out of three older adults dying with a form of dementia (Alzheimer's Association, 2018).

With dementia being a terminal, neurodegenerative syndrome, preparing for end-of-life (EOL) when persons with dementia (PWDs) still have capacity to make decisions is crucial in order for EOL care to be person-centered. Person-centered care is the notion that people should be treated as partners in making decisions regarding their healthcare because they are experts on their needs and are capable of contributing to their health and health outcomes (Health Innovation Network, 2016). The compounding impairments of memory loss, decline in executive function, and decline in ability to communicate eventually results in an inability for PWDs to engage in meaningful conversations, including about their preferences for healthcare at EOL (Hugo & Ganguli, 2014). Thus, because PWDs during the final stages of dementia are unable to inform healthcare providers and family members whether or not they want the invasive care associated with EOL for PWDs, such as feeding tube placement, CPR, or intubation and placement on a ventilator, PWDs are at great risk of not receiving person-centered care. Given these irreversible and progressive declines in cognitive and communication abilities, it is

imperative that discussions about advance care planning (ACP) be held with PWDs early in the dementia process. ACP is the process of evaluating, sharing, and recording personal values in regards to preferences for future medical care, with the goal being “...to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.” (Sudore et al., 2017). Researchers and healthcare providers are mostly in agreement that discussions should occur earlier in dementia, yet this is uncommon because everybody, including healthcare providers, PWDs, and family members of PWDs, are reluctant to discuss ACP (van der Steen et al., 2014). In order to develop interventions that can increase ACP engagement among PWDs during the earlier stages of dementia, we need to better understand the perspectives of PWDs in making decisions regarding engaging in ACP.

RESEARCH QUESTIONS

The specific aims for this study and the research questions were as follows:

Aim 1: Describe the decision-making process of PWDs to engage in ACP.

RQ1: What information do PWDs know about ACP?

RQ2: What is considered to be important when PWDs are deciding to engage in ACP?

RQ2a: What are benefits of ACP for PWDs?

RQ2b: What are the risks of ACP for PWDs?

RQ3: What support needs do PWDs have regarding ACP engagement?

RQ3a: What is the role of family members in their decisions about ACP?

RQ3b: What is the role of professionals in PWDs' decisions about ACP?

RQ4: What decisions do PWDs make regarding their level of engagement in ACP (e.g., intention to engage in informal discussion, actual completion of advance directives)?

Aim 2: Describe facilitators and barriers to PWDs making decisions about engaging in ACP.

RQ1: What facilitates PWDs engagement in ACP?

RQ2: What barriers prevent PWDs from engaging in ACP?

While ACP is arguably a health promoting behavior due to its potential for the promotion of quality of life (van der Steen et al., 2014), the purpose of this dissertation was to look at how PWDs actually make the decision to engage in ACP rather than explaining why PWDs engage in ACP. Describing PWDs engagement in ACP from this perspective is necessary because of the decisional conflict that they may be experiencing with ACP. Decisional conflict is defined as being uncertain about the best course of action when faced with making a decision and is associated with delayed decision making (O'Connor, 1997). PWDs are losing the ability to participate in ACP when they delay making a decision about ACP. Thus, the looking at how PWDs actually make the decision to engage in ACP rather than explaining why PWDs engage in ACP and using a decision-making theory from O'Connor & Jacobsen (2007), the Ottawa Decision Support Framework (ODSF), is appropriate given the aim of the study. The ODSF was used as a lens to provide a context for describing the findings. This framework identifies the decisional needs of patients and family members making decisions regarding the patients' health. According to the ODSF, these decisional needs include the information and values that affect decision making.

BACKGROUND

ACP became relevant in the United States (U.S.) with the passage of the Patient Self-Determination Act (PSDA) in 1990, which required health care facilities to ask admitted patients about the existence of advance directives and inform patients on their right to complete them. Although advance directives are not synonymous with ACP, the two are often discussed together as advance directives are the formal, written component of ACP that consists of recording one's wishes regarding medical care for a time when he/she is unable to communicate (Carr & Luth, 2017). The two most common advance directives are the medical power of attorney, or designation of a proxy decision maker, and the living will, or statement of medical care that is desired or not desired when in a condition that is either irreversible or terminal.

Despite the PSDA being nearly 30 years old, only about one third of adults in the U.S. have completed some form of an advance directive (Yadav et al., 2017). This lack of participation in the formal aspect of ACP is concerning as the aging Baby Boomer population means that there will be a greater demand for healthcare and eventually EOL care. Although ACP is important for every age group as death is not exclusive to older adults, most deaths in the United States occur among people 65 years and older (Kochanek et al., 2019). When people do not discuss their wishes for care at the EOL, their family and proxy decisionmakers are left guessing at what the person would have wanted. This uncertainty negatively impacts the decisionmakers in the moment as they struggle to make decisions (Chiarchiaro et al., 2015), and long term as they struggle to cope with the experience of having to make EOL care decisions on behalf of their family members (Azoulay et al., 2005). Furthermore, compared to responses from surrogate decision makers for patients who had not engaged in ACP, studies have found that care was more

likely to be consistent with decedents' wishes (Detering et al., 2010; Lantz & Meier, 2005; Morrison et al., 2005) and satisfaction with care was higher among patients at EOL who had engaged in ACP than patients who had not engaged in ACP (Gade et al., 2008). Studies have also reported that surrogate decision makers experienced less decisional conflict if critically-ill patients had previously engaged in ACP (Chiarchiaro et al., 2015).

Although discussing the financial costs of EOL care is unpopular, 25% of Medicare's expenses are from end-of-life care (Riley & Lubitz, 2010). ACP has the potential to change this as studies have found that ACP helps to decrease the cost of medical care at EOL (Hamlet et al., 2010; Lukas et al., 2013; Nicholas et al., 2014; Teo et al., 2014); Zhang et al., 2009. Thus, ACP is important in the older adult population because it provides the opportunity for people to receive the care that they want and may help to manage the costs of care at EOL.

In certain populations, ACP engagement is more common than among the general population. In a nationally representative, longitudinal study, 81% of people with terminal cancer had engaged in some form of ACP (Narang et al., 2015). This rate of engagement is likely higher than the general population since terminal cancers have a relatively predictable trajectory that is recognized by oncologists (Teno et al., 2001). However, this level of engagement is not seen among all people with terminal conditions. For PWDs, a reliable estimate for ACP engagement has not been established as rates reported by individual studies vary widely, from as low as 11.6% (Tay et al., 2015) to as high as 91% (Makino & Porsteinsson, 2015), based on sample size, setting of sample recruitment, and inclusion criteria such as not yet having an advance directive. Additionally, the influence of their living situation has made it difficult to report a rate that is accurate for all PWDs. Specifically, PWDs residing in nursing homes are more likely to have advance directives

than PWDs living in the community (Nicholas et al., 2014), which is likely related to the fact that all nursing homes in the United States are required to inquire about advance directive status and provide family members and residents with the opportunity to complete an advance directive at admission and throughout their stay at the facility. However, this should not be taken as an indicator of increased ACP engagement among nursing home residents with dementia since PWDs are often in the late stages of dementia at the time of admission (Gaugler et al., 2009) and thus lack the capacity to engage in ACP (Gregory et al., 2007).

Since dementia is not always recognized as a terminal condition (Mitchell et al., 2004; Mitchell et al., 2009) and the rate of decline for PWDs varies for each person (Alzheimer's Society, 2021), ACP is not always promoted to this group by healthcare providers. Even for healthcare providers that do understand that dementia is terminal, there is reticence to discuss planning for EOL since there is a concern that this discussion will make upset PWDs (Beck et al., 2017). Although it is the role of physicians and nurse practitioners to inform patients about diagnoses and prognoses related to dementia, all registered nurses are trained to be therapeutic communicators (National Council of State Boards of Nursing, 2018) who use active listening and conveying empathy to guide patients and families through difficult conversations. In addition to being the most abundant healthcare providers in the U.S., registered nurses spend more time with patients at the bedside in healthcare facilities than physicians do. This time spent with nurses may make it easier for patients and their families to confide in nurses about their thoughts, concerns, and EOL wishes. After all, nurses are consistently ranked as the most trustworthy profession (Brenan, 2018). The combination of nurses' ability to therapeutically communicate with patients and families and the time that they spend with patients and

families enables nurses to facilitate discussions to help patients understand their diagnoses and treatment options, increasing patients' knowledge while also empowering patients to make a decision that is right for them. In other words, nurses are capable of helping PWDs to engage in ACP and should be utilized for this purpose.

These skills are the embodiment of nurses' training to respect people's dignity by supporting self-determination, which results in nurses guiding patients in making informed decisions that are right for each individual (American Nurses Association, 2015). In fact, nurses' provision of respectful care that supports patients' dignity and autonomy, prepares nurses to deliver person-centered care. Person-centered care is based on Rogers' (1979) idea of the person-centered approach to therapy, that people have internal resources to contribute to their growth in therapy. Using a person-centered approach to healthcare allows for care to be personalized as an individual's values, circumstances, resources, strengths, and abilities are considered as appropriate plans for care are made (The Health Foundation, 2016; Health Innovation Network, 2016; Institute of Medicine, 2001). Therefore, engaging PWDs in ACP is an important part of person-centered care and nurses need to be involved in promoting engagement of ACP among PWDs because of their knowledge and skills in delivering person-centered care as well as their proximity to patients.

THEORETICAL LENS

The Ottawa Decision Support Framework (ODSF), developed by O'Connor et al., (1998), is intended to help healthcare providers support their patients as people by acknowledging patients' available resources and the resources needed in order to make a complex healthcare decision. Specifically, the framework suggests that decisional conflict

is a result of unmet decisional needs that have the potential to adversely impact decision quality, but addressing these needs through decision support improves decision quality (O'Connor & Jacobsen, 2007). Thus, the ODSF is a useful framework that can help identify ways to promote person-centered care. Specifically, it can help healthcare providers understand patients' decisional conflict and factors, such as uncertainty in knowledge, values, expectations, support, and current stance on the decision at hand. The healthcare provider can then identify appropriate decision-support that can address these contributing factors to the decision conflict.

Instances in which decisional conflict is experienced include when a person is unsure about the best course of action, such as when outcomes are uncertain, there is a significant gain or loss at stake based on the decision, personal values are at odds with the possible outcomes, or regret is anticipated due to not making a certain decision (O'Connor & Jacobsen, 2007). With these situations common in health care, ODSF was developed to help healthcare providers support patients and caregivers with making informed, value-based decisions regarding medical care. Moreover, ODSF is intended for "...health decisions that: (1) are stimulated by a new circumstance, diagnosis, or developmental transition; (2) require careful deliberation because of the uncertain and/or value-sensitive nature of the benefits and risks; and (3) need relatively more effort during the deliberation phase than the implementation phase" (O'Connor et al., 1998). Given these criteria, ODSF is applicable to ACP among PWDs since PWDs must deal with a new diagnosis and the progressive loss of their cognitive abilities, need to carefully consider what is important to them in care provided at the EOL, and the completion of advance directives and communication of wishes is easier than deliberating what kind of care they want to receive and who they want to make decisions on their behalf. Thus, the ODSF was a suitable lens

for this dissertation as PWDs in the early stages of dementia engaging in ACP meet this set of criteria.

Looking at the literature on the broader population of older adults, studies on their engagement in ACP have mostly used behavioral change theories. These studies offer conflicting findings on the benefits of popular behavior change theories such as the Health Belief Model (n=2) (Ko & Lee, 2009; Liu, 2018) and Protection Motivation Theory (n=2) (Allen et al., 2009; Payne et al., 2010) in studying engagement in advance care planning behavior. Thus, despite the popularity of these theories, there is not convincing evidence that they provide a sound theoretical explanation for how or why older adults engage in advance care planning.

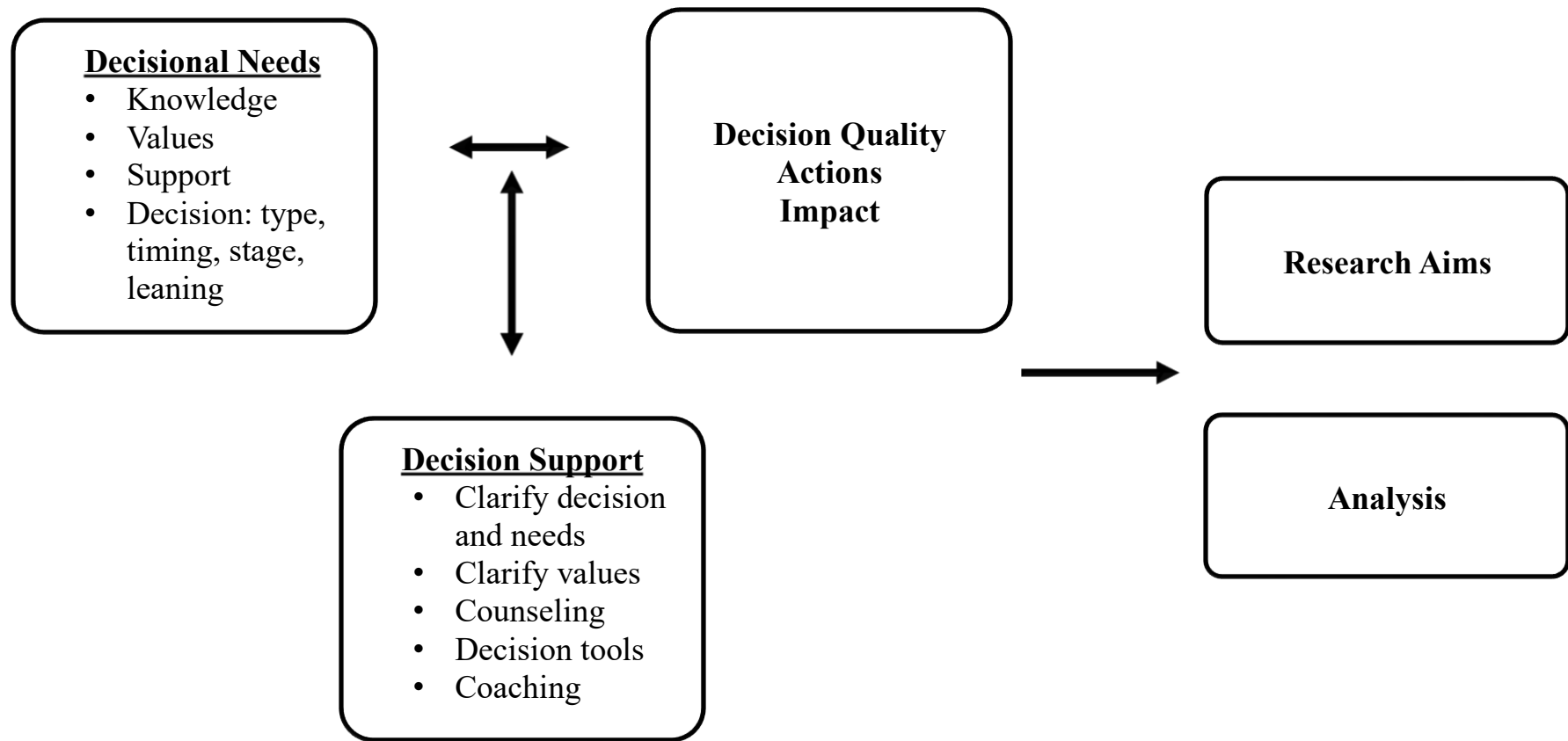
In the ODSF, concepts and constructs are organized within three boxes representative of essential elements of decision making: decisional needs, decision support, and decision quality (O'Connor & Jacobsen, 2007; See Figure 1). Decisional needs are intrapersonal and interpersonal factors that may be modified. Common decisional needs include lack of knowledge about options, unrealistic expectations about outcomes, lack of clarity regarding personal values, and a relationship that inhibits taking on the desired role in decision making. Modification of decisional needs can be achieved through the use of decision support, which includes "...clinical counselling, decision aids, and coaching..." (O'Connor & Jacobsen, 2007). Depending on the decisional needs of the patient, decision support may include clarification of needs and values, information on facts and probabilities of prognosis/outcomes, coaching through the decision-making process, and facilitating communication. The decision support provided to the patient and family member, if involved, affects the decision quality. While decision support is not intended to help a patient make a "correct" decision since the value of the outcomes is dependent on

the patient's perspective, decision quality is said to be "good" if the decision is informed and based on the patient's values. A patient can make an informed decision when he/she understands essential information about their medical condition, available options, and the benefits and harms associated with the outcomes of his/her decision (O'Connor & Jacobsen, 2007). The decision is values-based when the decision aligns with the values of the informed patient. For this dissertation, the decisional needs component of ODSF informed the aims and provided context for understanding the responses of PWDs. The questions that were posed to PWDs were asked in order to describe their knowledge and expectations, values, support and resources, and personal characteristics.

SUMMARY

Engaging PWDs in ACP early in the disease process is important in order for this population to receive person-centered care at the end of life. In order to attain this goal, researchers and healthcare providers first need to understand how PWDs decide to engage in ACP. Thus, the purpose of this study was to describe how PWDs make decisions about engaging in ACP and what facilitators and barriers they encounter in making decisions regarding ACP. The ODSF was used in formulating questions posed to PWDs and caregivers during interview, as well as a lens when analyzing data from the interviews.

Figure 1. Ottawa Decision Support Framework (ODSF) as a Lens



Chapter 2: Literature Review

Full disclosure: the majority of this literature review has been published in the journal of Geriatric Psychology and Neurology (September 2019, volume 32, issue 5) as *Perspectives and Experiences of Persons with Dementia with Advance Care Planning: An Integrative Literature Review*. The PI (L.G.) was first author, Dr. Kwak was second author, and Dr. Radhakrishnan was third author. Parts of the literature review have been edited to flow with the dissertation proposal format.

Considering the growing number of PWDs, it is imperative that advance care planning (ACP) be discussed with PWDs early in the disease process (de Boer, et al., 2012; Mitchell et al., 2012). Given the progressive decline in cognitive and functional abilities of PWDs, they and their families should revisit and update their wishes periodically while the PWD has capacity because although loss of memory and cognitive abilities accompany dementia, loss of personhood does not (Fazio, et al., 2018). Advance directives have increasingly received attention as an important means to respect and honor patient autonomy and as a critical element of palliative care, especially for PWDs (van der Steen et al., 2014). As mentioned in Chapter One, ACP engagement rates that have been reported for PWDs range widely and are inconsistent. Rather than focusing on ACP engagement rates, the known benefits of ACP and the continued poor outcomes at EOL for PWDs and their caregivers should be taken as evidence for the need for improved ACP among this population. Among people without dementia, ACP interventions have increased the occurrence of formal and informal ACP (Houben et al., 2014), increased the delivery of care consistent with participants' preferences (Houben et al., 2014), and reduced decision makers' psychological distress (Chiarchiaro et al., 2015; Hickman & Pinto, 2014). Among

PWDs, participation in ACP has been more limited compared to people with other terminal diagnoses, but ACP can help PWDs discuss their values, preferences, and treatment goals regarding EOL care with family members, other people important in their lives, and healthcare providers, as well as facilitate the recording of their wishes (Dixon et al., 2017; Robinson et al., 2012).

The available literature, however, suggests inadequate ACP among PWDs, as well as inadequate understanding of the wishes of PWDs among family members, resulting in challenges for surrogate decision-making, and poor outcomes for PWDs and family members (Forbes et al., 2000; Hirschman et al., 2006; Jeznach et al., 2015; Reamy et al., 2011; Shelton et al., 2017). In current clinical practice and research, the caregiver's perspective is often implicitly accepted as a proxy for the PWD's, even though studies have shown that it is difficult to predict the EOL preferences of PWDs (Denning et al., 2012). For PWDs who did not engage in ACP, these outcomes include aggressive EOL care including admission to an intensive care unit (Nicholas et al., 2014) and burdensome transitions between hospital and nursing home (Gozalo et al., 2011). Contrasting with these outcomes, PWDs who did engage in ACP are less likely to be admitted to a hospital at EOL (Garden et al., 2016), less likely to receive an enteral feeding tube (Gessert et al., 2000), likely to receive care consistent with their wishes (Livingston et al., 2010), and likely to die where they prefer (Garden et al., 2016; Livingston et al., 2010; Volicer et al., 2003). Likewise, caregivers of PWDs who engage in ACP have been found to be satisfied with the care that their family member received at EOL (Livingston et al., 2010) and have less conflict in making decisions compared to caregivers of PWDs who did not engage in ACP (Brazil et al., 2018). This difference in outcomes for PWDs and their caregivers who did and did not

engage in ACP is stark and highlights the need for better engagement in ACP in order to improve EOL care for this growing population.

