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Perceptions of Caregivers of Parkinson's Patients Regarding Using Advance Directives

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Abstract

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by

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MSW, Ohio State University, 2006

BS, University of Dayton, 2004

Dissertation Submitted in Partial Fulfillment

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Abstract

The increasing focus on end-of-life (EOL) care is influencing the role of advance directive (AD) documents. Difficult conversations among family caregivers and their loved ones are becoming more and more critical. Considering the value of communicating EOL wishes, family caregivers' perceptions about ADs for their loved ones with Parkinson's disease (PD) must be examined. Using the theory of planned behavior (TPB) as a foundation, the purpose of this generic qualitative study was to understand family caregivers of PD patients and their perceptions and experiences relating to AD documents. This study involved using purposeful sampling and semi-structured interviews with 11 family caregivers. The research question involved family caregivers' perceptions and experiences concerning ADs for PD patients. Phone interviews were conducted and recorded to collect required data. Interviews were transcribed by hand. Data analysis included reflexive journaling and member checking to enhance trustworthiness. Inductive analysis focused on identifying patterns and themes to synthesize data. Themes were used to organize study results, and each theme related to perceptions and experiences of family caregivers of PD patients regarding ADs. This study's findings will contribute to positive social change by developing a better understanding from family caregivers of PD patient's perceptions of ADs and their experiences relating to their loved one's use or non-use of ADs.

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Chapter 1: Introduction to the Study

Introduction

This study involved examining perceptions of family caregivers of Parkinson's disease (PD) patients regarding their experiences and understanding of advance directives (ADs). There was an existing gap in the literature regarding family caregivers' perspectives of advance directives, particularly for PD patients. This study had potential social implications, including filling a gap in literature regarding experiences of family caregivers and choices involving ADs for PD patients.

In Chapter 1, I discuss the background and scope of the study. I also describe the social problem and purpose of the research and details about the nature of the study. In addition, I present the research question.

Background

In this study, I addressed perceptions of family caregivers regarding ADs for PD patients. Roberto and Blieszner (2015) said that in general, most care falls on relatives. This could leave chronically ill adults at risk of having unmet care needs (Roberto & Blieszner, 2015). There remains a gap in literature involving examining family caregivers' perspectives of ADs and end-of-life (EOL) conversations.

Problem Statement

ADs are vital documents that specify EOL wishes for adults (Sonenberg & Sepulveda-Pacsi, 2018). Conversations surrounding ADs can be difficult, intense, and emotionally charged. One must know his or her preferences for EOL care (Callus, 2018). These preferences can be communicated verbally by having conversations with loved ones about the choices made regarding medical care or via written forms through the completion of ADs (Callus, 2018).

Flowers and Howe (2015) said 75% of Americans surveyed supported ADs, but only 20% of Americans completed an AD. Also, 90% of Americans in the study believed that talking to their loved ones about EOL decisions was essential, yet only 30% reported having those conversations (Flowers & Howe, 2015). In the U.S., people are reluctant to address EOL issues and wishes (Chaddock, 2016). The benefits of an AD included increased satisfaction with one's own EOL experience (Litzelman et al., 2016). Hilgeman et al. (2018) said 26% of community-dwelling adults completed an AD.

There are adverse effects for patients and caregivers who do not complete ADs (Chaddock, 2016; Fried et al., 2018; Litzelman et al., 2016; Sonenberg & Sepulveda-Pacsi, 2018). One of those consequences is an increase in the possibility that a patient who wishes otherwise will die in a hospital setting. Patients are more likely to die in a hospital setting if they do not have an AD (Tuck et al., 2015; Yoo et al., 2013). Yadav et al. (2017) said many patients prefer to die in their homes and not in hospitals. Also, patients without ADs can have unstable treatment preferences regarding EOL care (Fried et al., 2018). The lack of an AD can lead to increased hospitalization costs, unwanted treatments for patients, and difficult decisions for unprepared or grieving caregivers (Flowers & Howe, 2015). Family caregivers may experience guilt or doubt over decisions made on behalf of patients which can lead to emotional difficulties and ongoing complicated grief (Bowman & Katz, 2017). A lack of an AD can also increase the stress of family caregivers’ experiences regarding EOL for their loved ones (Sanders & Robinson, 2017; Shabalin, 2018).

Between 1 and 1.5 million people in the United States are affected by Parkinson’s disease (PD; Garcia-Willingham et al., 2018; Habermann & Shin, 2016; National Institute of Neurological Disorders and Stroke [NINDS], 2019; Tuck, Brod et al., 2015). PD is the 14th leading cause of death in the United States (Habermann & Shin, 2016; Moens et al., 2015; NINDs, 2019; Tuck, Brod et al., 2015; Tuck, Zive et al., 2015). PD is a progressive neurological illness considered to be chronic rather than terminal, which may impact how healthcare providers approach PD patients and discussions with them regarding their EOL wishes (Litzelman et al., 2016; Tuck, Zive et al., 2015).

Although there was research regarding ADs being used among adults in the United States, I found no research that explored ADs being used from the perspective of family caregivers of persons with PD. There is a lack of research regarding advance care planning for chronically progressive neurological illnesses such as PD. Literature had primarily focused on the role of EOL conversations and ADs in palliative and hospice care patients. Given this gap, further research was warranted to examine perceptions of family caregivers the choices involving ADs for patients with PD.

Purpose of the Study

The proposed generic qualitative study design was used to explore perceptions and experiences of family caregivers regarding EOL conversations about ADs for loved ones with PD. Understanding the perspectives of family caregivers regarding EOL conversations and ADs could help in terms of developing a better understanding of ADs, identifying how EOL conversations impact the completion of ADs, and increase patient-aligned outcomes during EOL care for patients with PD. Focusing on the lived experiences of family caregivers provided insight into how ADs are or are not used for PD patients.

Research Question

What are the perceptions and experiences of family caregivers regarding the use of advance directives for patients with Parkinson’s disease?

Conceptual Framework

The theory of planned behavior (TPB) was used as this study’s conceptual framework. This framework involves intention, attitude, norms, and perceived behavioral control for individual choices (Ajzen, 1991). This theory is one of the most commonly used theories in the research field of health promotion. Ajzen (1991) explained that intention is one of the most important predictors of behavior. Randall and Gibson (1991) said that the key to understanding behavior is understanding intentions. The TPB informed this study as it primarily focuses on the relationship between psychological determinants of a specific action. This theory directly applied to how decisions were made to perform a behavior, or the intention to plan for EOL care. The intention of following through with a health behavior can be connected to the completed health behavior such as completing an AD document. Fishbein and Ajzen (1975) said the stronger the intent to perform a behavior, the more likely one would perform that behavior. Understanding what factors influenced family caregivers’ intentions and behaviors to discuss EOL care and ADs was the aim of this study. A more thorough explanation of the TPB is presented in Chapter 2.

Nature of the Study

I proposed the use of a generic qualitative research approach for this study. Framed by the TPB, I sought to understand family caregivers' perceptions and experiences involving EOL conversations and the use of ADs for their loved ones. I looked to attach meaning to data gathered from these experiences. Interview questions were focused on understanding intentions, attitudes, and behavioral choices of PD patients from caregivers' perspectives. Caregivers of adults with PD were the target population of participants.

Data were collected through semi-structured interviews via telephone. Participants were residents of the U.S. and fluent in the English language. Processes included collection, coding, and analysis of the data. This allowed me to remain fluid and flexible and gather information that participants wanted to share in terms of their understanding of decisions made regarding ADs and EOL conversations and use in-depth data collection.

Definitions

Advance Directive (AD): An AD is a formal legal document authorized explicitly by state laws that individuals complete to be invoked if they become seriously ill and unable to make decisions (Yadav et al., 2017). ADs include living wills (LWs), healthcare power of attorney (HCPOA) forms, and do-not-resuscitate (DNR) forms for the purpose of this study.

Family caregiver: Family caregivers are related to patients and play an essential role in meeting healthcare and social needs and communicating with healthcare providers to the fullest extent of their abilities on behalf of the patient (Stellato et al., 2015).

Parkinson's Disease (PD): PD is a progressive neurodegenerative chronic illness characterized by a slow and progressive decline of physical and motor functioning (Habermann & Shin, 2016; Mayo Clinic, 2019).

Assumptions

Qualitative researchers consider a study with assumptions that guide inquiry. One assumption of this study was that participants answered questions honestly and candidly. A second assumption was that participants were forthcoming regarding their relationships with PD patients and primary caregiver status. A third assumption was that the inclusion criteria outlined in this study were appropriate. I screened participants to ensure they were family caregivers of a Parkinson's patient who had consistent contact with the patient at least five times per week.

Scope and Delimitations

The study involved family caregivers of PD patients who resided in the U.S. It was necessary for participants to be fluent in the English language. Family caregivers for individuals with chronic illnesses other than PD were not within this study's scope. The study was limited to family caregivers who had consistent weekly contacts with patients, at least five times each week. Furthermore, my sample consisted of family caregivers only, not individual PD patients. Family caregivers had to be a relative of the patient. These delimitations were boundaries that were set for this research study.

Limitations

One limitation of this study related to identifying enough participants who meet the study criteria. An adequate number of participants, ideally eight to 12 in total, or until saturation is reached, were intended to be interviewed. This study had a delimitation due to a small sample size that is demographically specific. A limitation for this study was identifying family caregivers of PD patients who were willing to be interviewed. Further, gaining permission to advertise for this study in local senior centers and Parkinson's support groups was a barrier due to Covid-19 restrictions limiting in-person interviews from potential participants.

Significance

PD impacts approximately 1 to 1.5 million Americans as documented in the literature (Garcia-Willingham et al., 2018; Habermann & Shin, 2016; NINDS, 2019; Tuck, Brod et al., 2015). PD is associated with progressive disability and reduced quality of life, particularly at the EOL (Gillard et al., 2019). The proper management of EOL wishes for PD patients could lead to outcomes that are more patient-aligned. Moreover, an understanding of the role of the family caregiver on ADs and EOL care conversations could help in terms of developing and using more effective interventions to address EOL wishes. Because there had been no current research regarding how family caregivers of PD patients understand and experience ADs and EOL care conversations, identifying common themes involving these experiences for this population was potentially beneficial to the literature. Providing insight regarding ADs for adults diagnosed with PD from family caregiver perspectives was the focus of this research. Exploring the reasoning regarding family caregivers' choice to discuss EOL care or complete ADs was used to discuss the completion of ADs with chronically ill PD patients. Another potential benefit to this research was the promotion of social change through providing valuable information that could help health practitioners to assist and support PD patients and their caregivers in terms of how they can be engaged in their EOL care, especially regarding ADs.

Summary

Focusing this study on family caregivers of PD patients' understanding and experiences regarding ADs filled an existing gap in the literature regarding this population and subject matter. Family caregivers potentially influence PD patients' decisions regarding ADs. Understanding caregivers' experiences was used to address EOL care planning.

Chapter 2: Literature Review

Introduction

Individual decisions involving EOL care are shared with loved ones via AD documents. While many studies have been conducted on EOL conversations and ADs for cancer patients, studies on using ADs with non-terminal illnesses had not been conducted. More Americans are facing chronic illness diagnoses (Chaddock, 2016). Chronic illnesses including neurodegenerative diseases should be studied to understand what implications ADs can have for patients and their caregivers. Understanding individual preferences for EOL care when facing a chronic illness such as PD can lead to honoring EOL choices for medical care. PD is a chronic neurodegenerative illness that affects approximately 1 to 1.5 million Americans (Garcia-Willingham et al., 2018; Habermann & Shin, 2016; NINDS, 2019). PD can lead to physical and cognitive declines, including motor and non-motor symptoms, tremors, depression, and dementia (Tuck, Brod et al., 2015). Understanding how family caregivers perceive the use of ADs for PD patients was the focus of this study. Family caregivers may be aware of what factors impact choices to complete these documents and discuss EOL care that will be different from those of patients or healthcare providers. After an exhaustive search of current literature, I was unable to find research regarding the perspectives of family caregivers in terms of how ADs are completed for individuals with PD. Examining perceptions of caregivers of PD patients requires an understanding of what barriers exist for caregivers, thus influencing EOL conversations with their loved ones.

