2021

End-Stage Renal Disease Patients' Experience of Anticipatory Grief

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Walden University
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Abstract

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by

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MSW, University of Georgia, 1999

BSW, Winthrop University, 1997

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Human Services

Walden University
November 2021

Abstract

Although prior researchers have suggested that end-stage renal disease (ESRD) patients experience depression that impacts their adherence to treatment and quality of life, there is a lack of understanding of how ESRD patients experience anticipatory grief related to their mortality and loss. This lack of knowledge has made it challenging for social workers to address treatment adherence and palliative care issues during the care planning process. The purpose of this qualitative study was to explore perceptions of loss and grief of ESRD patients who were undergoing hemodialysis treatment. The conceptual framework was anticipatory grief, specifically how patients perceive their own death and impending loss. A case study design was used. The research questions addressed how ESRD patients describe their experience with anticipatory grief while receiving hemodialysis at different points of time. The data came from interviews with 10 dialysis patients; the interviews were comprised of 16 questions. Using cycling coding, the thematic analysis process was administered to uncover familiar themes. The findings revealed common anticipatory grief indicators among the participating ESRD patients. The participants also expressed the lack of end-of-life planning. A conclusion is that end-of-life and palliative care educational programs, along with interdisciplinary training, need to be customized for ESRD patients, a change that may help to improve their quality of life. The findings may serve as a catalyst for further research to explore standardize tools and interventions to support patients experiencing anticipatory grief.

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Dedication

This dissertation is dedicated in loving memory to my spiritual mother, Betty Jean Humphrey, and one of my best friends, C. Boseman. I remember every encouraging word and challenging statement you shared with me so that I wouldn’t give up. Even though you are not here physically, the love is in my heart. I know you both are among the cloud of witnesses cheering me on!

Acknowledgments

This has been one of the longest educational journeys I have ever been on in my life. It is impossible for me to say that I made it to completion alone. I must begin by thanking my heavenly Father, who created within me gifts that I still have not discovered. It is my hope this accomplishment brings me closer to the many divine assignments that are set before me. I want to thank my loving parents, who are with me in spirit, Hosea and Leona Speed Sr., and all my family, who supported me every step of the way. Also, I want to show my appreciation to my church family, Valleybrook Outreach Baptist Church, who covered me in prayer. I want to honor Dr. Maria Caputi, my first dissertation chair, who truly taught me the importance of scholarly writing.

Dr. Hershberger, thank you so much for challenging me and showing me grace when I needed to take quarters off. Dr. Benoliel, I appreciate your challenging support, and your guidance in my last residency was invaluable. To my peers and my friends, who never gave up on me and always had a listening ear. Lastly, to my dear friends, Rowena, Tomeika, Kensa, Tamiko, Jessica, and Nicholas, thank you for loving me through this entire process. I love you all, and my heart is overflowing with gratitude for each of you.

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Chapter 1: Introduction to the Study

Background

End-stage renal disease (ESRD) is a condition that occurs when one’s kidneys are unable to function normally daily (National Institute of Diabetes and Digestive and Kidney Disease [NIDDK], 2016). NIDDK (2016) reported in 2012 that almost 500,000 individuals in the United States were receiving some form of dialysis treatment because of ESRD. As Velez-Velez and Bosch (2016) explained, due to the rigorous dialysis treatment psychosocial factors contribute to a patient’s adherence to treatment and include depression, isolation, and self-perception. As a result, social workers play a vital role within the interdisciplinary team, which also includes the nephrologist, nurse, and dietitian.

Nephrology social workers have undertaken a paradigm shift with their responsibility to identify psychosocial barriers, due to the redefined scope of practice under the Centers for Medicare & Medicaid Service (CMS) Conditions for Coverage, specifically with regard to assessment and plan of care documentation (Jackson, 2014). As a part of the interdisciplinary team, social workers must create a plan of care with specific evidence-based interventions to address the psychosocial barriers identified after assessing the patient (Callahan, 2011; Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule, 2008). Therefore, the basis of the social worker’s care planning should be on case management and counseling to treatment adherence per CMS’ Conditions for Coverage, Section 494.90.

These requirements have contributed to changes of social work practice in outpatient dialysis facilities (Velez-Velez & Bosch, 2016). Currently, social workers have placed more emphasis on providing supportive counseling to assist ESRD patients with coping and adjusting to outpatient dialysis treatment, especially within the first 3 months of treatment (Callahan, 2011). Velez-Velez and Bosch (2016) also noted that these changes were leading dialysis companies (e.g., DaVita and Fresenius Medical Care) to identify appropriate tools to assist with the clinical practice requirements.

According to CMS (Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule, 2008), social workers must address patient outcomes by using evidence-based measuring tools and interventions. Dobrof et al. (2002) found that social work scope of practice mandated by the U.S. federal government was to address the relationship between patient outcomes and psychosocial factors, mainly because of the strong correlation between the two variables. The patient outcomes mentioned are clearly outlined in the Kidney Disease Quality Outcomes Initiative (KDOQI) guidelines and encompass anemia, bone metabolism, adequacy, vascular access, and nutrition (National Kidney Foundation, 2020). One of the measuring tools to determine the impact of psychosocial factors on quality outcomes is the Kidney Disease Quality of Life (KDQOL) survey.

The KDQOL is used in most U.S. outpatient dialysis facilities given the CMS mandate for a health-related quality of life measure. Yarlas et al. (2011) confirmed that the KDQOL was both valid and reliable and the most frequently utilized tool among ESRD patients receiving dialysis treatment. They also explained that the KDQOL is comprised of five component scores, which are Mental Component, Physical Component, Symptoms and Problems, Burden of Kidney Disease, and Effects of Kidney Disease on Daily Life. Schatell and Whitten (2012) explained the Mental Component and Physical Component assess for “general health, activity limits, ability to accomplish desired tasks, depression and anxiety, energy level, and social activities” (p. 2) while the Symptoms and Problem Subscale focuses on specific physical issues such as shortness of breath and lack of appetite. The other two subscales, Effects of Kidney Disease on Daily Life and Burden of Kidney Disease, concentrate on patients’ possible frustrations with the dialysis regimen and their ability to carry out daily activities (Schatell & Witten, 2012). Schatell and Witten emphasized how that physical and mental component scores predict hospitalization and death. It is important to note that other researchers have found other correlations as well.

Previous researchers found a correlation between depression symptoms when using the Beck Depression Inventory tool and low KDQOL scores (G. B. Lopes et al., 2014; Nabolsi et al., 2015). Because depression is so prevalent among ESRD patients, health care professionals need to observe each patient’s perception of their health and wellness along with using the KDQOL given the physiological decline and demanding nature of treatment (Alsherif & Mohammad, 2012). Based on the occurrence of depression, CMS in 2016 also mandated that each ESRD patient be screened for depressive symptoms on an annual basis (Garcia, 2015). As a result, social workers are placing more emphasis on developing supportive counseling interventions to help patients cope with depression and changes in their quality of life. However, social workers have not been required to address grief among the dialysis population.

Interestingly, Periyakoil et al. (2012) noted a concern with the correlation between depression and anticipatory grief due to similarity in manifestation of symptoms related to other medical conditions. Eric Lindemann first introduced the term *anticipatory grief* in the 1940s to describe a soldier's wife preparing for her husband's possible death during World War II (Moon, 2016). Later, Elizabeth Kubler-Ross extended the concept beyond a person preparing for the loss of a loved one to a person preparing for their own death (Moon, 2016). It is possible that ESRD patients experience anticipatory grief due to their medical diagnosis, but the occurrence is unknown because federal regulations only prompt social workers to ask questions to identify depressive symptoms (Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule, 2008).

As stated, depression is the most common mental health experience in the dialysis population (Bohra & Nohra, 2015). Chilcot et al. (2010) observed that there is a relationship between depression and other psychosocial factors, specifically loss of control and role changes. Also, the prevalence of depression symptoms increases the risk of mortality and hospitalization (Preljevic et al., 2012), as indicated by the KDQOL's mental and physical component scores. Yet, even with the risks of mortality, the exploration of anticipatory grief appears limited with ESRD patients. Shore et al. (2016) noted that, despite the increased research on anticipatory grief with cancer patients, few interventions or measures exist to address palliative care issues. There is even less focus on symptoms of anticipatory grief with ESRD patients; instead the emphasis is on depression, with social workers, as well as physicians, commonly screening for and diagnosing depression based on manifested symptoms (Bohra & Novak, 2015).

Although anticipatory grief is not a part of the ESRD patient assessment and plan of care, CMS does require discussion of advance directives and end-of-life planning as Conditions for Coverage (Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule, 2008). Interestingly, according to National Institute of Diabetes and Digestive and Kidney Diseases (2016), individuals with chronic kidney disease have a high risk of mortality, even though the rate has decreased since 1996. Yet, Molzahn et al. (2012) noted that few researchers have conducted studies on dialysis patient views of death and dying. In their qualitative research, they found that some participants made end-of-life plans, especially after observing other patients dying in the facility or having near death experiences themselves. Further research is needed to explore patients' experience, as well as identify evidence-based tools and interventions to address death and dying among ESRD patients.

Problem Statement

Nephrology social workers, along with the interdisciplinary team, currently assess dialysis patients' quality of life and depression. However, there is a growing need to understand patients' perception of their own death to determine when to discuss end-of-life planning. This practice problem has compromised establishing an accurate psychosocial plan of care. Furthermore, the lack of understanding of anticipatory grief and end-of-life issues with ESRD patients hinders social workers' ability to establish a concise psychosocial assessment (Song et al., 2015). The interdisciplinary assessment would need to entail questions related to grief and loss to supplement the current questions related to advance care planning.

Purpose of the Study

The purpose of this case study was to explore ESRD patients' experience of anticipatory grief while receiving hemodialysis treatment. I wanted to obtain a better understanding of the dialysis experience and end-of-life issues from the patient's perspective. The in-depth interviews of 10 different ESRD patients allowed for a rich, descriptive analysis of anticipatory grief from a broader perspective. Study findings are a potential foundation for further research into this phenomenon and the identified population.

By conducting this research, I wanted to increase the awareness of anticipatory grief among ESRD patients. The goal was for these efforts to spur recognition of the ongoing need to assess and develop appropriate care related to end-of-life and palliative care for ESRD patients. ESRD patients struggle with their adherence to treatment and coping with the strict regimen (Velez-Velez et al., 2015). Therefore, it was imperative to explore the patient's perspective of their own death to encourage autonomy and provide psychosocial support.

Research Questions

Following are the research questions (RQs) I developed for this qualitative case study to explore patients' narratives of anticipatory grief:

RQ1: How do ESRD patients undergoing hemodialysis treatment describe experience with anticipatory grief through expressing loss and death?

RQ2: How do ESRD patients undergoing hemodialysis treatment explain their perception of anticipatory grief at different points of time of their diagnosis and treatment?

Conceptual Framework

The conceptual framework for this qualitative study was anticipatory grief theory, which was first mentioned by Lindemann in the 1940s when he discussed the grief experienced by World War II soldiers' wives and other family members (Reynolds, 2006). Lindemann (1944) concluded his study of acute grief with the discovery of a new phenomenon, anticipatory grief, which occurred not necessarily due the death itself of a loved one but actually the separation with the possibility of death due to war. Although, Lindemann (Granek, 2010) focused more on individuals experiencing anticipatory grief due to the separation or illness of their loved ones, later researchers (Fulton, 2003; Mystakidou et al., 2007) acknowledged anticipatory grief with terminally ill patients themselves. Fulton (2003) noted that anticipatory grief was experienced with patients at the time of terminal diagnosis of loved ones or closer to their impending death.

Moglia (2017) explained how Elizabeth Kubler-Ross, during the late 1960s, expanded the theory of anticipatory grief further to explain how an individual, diagnosed with a terminal illness, proceeded through a grieving process as their losses became more definitive. Kubler-Ross (1969) based her model of the stages of grief on in-depth interviews with persons who were actively dying. The theoretical model was comprised of five stages--denial, anger, bargaining, depression, and acceptance--that that could possibly be experienced and not necessarily in order. The model is supported by Montoya-Juarez et al. (2013), who noted that this progression causes individuals to become affected by insomnia and decreased hunger, as well as to socially isolate from family and friends. These symptoms are like the indicators of depression in ESRD patients (Bohra & Novak, 2015). I will provide further understanding of the theoretical framework of anticipatory grief in Chapter 2.

Nature of the Study

I conducted a case study, a qualitative research method, to answer the RQs. Simons (2009) pointed out that the use of a case study design enables the researcher to delve deeper than the survey method. This approach also provides insights on the experience of a phenomenon by an individual or a group at a specific moment in time (Simons, 2009). In the study, I examined the perspective of a dialysis patient of their medical condition. To gather data, I conducted individual, in-depth patient interviews using a narrative approach, Therefore, the rationale of using the case study approach was to explore patients' perceptions of their own impending death and loss based on the anticipatory grief theoretical framework. Yin (2012) further asserted that this form of research provides a clear opportunity to explore an individual or a group in an organized fashion to unearth premises to build further research.

Definitions

Anticipatory grief: A form of grief that an individual experience when diagnosed with some form of terminal condition and begins to experience changes in their physical functioning, social roles, and mental capacities before their actual death (Mystakidou, K. et al., 2007). Anticipatory grief can also occur when a person has a loved one who is dying from a terminal illness (Cheng et al., 2013; Mystakidou et al., 2008; Overton & Cottone, 2016).