The purpose of this integrative literature review is to identify and critically examine the current literature reporting on the perspectives and experiences of PWDs on ACP. In order for EOL care to be person-centered for PWDs, PWDs must be included in the ACP process and in research on ACP. Interventions for engaging PWDs in ACP cannot be effective if the perspective and experiences of PWDs on ACP is ignored. This review is necessary in order to inform current and future practice, and research, that is aimed to empower and engage PWDs in patient- and family-centered care planning throughout the dementia trajectory, including EOL care planning.

METHODS

Search Strategy

In November 2017, the CINAHL, Legal Collection, PsycINFO, PubMed, and SocIndex databases were searched for empirical studies reporting PWDs' perspectives on ACP. Search terms were comprised of combinations of: advance care plan, advance directive, living will, proxy, health care proxy, people with dementia, mental capacity, cognitive impairment, mild cognitive impairment, and mental competency. Figure 2 shows the specific search strategies used for each database. In order to capture all relevant literature, the start date was not restricted.

Eligibility Criteria, Screening, and Selection of Studies

Relevant literature met the following inclusion criteria: (a) interviews conducted directly with PWDs and (b) ACP for EOL as a topic of interest. Articles were excluded if they were not empirical; were literature reviews or case studies; were duplicates; were not

available in English; did not include interviews with PWDs; did not report findings obtained from PWDs as an individual group (i.e. findings were related to validating an instrument); did not focus on PWDs as the main population of interest; or studied ACP solely in terms of financial Advance directives. Of an initial 623 articles, a total of 14 were found relevant. A hand search identified 4 more, for a final total of 18. Figure 3 presents a flow diagram that shows when articles were included and excluded.

Data Analysis and Synthesis

Research on ACP with PWDs is new, so there were too few studies with similar methods and designs to allow a systematic review. Instead, an integrative review was appropriate, because both experimental and non-experimental studies were included (Whittemore & Knafl, 2005). By including quantitative and qualitative studies, an integrative review can provide a broader view of a topic than can other review types (Whittemore & Knafl, 2005).

Two of the authors independently reviewed each article; extracted information on key study design, method descriptions, and findings; and entered these data into a standardized extraction form in Microsoft Word, which was used to categorize the information within predetermined categories (e.g., purpose, research questions and hypotheses, methods, findings, limitations, etc.). Key domains or themes were identified based on the purpose and key research questions of each study reviewed. This process was performed by the first and second authors through reflection and iteration, first separately and then in discussion to resolve any discrepancies between the two authors' decisions.

The Mixed Methods Appraisal Tool (MMAT; Pluye et al., 2011) was used to assess the quality of the included studies. This quality assessment tool was well suited for this

review as it includes screening criteria for quantitative, qualitative, and mixed methods studies. While the criteria for each methodology and study design is different, criteria generally focus on sampling, data analysis, response rate, and reporting of findings. For each qualitative and quantitative study, four questions were answered to score the quality of the study. Three questions were answered for mixed method studies. While each criterion met was worth one point, (Pluye et al., 2011) recommend reporting the score as a percentage of criteria met, with the exception that a zero for a mixed methods study is equivalent to 25% and all three criteria met equals 100%.

The primary author (L.G.) independently assessed the quality of all 18 studies while the second author (J.K.) assessed 11 randomly selected studies to ensure reliability in scoring. Disagreements in scoring occurred on 6 studies and were resolved through discussion. The primary author revisited the scoring on the other 7 studies to confirm consistency in scoring, with only 2 studies requiring a change in score.

FINDINGS

General Characteristics

Designs and key findings from the 18 studies are summarized in Tables 1 and 2 respectively. Six studies were qualitative (de Boer et al., 2012; Dening et al., 2012; Dickinson et al., 2013; Goodman et al., 2013; Mulqueen & Coffey, 2017; Poppe et al., 2013), 10 were quantitative (Ayalon et al., 2012; Caplan et al., 2006; Fazel et al., 2000; Finucane et al., 1993; Garand et al., 2011; Hilgeman et al., 2014; Lewis et al., 2015; Makino & Porsteinsson, 2015; Tay et al., 2015), and 2 were mixed-methods (Karel et al., 2007; Lo et al., 2017). Of 13 observational studies, only 5 used longitudinal designs (de Boer et al., 2012; Finucane et al., 1993; Garand et al., 2011; Karel et al., 2007; Lo et al., 2017). Of 5

intervention studies, one used a randomized controlled design (Hilgeman et al., 2014). The studies were done in the U.S. ($n = 6$), UK ($n = 5$), Singapore ($n = 2$), Australia ($n = 2$), the Netherlands ($n = 1$), Israel ($n = 1$), and Ireland ($n = 1$). Overall, the sample sizes were small, but they ranged from 6 to 661. Only one study used a theoretical model (Hilgeman et al., 2014). Two (Garand et al., 2011; Lingler et al., 2008) drew samples from the same pool of participants: Garand et al. (2011) conducted a longitudinal analysis of changes in ACP completion in a subsample of 127 participants who did not have any form of ACP at baseline, drawn from a total sample of 661 patients who presented at a memory clinic over a 5-year period. Lingler et al. (2008) conducted a cross-sectional analysis of ACP completion among all 661 patients and an additional 84 participants recruited from the community who did not have dementia.

Quality of Included Studies

Overall, the quality of included studies was relatively low. Only 5 studies (Caplan et al., 2006; Hilgeman et al., 2014; Lingler et al., 2008; Makino & Porsteinsson, 2015; Tay et al., 2015) met 75% or more of the quality criteria for their respective study methodology and design. Thus, studies were not excluded on the basis of quality as this would have limited the number of included studies. Qualitative studies were consistently low in their scores because not one reported on a guiding epistemology, theoretical perspective, or methodology. Furthermore, none of the studies mentioned how the researchers' perspectives influenced any stage of their studies and only one study (Goodman et al., 2013) mentioned how the setting may have affected their findings. For quantitative studies, quality was negatively affected by information missing on the sample or sampling strategy.

The two studies which used quantitative and qualitative methods did not meet any of the criteria for mixed methods studies.

Synthesis of Findings

The 18 studies, which sampled 1,304 PWDs, focused on four domains: engagement in and correlates of ACP participation ($n = 5$), ability and attitudes toward ACP participation ($n = 7$), values and preferences at EOL ($n = 7$), and ACP interventions ($n = 5$). Four studies addressed at least two domains (Denning et al., 2012; Goodman et al., 2013; Karel et al., 2007; Makino & Porsteinsson, 2015).

Engagement in and correlates of ACP participation.

This domain was defined as PWD's engagement in ACP and their characteristics associated with ACP participation. ACP participation rates by PWDs reported by 4 studies (Garand et al., 2011; Lingler et al., 2008; Makino & Porsteinsson, 2015; Tay et al., 2015) varied. Two cross-sectional studies that recruited participants from memory clinics (Lingler et al., 2008; Makino & Porsteinsson, 2015) reported ACP participation rates (70%-90%) which were substantially higher than the average national rate of 30% for all U.S. adults (Yadav et al., 2017). Findings on correlates of ACP participation also varied. Lingler et al (2008) reported that being older, white, and college educated were associated with advance directive completion whereas Garand et al (2011) reported that being younger (less than 65 years old) was associated with completing an advance directive if participants were male, married, had more severe cognitive impairment, had a family member with Alzheimer's disease, or did not have depression at the start of the study. Lo et al (2017) found that the only significant correlate of ACP engagement was having never been married. Tay et al (2015) reported that PWDs' not thinking about ACP was the most

commonly cited barrier to ACP; other barriers were passive coping, measured as having no immediate plan in one's day-to-day life to participate in ACP, and a reliance on family to make future decisions.

Ability and attitudes toward ACP participation

This domain includes 7 studies that examined PWDs' ability to participate in ACP or PWDs' reporting of their attitudes toward ACP participation. Of the 6 studies that assessed the ability of PWDs to participate in ACP, 3 studies with PWDs in early or mild dementia reported that participants were able to meaningfully participate in ACP by expressing their values and preferences regarding EOL care (de Boer et al., 2012; Goodman et al., 2013; Karel et al., 2007). Three other studies, however, found that PWDs and caregivers reported ACP to be challenging for the PWD. These included 2 qualitative studies with PWD/caregiver dyads (Denning et al., 2012; Dickinson et al., 2013) citing challenges of thinking about future selves and ACP process being cognitively demanding. Similarly, Finucane et al. (1993) interviewed 6 PWDs 3 times, and found that only 2 participants gave meaningful, consistent answers, based on the interviewer's clinical judgment of each participant's understanding and reasoning.

Regarding attitudes toward ACP, Karel et al (2007) reported that more than half of PWDs did not find value assessment interviews to be a problematic experience. A study by Poppe et al (2013) reported that for PWDs interested in ACP completion, motivation was primarily due to worrying about their memory or having a desire to plan for when they would not be able to make decisions for themselves. Nine out of 12 PWDs who used the ACP tool found the discussions helpful. As for timing, all participants believed that earlier discussions about ACP with PWDs would be better.

Four qualitative studies, however, reported negative attitudes toward ACP among PWDs and caregivers. These studies included community-dwelling PWDs (de Boer et al., 2012; Denning et al., 2012; Dickinson et al., 2013) and PWDs living in nursing homes (Goodman et al., 2013). Reasons for negative attitudes toward ACP or not having completed an advance directive included perceptions that the utility of ACP to ensure respect for PWDs' preferences was limited (Denning et al., 2012; Goodman et al., 2013), that ACP was not relevant to everyday life (de Boer et al., 2012; Dickinson et al., 2013), that the opinions of PWDs had little value due to their cognitive decline (de Boer et al., 2012; Goodman et al., 2013), and that it was not the right time to begin ACP (Dickinson et al., 2013). Other cited barriers included lacking knowledge of ACP, preferring informal discussions and plans, restrictions on choices about future care options, and lacking of support to engage in ACP (Dickinson et al., 2013).

ACP interventions

This domain included 5 studies that developed and/or tested an intervention that either aimed to increase ACP participation by PWDs or included ACP as a part of the intervention to improve quality of life (QOL) of PWDs. Four studies tested ACP interventions for PWDs to increase ACP engagement (Caplan et al., 2006; Lewis et al., 2015; Lo et al., 2017; Poppe et al., 2013) and an additional study tested an intervention intended to improve health outcomes (Garand et al., 2011). Sample sizes ranged across these studies from as few as 19 participants (Hilgeman et al., 2014) to 158 (Lo et al., 2017). One study was a randomized controlled trial (Hilgeman et al., 2014), one did not randomly assign participants (Caplan et al., 2006), and the other three lacked control groups (Poppe et al., 2013; Lewis et al., 2015; Lo et al., 2017)

Of the 4 studies that tested an intervention to increase ACP engagement, only 3 reported ACP engagement rates (Caplan et al., 2006; Lewis et al., 2015; Lo et al., 2017; Poppe et al., 2013). None reported significant increase in ACP engagement rates post intervention. An informative seminar about ACP resulted in only 5 (2 caregivers, 3 PWDs) of 18 participants in the seminar actually completing an advance directive (Lewis et al., 2015). Lo et al (2017) provided 158 participants with MCI or dementia with a psycho-educational intervention about ACP and then assessed whether they wanted further discussions about ACP. After 12 months, only 10.6% of participants chose to complete an advance directive. Poppe et al. (2013) used the Advanced Care Planning in Early Dementia tool to assess how PWDs, informal caregivers, and memory service staff perceived ACP discussions. Despite testing an intervention for structuring ACP conversations, Poppe et al. (2013) did not collect information on ACP participation.

Two studies that examined the effect of ACP engagement on health outcomes reported significant, positive findings (Caplan et al., 2006; Hilgeman et al., 2014). Caplan et al.'s (2006) intervention focused on increasing ACP among nursing home residents by targeting residents, families, and nursing home providers with education and counseling at 19 nursing homes. At the end of a 3-year follow-up period, for those in the intervention group, calls to emergency services had decreased, fewer residents had been admitted to the hospital, and the number of days that residents spent in the hospital had decreased, whereas for controls, the numbers on all 3 of those measures were increased. Another intervention study (Hilgeman et al., 2014) aimed to improve physiological and psychological health through ACP among PWDs. Over 4 sessions, participants engaged in a reminiscence activity that allowed them to create an identity-preserving product such as a scrapbook or family tree. During one of these sessions, researchers engaged participants in discussing

how to talk about ACP and how to initiate such a conversation with family. In comparison with the control group, participants reported significant improvements in depression, QOL, decisional conflict, and mobility. Family members of intervention participants also reported that PWDs were less depressed, had a higher QOL, and had greater well-being. The study did not report on ACP documentation as an outcome.

Values and preferences for EOL care

This domain included 6 studies that examined PWD's values and priorities at the end of life, and life support treatment preferences. Four studies explored the end of life values and priorities for PWDs: three studies compared the reports between PWDs and non-PWD counterparts (Karel et al., 2007), family members (Denning et al., 2012), and nurses (Mulqueen & Coffey, 2017) while one study interviewed only PWDs. Priorities at the end of life for PWDs as well as life support treatment preferences varied depending on the respondent types, that is, PWDs and non-dementia counterparts vs. family members or healthcare providers. In Karel et al.'s (2007) study, both community-dwelling people with mild/early dementia and people without dementia prioritized autonomy, interpersonal relationships and communication as essential values to them. They responded that life would not be worth living with illness and loss of function, loss of mental capacity, a negative change in interpersonal relationships, loss of autonomy, or decreased QOL. The most important characteristics that would influence their decisions on receiving treatment were being able to make their own decisions, being able to communicate, QOL, and the emotional effect on their family.

PWDs prioritized family, place, and comfort in two other studies that compared PWD's reports with those by family members (Denning et al., 2012) and nurses (Mulqueen

& Coffey, 2017). On the other hand, informal caregivers of PWDs identified being in control as most important to PWDs, followed by more abstract concepts such as QOL and quality of care (Denning et al., 2012), and nurses perceived the preferences of PWDs from most to least important as communication, pain management, ACP, family involvement, and staff knowledge (Mulqueen & Coffey, 2017). The nurses emphasized clinical components of care such as communication, ACP, and pain management.

Goodman et al. (2013) asked PWDs open-ended questions such as “How would you like to be looked after when you are near the end of your life?” and “How would you like to be looked after if you became very ill/very poorly?” The authors identified three themes in participants’ responses: dementia and decision making, everyday relationships, and the significance of purpose and place. PWDs devalued their opinions due to their disease, that positive relationships with the staff increased their confidence that their wishes at EOL would be followed, and that previous losses negatively affected their perceptions of living and dying in a nursing home.

With respect to the preferences for life support treatments, Fazel et al (2000) found no difference in preferences for life-sustaining treatments (tube feeding, medical testing, and antibiotics) between PWDs and people without cognitive impairment. They also found that people with a higher Mini Mental State Examination (MMSE) score were more likely to choose nonintervention over life-sustaining intervention. Another study found that spouses could moderately predict PWDs’ preferences for treatment preferences at the end of life (Ayalon et al., 2012). In the case of severe dementia, a higher proportion of spouses of PWDs reported that their significant other would want CPR, mechanical ventilation, and artificial feedings than the PWDs reported to want for themselves. Similarly, a higher

percentage of spouses predicted that the PWD would want CPR or mechanical ventilation in the case of coma.

DISCUSSION

In the last few decades, ACP has been recognized globally as a critical element of palliative care, especially for PWDs (Jimenez et al., 2018; van der Steen et al., 2014). In the U.S., for example, since the passage of the 1990 Patient Self-Determination Act, broad efforts have been made to promote ACP by facilitating patients and their families to consider, discuss, and document their preferences for EOL care. Although the literature on ACP in general has proliferated since then, our review suggests that research to better understand the needs and preferences for ACP from the perspectives of PWDs is still new. Fourteen of the 18 studies reviewed here were published in the past 10 years. It is therefore unsurprising that no or few studies have utilized representative samples with well-defined groups of PWDs based on clinical assessments of dementia type and severity, prospective designs, standardized and psychometrically sound measures, and randomized controlled designs.

The small number of studies and the methodological problems in this research preclude definitive conclusions about PWDs' perspectives on and engagement with ACP. Nevertheless, the studies in this review present important initial steps in exploring and documenting the participation, attitudes, and preferences of PWDs for ACP. These studies have identified knowledge gaps, and they provide directions for practice and future research.

Four studies in this review explored engagement in and correlates of advance directive completion among PWDs, focusing mostly on the sociodemographic and clinical

characteristics of PWDs. Study designs and findings varied. Again, the small number of studies ($n = 6$) of the abilities and attitudes of PWDs with respect to ACP participation precludes definitive conclusions. The small number of educational interventions ($n = 5$), which included only one RCT, did not deliver promising results on increasing actual participation in ACP among PWDs, although most PWDs who participated in ACP did not experience undue distress, and many reported it as a positive experience.

Two consistent patterns, however, were observed. First is the role of family across all four domains. Families were critical facilitators as well as barriers to ACP among PWDs. While being married was reported as a significant correlate of having completed an advance directive, or having discussed EOL preferences with family, it was also the case that PWDs would not find ACP as relevant or urgently needed because they felt that families would make decisions for them. PWDs also reported that families and interpersonal relationships are key priorities at EOL while they felt that their values or preferences would not matter as much as what other family or professional caregivers would consider to be important. Such a critical role of family members in the lives of PWDs was recognized in ACP interventions for PWDs. Although studies reviewed were not explicitly clear on whether their interventions targeted both members of dyads, these interventions often included family members in the ACP discussions.

Another pattern that emerged from our review was that values, priorities and preferences for EOL care differed depending on the type of respondent. PWDs and persons without dementia identified similar priorities such as autonomy, interpersonal relationship including family, communication, and comfort. On the other hand, family members prioritized QOL and quality of care, and nurses reported clinical components of care (e.g., communication, ACP, and pain management) as priorities. Similarly, one study found

moderate association between the preferences of PWDs for life support treatment and spouse's prediction for the preferences of PWDs. These findings suggest that informal caregivers may or may not always be a reliable source for the values and preferences of PWDs for EOL care (Denning et al., 2012) or for life supporting treatments (Ayalon et al., 2012). The same is true of professional caregivers (Pope et al., 2013).

Strengths and Limitations

Given that most of the literature on ACP and PWDs focus on the perspective of healthcare providers and family caregivers, it is a strength of this integrative literature review that focus was placed on the perspective, preferences, and attitudes of PWDs. By including all available literature on this topic, regardless of methodology or quality, this review provides a broad overview of how researchers have already sought to understand ACP among PWDs. However, limitations of this integrative literature review include heterogeneity of the studies' samples, methods, and findings; the low number of studies on ACP among PWDs; the low methodological quality of the included studies. Readers should therefore understand these to be early findings which warrant further investigation wherein samples are well-defined and methods are well-described in order to produce higher quality research that can lead to improved engagement in ACP among PWDs.

Implications for Practice

Together, despite mixed findings, our review of the current literature reaffirms that the perspectives and lived experiences of PWDs should be a key consideration for clinical practice, especially engaging PWDs and families in ACP, as well as for research on how to develop and test patient-centered ACP and EOL care for this vulnerable, growing population. Not including PWDs in ACP is a failure to provide person-centered care.