In this chapter, current literature that was relevant to my research topic was comprehensively reviewed. Issues addressed in the literature review include ADs, LWs, HCPOA forms, and DNR orders. I also discuss EOL care conversations and the benefits and disadvantages of ADs. This research adds to existing knowledge by concentrating on the understanding of ADs for PD patients' family caregivers. Additionally, this chapter includes an in-depth review of advantages and disadvantages of ADs, adults' attitudes regarding ADs, family caregivers' potential influence on the completion of ADs for this population, and the TPB. Peer-reviewed journals were most of the sources accessed for this study.

Literature Search Strategy

Most sources in this study were from primary sources of peer-reviewed journals. However, secondary sources of information were also reviewed, including governmental research and meta-analysis studies. The Walden University Library was used to search for and obtain useful articles in ProQuest, SocIndex, PsycArticles, and PsycInfo databases. Other databases used included the SAGE Full-Text collection and Google Scholar. Materials were also gathered from the World Health Organization (WHO), Centers for Disease Control and Prevention (CDC), and American Medical Association (AMA). The web site from the United States Census Bureau provided additional statistical information.

Keywords used to search for relevant literature included *advance directive*, *EOL conversation*, *caregiver*, *Parkinson's*, *older adult*, *POLST*, *do not resuscitate*, *living will*, *negative effects of advance directives*, and *EOL planning*. Most of the literature was published between 2015 and 2019. This literature review served as a foundation for establishing the significance of this research. It served to compare findings of this study with those of earlier studies that have explored ADs concerning EOL care. Connecting the proposed research to the TPB led to additional insights regarding how family caregivers' attitudes, beliefs, and perceptions impact choices regarding ADs for PD patients.

Conceptual Framework

The TPB was chosen as the conceptual framework for my research. This theory provided a basis for understanding behavior modification, psychological processes related to the selected action, and the prediction of behavior. Applying this theory to the perceptions of family caregivers regarding the completion of ADs provided insight into how intentions and attitudes related to completion rates.

Description of the Theory

The TPB is based on assumptions related to attitudes, intentions, perceived behavioral controls, and subjective norms. It centers on how intentions impact an individual's attitudes and beliefs toward an expected behavior (Ajzen, 2005; Randall & Gibson, 1991). Individual beliefs are connected to choices (Ajzen, 1991). Principles of both cognitive self-regulation and accumulation of beliefs form part of the foundation of TPB (Ajzen, 1991). Ajzen and Fishbein (1972) said the more favorable a person evaluates performing a specific behavior, the more likely they will perform that behavior. Relating how one's attitude affects intentions can help in terms of understanding how a person chooses to behave in specific ways. Behavior is deliberate and planned, and works to predict intentional behavior (Ajzen, 1991). If an individual sees value in performing an action, and this is reinforced through subjective norms and self-efficacy, it is more likely that behavior will be carried out (Ajzen, 2005). The assumption that one’s attitude toward a behavior relates to subjective norms can be relevant in predicting the intended behavior (Ajzen, 2005). Addressing what family caregivers of PD patients experience and attitudes and intentions towards ADs can connect to the TPB.

Through qualitative interviewing, understanding family caregivers’ perspectives and belief systems regarding EOL conversations and ADs was used to provide insight into their perceptions, feelings, and experiences involving using ADs. Their intention to discuss and then plan for EOL care was examined to understand if planning for EOL care led to a behavioral outcome. This research was aimed to help the reader understand family caregivers’ experiences with EOL conversations and the completion of ADs with their loved ones who have PD.

Benefits of Advance Directives

ADs are defined as formal, and legal documents invoked when an individual becomes seriously ill and is unable to make healthcare decisions on his or her behalf (Piili et al., 2018; Yadav et al., 2017). ADs are written statements that explain EOL preferences for patients and are one aspect of advance care planning (ACP). An AD can include a HCPOA, LW, or DNR (Yadav et al., 2017). These documents specify patients’ wishes, including preferences for the use of life-sustaining treatments and therapies if an individual becomes incapacitated (Yadav et al., 2017). ADs should be shared with patients’ healthcare agents, trusted loved ones, doctors in charge of healthcare, and any hospital or healthcare facility the patient receives treatment from (Anderson et al., 2018). According to Anderson et al. (2018), an AD can be changed at any time by the patient for as long as the patient has mental capacity, and should be reviewed throughout a person's life, especially after a significant life change or during hospitalization or diagnosis of illness. Chiu Wu et al. (2019) said adults should learn about ADs and ACP to help determine their preferences for end-stage treatment of chronic or terminal illnesses to promote making choices and planning for their EOL care.

EOL conversations are opportunities for adults to make their preferences known to their caregivers and healthcare team regarding medical choices (Yadav et al., 2017). These conversations can occur at any age but may be more critical for adults with changing health or facing a chronic illness such as PD. Communicating with supportive people can become crucial as health status changes (Anderson et al., 2018). Higher satisfaction was documented for patients who make EOL decisions with their caregivers and healthcare teams (Reinhardt et al., 2017). EOL conversations may lead to ACP, including ADs.

Completing ADs leads to EOL care plans and can be beneficial for the living post-death (Sanders & Robinson, 2017). Some barriers in the U.S. healthcare system include providers focused on curative rather than palliative medicine and the hesitancy of providers to communicate with patients regarding difficult subjects such as death and dying (Litzelman et al., 2016). Additionally, Beck et al. (2016) said understanding health professionals' intentions through the lens of the TPB can influence health behavior models and may lead to understanding in terms of this effect on EOL care planning.

Challenges with Completing and Implementing Advance Directives

Although ADs are shown to be beneficial, there can be negative aspects of completing these documents. Hilgeman et al. (2018) said when adults have completed an AD, they are not consistently offered information about potential risks, benefits, or alternatives to life-sustaining medical treatments and procedures. Unless prompted, healthcare providers may not explain possible options for patients when an AD is present. This could limit or reduce treatment options or length of life for patients.

An AD can also be difficult to access when needed by healthcare providers. The lack of accessibility of ADs for emergency responders, as well as within healthcare systems and settings, can reduce the usability of ADs (Yocom, 2019). Additionally, there are existing problems in terms of portability of advance planning documents across state lines. If a patient who resides in one state has current ADs, travels to another state, and has a medical emergency, health records in that second state may not be accessible from the patient’s home state. Therefore, an AD may not be available or known to the healthcare team treating the patient. These challenges can discourage patients from completing or updating ADs.

A third negative component of completing an AD was patients with progressive neurological diseases such as Parkinson’s do not tend to discuss their choices with their healthcare team (Clarke et al., 2018). Patients with progressive neurological diseases may not understand what their treatment options are because they have completed their AD without consulting with healthcare providers. Therefore, they could miss available options that may improve their quality or length of life (Clarke et al., 2018). If these EOL treatment choices are not communicated with patients and primary caregivers, EOL wishes may not be honored. An existing AD could state what the patient does and does not want for life-sustaining treatments. However, if a caregiver has not been privy to a conversation with the patient about their ADs and EOL wishes, it may not be possible to honor the patient's wishes fully. Lopez and Vars (2019) said even when a patient's wishes are known, they are not necessarily honored by healthcare providers or family members. Providers expressed concern that wrongful death claims and lawsuits may occur if all viable measures were not taken to sustain life (Lopez & Vars, 2019). If an AD is not carried out explicitly how a patient wanted, it violates the patient's right to self-determination and autonomy in terms of their EOL wishes (Lopez & Vars, 2019).

Another challenge of AD completion is that EOL care planning can be time-consuming for healthcare providers to initiate and facilitate (Dixon & Knapp, 2018; McGlade et al., 2017). Workloads are often high in healthcare settings and discussing what EOL wishes a patient has and then assisting them in completing an AD may be difficult for healthcare providers who have limited time to spend with each patient. Providers may need additional training to initiate these conversations and understand necessary details of ADs (McGlade et al., 2017; Reidy et al., 2017). Reidy et al. (2017) said that 40% of hospitalists surveyed reported insufficient past training in terms of conducting EOL care conversations with their patients. Hospitalists may not be comfortable initiating EOL conversations and thus discussing ADs without further training. Training is not only time consuming but can be costly for healthcare facilities (Reidy et al., 2017). Limited resources such as time and money for training can reduce the availability of provider education regarding ACP (McGlade et al., 2017; Reidy et al., 2017). Understanding the complexity of external challenges associated with ADs could provide awareness in terms of choices associated with completing these documents.

Internal reasons for not completing ADs can also create challenges for implementing these documents. Navigating individual values, including caregivers of PD patients if they are involved in healthcare goals, is essential when seeking to understand AD usage (Rosenberg & Speice, 2013). Understanding patient’s priorities and how these priorities align with personal values can work to focus AD documents to these wishes. Personal values may not be communicated openly through advance directives. Fear of the dying process, not wanting to take away hope or cause any psychological pain with challenging EOL conversations, fear of intense emotional reactions to these conversations, and anticipation of disagreements between patient’s wishes and caregivers are reasons to for patients to not share their values with their caregiver have all been documented in the literature (McClatchey & King, 2015; Scott & Caughlin, 2012; Shabalin, 2018; Sorrell, 2018). When chronically ill patients’ values and goals are undocumented or not discussed with family caregivers, per Litzelman et al. (2016), aligning care received with internal wishes can be challenging.

Advance Directives with Chronically Ill Patients

A growing population of chronically ill adults in the U.S. has increased the focus on ACP as evidenced through Medicare and Medicaid services. The Centers for Medicare and Medicaid Services have expanded to include a physician fee schedule in 2016 that was updated to include a payment rate for ACP services for Medicare beneficiaries.

Before 2016, physicians were not given a payment rate specifically for ACP services (Sonenberg & Sepulveda-Pacsi, 2018). Medicare is a health insurance benefit for all adults in the United States over 65 or older or those who have been disabled for 2 or more years (Sonenberg & Sepulveda-Pacsi, 2018). This includes individuals with chronic disease diagnoses such as PD. Medicare has not been updated to influence more timely access to ACP for patients with chronic illness diagnoses (Fine & Davis, 2017).

EOL care can be patient-centered when the patient's wishes are known and understood, and consequently documented in an advance directive. Chronically ill patients may have different opportunities to plan for their EOL care with changes in their disease processes. It was discussed in the study by Kim and Choi (2014) that respondents were significantly inclined to complete an advance directive after their understanding of life-sustaining treatments increased through educational efforts (Kim & Choi, 2014).

It was suggested by Gillard et al. (2019) that there is a lack of research on advance care planning for patients with chronic illnesses, including chronically progressive neurological illnesses such as PD. These authors stated that there is a lack of research on advance care planning utilization for caregivers who have been exposed to a chronic illness within their family members (Gillard et al., 2019). Americans continue to be diagnosed with chronic illnesses, there will be a growing need to improve advance care planning for adults to ensure the EOL care that is received aligns with individual preferences and values in life (Litzelman et al., 2016).