Depression: A disease, symptom, or disorder manifested in various ways (e.g., sleep disturbance, appetite change, lack of hope for the future, and feelings of guilt or lack of self-worth). A person's physical condition can have direct effect on the presence or level of depression (Makara-Studzinska & Koslak, 2011; Periyakoil et al., 2012).

End-stage renal disease (ESRD): A condition arising from the lack of functioning of the kidneys due to various condition such as diabetes, hypertension, polycystic kidney disease, and lupus (CMS, 2008; John Hopkins Medicine, 2017).

Hemodialysis treatment: A form of dialysis wherein a machine acts as one's kidney by filtering the blood and removing unwanted waste from the body. Physical access is created as an entry way to place for needles to rotate the blood through the filtered dialyzer back into the body (National Kidney Center, 2013). The process varies in time from 3 to 6 hours for at least two to three times a week based on body mass (National Kidney Center, 2013).

Palliative care: A method for interdisciplinary teams to assist patients with end-of-life decisions due to terminal illness. The goal is to provide pain relief and psychosocial support to reduce the level of suffering for the dying patient (Wasylynuk & Davison, 2015).

Peritoneal dialysis treatment: An alternate form of dialysis entailing use of the lining of the abdomen to acts as a substitute kidney to clean an individual's blood by using a special mixture of substances with the capacity to absorb unwanted wastes and remove from the body (National Kidney Center, 2013). The process can either be done manually several times each day or every night with the assistance of a machine (National Kidney Center, 2013).

Assumptions

There were three assumptions underlying study. First, I assumed that participants would be open to discussing their perceptions of their own death. Also, I assumed that the 10 ESRD patients in the study understood their diagnosis and the need for life sustaining treatment. Last, I assumed that the participating patients would be comfortable enough to express thoughts about their death and loss, while providing honest explanations to the best of their knowledge.

Scope and Delimitations

The study was focused on ESRD patients who had been on dialysis between 3 months and 15 years in the South Carolina area. All 10 participants came from a dialysis outpatient facility in the Columbia and surrounding area rather than the outpatient dialysis facility where I work. Therefore, patients from other geographical areas were excluded from the study. Last, because the research was conducted over a short period of time, the study will not show perceptions of death changing over time.

Limitations

The perceptions of the participants concerning their diagnosis of ESRD and anticipatory grief and loss varied. Based on the narrow focus of the study, it proved challenging to get patients to talk about their experience of anticipatory grief and end of life. Because of the small number of participants, the study is not generalizable to other ESRD patients. Another limitation of this study was that the interview questions limited the responses of the patients, which impacted whether the results are valid and reliable with the capacity to address the RQs. The study had five other limiting factors, which are as follows:

- Only ESRD patients who live in South Carolina were selected for the study.
- Different companies own dialysis facilities; however, I chose Fresenius Medical Care because of my access as an employee.
- The patients were chosen based on their treatment modality of hemodialysis as their form of renal replacement therapy. I did not include ESRD patients who received any form of home therapy treatment or transplant.
- The patients were not selected based on age, race, gender, support system, or religious preference.
- Due to the restricted COVID-19 pandemic protocol for allowing outside individuals in the facilities, the interviews were not done in person. Instead, I completed the interviews by Zoom conference call.

Significance

The purpose of the qualitative case study was to explore anticipatory grief experience among ESRD patients receiving hemodialysis. Several earlier researchers (e.g., Bloembergen et al., 1995; Fenton et al., 1997) compared hemodialysis and peritoneal dialysis patients based on their quality of life, mortality, and nutritional status. However, little to no research has focused on the distinctions of anticipatory grief among hemodialysis patients. The results from the study provide nephrology social workers a foundation to determine whether a patient displays symptoms of anticipatory grief. Also, social workers and the remaining interdisciplinary team could create individualized plan of care goals with the patient to improve their quality of life based on modality.

This study is also relevant to researchers and social workers because it contributes insights that future researchers might use to develop interventions and tools to address anticipatory grief with dialysis patients. Evidence-based practice is pivotal for nephology social workers to address the complexities related to the major life adjustments for dialysis patients (Dobrof, J. et al., 2002). Therefore, the study would broaden the scope and allow opportunities for future research to create a theoretical framework for anticipatory grief with dialysis patients. Ultimately, the study established the necessity for more research to explore how anticipatory grief may predict mortality in dialysis patients.

Summary

ESRD patients often have difficulty coping with their diagnosis and rigid treatment regimen. The mental and emotional state of the patient is an important concern to the interdisciplinary team because of its direct impact on patients' quality of life (Zamanian, H., 2018). Therefore, developing interventions to address the possible symptoms of anticipatory grief is critical. ESRD patients can benefit from knowing and understanding how the diagnosis has affected their resiliency to adjust to their treatment (Kristofferzon, M .et al., 2011) This qualitative study was a means to examine whether hemodialysis patients live with anticipatory grief.

In Chapter 2, I review research related to anticipatory grief, depression, palliative care, and quality of life to support the study. This review contains a review of literature on ESRD patients and depression and its impact on their quality of life. In addition, gaps in literature will be identified related to grief and ESRD patients.

Chapter 2: Literature Review

Introduction

In this chapter, I review the literature related to how ESRD patients experience anticipatory grief related to their mortality. The purpose of this review is to identify the psychosocial factors, specifically depression experienced by ESRD patients, that affect patients' quality of life. Second, I want to provide further insight on palliative care with ESRD patients. The literature review includes sections on the following topics:

- an overview of perspectives on the occurrence of depression among ESRD patients, including an examination of depression and quality of life as an integrated model
- an exploration of palliative care among ESRD patients
- discussion of the evolution and definitions of anticipatory grief and its connections to terminal illness.
- differentiation of the phases of anticipatory grief and its relationship to depression in terminally ill patients
- an examination of the methodology to explore anticipatory grief on ESRD patients
- a review of instruments used to assess anticipatory grief in terminally ill patients

The chapter begins with an overview of the literature search strategy. This overview is followed by an exploration of the conceptual framework of anticipatory grief and its occurrence with chronically ill patients.

Literature Search Strategy

Sources for the literature review included peer-reviewed articles, as well as federal health organizational websites. I accessed Walden Library databases and search engines: (a) Academic Search Premier, (b) ProQuest Central, and (c) Google Scholar. The terms used to conduct the search included *anticipatory grief*, *preparatory grief*, *grief*, *depression*, *KDQOL*, *end-stage renal disease*, *dialysis*, *hemodialysis*, *peritoneal dialysis*, and *palliative care*. The results revealed no studies focused on the study variables, which include anticipatory grief and ESRD, supporting the proposition of the limited research and intent of this study. The review of literature in this chapter will solidify the purpose of the qualitative study.

Conceptual Framework

Anticipatory grief is a phenomenon that has been studied within the cancer population. Qualitative and quantitative researchers have explored a person’s end-of-life experience, specifically with terminally ill patients and aging older persons. Lindemann (1946) first introduced the concept of anticipatory grief from an individual perspective of someone preparing for the death of a loved one. Rando (1986, as cited in Cheng et al., 2013) added that this phenomenon extends beyond the anticipation of one’s death to include a compilation of various degrees of loss, such as physical decline, changes in role identity, and future goals. The purpose of this study was to explore this form of grief among the ESRD population.

Another term commonly used when considering one’s own impending death is *preparatory grief*, which was initially introduced by Kubler-Ross (Moon, 2016).

According to Shore et al. (2016), preparatory grief is “an unconscious process that happens when stability is threatened, most often by a new and unwelcomed diagnosis” (p. 15). It is not just the loss of life itself, but also the continued loss related to one’s role within their family and support systems, physical challenges, financial strain, and declining contribution to their environmental space. A person’s ability to manage the compounded loss creates a level of stress that becomes difficult as they adapt to an ever-changing new normal (Shore et al., 2016). Again, Rando (1986, as cited in Patinadan et al., 2020) reasserted that this form of grief is not only experienced because of the loss of a loved one but the expected loss of one’s own life, as well as a sense of independence and a planned future. Despite the similarity between depression and anticipatory grief, researchers have proposed that health care providers approach the two quite differently. The goal is not to eliminate or reduce the experience of the grief; instead, the professional caregiver should identify interventions to support and guide the process (Lebow, 1976, as cited in Patinadan et al., 2020).

Literature Review Related to Key Variables and/or Concepts

Depression and the ESRD Patient

Depression is a major psychosocial experience that is common among ESRD patients (Junior et al., 2014). The diagnosis of ESRD and the ramifications of the illness have caused researchers to examine the mechanisms that contribute to the manifestations of depression. Widera and Block (2012) explained that the prevalence of depression among persons with severe physical conditions occurs due to decline in daily activities and enjoyment of life. The medical conditions highlighted by Widera and Block were more related to cancer, lung disease, and heart disease and did not include ESRD. However, in 30% to 50% of ESRD patients, depressive symptoms are more likely to occur when compared with the non-ESRD patients (Makara-Studzinska & Koslak, 2011). Bohra (2015) provided a clear causality for depression in ESRD patients, in his review of the prevalence and treatment, by emphasizing the concept of loss related to loss of kidney function itself as well as changes in family dynamics and mental capacity.

Junior et al (2014) performed a study to determine the frequency of depression among ESRD patients and its potentiality to increase the risk of mortality. The researchers noted that depression is the second most common medical problem after hypertension among ESRD patients. They used the Beck Depression Inventory Scale to assess patients in two Brazilian facilities and concluded that symptoms of depression are often not diagnosed or recognized in the patients. Also, there is a strong correlation between depression and mortality, as well as nonadherence to treatment. However, the authors did not suggest any possible interventions; instead, they encouraged further extensive studies in depression among ESRD patients.

Feroze et al. (2010) completed a review and noted more stressors as root causes of depression in the ESRD population. Stressors included adherence to treatment, diet, and fluid restrictions; increases in outpatient and inpatient hospitalizations; and the dread of death and physical inabilities. Unlike Junior et al. (2014), Feroze et al. explored the various interventions comprised of not only medications, but also cognitive behavioral therapy, physical exercise, and social support.

Rajan (2016) performed a quantitative study to validate the relationship between anxiety and depression and their negative impact on ESRD patients. He concluded that the psychosocial factors, based on utilization of depression and anxiety tools, were barriers to patient adherence to dialysis treatment. Farrokhi (2012) supported this study by asserting that depression decreases the patient's ability to maintain self-care, which ultimately creates a higher occurrence of nonadherence. Furthermore, the prevalence of depression led to an increased risk of limited quality of life and mortality.

However, , Wang and Watnick (2004) explained the difficulty in identifying depression, despite its prevalence in the ESRD population, because of other prevailing comorbid conditions. Within their case report, they noted a decrease in the depression symptoms as the patient progressed with hemodialysis treatment and was less fatigued due to uremia. In a similar article, Zalai and Novak (2008) identified these commonalities between depression and physical functions (e.g., weakness, sleep disturbance, mental impairment, and physical pain). Therefore, they established the need to conduct depression screenings before making assumptions based on the listed symptoms.

Another reason for more reliable screenings and diagnosis of depression is its direct relationship to treatment adherence, hospitalizations, and mortality. Lopes et al. (2014) gathered patient data from the Dialysis Outcomes and Practice Pattern Study and concluded that depression was associated with limited physical activity and mortality. This quantitative study involved a simple self-reporting questionnaire to determine the level of physical activity, as well as the standardized Health Related Quality of Life Tool and Center for Epidemiological Study-Depression Tool (CESD-10). The findings showed that physical activity reduced symptoms of depression. Yet, the investigators did not explore whether adherence to treatment or dialysis treatment modalities could have an influence on the patient’s willingness to participate in physical activity. Depression not only impacts treatment adherence but has been found to be a barrier to medication adherence as well (Ossareh, S. et al., 2014).

Ossareh et al. (2014) sought to determine if depression and perceptions of quality of life directly affected patients’ ability to manage their medication regimen. CMS requires the interdisciplinary team review the patient’s quality outcomes, which includes phosphorus levels. It is important for patients to control these levels by taking phosphate binders to reduce the risk of bone calcification, which increases the risk of cardiovascular disease and death (Rabbani et al., 2019). In their quantitative study, Ossareh et al. used related questionnaires, such as the Simplified Medication Adherence Questionnaire and Drug Intake Percentage Questionnaire, as well as the Beck Depression Inventory questionnaire and Health-Related Quality of Life Survey, with 150 hemodialysis patients. The researchers discovered that if the Beck Depression Inventory score was greater than 15, then the patient was more likely to be nonadherent to their phosphate binder medication management, regardless of the quality-of-life scores. The researchers concluded that depression not only impacts treatment and medication adherence but also fluid management.

Cukor et al. (2014) further concluded that an improvement in fluid management and quality of life can occur when depression symptoms are addressed. They identified two dialysis groups of patients, one of which would receive cognitive behavior therapy.

The intervention group reflected improvement in several depression scales as well as quality outcomes. Introducing effective evidence-based interventions can address some of these issues. However, the researchers emphasized the need for longer empirical studies to see if the interventions would impact mortality rates, in addition to overall wellness and adherence.

Kellerman et al. (2010) noted that ESRD patients are often not diagnosed or treated for depression. The purpose of the study was to discover the significance of the relationship between depression and mortality with the dialysis population over a 7-year period. The outcome indicated a strong association between depression and increased possibility of mortality. Unlike Cukor et al. (2014), the researchers focused more on depression and mortality without the activity component.