Several recommendations from van der Steen et al. (2014) can be considered for clinical practice. Health care providers should treat PWDs and family caregivers as partners in care, and this relationship should be established in clinical practice in order to deliver care that is person-centered. This can be accomplished by inquiring about each person's information needs throughout the stages of dementia, including while receiving palliative care. Healthcare professionals should recognize varying cognitive abilities and preferences among PWDs for ACP and initiate and offer multiple opportunities for PWDs and family caregivers to consider the values and preferences of PWDs throughout the illness trajectory, recognizing that ACP is a process.

Given the critical role of family caregivers in the lives of PWDs and in care decision-making and planning, providers need to be prepared to offer support to families as they take on tasks and burdens associated with being caregivers and decision makers (van der Steen et al., 2014). Support provided by providers to families should include education on the progression of dementia; resources to help the family caregiver manage caregiver burden; and resources to navigate challenges that often accompany a dementia diagnosis (e.g., problematic behaviors, health problems, death). It is also important for providers to recognize and address ethical dilemmas that may emerge as the preferences of PWDs change or disagreements arise with families or providers about the PWD's preferences.

Implications for Research

The research on ACP with PWDs could clearly benefit from a number of improvements in methodology. These would include an increased linkage of research with theory to better understand the perspectives and lived experiences of PWDs, the use of

longitudinal designs, the inclusion of racially and ethnically diverse samples of PWDs and families, and the use of psychometrically valid instruments to measure the preferences of PWDs regarding ACP. Of the studies in this review, only Hilgeman et al. (2014) included a conceptual model—the stress process model—with which the authors proposed how their ACP intervention could affect coping and thus improve emotional and health-related outcomes. In designing a study, theory can inform a study’s rationale, the methodology behind its design, the instruments for collecting data, and the analysis of findings (Stewart & Klein, 2016). Furthermore, theory is important for organizing knowledge and developing critical innovations (Walker & Avant, 2011). Theoretically guided research is needed to explore how PWDs decide to participate in ACP, how the values and preferences of PWDs for EOL care change over time, and how family caregivers and providers identify and respond to such changes; it should also consider ethical dilemmas that emerge as the preferences of PWDs change over time or contradict the preferences and clinical opinions of family and professional caregivers.

Future studies should prospectively follow both PWDs and cognitively intact older adults to assess changes in attitudes about ACP and cognitive abilities to participate in ACP and should systematically identify both modifiable (e.g., care settings, access to primary care physicians or specialists) and non-modifiable (e.g., demographic characteristics) correlates of ACP participation among PWDs. This research should be joined by efforts to develop, test, and use reliable and valid instruments to measure attitudes and values of PWDs regarding ACP. Both observational and interventional studies should investigate the experiences of and attitudes toward ACP in PWDs and family caregivers in terms of the utility and timing of conversations. By identifying facilitators and barriers related to ACP and determining when it is appropriate to introduce ACP, healthcare providers can better

understand how to involve PWDs in ACP, especially when PWDs they are hesitant. Such findings can inform the design of future intervention studies that go beyond educating PWDs and their caregivers. For example, the incorporation of games as an ice-breaker or preludes to educational interventions can be a strategy to reduce emotional barriers to ACP among PWDs and caregivers (Radhakrishnan, 2017; Van Scoy, 2017).

Most studies in this review reported that their participants were mostly white (Denning et al., 2012; Fazel et al., 2000; Garand et al., 2011; Hilgeman et al., 2014; Karel et al., 2007; Lingler et al., 2008). Despite a significantly higher incidence of dementia among racial or ethnic minorities (Mayeda, Glymour, Quesenberry, & Whitmer, 2016; Plassman et al., 2007), such populations are significantly less likely to participate in ACP than their white counterparts (Lingler et al., 2008; McGuire, Rao, Anderson, & Ford, 2007; Triplett et al., 2008). An important, urgent priority for future research is to increase the diversity of study participants in order to better understand the roles of race, ethnicity, and culture in ACP participation among PWDs. Moreover, there is a need for more cross-cultural studies that compare and contrast cultural values and norms as well as legal frameworks and policies that influence how different cultural groups or societies operationalize the main underlying ethical principles of ACP and medical decision-making in the context of dementia. Ethical principles such as autonomy, informed consent, beneficence, nonmaleficence, and justice, while embraced by all, may be prioritized differently across differential cultural contexts (Johnstone & Kanitsaki, 2009). For example, decision-making can occur along a continuum, ranging from an approach based on individual autonomy (e.g., a western bio-medical cultural view) to an approach based on collective, family-centered decision-making (e.g., other cultural views). Thus, in the context of ACP with PWDs, where the PWD will experience diminished cognitive and

functional capacity over time and require increasing involvement of family members and healthcare providers in decision-making, it is important to examine how different cultures and countries apply key ethical principles to ACP with PWDs and their families.

Finally, the lack of a clear rationale for defining types and severities of dementia complicates the comparison of findings across studies. Because dementia is a syndrome caused by different diseases, researchers need to identify the different causes and levels of severity included in studies so that we can compare how PWDs with different diagnoses view ACP.

CONCLUSION

Planning for future care such as EOL care is emotional and cognitively challenging. ACP may be especially challenging for PWDs and family caregivers who deal with the everyday challenges of living with dementia. Yet with one third of older Americans dying with a form of dementia, it is essential that PWDs have opportunities to consider and discuss their values, preferences, and options for their future healthcare, including EOL care, with their loved ones and healthcare providers. Although PWDs or their families may not view ACP as urgent, it is important for healthcare providers to continue to talk with PWDs and their informal caregivers about it. More research, guided by theoretical frameworks and rigorous methodological designs, is needed to systematically examine cognitive, psychosocial, and environmental factors that influence the beliefs, attitudes, preferences, and choices of PWDs, as well as effects of interventions that promote ACP engagement of PWDs.

By performing this literature review, the PI was able to understand what is known about ACP among PWDs as well as identify gaps in the literature. Specifically, this

literature review guided the dissertation proposal by helping the PI realize that qualitative data was needed from the perspective of PWDs in order to better understand why they are not engaging in ACP and why ACP interventions are not working for them. The current literature is not adequate for understanding how PWDs make decisions, nor what PWDs see as facilitators and barriers to ACP. Furthermore, this review brought to light the limitations of some methods. For example, caregivers for PWDs tend to answer on behalf of PWDs as well as influence further responses by PWDs.

Table 1. Study Characteristics and Outcomes Measured

Study	Aims	Design	Country, Setting	Sample size, age, gender, race/ethnicity, dementia type and severity	Outcomes
Ayalon et al. (2012)	To evaluate concordance between PWDs and their spouses on PWDs' preferences for CPR, mechanical ventilation, and artificial nutrition	Quantitative, structured interviews	Israel Two psychogeriatric clinics	n = 53 (PWDs) Mean age: 75.8 32% women Race/ethnicity: not reported Dementia type/severity: MCI or dementia n = 53 spouses	Concordance between PWDs and spouses on PWDs' preferences for CPR & mechanical ventilation, and artificial nutrition in the case of two scenarios: severe dementia and coma
Caplan et al. (2006)	To evaluate an ACP education program for nursing home residents, families, and providers	Quasi-experimental design with intervention and control group	Australia 19 nursing homes	N = 45 Mean age: not reported Gender: not reported Race/ethnicity: not reported Dementia type/severity: not reported Mini Mental State Exam Score ≥ 16	Discussion of ACP, completion of advance care directive, documentation of preferences and plan of treatment in chart, location of death, number of emergency calls, hospital admissions, hospital bed-day use, and mortality
de Boer et al. (2012)	To explore the views of PWDs on ACP	Qualitative, semi-structured interviews	Netherlands Two university associated memory clinics	N = 24 Mean age: 76.3 42% women Race/ethnicity: not reported	Attitudes toward ACP and EOL planning using open-ended questions about

				Alzheimer's/Early dementia based on Global Deterioration Scale score	thoughts about the future (with a focus on health and care) and involvement in ACP
Dening et al. (2012)	To explore whether PWDs and their carers can identify and rank preferences for EOL care, as well as whether carers influence the preferences of PWDs	Qualitative, modified nominal group technique	UK Memory service	n = 9 (PWDs) Mean age: 83.3 66.7% women Race/ethnicity: 77% white Dementia type/severity: late onset Alzheimer's (n = 4), Atypical or mixed type Alzheimer's (n = 4), Alzheimer's of unspecified type (n = 1) n = 8 (carers)	Values and priorities for EOL care using open-ended questions about how PWDs define their wishes and preferences for EOL care, how family carers define preferences for their own EOL care, and whether the expression of the wishes and preferences of the PWD is facilitated or inhibited by the carer's being present
Dickinson et al. (2013)	To explore PWDs' and their carers' preferences for content, process, and timing of ACP	Qualitative, semi-structured interviews	UK Older people's services	n = 17 (PWDs) Mean age: not reported 29.4% women Race/ethnicity: not reported Dementia type/severity: Alzheimer's, Huntington's disease Dementia with Lewy bodies Vascular, mixed (Alzheimer's and Vascular dementia) Mild/moderate dementia	Preferences for content, process, and timing of ACP using open-ended questions about participants' attitudes and preferences for future care

				n = 29 (carers)	
Fazel et al. (2000)	To assess effects of cognitive impairment, intelligence, and capacity on treatment preferences	Quantitative, structured and semi-structured interviews	UK Two community psychogeriatric teams. Non-PWDs recruited from lunch club	n = 50 (PWDs) Mean age: 79.8 Gender: not reported Race/ethnicity: 99% white Dementia type/severity: not reported n = 50 (comparison group)	Completion of advance directives and preferences for life support for three vignettes: feeding tube post cerebrovascular accident, diagnostic testing post mild Alzheimer's disease, antibiotics/ hospital admission post severe Alzheimer's disease
Finucane et al. (1993)	To explore the level of burden of EOL questions on PWDs' capacity to participate in ACP, and reliability of PWDs' responses to EOL questions over time	Longitudinal quantitative, structured interviews	USA Alzheimer's disease support groups in Baltimore	N = 6 Mean age: 74 33% female Race ethnicity: not reported Dementia type/severity: Alzheimer's/ Early dementia	Consistency of PWDs' preferences over time by assessing preference for treatments in two scenarios, 5 closed-ended items assessing adverse emotional effect of interview, and clinical judgment (by clinicians) of meaningfulness of decision
Garand et al. (2011)	To longitudinally examine correlates of ACP completion over 5 years	Longitudinal quantitative, secondary data analysis	USA University affiliated Alzheimer's disease research centers	N = 127 Mean age: not reported 57% female Race/ethnicity: 90% white	Formal advance directive completion of either a durable power of attorney or living will

				Dementia type/severity: MCI and Alzheimer's/early to severe Alzheimer's	
Goodman et al. (2013)	To explore what factors influence preferences for EOL care	Qualitative, semi-structured interviews	UK Residential care home	N = 18 Mean age: 84 Female: 66% Race/ethnicity: not reported Dementia type/severity: not reported	Preferences for EOL care using open-ended questions were about wishes for EOL care and wishes for care when ill
Hilgeman et al. (2014)	To test the effect of an ACP intervention on physical and emotional health-related outcomes	RCT	USA Various institutional and community-based settings	n = 19 (PWDs) Mean age: 82.8 Female: 68.4% Race/ethnicity: 94% white Dementia type/severity: Alzheimer's (n = 4), dementia of unknown etiology (n = 8), vascular (n = 4), other (n = 2) Mild or early stages n = 19 (Family/friend)	Subjective health, Physical health (Self-Maintenance and Instrumental Activities of Daily Living Scale, Cornell scale for depression in dementia, Bath assessment for subjective quality of life in dementia), quality of life in Alzheimer's disease (QOL-AD), EuroQol-5 (EQ-5D), Decisional Conflict Scale
Karel et al. (2007)	To assess utility of three health care values assessments	Longitudinal mixed-methods, structured interviews	USA Various institutional and community-based settings	n = 81 (PWDs) Mean age: 75.42 Female: 42% Race/ethnicity: 92% white Dementia type/severity: Alzheimer's, vascular,	PWDs' ability and burden to participate in ACP and values that matter at EOL using a healthcare values survey with open-ended questions (2 items),

				Parkinson's, and/or alcohol-induced (subtype was not tracked) Early or mild dementia n = 84 (comparison group without dementia)	forced-choice questions (14 items), rating scale questions (13 items), naming of trusted and non-trusted surrogate decision maker; difficulty answering questions, 1 open-ended question about difficulty answering questions
Lewis et al. (2015)	To test ACP pilot program	Quasi-experimental intervention with no control group	Australia Cognitive Dementia and Memory Services, Victoria	n = 34 (PWDs) Mean age: 79.8 Female: 52.9% Race/ethnicity: not reported Dementia type/severity: MCI (n = 16), Alzheimer's: (n = 7), mixed dementia (n = 8), other (n = 3) n = 48 (carers)	Knowledge of ACP, formal advance directive completion, evaluation of experience (method not reported)
Lingler et al. (2008)	To identify correlates of completion of written advance directives	Retrospective analysis, semi-structured interviews	USA Memory Disorders Clinic, University of Pittsburgh Alzheimer Disease Research Center	n = 661 (PWDs) Mean age: 74.4 Female: 63% Race/ethnicity: 93% Mean age: 74.7 Dementia type/severity: MCI/early Alzheimer's (n = 369), moderate/severe Alzheimer's (n = 292) n = 84 (people without cognitive impairment)	Designation of a durable power of attorney or completion of a living will

Lo et al. (2017)	To identify correlates of ACP completion	Longitudinal, mixed methods	Singapore Memory clinic at a tertiary hospital	N = 158 Mean age: 76.2 Female: 60.8% Race/ethnicity: 61% Chinese, 39% non-Chinese Dementia type/severity: MCI or early dementia	Completion of formal documentation of values, wishes, and beliefs, formal identification and appointment of proxy decision makers
Makino and Porsteinsson (2015)	To explore ACP experiences and care preferences.	Quantitative, semi-structured interviews	USA Local memory care clinic or research study	n = 23 (PWDs) Mean age: 75.6 Gender: not reported Race/ethnicity: not reported Dementia type/severity: MCI (n = 17), early Alzheimer's (n = 5), other (n = 2) n = 23 (study partners)	Preferences for CPR, artificial nutrition, and ventilator; completion status of health care proxy, living will, and Medical Orders for Life Sustaining Treatment form.
Mulqueen and Coffey (2017)	To explore the PWDs' preferences for EOL care, and nurses' perceptions of PWDs' preferences	Qualitative study with nominal group technique	Ireland Nursing home	n = 6 (PWDs) Mean age: not reported Gender: not reported Race/ethnicity: not reported Dementia type/severity: Dementia/mild dementia n = 6 nurses	PWDs ranking their preferences for EOL care

Poppe et al. (2013)	To assess the acceptability of a tool for discussing ACP with PWDs	Quasi-experimental qualitative, semi-structured interviews	UK Two memory clinics in South London	n = 12 (PWDs) Mean age: not reported Gender: not reported Race/ethnicity: not reported Dementia type/severity: Dementia/Mild dementia n = 8 (carers) n = 6 (staff)	Perception of the ACP intervention, timing of discussions, and barriers to ACP
Tay et al. (2015)	To assess willingness to participate in ACP and to identify correlates of the willingness to participate in ACP, and barriers and benefits to ACP	Quantitative, structured interviews	Singapore Memory clinic, tertiary hospital	N = 98 Mean age: 73.6 Female: 52.6% Race/ethnicity: 90.7% Chinese Dementia type/severity: MCI or mild dementia	Readiness to engage in ACP by assessing whether participants had already made plans, were intending to start soon, or were not ready to initiate ACP. 9-item Modified Perceived Barriers Scale, and 5-item Modified Perceived Benefits Scale for measuring beliefs and attitudes

Note. PWD = person with dementia; CPR = cardiopulmonary resuscitation; ACP = advance care planning; EOL = end of life; RCT = randomized controlled trial; MCI = mild cognitive impairment

Table 2. Key Findings from Included Studies

Studies	Findings
Correlates of ACP Participation	
Garand et al. (2011)	At baseline, no patient had participated in ACP. Over 5 years, 39% completed advance directives. Age (being younger) was the only significant correlate of advance directive completion in multivariate analysis. Sub-analysis revealed that being younger was associated with higher likelihood of initiative of advance directive among those who were male (vs. female), married (vs. not married), not depressed (vs. depressed), with a family history with dementia (vs. without), and with moderate to severe Alzheimer's (vs. less severe Alzheimer's).
Lingler et al. (2008)	ACP rates were 69% for non-PWDs, 71% for MCI/early Alzheimer's, and 70% for mild/moderate Alzheimer's. Being older, white, and married, and having college education were significant correlates of advance directive completion.
Makino & Porsteinsson (2015)	Of 23 PWDs, 91% had a healthcare proxy, 74% had a living will, and 4% had medical orders for life sustaining treatment. More participants (47.8%) found their lawyer to be a good resource for ACP than participants (26.1%) who found their primary care provider to be a good resource
Tay et al. (2015)	Of 98 PWDs, 11.3% of people with MCI or early Alzheimer's had already participated in ACP, 42.3% planned to participate in ACP, and 46.4% were not ready to participate in ACP. Higher levels of education and executive functioning were significant correlates of the willingness to participate in ACP.
Ability, attitudes, and burden in ACP participation	

Studies	Findings
de Boer et al. (2012)	PWDs were able to articulate their expectations of the future from their perspective of living with dementia. PWDs preferred to cope with those expectations by not worrying about the future and living one day at a time instead. PWDs did not find ACP and advance directives to be relevant in day-to-day focus of PWD.
Dening et al. (2012)	PWDs struggled to think about and plan for the future including EOL care due to difficulty with considering their future self. Most PWDs did not see the potential value of ACP or how expressing preferences and wishes now could influence care later. Carers did not see ACP as a way to ensure PWDs' preferences.
Dickinson et al. (2013)	PWDs and carers engaged in personal, and financial future planning but experienced difficulty with formal ACP. Barriers to ACP for PWDs and their families included lack of knowledge, trouble finding the right time, preferring to make informal plans rather than documenting plans, limits on wishes being met, and lack of support to participate in ACP.
Finucane et al. (1993)	No burden in completing ACP conversation was reported. Only two participants had meaningful and consistent interviews and decisions.
Goodman et al. (2013)	PWDs were able to express their perspectives on EOL care. PWDs did not think their voice had value due to their dementia diagnosis, but given the opportunity, were willing to talk about their experiences. Due to living in a nursing home, PWDs did not expect their EOL preferences to be respected as they believed decisions would be made for them.
Karel et al. (2007)	There was no difference in the ability to consistently respond to an assessment on values regarding EOL care as well as name a proxy decision maker between PWD and non-PWD.

Studies	Findings
	The majority of participants (63.4%) identified completing value assessments as a positive experience. Only 13% reported the questions as emotionally challenging.
ACP interventions	
Caplan et al. (2006).	An ACP education program for nursing home residents, families, and providers was offered and implemented in 19 nursing homes. Among nursing home residents with capacity, 5 nursing home residents participated in ACP discussions and decisions were documented in their notes. Among 40 nursing home residents without capacity, 3 proxy decisionmakers completed plans of treatment on behalf of residents, 20 residents participated in discussion and had preferences recorded in notes (without signing an advance directive), 10 residents participated in discussion without documentation in notes or advance directive, while 6 proxy decisionmakers declined ACP discussion. The location of death for participants was congruent with documented wishes for all 32 (out of 45) of the participants who died two years after initiation of the study In the second year, emergency calls were significantly different as they decreased for the intervention homes by 1% while increasing by 21% for the control homes. The intervention nursing homes had a decrease (35.4%) in residents admitted to a hospital over 3 years while admission from the control homes increased (20.1%) over the same time period, resulting in a significant difference. Bed-days occupied by residents changed significantly over 3 years as the intervention home decreased (5.734 days) while increasing for residents from the control home (12.755 days).
Hilgeman et al. (2014)	Intervention was a two-pronged approach, Preserving Identity and Planning for Advance Care combines one self-adjusting, future planning component and one self-maintaining, reminiscence-

Studies	Findings
	based component. Comparison group received a minimal support focusing on empathic listening and supportive reflection administered via telephone. Compared with the comparison group, PWDs in the intervention group reported less depression, less decisional conflict in ACP, more coping strategies, less dependence in mobility, and increased subjective QOL. Large effect sizes were reported for the first 4 measures; the last measure had a moderate effect size. Large effect sizes were calculated for the families' perspectives of PWDs in the intervention group as having higher QOL in Alzheimer's disease as well as having greater well-being in terms of being less depressed and less dependent on help in usual activities. Moderate effect sizes were also calculated for their perspectives of PWDs having less depression and less dependence on help in self-care.
Lewis et al. (2015)	After completing an in-person seminar on ACP, 86% showed interest in ACP. 4% of carers and 8.8% of PWDs actually completed advance directives. 64.7% of PWDs were aware of Financial enduring power of attorney (EPOA) and 61.8% of PWDs were aware of Medical EPOA, but among those who were aware, only 26.5% completed a Financial EPOA and 23.5% completed a Medical EPOA. After completing the advance directive documentation, an unreported number of participants reported the experience to be positive.
Lo et al. (2017)	After attending an educational session about ACP, 77 patients (49%) were keen on further ACP conversation, and 81 patients (51%) were not. Of those 49% (n = 77) who were keen on further ACP session, 22% completed the advance directive. Being single was the only predictor of advance directive completion.
Poppe et al. (2013).	After receiving the Advance Care Planning in Early Dementia (ACP-ED) educational intervention, participants thought ACP-ED was comprehensive in covering relevant issues related to discussing ACP.