Parkinson’s Disease and End-of-Life Planning

Parkinson’s disease (PD) affects approximately 1 to 1.5 million people in the United States (Garcia-Willingham et al., 2018; Habermann & Shin, 2016; National Institute of Neurological Disorders and Stroke, 2019; PR Newswire, 2018; Tuck, Brod, et al., 2015). It is the 14th leading cause of death in the nation (Habermann & Shin, 2016; Tuck, Brod, et al., 2015). As the adult population grows in the United States, the number of people living with PD is expected to increase (Moens et al., 2015). PD can be defined as a neurodegenerative disorder that equates into a wide range of both motor and non-motor symptoms (Clarke et al., 2018; Tuck, Brod, et al., 2015; Tuck, Zive, et al., 2015). These symptoms may include tremors, rigidity, difficulty swallowing and risk of aspiration, pain, depression, urinary tract infections, agitation, postural instability, and dementia (Clarke et al., 2018; Habermann & Shin, 2016; Tuck, Brod, et al., 2015; Tuck, Zive, et al., 2015). PD is characterized by a slow and progressive decline with care needs gradually increasing over time (Habermann & Shin, 2016). In an article by Schrag et al. (2018), it was found that the average age of onset for PD in survey respondents was 58.5 years of age, with the youngest diagnosis reported at age 25. This could impact the choice to discuss EOL care and advance directives. The disease trajectory for PD can be challenging because it is longer and less predictable for healthcare providers and patients than other progressive illnesses such as cancer (Moens et al., 2015). Because PD is not considered a terminal illness, clinicians may not initiate EOL conversations with patients (Tuck, Brod, et al., 2015).

Discussing EOL (EOL) wishes and creating advance directives (ADs) can be beneficial in PD (PD) patients because, as in other neurodegenerative diseases, as the illness progresses the decision-making capacity and communication abilities of the patient may become impaired or lost (Clarke et al., 2018; Habermann & Shin, 2016). It was noted in multiple studies that when patients with neurodegenerative diseases, including PD, choose to complete ADs and have EOL conversations with their loved ones, they can experience an increased sense of autonomy, garner some control over future healthcare treatments, and improve quality of life and coping (Clarke et al., 2018; Habermann & Shin, 2016; Kent, 2015). In contrast, Habermann and Shin (2016) explained that a lack of information provided to PD patients and their caregivers regarding what disabling symptoms may occur as the disease progresses and allowing for decision-making goals to be addressed could hinder the quality of life at EOL for PD patients. Choosing to have EOL conversations and create AD documents could clarify the EOL wishes for both patient and caregivers. In a study by Gillard et al. (2019), the authors noted that PD (PD) patients were more than twice as likely to have Advance Directives (ADs) than study participants with PD who had not received any educational interventions on ADs. Additionally, caregivers of PD patients were found to have increased their use of ADs compared to the participants who did not receive any educational interventions relating to ADs in the study (Gillard et al.).

Research has shown that PD patients have preferences as to when they want to discuss their EOL planning and healthcare needs. Tuck, Brod, et al. (2015) noted that 94% of PD patients wanted prognosis and treatment information early on, with 12-13%

wanting to discuss their EOL care planning at the time of diagnosis. This included half of the PD patients in this study wanting to discuss AD documents initially (Tuck, Brod, et al.). As described in the study by Habermann and Shin (2016), most care for PD patients is provided at home by family members. Therefore, integrating family caregivers into the EOL (EOL) conversations and AD planning could lead to honoring the patient’s wishes. The negative consequences of not completing advance directives can be exaggerated for individuals with PD (PD), as described in the literature (Clarke et al., 2018; Gillard et al., 2019; Habermann & Shin, 2016; Kent, 2015; Tuck, Brod, et al., 2015; Tuck, Zive, et al., 2015). Advance care planning for PD patients should be a fundamental yet voluntary component of their care (Kent, 2015). Understanding the reasons surrounding family caregivers’ choices to discuss the EOL preferences and advance care plans with the Parkinson’s patient may lead to more conversations about ADs between the caregiver and person with PD.

Caregivers’ Influence on Completion of Advance Directives

Caregivers for patients with chronic illnesses may impact the completion of advance directives (ADs). Focusing on how family units influence caregiving for adults, Roberto and Blieszner (2015) sought to understand how traditional and pluralistic families face caregiving challenges. These authors noted that in general, most elder care falls on relatives. This was shown to leave adults at risk of having unmet care needs (Roberto & Blieszner, 2015). This study can relate to the TPB in seeking insight into how normative beliefs impact intention and behavior.

External factors may also influence caregiver's choices regarding EOL conversations and advance directives (ADs). In a study by Roberto and Blieszner (2015), efforts to shorten hospital stays and decrease the expenses related to long-term care for adults with chronic health conditions negatively impacted caregivers). Even though primary caregivers are often tasked with making EOL choices on behalf of the patient if the patient becomes unable to speak their wishes, caregivers may not plan for this for patients with a chronic illness diagnosis. In the study by Hickman and Pinto (2014), it was noted that the presence of an advance directive could mitigate decisional burdens for primary caregivers of patients with a chronic illness. However, these authors concluded that most primary caregivers did not know the patient's preferences for life-sustaining therapies, which consequently led to the risk of an increased decisional burden (Hickman & Pinto). This could be influenced by a lack of understanding from either patient or caregiver on what role advance directive documents play in advance care planning.

Piili et al. (2018) further stated in their research that family member's requests for aggressive treatments significantly decreased when the patient had completed Advance Directive documents, moving treatment options to a more palliative approach at the EOL. Honoring the patient's wishes, when expressed legally through an AD, can provide support to both the patient and the caregiver during difficult healthcare decision making. It was noted in the research by Sonenberg and Sepulveda-Pacsi (2018) that the Institute of Medicine recommends reform regarding EOL (EOL) care to include family-oriented EOL care. In a study by Fried et al. (2018), caregiver outcomes were found to be positively correlated to advance care planning, demonstrating decreased stress levels for caregivers of patients with EOL planning and increased understanding of what the patient's wishes included for EOL care. Family caregivers are a population not studied thus far in the literature concerning advance directives and patients with PD. Because of a family caregiver's ability to influence the completion of ADs and to have EOL conversations, understanding what experiences and perceptions impact the completion of advance directives may provide insight into the patient's EOL experiences.

Advance Directives for Caregivers of Parkinson Disease Patients

Caregivers for patients with PD face a chronic illness diagnosis and disease process that can vary from other illnesses. In the study by Tuck, Brod, et al. (2015), PD patients reported wanting their family caregivers involved in their initial diagnosis discussions, including discussing advance directive documents early in the disease process. Considering PD is a progressive, neurological disease accompanied by complex and unpredictable changes in physical, cognitive, emotional, and behavioral functioning, it is important to discuss EOL wishes as soon as possible (Clarke et al., 2018). These declines can limit communication and decision-making capacity between the caregiver and the PD patient (Clarke et al., 2018). Combined with increased stressors that coincide with caregiving for an individual with a chronic illness, family caregivers may also experience ambivalence toward advance care planning to avoid tension with the Parkinson's patient (Habermann & Shin, 2016). These barriers could impact a PD patient caregiver's ability to plan for the EOL care through advance directives.

PD diagnosis has also been shown to increase advance care planning and advance directive (AD) documents. Gillard et al. (2019) noted increased rates for caregivers of PD patients having a LW or HCPOA. It was suggested by Habermann and Shin (2016) that pursuing advance care planning can help PD patients to achieve autonomy in their EOL care. These benefits were also discussed by Kent (2015), who found that advance care planning can help improve patient and family satisfaction levels, including reducing conflict and anxiety levels. Understanding how advance directives specifically impact EOL care planning for Parkinson's patient caregivers could contribute to the existing literature in this arena.

Summary

PD is a leading cause of death in the United States, with increasing numbers of Americans being diagnosed each year (Habermann & Shin, 2016; Moens et al., 2015; National Institute of Neurological Disorders and Stroke, 2019; Tuck, Brod, et al., 2015). It is a neurodegenerative disorder that equals a wide range of both motor and non-motor symptoms, including tremors, rigidity, risk of aspiration, pain, depression, and dementia (Clarke et al., 2018; Habermann & Shin, 2016; Tuck, Brod, et al., 2015; Tuck, Zive, et al., 2015). Because it is a non-terminal illness, healthcare providers may not initiate the EOL (EOL) conversations with patients and their caregivers (Tuck, Brod, et al., 2015). This can impact the advance directive (AD) completion in this population. There are benefits and downfalls to having EOL conversations and completing ADs. Family caregivers can influence EOL conversations (Roberto & Blieszner, 2015). If a family caregiver sees value in having EOL conversations, the likelihood that these conversations will occur increases (Gillard et al., 2019). Understanding the caregiver's perceptions and experiences relating to EOL care and conversations will connect to the primary goal of the TPB, which seeks to realize an individual’s intentions and behaviors (Ajzen, 1985). When these conversations take place with family caregivers, PD patients, and their healthcare team, higher levels of satisfaction with EOL care wishes were honored (Litzelman et al., 2016; McGlade et al., 2017; Reinhardt et al., 2017). Advance care planning can help both patient and loved ones prepare for dying, relieve anxiety, avoid prolonging death, and strengthen interpersonal relationships (McGlade et al., 2017; Sonenberg & Sepulveda-Pacsi, 2018). However, challenges in completing ADs must also be acknowledged, including ignoring patient wishes that are expressed in their ADs by healthcare providers and family caregivers, the potential difficulty in accessing ADs in health care settings, and limited amounts of time and resources that healthcare providers can invest into training and implementation of EOL conversations (McGlade et al., 20017; Reidy et al., 2017). Understanding the perceptions and experiences of family caregivers of PD patients and how their choices surrounding advance directive usage may provide insight into additional strengths and challenges regarding these preferences.

Conclusion

This study was significant because it filled a gap in the existing literature regarding how family caregivers of PD patients understand advance directives and EOL conversations. This study contributes to the body of existing literature on advance care planning and caregiver support during EOL care. Furthermore, this study sought to understand how advance directives can be utilized for PD patients and how family caregivers influenced these decisions. The literature review has addressed how involvement with healthcare teams and family caregivers is correlated with patient care that is communicated and chosen by the patient. Honoring patient wishes is at the center of understanding what beliefs and attitudes influenced EOL care conversations regarding advance directives.

Chapter 3: Research Method

Introduction

The purpose of this generic qualitative study was to understand the experiences and perceptions of family caregivers of PD patients and their use of ADs. Percy et al. (2015) defined a generic qualitative inquiry as research that involves participants' subjective opinions, attitudes, and beliefs about their experiences. The focus of this research was to gather information, analyze data, and draw conclusions solely from family caregivers' descriptions of their perceptions and experiences concerning ADs and only in that context. The data collection process included qualitative inquiry using the established interview protocol. Through interviewing participants, I sought to identify participant perceptions of ADs for PD patients they care for. After an exhaustive search of the literature, I was unable to find any existing studies regarding the use of ADs for PD patients from family caregivers' perspectives.

Research Question

What are the perceptions and experiences of family caregivers regarding the use of ADs for patients with PD?

Research Design and Rationale

Comparing other qualitative research approaches to the chosen methodology was important. This study did not involve using a phenomenological approach because it did not focus on the how; instead, I sought to understand what and why questions. An ethnography approach would not fit this study because it was centered on one specific group rather than sociocultural experiences collectively. I did not use a case study approach because it involves focusing on the sum of experiences of a collective group of individuals rather than a single case. Generic qualitative studies involve deriving themes from experiences of participants, rather than developing a theory. This research included gathering and examining information regarding the experiences and perceptions of family caregivers of PD patients and their choices regarding ADs, framed using the TPB.

I used purposive and snowball sampling methods. The research was results-oriented with rigorous data collection and analysis. Using multiple participants provided the opportunity to identify themes that emerged across data. Remaining fluid and flexible throughout the data collection process and gathering all information each participant wanted to share ensured all information shared was collected and included in this research. Additionally, using the TPB provided a lens through which to view various phases of the study design as well as participants' attitudes, beliefs, and social norms regarding ADs.