Although they were able to prove a strong relationship between depression and patient coping skills, Ibrahim et al. (2013) were unable to explore all of the possible facets of depression (i.e., comorbid conditions and previous history of depression). However, they suggested counseling be provided to help patients identify coping skills. In an earlier study, Chan et al. (2011) went further by performing a meta-regression analysis to identify the psychosocial risk factors for depression by reviewing other studies between 1988 and 2020. The systemic review was centered on five major factors, which were personality attributes, stressors, social support, cognitive levels, and coping skills. Interestingly, patient with cognition barriers, specifically their memory of past traumatic experiences, and a personality with limited self-confidence were more at risk to develop depression. Also, the patient’s self-confidence and ability to identify their support system contributed to their depression scores. Overall, the study supported the need for intervention direction and implementation of support groups. With the continued lack of interventions, some researchers have proposed that there is still lack of awareness of the importance for practical implications.

Baykan and Yargic (2012) suggested the need to acknowledge the gravity of ESRD and other medical diagnosis affecting a patient’s ability to adjust to illness. They also confirmed a direct correlation existed between cognition or comprehension of the condition and level of depression. When a person faces a terminal condition with the possibility of physical debilitation, medical disciplines need to consider the prevalence of distress and depression. In the process of approaching this daunting task of diagnosing depression among the dialysis population, the goal is to improve a patient’s quality of life.

In the review, provided by Bautovich et al. (2014), they echoed the sentiments of ongoing occurrences of depression symptoms among patients with chronic kidney disease and its impact on hospitalization, quality outcomes, and risks of mortality. They also noted that despite the prevalence of depression, it is difficult to clearly diagnose patients because of the similar symptoms between chronic kidney disease and depression. While this study focused on Australian patients, Ibrahim et al. (2014) performed a study with the Asian Pacific dialysis patients and came to similar conclusion related to depression and chronic kidney disease. They went further to highlight patients tended to retain coping skills from their family, specifically their parents. They determined that if a patient had difficulty adjusting to dialysis, then it would plausible to introduce some form of therapeutic interventions to promote positive coping skills.

Kokoszka et al. (2016) supported this assertion with their study showing depression's impact on the patient's perception of their chronic kidney disease. With the utilization of the Mini-International Neuropsychiatric Interview, Beck Depression Inventory, and Acceptance of Illness Scale, the researchers were able to observe a strong correlation between depression and the acceptance of chronic kidney disease. One main limitation of the study was all the participants were from the same treatment center. Nevertheless, the practical implications suggest routine assessment of depression to address their adjustment to their illness.

Depression and Quality of Life in ESRD Patients

Depression has been found to have a direct impact on the quality of life for ESRD patients (Rebello-Rubio et al., 2017; Bujang et al., 2015). Several variables, including depression, tend to worsen the quality of life, such as "medication side effects, psychological distress, illness effects, impaired social support, functional decline, financial burden, increased symptom burden, and loss of vocational capacity" (Weisbord, 2016, p. 159). Therefore, it is important to understand the relationship between these depression and quality of life to better ascertain its impact on a patient possibly experiencing anticipatory grief.

Researchers (Ho & Li. 2016) studied the influence of quality of life of ESRD patients based on their treatment modality. The Health-Related Quality of Life was a model comprised of how a patient perceived their health, daily tasks, social dynamics, and mental health (Mau et al., 2008). The level of quality of life has become such an important component in the assessment and the plan of care development for ESRD patients that the CMS mandated the health-related quality of life measure be integrated into the dialysis facility's assessment and plan of care under the Conditions for Coverage, which must be administered at least annually (Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule, 2008). Since the KDQOL was completed with patients, regardless of their modality. It is important to determine if there are any score differentiations based on treatment modality.

Eneanya et al. (2019) performed a longitudinal study to identify in possible trends that may be beneficial to the dialysis team. The major conclusions were related to dialysis treatment modality. First, home dialysis treatment patients tend to have a higher quality of life scores compared to in-center hemodialysis patients. Also, patients who transitioned from home dialysis treatment to in-center hemodialysis treatment had lower quality of life scores. The researchers also recommended dialysis practitioners play close attention to the Burden of Kidney Sub score, as it tended to decline over time as the patient began to experience more disruptions due to their diagnosis and treatment. However, Cohen et al. (2019) performed a similar study with a large population of dialysis patients. Unlike Eneaya et. al, they found little differentiation between patients based on their treatment modality. Due to the disparities within the studies, Bonenkamp et al. (2020) performed a meta-analysis by reviewing previous research and resolved several studies showed patients on home dialysis tend to have better physical health compared to in center hemodialysis. However, they noted many studies had potential bias and the study designs impacted their conclusion.

Now similar to Eneaya et.al (2019), Ho and Li (2016) determined that PD patients tended to have a better quality of life, although symptoms of depression tended to be a prominent condition. In this comparative study, PD patient depression related more to their body image than to their access to care. A study exploring quality of life and PD patients took place in Turkey. Senol et al. (2010) came to similar conclusions with PD patients. Specifically, fatigue played a major role in predicting depression and a low level of quality of life. Therefore, helping patients develop coping skills to increase involvement in their care has proven to improve their quality of life (Nabolsi et al., 2015).

So even if healthcare practitioners determined one treatment modality would predict better quality of life for a patient, they had no guarantee that their measured perception would improve. Mitema and Jaar (2016) performed a study to ascertain the best methods to improve the dialysis patient's perception of their diagnosis beyond treatment modality options. They explored various studies particularly around anemia management, exercise, increase in treatment frequency, support systems, transplantation, as well as addressing sleep issues, sexual dysfunction, and depression. Overall, the researchers recommended using more tools beyond the KDQOL to assess a patients' quality of life and develop individualized plans. While Mitema and Jaar (2016) noted how increased frequency in dialysis treatments positively impacted the KDQOL's physical component sub score. There are several other outcomes that can positively impact the dialysis patient's quality of life.

Treatment recovery time is considered the time it takes for a patient to feel relatively better after a hemodialysis treatment. Lopes, A. et al. (2014) noted that dialysis patients with longer recovery times had lower quality of life scores and higher depression scores. Therefore, emotional, and social support would be beneficial to this group to cope with the effects of the treatment. However, Lopes, A. et al. (2014) identified various factors with a strong relationship by using the DOPP Studies and HRQOL scores beyond depression (e.g., physical activity and mortality). Concluded were the factors applicable to the plans of care and the quality of life of these patients reflected overall improvement. With the many hindrances to one sustaining a quality of life in dialysis, some researchers still found physical activity to positively impact survival. Nabolsi et al. (2015) explored quality of life of a dialysis patient and noted a correlation between depression, adherence, and perception. They further confirmed patient with the high quality of life scores were more likely have positive perception of their wellness. Weisbord (2020) supported these inferences by confirming in his systemic review the positive association between depression, quality of life, and pain. He noted depression and pain have similar symptoms with both contributing to hospitalization and mortality.

With that said, there are predictors, ranging from sleep disturbance due to fatigue, the analysis of depression in hemodialysis and peritoneal dialysis patients, supported the need to further explore their quality of life. Due to the prevalence of depression in the ESRD population and its prediction of hospitalization and mortality, the need to exhaust the contributing factors to develop the most effective interventions were essential. Alsherif and Mohammad (2010) in their study of psychological feelings experienced by

ESRD patients found the development of interventions must be patient-specific to consider coping mechanisms to the various stressors.

Stressors, such as sleep disturbance, could possibly contribute to a dialysis patients' perception of their quality of life. Theofilou (2013) found that insomnia issues, such as restless leg syndrome and sleep apnea, does contribute to a lessened quality of life. The study not only included hemodialysis patients, but also peritoneal dialysis patients, who were asked to complete several assessment tools, which included World Health Organization Quality of Life instrument, General Health Questionnaire, State Trait Anxiety Inventory and Center for Epidemiologic Studies Depression Scale (Theofilou, 2013). He noted that almost half of the patients within the study shared problems with sleep compared to a little over tenth of the general population. Several factors contribute to the recognized sleep disorders, such as "anxiety, depression, and physical disturbance, such as hypertension, muscle cramps and electrolytes or body fluids imbalances" (Theofilou, p. 71). Ultimately, the study concluded a positive correlation between not only sleep disturbance and quality of life among ESRD patients, but also the relationship causing symptoms of depression and anxiety. These correlations have been proven by various epidemiological studies which also acknowledge how this impacts the patient's ability to accept their illness. Pan, K. et al. (2019) performed a similar study by considering the impact of social support on sleep issues, depression, and quality of life. Utilizing a correlational design, they also agreed dialysis patients with poor sleep patterns and depression had a lower quality of life. In addition, the researchers found when social support was present, depressions symptoms and sleep issues declined over time.

Jankowska-Polanska et al. (2016) pointed out as the dialysis patient acceptance of their illness improves, it would directly improve their quality of life predict a longer lifespan. The life expectancy increases because the patient is more apt adhere to treatment and the strict dietary regimen. From the study, the researchers determined that if the acceptance to illness is low then the risk of mortality increases. Similar to Loon et al. (2017) who also performed a quantitative study related to quality of life and the risk of mortality, specifically based on the dialysis person's age. "Due to the aging of society, more and more patients will develop ESRD and consequently the dialysis population will increasingly be characterized by patients with impairments such as functional dependencies, cognitive decline and psychological impairments" (Loon et al., 2016, p. 6). Interestingly, with the utilization of the Health-Related Quality of Life (HRQOL) tool, they found the emotional health subscale was not impacted by age, in comparison to the physical health. The authors proposed the emotional health may be better in older adults because end of life planning was more a part of their overall care plan, unlike younger dialysis patients. Therefore, they recommended the HRQOL would be useful to prompt discussion related to advance care planning and shared decision making. These recommendations were supported by another study, which focused specifically on older adults. Hall et al. (2018) supported these recommendations within their study on older patients on hemodialysis, which also concluded there is a strong relationship between the KDQOL physical component score subscale with risk of mortality and increased hospitalization. Ultimately, regardless of the type of quality of life assessment utilized, these subscales should be prompt the interdisciplinary to address end-of-life decision.

Palliative Care and ESRD Patients

End-of-life considerations is a subject that ESRD patients are faced with due to their terminal diagnosis, despite available sustaining treatment. Therefore, the nephrology community has broadened the interdisciplinary team scope of care planning to include palliative care (Phillips et al., 2018; Goff et al., 2019). World Health Organization (2002) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

However, several studies have explored the underutilization of palliative care for ESRD patients (Bull et al., 2014; Davison et al., 2016; Haras, 2008). Wasylynuk and Davison (2015) explained how the increasing aging ESRD population with compounded comorbidities pressures the care team to integrate not only the emphasis of quality of life, but also quality of death through utilization of a decision-making framework and advance care planning. Another study validated the growing need for palliative care due to a rising of elderly ESRD patients, who also have cardiovascular disease (Fassett et al., 2011). The same authors also asserted the perceptions of mortality psychosocial factors, including ethnic distinctives must be conceded to address fear and anxiety of death. Another study confirmed the need of palliative care by stating the degree of hospitalizations are more compared to other conditions, such as heart and lung disease (Davison et.al., 2015).

Interestingly, in conjunction with the care plan team hesitation to discuss end-of-life issues, Davison et al. (2016) concluded dialysis patients have limited knowledge of hospice services and believe it is for only cancer patients. The authors concluded a huge opportunity to train the dialysis care team on palliative care and health literacy to expand their end-of-life options. Consistently, Phillips et al. (2018) in their quantitative study, using a survey design, found a disparity in not only the understanding of palliative care planning by patients, but also their nephrology professional care providers. Again, the patients do not consider ESRD an illness that will continuously worsen over time. However, the study found that patients open to have end-of-life discussion, especially if they have declining health. A similar study focused on nephrologist's view of end-of-life care and discovered a knowledge deficit, as well (van Biesen et al., 2015).

The extension of the complexed patient's perceptions of dialysis withdrawal were ascribed in a qualitative study in Singapore. Through nine patient interviews, who had decided to not receive dialysis treatment, the authors found common trends related to disease burden and uncertainty of the future on dialysis. Remarkably, the same conclusions were drawn with a need to explore and train care givers on the end-of-life decision making process. Instead of phenomenological approach, Koshy et al. (2012) performed a case study approach contrasting two patients. One patient had integration of palliative care, while the other case had limited end-of-life planning. The study concluded early involvement of patient and family in palliative care decisions allows for clear communication and perceptions.

Due to the increased need for palliative care planning, Goff et al. (2019) performed a study to determine the efficiency of Share Decision Making Renal Supportive Care as an intervention specifically with hemodialysis patients. This intervention was comprised of advance care planning sessions for dialysis patients and their families provided by nephrologists and social workers. The major barrier found with utilizing this intervention was the lack of time to hold the sessions with the patients, since it was not a part of the interdisciplinary team workflow within the facilities, which can be resolved be to normalize the intervention as a part of the care planning process.

In response to the time-constraints to have end-of-life discussions and planning with patients, O'Halloran et al. (2018) shared in their systematic studies review, it was best to develop a few short questions that can be added to existing interdisciplinary assessments to stimulate conversations. It is also important to ensure dialysis facility management provide standardized training to their staff on how to foster end-of-life discussions. However, the authors noted "the pressures of (and focus on) routine clinical work, a "conveyor-belt" culture in relation to provide hemodialysis, lack of funds to support staff training, and poor continuity of medical care, all militated against the uptake of advance care planning" (O'Halloran et al., 2018, p. 800). Berzoff et al. (2020) also noted that a similar barrier in their study using the Shared Decision Making and Renal Supportive Care intervention. Despite its effectiveness, the researchers could not ignore the hindrances related to the managerial demands of the daily tasks and more importantly deciding which member of the interdisciplinary team should have the discussion with the patient. Another barrier is related to the perceptions held by the interdisciplinary team that having end-of-life discussions would cause the patient not to focus on living life and adjusting to their illness. The social work participants in the study also recommended the patient’s spirituality and lack of support system be integrated within the training. In conjunction with social workers, nephrology nurses have shared similar concerns. Moran (2018) emphasized nurses are vital team members since they provide a large portion of the care during treatment. However, like social workers, the time constraints and limited training causes them to avoid the conversation and steer towards discussions about adherence and self-care.