Studies	Findings
	9 out of 12 PWDs found the experience positive & helpful. PWDs, carers, and staff agreed ACP discussions should happen sooner in the dementia process, but doing this at the time of diagnosis would be unacceptable.
Values and preferences for EOL care	
Ayalon et al. (2012)	Spouses were able to moderately predict ($ICC = 0.42$) PWDs' preferences for life support. PWDs were more likely to opt for life sustaining measures than spouses were to opt for life support for themselves ($p < .001$).
Dening et al. (2012)	The PWD-only group identified the following values in order of priority: to maintain family links, to maintain independence, to feel safe, not to be a burden, to be treated with respect and dignity, to have a choice in the place of care, pleasurable activities, person-centered care, to be in touch with the world, and to have a comfortable environment. The PWD and Carer group identified the following values in the order of priority: choice of place of care, not to be a burden, to be treated with respect and dignity, no unnecessary prolonging of life, to be active, to maintain contact with family, and to make legal preparation. When interviewed together, carers tended to speak for PWDs and influence what were identified as important values.
Fazel et al. (2000)	There was no difference between PWDs and non-PWDs in preferences for life support. There was a difference in preferences based on competence level measured by the Mini-Mental State Exam (MMSE). People with higher MMSE scores (i.e., higher competence levels) were more likely to opt for nonintervention measures.
Goodman et al. (2013)	PWDs' experiences with nursing home staff, specifically how they were cared for on a day-to-day basis and if PWDs believed staff understood them, influenced how PWDs expressed priorities and preferences for future care including their confidence that their wishes for EOL care were known, and whether the care home was where they wanted to be or not.

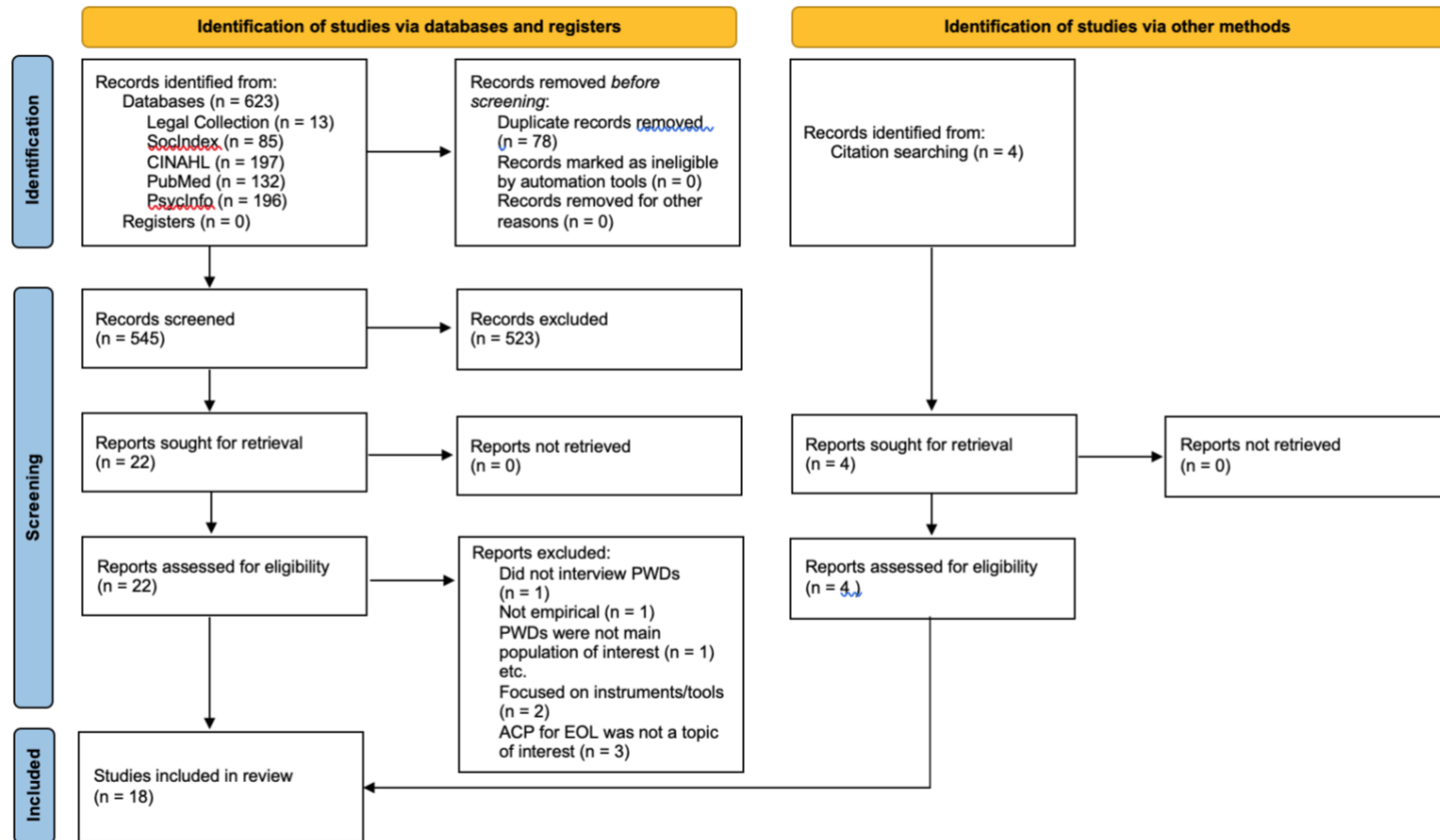
Studies	Findings
	PWDs who had suffered previous losses (i.e., outliving loved ones, loss of function) were apathetic about where they lived and died.
Karel et al. (2007)	Over 50% of participants (PWDs and non-PWDs) identified the following values as influencing a decision about medical care a lot (opposed to a little or not at all): PWDs' ability to still make decisions for themselves (80%), ability to still communicate with others (77%), emotional impact on family (70%), quality of life (63%), the financial impact on family (60%), who (family members or professionals) would provide personal care (59%), the extent to which the PWD would depend on others for personal care (58%), and ability to enjoy simple pleasures (53%). Having previously made a life-sustaining decision for another person correlated with emphasizing pain management, self-sufficiency, and quality of life as important values at EOL. Most participants (75.7%) preferred death to receiving tube feeding if very cognitively impaired and terminally ill.
Makino & Porsteinsson (2015)	Of all PWDs, 34.8% indicated that they would not want CPR, 78.3% would not want artificial nutrition, and 65.2% would not want to be connected to a ventilator.
Mulqueen & Coffey (2017)	PWDs emphasized human needs (i.e. comfort, family involvement, and familiar surroundings and staff) while nurses emphasized clinical care (i.e. as communication, ACP, and pain management) in values on EOL care. Both groups identified family involvement and communication as important values, though they were ranked differently (family involvement ranked 2nd for PWDs and 4th for RNs; communication ranked 4th for PWDs and 2nd for RNs).

Note. ACP = advance care planning; PWD = person with dementia; EOL = end of life; MCI = mild cognitive impairment; CPR = cardiopulmonary resuscitation.

Figure 2. Databases and Search Strategies Used

Database	Date Searched	Search Strategy
Legal Collection	11/14/17	((DE "ADVANCE directives (Medical care)" OR DE "ADVANCE directives (Medical care) -- Law & legislation" OR DE "HEALTH care proxy" OR DE "DO-not-resuscitate orders")) AND (DE "DEMENTIA" OR DE "DEMENTIA patients" OR DE "MILD cognitive impairment" OR DE "MENTAL competency (Law)"))
SocINDEX	11/14/17	("people with dementia" OR "cognitive impairment" OR competenc* OR "mental capacity" AND ("living will" OR "advance care plan*" OR "advance directive*" OR "health care proxy"))
PsycINFO	11/15/17	(DE "Advance Directives") AND DE "Senile Dementia" OR DE "Dementia" OR DE "Cognitive Impairment" OR DE "Competence" Filters: English
CINAHL	11/16/17	("advance care plan*" OR "advance directiv*" OR "living will" OR "health care proxy") AND ("people with dementia" OR "cognitive impairment" OR "mental capacity")
PubMed	11/16/17	(((((("advance care plan*" AND English[lang])) OR "advance directive*") OR "living will") OR proxy[MeSH Terms]) AND English[lang])) AND (((("people with dementia") OR "mental capacity") OR "cognitive impairment"))

Figure 3. PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources



Chapter 3: Research Methods

DESIGN

The purpose of this study was to describe how PWDs make decisions regarding engaging or not engaging in ACP by conducting a qualitative descriptive study, using the ODSF as a lens for obtaining and analyzing data from a completed study. A qualitative descriptive design was used because it allows for describing the perspectives of PWDs, caregivers, and healthcare providers with minimal interpretation by the researcher (Sandelowski, 2000), which allows for findings to be centered around the perspectives, needs, and values of PWDs. Keeping the focus on the descriptions of engaging in ACP by PWDs is imperative in order for the data to provide implications for practice and research which are truly informed by PWDs and those who care for PWDs. This study was undertaken as the first step in identifying how to better engage PWDs and their family members in ACP based on their unique needs and abilities. The source of this dissertation study data is a mixed methods pilot study conducted to examine feasibility and acceptability of a decision aid to guide PWD and caregiver dyads.

THE ORIGINAL STUDY

The purpose of the original study was to develop and test a decision aid with the intention of improving ACP engagement among persons with dementia, cognitive impairment, and memory problems and their caregivers. The original study was completed in two stages: alpha testing for usability to gather feedback on the decision aid in its current state, and beta testing of the modified decision aid to determine feasibility of using the decision aid in real life settings.

Sample and Setting

The target population of the original study were inpatient and outpatient persons with memory problems, cognitive impairment, or dementia as diagnosed by a healthcare provider (hereto referred to as patients), and one of their family members that the patients identify as their caregivers. The patient and his/her caregiver were referred to as a dyad. Outpatient participants were recruited from one location of a managed care system which has a chain of medical clinics in Texas that exclusively serve Medicare patients. The organization has 12 locations in the Central Texas region and the location partnered with the research team served around 80-85 PWDs at the time of the study. The location of the outpatient clinic served diverse older adults as this geographic area has a high concentration of residents who are African American (City of Austin, 2011a), Hispanic (City of Austin, 2011b), and lower income (City of Austin, 2015).

Inpatient study dyads were recruited from a hospital affiliated with a medical school in Austin, Texas. This hospital is a Level I trauma facility that serves 11 counties in the Central Texas region (Seton, 2018). In addition to dyads, healthcare providers were recruited from the outpatient clinic and the hospital in order to obtain provider input on the design and usability of the decision aid.

In addition to these two sites, recruitment was expanded to additional sites including an outpatient memory clinic and local independent and assisted living facilities. Community-dwelling dyads were recruited through educational seminars on dementia hosted by the research team at independent and assisted living facilities. At these seminars, the author of this dissertation presented research-based recommendations for preventing cognitive decline and answered attendees' questions about dementia. These seminars were used to recruit potential study participants.

Sample size

After these various recruitment efforts were used, the final number of study participants included six dyads and one triad: one dyad from the hospital, three dyads from the outpatient clinic, one triad (one PWD and two caregivers) from the outpatient clinic, one dyad from the memory clinic, and one self-referred dyad with a total of seven PWDs and eight caregivers. Several other self-referred dyads were interested in participating in the original study, but meetings were postponed and ultimately cancelled due to the emergence of the COVID-19 pandemic. Two healthcare providers were recruited from the hospital and two were recruited from the outpatient clinic. While power analysis would normally be used to estimate the sample size needed to conduct a study with less risk of accepting a false null hypothesis (Polit & Beck, 2011), the original study was a pilot study that was seeking to determine the usability and feasibility of the decision aid rather than its efficacy. Thus, a smaller sample size and lack of power was acceptable.

For my purpose of performing a qualitative study, this sample size is adequate. Data saturation, which is the absence of new information as new study participants are interviewed (Polit & Beck, 2011), would normally dictate the number of interviews that would be included in a qualitative study. While this approach of attaining data saturation by interviewing participants and concurrently analyzing interviews until no further new themes are identified (Morse, 2015) was not an option since the sample was fixed, achieving saturation is still a possibility while conducting a secondary analysis (Szabo & Stang, 1997).

Inclusion criteria

Patients were included if they were: 65 years of age or older; spoke English; had a diagnosis of a form of dementia, cognitive impairment, or memory problems; lived in a

community setting (including independent and assisted living); had a family member that was able to meet with the patient and research team; and a minimum score of 10 or higher on the Mini-Mental State Exam (MMSE; Folstein et al., 1975) to determine that the patient did not have severe dementia and had the capacity to participate in the study. Family members were included if they were: 18 years of age or older, spoke English, and were a family member of the PWD as identified by Texas law.

Healthcare providers were included if they had engaged in ACP with patients.

Exclusion criteria

Patients were excluded if they scored lower than 10 on the MMSE or had an advance directive. Having an advance directive was not an exclusion criterion for self-referred participants since advance care planning is a process that does not end when an advance directive is completed. Additionally, advance directive status of self-referred participants did not affect studying the benefit of the decision aid during alpha testing since the purpose of this phase was to gather feedback for modifying the decision aid. For my purposes, including persons with cognitive impairment who had completed an advance directive provided the opportunity to describe why an advance directive was completed and how the process went from the perspective of that participant and their family member.

Recruitment Plan

Convenience sampling was used as eligible patients at the hospital were identified by nurse practitioners and chaplains. Chaplains are often consulted by healthcare providers for patients who lack advance directives or request more information on ACP. At the outpatient clinic, a geriatrician and social worker screened records of current patients with dementia for eligibility. Similarly, social workers and employees at the memory clinic

referred patients who lacked advance care planning. At these three sites, the health care personnel introduced the research project to patients and their caregivers that met our inclusion/exclusion criteria and asked for their permission to be contacted by the research team. After being informed that verbal permission to be contacted had been obtained from the patients or their family members, the research team established contact with the patient or family member via telephone. These phone calls briefly conveyed the purpose of this study and offered to schedule a meeting with interested patients and their identified family member. During the face-to-face meeting, two members of the research team provided the patient and his/her family member with in-depth information on this study.

Secondary Analysis

To answer my research questions, I used the qualitative data collected from the original study (Appendix B) and introduced several questions of my own, listed below under Data Collection. I asked PWDs about their knowledge of ACP, perspective on ACP, and to describe their responses in more detail during the completion of the decision aid. Due to the original study being unexpectedly halted because of the COVID-19 pandemic, my study shifted from an ancillary study of solely the perspective of PWDs, to a secondary analysis that also included the perspective of family members and healthcare providers (HCPs) who care for PWDs. Sources of qualitative data included transcriptions from audio recorded semi-structured interviews, responses to the decision aid, and field notes.

Data Collection

For PWDs recruited from the hospital, data were collected in their room while they were inpatient. For PWDs recruited from the medical clinic, data were collected in their home, the home of the caregiver, or the clinic, depending on the preference of the patient

and caregiver. Quantitative and qualitative data were gathered through answers on the decision aid and audio recording of the semi-structured interview. After receiving written consent and/or assent, a HIPAA release form was completed by PWDs recruited from clinic or hospital so that the researchers could review their medical record to collect the following demographics: age, sex, ethnicity, admitting diagnosis/main diagnosis, dementia diagnosis, current treatments, and living situation. This data was not collected from self-referred PWDs or PWDs referred from the memory clinic. After completing the aforementioned consent/assent and HIPAA release forms, PWDs were asked:

1. What are some things that [name of family caregiver] helps you with?
 - a. On a daily basis
 - b. Long term
2. Are there things that you help [name of family caregiver] with?
 - a. On a daily basis
 - b. Long term
3. Speaking of long term, what does the term advance care planning mean to you?
 - a. What about advance directives?
 - b. Living will?
 - c. Medical power of attorney?
4. Are you interested in completing an advance directive/living will/medical power of attorney?
 - a. Why/Why not?

After asking these questions which sought to understand the patient's knowledge and perspective on ACP and advance directives before participating in this study, the dyad was educated on the definition, purpose, and benefit of completing a medical power of attorney and directive to physicians and family or surrogates. Directly after receiving the definition of ACP and ADs, question five was posed in order to check the patient's understanding of these terms:

5. What does the term advance care planning mean to you?
 - a. What about advance directives?

6a. What are some of the reasons why you have not completed an advance directive?
a. Are there any reasons why you want to complete an advance directive?

b. What would need to happen for you to complete an advance directive?

Or

6b. What were some of the reasons why you completed an advance directive?

a. Were there any reasons why you did not want to complete an advance directive?

Question six was intended to explore patient's perceived benefits and drawbacks of engaging in ACP and completing advance directives after they had a basic understanding of what was being discussed. From here, the dyad completed the decision aid through a semi-structured interview. In addition to these planned questions, follow-up questions were asked when clarity was needed on a patient's response in order to have a thick description that would allow me be able to sincerely describe their perspective on engaging in ACP.

7. Overall, how do you feel about engaging in ACP with family members or a healthcare provider?

a. Why do you feel that way?

8. Are you interested in completing/modifying an advance directive?

a. Why?/What do you mean by maybe?

Question seven sought to explore the perspective of the patient on ACP after having the opportunity to engage in ACP by reflecting on their values and considering what kind of care they would want if they were unable to communicate. This question was also asked in order to answer what decisions do PWDs make regarding their level of engagement in ACP. Additionally, question eight was asked in order to explore what benefits and/or risks patients identified with completing advance directives. Within the decision aid, patients were asked to answer how important certain values are in deciding if they should complete advance directives or not. Responses on the decision aid were recorded on a scale of 1 to 3, with 1 not being at all important and 3 being a great deal important. How the patients

answered these items reflected personal values such as autonomy and the wellbeing of their family. Question seven and eight were asked after the decision aid had been completed in order to increase the chances that the patient will provide a more candid response about their perspective on engaging in ACP.

9. What did we discuss today that you had not considered before?
 - a. How does that affect your perception of advance care planning?

Question nine was asked in order to describe what information about ACP helps or deters PWDs from engaging in ACP.

10. Is there anything else that you would like to share?

Lastly, question 10 was asked in order to allow patients an opportunity to talk about anything else that I had not thought to ask about, but that they would like to share.