Role of the Researcher

In qualitative studies, the researcher acts as the instrument of data collection (Cypress, 2018). The researcher can influence data findings in qualitative inquiries, so it was necessary to realize how this could potentially influence the results and intentionally address any bias. I have worked with AD documents for clients and have discussed the use of ADs on multiple occasions. I chose to study the family caregivers of PD patients. The reasoning behind studying this population was to address how family caregivers perceived the use of ADs for their loved ones experiencing chronic but not terminal diseases such as PD. As the researcher, I remained neutral and built rapport, and encouraged the open sharing of experiences and perceptions and recorded interviews for analysis. Although neutrality was the goal, in qualitative inquiries, the researcher acts as the instrument. Thus, I needed to participate in the data collection process, which challenged my ability to address biases. Being mindful of my assumptions and biases throughout interviews and analysis protected the originality of data. According to Archibald et al. (2015), member checking can reduce internal and external researcher bias. Hall et al. (2016) said member checking is the most critical validation technique to determine the credibility of findings and interpretations. Additionally, maintaining neutral body language and limiting verbal cues can also reduce bias (Archibald et al., 2015). Bracketing can be used by the researcher to clarify bias. Being aware of my ontologies, choosing to bracket findings with evaluation, and systematic feedback increased my level of consciousness as a researcher in terms of interpreting raw data. Lastly, I enlisted the assistance of another person to review findings to ensure they made sense and were being interpreted by me as they were recorded. I had a colleague who agreed to do a peer review of findings to enhance the study's validity.

Methodology

The focus of this research was to identify themes and draw conclusions about participants in the study. The data collection process included interviews with participants regarding their perceptions of and experiences with ADs for PD patients. Data were collected through an established interview protocol approved by the Walden Institutional Review Board (IRB). The interview protocol included an informed consent form and interview questions. In the informed consent form, criteria for inclusion and the purpose of the study were discussed. Kazmierski and King (2015) said a protocol with these components allows for rich data to be gathered by allowing participants. At times this rich data is gathered by allowing participants to walk through their experiences, with lengthy episodes of narration provided.

I focused on participants’ perspectives regarding ADs for PD patients they have cared for. To present an in-depth understanding of the cases, I collected data that included interview transcription and reflexive journaling notes. All interviews were audio-recorded, with written permission from participants, and varied in length from 60 to 90 minutes. Interviews were semi-structured with open-ended questions, which allowed the family caregivers to engage in intentional conversation.

Participant and Sampling Strategy

For this study, I used purposive and snowball sampling methods to identify family caregivers of adults who met the criteria. Participants were family caregivers of PD patients who had contact with patients at least five times each week. Family caregivers had to be a relative of the patient. I used a sample of eight to 12 participants. If, after 12 participants, I had not reached data saturation, additional participants would have been recruited and interviewed until data saturation was achieved. Purposeful sampling allowed me to focus on participants who had rich experiences from which I gained in-depth information about the study’s central focus. Also, for participants to be eligible for this study, they needed to be willing to discuss ADs for PD patients. There were no exclusions based on age, gender, or cultural background.

Procedures for Recruitment, Informed Consent, Participation, and Data Collection

Letters of agreement were obtained before beginning the recruitment process from the North County Senior Center, Your Aging & Disability Resource Center, and South Palm Beach Parkinson's Foundation offices. Participants were also recruited using flyers that explained the nature of the study and requested individuals to be interviewed. Participants were also recruited via social media resources that were preapproved by the IRB before I posted online to recruit. I collected data via telephone interviews which lasted between 60 and 90 minutes. An established interview protocol was used during each interview to promote uniformity of data collection for all participants. I expanded upon interview questions to probe for clarity if new themes emerged that required additional questions. I received written permission from participants to audio record all interviews, and then transcribed them by hand. Each participant was allowed to expand on or discuss any additional items before concluding the interview and debriefing. My contact information was provided to each participant in the event they had follow-up questions or information to share after the initial interview. I also sent a PDF copy of each participant's transcript to them for member checking. A hand-written thank you note was given to each participant, along with a $10 gift card after each interview.

Instrumentation

I was the primary instrument for this study. Having worked in a healthcare setting for over 10 years, I have had many conversations about ADs with clients I have served. My familiarity with ADs was sound and guided the development of the interview protocol to access as much information about caregivers' perceptions and experiences regarding ADs. To control for bias, I used member checking and bracketing during each interview to ensure my interpretations and understanding of what was said accurately aligned with participants’ statements. I am an experienced interviewer, and I have conducted multiple interviews in my professional work. However, interviews done for this research were structured based on preplanned interview questions to minimize bias or researcher influence during the interview process. My nonverbal cues and body language responses were controlled for these interviews to not affect participants during their responses.

Data Collection

The primary method of data collection was interviewing participants. Participants who are family caregivers of PD patients were recruited using flyers (see Appendix A) that were posted at three local community resource centers as well as through online social media. Letters of agreement from three agencies were obtained before beginning the recruitment process in alignment with Walden’s IRB guidelines to explain the nature of the study and request individuals who agreed to be interviewed. Participants needed to reside within the U.S. and be fluent in the English language. After identifying participants who fit criteria outlined for this study, I scheduled 60 to 90 minute interviews for participants when convenient. Permission to audio-record interviews was requested by me before scheduling interviews, with written consent given at the time of the interview. Interviews were recorded with a Sony Voice Recorder that saved the files on my computer for future data analysis. I interviewed participants via telephone. This was done to provide confidentiality and privacy for participants being interviewed. Self-reports of participant perceptions and experiences were encouraged so that each participant could potentially contribute to knowledge gained on this subject. Reflexive journaling was also used during all interviews and encounters with participants to record nuances observed among participants. This was used to notate any ideas that needed further examination via additional questions. According to Maharaj (2016), reflexive journaling can lead to a more critical reflection of data collected and enhance self-awareness and open-mindedness in terms of differing perspectives regarding lived experiences. Semi-structured open-ended interview questions encouraged participants to share their complete perspectives. Percy et al. (2015) suggested qualitative interviews begin with a social conversation to create an environment that is relaxing and trustworthy for participants. This encourages each participant to respond openly and honestly. Part of the data collection process included member checking of findings. After each interview, participants were offered free and local counseling services if they sought additional support. This is discussed in greater detail in the ethical procedures section.

Data Management and Analysis Plan

Data were generated via semi-structured interviews. Interviews were recorded using an audio recorder. Audio recordings were saved in a file with no obvious demographic identifiers included. Recorded interviews were then transcribed by me verbatim and incorporated into the coding process. I provided my chair with raw data from interviews and a copy of my first interview transcript to ensure accuracy and receive feedback. Inductive analysis (IA) was conducted, including analyzing participants’ data individually. Once themes were identified, I arranged them in a matrix with corresponding supportive patterns noted. I then combined patterns and themes that were consistent across participant data collectively to form a synthesis. Repeating patterns and themes from all participants were then synthesized to interpret meanings or implications from data related to the research question under investigation.

Data Management

I began analysis during data collection by noting and documenting any emerging patterns and possible themes. It was necessary, as I am a novice researcher, to take inventory of data and subsequently label, date, and organize data elements continually. I protected data by backing it up on an external drive, separate from my computer, and securing it to ensure confidentiality. I used a preassigned number for each participant as pseudonyms for identification purposes. Also, I removed any identifying information from interview responses. I used hand-coding and entered data into Microsoft Excel to organize data by themes. As the investigator, I maintained an analysis log. I organized data into a chart for analysis and visual demonstration of data.

Data Interpretation

For this study, I sought to address perceptions and experiences of family caregivers of PD patients regarding ADs. I examined data in-depth to provide detailed information regarding caregivers' understanding of their experiences. Data interpretation consisted of categorizing and coding data and grouping it into themes. While identifying themes, I focused on the research question and how it correlated with the themes that emerged. Sorting data collected within Excel reduced data manageable format.

Issues of Trustworthiness

Strategies to ensure credibility, transferability, dependability, and confirmability were necessary to verify trustworthiness in qualitative research (Fitzpatrick, 2019). Credibility can be defined as the data being correctly interpreted from what was originally stated by participants to ensure the truth is drawn from the data collected (Korstjens & Moser, 2018). Transferability is a component of trustworthiness because it allows for the applicability of findings across other contexts through the use of thick descriptions from participant's lived experiences (Korstjens & Moser, 2018). According to Connelly (2016), dependability refers to the stability of the data and over time and the conditions of the study over time being dependable to increase trustworthiness. Confirmability is important because it looks at the neutrality of the data collection process, monitoring the findings are consistent, and that they could be repeated (Connelly, 2016). Fitzpatrick (2019) stated that a researcher could gain confidence in inferences and conclusions when focusing on participant's larger stories and dissenting voices from the data collected. Member checking within the interviews was done to replay what participants stated to confirm I understood their experiences accurately. Also, including the audio recording and the transcription of the recording during member checking increased trustworthiness (Fitzpatrick, 2019). Finally, a copy of the transcript, shared in PDF formatting, was sent to participants after transcription completed for member checking purposes. Feedback from participants drove any edits or modifications needed for the data analysis.

Credibility and transferability were established by the researcher providing a thick, rich description of the interview, including the setting, participants, themes, and details that allowed for a reader to generalize naturalistically and connect the experiences of the narrative with their own experiences (Fitzpatrick, 2019). Audit trails were completed, to gain dependability, including triangulating data collected throughout the analysis processes (Fitzpatrick, 2019).

Confirmability is an important construct in qualitative research trustworthiness. Because confirmability necessitates a degree of neutrality of the findings of a study, centering on the participant's experiences rather than on researcher bias or interests (Amankwaa, 2016), it increases trustworthiness. It is being mindful of my bias and motivations as a researcher when coding data that worked to establish confirmability through reflexivity.

Potential Conflicts and Biases

One potential bias of this study was my experience working with advance directives for hospice patients I have served. The interpretive lens of a researcher's beliefs and motivations can interact with the data and lead to bias (Kennedy, 2016). Though I planned to be objective in proposing the interview questions and throughout the coding and analysis processes, my inherent knowledge and attitudes toward advance directives afforded me insight into potential benefits or challenges with these documents. Limiting any verbal and non-verbal feedback controlled for some researcher influence. Bracketing was also utilized, which added to the scientific rigor and validity of the study.

Being self-aware and using self-reflection throughout the collection and analysis of data steered bias and conflicts away from the results of this study (Kennedy, 2016).

Ethical Procedures

Although a vulnerable population, such as a person diagnosed with PD, was not being studied, their family caregiver's identities needed to be protected. As a licensed clinical social worker, it was my professional duty to protect any aspects of the study that could impose harm or undue distress on participants (Frunza & Sandu, 2017). All components of the interview protocol were pre-approved by Walden's Institutional Review Board before beginning recruiting and data collection for this study. I provided any information that each participant sought before beginning data collection, so the participants knowingly and willingly decided to participate in my research. As the key instrument, I ensured the confidentiality of study participants by assigning a number to each participant. Also, I separated any identifying information of the participants from the interview responses. Written Informed Consent (Appendix C) was also established with participants before being interviewed. The recruiting of potential participants was completed without coercion or persuasion.

Participants were provided with access to free ongoing counseling services. In the area of Florida that this study was conducted, there are two existing free 24-hour mental health crisis hotlines, including South County Mental Health Mobile Crisis Team and the Jerome Golden Mental Health Mobile Crisis Team. If participants desire ongoing counseling support, information for the Florida Mental Health Hotline and the Resource & Referral Hotline were provided. These referral services are free of charge to callers.