While social workers and nurses have shared their lack of experience, it has also been observed nephrologist due not share the same deficiency among nephrologists. Fung et al. (2016) performed quantitative study by providing nephrology medical directors of dialysis clinics a questionnaire to assess their preparedness to facilitate the palliative care decisions. Based on the responses, almost 70% of the participants felt very prepared to have these discussions. However, the researchers noted there may be a survey bias since only over half of the surveys were completed by the physicians. Yet, they were able to observe a positive trend in more prepared nephrologists 2013 compared to less than 10 years ago. Despite nephrologist feeling prepared to have end-of-life discussions, Moss (2017) recommended developing a collaborative approach between the dialysis interdisciplinary team and supportive care specialists. The author also explained American nephrologists would benefit from this collaboration and assistance when discussing end-of-life and comprehensive conservative care planning.

Another concern posed by Lazenby et al. (2016), is not only the interdisciplinary teams experience, but also the timing of the discussion. In their qualitative study with a small group of physicians and nurses, they found the healthcare team is not having the discussion until a decline in the patient's health. Several barriers were identified to impact the timing, such as patient's desires are not documented, lack of patient awareness and education, and responsibility and culture. As a result, the study found end-of-life decisions are not made in a proactive manner, instead it is the time of a health emergency. Culp et al. (2016) drew similar conclusions in a quantitative study to analyze formal caregiver's perception of the need for supportive care to assist with end-of-life issues. Based on the online survey, the respondents continued to express the lack of time, adequate training, and support to address and implement palliative care planning in their facilities. In response to this issue, Axelsson et al. (2019) facilitated a focus study group, comprised of dialysis nurses and physicians, who also shared the importance of being proactive in having early discussions with patients about end-of-life planning. They also shared collaborate approach with palliative care professions would be beneficial, as well as standardized training.

Depression and Anticipatory Grief

One factor with limited exploration with the ESRD population is the potential experience of anticipatory grief. The major hindrance in exploring anticipatory grief was depression is the discomfort found among nephrology health care professionals. Molzahn et al. (2018) confirmed the lack of studies being performed exploring the ESRD patients end-of-life experience. Therefore, the authors conducted a qualitative study in Canada made up of patients and their caregivers. The participants not only spoke of their impending death, but along with loss. Therefore, the major recommendation is for the dialysis team to create more opportunities for end-of-life discussions to ensure we are developing more individualized care planning. Widera and Block (2012) noted that many patients with terminal illness were not depressed, but rather grieving. In the literature review, distinct symptoms were to help identify grief from depression. For example, a person with depression had more constant sadness and an extreme sense of regret, while grief had momentary sadness and regret over specific events.

Periyakoil et al. (2012) came to a similar conclusion about the difficulty in diagnosing grief from depression, due to similarity in symptoms (i.e., changes in weight, loss of appetite, sleep problems, and weakness). The design of this quantitative study enabled researchers to determine the reliability and validity of a new proposed instrument, the palliative grief depression scale. The concept of preparatory grief was a major component often misdiagnosed as depression. The authors provided a clear definition of preparatory grief, also known as anticipatory grief, experienced by terminally ill patients preparing for their death.

Bennett et al. (2008) further defined preparatory grief for the terminally ill patient as constant changes (e.g., physical and behavioral changes that caused them to face and eventually access the loss and their death) occurring for a terminally ill patient. Unlike the previous studies, the authors provided some indicators to assist in defining the difference between depression and anticipatory grief, (e.g. perception of self, sense of hope, and view of the future).

In order to form a more distinction between depression and grief, Jacobsen et al. (2010) performed a factor analysis by using an Inventory of Complicated Grief and Structured Clinical Interview for DSM-IV with over 100 cancer patients. Their conclusion was the symptoms were more distinct than researchers suggested in the studies. However, a major barrier in their study was the length of time of the patient's diagnosis and when their grieving process initiated. Also, the measurements did not include what may be causing the grief rather the roles or the loss of physical functioning.

The understanding of the evolution of anticipatory grief was important to consider before exploring further its implications with terminally ill. During the 1940s, Lindemann used the concept to describe parental loss of a child (Fulton, 2003). In later years, anticipatory grief expanded to include spousal grief of a terminally ill patient. However, further posited was that anticipatory grief of a loved one was difficult to define because of mental and cultural factors that could affect the evidence.

From Lindemann's (1944) work spawned a trend to explored death and dying from the patient's perspective. Riley (1983) mentioned the phases of dying developed by Kubler-Ross, who performed extensive qualitative research with terminally ill patients. From this work evolved the conceptualization of the emotional response stages to death and dying, denial, anger, bargaining, depression, and acceptance.

Reflecting on the previous work, Lindemann (1944) suggested the beneficial use of the socialization theory was understand when the patient began the process of separating themselves from their families and community. Another article reflected on the work by Kalish from the 1980s was anticipatory grief as a multi-faceted and three levels constructs: mental, relational, and social (Mystakidou et al., 2005).

After reviewing the literature and research concerning anticipatory grief, a vast portion of studies were about the cancer population. Cheng et al. (2010) conducted qualitative study to examine the experience of anticipatory grief among seven advanced cancer patients. The researchers presented a valid point that the absence of a clear measurement caused barriers by making it difficult to conclude whether this form of grief caused patients to cling to their families or begin the process of separation. However, from the three focus groups for the study, common themes were apparent, but varied depending on the stages of dying. Some of the themes included resisting death and experiencing multiple losses, such as physical functioning and family roles.

Mystakidou et al. (2006) agreed that Pattison's work supported these themes by stating that during the time between the diagnoses until their death, the person had the potential to grieve the loss of their health and mental functioning, as well how it affected their family. Hottensen (2010) supported these factors by reporting the discovery of patient's losses (i.e., independence, career, family, and mental functioning). Therefore, the author encouraged healthcare teams to allow patients to share their experiences as a way of coping with the anticipatory grief.

A few years after the development of the PGAC scale, a group of researchers explored the correlation between the stressful event of the disease and anticipatory grief. Tsilika et al. (2009) supported the need for the study based on the two forms of loss, (i.e., actual versus one's perception). DSM-IV identified terminal illness as an example of painful stress. Also, other researchers argued terminal illness was a form of Post-Traumatic Stress Disorder.

Mystakidou et al. (2008) performed a similar study to investigate the preparatory grief and is relationship to not only psychological distress, but also hopelessness. Using the PGAC scale, along with the Greek Hospital Anxiety and Depression Scale, and the Beck Hopelessness Scale, the most significant relationship was between anticipatory grief, hopelessness, and depression. No strong relationship existed between anxiety and anticipatory grief. Once again, the research supported the need for healthcare providers to recognize these factors and provide effective interventions to address anticipatory grief among terminally ill patients.

Methodological Review

The literature review for this section involved an examination of several approaches used to explore the ESRD experience as it related to their perceptions of their own death and dying. While researchers have not considered anticipatory grief in relation to the ESRD population, the need for this type of study would be beneficial to these patients. The methods to explore the subject were from both the quantitative and qualitative research approaches, along with attempts to analyze the data from case studies to survey methods.

Over a five-year period, Jacobsen et al. (2010) interviewed 123 terminally ill cancer patients. The sample completed two instruments (i.e., the Inventory of Complicated Grief-Revised and the Structured Clinical Interview for DSM-IV [SCID]. The purpose of this quantitative study was to discover whether a significant difference existed between grief and depression experienced by cancer patients who had unsuccessful chemotherapy and would die within 4 months.

In other studies, Widera (2012) investigated how patients manage depression and grief with the terminally ill population. These studies enabled the researcher to not only assess for depression, grief, and suicidal ideation, but also examine the treatments provided for each patient. Montoya-Juarez et.al (2013) also used case study methodology with terminally ill patients. They determined patients can cope once they have accepted their diagnosis and perception of their end.

Another study with a phenomenological analysis of seven cancer patients from the Statin Hospital day hospice involved their experiences with anticipatory grief (Cheng et al. 2010). The group of patients participated in a four-week session of anticipatory grief therapy. After completing therapy, the participants became part of a focus group, where they shared their experiences. However, the study had a small sample of patients and focused only on cancer patients.

Based on the review of methodologies, a variety of research approaches and methods were available to study anticipatory grief. The findings about depression tended to reaffirm the findings of previous studies. Others, such as the introduction of the PGAC tool, presented new ideas about the subject. The primary recommendations included the need to use the survey methodology to begin the exploration of anticipatory grief. Mystakidou et al. (2005) proposed the survey method to determine the effectiveness of the PGAC tool, because of its utility with any cancer patient.

Overview of Depression and Anticipatory Grief Instruments

The mental health of dialysis patients is vital to the journey of coping and adjustment to ESRD, as a life-threatening illness (Bohra & Novak, 2015; Ibrahim et al., 2013; Farragher et al., 2017). Therefore, it was beneficial to determine various tools to assist the interdisciplinary team in assessing patients allowing effective individualized care planning. Several studies have been performed to identify the most appropriate tools to utilize with ESRD patients. For example, Makara-Studzinska and Koslak (2011) concluded that depression had a significant relationship with increased hospital admissions, as well as increased risk of death and suicidal ideation. Furthermore, ESRD patients scored higher on the Beck Depression Inventory than healthy, non-ESRD patients. Still, the Beck Depression Inventory was not reliable because of the similarities to depression and ESRD physical symptoms.

To address the issue, Periyakoil et al. (2012) used the Palliative Grief Depression Scale to help identify whether a patient is experiencing grief or depression. The basis of the scale are its theoretical frameworks, which are loss-oriented grief and restoration-oriented grief. The goal was to develop a much simpler scale that could be completed by self-reporting. Although a valuable tool, the authors noted that further study would be needed from a longitudinal perspective.

Cruz et al. (2010) completed a similar study in Brazil with not only renal patients, but heart disease patients on a different depression scale (the Mini-International Neuropsychiatric Interview-5.0), and an additional quality of life scale (the World Health Organization Quality of Life Instrument-brief). Their conclusions were that high depression scores could predict low levels of quality of life. With the expansion of variable to include mortality, Morsch et al. (2007) followed a small population of 40 patients over a 12-month period. The results established not only a correlation between nutritional intake and anemia with quality of life scores, but also patients with low scores of perceptions of physical functioning had a higher risk of mortality.

Most research found on the topic of the dialysis modality between in-center hemodialysis and home therapies related to quality of life focused one particular form of treatment, rather than performing a comparative study. For example, Ho and Li (2016) analyzed the quality of life outcomes with specifically hemodialysis and peritoneal dialysis patients. The conclusion was the quality of life scores were higher for peritoneal patients compared to hemodialysis patients. However, they did not discover much difference between these patients related to its impact on their physical health.

Even from when determining prevalence of depression between these modalities, Klaric and Klaric (2012) used the Hamilton Depression Rating Scale to identify depression in a small population of ESRD patients. Their conclusion was that hemodialysis patients had more major depressive symptoms compared to peritoneal dialysis patients. Additionally, patients who changed modality from hemodialysis to peritoneal dialysis experienced a decrease in their depressive symptoms.

Although few researchers found differences in the QOL scores between hemodialysis and peritoneal dialysis patients, Lew and Piraino (2005) identified definitive distinctions between the quality of life between hemodialysis and that of peritoneal or home dialysis patients. Since ESRD patients often chose peritoneal dialysis

(PD) treatment, to maintain a sense of control and independence, they were more actively involved in their own care, because this form of treatment requires little to no assistance. Consequently, peritoneal dialysis patients tended to score higher on the QOL survey than did hemodialysis patients.

In response to the growing need to adequately assess anticipatory grief in cancer patients, a group of researchers developed a tool, known as the Preparatory Grief Advanced Cancer (PGAC) Scale. Mystakidou et al., (2005) developed a 31 question self-report scale, based on the three levels, and administered to 200 patients to determine the reliability and validity of the tool. Cancer patients with low quality of life had higher scores of physical symptoms on the PGAC scale. The PGAC developers suggested that the scale would be useful as an assessment tool to help healthcare providers be aware of the need for grief interventions for these patients.

Further studies performed analyses of the possible predictors of anticipatory grief with the PGAC scale. The PGAC scale had seven components, consisting of self-awareness, coping to diagnosis, physical discomfort, impact of religion or faith, social support, and unhappiness, and resentment (Mystakidou et al., 2006). One major predictor was age with a notation that younger cancer patients had higher levels of fear of death than older patients.

Using the PGAC scale and the Impact of Events Scale-Revised, Tsilika et al. (2009) performed a further analysis of demographics and clinical indicators. A gain existed between the low quality of life of the patient and high levels of anticipatory grief. Also, a strong correlation occurred between symptoms of PTSD and anticipatory grief symptoms (e.g., sleep deprivation, anger, and denial of current physical or psychological condition).