ANALYSIS

The transcripts and decision aids were analyzed using content analysis. According to Sandelowski (2000), content analysis is the strategy of choice for analyzing data in a qualitative descriptive study because it is the least interpretive approach to analyzing qualitative data. The unit of analysis was each PWD, caregiver, and healthcare provider. Using the stages of content analysis laid out by Elo & Kyngäs (2008), analyzing the data during the preparation stage began with the researcher manually transcribing the audio recordings of each interview verbatim into Excel spreadsheets. The researcher then compared the transcripts to the audio recordings to check for accuracy. Continuing in this stage, transcripts were read to gain a sense of the whole unit (Vaismoradi, Turunen, & Bondas, 2013; Graneheim & Lundman, 2003). Analyzing the manifest content and identifying categories, open coding was used to organize the data (Vaismoradi et al., 2013). Meaning units were identified from the transcript through condensing, abstracting, and

finally coding (Graneheim & Lundman, 2003). After coding a transcript, this process of condensing, abstracting, and coding were repeated in order to identify categories, and then repeated again in order to identify themes. In order to control bias, the decision aid and field notes were used to triangulate and corroborate participant's responses in the interviews in order to increase certainty about the researcher's interpretation when coding, categorizing, and identifying themes.

After coding and categorizing data while minimizing influence from external perspectives besides the interviewees, themes were identified through the lens of the ODSF. Specifically, concepts from the ODSF were considered when identifying themes related to the PWDs' decisional needs and support roles of family caregivers and healthcare providers.

TRUSTWORTHINESS

Trustworthiness was established by using a recently graduated professor from the doctoral program who had experience with mixed methods and an undergraduate nursing student with experience in qualitative coding to act as second coders. The secondary coders were provided a codebook created by the PI (LG), and independent coding of categories and themes were performed to establish intersubjective agreement. Before completing coding on each interview, 100% agreement was achieved between the coders on the codes used. Disagreements between coders were settled through discussion of how the coders arrived to their categories and themes. Credibility was also established through triangulation by using multiple sources of information (PWDs, caregivers, and healthcare providers) for content analysis (Polit & Beck, 2011). Investigator triangulation, defined by Denzin (1978) as multiple researchers from one study providing multiple perspectives and

conclusions to confirm findings, was also utilized to build credibility. Trustworthiness was also sought through reflexivity by using reflective journaling during data collection to examine the researchers' own biases and beliefs (Polit & Beck, 2011), seeking thick description in interviews, keeping codes close to the data, and presenting authentic citations in the final product. Since researchers only met once with dyads and healthcare providers, member checking was not an option for establishing neutrality/credibility and trustworthiness of themes.

ETHICAL CONSIDERATIONS

Consent and Assent

MMSEs were conducted with each PWD willing to participate in the study in order to determine if they were capable of participating in the study. If patients scored a 10 or higher on the MMSE, the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC) screening was used to determine their capacity to consent to participate in the study (Jeste et al., 2007). If PWDs scored 14 or less on the UBACC, they completed an assent form while their caregiver was asked to consent on behalf of the patient. If PWDs scored higher than 14 on the UBACC, they completed their own consent form. Informed consent was also obtained from PWDs' caregivers and healthcare providers for their participation in the study.

All participants were informed that they may refuse to answer any question or end the interview at any time. Additionally, PWDs referred from WM and DSMC were informed that refusal to answer questions or end their participation in the study would not affect the care that they received from the referring medical facility.

Confidentiality

As approved by The University of Texas at Austin Institutional Review Board, study participants identities were kept confidential by keeping hard copies of files in a locked cabinet in a locked office accessible only to the study team. These files are identified by numbers assigned to study participants by the researchers. A cross list connecting patients to the data stored separately from the data. Additionally, initials instead of full names are collected on the individual receipts used to confirm that the participant received a \$10 H-E-B gift card as a thank you for their time. Electronic copies of files were stored on password protected and encrypted computers as well as within UTBox, which is HIPAA compliant. Transcripts of audio recordings were de-identified and dyads and HCPs were assigned a number for identification purposes. Referrals for our study by healthcare providers were sent through encrypted emails and deleted after the information was recorded.

In summary, by exploring the importance of concepts from the ODSF among inpatient and outpatient persons with dementia, cognitive impairment, and memory problems, this study described how PWDs made decisions to engage in ACP.

Table 3. Participant Characteristics

Characteristics		PWDs n=7	CGs n=8	HCPs n=4
Sex	Female	5 (71)	7(88)	3(75)
	Male	2(29)	1(12)	1(25)
Race	White	3(43)	3(37.5)	3(75)
	Non-white	4(57)	5(62.5)	1(25)
Age	Mean (SD)	83 (6)	63 (11)	
	PWDs #1	>90	70	
	PWDs #2	77	58	
	PWDs #3	80	60	
			63*	
	PWDs #4	84	57	
	PWDs #5	77	49	
	PWDs #6	**	87	
	PWDs #7	>90	63	
MMSE	PWDs #1	13		
	PWDs #2	17		
	PWDs #3	20		
	PWDs #4	23		
	PWDs #5	23		
	PWDs #6	28		
	PWDs #7	28		
Relationship of PWDs & CGs	Biological		75%(n=6)	
	Child			
	Step Child		12.5%(n=1)	
HCP Place of Employment	Spouse		12.5%(n=1)	
	Inpatient			50%(n=2)
	Outpatient			50%(n=2)

Note. PWD = persons with dementia; CG = caregiver; HCP = healthcare provider

*one PWD had two CGs participate in their interview

**one PWD did not report their age

Chapter 4: Findings

CHARACTERISTICS OF STUDY PARTICIPANTS

Nineteen participants were interviewed in the original study. This consisted of four healthcare providers and seven caregiver/PWD dyads. Two of the healthcare providers worked at an outpatient clinic and two worked at hospitals. Occupations of interviewed healthcare providers included nurse practitioner, medical assistant, chaplain, and social worker. One of the dyads included two family caregivers in the interview with the PWD. The mean age for caregivers was 63 years old, and six of the eight caregivers were younger than 65 years old. All PWDs were over 65 years old, with the youngest PWD at 77 years old and the mean age was 83 years old. Mini-Mental State Examination scores of PWDs ranged widely from 13 to 28 as inclusion criteria were altered over the course of the original study in order to increase recruitment of dyads. See Table 3 for detailed background characteristics.

OVERVIEW OF THE RESEARCH AIMS AND RELATED THEMES

The first aim for the study was to describe the decision-making process of PWDs to engage in ACP, specifically about their information needs about ACP, value clarity about benefits and risks of ACP, support needed to engage in ACP, and decisions that PWDs make with regards to ACP engagement. Themes related to the first aim included: PWDs' lack of knowledge about ACP concepts and process, benefits of ACP to caregivers as surrogate decision-makers, caregivers' essential role in facilitating PWDs' ACP engagement, PWDs' distrust of healthcare providers, health care providers' role in facilitating ACP, and PWDs' readiness to complete ACP tasks.

Some of the themes related to the first aim were also themes for the second aim of the study, to identify facilitators and barriers to PWDs' decision to engage in ACP. Themes from the first aim that were also themes for the second aims were: PWDs' lack of knowledge about ACP concepts and process (barrier), benefits of ACP to caregivers as surrogate decision-makers (facilitator), PWDs' trust of family caregivers (facilitator), health care providers' role in facilitating ACP (facilitator) and PWDs' distrust of healthcare providers (barrier). Additional themes of the second aim that emerged include difficulty in predicting the future (barrier) and discomfort in discussing ACP (barrier).

AIM 1. DESCRIBE THE DECISION-MAKING PROCESS OF PWDs TO ENGAGE IN ACP.

PWDs' Lack of Knowledge about ACP Concepts and Process

The first theme that emerged was PWDs' lack of knowledge about ACP concepts and process. In order for people to meaningfully engage in ACP, they need to first be knowledgeable about the concepts and processes of ACP. Being knowledgeable about ACP concepts means understanding the definitions of ACP and advance directives, the purpose of advance directives, and which advance directives are used in their state. Being knowledgeable about ACP processes entails understanding that they should think about their wishes for end-of-life care and discuss their wishes for end-of-life care with persons that they want to serve as medical power of attorney (MPOA) and their healthcare providers. Yet most of the participating PWDs' knowledge about ACP terms, including ACP, advance directives, and living will, was vague, inaccurate, or non-existent.

Knowledge of the term ACP was very low among PWDs, with five of the seven PWDs not being able to accurately describe ACP before being told of the definition by

the researcher. Additionally, PWDs had inaccurate knowledge about the term. Several PWDs who had inaccurate knowledge about ACP associated it with financial planning. When asked what ACP means to her, PWD #7 responded

Uh well it-it-it means that I should have my financial stuff in order so that I can [cough] decide right now even though the situation might be different, but right-right now I could decide uh financial things and maybe some other things that uh, but then uh if you expect to uh die within 6 months then you can be in that category where you're expected to die in 6 months and, uh ,well I guess that's it, with my-my my stuff where it's supposed to be [laughs].

Only a couple of PWDs could accurately but vaguely define ACP. When asked to define ACP, PWD #4 responded, "Well, this is, I guess, something that you may need ahead and then you are ready to-to use it, to help them." Another participant (PWD #5) described ACP as something that "I guess, take care of me once I can't take care of myself."

Most PWDs also had an inaccurate understanding of the term advance directives. Similar to ACP, several of the PWDs believed that advance directives were associated with financial planning or the distribution of their belongings. When informed that the advance directives being discussed were about his health and not his finances, PWD #1 responded "What the hell are we doing this for, if we're not, talking about the finances?" Lack of knowledge was also evident through comments about lack of familiarity and not understanding the purpose of ADs. When asked if he had heard of ADs, PWD #5 responded "That doesn't that, that doesn't, that doesn't ring a bell." PWD #4 was also unfamiliar with ADs as he said he did not think he had heard of the term before. Only one

PWD identified advance directives as being different from ACP. PWD #7 identified advance directives and living wills as being part of the same “package” as ACP and believed that she knew enough about advance directives. While three PWDs stated that they did not know enough about ADs, PWD #1 and PWD #3 believed that they knew enough about advance directives, although their initial responses to questions about advance directives revealed that their knowledge about advance directives was inaccurate.

Of the ACP terms that PWDs were asked to define, most participants had some knowledge about the term medical power of attorney (MPOA). Over half of the PWDs verbalized that a MPOA made decisions on behalf of another person. When asked to define medical power of attorney, PWD #6 responded “Yeah, that’s some, that’s what you give to another person in case you’re out of it, to make decisions.” When told that there are two forms of advance directives that we would discuss, PWD #2 stated “now the power of attorney, that would be the person in charge.”

Unlike MPOA, PWDs lacked knowledge about living will/directive to physicians and family surrogates and struggled with describing its purpose. PWD #7 could only define living wills as being a part of advance directives. When PWD #6 was asked what living wills means to her, she responded “Uh. I’m not, I’m not sure.” All other PWDs could not provide their definition for a living will.

Even after having medical power of attorney and directive to physician defined by a researcher or their family members, a few PWDs struggled to understand the purpose of MPOAs or the difference between the two forms of advance directives. After his caregiver explained the MPOA, PWD #1 responded that he understood, but did not know why he needed an MPOA. When PWD #2

was asked if she had a preference between the directive to physicians and medical power of attorney, the PWDs responded, “So that’s the... that’s the same thing isn’t it? No, those the same question? That you’re asking me.” When discussing his preference between the two types of advance directives, PWD #4 reported that he didn’t know enough about advance directives. Similarly, PWD #6 reported that she probably did not know enough about advance directives.

Beyond knowledge about ACP terminology, more than half of PWDs also lacked knowledge of the ACP process or had incorrect knowledge. For example, PWD #1 did not know that ACP includes discussing their wishes with their health care provider and with their family members, PWD #2 misunderstood what topics ACP covered, and other PWDs were uncertain what ACP process entails. After the directive to family and physicians was explained, PWD #1 asked “You mean, am I going to tell the doctor how to, how to doctor me?” While completing the decision aid, PWD #1 also said “‘I don’t know how to talk to my doctor about it’. Well hell I haven’t ever tried. Should, should I am, am I supposed to do that?” PWD #2 seemed to be confusing ACP with funeral planning when asked if there was anybody else that she wanted to talk to about ACP. She said “Well the church members they all know. They all know. Yeah. And because friends know...they all know, I want to get in, get out, don’t prolong it. Cause you know how some funerals can go on for days and days”. The caregiver for PWD #4 believed that the PWD lacked knowledge about the ACP process by stating that the PWD was “Not sure what it all entails” when the PWD was asked about his confidence with ACP. Although not specific about what knowledge they lacked, two PWDs (#4 and #6) acknowledged that they did not know enough about advance directives and PWD #5 admitted that he did

not know enough about the directive to family and physicians after the researcher asked why he preferred the MPOA to the directive to family and physicians.

Several PWDs were aware that the process of choosing a MPOA required talking to the person who would serve as a MPOA, but the depths of the discussions that they had with their caregivers varied. PWD #2 identified her daughter as her MPOA, "...who knows that already, we talked about it." PWD ID #5 asked his caregiver to be his MPOA on their drive over to participate in the study, but as it was their first time discussing the topic, his caregiver did not have clarity about the wishes of the PWD, "So this is—am, am I clear what he wants in his direct—directive care—I mean, in his advance directives. Uh, no, I'm not sure". As the only participant who had previously engaged in ACP and completed advance directives, PWD ID #7 had previously completed a MPOA form and continued to regularly discuss her wishes with her caregiver.

From the HCP's perspective, two HCPs (#2 and #3) believed that most patients lack the medical knowledge to make complex decisions in their advance directives. Additionally, these two HCPs believed that most people's lack of medical knowledge makes it difficult for them to make more nuanced decisions about life support options in advance directives.

Benefits of ACP to Caregivers as Surrogate Decision-Makers

Most PWDs did not explicitly report benefits to engaging in ACP except for PWD #4, who found ACP to be beneficial as he stated, "Always good, you know, get to decide for myself. As soon as I get sick, you know, forget everything. As it is, I'm forgetting to, you know, to do some like, interest in doing anything." Caregivers on the other hand, perceived ACP as helpful. Although most caregivers did not explicitly identify benefits

of ACP, caregivers did identify situations when completed ACP would be of benefit, such as avoiding indefinite use of life support and knowing PWDs' wishes for medical care when the PWD were to be seriously ill. For example, the caregiver for PWD #6 discussed how life support can become indefinite,

There are a few cases of people who get stuck on these machines you know then some family member says, oh we'll keep them on forever, it's tough to get off then, cause you're not in a position usually at that point to say anything.

The caregiver continued to elaborate how costly that care can become, "Years of being kept on a ventilator, it costs a few million dollars a year, and with no hope for the person to recover."

A couple of caregivers expressed the desire to know the exact wishes of the PWDs for receiving medical care when seriously ill. While PWD #7 answered a question on the decision aid about her desire for loved ones to make decisions on her behalf, the caregiver for PWD #7 stated, "You know what would bring me peace is doing exactly what she says." When PWD #1 was struggling to answer the same question, the caregiver for PWD #1 reported a similar sentiment, "Would it help if I told you that for me to feel comfortable, it would be for you, to tell me to do exactly what you asked?"

In thinking through their responses to questions on the decision aid, some PWDs verbalized how they wanted their decisions to benefit their family, specifically in regards to how long they receive medical treatment. Looking at how the PWDs responded to the decision aid item, "How involved do you want your loved ones to be? Do you want your loved ones to do exactly what you have said even if it makes them uncomfortable, or do you want your loved ones to do what brings them peace even if it goes against what you

have said, or somewhere between the two?”, four of the PWDs responded that they want their family to do what brings them peace, even if it goes against the PWD’s wishes. This included both PWDs who did and did not know what care they wanted at the end of life. For PWD #1 and PWD # 2, not being a burden or source of tension to their family caregivers was important. Although not directly verbalizing how she wants her decisions to benefit her caregivers, PWD #3 was vocal about how her caregivers were the decision makers on her behalf, “Researcher: Okay. Is there anybody else that you want to talk to about advance directives? PWD: No. I would rather for my children to know. Researcher: Your children. PWD: Mm-hmm [affirmative]. Whatever they say, it goes.”

Caregivers’ Essential Role in Facilitating PWD’s ACP Engagement

Support from family for PWDs to engage in ACP

Most PWDs believed that they had enough support from families to make decisions about advance directives, and felt that they had discussed ACP enough with their families. For PWD #7 and her caregiver, ACP was regularly discussed. PWD #7 explained that completing her ADs was the purpose for her caregiver travelling out to visit her. For PWD #5, participating in this study was an impetus to talk to his accompanying caregiver, his stepdaughter, about being his surrogate decision maker. When asked who else the PWD wanted to talk to about advance directives, the participant said

PWDs: My stepdaughter will be able to take care of, uh, what needs to be took care of. Yeah. Because we’ve already discussed, discussed that when we, when we were coming over here, but I asked her if she was

willing to, you know, to take, to take the, take—the step forward you know, if—That, I mean, if—they—would she feel right about it, you know. Said yes.

PWD #6 was the only participant who answered that she did not have enough support and advice to make a decision about advance directives. This PWD wanted her daughter to be involved in end of life decision making on her behalf along with her spouse, but the PWD had not yet spoken to her daughter about her wishes.

PWDs' trust of caregivers to know and make the right decisions

The PWDs who participated in this study vocalized trust of their caregivers making decisions on their behalf in the future and also readily identified their caregivers as their future MPOAs. All PWDs identified their caregivers or another family member as their MPOA despite six of seven PWDs not having completed advance directives before. Additionally, PWDs expected their caregivers to already know what decisions to make on their behalf. For example, when PWD #2 and their caregiver were discussing who would make the decision if the PWD were to be in the hospital, the PWD said “So—I’m sure they would be gathered around the hospital. And they, they would know... Well, um. It’s just the two of them so they— [name of MPOA redacted].” Similarly, PWD #3 stated that her daughters would know what care she would want in the future even though she did not know what she wanted.

Researcher: ...you don't know what you would want in the future.

PWDs: I wouldn't know what I want, but my—I think my girls would know. They would be doing the best thing for me. They wouldn't want me to dry up and... And then say, "It's time."

When responding to the item on the decision aid, “people won’t follow your wishes” in regards to what values are important in deciding whether to complete advance directives, five of the seven PWDs answered that they trusted their caregivers to follow their wishes. Moreover, while PWD #6 did not answer the question posed about whether she was leaning towards completing an advance directive or not completing one, she responded that she trusts her caregiver to make medical decisions on her behalf.

Researcher: Okay. Do you have uh an inkling of interest one way or another, of completing an advance directive or not?

PWDs: I would, I think I would trust him...In terms of making a decision as to what to do medically

Because PWDs believed that their family caregivers would make the right decisions on their behalf, PWDs gave them lots of leeway to make decisions as surrogate decision-makers. For instance, two PWDs (# 2 and #3) selected the response on the decision aid that “I want my family to do what brings them peace, even if it goes against what I have said” when answering an item about how involved PWDs want their caregiver to be in making decisions on their behalf if they were seriously ill. Moreover, PWD #3 was vocal about how her caregivers were the decision makers on her behalf and she even acquiesced to her caregivers plans for pursuing indefinite life support after stating that quality of life was more important to her than quantity of life.

Specific role of caregivers: Explain and clarify

Most caregivers clarified and explained ACP concepts to PWDs as well as clarified and explained the PWDs’ responses for the researchers. When PWDs struggled to understand what was being asked or said, whether due to an auditory or cognitive

deficit, five of the seven caregivers clarified for them, allowing the PWDs to meaningfully participate in the interviews. Caregivers would either repeat what the researcher said or rephrase what was said in the caregiver's own words. This was exemplified by the caregiver for PWD #7, who clarified for her when the PWD did not understand a question asked by the researcher.

Researcher: Um overall how do you feel about engaging in advance care planning with your family?

PWDs: H-how much at ease I am?

Researcher: How do you feel about engaging in advance care planning?

CG: Do you think, can I rephrase is that alright? And you can correct me If I'm wrong. Well yes, kind of how at ease are you, how do you feel doing the process of advance care planning

PWDs: Oh. It's okay

CG: You feel okay?

PWDs: Yeah I feel okay, sure.

For PWDs with auditory deficits, caregivers would frequently check if the PWDs understood what the researcher said and then rephrase what was said if the PWDs did not understand. This can be seen in the interaction between the caregiver and PWD #1, who had hearing loss.

CG: Do you understand what she said?

PWDs: I don't know.