Summary

This chapter included a description of the sample selection strategy and descriptions of the instrumentation and data management and analysis plan. This generic qualitative study sought to understand the perceptions and experiences of family caregivers of PD patients regarding their advance directives. The data was collected through interviews via telephone. I analyzed data from 11 interviews, or until data saturation was met. Participants were family caregivers for a Parkinson's patient who they have contact with five or more times per week. Participants were also willing to discuss their experiences with advance directives and EOL conversations for the Parkinson's patient. The current study sought to illuminate emergent themes regarding choices surrounding EOL conversations and completing advance directives. This study contributes to social change as it opens dialogue about how attitudes, beliefs, and perceptions influence this population of family caregivers. The purpose of the research was to collect data that provides depth and breadth to this field of study that aligns with the experiences and perceptions of the family caregivers interviewed.

Chapter 4 includes data that were gathered through semi-structured interviews.

Chapter 4: Results

In this study, I used a generic qualitative approach to examine family caregivers' perceptions and experiences with AD documents for the PD patient they care for. Family members depend on one another throughout ACP processes (Bowman & Katz, 2017). Relationships between family caregivers and PD patients may impact AD decisions. Understanding the dynamics between PD patients and family caregivers concerning ADs may lead to an understanding of how EOL choices are made.

This generic qualitative study aimed to contribute to the existing body of literature by filling a gap in research regarding family caregivers' perceptions and experiences regarding use of ADs for PD patients. The research question that guided this study was as follows:

RQ: What are the perceptions and experiences of family caregivers regarding the use of ADs for patients with PD?

This chapter is organized into the following sections: research setting, demographics, data collection, results, data analysis, evidence of trustworthiness, credibility, transferability, dependability, confirmability, study results, and summary.

Field Test

A field test was conducted for my interview protocol via this dissertation's chair. This was done by emailing the audio recording and transcript from the first interview I conducted. It was determined by the dissertation chair that the first interview was too rigid and did not provide a deep enough understanding of the participant's experiences. I modified my approach to the interview protocol and was less structured during study interviews to allow for a more in-depth examination of each participant’s experience. This allowed for interview process to be more conversational and led to richer data for this study.

Setting

In-depth semi-structured interviews were conducted between December 12, 2020, and January 9, 2021. All interviews were conducted via telephone. I distributed recruitment flyers via email and Facebook. I was contacted by participants who met the research criteria either through email or Facebook Messenger. I scheduled dates and times to interview each of the potential participants. Before each interview began, I reviewed the informed consent document with the participant and asked them to sign the form and return it to me via email. I received verbal and written permission from each participant to record interviews.

Demographics

All participants resided in the U.S., were English-speaking, and self-identified as a family caregiver for a Parkinson’s patient. They self-identified as currently living in Florida (6), Maine (1), Missouri (1), Texas (1), and West Virginia (2). Participants consisted of eight wives, one husband, and two daughters. Participants in this study were of legal age and competent to answer the questions during the interviews. Table 1 shows participants’ demographic information. Included in this table is what advance directives the Parkinson’s patient and the caregiver reported having at the time of the interview. These ADs include a DNR, LW, and HCPOA.

Table 1

Summary of Participant Demographics

Name	Relationship to Parkinson's Patient	Age of Caregiver	Length of Caregiving for Parkinson's Patient	Advance Directive Documents for Parkinson's Patient	Advance Directive Documents for Caregiver
Participant 1	Wife	70	3 Years	DNR, LW, & HCPOA	DNR, LW, HCPOA
Participant 2	Wife	72	10 Years	LW & HCPOA	LW & HCPOA
Participant 3	Wife	67	12 Years	DNR, LW, & HCPOA	DNR, LW, HCPOA
Participant 4	Wife	72	3 Years	DNR, LW, & HCPOA	DNR, LW, HCPOA
Participant 5	Wife	78	3.5 Years	DNR, LW, & HCPOA	LW & HCPOA
Participant 6	Wife	62	11.5 Years	LW & HCPOA	None
Participant 7	Daughter	58	2.5 Years	DNR & HCPOA	None
Participant 8	Wife	73	8 Years	DNR, LW, & HCPOA	DNR, LW, HCPOA

Name	Relationship to Parkinson's Patient	Age of Caregiver	Length of Caregiving for Parkinson's Patient	Advance Directive Documents for Parkinson's Patient	Advance Directive Documents for Caregiver
Participant 9	Daughter	38	4 Years	LW & HCPOA	LW
Participant 10	Husband	65	5 Years	DNR, LW, & HCPOA	DNR, LW, HCPOA
Participant 11	Wife	74	8 Yes	DNR, LW, & HCPOA	DNR, LW, HCPOA

Data contained in Table 1 were obtained from participants. I did not use names of participants to ensure confidentiality. Eight participants were wives to PD patients. One caregiver was a husband to a Parkinson’s patient. Two caregivers interviewed for this research were adult daughters of their mothers who are PD patients. As shown in Table 1, the average age of caregivers is 66. None of the caregivers interviewed have been primary caregivers to any loved ones prior to caring for PD patients. All 11 of the PD patients have an AD. Nine of the caregivers have AD documents of their own.

Data Collection Process

A total of 11 participants were interviewed for this study. I collected data via one-on-one telephone interviews to generate in-depth information from participants regarding their perceptions and experiences related to ADs. During interviews, responses received involved participants’ firsthand experiences and were the foundation for data collection. Data collection was intended to include information regarding family caregivers’ perceptions and experiences with PD patients. I sought to provide information regarding the use or non-use of ADs for PD patients according to family caregivers. The qualitative methodology was best to ensure questions reflect respondents’ experiences rather than any researcher assumptions.

In qualitative research, the researcher is the primary instrument and facilitates the direction of the interview process (Cypress, 2018). I conducted interviews over 4 weeks via telephone. The interview duration ranged from 60 minutes to 90 minutes. Each participant signed a written consent form and authorized use of a digital tape recorder to record interviews. I monitored recordings throughout each interview and tested them to guarantee proper recording. Later, tape recordings served as a means to check accuracy of participant answers against transcriptions. After interviews, I thanked participants and ensured them I would be in contact for member checking. An external removable USB drive was used to store transcripts from interviews for 5 years. This USB drive will be locked and secured until more than 5 years have passed.

Qualitative researchers have to be vigilant and aware that their biases might influence study outcomes. Only what is revealed through research methods can be described as authentic and valid. Processing data via analysis that is clearly defined and transparent can reinforce the validity of findings.

As part of the interview process, participants were able to ask questions about the research. Interviews were recorded with a digital voice recorder. I also took notes during each interview to later review using reflexive journaling. There were no unusual circumstances encountered during data collection. I was only able to collect data via telephone interviews due to the current COVID-19 pandemic in the United States, which prevented safe data collection via in-person interviews.

It was important to be upfront and transparent about my decisions and choices relating to the participant interview process. I was minimally reactive during interviews to increase reliability of interviewee responses. Participants were assumed to have given the same answers if questions were asked at a different time or place, or by another researcher. I then coded, analyzed, and interpreted data gathered throughout the research.

Data Analysis

The interview protocol consisted of 21 questions, including demographic questions, with content ranging from care routines they shared with their loved ones to perceptions of AD documents. The methodology included qualitative analysis of data collected from interviews. Interviews were transcribed, and data were then grouped to identify similar categories and answers. I transcribed recorded interviews by hand and then organized the data into an Excel spreadsheet for analysis. I recorded themes based on how many participants answered the same questions with similar answers. After transcribing all interview data and coding them into categories, I analyzed data. From interviews with participants, I identified four themes.

Coding

A qualitative researcher’s primary task is to analyze data by organizing it into patterns, concepts, categories, and themes. I uploaded all transcribed data into an Excel spreadsheet for coding purposes. I then looked at the data collectively to address patterns, categories, and themes. Many patterns were noticed, and as a result, 10 categories were identified. These 10 categories led to four themes. Addressing connections between themes and categories that relate to the research question was the goal.

The following categories emerged from data. These categories are displayed in Table 2. Identified themes relate to these categories and are explained further.

Table 2: Categories

Summary of Categories	*Participants*	*Comments*
Common Care Routine Component	1, 3, 4, 6, 7, 8, 9, 10	"Administer medication". "Sets up and reminds him to take medication throughout the day". "Organize pills". "Prompt him to take his medicine".
Time Spent with Parkinson's Patient	1, 2, 3, 5, 6, 7, 8, 10	"Most hours of the day". "24/7, it never ends". "24 hours a day until he needed moved to an assisted living facility".
Caregiver's Understanding of Do-Not-Resuscitate	1, 2, 3, 4, 5, 6, 7, 8, 9, 10	"No heroic measures". "Not doing CPR if he stops breathing". "If his heart stops they won’t resuscitate him".
Caregiver's Understanding of Living Wills	1, 3, 4, 5, 7, 8, 9, 10	"Limits medical care in a hospital setting". "Explains who will guide her care if she doesn't have capacity". "A plan for future healthcare goals, values and preferences".
Caregiver's Understanding of Healthcare Power of Attorney	1, 2, 3, 4, 5, 6, 7, 8, 9, 10	"Outlines who can make decisions on our behalf". "Allows me as the caregiver to make healthcare choices for him". "Transfer of decision making if he becomes incapacitated or not of sound mind".

Summary of Categories	*Participants*	*Comments*
Discussion by Caregivers with Parkinson's Patient	All Caregivers	"We discussed end-of-life situations long before we were old". "In agreement with end-of-life choices". "Completed advance directives to spare our adult daughter any complications". "I initiated conversations with him after he was diagnosed with Parkinson's disease".
Prevalence of Caregiver's Advance Directives	1, 2, 3, 4, 5, 8, 9, 10	"I completed mine due to the death of my young son and then my son-in-law". "Family members died and it prompted use to have conversations about our wishes and preferences". "I have a living will because I have children and I don't want them to have to guess at what my wishes are".
Positive Thoughts about Advance Directives	1, 2, 3, 4, 5, 6, 7, 10, 11	"Invaluable and absolutely necessary". "Reduce the burden". "A good thing to have because you never know".
Healthcare Staff Conversations with Caregivers	1, 2, 3, 4, 6, 9, 11	"Almost nothing except asking if we had the legal documentation". "Say yes and that is the end of the conversation". "We have been asked but there wasn't follow up on his actual preferences and wishes".
Most Challenging Aspect of Care	1, 2, 8, 9, 10	"Intellectual and mental deterioration is the hardest". "Mental aspects with hallucinations and paranoia". "Cognitive and psychological changes that occurred with Parkinson's disease".

From these categories, connections became apparent in terms of identified themes. Overall, participants reported accurate understanding of the three different ADs chosen for this study. The first theme was caregivers’ understanding of how these documents work regarding PD patients or their own EOL care wishes. Additionally, participants have ADs themselves as well as reasons why they chose to have these documents.

The third theme came from category 10, related to the most challenging aspect of the care provided by the caregivers to the Parkinson’s patient. Five participants discussed how much the mental and cognitive changes in the Parkinson’s patient impacted their care routines. They shared how they have had to adjust the care provided to the patient as a result of these cognitive changes. And collectively they said that they were thankful to have ADs in place prior to these cognitive changes so that the Parkinson’s patient’s wishes are already known and understood because they may no longer be able to express these choices. These participants have relied heavily on the existing ADs to ensure the patient’s choices are being honored.

The last theme identified emerged from the questions regarding discussions that the caregivers had with healthcare staff about ADs. This is explained further in category 9. The majority of the participants relayed that healthcare staff would inquire if the Parkinson’s patient had an existing AD. However, if the AD was already reported by the caregiver as being in place, no further questions were asked by the healthcare staff as to what the patient’s wishes or preferences were as documented on the AD. Below, the themes will be explained further and summarized.

The following themes emerged from the data collection process: (a) the caregiver’s understanding of advance directive documents for the PD patient and the caregivers, (b) the caregivers prevalence of advance directives for their own EOL wishes and the reasons why the caregivers said they have their own ADs, (c) the importance of the ADs due to cognitive changes in the PD patient, and (d) the discussions healthcare workers had with the PD patient and the participants regarding advance directives.