Although, few, if any studies, existed on anticipatory grief with the ESRD population, studies and discussions were available about end-of-life issues. Cohen et al. (2001) explored the experience of a patient, who withdrew from dialysis treatment. The purpose of the case study was to explore the definition of the quality of death or what is deemed a *good death*. The Dialysis Discontinuation Quality of Dying Tool consisted of three domains: (a) physical discomfort, (b) mental and (c) social capacities, and the length of time the patient lives beyond the discontinuation of treatment. Unfortunately, the tool was not useful for ESRD patients when continuing some form of dialysis treatment. Brown (2007) identified the need for palliative care for ESRD patients. The goal of this study was to ascertain the relevance and necessity for providing palliative care for ESRD patients to ensure presence of self-determination, respect, and autonomy. Mystakidou et al. (2007) performed a similar quantitative study, but used a different measurement, known as the Preparatory Grief Advanced Cancer Patient Scale, to analyze grief among advanced cancer patients. The goal of the study was to identify whether particular demographic indicators predicted the level of grief among cancer patients.

Quantitative studies were also useful in investigating depression among ESRD patients. Makara and Koslak (2011) studied the prevalence of depression with ESRD patients with those who did not have renal failure. The authors provided the Beck Depression Inventory to 323 ESRD patients and 200 non-ESRD patients. The symptoms of depression occurred an average of 85% among the ESRD patients, as contrasted to

45% of the Non-ESRD patients. Khalil and Frazier (2010) analyzed, compared, and contrasted 44 quantitative studies on depression with ESRD patients, who were non-adherent to dietary restrictions. They concluded a strong correlation between depression and health outcomes, which was greatly impacted by adherence to treatment.

Despite the various research approaches discussed, the growing need to understand the life experience of a dialysis patients and how they perceive their own death would be greatly beneficial. Several researchers have performed studies to increase the awareness of the dialysis interdisciplinary team's role in addressing dialysis patient's end-of-life issues. To truly capture the voice of the patient, the in-depth interview approach using narrative inquiry confirmed the quantitative studies and also stimulate further research of anticipatory grief.

Summary and Conclusions

The literature review consisted of an examination of the outcomes from both quantitative and qualitative approaches, related to depression, quality of life, and anticipatory grief. Additionally, the focus was on the analysis of variables essential to this study. Depression was prevalent among ESRD patients, but similar symptoms appeared as grief. Although, the studies on anticipatory grief had samples of cancer patients, the subject was broad enough to reach beyond to other chronic diseases, like ESRD.

The reoccurring themes that seemed to be surfacing were ESRD patients experienced depression and their quality of life stifled by the psychosocial factors. It appeared that ESRD patients, who had depressive symptoms, might be actually displaying signs of anticipatory grief. Consequently, no studies existed to explore whether ESRD population experience anticipatory grief. Therefore, there is a gap in qualitative research to explore the experience of ESRD patients related to anticipatory grief.

Chapter 3: Research Method

Introduction

The purpose of this case study was to explore ESRD patients' experience of anticipatory grief while receiving hemodialysis treatment. I used qualitative case study approach with a narrative inquiry design in which I interviewed patients who had been receiving hemodialysis within 3 months to 15 years. My goal was to observe any changes within their experience with death, grief, and loss from an anticipatory grief perspective. The approach was most appropriate because it allowed me to explore a phenomenon experienced by a described set group of individuals within a common established place. Colorafi and Evans (2016) stated that a

> qualitative description is especially amenable to health environments research because it provides factual responses to questions about how people feel about a particular space, what reasons they have for using features of the space, who is using particular serves or functions of a space, and factors that facilitate or hinder use. (p. 17)

Therefore, the interview questions were constructed to allow the participating patients to describe their feelings and perceptions about their diagnosis of ESRD, as well as thoughts of death and dying under the premise of anticipatory grief. I was able to scrutinize the responses to the in-depth questions to discover possible themes within the given context (Yin, 2018). This chapter contains a description of the research design and approach, participants, sample size, instrumentation, and data collection and analysis processes.

Research Design and Rationale

RQ1: How do ESRD patients undergoing hemodialysis treatment describe experience with anticipatory grief through expressing loss and death?

RQ2: How do ESRD patients undergoing hemodialysis treatment explain their perception of anticipatory grief at different points of time of their diagnosis and treatment?

In this study, I explored the experience of anticipatory grief among ESRD patients who have chosen hemodialysis treatment as a renal replacement therapy. I chose a qualitative case study approach to achieve this purpose instead of quantitative or mixed method. Using quantitative approach would produce more generalized conclusions with this population, but my ability to explore dialysis participants' perception of having ESRD and being on dialysis treatment as well as possibly experiencing the phenomenon of anticipatory grief would be inhibited (Yin, 2012). Also, although use of the quantitative method would have allowed me to determine the prevalence of anticipatory grief, it would not have allowed for an in-depth understanding of the emotions and experiences of the phenomenon. A researcher using a mixed-methods approach combines quantitative and qualitative approaches to address the RQs (Schoonenboom & Johnson, 2017). An exclusive qualitative approach was more appropriate compared to the mixed-methods approach because it allowed me to discover the complexity of the patient's view of the anticipatory grief phenomenon related to their life on dialysis. Gilliam (2010) emphasized how qualitative methods allow researchers to observe specific environments with limited previous study. Because little is known about anticipatory grief among dialysis patients, this study met the criteria of a qualitative case study on the continuum inquiry. Without the ability to have a narrative-style interview with the patients. I would not have been able to obtain an expanded observational view of anticipatory grief as an event on the spectrum of the dialysis patient experience.

McLeod (2010) stated that the case study design is the best approach to understand theories and recommended having several distinctive cases to discover various aspects, not just one perspective. In this study, I discovered the possible phenomenon of anticipatory grief with dialysis patients. McCleod (2010) noted that when a practitioner wants to persuade colleagues to consider an important concern, such as anticipatory grief, then it is most beneficial to not just write a narrative account but to provide case examples. Because I explored anticipatory grief as a theoretical framework, then the study was a “theory led” rather than a “theory generating” case study (Simons, 2009, p.12). My goal was not to develop the theory of anticipatory grief; instead I wanted to consider this theory as it relates to dialysis patients.

In this study, I discovered prevalent themes by conducting interviews with hemodialysis patients regarding their experience with ESRD and thoughts of anticipatory grief. Gilliam (2010) asserted that the resourcefulness of a case study broadens the researcher’s opportunity to delve into an individual’s perspective from their vantage point. Hottenson (2010) used the case study approach to explore anticipatory grief in cancer patients to help professional caregivers have a better understanding on emotional support strategies and interventions. Therefore, it was applicable to use the same research design to grasp the complexity of anticipatory grief with ESRD patients.

Conducting a collective case study created an opportunity for me to explore several dialysis patients who were experiencing ESRD. Heale and Twycross (2018) pointed out that case-study researchers can view different cases as one entity, while comparing the distinctions and commonalities, which will reinforce the reliability of the study. Schrank (2006) defined a case study as consisting of “interviews with key informants, surveys of representative populations of actors, archival materials, observations by participants (ethnographies), or any other widely accepted source” (p. 2). However, the goal in this case study was to focus more on participants’ story, rather than medical documents or responses scripted questionnaires. Instead of gathering demographic information from medical records, I asked the patients set questions to provide the same information with freedom to elaborate as warranted. Gilliam (2009) agreed that the case study approach is most beneficial when the researcher can collect as much data as possible to understand individuals or a group. Yin (2018) further explained that having multiple cases will allow more inferences, which will reinforce the themes and findings. With the interviewing process in this study, I was able to elicit the participating patients’ perception of their current medical state and how they viewed their own mortality amid changes due to ESRD.

A case study, according to Heale and Twycross (2018), is “an intensive, systematic investigation of a single individual, group, community or some other unit in which the researcher examines in-depth data related to several variables” (p. 7). This study could have been based on one dialysis patient; I included 10 patients with two common variables pertaining to their diagnosis and treatment regimen. Saldana (2014) noted that the collective case study allows researchers to explore distinctive experiences and points of view within the same context. This study afforded me the opportunity to examine different individual cases based on their anticipatory grief experience on the dialysis life spectrum. By asking open-ended interview questions, I was able to gain a better understanding the dialysis patient experience and achieve the objective of the study. The context of the interviews was clear and consistent, yet the responses obtained came from a plethora of experiences within and outside participants' diagnosis and treatment. Yin (2009) noted that using open-ended questions in participant interviews provides an in-depth understanding of the participant perspective, which is not possible when giving responses to surveys or questionnaires like a quantitative survey method.

Gilliam (2010) provided reasons why the qualitative approach is the best method to answer the RQs. First, he affirmed that the way to understand a person's perception is by analyzing them within their environment, such as the dialysis setting. Gilliam also pointed out that the quantitative method leads researchers to results, but not a better understanding of a person's experience. Therefore, the qualitative case study approach was an optimal method to grasp the true dialysis experience of a patient as they grappled with loss or accepted their impending death.

Role of the Researcher

I reviewed the literature to support the use of a qualitative approach using case study design. As a researcher in this study, I became the conduit through which information was gathered by journeying with the patient as they narrated their story, while I navigated through the meanings. Karagiozis (2018) shared how the interviewer plays a vital role with the interviewee by developing a connection, while being cognizant of the flow of the questions and potential pivots in the story as the person attempts to make impressions of their own experiences. The discussion of death and dying created several emotions based on experiences within the context of working in a dialysis facility as well as personal loss of a loved one. Rowling (1999) noted that the challenges of researching on such a sensitive topic as death and dying with the possibility of creating heightened emotions for researcher. So, it was important to maintain the distance as a researcher with a goal to hear the story, while not actively engaging in the narrative. Probst (2015) approached this topic by acknowledging the potential for reflexivity, which occurs when the researcher's connection with the case or interviewee's responses affects them personally. Probst noted that a researcher can address the issues stemming from reflexivity through ongoing self-examination.

To promote consistent findings, I functioned as the primary interviewer, data collector, and data analyst. I am an employee of Fresenius Medical Care and supervise the social work department, which provides psychosocial services to dialysis patients in outpatient facilities. To minimize the possibility of preconceived ideas from my experience as a social worker, I chose patients outside of my direct practice in other geographical areas within South Carolina. Therefore, I did not have any professional or personal connection to the identified patients, because I did not provide direct patient care.

I minimized the potential for researcher bias and power within the researcher and subject relationship by following the ethical guidelines in consent and research standards and respecting privacy and confidentiality. The participants had the power to determine their level of involvement throughout the entire study with informed consent. My responsibility was to follow the interviewing techniques to direct the study. The entire case study was facilitated by me with answering the RQs as the defined objective.

Methodology

Participant Selection Logic

The research population consisted of ESRD patients, who had started dialysis treatment within 3 months and 15 in South Carolina. Fresenius Medical Care currently has approximately 2200 dialysis facilities divided into two division, East and West, in the United States. The East Division has further subdivisions of 26 regions. The Columbia area is in the South Carolina Region with approximately 40 facilities. As of January 2017, Fresenius Medical Care Dialysis Company had a patient database for the South Carolina territory of approximately 2000 patients receiving treatment in their dialysis facilities (Fresenius Medical Care Quality Status Report, 2014).

Considering the critical thought related to the sample size for a qualitative case study, Boddy (2016) addressed the barriers that tend to impede on the determining a definitive number. Ultimately, he concluded the size will depend upon whether one's goal of the study. In this case, the goal was to obtain an in-depth view of the particular experience of dialysis patient, which occurred with one case study. However, I expanded the sample size to 10 participants based on the number of years with the commonality of same diagnosis and treatment modality. The goal was to be obtain enough rich and meaningful findings to prompt further research.

Instrumentation

The case study comprised of patient interviews via Zoom. The tools to obtain the audio recordings for transcription were created through Zoom and Otter ai. The interviewing process took approximately an hour to complete the 16 questions. Five of the questions were designed to obtain demographic and medical information, while the remaining were open-ended questions. Appendix A contains the interview questions for the study.

Procedures for Recruitment, Participation, and Data Collection

In this study, five of the dialysis participants have been on dialysis for between 3 months to 10 years, while the other five patients have been on dialysis between 10 to 15 years. The objective was to gather data by using participants, who are experiencing similar events, in this case all of the patients had chosen hemodialysis as their treatment choice. In this study, the participants had been referred by a nephrologist to be admitted into the outpatient dialysis facility for treatment because of ESRD. The exact number of participants were determined to ensure the patients' time on hemodialysis span between 3 months to 15 years to observe change in perception. After I obtained additional approval from Fresenius Kidney Care IRB Department, I sent a recruitment poster with my contact information to 10 social workers, in the South Carolina area, to post in the patient dialysis facility lobby requesting participation in the study (see Appendix B). Once contacted by the potential participant, I explained the purpose of the study and obtained verbal consent. Next, I scheduled an interview with the participant to be facilitated on a day they were not receiving dialysis treatment to be completed by Zoom conference call or Zoom virtual conference. The consent included a written explanation that the participation in the study would not impact their dialysis care provider relationship.

Due to the sensitivity of the subject, I informed the patient during review of the consent that should contact their facility social worker for further discussion and support related to grief or end-of-life issues. I chose to notify the facility social worker prior to the interview to re-ensure confidentiality. However, I did provide a brief description of the topic to be discussed for the patient's review to minimize discomfort and increase preparedness for the discussion.

Upon approval from Fresenius Medical Care Research Department and the Walden University IRB, I sent flyer to 10 facility social workers to place in the patient dialysis lobby. The participant received a detailed explanation of the study and its purpose, as well as confirmed confidentiality and privacy. No identifying information was maintained on the participants. Instead each patient was assigned an identified coded number in the study. The interviews were saved on password protected documents on a Microsoft OneDrive that are maintained in a secured location for 5 years after completion of the study, then it will be deleted.