CG: Okay. You can choose, to tell us exactly how you want your body, yourself, to be handled in case you expire. And if you want, like say me, to be the Medical Power of Attorney, to make the decision—to—decide

what it is that you want done and to make it logically and in your—your wants and needs. Do you, Did you understand that?

PWDs: I. I understand it but I don't know why.

When PWDs could not define terms related to ACP or did not understand the conversation occurring about ACP, caregivers readily clarified for PWDs to help them understand what was being discussed. Caregivers for four of the seven PWDs clarified information about ACP for PWDs. For example, after the researcher defined ACP, the caregiver for PWD #1 explained to the PWD why ACP was being discussed. “CG: So it's. We're talking about it before it happens. So that we know in case you go into a coma, what it is that you want. How you want to be taken care of.” Caregivers also clarified the difference between the different forms of advance directives discussed as well as the difference between ACP and estate planning, such as when the caregiver for PWD #3 had to clarify that ACP was not about the PWD's possessions.

PWDs: Cause I got stuff I want my grandchildren to have, especially her daughter. And, uh, my other granddaughters—

CG1: They, they, they're not talking about that.

CG2: That's not what they're asking.

CG1: They're talking about your medical condition.

PWDs: Oh, okay. Okay. Okay.

It was not uncommon for PWDs in the study to answer questions tangentially or to talk about a different topic altogether. Caregivers also helped to clarify the responses of PWDs when they did not understand what was being asked or did not answer a question. When answering questions in the decision aid, PWD #2 seemed to be confusing ACP with planning for her funeral. Thus, throughout the interview, the caregiver for

PWD #2 repeatedly clarified that questions were about her health care and not about her funeral. Caregivers clarifying of PWDs' responses not only helped to collect direct answers to questions posed by the researcher, but also to ask important follow up questions. This could be seen when PWD #7's caregiver clarified what the PWD meant when PWD #7 was asked about her comfort level regarding talking to healthcare providers about ACP.

PWDs: Okay and then he got sick, instead of giving his practice to somebody else or selling it, he has uh three nurse—

CG: nurse practitioners. Nurse practitioners, right?

PWDs: Yeah, uh huh, right. And so I see one

CG: Well could you talk to her? Do you feel comfortable talking to her?

PWDs: Oh no, no.

Caregivers also explained different terms to PWDs including life sustaining measures and facts about the PWD. For example, the caregiver for PWD #1 explained a feeding tube as follows:

CG: Tube. Feeding. Tube. They would run a tube down your throat, into your stomach so that your body keeps getting nourishment even if you can't eat.

...

PWDs: A feeding tube.

CG: Yeah. That's another artificial way of keeping you alive.

PWDs: I don't want that.

Caregivers also provided the researchers with information about the PWDs that might explain their relationship with ACP. Specifically, caregivers shared with

researchers the complicated relationships of PWDs with healthcare providers. Of the four PWD who discussed negative experiences with healthcare providers, three of the caregivers shared with the researchers about the specific issue that the PWDs had with healthcare providers. The caregiver for PWD #7 exemplified this role when she revealed that the PWD needed a new doctor. “CG: She's in a weird situation like her primary care doctor got sick...and she doesn't really like him. She needs a gerontologist. But I'm not sure if she'll let us.”

Specific role of caregivers: Help PWDs understand their wishes.

Throughout the interviews, six of the seven caregivers helped clarify what care PWDs wanted when answering questions in the decision aid. The caregivers often framed the questions in different scenarios for the PWDs to help them think about their wishes. When PWD #2 was struggling with answering how long she would want to receive medical care if she was seriously ill, her caregiver tried to help clarify the PWD's response by framing the question as a scenario.

Researcher: Let's see, how long do you want to receive medical care, indefinitely no matter how uncomfortable treatments are or is the quality of life more important to you than the quantity of life?

CG: Again, like if you was in a coma.

P: Hmm... well... 3 I guess. I don't know, I don't know. If I'm in a coma...

CG: Do you want to be in there forever and a day?

P: Not necessarily. Because... that's going to put tension on you all. You know. Uh, just come and see me every now and then.

The caregiver for PWD #6 also posed scenarios to the PWD to help identify what care she would want in different situations.

CG: If you get pneumonia, if you want full, do you want full uh

PWD: medical

CG: full medical care

PWD: Mhmm

CG: or do you just want to die. That's

PWD: I want full medical care in that case

CG: for pneumonia

PWD: Yes

CG: And if you have a major heart attack and a stroke at the same time, do you want full medical care or do you just want to die?

PWD: Probably full medical care for a time period, if, depends on how um complete or comprehensive the stroke is and whether there's been sufficient um rehabilitative help before you give up, because most strokes there can be some recovery from.

Role of caregivers: Surrogate decision maker for now and the future.

Throughout interviews, PWDs treated caregivers as surrogates by deferring decision making and tasks to their caregivers. PWD #3, for example, gave her caregivers carte blanche in decision making about her end of life care.

Researcher: Is there anybody else that you want to talk to about advanced directives?

PWD: No.

Researcher: Okay.

PWD: I would rather for my children to know...Whatever they say, it goes.

Caregivers would also act as surrogates during the interview by responding on behalf of PWDs when the PWD did not answer a question. When the PWD did not understand a question, the caregivers for PWD #3 clarified and then answered on her behalf.

CG1: So repeat—read the question again.

CG2: So, put both.

CG1: Mm-hmm.

Researcher: So of those...Of those two directives...Do you have a preference?

CG2: Of either/or—

Researcher: Mm-hmm. [affirmative]

CG2: ...or both.

CG1: Both.

PWD: Both

Similarly, the caregivers for PWD #1 and PWD #4 answered questions on the decision aid on behalf of the PWDs when they did not have an answer to a question. At times, PWD #4's caregiver would just answer questions on behalf of the PWD before giving him an opportunity to respond.

Researcher: Okay. I don't know how to talk to my doctor about it?

CG: No, I think he just hasn't had that conversation with him.

...

Researcher: Uh, are you clear about what matters most to you in deciding advance directives?

CG: Somewhat he does.

Five of the seven caregivers answered yes on the decision aid item asking if they were clear about what matters most to the PWDs in making decisions about advance directives. These caregivers were comfortable with making decisions on behalf of the PWDs when the PWDs would be unable to do so for themselves. For example, the following is the caregiver's conversation with PWD #7 as the caregiver explained why she felt confident of her understanding of PWD's wishes.

Well I think, with our talks together, I feel like I have a pretty good idea, of what your priorities are and what you would want. And sometimes I ask you questions when they pop in my head and I think in terms of having something to show to a doctor or a hospital it's helpful that it's written down, but you're right, you can't think of every eventuality and so at some point, hopefully, they will have to take my word for it if she can't articulate it herself.

From the HCPs' perspective, HCP #2 and HCP #3 described how patients' have wanted their family members to be surrogate decision makers and make end of life decisions on their behalf. According to HCP #2,

...sometimes patients don't want to have, they don't want to make their own decisions. Sometimes they want their, their family to make those decisions. Um, and, and I think that's, you know...like, that is patient autonomy. To say, no. I don't...I don't want to do it. Like, I've had...uh, uh, patients that filled out an MPOA. And, and said, "good.

Finally. Now, you can stop asking me all this stuff. Tell it to my daughter.
Don't tell me all the news. She makes the decisions. She gets the news. I
don't want to hear it. She's going to do what's best for me. I trust her"

PWD's Distrust of Health Care Providers

PWDs with negative experiences with healthcare providers did not see talking to HCPs as a necessary step of ACP. For PWD #1, he did not see a point in talking to HCPs because he believed that doctors did not care about his wishes. "Researcher: Alright. Now, how confident are you to talk with your doctor about what you want and don't want? PWDs: No I don't give a, give a kick, he doesn't." Throughout the interview PWD #1 reiterated his skepticism about talking to doctors and whether doctors cared about his wishes. PWD ID #7 did not believe that her healthcare provider cared about her end of life wishes. When answering questions on the decision aid about talking to a doctor, she referred to her son-in-law who is a doctor. Towards the end of the interview, after being reminded by her caregiver that her son-in-law is family and not her doctor, the PWD admitted her feelings about her healthcare provider.

PWD: I-I-I honestly do not have a doctor. My doctor was a really good
doctor, we had 20-30 years. Okay and then he got sick, instead of giving
his practice to somebody else or selling it, he has uh three nurse

CG: nurse practitioners. Nurse practitioners, right?

PWD: Yeah, uh huh, right. And so I see one

CG: Well could you talk to her? Do you feel comfortable talking to her?

PWD: Oh no, no. She-she is...She is not- she is not the least bit interested
in me. She wouldn't- she wouldn't no- she wouldn't answer me.

PWD #6 also lacked a primary care provider, but her and her caregiver did not think it was a barrier to her engaging in ACP,

Researcher: Gotcha. Do you feel like not having a primary care provider, has affected you completing an advance directive at all?

...

CG: Do you think that the fact that you don't have a primary care provider has prevented you from filling an advance directive or had any effect on it

PWDs: Um no, we just we just haven't

CG: I've got one and it hasn't affected me, I haven't I haven't done it so

The caregiver for PWD #6 also shared this belief that there is no point in talking to a primary care provider about ACP, specifically because that HCP would not be the one to see a patient in a hospital setting. PWD #5 outright stated that he did not trust his HCPs because he believed that they were responsible for his wife's death.

While other PWDs did not vocalize a resistance to talking to their healthcare provider about ACP, none of the PWDs identified their healthcare provider as somebody that they wanted to talk to when answering the question on the decision aid "Who else do you want to talk to about advance directives."

Health Care Providers' Role in Facilitating ACP

The HCPs that participated in this study all had different jobs, but saw their roles in ACP similarly. Three of the four HCPs emphasized that their role in ACP was to support patients and allow patients to control the ACP conversation. HCP # 2 acknowledged that it is important for them to let patients guide ACP conversations.

... I think just part of what chaplains do is, is, kind of, um, you know, non-standardized in many ways that, you know, we kind of use some assessment tools but a lot of it is, you know, just creating space to listen to what's really important and— kind of letting a patient guide a conversation more.

HCP #1 echoed this sentiment and highlighted the need to establish trust,

But, um, the main thing is just kind of getting their input and not talking so much. Just seeing how they feel about, you know, "If you weren't able to make a decision, what would be your next"—you know, "what would be your wishes?" And then we just have an open discussion in—on that end. And, you know, just establishing trust is the main thing, because, um, you know, if they feel like you're targeting something, then that's makes people defensive, and it doesn't go smoothly. So I just have them talk, and then we just ask questions—on that end.

Similar to the family caregivers of PWDs, some HCP participants saw their role was to clarify when it comes to ACP with patients. As clarifiers during ACP, HCP help clarify the values of patients. HCP #1 and HCP #2 identified exploring the values of the patient as the top priority in ACP discussions. HCP #1 informed the researchers how she believes clarifying the values of patients is more important than identifying the surrogate decision maker when it comes to ACP.

Yeah. Just values of your—quality of life. You know—what they value in—their life, you know, their end of life. Um, I think that's—probably more important than who's going to make the decision—this—just make sure that, you know, you actually ask them, "What do you value?" Like,

"What's the most important thing that you would want at the," you know—"if you couldn't make a decision."

When family members have to make decisions on behalf of a patient who can no longer communicate their wishes, HCP #2 seeks to clarify with family members what the values were of the patient.

I, so, sometimes in the, in the work that we do, that's part of the discussion is, um, you know, what, what are the values that they've stated before? Have they ever talked to you about end of life? Um, have... You know, what, what's the things that really mattered to this person?

For another HCP (#3), an inpatient nurse practitioner, believed that identifying a surrogate decision maker was the top priority of ACP conversations while HCP #4, a medical assistant, mostly discussed going over the clinic's ACP information with patients and being available to answer questions for patients.

All four HCPs mentioned monitoring and facilitating progress of ACP in some capacity in their different roles as HCPs. Monitoring progress for HCPs involved monitoring readiness to complete advance directives. HCP #2 illustrated how he monitored patients' readiness to complete advance directives after educating patients about the forms,

"Would you, would you like to fill out one or the other, or, or both of them? Um, or, or—neither right now? You know? Or, or is there another way you'd like for me to follow up? That's the way that, so when I go and talk to, to patients about that, that's, kind of, usually the way that I'll, kind of, segue into that portion. Like, okay. Do you have any more questions about this? Right? And, okay. No, I don't have

any more questions. Okay. Well, um, is, is this something that you'd like to fill out now? I can, I can help you fill it out now if that's helpful. ...And then just take—that as a, you know, whichever one they want, that's, that's their decision. You know?

HCP #1 and HCP #4, who worked in an outpatient setting, reported having to continually monitor advance directive completion since patients took advance directive forms to complete them with their family, but often did not bring the forms back.

HCPs reported different strategies that their facilities use to facilitate ACP among their patients. Strategies used by HCP #1 to engage patients in ACP included slowly introducing ACP in order to avoid overwhelming patients. Strategies used by HCPs in an outpatient included introducing ACP slowly, scheduling separate appointments for ACP, and having a notary in an outpatient clinic. One physician at HCP #4's facility scheduled separate appointments in order to spend the time engaging patients in ACP.

So, yeah, because it became too overwhelming for us to manage their health. So, [physician] and, um, I started having the patient come back at her next available or in a week or two weeks down the line to schedule specifically for advanced directives or advanced planning. And she has also explained that to them in that visit.

PWD's Readiness to Complete ACP Tasks

During the interviews, PWDs were asked "Overall, how do you feel about engaging in ACP with family members or a healthcare provider?" and "Are you interested in completing/modifying an AD?". Data were also gathered from PWDs' responses to decision aid items relating to "How Confident Do You Feel About Advance

Care Planning?”, “How Ready Do You Feel About Advance Care Planning?”, and “Of the two options for advance directives, which do you prefer the most?”

Based on PWDs responses to items on the decision aid, all participants reported being ready to complete MPOAs and talk to their MPOAs about their end of life wishes (see Table 4). Fewer participants reported being ready to talk to their doctor about their end of life wishes or to ask their doctors questions about making good medical decisions. One PWD responded that they were not ready, one PWD did not answer because they did not have a current physician, and one PWD did not answer because they believed it was the same question that they already answered about being confident. Only three PWDs also responded that they were ready to talk with their doctor about who they want to be their MPOA. In addition to the previously listed reasons for not being ready to talk to their physicians because of lacking a doctor and believing the question was repetitive, one PWD #1 did not believe that it was the physician’s business to know who he selected as his MPOA,

Talk with your doctor about who you want your medical decision maker to be. Well I, I don't know why I need to have a conversation with him about that. If I've decided who I want to, make these decisions that, he's got no business in that.

AIM 2: DESCRIBE FACILITATORS AND BARRIERS TO PWDs MAKING DECISIONS ABOUT ENGAGING IN ACP

Themes related to barriers and facilitators included many of the themes related to Aim 1 with some additional new themes. Facilitators to ACP from themes in Aim 1 included benefits of ACP to caregivers as surrogate decision-makers, PWDs’ trust of family caregivers and health care providers’ role in facilitating ACP. Barriers identified

from the themes in Aim 1 included: lack knowledge about ACP concepts and process and PWDs' distrust of healthcare providers. Additional new themes on barriers included difficulty in predicting the future and discomfort in discussing ACP.

Facilitators to ACP Engagement Among PWDs

Benefits of ACP to Caregivers as Surrogate Decision-Makers

In completing the decision aid, all seven participants responded that it was a great deal important that their family knew what they want and do not want, that their doctor know what they want and do not want, and that family will disagree less because they know what the PWD wants. This unanimous response to the importance of family knowing the wishes of PWDs and avoiding disagreement was consistent with the motivation for PWD #7, who had previously completed advance directives. PWD #7 informed the researcher about how her family was a facilitator for completing advance directives when her husband died.

Researcher: Okay. So, when did you complete the uh advance directives?

The living will and the medical power of attorney. When did you complete those?

P1: A couple of years ago. Yeah, because when my husband died they wanted to know uh, what I wanted

Q: Gotcha. So was that the big reason... For completing the forms, was because of your husband's death?

P1: Yeah, right right... Well that's when it first came up I umm, my husband simply got ill so there was no question but I was still alive, so they really want to know

Q: Mhmm. So do you feel like it was your family who encouraged you to fill out those forms?

P1: Yes yes.

Additionally, six out of seven PWDs responded that it was very important that family will experience less stress because they know what the PWD wants. Four out of seven PWDs responded that it was very important that family avoid potential legal issues. Six out of seven participants responded that receiving the care that they want was a great deal important. According to the ODSF, value clarity is important in making informed decisions. PWDs in this study were clear about their values, specifically, that they valued getting the care that they want at the end-of-life, and having their family members know their end-of-life wishes.

PWD's Trust of Family Caregivers

Despite only one PWD having experience completing an advance directive, all PWDs readily identified family caregivers as MPOAs. Additionally, PWDs trusted their family caregivers to make decisions on their behalf even though the extent of PWDs discussion of their wishes with their family caregivers varied in depth. Because PWDs trusted their family caregivers, family caregivers were an important source of support in facilitating ACP engagement. As identified by the Ottawa Decision Support Framework, family caregivers were able to provide decision support to PWDs by clarifying the decisions and needs of PWDs. Additionally, family caregivers clarified the values of PWDs in their role of helping PWDs understand their wishes.

Barriers to Engagement in ACP Among PWDs.

PWDs' Lack Knowledge about ACP Concepts and Process

As previously discussed in Aim 1, people need to be knowledgeable about the concepts and processes of ACP in order to meaningfully engage in ACP. Based on the analysis of the interviews of PWD and caregiver dyads, it is clear that PWD participants' knowledge about ACP terms including ACP, advance directives, and living will was vague, inaccurate, or non-existent. Additionally, more than half of the PWDs in this study also lacked knowledge of the ACP process or had incorrect knowledge about the process. As identified by the Ottawa Decision Support Framework, inadequate knowledge is an unresolved decisional need that negatively affects decision quality. In other words, without receiving the appropriate information about ACP concepts and processes, PWDs engagement in ACP will continue to be minimal and potentially inadequate.

PWDs' Distrust of Healthcare Providers

Interviewed HCPs emphasized the importance of establishing trust when talking to patients about ACP, but it was evident that prior negative experiences with HCPs resulted in interviewed PWDs distrusting HCPs in general. Additionally, none of the interviewed PWDs viewed HCPs as a resource for talking to about ACP. This lack of trust of HCPs among PWDs is a barrier to ACP engagement as HCPs are a valuable source of decision support in terms of ACP. Through the lens of the Ottawa Decision Support Framework, HCPs support patients' deliberation and communication regarding ACP, clarify patients' values, and monitor and support patients' ACP progress, but the lack of trust means that PWDs are not reaping the benefits of HCPs' decision support.

When PWDs, and people in general, do not trust healthcare providers it is a notable barrier to engaging in ACP.

Difficulty in Predicting the Future

Although PWD #7 had previously engaged in ACP, she explained that she had not engaged in ACP again because she was uncertain about what kind of life prolonging care that she would accept due to advances in medical care. PWD #7 was also uncertain about completing advance directives again because she was uncertain of how she will die.

But I-I have been thinking about it, but at the same time, not knowing because I don't know what's going to happen...Oh no, it's just, no it's not that I don't want to, well I just think of different things you know, what if I lose my kidney Then that's also the end for me... And if it is my heart, then it's easy because then I'm done. So you know, it's not that I'm not willing, it's just that, I don't know.

Similar to PWD #7's explanation for not engaging in ACP, the caregiver for PWD #6 stated that a reason for not engaging in ACP was, "It's hard to make decisions about you know where is the line when you want to be resuscitated or not. If you like to cut off at the ankles, the knees, or the hips. Where does it stop?" For example, in a scenario of simultaneously experiencing a major heart attack and stroke, PWD #6 responded that she still wanted to receive full medical care for some time because she did not know the severity of the stroke and believed that some recovery might be possible. Elaborating further on why they had not engaged in ACP, the caregiver for PWD #6 stated "You can't be comfortable without somehow being able to define how sick you want to be or how terminal you are, or what your prospects of recovery are, and the forms don't really

leave space for that I think.” HCP #3 echoed this sentiment by providing an example of how her own father was hesitant to share his advance directives when hospitalized because, ““If I tell them I have a terminal, irreversible condition, I want—I don't want extraordinary measures, that they're just not going to offer me treatment,’ you know?’” Some people are hesitant to engage in ACP because they cannot predict what their cause of death will be and thus do not want to specify what kind of care they would or would not want at the end of life.