The process of coding was simple because the participants were all asked the same questions. At times, I had to ask the participant to elaborate or explain something more thoroughly than they had initially shared, but the questions maintained the same focus. The goal was to identify similarities and differences in the responses and then categorize them. These categories then led into themes, as discussed above. I coded each question for all participants to identify phrases that supported a common category and then common themes. Table 3 shows the details of the participant’s supporting phrases. Table 3 also lists significant statements and reoccurring words that led to the four themes. Each theme is discussed below in the following subheadings.

Table 3

Summary of Themes

Themes	Supporting Phrases
Caregivers Understanding of Advance Directives for the Parkinson's patient and the Caregivers	All eleven participant's gave detailed descriptions about their mental impression of advance directives. The participants overall perceived the advance directives to be of benefit to the patient and themselves. Participants 1 & 10 said they are "invaluable" and "absolutely necessary", a "good thing to have because you never know" (Participant 2), to "reduce the burden" on others making the decisions (Participants 3, 4, 5, & 10), reassuring and provide peace of mind (Participants 8 & 10). Participant 5 said "they are a great courtesy to survivors".

Themes	Supporting Phrases
Caregivers Advance Directives for Their Own End-of-Life Wishes & Reasons for having their own Advance Directives	Eight caregivers (Participants 1, 2, 3, 4, 5, 8, 9, & 10) have their own ADs, which was largely influenced by the experiences and conversations with the Parkinson’s patient regarding end-of-life choices. Two other caregivers (6 & 7) have had conversations with their loved ones about ADs so their wishes are known but not yet documented in an advance directive. Three caregivers (2 & 7) stated that they completed an AD with the Parkinson's patient, for both themselves and the patient, after the patient was diagnosed with Parkinson's disease. Five caregivers (1, 4, 5, 6 & 10) said that they had completed ADs for both themself and the Parkinson's patient prior to the diagnosis of Parkinson's disease. Six of the caregivers said their choice to complete an AD was directly related to their experience with other deaths in their families (1, 4, 5, 6, 8 & 10).
Importance of Advance Directives for the Caregivers due to Cognitive Changes in the Parkinson's Patient	Five caregivers discussed how the cognitive changes have impacted the patient's ability to make decisions for themselves (1, 2, 8, 9 & 10). They collectively said that because the patient has ADs in place, the caregiver knows what end-of-life wishes they have even though the patient is no longer able to express these wishes.
Discussion with Healthcare Workers regarding Advance Directives	The majority of participants (1, 2, 3, 4, 6, 9, & 11) stated that while they were asked if the Parkinson’s patient had an advance directive, if their response was “yes”, then no further discussion was had about the advance directive. Their mental impression of healthcare workers assisting with advance directives is that “it didn’t rise to the level of a conversation” (Participant 2), and that it felt like the healthcare professional was “simply checking a box and not actually following up on preferences and wishes” (Participants 3 & 9).

Evidence of Trustworthiness, Credibility, and Transferability

Qualitative research relies on the credibility, transferability, dependability, and confirmability of rigorous methodology to render data with trustworthiness (Korstjens & Moser, 2018). Trustworthiness in qualitative research refers to the amount of rigor and confidence of the data, the interpretation of the data, and the methodology utilized to ensure the research study is of high quality (Linneberg & Korsgaard, 2019). To ensure trustworthiness and rigor in the interview process, I wrote down my thoughts and bias as they emerged. This allowed for bracketing to organize my thoughts and reflections of the interview subject. Also, I recorded each interview to improve the quality of data collection and increase my transcriptions' accuracy. I repeatedly replayed the recording of each interview while transcribing the data to verify the data's content.

Credibility is one of the most important criteria to develop confidence in the study's substance and the findings. Working systematically throughout the coding process allows the qualitative researcher to observe transparency, leading to credible data interpretations (Linneberg & Korsgaard, 2019). Credibility is further increased by the researcher verifying the findings with participants. Raskind et al. (2019) explained that both member checking and peer debriefing are components of trustworthiness that can be included in qualitative research to improve data analysis transparency. The credibility of this study relied on the coding procedures, debriefing with participants, and member checking. These procedures can increase quality and enable replication of the study, leading to a more significant impact of the research in the field of study.

Qualitative research’s transferability relates to applying the study’s findings to other contexts or settings with other participants (Korstjens & Moser, 2018). Transferability can be supported through rich, detailed descriptions of the location, context, and individuals studied and transparent during data analysis (Maxwell, 2020). Providing sufficient information on the study participants and the context of the research allows the reader to assess the study’s findings as transferable. I can only give the reader enough information to determine if the study’s conclusions could not be transferred. I have described the themes as accurately as possible to provide context to the data analysis.

Study Results

Many participants were identified during the distribution of flyers and through online social media posts on Facebook. Follow up emails or phone calls were made to determine if the volunteers fit this study’s criteria. Eighteen individuals initially responded, four lived outside of the United States and therefore, did not meet the study’s requirements, and three never returned the Informed Consent form. Participants were given an overview of the research and had the chance to ask questions of this researcher. I maintained confidentiality through this process.

All eleven respondents stated that they knew what an advance directive(s) was and that they were aware of the PD patients’ decision to obtain these documents or not. All respondents interacted with the Parkinson’s patient at least five days per week, as was the minimum established in the study criteria. No caregivers reported being paid for their caregiving duties, although this would not have excluded them from being included in the study.

The results are organized by theme, and each theme relates to the caregiver's experiences and perceptions related to advance directives for the Parkinson's patient.

Theme 1

The results showed that all eleven participants had some understanding of advance directive documents. The advance directive documents included in this study were a DNR, a LW, and a HCPOA. Common descriptions related to DNRs received from the caregiver's included language such as allowing an individual's heart to stop, not performing CPR if a person stops breathing, no heroic measures, and not using any extraordinary measures to bring a person back to life. These words clearly explain that participants realize the significance of PD patients' choice to complete a DNR. Lack of intervention if the patient stops breathing or their heart stops will likely result in death. Seven of the participants said the PD patient had a DNR completed. All seven caregivers reported agreeing with the PD patients' choice regarding the DNR.

When asking the participants about their understanding of a LW, nine expressed that this document limits medical interventions or explains the patient's medical care wishes. These caregiver's perceptions about a LW were accurate with how this document is utilized. The remaining two participants were unsure what the LW was intended for. The participants collectively expressed understanding that an LW was not a legal document but only for medical decisions. Four participants (3, 7, 8, & 9) stated that specific interventions such as feeding tubes and breathing interventions were chosen by the PD patient in the LW document. All ten caregiver's whose PD patient has an LW reported being in agreement with the PD patients' choices in the LW.

While discussing the health care power of attorney (HCPOA), eight participants understood that this document was to become active when the patient could no longer make their own healthcare decisions (1, 3, 4, 6, 8, 9, 10, & 11). Many participants (2, 7, 10, & 11) talked about the HCPOA giving them the ability to communicate with healthcare providers on behalf of the PD patient, as well as make decisions on behalf of the patient if they were incapacitated (1, 2, 4, 6, 7, 8, 9, & 11). One participant (5) expressed that an HCPOA was designed to allow for financial decisions to be made, which is not accurate.

Overall, the participants regarded positive aspects of their experiences with advance directives for the PD patient or themselves. The participants collectively used words related to completing their advance directives as providing reassurance, reducing burdens, and being a great courtesy to the decision-makers listed on their documents (1, 2, 3, 4, 5, 6, 8, 10, & 11). Participant 2 explained that it is "a good thing to have an advance directive because you never know." Also, participants shared that ADs can "reduce feelings of uncertainty for people in charge of making these decisions" (4) and that it "is a kindness to others to put your wishes in writing" (5). Participant 7, whose PD patient has died, said she doesn't "feel bad about anything because I knew her wishes, and I followed those wishes through her death." Participant 9 talked about how difficult it was to have conversations about the ADs with her PD patient. She said, "death and dying are difficult to talk about, but it needs to be talked about."

Theme 2

A second theme that arose was that the majority of the caregivers reported having their own AD documents. The participants perceptions and experiences with the PD patient’s choices regarding ADs influenced their decisions around completing these documents for themselves. Their words painted a picture of engaging in their own EOL decisions because of their experiences with the PD patient, as well as other life experiences. The majority of the participants have at least one advance directive. The participants that reported having all three documents include 1, 3, 4, 8, 10, & 11. Participant 9 said she has a living will only. And three participants said they do not have any advance directive documents completed (6, 7, & 11). However, two participants (6 & 7) also noted that they have had conversations with their adult children on their wishes. Both said they plan on completing an AD for themselves. Participant 6 said that even though she has discussed her wishes with her adult daughter, she is “too young to worry about it yet”. Participant 7 shared that she has discussed her EOL wishes at length with her two adult children but “hasn’t made time to complete the documents yet”. Even though these two participants (6 & 7), as well as participant 11 who has not discussed nor completed any ADs for herself, noted that the ADs were beneficial for the PD patient, they have not yet completed their own. A lack of these documents could cause or allow for uncertainty to develop for individuals facing healthcare decisions without the clarity of making difficult decisions in advance regarding ADs.

Part of this theme that emerged during the data analysis relates to the reasons why caregivers stated they chose to have their own ADs completed. Eight of the eleven participants reported having their own ADs (1, 2, 3, 4, 5, 8, 9 & 10). The caregivers reported this was largely influenced by their experiences and conversations with the PD patient. Participants 2 & 7 said they completed their AD with the PD patient after the patient was diagnosed with PD. Five of the participants (1, 4, 5, 8 & 10) said they had completed ADs for both themselves and the patient prior to the diagnosis of PD. Six of the caregivers (1, 4, 5, 8, 9 & 10) said that their decision to complete an AD was directly related to their experience with other deaths in their families. Most of these deaths were from their parents while one was from the death of their young child (5). These experiences, both with the PD patient and in their families, directly impacted their perception of the importance of having an AD completed and this theme reoccurred during data collection.

One component to this theme is that some participants said they are reviewing their existing ADs (8 & 9) or wanting to update these documents (2, 6, & 9) because they participated in this research. The experiences they have had and their perceptions of the importance of ADs for the PD patient has resulted in their desire to update these ADs. This insight is leading them to protect their own potential EOL care by choosing to refresh their ADs prior to facing any healthcare challenges.

Theme 3

In the interview protocol, one question asked what the participants would describe as the most challenging aspect of being a caregiver to the PD patient. Participants regarded mental changes or cognitive declines of the patient (1, 2, 3, 8, & 10) as a challenge. As a result of these cognitive changes, these participants noted how beneficial it was to have ADs already documented so that they are clear as to what preferences the patient has for their EOL care. Participant 1 stated that “intellectual and mental deterioration is the hardest part” so falling back on the AD “when we become in capacitated makes the decisions simpler”. Additionally, it was stated that because of “psychological changes that occurred, he couldn’t make decisions for himself anymore. So, I was put in charge of decision making which was easier because he had outlined what he did and did not want in his living will” (Participant 8).

An overall impression from participants regarding this theme is that they would like more education or discussion about the mental and cognitive changes that may occur for the Parkinson’s patient in order to better plan for decisions that could need to be made related to EOL care. Participant 5 had a positive experience with her Parkinson’s Support Group when they had a physician come and speak about ADs and “they answered any questions we had related to his ADs, so I understood exactly what he wanted. This gave me peace of mind”. Had other healthcare staff taken the time to discuss ADs with the participants, perhaps more questions could have been answered to help inform them of what potential decisions may need to be made on behalf of the patient. More information about the disease process would also directly impact decisions and discussions surrounding ADs between the patient and participant. For example, participants said that the healthcare providers did not educate them on what to expect regarding possible mental changes. Therefore, the impression was that it is even more important for an AD to be in place because of the potential for cognitive changes in the patient. (Participant 1, 8, & 9). Participant 3 said that “I wish it was discussed more so more could be done ahead of time to reduce the burdens on the person or people having to make decisions". This could benefit PD patients who have not anticipated this challenge related to cognitive changes, so they have the opportunity to discuss their preferences and wishes for treatments and interventions through updating or modifying of their ADs.