The participant had a right refuse to be interviewed at any time during the study period. The aim was to ensure no harm to the patients, as a result of participating in the study. To preserve the participant's identity, the data validating the identity will be held for 3 months after the defense of the study for questions related to the participants.

The sample and population for this study were based on one population, ESRD patients, who had received hemodialysis treatment. All 10 participants came from a dialysis outpatient facility in the Columbia and surrounding area. Gender, race, age, income, or comorbidities were not determining factors in the selection of the 10 participants. The patients had to be English speaking and cognitively stable to participate. The families and support systems did not participate in the study. However, the participants were asked question about their family and social support. The interviews were based on the patient perception and thoughts of their own impending death and experience of anticipatory grief. The participants interviews were recorded electronically through Zoom, transcribed using Otter, saved onto password protected Microsoft Word document, and then coded using password protected Microsoft Word and Excel spreadsheet. The instrument for the case study was an interview protocol. The purpose of the data was to determine if common themes would emerge from the dialysis patient interviews.

Data Analysis Plan

The interview sessions occurred via Zoom conference calls based on participants' choice and obtained through audio taping using Zoom. I asked for permission to audio or video record the conversation for purposes of transcription. The sessions from the audio recordings were transcribed using Otter, then transferred into Microsoft Word, and lastly transferred into Microsoft Excel for a data analysis. I was careful with categorizing and identifying themes within the coding method. Since the patients had distinctive perspectives, I listened for similar phrases or sentences to create codes. After the interview had been transcribed in Otter ai, I transferred into a Microsoft Word document, then I added line numbers to each line as reference to coincide with the words noted in the Microsoft Excel spreadsheet. Meyer and Avery (2009) stated that Microsoft Excel can be used within qualitative analysis for the purposes of coding and analysis. Excel has several features that allows the researcher to sort and filter, as well as track and trend data with adequate visualization. With the guidance provided by Walden University (2016), I was be able to utilize Excel to implement the cycle coding method to compartmentalize the data for further analysis to identify themes and meanings. As a part of the coding process, the first cycle of coding will identify themes based on the questions from each participant (Walden University, 2016). The second cycle of the descriptive coding focused on each question across all 10 participants to isolate any patterns based on the interpretation of responses. After the completion of the coding process, I gathered all of the cycles to assist with the summarization for final analysis.

Issues of Trustworthiness

In order to govern the trustworthiness of the data, I compared the data to similar peer reviewed articles. I also performed a thorough review of the transcription of the interviews while listening to the audio recordings to establish findings. It was also imperative to minimize the tendency to make assumptions based on my experience with the dialysis population. Therefore, my goal was to link the peer-reviewed literature to the data obtained from the study.

The trustworthiness was also maintained by ensuring the transcripts are correct for analysis and interpretation. Connelly (2016) explained how credibility can be reinforced by not only following up with the participant to ensure the information was interpreted correctly, but also the researcher should journal their own thoughts about the interviewee’s responses. Since, I did not follow up with each patient to review transcriptions following the interviews, I maintained a journal to document my thoughts after the interview and after completion of the transcription. Also, in order to reinforce transferability, I reviewed the audio recordings at least three to four times to ensure I had not omitted any detail from the interviewee’s responses.

Ethical Procedures

I protected the rights of the participants by neither disclosing names of patients, nor their dialysis facility. Since the treatment had the consent of the respective dialysis facility based on physician orders, no risks existed for participating in this study. I informed the patient the information gathered did not impact their care or services provided by the Fresenius Medical Care staff. The patients did not face disclosure of personal information, unwelcomed solicitation or imposition of privacy, or financial loss. The patients were given my contact information to discuss any concerns or questions that might occur during or after the interview.

Although I serve in a management capacity for Fresenius Medical Care, the sample population did not be under my direct care. Therefore, the patients did not experience any coercion to participate in this study. The data collected was in the form of interviews transcribed from audio recordings. The participants did not have access to the recordings following the interviews.

My goal was to ensure all ethical safeguards were adhered to within the study. I assigned each patient an identified number to protect their identity with the date of the interview. The participants were all dialysis patients at Fresenius Medical Care. To comply with Fresenius Medical Care guidelines related to research. I submitted a proposal and completed and obtained certificates for the required CITI Principle Investigator and CITI Good Clinical Practice Trainings. As a result, I obtained approval from the company's research committee and each dialysis facility's governing body, which is comprised of a Director of Operations, Medical Director, and Clinical Manager. After obtaining the company's approval as well Walden University approval number, which is 08-27-20-0087666. I was able to begin distributing the recruitment posters for volunteer participants by mailing them directly to the facility social workers. To protect the participants autonomy, I was unable to contact the participant until their initiated contact by email or phone. Before beginning each interview, I reviewed the informed consent and reiterated the participant's right to refuse to answer any questions or terminated the interview at any time. By following Walden University and Fresenius Medical Care proposed ethical guidelines, the participants were not exposed to any harm. However, due to the sensitive topic, they were instructed to speak with their dialysis social worker if they had any concerns related to grief and loss. Lastly after collection of the interview data, the audio recordings from Zoom and Otter ai were deleted and the transcriptions are stored in a password protected One Drive.

Summary

In this section, information included the research method and approach, research questions, the setting and sample, instrumentation and materials, the data collection, and participants' rights are presented. A qualitative case study approach was the best design to address the research questions. This design allowed me to explore the dialysis patients' perceptions related to their own death and experience of anticipatory grief. The data collection instrument was comprised of a list of interview questions. Due the COVID pandemic, the setting was Zoom conference calls with 10 patients, who chose the location where to have the interview. The sample was ESRD patients who had been on dialysis between 3 months and 15 years. In Chapter 4, I will discuss the data obtained from the interviews and describe the common themes. Chapter 5 will encompass a summary, conclusion, and recommendations.

Chapter 4: Results

Introduction

The purpose of this qualitative case study was to understand how anticipatory grief was experienced by individuals with ESRD who are currently receiving hemodialysis treatment in an outpatient facility for at least 3 months and less than 15 years. I collected data through semi-structured interviews with 10 participants who met the criteria. After completion of the transcription process, I performed the coding process and analyzed the data by theme identification. In this chapter, I provide a synopsis of the conclusions from the participant interviews. I restate the initial RQs and explain the participant selection criteria and ethical considerations. Next, I define the data collection, recruitment, and data analysis. The chapter concludes with evidence of trustworthiness and presentation of thematic findings. The two RQs in this study were

RQ1: How do ESRD patients undergoing hemodialysis treatment describe experience with anticipatory grief through expressing loss and death?

RQ2: How do ESRD patients undergoing hemodialysis treatment explain their perception of anticipatory grief at different points of time of their diagnosis and treatment?

Setting

I facilitated each interview for this case study in Columbia, South Carolina, dialysis facilities. I began interviews on December 12, 2020, and the final interview was held on July 18, 2021. Each participant was given the option to participate via Zoom with video or by phone. All participants decided to meet for a Zoom conference call. The participants provided me with the best time for the interview, which were on a day they did not receive hemodialysis treatment.

Demographics

I did not require participants to provide any demographic information, such as gender, age, or race, as confirmed in the consent form. The length of time the participants had been diagnosed with ESRD ranged from 6 months to 24 years. As mentioned, I excluded other demographic information, including the name of the dialysis facility, from my data collection to ensure confidentiality. The data collected from the interviews included participants' cause of renal failure, length of time on dialysis, the cause of renal failure, other comorbid conditions, initial concerns and feelings of ESRD, experience on ESRD, family relationships, and topics related to death and dying. Gathering these data assisted me in responding to the RQs.

I assigned a number to each participant to replace their names. A description of each participant follows:

- 12.10.20_Dialysis_121P: A hemodialysis patient who has been on dialysis for 5 years. They self-reported that the cause of their ESRD was high blood pressure with no other comorbid conditions. They are married with four children, including a disabled child requiring total care. Due to health decline, they were unable to maintain a full-time job.
- 12.18.20_Dialysis_141P: A hemodialysis patient who has been on dialysis for 1 year. They self-reported that the cause of their ESRD was diabetes. The other medical conditions stated were hypertension post-ESRD diagnosis, as

well as neurogenic bladder requiring a nephrostomy bag. They are disabled and unmarried with four adult children, including one son who passed away at birth.

- 12.17.20_Dialysis_151P: A hemodialysis patient who has been on dialysis for 3 years. They self-reported that the cause of ESRD was diabetes with no other comorbid conditions. They are currently retired and married with adult children.
- 07.06.20_Dialysis_161P: A hemodialysis patient who has been on dialysis for 14 years. They self-reported that the cause of ESRD was polycystic kidney disease. The other historical comorbid conditions stated were kidney cancer and diabetes, which are not currently active. They had several family members who also were previously on dialysis, including their mother. They are retired and married with adult children.
- 07.06.21_Dialysis_171P: A hemodialysis patient who has been on dialysis for 8 months. They self-reported that the cause of ESRD was diabetes and overuse of Naproxen for pain with no other comorbid conditions. They are retired and married with one adult son. Although interested in transplantation, they currently due not qualify due to calciphylaxis.
- 07.12.21_Dialysis_181P: A hemodialysis patient who has been on dialysis for 5 years. They self-reported that the cause of ESRD was hypertension. The other comorbid condition stated was congestive heart failure. They are single

with one adult son. They are disabled and unable to work due to ESRD complications.

- 07.08.21_Dialysis_201P: A hemodialysis patient who has been on dialysis for 5 years. They self-reported that the cause of ESRD was high blood pressure and diabetes, as well hypertension medication usage while pregnant with no other comorbid conditions. They are still working full-time as a teacher and are single with three children under the age of 18. The patient is interested in transplantation but does not qualify due to weight.
- 07.08.21_Dialysis_211P: A hemodialysis patient who has been on dialysis for 2 years. They self-reported that the cause of ESRD was diabetes and hypertension. The other medical condition stated was being legally blind. They are disabled and single with no children. However, they deemed their siblings as their primary support system.
- 07.08.21_Dialysis_231P: A hemodialysis patient who has been on dialysis for 3 years. They self-reported that the cause of their ESRD was diabetes. The other comorbid condition stated was chronic obstructive pulmonary disease. The patient is retired with a significant other. They noted one adult daughter, who needs total care due to a stroke.
- 07.18.21_Dialysis_241P: A hemodialysis patient who has been on dialysis for 9 years. They self-reported that the cause of their ESRD was focal segmental glomerulosclerosis. The other comorbid conditions stated was high blood pressure and gastroesophageal reflux disease. They work full-time remotely

due to COVID-19 and are single with no children. They are interested in transplantation but do not qualify due to weight.

Data Collection

For this qualitative study, I interviewed 10 patients who had ESRD and had been on dialysis for more than 3 months. I used the interview outline with open-ended questions for all participants. As mentioned by Howsen (2021), in-depth interviews create an opportunity to explore an individual's perspective on a personal subject with use of open-ended questions. I applied the guidance given by Mahat-Shamir et al. (2021), who noted that the format of semistructured interviews allows the researcher to extrapolate themes related specifically to their understanding of loss. I used a similar method to craft the interview questions.

After obtaining permission from each of the 10 dialysis governing bodies, I displayed a poster in the facility lobby of different approved outpatient dialysis facilities in the study, which provided a brief overview of the study, along with eligibility criteria and contact information. The contact information contained my Walden University email address and a temporary Google number. When the participant volunteered to be interviewed, I reviewed the purpose of the study and sent a mailed copy of the informed consent. Once the signed informed consent was received, I scheduled the interview based on their preference of Zoom virtual or Zoom conference call number. Each participant preferred to use Zoom conference call only. I audio recorded each interview using Zoom. The length of the interviews spanned from 15 minutes to 55 minutes, with a comprised total of 284 minutes. The Zoom recordings were automatically transferred to Otter.ai for transcription purposes. Then, the recordings were identified by the assigned number with no demographic information. I transferred the audio files to my password-protected computer and to Microsoft One Drive and deleted audio files from Zoom, as well transcriptions from Otter.ai.

I recruited participants by having social workers display the posters in the dialysis facility lobby. The participants were all receiving hemodialysis treatment from one of the participating facilities in the Columbia, South Carolina, area. I was able to recruit five participants who had been dialysis between 3 months to 10 years. The other five participants had been dialysis for 10 to 15 years. One participant had been on dialysis for 24 years. I interviewed 10 of the 11 people who volunteered to participate in the study. One volunteer had not been on dialysis long enough to participate in the study.

Before initiating the interview, I reviewed the informed consent form in its entirety with each participant and extended time to answer any questions or address any concerns. I also reiterated that any questions related to their emotional distress due to the topic could be addressed by their facility social worker. The scanned signed informed consents were saved in a password-protected file on my personal computer. I facilitated the interviews via Zoom conference call at a scheduled time chosen by the participant. Also, before beginning the interview, I obtained oral consent to record. As stated, all transcriptions were saved on my personal computer in a password-protected documents in a Microsoft One-Drive. After each interview, I documented my initial thoughts and feelings to examine my intent and perspective of the participant and their responses.

After completion of each interview, I confirmed that the bridge between Zoom and Otter.ai had occurred to perform the initial transcription. Then, I saved a copy of the Otter.ai transcription in Microsoft Word to begin the second round on transcribing. I reviewed each Otter.ai transcription, while listening to the recording to make any corrections necessary. Then I began the coding process using Microsoft Excel and Microsoft Word.