Discomfort in Discussing ACP

HCP #2 and HCP #4 believed that PWDs’ lack of desire to think about and discuss their end-of-life is because of the discomfort of doing so and is therefore another barrier to people engaging in ACP. When listing barriers to ACP, HCP #4 suggested that people, “...they’re undecided or they’re not very comfortable about talking about, about these types of situations.” HCP #2 elaborated further on how people do not engage in ACP because they are not comfortable thinking or talking about dying.

Um—I feel like most, most people don’t-, aren’t comfortable thinking about or talking about their own death, you know, in a very real sense. And so, um, I think a lot of times, that’s one of the biggest prohibitors for, you know, that are reasons why people don’t fill them out. Um, is that they think they don’t—you know, need them. And it’s morbid. And why should I—You know—be thinking or talking about this.

Towards the beginning of the interview, PWD #6 cited simple reasons for not having engaged in ACP, “We just haven’t gotten around to it I think.” Her caregiver added on that they have been lazy. But when the dyad was asked why they think people do not

engage in ACP, PWD #6 suggested that “They don’t like thinking about death” and agreed that reason was applicable to her as well. However, when it came to responding to the item on the decision aid, “I am uncomfortable to talk about future illness”, PWD #6, and all other PWDs responded no, they are not uncomfortable talking about future illness. Participants were not asked if they were uncomfortable thinking or talking about dying.

SUMMARY

In this chapter, themes and subthemes were described about PWDs’ lack of ACP knowledge, the benefits of ACP to caregivers, caregivers’ essential roles in ACP for PWDs, PWDs’ readiness to complete ACP tasks, PWDs’ trust of caregivers, PWDs’ distrust of healthcare providers, difficulty in predicting the future, and discomfort in discussing ACP. Quotes from PWDs, caregivers, and healthcare providers helped provide a rich description of these themes and subthemes. These findings were arranged in order to answer the research questions.

Table 4. PWDs Responses to Decision Aid Items Regarding Readiness and Confidence

	# of PWDs that answered affirmatively (n=7)
Talking to MPOAs	
Confident and ready talk to their MPOA about the kind of medical care that they want	7
Confident and ready to talk to their MPOA about the flexibility/leeway that the PWDs wants to give their MPOA	7
Confident and ready to ask someone to be their MPOA	6
Talking to HCPs	
Confident and ready to talk to their doctor about how much flexibility they want to give their MPOA	6
Confident and ready to talk to their doctor about the kind of medical care they would want if they were very sick.	5
Confident about having a discussion with their doctor to help them make good medical decisions	5
Ready to ask their doctors questions to help them make good medical decisions	4
Ready to talk with their doctor about who they want to be their MPOA	3
Completing advance directives	
Confident and ready to sign papers naming a MPOA	7
Ready to sign official papers putting their wishes into writing	7
Prefer to complete both a living will and medical power of attorney rather than just one of the advance directives	4

Chapter 5: Discussion

As dementia progresses to the advanced stage, PWDs have trouble communicating and expressing their wishes for end of life care. As such, PWDs need to be engaged in ACP in earlier stages of the disease in order to have the opportunity for their end of life care to align with their wishes. Empirical data from the perspective of PWDs on ACP is lacking in existing literature, especially around reasons for limited participation of PWDs in ACP and how to best support them in ACP. The purpose of this dissertation was to fill this gap by describing in depth how PWDs make decisions regarding engaging or not engaging in ACP. The ODSF was used as a lens for analyzing data from an ongoing study because this framework helps with understanding the decisional needs of people making health decisions. The perspective of PWDs' family members and healthcare providers were also included in order to highlight the decision support needs of PWDs in ACP.

This chapter first discusses the study findings through the lens of the ODSF in respect to the aims and research questions of this study. Next, limitations of this study are discussed, followed by implications for practice and future research.

AIM 1: DESCRIBE THE DECISION-MAKING PROCESS OF PWDs TO ENGAGE IN ACP

The ODSF was created around the nursing diagnosis of decisional conflict, which is defined as uncertainty about which option is best due to “risk, loss, regret, or challenge to personal values” (Carpenito, 2000). Due to decisional conflict being associated with delayed decision making (O'Connor & Jacobsen, 2007), the first aim of this study was to describe the decision-making process of PWDs to engage in ACP. This included describing PWDs' information needs about ACP, value clarity about benefits and risks of ACP,

support needed to engage in ACP, and decisions that PWDs make with regards to ACP engagement.

Information Needs of PWDs with Regards to ACP Engagement

The first research question, “What information needs do PWDs have about advance care planning (ACP)?”, was asked in order to determine what knowledge PWDs’ possessed about ACP. The PWDs in this study possessed very little knowledge about ACP concepts including advance directives, living will, and directive to physicians. These PWDs also lacked knowledge about the ACP processes of talking to others about their wishes, seeking advice from experts, and formally recording their wishes in advance directives. The knowledge that PWDs’ did possess about ACP was often inaccurate. A common misunderstanding was that ACP was related to financial planning for end of life. The limited knowledge that PWDs possessed about ACP that was accurate was about the concept of a MPOA. HCPs acknowledged that most people lack the knowledge to make complex and nuanced decisions in advance directives regarding life sustaining measures.

These findings are consistent with findings from prior studies. Lewis et al. (2015) reported less than a quarter of their interviewed PWDs were aware of ACP compared to over 65% of PWDs that were aware of a financial planning option for end of life and 62% were aware of the Australian version of a MPOA. Similarly, Dickinson et al. (2013) found that their sample of PWDs in the UK had knowledge and experience with financial planning and lacked knowledge about the UK version of living wills and MPOAs.

It is difficult for PWDs who do not feel knowledgeable about advance directives to engage in ACP. Indeed, in this study, it was often the case that even when advance directives and ACP were repeatedly explained to the PWDs, they would often forget what

they were, or had difficulty comprehending the purpose or process involved with ACP. Advance directives have the potential for people to detail what care they find appropriate or inappropriate at the end of life. However, without a basic understanding of the concepts of ACP, process of ACP, and purpose of AD forms, focusing on the finer details of advance directives may be futile.

It would be important for HCPs to engage PWDs in ACP early in the diseases process when PWDs can still meaningfully engage. Moreover, more research is needed to better understand the ability and willingness of PWDs at different stages of dementia to participate in ACP in ways that promote understanding of PWD's preferences and values, and consider EOL care options along with their values. Building on such research findings, HCPs may be able to provide more tailored ACP education and coaching for PWDs across the different stages of dementia.

What is important to PWDs when deciding to engage in ACP?

According to the ODSF, when making a healthcare decision, patients weigh the benefits and risks of options based on their values (O'Connor & Jacobsen, 2007). The aim of this second research question was to identify what PWDs commonly believe is important in terms of benefits and risks when deciding to engage in ACP, allowing researchers to refine decision aids to help healthcare providers and PWDs with decisional conflict clarify their values and better contemplate which benefits of ACP outweigh risks of ACP for them personally and thus how they should engage in ACP.

Benefits of ACP for PWDs

Most of the PWDs did not report benefits to engaging in ACP, which could be related to previous findings of PWDs preferring to live day-to-day and not seeing the

relevance of ACP in their focus on day-to-day life (de Boer et al., 2012). Most caregivers also did not explicitly identify benefits of ACP, but through content analysis perceived benefits for surrogate decision-makers were identified. These benefits for caregivers included avoiding the PWD being on life support indefinitely and knowing the wishes of the PWD if they were to become seriously ill. Most PWDs reported wanting their family caregivers to do what brings them peace when the PWD is unable to make decisions for themselves, even if that goes against the PWDs' wishes. PWDs considering the impact of medical decision making on their family members was consistent with findings from Karel et al. (2007), in which 70% of study participants identified the emotional impact on family as a value that would influence their decision about medical care. Thus, the benefit of ACP to PWDs was that it helped their family members, whose welfare was a priority to these PWDs, even if the PWDs did not explicitly identify this benefit. As such, it may be important to consider educating family members of PWDs of this benefit as a way to help PWDs and families to more proactively engage in ACP.

Risks of ACP for PWDs

None of the interviewed PWDs, family caregivers, or healthcare providers explicitly identified risks of engaging in ACP for PWDs. However, themes on barriers to ACP suggest potential risks of ACP perceived by PWDs. These barriers and potential risks are discussed later in this chapter.

Support Needs of PWDs Regarding ACP Engagement

The essential roles of family caregivers in PWDs' ACP engagement

The third research question asked what support needs PWDs have regarding ACP engagement, with the sub-questions being "What is the role of family members in their

decisions about ACP?” and “What is the role of professionals in their decisions about ACP?”. The purpose of these research questions was to identify what support PWDs received and what support PWDs lacked when it comes to engaging in ACP from family caregivers and healthcare providers. Although prior studies about ACP amongst PWDs included family members in their study to assess the congruency of PWDs’ values and caregivers’ values in terms of end of life care (Ayalon et al., 2012), ACP engagement (Caplan et al., 2006), and the attitudes of caregivers for PWDs towards ACP (Denning et al., 2012), the literature lacks evidence about how caregivers support PWDs in engaging in ACP. In this study, most PWDs believed that they already had enough support from their families to engage in ACP. Moreover, PWDs trusted their family caregivers to know and make the right decisions on their behalf in terms of end of life care despite most of the PWDs not having engaged in ACP with a healthcare provider nor having recorded their wishes in advance directives

Although the inclusion of family members/caregivers in research is often forewarned against because they may answer on behalf of the population of interest, the inclusion of family caregivers in this study empowered PWDs to meaningful interact with the study. According to the ODSF, decision support includes clarifying the decision and needs, providing facts and probabilities, clarifying values, guiding/coaching/supporting skills, and monitoring/facilitating progress (O’Connor & Jacobsen, 2007). In this study, several roles that caregivers played in supporting PWDs’ engagement in ACP were consistent with the ODSF. Roles of caregivers included explaining and clarifying, helping PWDs understand their wishes, and serving as a surrogate decision maker now and in the future. Caregivers provided facts and probabilities to PWDs by explaining and clarifying concepts related to ACP for PWDs as well as explaining and clarifying PWDs’ responses

for the researchers. By helping PWDs express their wishes, caregivers helped PWDs clarify their values for their own, the PWDs', and the researchers' understanding. Caregivers also provided decision support by being prepared to make decisions for the PWD at the time of the interview as well as in the future. The one dyad in this study in which the caregiver frequently responded on behalf of the PWDs was with a PWD whose English was limited (unable to read English).

Based on these findings of how PWDs report being supported by family caregivers and family caregivers serving in different roles to support PWDs, it is evident that inclusion of family caregivers in this study empowered PWDs to meaningfully participate in the study. Thus, including family caregivers to be participants, but not the primary respondent, in ACP discussions with PWDs is important in order for healthcare providers to have meaningful conversations with this population. Strategies that HCPs can use to incorporate caregivers into ACP conversations with PWDs should include using a patient-focused approach and collaborating with the dyad (Riffin et al., 2021). Taking a patient-focused approach means focusing on conversing with the PWD at their cognitive ability with the caregiver in the room. Collaborating with the dyad would include listening without judgment to validate perspectives, building consensus, and shared decision making.

The role of professionals in PWDs' decisions about ACP

Given that most people learn about ACP from healthcare providers, it is important to understand how PWDs perceive the role of HCPs when it comes to engaging in ACP. Existing studies have described how PWDs' EOL wishes were affected by their experiences with nursing home staff (Goodman et al., 2013) and the similarities and differences between PWDs' preferences for EOL care and nurses' perceptions about

PWDs' preferences for EOL care (Mulqueen & Coffey, 2017), but the literature fails to describe how PWDs view HCPs as a resource for engaging in ACP. In terms of the role of HCPs, PWDs did not see HCPs as essential to engaging in ACP. None of the PWDs identified their HCP as somebody that they wanted to talk to about advance directives. Additionally, PWDs who had negative experiences with healthcare providers did not see talking to HCPs as a necessary step for engaging in ACP. Specifically, these PWDs did not trust HCPs because they believed that HCPs did not care about their wishes.

On the other hand, the HCPs included in this study viewed themselves as a source of support when it comes to patients engaging in ACP. Through the lens of the ODSF, there was overlap between the different roles of HCPs supporting patients engage in ACP, despite their varied jobs. All HCPs reported monitoring and/or facilitating ACP progress, including monitoring patients' readiness to engage in ACP and facilitating completion of advance directives. Most HCPs also emphasized their role of facilitating ACP engagement by establishing trust with patients and allowing patients to guide ACP conversations. Some of the HCPs also identified their role as clarifying patients' values, both amongst patients and amongst family members.

Based on these findings, PWDs that participated in this study have support from their family members but are missing out on the support of HCPs because of their negative past experiences with HCPs. These findings are consistent with those of Makino & Porsteinsson (2015) who found that 90% of the PWDs in their study had discussed MPOAs with their spouse and 67% had discussed MPOAs with an adult child, whereas only 33% of PWDs had discussed a MPOA with a general doctor and 19% had discussed MPOAs with a specialist. This means that HCPs, especially primary care providers, need to work

harder to improve communication and build trusting relationships with both PWDs and their caregivers in order to improve ACP engagement amongst PWDs.

Research question 4 asked “What decisions do PWDs make regarding their level of engagement in ACP?” to describe PWDs’ intention to engage in ACP and completion of advance directives. In this study, all PWDs reported being ready to talk to their family caregivers about their end of life wishes and complete a MPOA form, but only one PWD had previously done either of these ACP tasks. Consistent with how PWDs view HCPs’ role in ACP, fewer participants reported being ready to talk to their doctor about their end of life wishes, who they want to be their MPOA, or ask doctors questions about making good medical decisions. In summary, PWDs are more comfortable making decisions that involve talking to their family members about ACP than talking to HCPs about ACP.

Given that PWDs have significant information needs regarding ACP concepts and the ACP process, due to their lack of knowledge, it makes sense that PWDs would be unaware of the benefits of ACP, not see a necessity in talking to HCPs about ACP, and have not made many decisions about engaging in ACP. These findings are consistent with the literature on ACP amongst PWDs. Dening et al. (2012) reported that most PWDs did not see the potential value of ACP or how expressing preferences and wishes now could influence care later. Additionally, Dickinson et al. (2013) found that PWDs and their caregivers engaged in personal and financial future planning but experienced difficulty with formal ACP. These findings highlight the importance of HCPs taking the initiative to engage PWDs in conversations about ACP rather than waiting for PWDs to initiate these conversations. Additionally, HCPs need to involve the caregivers of PWDs in these conversations because of the many roles that caregivers serve in to help PWDs express

their wishes. Lastly, it's imperative that HCPs start conversations about the ACP process early with PWDs so that PWDs can still meaningfully engage.

AIM 2: DESCRIBE FACILITATORS AND BARRIERS TO PWDs MAKING DECISIONS ABOUT ENGAGING IN ACP

The second aim for this study was to identify facilitators and barriers to PWDs' decision to engage in ACP. Identifying facilitators and barriers to PWDs' ACP decision making may help identify possible modifiable factors of ACP participation as well as PWDs values, which researchers can focus ACP interventions on and HCPs can base ACP conversations around in order to better engage PWDs in ACP.

Facilitators to PWDs Engagement in ACP

The first research question of Aim 2 asked "what facilitates PWDs engagement in ACP?" The PWDs who participated in this study did not explicitly identify facilitators for engaging in ACP. However, the responses of PWDs to items on the decision aid relating to their family knowing their wishes, avoiding disagreement, and avoiding stress, as well as PWDs interactions with their family caregivers during the interviews indicated that PWDs value that their family members benefit from their engagement in ACP. Moreover, the portions of ACP that these PWDs were ready to engage in demonstrated their trust of their family members. These findings highlight the importance of family to PWDs when it comes to ACP and thus the inclusion of family members when engaging PWDs in the ACP process. These findings are consistent with previous studies which reported that family involvement was a priority for PWDs during end-of-life care (Denning et al., 2012; Mulqueen & Coffey, 2017) and that the emotional impact on family was an influence in making decisions about medical care on PWDs and non-PWDs (Karel et al., 2007).

HCPs identified themselves as sources of support to PWDs engaging in ACP. Moreover, the support that HCPs described providing aligns with different forms of decision support described by the ODSF, which included clarifying values of the PWD and monitoring and facilitating ACP progress. HCPs also emphasized allowing patients to guide conversations about ACP and different strategies that their facilities had implemented to improve ACP engagement. However, PWDs did not view HCPs as a source of support for engaging in ACP, and PWDs' lack of trust of HCPs was one of the identified barriers to PWDs engaging in ACP, as discussed further below. Once again, PWDs trusting their caregivers over healthcare providers can be seen in how PWDs were confident and ready to talk to their MPOAs about ACP rather than talk to their physicians about ACP. Based on these findings, PWDs' trust of their family caregivers may be a facilitator to engaging PWDs in ACP.

Barriers to PWDs Engagement in ACP

Just as PWDs and caregivers did not explicitly identify facilitators to engaging in ACP, PWDs did not explicitly identify barriers to ACP engagement. As discussed previously, limited and inaccurate knowledge is a clear barrier to ACP engagement since people cannot make informed decisions about their healthcare when they do not know what the decision entails, or that there is even a decision to be made. This is consistent with previous findings of barriers to ACP among PWDs, which included lack of knowledge about advance directives (Dickinson et al., 2013).

The second identified barrier was PWDs' distrust of HCPs. None of the PWDs or their caregivers outright said that engaging in ACP was an issue because of their physician or lack thereof, but negative attitudes towards physicians was a barrier to engaging in ACP

for several PWDs and at least one caregiver. Individual experiences color the lenses through which PWDs view ACP and talking to HCPs about ACP. This is why it is important for HCPs to include family caregivers in ACP conversations, because they have insight into the perspectives of PWDs and where there are hesitations and hang-ups for PWDs. HCPs are an important source of information on ACP, and PWDs' distrust highlights the need for HCPs to build relationships based on trust with their patients so that patients feel comfortable having conversations about their EOL wishes and asking questions about ACP. Furthermore, HCPs need to regularly discuss ACP with their patients so that patients are educated and not put-off when the topic is brought up. Until these changes are standard in healthcare, it is unlikely that PWDs will view HCPs as a resource on ACP.

The other barrier identified through thematic analysis was PWDs' hesitancy to engage in ACP because of difficulty in predicting the future. Some of the PWDs were not ready to engage in ACP because of their uncertainty of when and how they will die. From the perspective of PWDs, planning for a possible outcome of being in an irreversible and terminal condition is too vague and that it's hard to determine when their condition is actually terminal. This finding is consistent with the findings of Denning et al. (2012), who reported that PWDs struggle with thinking about their future self and therefore struggle with planning for EOL care. PWDs' desire to plan for specific scenarios again highlights the importance of including family caregivers in ACP discussions so that they have a sense of what the PWD values in case they have to make decisions about a situation that the PWD had not anticipated.

The final barrier identified to PWDs engaging in ACP was discomfort in discussing ACP. This barrier was primarily identified by healthcare providers who believed that

PWDs, and people in general, are not comfortable discussing death. PWD #6, who identified that thinking about death was a barrier to engaging in ACP, admitted that this was the case after suggesting that other people are uncomfortable thinking about death. Interestingly, all PWDs responded on the decision aid that they are not uncomfortable discussing their future illness. It is possible that PWDs do not want to admit their aversion to discussing their future selves nearing death, but it is also possible that PWDs are uncomfortable engaging in ACP because of the difficulty in predicting their future condition, their distrust of HCPs, and/or their lack of knowledge about ACP.