Theme 4

This theme focuses on the occurrence of conversations with healthcare providers. A few participants felt they had productive conversations regarding ADs (5, 8, & 10). Participant 8 noted that a "medical student fellow had a conversation with both of us that was very helpful." Also, for participant 5, they were offered information through their Parkinson's Support Group, "including a physician and a nurse that answered any questions we had related to advance directives." This allowed the patient and the participant to feel educated on the subject and comfortable completing the documents. Participant 7 said that hospice staff had been helpful with the documents, "but we didn't utilize hospice until the last six months of my mom's life." The impression from that statement is that other healthcare staff could have discussed the ADs with the patient and participant prior to the last six months of the patient's life.

The majority of the participants (1, 2, 3, 4, 6, 9, & 11) said they were asked if the PD patient had an AD by healthcare staff. However, after responding "yes," there was no additional conversation about the AD, or the preferences stated within these documents. These participants perceived that the healthcare staff were not going to go into any details regarding the ADs if the patient already had one in place. Participant 2 said that this "did not rise to the level of a conversation" and that they felt that the healthcare staff was "simply checking a box and not really interested in talking about it with us" (Participant 9). Participants 3, 4 & 6 mentioned that the healthcare staff never asked to see the AD during an emergent hospitalization situation. The mental impression these participants had was that the content in the AD did not matter enough to review this with the participant and patient. Participant 4 said that "in an emergency, a nurse asked if he had a DNR but then never asked me to provide a copy of that document. I am not sure what would have happened if his heart had stopped."

Many participants (1, 2, 7, 9, & 11) talked about hiring a lawyer to complete ADs with the Parkinson's patient because they wanted to be sure the documents were legally binding and done correctly. The participants did this at their own expense. The impression from these participants was that they were thankfully able to pay an attorney to complete ADs. However, these healthcare documents do not require the assistance of an attorney and therefore they may have spent money unnecessarily because healthcare staff did not assist them with completing an advance directive. The Center for Disease Control (2021) has a thorough listing of free advance directive resources, including documents for each state in the United States, that individuals can download and fill out on their own. These forms typically require a witness or a notary to validate the documents.

Summary

I strove to understand family caregiver's experiences and perceptions related to the ADs for their PD patients. I conducted this research through in-depth, semi-structured interviews conducted via the telephone with eleven family caregivers, who were the participants for this study. The interview protocol had a demographic questionnaire section that included five questions and a set of semi-structured interview questions with sixteen questions. These questions were aimed at answering the stated research question. Based on the eleven participants' data, I concluded that advance directives had a positive impact overall on the participants' experiences as a caregiver to the PD patient. The four themes above explain how advance directives have impacted the participant's experiences related to caring for PD patients. Participant 5 said that these documents give her "peace of mind to have them in place." There are still opportunities for healthcare professionals to be of greater assistance to PD patients and the participants, as discussed in theme 5. And more support is wanted by participants regarding cognitive changes and declines for their Parkinson's patient (theme 4) to ensure the ADs are thoroughly understood by the caregiver prior to potential cognitive changes in the patient. Overall, the impression that participants gave was that the advance directives have positively served them and impacted their understanding of what the Parkinson's patient wants for their EOL care. Also, the participants have chosen to complete ADs for themselves as a result of conversations with the Parkinson's patient and their experiences with the patient's ADs.

Based on the themes, advance directives are overall having a beneficial effect on the participants. Chapter 4 included sections outlining the results of this generic qualitative study. To present these results, this chapter went over the results, the demographics of the participants and the Parkinson's patient, data collection methods, a discussion on evidence of trustworthiness, and the study results. Chapter 5 will include the conclusion of this research study.

Chapter 5: Discussions, Conclusions, and Recommendations

Introduction

The purpose of this generic qualitative study was to understand perceptions and experiences of family caregivers of PD patients regarding their use of AD documents. Inherently in qualitative research, the researcher describes not just behaviors and experiences of participants but also their context (Korstjens & Moser, 2018). This study involved using a qualitative paradigm with a generic approach. In general, a generic qualitative researcher seeks to build a logical link between chains of evidence (Raskind et al., 2019).

The interview protocol consisted of 21 questions designed to answer the following research question: What are the perceptions and experiences of family caregivers regarding use of ADs for patients with PD? Questions in interviews related to the conceptual framework and existing literature. The participants said they either have or will follow the directives describing the patient's preferences as appropriate for healthcare decisions.

Interpretation of Findings

Findings for this study confirm specific aspects of what has been found in the existing literature. 90% of Americans in the study by Bowman and Katz (2017) said that it is important to talk with loved ones about their EOL care wishes. It was found that only 20-30% of Americans had completed an AD (Chaddock, 2016; Flowers & Howe, 2015). In this study, all participants had conversations about EOL preferences. Additionally, all

11 participants had ADs that outlined their wishes. This research study shows a marked increase among individuals who have a completed AD.

Jeong et al. (2010) said 10.8% of physicians reported understanding ADs in detail. However, knowledge of physicians on this subject seems to be increasing. Park et al. (2019) said 8.3% of physicians in this study said not have enough knowledge about ADs. In this research, only two participants reported speaking with a physician about patients' AD (P5 and P10). The majority of participants who discussed ADs with healthcare staff had these conversations with nurses (P2, P3, P4, P6, and P9). Flowers and Howe (2015) said physicians avoid conversations regarding ADs due to fear of taking away the patient's hope and because of inadequate skill to communicate this type of information. Aultman et al. (2018) said nurses eported barriers to discuss ADs with patients including lack of time, lack of communication skills needed for this subject matter, and insufficient knowledge and confidence levels. Perhaps these are reasons why seven out of the 11 participants in this study reported healthcare workers asked only yes/no questions to ascertain if the Parkinson's patient had an existing AD. Participants said the healthcare staff did not follow up with significant conversations about their preferences. Reinhardt et al. (2014) said family caregivers who had structured conversations with physicians and other healthcare staff had significantly higher levels of satisfaction with EOL care wishes being honored. Participants in this study did not disclose any incidents where AD documents preferences had not been followed. However, participants' overall sense of frustration and disappointment when healthcare professionals did not take time to discuss or update ADs with patients is significant.

There have been national efforts to promote the completion of ADs among adults in the United States. These efforts include Respecting Choices: Person-Centered Care, the Conversation Project, the American Bar Association’s Health Care Decision Making program, and the POLST form. These programs, conversations, and completion of ADs impact EOL care. Participants in this research confirmed that PD patients’ choice to have ADs impacted participants by reducing burdens associated with decision-making and giving participants peace of mind in terms of what they understand the patient wants for their healthcare. Sorrell (2018) said when patients and their caregivers discuss values and beliefs regarding their EOL care preferences, outcomes improved for both patients and caregivers. Participants in this study conveyed similar beliefs. When they understood the Parkinson’s patient’s preferences, they were comfortable carrying out those wishes or anticipating the need to follow through with the responsibility of carrying out those wishes when it becomes necessary. Also, having EOL care discussions and documenting preferences for care allows patients and caregivers the opportunity to share intimate and meaningful conversations about wishes (Sorrell, 2018).

Part of ACP is making informed decisions for both patients and caregivers. Litzelman et al. (2016) said care planning aligns patient care with patient wishes, increases patient and caregiver satisfaction, and reduces levels of stress and depression for caregivers. Many participants in this research talked about their burden being reduced because of AD documents being in place. Participants were responsible for carrying out patients’ wishes but not responsible for making decisions about what the patient would want because of ADs in place. Knowing definitively what PD patients want in their EOL care reduced participants' perceived stress and concern.

Family caregivers have anxiety about preparing for EOL care. Park et al. (2019) said 23% of family caregivers surveyed said they were uncomfortable and anxious about preparing for declining health. This could lead to a lack of intention to prepare an ADs. Three of the eleven participants in this research did not have ADs for themselves. Two of the participants who did not have existing ADs have had intentional conversations with their loved ones about their wishes, though they have not yet documented these wishes in a formal AD. Most participants in this study have chosen to plan their EOL care through the completion of AD.

Wolff and Benge (2019) said caregiving difficulties increased with overall cognitive declines. These difficulties are related to activities of daily living, communication challenges, and increased motor disability (Wolff & Benge, 2019). When participants in this research study were asked their most significant challenge related to caregiving, 5 out of 11 participants said it was handling cognitive changes and declines in cognitive functioning in PD patients. This also impacted their experiences with ADs. Participants said ADs became more reassuring after cognitive decline began because they already understood expressed EOL care wishes for patients through these documents.

Limitations of the Study

This study was limited in terms of number of participants included. The 11 participants in this study were enough to achieve data saturation. A sample of 8 to 12 participants is suggested in qualitative research (Cheng et al., 2018; Turner-Bowker et al., 2018). Saturation was achieved by the tenth interview, and an eleventh interview was completed to confirm saturation. Participant selection was made carefully to ensure they met research criteria for family caregivers.

Another limitation of this study is that all 11 PD patients were described by participants as having an existing AD. This was not a component of the selection criteria and therefore is a limitation to this study. This may impact caregivers' understanding of ADs because all patients had existing documents. Also, participants' experiences with healthcare staff may be different if they did not already have an AD. This could be avoided in future research by intentionally seeking participants for this type of study who do not have any existing ADs. This may lead to different perspectives regarding the importance of perceptions and experiences of family caregivers for PD patients.

Another limitation involved the data collection method. By conducting semi-structured in-depth interviews via the telephone, participants might not have answered questions as honestly compared to face-to-face interviews. Some participants may have been selective with what information they shared about their roles as caregivers or regarding the condition of PD patients. Most participants were spouses of PD patients. This could have impacted information they had regarding patients' ADs and caregivers' experiences with PD patients. Interviews were based on personal experiences, and these experiences could vary with a different sample of anonymous participants.

Recommendations

This study was conducted with a sample size of 11 participants that led to data saturation. It involved experiences and perceptions of AD documents for PD patients from family caregivers' points of view. I was able to identify a new area of research and address a gap in the literature involving experiences of family caregivers and choices regarding ADs for PD patients. The results of this study could lead to other researchers studying this subject. Future qualitative studies with more resources could increase the participant size and findings. Additionally, because all participants in this study reported that PD patients had at least one existing AD, an area for future research would be to gauge perceptions of family caregivers of PD patients who do not have existing ADs.

Another idea for future research is to study how healthcare professionals can better assist PD patients and their caregivers in completing ADs. Conversations discussed by the healthcare staff with participants were limited and potentially not very helpful to the dyad. Investigating what would be most supportive for family caregivers could lead to new insights in terms of how to have successful conversations regarding ADs.

Finally, an additional field of future study would be how to best educate family caregivers of PD patients regarding cognitive declines and changes that were reported by participants in this study. An important component of this education would be to manage these cognitive changes through behavioral interventions, mental health support for both patients and caregivers, and medication management. Understanding what cognitive changes may occur or have already begun to occur may allow caregivers to manage PD symptoms. Also, support groups specifically for family caregivers of PD patients who have cognitive challenges may benefit this population. Online forums for family caregivers of PD patients are available through social media. These supportive resources may be beneficial for this population if offered in person as well. This could be challenging during a pandemic. However, the American PD Association is a resource to connect family caregivers to local support groups across the U.S. This resource could be recommended to family caregivers seeking in-person support from other caregivers with PD patients.