Data Analysis

The purpose of this qualitative case study was to understand the experience of ESRD patients who were receiving hemodialysis. I also explored their initial thoughts and feelings about having this medical condition. I sought to grasp participants' experience of their loss from an anticipatory grief perspective. With this understanding, I sought to identify the potential gap in service provided by the dialysis interdisciplinary team related to end-of-life issues with the patient. To alleviate any research bias, I did not include any participants who I may have served as their social worker. I chose facilities that I had never worked in during my professional career.

During the initial phase of reviewing the interview responses, I performed a deep dive into the transcriptions daily and listened to the audio files to familiarize myself with the data. Following process outlined by Saldana (2016), I focused primarily on identifying descriptive codes by rereading the participant phrases. The coding process promoted the perspective of the "five Rs" mentioned by Saldana (2016), which I was able to find meaning specifically pertaining to relationships, routines, and roles. As a dialysis social worker in this field for more than 20 years, I distinctively began to clearly observe themes among the first four to six participants. I assessed the data from the theoretical lens of anticipatory grief and loss proposed by not only Shore (2016), but also Rando (1986, as cited in Patinadan et al., 2020). Also, as recommended by Yin (2009), I began to confirm between the research questions to answered by the interview data.

In the beginning phase of cycling coding, after transferring the transcriptions into an excel spreadsheet, I reviewed the data several times and identified emerging descriptive codes derived from the interview guide (Stuckey, 2015). I chose a deductive approach by initially forming “pre-defined codes”, which closely supported proposed literary framework (Linneberg and Korsegaard, 2019). The initial set of codes were documented and logged in a separate tab in the same excel spreadsheet (Ose, 2016). During the second cycle of coding, I assigned descriptive codes by reviewing each statement as a segment extract collective meaning. With this level of coding, I discovered patterns by compiling the participant responses and categorizing them by each question. This step in the coding process allowed me to synthesize the data to infer new meanings separate from the individual participant (Ose, 2016). From the meanings, I was able to achieve six emerging themes. Miller (2020) instructed the themes be clearly defined for further analysis of the narrative.

In the developmental stage of the data analysis, Braun and Clarke (2006) estimated one of the advantages of thematic analysis is to compare the themes with the presented theoretical framework. Therefore, I began to equate the definitive themes with the anticipatory grief theory. This study anticipated potential experiences of loss and grief by the dialysis participants impacted by ESRD. The participants used phrases such as “I had fear of the unknown", "I thought my life was over", and "I'm finna die". These statements contributed to the second cycle of coding before I began interpreting the data. However, there were some rival phrases that tended to compete with the base theoretical framework. For example, two of the participants made the statement, "don't depend on nobody for nothing" and "I can do what I was doing before", which eludes to the limited loss in their independence. Yin (2012) noted that it vital to search for rival explanations to add complexity to the research. With my knowledge in the field, I had to acknowledge the challenging thought of dialysis improving one's quality of life. However, it was not a continued explanation across all 10 participants. After a thorough analysis of the data, I created broad summarizing codes to formulate the themes.

Evidence of Trustworthiness

Credibility

Connelly (2016) explained credibility can be attained in a qualitative study when conclusions can be trusted. I made every effort to safeguard credibility by taking necessary actions to decrease any personal biases. The trustworthiness was reinforced by remaining constant with the proposal and outlined protocol approved by the IRB. Also, I reviewed similar peer-reviewed articles related to end-of-life issues with ESRD patients (Connelly, 2016). To address potential biases, I maintained a journal of my own thoughts about the responses given after each interview and following review of the transcription. I reviewed the audio recordings and transcriptions four to five times to guarantee I had not missed in crucial details from the interviews. Lastly, I provided direct quotes to validate the emerging themes.

Transferability

Korstjens and Moser (2018) emphasized the importance of providing as much detail about the participants for other researchers to compose new constructs with comparable theoretical frameworks. Therefore, I provided valuable descriptions of each participants' interview responses and themes. Also, I implemented the concepts of prolonged engagement and persistent observation to reinforce the credibility by integrating follow-up questions as well as, re-reading and performing cycling coding of the data (Korstjens and Moser, 2018). These actions were taken to reaffirm the transferability of the study.

Dependability, and Confirmability

It was also important the dependability and confirmability were affirmed to ensure consistency with an unbiased approach. Even though I had a small group of participants, which could pose a challenge to dependability. I intentionally recruited from different dialysis facilities and patients with various lengths of time with ESRD. While exploring their personal journeys on hemodialysis, I was able to gather multiple perspectives related to their experiences with rich history. Also, as stated, I maintained a journal to reduce the influence of my potential bias or opinions and create an audit trail (see Korstjens and Moser, 2018). My audit trail was not only comprised on journal notes, but also the transcripts, data analysis, and process notes (Cope, 2014). All of these research activities upheld the ultimate goal of trustworthiness and credibility of the study.

Ethical Considerations

To ensure all ethical considerations were sustained, I reflected on previous dissertation chapters. Also, before data collection was initiated, approval of my research study and consent forms was obtained from the Walden University Institutional Review Board. The IRB Approval for this study is (08-27-20-0087666). My study protocol was not only vetted by the University but also Fresenius Medical Care Research Review Board and approved by each dialysis facilities governing body. I adhered to all ethical protocols accepted by both ethical review committees. One main consideration was related to my relationship to the participants, since I work for the large dialysis company, from which they receive treatment. Therefore, I ensured I had not provided direct services within the selected dialysis facilities. Sanjara et al (2014) asserted the importance of taking such actions to warrant autonomy of the study.

Results

The objective of the qualitative case study was to grasp an understanding of the experiences of hemodialysis patients with ESRD as it related to anticipatory grief and its potential impact on the interdisciplinary team’s service delivery. After completion of an in-depth analysis of the data with the process of assigning pre-defined codes and descriptive codes, I created two categories to assign the themes.

The first category was the initial experience of anticipatory grief to address the primary research question. The question was how do ESRD patients undergoing hemodialysis treatment describe experience with anticipatory grief through expressing loss and death? The participant responses to this question exposed the complexities around the narratives of being informed of ESRD and the required treatment. It also created a space for the participants to be transparent about their first thoughts and concerns, in which fear, depression, and frustration were constant themes. Within this space, the secondary category addressed the following research question, which is how do ESRD patients undergoing hemodialysis treatment explain their perception of anticipatory grief at different points of time of their diagnosis and treatment? The participant's responses to how ESRD has influenced their life highlighted loss of independence and control, and perception of their own death.

Despite the small sample group, the various responses alluded to repetitive and common meanings that the participants stated when speaking of their initial experiences on dialysis. I was able to categorize the major themes that surfaced from the deductive coding process. I unearthed candid statements from the interview discussions with the participants and inserted some of the responses within the study to complement my discoveries for the purposes of validity. In this section, I summarized the progression of the cycling coding from the predefined codes and descriptive codes to a theme with the process of deduction.

First Category (Initial Experience of ESRD)

Theme 1: Fear of Unknown

The first theme emerged from the initial experience of ESRD was the daunting fear of the unknown. The participants narrated how they were informed of their diagnosis and treatment. Although the beginning of their journeys varied, the experience of shock from the loss of their kidney function and the need for dialysis treatment continued to surface. Some of the patients noted they knew dialysis was in their imminent future but were jolted when it became a reality. Also, the participants continued to express the fear of what would become of their life and their future.

12.20.20_Dialysis_121P noted the following:

> He (the nephrologist) put me on dialysis. And I was shocked because I went from working and thinking I'm going to the doctor just to get a checkup and they told me my kidneys failed. And I was like, whoa, it took a lot from me because it just hit me all at once. I didn't have enough time to prepare for it like a lot of people.

07.08.21_Dialysis_201P) shared a similar experience by stating:

> It winded me for a minute, you know, like I said, I had to start to process. Okay, so how is it going to work and will I still be able to have my job. You know at the time, in my 30s still I was thinking I'm not even 40 so how is this happening until, you know, you're 70-80 years old. And it just was a lot all at once.

12.18.20_Dialysis_141P simply expressed their fear of the unknown by stating, "everything is unpredictable…it was a like a blind date".

07.18.21_Dialysis_241P supported this fear by stating:

> I understand that my kidneys are not able to flush out the toxins, so I need dialysis. I had to look for that information because no one was forthcoming. Even in the hospital they just said you are starting dialysis and really didn't give a lot of explanation of what all that meant. So, I didn't know if that was indefinite or just a short period of time.

Two other participants voiced their fear of unknown by speaking of possibly not having a family or having decline in health to the point of being bedbound. One participant provided an analogy to explain the fear of every treatment by saying,

> It's like a crackerjack box, you don't know what you are going to get. Sometimes you don't have your good days, you will have a bad day. Some days you go in and you get on the dialysis machine, you won't feel good. You won't your treatment to go well but some days, your blood pressure may dry you out or you might cramp, or you just might not feel good, so you just don't know how you're going to get there and go on the machine.

Theme 2: Overwhelmed and Depressed

When analyzing the data to explore the various feelings experienced by the participants with ESRD. Two re-occurring themes that seemed to co-exist within the responses given to the questions related to their initial experience were feelings of being overwhelmed and depressed. The participants continuously use these two phrases multiple times but also signs of depression resonated throughout the discussion, such as guilt, regret, shame, and loss of self. For example, one participant spoke with her role of pianist at her church. However, she stated "I don't feel like I've got that time anymore, since I'm doing dialysis three days a week". She followed up to expressing her how she gave up the piano and feels guilty because the church wants her to return. Another participant expressed regret of time wasted by noting, "I lost a lot of that before dialysis. I really did because it's like these last five years were the worse five years of my life.

12.17.20_Dialysis_151P also mentioned, “I was very emotional and was so overwhelmed that I lost all of my hair”

07.12.21_Dialysis_181P communicated that they were “devastated…and when he (MD) told me I had to on dialysis. I cried”.

07.08.21_Dialysis_211P also stated “I had moments where when I first came out of the hospital when they gave me a catheter in my neck that really bothered me. And one morning I just broke down and cried because it was overwhelming.

07.06.21_Dialysis_171P talked about being depressed due to regret. “If I’d taken better care of myself, I probably wouldn’t be in this position”.

07.08.21_Dialysis_201P mentioned being overwhelmed with the strict regimen. “You can’t win for losing. Every time I open my mouth, I have to think about what I’m eating and drinking”.

07.18.21_Dialysis_241 went into detail about how her depression has impacted her socially due to fatigue and self-image.

> It can be very overwhelming. It is on my mind every day. I just found myself being less social because I didn’t want people to ask my questions. I’m just so tired all the time and don’t feel like doing anything. I hate going out because I feel like I have let myself go. I don’t get my hair done like I use to and I don’t want people to see me like this. Even this weekend, one of my friends had a party and I didn’t go because I didn’t want to have them look at me. I’m sure it’s more me than them but I just

> don’t want people seeing me look worn out and tired. Even at work I feel like people use my illness to define me.

One participant provided a detailed experience of regret and depression that led to lasting consequences. They emphatically refused the physician orders to have fistula placement in their arm because of concerns with body image. This participant specifically said,

> My issues with self-image cause me to make horrible, horrible decisions, we put it that that led to issues I could have avoided, had I made the correct decisions in the first place. I was like I don’t want a fistula because I’m not getting ‘popeye’ arms. I just wasn’t going to do it.

The long-term use of catheters caused infections. The severity of the infections required heart surgery, which cause even more scarring, which impacted body image. This participant continued expressed regret by stating, “I ended up having disfigurement anyway. So, I did all of that to avoid something that was unavoidable”.

Theme 3: Frustration

Many of the participants admitted their frustration with the initial experience of ESRD. The reasons for the frustration were rooted in feeling imprisoned by the required treatment regimen, but more importantly the massive changes that impacted their very existence. One participant described their frustration by saying, “Before, I had dreams and ideas of things I wanted to do but I’m afraid to commit because I don’t’ know I feel from day to day”.

12.28.20_Dialysis_141P expressed their difficulty in adjusting to all of the life changes:

My eating habits really changed. And I love to work and when I wasn't able to work that really changed my life a lot. Because I'm a person that loves to get out there and work and I had been on my job for 25 years. It was a slap in the face. All of that changed my life. It was like a change in the blink of an eye.

12.10.20_Dialysis_121P stated:

I was really frustrated because I stayed sick a lot. I have to eat a whole different way. I was used to eating fries and tomatoes and I really stress about this. I love to take trips. I can't do it like I used to because I got to like worry about getting my dialysis. I don't be up to doing that no more, because of my energy.

12.17.20_Dialysis_151P spoke of being frustrated with hindrances of dialysis:

My daughter had surgery and I know her. She's my oldest and I know how she handles pain really bad. I wanted to be there with her but I couldn't because the place that I did dialysis didn't have an opening. I couldn't leave without making sure they put in the paperwork and everything for dialysis. If they can't do it, and you can't find it, you can't go. I cried because that was first time I wasn't there with them.