These last two barriers are not exclusive to PWDs engaging in ACP. People without dementia also struggle with making unfamiliar decisions about a seemingly nebulous state of health (Barnato, 2017). People have difficulty with accepting the utility of ACP because it is like planning for a moving target, which makes it a challenging decision for many people in general. Furthermore, EOL is a difficult topic to think about so people in general avoid doing so. While PWDs may have a greater need than the general population to engage in ACP earlier, due to the progressive decline of their cognitive state, that does not make it necessarily easier for PWDs to accept ACP. Thus, a multipronged approach is needed to educate both the patient and caregivers initially and over time as the disease progresses. Moreover, primary care providers also need to have more understanding and training about ACP to help PWDs and their families.

HCPs are an important source of information on ACP because of their experience with caring for people at EOL and their specific knowledge about life-sustaining procedures. PWDs' distrust of HCPs highlights the need for HCPs to build relationships based on trust with their patients so that patients feel comfortable having conversations about their EOL wishes and asking questions about ACP. HCPs also need to improve

communication about ACP with PWDs by regularly discussing ACP with their patients, so that patients are educated and are not put-off when the topic is brought up. Furthermore, family caregivers need to be included in these conversations because family caregivers fill multiple roles in terms of decision support for PWDs, PWDs trust them, and PWDs may engage in ACP to benefit their family.

LIMITATIONS

As with any study, this study had several limitations. The first limitation was lack of opportunity to check for data saturation before the data collection was completed. The COVID-19 pandemic halted the original study while data collection was still ongoing. Data saturation would normally dictate the number of interviews that would be included in a qualitative study, but conducting a secondary analysis of existing data as well as the premature conclusion of data collection due to the COVID-19 pandemic prevented the researcher from being able to attain data saturation through the traditional means of interviewing participants until no new categories were identified during concurrent analysis of data (Morse, 2015). However, the relatively small sample size of seven PWDs was compensated for by including the perspectives of family caregivers and healthcare providers.

Another limitation is that since this started as an ancillary study of a larger study, the sample was not drawn to answer questions for this study, which introduces further limitations and potential challenges. For example, participants may have been unwilling to be forthcoming in answering questions which were asking for their perspective on a topic that many people avoid, planning for EOL. Furthermore, participants who were forthcoming in their answers may have not continued to do so when the topic became too

emotional. Similarly, participants may have provided responses based on what they think the researcher wants to hear and held back negative responses and provided neutral or positive responses instead.

Another limitation is the heterogeneity of the sample. Inclusion of persons with memory problems and cognitive impairment in addition to PWDs makes the sample more heterogeneous, but it was justified because dementia is often not diagnosed until later stages, increasing the chances of unintentionally recruiting more PWDs with moderate dementia over PWDs with mild dementia.

Other limitations of this sample were that: PWDs, caregivers, and HCPs in this study were recruited from one geographical area; dyads were people who were willing to discuss planning for end of life, a sensitive topic, possibly leading to biased sample of participants with more favorable view on ACP; PWDs included in this study had family members and findings may not be applicable to PWDs without families or those without family members involved in their care.

Qualitative description was selected as the methodology for this study because of the minimal interpretation used in analyzing collected data (Sandelowski, 2000), allowing findings to be a closer representation of PWDs', caregivers', and HCPs' perceptions. However, no research is without bias. As a nurse with experience working primarily with older adults, I had preconceived notions about the value of ACP for end of life planning amongst older adults, especially those with terminal conditions such as dementia. Triangulation between the participant responses on decision aids and their qualitative interview transcripts and peer checking were used to limit my bias and validate my findings.

Another potential challenge was the cognitive burden imposed on PWDs by this study. PWDs were asked to complete six instruments and then complete the decision aid. This may have led to fatigue among some PWDs, decreasing their willingness to complete the study and discuss their true feelings after their limitations had been exposed to the researcher. However, the interviewers were well trained to ensure to check in with the study participants frequently to assess any sign of fatigue or discomfort, and offer a break or even ending the interview if the participant requested. Interviewers did not notice fatigue and the two PWDs who became uncomfortable when discussing loved ones' deaths declined to end the interview when asked if they would like to stop. Nevertheless, it is possible that PWDs did not overtly express their feelings or interviewers missed such signs.

Finally, a possible limitation of caregivers' presence during this study was that they could have tried to answer on behalf of the PWD during the semi-structured interview. Indeed, interviewers noticed that some caregivers would sometimes answer questions on PWDs' behalf. However, this risk was necessary to endure in order to have access to this vulnerable population and to describe the lived experiences of PWDs and their caregivers as they consider important health information and decision-making needs. The best way to overcome this potential challenge was to remind caregivers that while we appreciate their participation, we do want PWDs to answer for themselves.

Despite these limitations, this study adds the perspective of PWDs and their caregivers to the body of research on ACP amongst PWDs. Specifically, information needs and support needs of PWDs as well as facilitators and barriers to PWDs engaging in ACP were identified. This information has implications for future research and nursing practice.

IMPLICATIONS FOR FUTURE RESEARCH

Further research on ACP engagement amongst PWDs is needed and findings from this study can be used to improve future research. Future studies on ACP amongst PWDs should include family caregivers as participants due to the decision support that they provide PWDs. Additionally, theoretical frameworks should be utilized to test how PWDs and family caregivers decide to participate in ACP. Future studies should be longitudinal in order to examine if and/or how PWDs' preferences and decision-making styles change over time. Participants should be separated by stages of dementia in order to study more about what critical decisions should be discussed at different stages of the disease and how HCPs can better communicate these decisions. Lastly, researchers of future studies should examine how decisions are made in different care settings, such as community versus long-term care settings. Through these improved designs and approaches, researchers can develop more tailored means to educating and providing decision-support for PWD/caregiver dyads at different dementia stages as well as learn how providers can help and coach better across care settings, and develop culturally sensitive approaches to ACP amongst PWD/caregivers dyads.

IMPLICATIONS FOR NURSING

Nurses that participate in admitting patients to hospitals, nursing homes, home health agencies, and hospice already engage patients in ACP as they are required to ask about existing advance directives and offer patients/family members the opportunity to complete them (Patient Self Determination Act, 1990). However, in many cases PWDs are already in the severe stage of dementia in these situations and therefore cannot meaningfully engage. Additionally, these discussions are usually limited to nurses just

asking if the patient has advance directives and if not, are they interested in completing advance directives.

Nurses and nurse practitioners in outpatient settings along with other healthcare team members need to engage PWDs early in the disease process when they can still meaningfully engage in ACP. Through the lens of the ODSF, decisional needs of knowledge and support from healthcare providers need to be addressed, and family members needs to be integrated into ACP conversations with PWDs to provide decision support. When utilizing decision aids or other guides on ACP, they should be seen as a starting point for HCPs to explore the knowledge, beliefs, and values of PWDs about ACP rather than seen as an endpoint. Moreover, HCPs should explore PWDs responses with the PWD and CG to identify any gaps in knowledge and concerns that need to be addressed in order to ensure PWDs and CGs are making informed decisions when it comes to ACP and AD completion. As seen during interviews in this study, PWDs do not readily admit to a lack of understanding of ACP terminology and processes. HCPs should not rely on yes or no questions when engaging PWDs in ACP or expect PWDs to understand advance directives after simply providing the forms to be completed. Nurses have consistently ranked as the most trusted profession in Gallup polls over the past 20 years (Brenan, 2023) so they should be involved in ACP with PWDs since lack of trust of HCPS is a barrier to ACP amongst PWDs in this study.

CONCLUSION

With the aging Baby Boomer population, providing appropriate care for PWDs will continue to be a prevalent issue in the American healthcare system, and engaging PWDs in ACP is part of providing appropriate care. ACP conversations need to occur early in the

disease process, be substantial and ongoing, and aim for PWDs to provide honest answers about their thoughts and feelings with the involvement of their CGs for support. Simply providing definitions and asking PWDs yes/no questions about their understanding of ACP and ADs, as is the case in certain inpatient settings, will not reveal their true feelings. Most importantly, healthcare providers need to build trusting relationships with PWDs and their caregivers in order to be seen as a source of decision support for engaging in ACP as well as someone worthy of being informed of PWD's wishes.

Appendix A: Decision Aid

Preparing for Your Future Healthcare

Advance Care Planning Workbook for Patients and Families

Everyone, regardless of age or health, should have conversations about their values, beliefs, and preferences about their healthcare with their families, friends, and healthcare providers.

This short workbook is about how you can prepare for and talk about how you want medical decisions to be made in the future, when, and only when, you are too sick and need someone else to make the decisions the way you want. We call this **advance care planning**.

Advance care planning includes the following steps:

1. Think about what medical treatments you want and don't want if you are seriously ill and can't make the decision yourself in the future.
2. Share what medical treatments you want and don't want with your family members and medical doctors if you are seriously ill and can't make the decision yourself in the future.
3. Ask someone to be the person to make the decision on your behalf if you are too seriously ill and can't make the decision yourself.
4. Put your preferences in writing:
 - a. **Directive to Physicians and Family or Surrogates**, and
 - b. **Medical Power of Attorney**.

This workbook is designed to help you to think about these steps. **Both the patient and family members** should complete this guide together.

A trained professional, we call this person as **decision coach**, will help you to complete this workbook, and talk to your doctors about your preferences for advance care planning.

First, a few questions for you.

Respondent: P [] F []*

Have you heard of advance care planning or advance directives before today?

What do you know about advance care planning or advance directives?

Do you have advance directives? Why or why not?

Okay, let's review the workbook together now.

2. Advance Care Planning Steps and Options

Advance care planning steps

1. **Think** about what medical treatments you want and don't want if you are seriously ill and can't make the decision yourself in the future.
2. **Share** what medical treatments you want and don't want with your family members and medical doctors if you are seriously ill and can't make the decision yourself in the future.
3. **Ask** someone to be the person to make the decision on your behalf if you are too seriously ill and can't make the decision yourself.
4. **Write** your preferences using advance directives.
 - a. **Directive to Physicians and Family/Surrogates**
 - b. **Medical Power of Attorney**

Your Options on Advance Directives

1. Complete **Directive to Physicians and Family/Surrogates**
 2. Complete **Medical Power of Attorney**
 3. Complete **Both**
 4. Complete **None**.
- These advance directives apply only to health care decisions, NOT financial matters.
 - You can change your mind or revoke your advance directives at any time for any reason.
 - These advance directives must be witnessed and do not require a notary.

What is Directive to Physicians and Family/Surrogates?

What is it about?	- You tell others what treatments you want or don't want in the future. - It is about your values, beliefs, and preferences.
What does it involve?	- Think about which treatments you want and don't want when you are seriously ill. - These treatments typically include: (Hanson, 2016) - Cardiopulmonary resuscitation (CPR) - Breathing machine (called ventilator) - Feeding tube (for artificial nutrition and hydration). - Each treatment has benefits and harms. - Think about how much harm of a treatment you are willing to accept to receive certain benefits from the treatment. - Complete the form and share with your family members and doctors.
When does it matter?	It is only valid when you can't make your own decisions or can't express what you want because of illness or injury.
Why do it?	- You receive the care and treatment you want. - Your family and doctors know what you want and don't want. Your family will have less stress and conflicts among themselves.
Why not do it?	- Thinking about your health and treatments in the future may be uncomfortable. - Talking to your family and doctors about your preferences may not feel comfortable. - Completing documents can take time.

What Is Medical Power of Attorney?

What is it about?	• You name a person as the medical power of attorney to make any and all health care decisions for you following your wishes. • Your medical power of attorney must follow your instructions when making decisions on your behalf.
What does it involve?	• Think about the best person(s) to be your medical power of attorney. • Talk to the person(s) about 1. What you want and don't want. 2. How much leeway you want them to have. In other words, should they make the best decision for you even if you that is not what said you wanted in your medical directive? • Decide who will be able to follow your wishes and make the best decision on your behalf. • Complete the form and share with your family members and doctors.
When does it matter?	It is only valid when you can't make your own decisions or can't express what you want because of illness or injury.
Why do it?	• Your family know what you want and don't want. • You can help prevent conflicts among your family members. • Your family can avoid complex legal issues.
Why not do it?	• Thinking about your health and treatments in the future may be uncomfortable. • Talking to your family and doctors about your preferences may not feel comfortable. • Completing the document can take time.

2. How important is the following to you as you decide whether you should complete advance directives?

Respondent: P [] F []*

	1= Not at all; 2 Somewhat; 3= A great deal; DN= Don't Know
I will receive the treatment that I want.	1 - 2 - 3 - DN
Family will know what I want and don't want.	1 - 2 - 3 - DN
Doctors will know what I want and don't want.	1 - 2 - 3 - DN
Family will have less stress because they will know what I want.	1 - 2 - 3 - DN
Family members will have less disagreement with each other because they will know what I want.	1 - 2 - 3 - DN
Family will avoid potential legal issues.	1 - 2 - 3 - DN
I am uncomfortable to talk about future illness.	1 - 2 - 3 - DN
My family is uncomfortable to talk about my future illness.	1 - 2 - 3 - DN
My doctor is uncomfortable to talk about my future illness.	1 - 2 - 3 - DN
I don't know what I would want in the future.	1 - 2 - 3 - DN
My health or illness is up to God to decide.	1 - 2 - 3 - DN
People won't follow my wishes.	1 - 2 - 3 - DN
Bad things can happen to my health if I think about illness.	1 - 2 - 3 - DN

Other:	1 - 2 - 3
Other:	1 - 2 - 3

Note: * If the patient has difficult answering, ask the family caregiver to think about what the patient would think (substituted judgment).

3. Who else do you want to talk to about advance directives? (Murray, 2010)

Respondent: P [] F []*

Person 1	Name & Relationship / How Can They Help You? (Murray, 2010)
Person 2	Name & Relationship / How Can They Help You? (Murray, 2010)
Person 3	Name & Relationship / How Can They Help You? (Murray, 2010)

4. How do you feel about completing advance directives?

	Patient	Family**
Do you know enough about your <i>health situation</i> right now? (Kryworuchko, 2015, p.4)	☐ Yes ☐ No	☐ Yes ☐ No
Do you know enough about <i>advance directive options</i> ?	☐ Yes ☐ No	☐ Yes ☐ No
Are you clear about what matters most to you in deciding <i>advance directives</i> ?	☐ Yes ☐ No	☐ Yes ☐ No
Do you have enough support and advice to make a choice about the <i>advance directives</i> ? (Murray, 2010)	☐ Yes ☐ No	☐ Yes ☐ No
Have you talked to your family members about your preference for <i>advance directives</i> ?	☐ Yes ☐ No	☐ Yes ☐ No

Have you talked to your doctors about your preference for <i>advance directives</i> ?	☐ Yes ☐ No	☐ Yes ☐ No
Do you feel sure about your decision about <i>advance directives</i> ?	☐ Yes ☐ No	☐ Yes ☐ No
Note: ** Q1-Does the caregiver know about the patient's health situation? Q2 – Does caregiver know about AD options? Q3- Is the caregiver clear about what matters most to the patient in decision about AD? Q4 - Does patient and caregiver have enough support to make decisions about AD? Q5, Q6– Has the patient or caregiver talked to family / MD about preference for AD? Q7- Is the caregiver clear about the decisions about AD for the patient?		

6. How Confident Do You Feel about Advance Care Planning? P [] F []*

How Confident are you that today you could	0=Not at all, 1= Not Sure, 2 = Completely
Ask someone to be your medical power of attorney?	0 - 1 - 2
Talk with your medical power of attorney about the care you would want if you were very sick or near the end of life?	0 - 1 - 2
Talk with your medical power of attorney about how much flexibility or leeway you want to give them?	0 - 1 - 2
Talk with your doctor about how much flexibility or leeway you want to give your medical power of attorney?	0 - 1 - 2
Talk with your doctor about the care you would want if you were very sick or near the end of life?	0 - 1 - 2
Have a discussion with your doctor to help you make good medical decisions?	0 - 1 - 2

7. How Ready Do You Feel about Advance Care Planning? P [] F []*

How Ready are you to	0=Not at all, 1= Not Sure, 2 = Completely
Formally ask someone to be your medical power of attorney?	0 - 1 - 2
Sign official papers naming a person or group of people as medical power of attorney?	0 - 1 - 2
Talk to your medical power of attorney about the kind of medical care you would want if you were very sick?	0 - 1 - 2

Talk to your medical power of attorney about how much flexibility or leeway you want to give them?	0 - 1 - 2
Sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick, i.e., directive to the physician and family?	0 - 1 - 2
Talk to your doctor about how much flexibility you want to give your medical power of attorney?	0 - 1 - 2
Talk to your doctor about the kind of medical care you would want if you were very sick?	0 - 1 - 2
Talk with your doctor about who you want to be your medical power of attorney?	0 - 1 - 2
Ask your doctor questions to help you make a good medical decision?	0 - 1 - 2

8. Of the two options for advance directives, which do you prefer the most?

P [] F []*

- ☐ Directive to Physicians and Family/Surrogates
- ☐ Medical Power of Attorney
- ☐ Both
- ☐ None

9. How do you like to make decision when it comes to your medical and personal care? P [] F []*

1. I make the decision alone
2. I and my family make the decision together
3. I and my family the decision together, after considering the healthcare team's opinion
4. The healthcare team makes the decision
5. The healthcare team makes the decision, after considering our opinion
6. Our family including me, and healthcare team make the decision together

10. If you were seriously ill, how much do you think the following would matter to you? P [] F []*

As a patient, I'd like to know.....

1 -----2----- 3-----
----- 4

Only the basics of my condition and my treatment

All the details about my condition and my treatment

As doctors treat me, I would like...

1 -----2----- 3-----
----- 4

My doctors to do what they think is best

To have a say in every decision

How long do you want to receive medical care? (Hanson, 2016)

1 -----2----- 3-----
----- 4

Indefinitely, not matter how
uncomfortable treatments are

Quality of life is more important
to me than quantity

How involved do you want your loved ones to be?

1 -----2----- 3-----
----- 4

I want my loved ones to do exactly what
I have said, even if it makes them
uncomfortable

I want my loved ones to do what
brings them peace, even if it
goes against what I have said

If I had a terminal illness, I would prefer to...

1 -----2----- 3-----
----- 4

Not know how quickly it is progressing

Know my doctor's best
estimation for how long I have to
live

11. Plan the Next Steps about Advance Care Planning Decision based on Your Personal Needs.

Knowledge If you feel you do NOT have enough facts ☐ Patient ☐ Family	Questions you have about <u>Directive to Physicians</u> <u>Attorney</u> <u>and Family/Surrogates</u> <u>Medical Power of</u>
Value If you are NOT sure what matters most to you ☐ Patient ☐ Family	Patient Your preference(s) for Advance Care Planning is: ☐ Directive to Physicians and Family/Surrogates ☐ Medical Power of Attorney ☐ Both ☐ None Your reason(s) for your choice is: What Matters Most to You is:
Support	Want to discuss advance care planning options with: ☐ <u>Attending Physician</u> (Name/Tel.)

If you feel you do NOT have enough support ☐ Patient ☐ Family	☐ <u>Nurse</u> (Name/Tel.) ☐ <u>Social Worker/ Care Manager</u> (Name/Tel.) ☐ <u>Others – e.g., family members</u> (Name/Tel.)
Ready for the next steps for Advance Care Planning?	☐ Review the advance directives ☐ Talk to family members ☐ Talk to the doctor ☐ Complete the forms ☐ Give copies of the forms to family members ☐ Give copies of the forms to the doctors

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Treatment options on page 3 and duration of care question on page 8 are from Hanson's A Decision Aid about Goals of Care for Patients with Dementia video (Hanson, <https://www.med.unc.edu/pcare/resources/goals-of-care/>)

Other persons to talk about advance care planning with on page 6 is adapted from Murray's When you need extra care, should you receive it at home or in a facility? Decision Aid tool (Murray, https://decisionaid.ohri.ca/docs/das/Place_of_Care.pdf)

Question about patient's health situation right now on page 6 is adapted from Kryworuchko's Planning care for critically ill patients in the Intensive Care Unit (Kryworuchko, https://decisionaid.ohri.ca/docs/das/Critically_Ill_Decision_Support.pdf)

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