Implications

I specifically focused on family caregivers of PD patients. I chose this demographic to gather insight into experiences and perceptions regarding ADs. PD patients are a vulnerable population because their disease can lead to dependency on others and increase healthcare needs related to their chronic illness. They rely on their caregivers for daily care in many different capacities, and this can become more extensive as the disease progresses. Participants discussed ways that they provide care and support to PD patients during most hours of the day. These caregivers describe becoming advocates for PD patients to ensure they are receiving the healthcare they prefer and following through with patients' wishes expressed in ADs. This study provided evidence that explained how ADs had an impact on participants in terms of healthcare options. The support and care participants provide to patients were conducive to open communication regarding ADs for these caregivers. Participants' desire to carry out EOL wishes for PD patients was apparent in this study. Future research should involve how to better support family caregivers on behalf of patients as they navigate challenges associated with symptoms of PD and the healthcare system.

Communication between PD patients and family caregivers is imperative to ensure caregivers are aware of preferences related to their healthcare and EOL care. This can provide opportunities for connection and understanding of patients' individual needs and choices. Future research could also involve how AD presence affects bereavement outcomes and feelings about the death and dying process for family caregivers.

At the onset of this research study, I had ideas on what questions needed to be asked to understand family caregivers' experiences with PD patients regarding their advance directives. The more interviews I completed, the more I realized that there is more to learn and more questions to ask. There are many paths that could be taken to build upon the insight gained in this study from the family caregiver's who participated. Greater satisfaction is documented for patients who make EOL decisions with their caregiver's and the healthcare team (Reinhardt et al., 2014). Unfortunately, seven of the participants in this study noted very simple yes or no questions being asked by healthcare staff regarding the existence of advance directives for the patient. In-depth conversations did not follow these questions if the patient already had an advance directive document in place. The healthcare staff did not inquire about what preferences were stated on these documents. If preferences are known through the expression of advance directives, fewer adults in the United States die in a hospital, and adults are more likely to receive care aligned with their personal preferences (Yadav et al., 2017). Besides positively impacting the EOL care for older adults who understand the positive effect of advance directives (Reinhardt et al., 2014), the potential benefits of known EOL care wishes will benefit the family caregiver (Fried et al., 2018). The overall benefits of advance directives and EOL planning are unlimited for society. By increasing the number of adults who complete advance directives, these social change efforts will be impacted for the dying person. As

Americans look toward their future, considering what medical interventions they want to include in their healthcare plan is paramount to dying on our terms.

Throughout the study, the data revealed that even though all PD patients have advance directives, there are things that healthcare staff and the Parkinson's community can do to better support family caregivers. More training for healthcare professionals on how to have conversations regarding advance directives and allowing for more time to discuss these decisions with the dyads would benefit the caregiver and the patient. Also, providing more education on potential cognitive changes for PD patients may allow family caregivers to manage these symptoms. This awareness could lead to care that is more tolerable and more successful for the patient and caregiver.

This study's impact on society would be to improve how healthcare professionals have conversations with patients about advance directives. The participants' overall sense of frustration and disappointment when healthcare professionals did not take time to discuss or update advance directives for the patient is significant and could be a potential area for future research to be completed. The impact would also be to provide more education to PD patients' family caregivers to explain what symptoms may arise concerning cognitive changes, to allow the caregivers to plan better and anticipate these changes. Piili et al. (2018) found that most patients want their loved ones to be involved in their EOL care and decisions. Educating these caregiver's on how to best support the Parkinson's patient as the disease progresses will allow for a better chance of successful care. Methodological impacts for this research would be to encourage future studies to focus on family caregivers' experiences. This could open potential research for other diseases besides PD. Many non-terminal, chronic conditions warrant investigation, and future research could approach these studies from the family caregiver's perspective. The role of being a caregiver can be difficult and challenging daily. Alternatives to being cared for at home are not always desirable to the patient. Conversations regarding advance directives are associated with care that is more consistent with patient preferences, less fear and anxiety, and reduces negative emotional effects on the patient's caregiver's (Bowman & Katz, 2017). Identifying ways to best support those caring for individuals with chronic disease diagnosis may allow for care better aligned with what the patient prefers.

Conclusion

Based on the literature, advance directives are both relative and important to individuals facing healthcare challenges or disease diagnosis. These documents can be helpful to both the patient and the caregiver. Completing ADs leads to better EOL care and can benefit the living post-death (Sanders & Robinson, 2017). Some barriers that exist in the healthcare system of the United States include providers focused on curative medicine rather than palliative medicine, providers being hesitant to communicate with patients regarding difficult subjects such as death and dying, and patients and families feeling uncomfortable discussing death because they do not want to discourage or dissuade the patient (Litzelman et al., 2016). While many studies have researched the EOL conversations and advance directives for cancer patients (Cammy, 2017; Carlozzi et al., 2018), other adults without a cancer diagnosis have not been studied in this subject area. Also, family caregiver perspectives about advance directives for deceased adults have not been researched thus far. Impacting the use of advance directives for adults requires understanding what barriers keep caregivers from having EOL conversations with their loved ones, thus not documenting EOL wishes before death.

These findings give a voice to the current needs of family caregivers for PD patients. Healthcare professionals are an essential component of educating patients and caregivers about ADs. This can be improved through the use of education to the caregiver's and support groups for both the caregiver and the patient. Encouraging open and supportive relationships between the PD patient and their caregiver may lead to more meaningful conversations about EOL wishes.

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Appendix A: Demographic Questionnaire

Project Title: The Perceptions of Caregivers of PD patients on Utilizing ADs

First Name: ____ Age: __________

How long have you been a caregiver for your loved one diagnosed with

PD? _______________________________

Prior to the Parkinson's patient you were a caregiver to, have you been a caregiver to any other loved ones? Yes No

Did (name of loved one) have any advance directives completed, including a do not resuscitate order, a living will, or a healthcare power of attorney?

Appendix B: Interview Protocol

Interview Guide: The Perceptions of Caregivers of PD patients on Utilizing ADs

Introduction: My name is Meghan on (date) with participant (assigned #). Thank you for your time today. I am going to ask you some questions about your experience with advance directive documents for the Parkinson's patient you were a caregiver to. There are no right or wrong answers to these questions, as I want to hear about your experiences and perceptions. I want to understand your insight into advance directive documents.

1. Can you tell me about your care routine?
2. How often did you spend time with (name of loved one)?
3. What do you find challenging in caring for (name of loved one)?
4. What is your understanding of ADs?

   What is your understanding of a do not resuscitate order?

   What is your understanding of a living will?

   What is your understanding of a healthcare power of attorney?
5. What, if any, conversations did you have with (name of loved one) regarding their advance care planning?
    a. If Yes: what were the circumstances that made you/them decide to start this conversation?
    b. If No: What was the reason you decided not to start this conversation?
6. What are some of the feelings and thoughts you have about ADs?

7. What do you believe to be the most challenging part about having a conversation with your loved one about ADs?
8. What conversations have healthcare workers, including physician, nurse, social worker, etc., had with you about ADs?
9. How did you come to your decision about whether or not to create an advance directive?
10. Did (name of loved one) have any advance directives completed, including a do-not-resuscitate order, a living will, or a healthcare power of attorney?
11. How has your experience influenced your personal decision on the use of advance directive documents with your loved one?

Appendix C: Recruitment Flyer

Seeking Participants for Walden University Doctoral Study (Dissertation).
The Perceptions of Caregivers of PD patients on Utilizing ADs

A doctoral candidate in the field of Human Services at Walden University is seeking participants to contribute to knowledge through an interview on the subject of Advance Directives for PD patients from the family caregiver's perspective.

I would like to hear from you if you meet all the following criteria:

- You are a family caregiver of a Parkinson's patient
- You have contact with the patient 5 or more times per week
- You are a resident of the United States of America and fluent in English

For more information on the project, including how to participate, please contact Meghan Morgan, Walden University doctoral candidate. All inquiries will be treated privately and confidentially.

Phone: (561) 485-3558 (Text or Call)

Email: meghan.morgan@waldenu.edu

Appendix D: Letter of Agreement for North County Senior Center

[Date]

To the Walden University Institutional Review Board (IRB):

I am familiar with Meghan Morgan's research project entitled "The Perceptions of Caregivers of PD patients on Utilizing ADs". I understand Walden University's involvement regarding allowing students to interview human subjects for academic research purposes. I understand the interviews will last between 60 and 90 minutes and that the interview will be audio recorded. The data collected will then be analyzed and compared with other interview subject's interviews.

As the student researcher, Meghan Morgan, conducts this research project I understand and agree that:

- This research will be carried out following sound ethical principles and that it has been approved by the IRB at Walden University
- .• Participation in this project is strictly voluntary. There are no contingencies for family caregivers who choose to participate or decline to participate in this project. There will be no adverse consequences as a result of participation in this study.
- To the extent confidentiality may be protected under State or Federal law, the data collected will remain confidential, as described in the protocol. The name of our agency or institution will not be reported in the results of the study.

Therefore, as a representative of North County Senior Center, I agree that Meghan Morgan's research project may be conducted at our agency/institution, and that Meghan

Morgan may assure participants that they may participate in the interviews and provide responsive information without expectations of participation.

Sincerely,

Executive Director, North County Senior Center

Appendix E: Letter of Agreement for Your Aging & Disability Resource Center

[Date]

To the Walden University Institutional Review Board (IRB):

I am familiar with Meghan Morgan's research project entitled "The Perceptions of Caregivers of PD patients on Utilizing ADs". I understand Walden University's involvement regarding allowing students to interview human subjects for academic research purposes. I understand the interviews will last between 60 and 90 minutes and that the interview will be audio recorded. The data collected will then be analyzed and compared with other interview subject's interviews.

As the student researcher, Meghan Morgan, conducts this research project I understand and agree that:

- This research will be carried out following sound ethical principles and that it has been approved by the IRB at Walden University
- .• Participation in this project is strictly voluntary. There are no contingencies for family caregivers who choose to participate or decline to participate in this project. There will be no adverse consequences as a result of participation in this study.
- To the extent confidentiality may be protected under State or Federal law, the data collected will remain confidential, as described in the protocol. The name of our agency or institution will not be reported in the results of the study.

Therefore, as a representative of Your Aging & Disability Resource Center, I agree that Meghan Morgan's research project may be conducted at our agency/institution, and that

Meghan Morgan may assure participants that they may participate in the interviews and provide responsive information without expectations of participation.

Sincerely,

Dwight Chenette

Executive Director, Your Aging & Disability Resource Center

Appendix F: Letter of Agreement for South Palm Beach Parkinson's Foundation

[Date]

To the Walden University Institutional Review Board (IRB):

I am familiar with Meghan Morgan's research project entitled "The Perceptions of Caregivers of PD patients on Utilizing ADs". I understand Walden University's involvement regarding allowing students to interview human subjects for academic research purposes. I understand the interviews will last between 60 and 90 minutes and that the interview will be audio recorded. The data collected will then be analyzed and compared with other interview subject's interviews.

As the student researcher, Meghan Morgan, conducts this research project I understand and agree that:

- This research will be carried out following sound ethical principles and that it has been approved by the IRB at Walden University
- .• Participation in this project is strictly voluntary. There are no contingencies for family caregivers who choose to participate or decline to participate in this project. There will be no adverse consequences as a result of participation in this study.
- To the extent confidentiality may be protected under State or Federal law, the data collected will remain confidential, as described in the protocol. The name of our agency or institution will not be reported in the results of the study.

Therefore, as a representative of South Palm Beach Parkinson's Foundation, I agree that Meghan Morgan's research project may be conducted at our agency/institution, and that

Meghan Morgan may assure participants that they may participate in the interviews and provide responsive information without expectations of participation.

Sincerely,

Executive Director, South Palm Beach Parkinson’s Foundation