07.08.21_Dialysis_201P explained her frustration with the kidney transplant process due to other co-morbid conditions:

My other diagnosis came to me in the middle of me trying to go on the transplant list, what would happen is I will go through the whole process, get almost to the end. And there will be something that the transplant surgeon was concerned about. They told me they didn’t want to put me on the list because I weighed too much. And the surgeon like you might even want to think about getting gastric bypass or sleeve and wait for that to other condition heal and then come back and try again. And there are certain regular general physical appointments you have to have like you have to have a pap smear and I want to say Charlotte (A transplant center) didn’t finish with me because I didn’t have a recent dental appointment. Well, we need a recent dental appointment for you to come back. Now mind you at that point I have to pay all these co-pays and get them done in a timely fashion and every time I would go back and do the stuff they'd asked me to do. It would be a year would go by. It would take me all year. And by the time I come back, you're like, Oh, well, this test has expired. Now you got to go back, and the test is higher, but you got to go back and get it within the last year. It's been more than a year. And that kept happening over and over and over again. Again, I'm missing work for this. But then they keep telling me No. And I was getting frustrated. So, I thought I haven't thought about the living donor process. I have had so many people who were willing to donate me a kidney but can't. My mother is a diabetic. My dad, I can't remember what's wrong with his kidneys. He can't donate one. My son’s father was going to donate one. Right when I told him that, I needed a kidney. Okay, so he was like I will get a physical? He got a physical and found out he is a diabetic and he didn't know it. I have two cousins willing to donate

> even in prison and he's had some other issues. So, he's not sure if he can even be suitable to donate. So, I don't have anybody

Second Category (Experience of Living With ESRD)

Theme 1: Loss of Independence

When I evaluated the participants' accounts of how they were living with ESRD over a period of time, the first theme that materialized was the loss of independence. During several of the interviews, the participants cited distinct examples of depending on their family to help with daily responsibilities and being faced with the decline of their own health over time. One of the participants noted, "I'm just so tired all the time". Two participants shared the loss of independence was more related to their decline in health caused them to not do much of anything.

> 12.10.20_Dialysis_121P responded to how ESRD had influenced their life over the last five years:
>
> Well, sometimes I do a lot because I got a disabled child, I got four kids and my last son was born disabled. I have to take care of him. And a lot of days, dialysis, if I have hard pull, then it be hard to take care of my baby. But thank God that I got my husband to take care of that him. But like I used to do it myself on dialysis, I could take care of him myself. But now, I need my husband to help me because dialysis have me so weak sometimes. Sometimes, I be so sick, my husband has to help me take a bath, he has to help dress me, my socks and stuff helped me put on. And some mornings, he has to totally take my bath. I be feeling so bad. He has to take my whole bath for me. So yes, I do have to depend on

people. And then so my mom, she will come sometimes. She will come help me. But I'm not used to it, because I'm used to doing things myself. It put a big impact on me.

12.17.20_Dialysis_151P stated they have communicated with their family the concern of being a burden due to decline in health:

If that's all you can do is put me in a nursing home, as long as you take care of me, make sure I'm getting what I need. I don't' have a problem with it. Don't ever think I will be upset because I won't. I lived my life made my decisions and I expect you to live your life. So I don't expect you to just give up your life to take of me. You do what you can do, make sure they're taking of me, if you can't do it.

07.06.20_Dialysis_161P spoke of independence as it relates to freedom:

Well it does change life because like when my wife's brother died up north. She could go but with I would have to find a kidney place to go to and we didn't really know about places up there, so changes your life a whole lot. And sometimes my kids want me to go places with them I can't go because I'm on kidney machine. It doesn't make since to have to go on a machine somewhere else for one day, so I usually stay home. Let them go on without me. I don't want to go to another place for dialysis and taking up time trying to find a place to dialyze because that just aggravates me, so I decide not go and my wife just stays home with me.

07.08.21_Dialysis_201P spoke of how kidney failure takes away your independence:

> As the disease progresses you urinate less and less, so then you're more and more dependent on your bowel movement to get rid of waste. So, if I'm not going to get rid of waste, when makes me even more dependent on the dialysis to really flush my body which is more wear and tear on my body, because it has to adjust to the machine to kind of pull on me harder to really clean me good.

Theme 2: Lack/Loss of Control

After divulging the way their independence had been loss due to ESRD, the participants also revealed the lack and loss of control as well. The participants indicated not having any control of over their treatment time and what even happens during the treatment. A participant mentioned having to wait to longer than the scheduled treatment time because of staffing or patient issues. Also, they spoke about not being able to go to restroom during treatment. While another participant shared how the dialysis treatments inhibits them from supporting their children's extracurricular activity.

07.08.21_Dialysis_231P stated:

> Now I get really weak, sometimes the legs won't allow me to do a whole lot of walking and stuff and I get real tired. And I wasn't like that before. But now that I be real tired from time I have to sit down and rest a little bit. And if I go from my garage into my kitchen and come back, it seems like I am worn out. And I only just went a few feet into the kitchen. But it (ESRD) just kind of slowed me down a little bit. I don't get out much anymore, just to dialysis.

07.06.21_Dialysis_171P reiterated the lack of control to participate in normal activities due to ESRD by stating:

And we love the pool, and I love being in pool, but it's hard for me to get in and out now. Taking care of it, he can't take care of it. So, I have had to bite the bullet. And I've had somebody to come and take care of it once a week. So that's working out well, because the grandchildren love it. And I want it to be there for them. I even got in one day with my little granddaughter. You know, you get inside. I have bad knees. And I had knee surgery on one and I need to have the other day done. But with this calciphylaxis (due to ESRD) I don't think they'll do that. And I got inside, but the water kept pulling down, and then trying to get out with a little bit hard. And they say it's really good exercise. You know, I can do my knee, knee therapy in there and it really, but getting out is a pain, so I haven't gotten back in. My son even looked into one of those things they have at nursing home that puts you in the water and pulls you back out. And I said yeah, right. 07.18.21_Dialysis_241P discussed how dialysis was barrier to their work and career. I was concerned about my job I wanted to still work but had to run five hours on the machine and I didn’t want people in my job to find out. I kept feeling like career growth was going to be limited because dialysis became my second job. Also, I feel stuck in my job because I don’t want to lose my insurance. I want to try something else but don’t want to chance it. So honestly, I don’t feel free to do what I want. I have limited choices about everything from what I eat to even going anywhere. Even when I look for jobs in other states, I have to think about is there a dialysis clinic there that can work with my schedule and run me for five hours.

Theme 3: Perception of Own Death

Although many participants appeared uncomfortable with the subject of death and dying, the emerging theme was still found in the narrative responses about their fear of death and thoughts of dying. I found this portion of the interviews to be most difficult for some of the participants based on their short responses. When I asked about advance directives, nine out of the 10 participants revealed they did not have one but felt they should get one at some point, believed their family should make those decisions, or provide a response based on their spiritual beliefs. Some of the participants made statements, such as “I just expect my husband to make decision”, “I hope that if I get in that shape the good Lord will just take me home”, “I guess you put it off. I just don’t want to have to deal with it right now”. One participant stated:

> End-of-life things are a little difficult. I’ve always had a normal apprehension about end of life. But it’s something I’ve been wanting to do. And every time I have a heart surgery and some of other major surgery that they always ask me, do you have one? We will make sure we provide you information. I have information on all of that and how to get that done. I just need to do it, just do it.
>
> 12.10.20_Dialysis_121P spoke of her spirituality:
>
> To be honest with you, I just keep saying I always talk to God. That’s how I prepare myself at night. I’m a strong believer in God. And I talk to the Lord, when I get ready to go and I say whatever it is, it’s Your will. Like a couple of months ago, I went to dialysis. I was feeling bad when I went in, I collapsed, and my heart stopped. They had to call the ambulance from dialysis and they rushed

> me to the hospital. I died four times, but I never gave up because I know God. God is good. I was on life support. Even the doctor told me when I cam back. He said, I don't know how you did that. You are a living testimony. I said I know. The God I serve is a good God.

12.17.20_Dialysis_151P responded:

> My kids talk about it because they just want to know. My husband is afraid and says those kids are going to be in control, so you need to tell them. You know, and my oldest daughter, she knows me well enough to know exactly. Like I told her I don't want them to keep me on a machine, you know stuff like that. Just give me a limited time and see what the doctors would say and then put me out, you know, just let it go.

While some participants wanted to leave the responsibility to their families, one participant shared a different perspective even with hesitancy, "I know I need to, and I have thought about it several times. I need to get my things in order to make it easier on my family".

Beyond the responses related to advance directives specifically, the participants brought to light their thoughts about their own death through conversations with their friends and family or when they speak of their dialysis peers. One participant mentioned, "since I've been there two people done passed away. And I'm like this is always for people every day". The participants also made statements related to shorter life expectancy, such as "I'm not going to live long"

07.06.21_Dialysis_171P communicated:

> My husband and I’ve talked about it, we talked about how we’ll miss each other, and you know, I want to go first? He says no, I want to go first. And I talked with a friend, a dear friend, more like a sister to me. We talked about our thoughts and fears for our death, I think, you know we hope that’s not too soon, but you never know.

07.18.21_Dialysis_241P expressed:

> Yes, I was like so will I life five years or 10 years, but no one has really said anything. Like I said, I think about it. I don’t feel I will be here to my little cousins graduate but of course no one wants me to say that out loud.

Summary

In this chapter, I provided a synopsis and a comprehensive report of my outcomes. Each participant voluntarily consented to participate in this study. The criteria to participate in the study were met by all of the individuals and the interviews were completed within an hour time frame. I utilized Yin (2009) and Saldana (2016) and other researchers’ theoretical frameworks for case studies on data analysis for the transcription and coding process of the interviews (Stuckey, 2015; Linneberg and Korsegaard, 2019; Ose, 2016).

Once the data was analyzed multiple times, I created two categories and use them as collections from the emerging themes. The first category was based on the initial experience of ESRD. There were three themes for this category: (a) fear of unknown, (b) overwhelmed and depressed, and (c) frustration. The second category focused on living on ESRD over a period of time. The primary themes from the findings: (a) loss of independence, (b) lack/loss of control, (c) perceptions of death. Respectively, the themes undergird the theories of anticipatory grief.

During the interview process, I noticed that most of the participants experienced similar feelings and concerns. When I facilitated the interviews, I asked each participant about having ESRD and its impact on their quality of life initially and the following years after. The participants provided in-depth narratives to the open-ended questions related to the beginning of their dialysis journey and how it has evolved over time. Even though the discussions eluded to topics about loss and grief, the participants were not as forthcoming about end of life.

In the following chapter, I will discuss how the findings from the study's themes substantiated the theoretical framework of anticipatory grief. Also, I will explain how my findings expands the knowledge of this theory into world of nephrology, as we provide social work services to individuals living with ESRD. Lastly, I will discuss the limitations of the study and recommendations for the implementation of the findings and future research.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative case study was to understand how patients who have ESRD and receive hemodialysis treatment experience anticipatory grief. I sought to discover the initial thoughts and concerns that the participating patients had about being told they have kidney failure and how they were currently living on dialysis from the perspective of grief and loss. Due to the limited research on the anticipatory experience of ESRD patients, I used a qualitative approach to provoke a rich narrative of patient experiences. Colorafi et al. (2016) pointed out that this approach is beneficial in order to understand the participants' journey and find connections between the theoretical framework and an identified population. Therefore, this approach was optimal to explore and achieve a better understanding of the ESRD patient experience.

Interpretation of the Findings

The key findings from this qualitative study are aligned with current research related to anticipatory grief. These findings highlight obstacles and impediments faced by the hemodialysis patients with the initial diagnosis with ESRD. The patients in this study reported experiencing fear of the unknown with feelings of being overwhelmed, depressed, and frustrated. Also, I designed the study to achieve an increased awareness of their journey of living with the disease. The key findings identified were related to a loss of independence, lack and loss of control, as well as their perceptions of death. Shore et al. (2016) confirmed that this form of grief was about more than facing death itself; it also related to health concerns, role changes, and depression. This observation is aligned with my findings. These ideas also corroborated the study's suggestion that ESRD patients experience anticipatory grief and are faced with end-of-life issues. Yin (2012) suggested that the role of theory in a qualitative case study is to point the researcher to the relationships found in study data, which allows the researcher to answer the RQs.

Theme 1: Fear of the Unknown

This case study expanded the understanding of anticipatory grief related to a person having a fear of the unknown, from previous studies of individuals with cancer, to also those diagnosed with ESRD. Cheng et al. (2010) noted that these fears occurred due to lack of explanations of their diagnosis and vagueness concerning treatment. In their qualitative study, Cheng et al. also shared a similar experience within one of the themes, in which the cancer patient described "her process of discovery was filled with apprehension and anxiety. She described the experience as 'opening one door after another' as she anticipated apprehension" (p. 696). This description is similar to that of Participant 12.10.20_Dialysis_121P, who stated "It's like a crackerjack box, you don't know what you are going to get." Several participants in this study who had comparable feelings alluded to the lack of communication by healthcare providers and the dialysis process itself as contributing to these fears. One participant (12.17.20_Dialysis_151P) noted that the staff did not communicate things clearly, so they felt unprepared for their first day at dialysis, by articulating, "I realized once I got into the clinic that it was not the same, it was totally different. And it wasn't a good experience for me for the first time." The results from my study were consistent with those of Cheng et al. (2010),who have examined cancer patients' experiences of anticipatory grief.

Additionally, I discovered fear connected to the dialysis treatment itself. Han et al. (2019) also found this pervasive fear of the unknown as a subtheme within their qualitative study of the biopsychosocial impact of ESRD. They determined similar root causes associated to "a fear of disease and treatment outcomes, including fear of the unknown, fear pain and suffering, and fear of loss of freedom in daily life" (p. 5). Although none of the participants mentioned fear of the possible pain, one participant noted fear of the staff damaging their dialysis fistula access by stating

> They trying to put this thing in my arm for dialysis. I mean, he had messed up my whole arm trying to put that thing in. And when I went back to dialysis, it was wasn't working. But I told them before they even started sticking me, I say I have very weak veins. You barely can get anything from me. So ya'll shouldn't have tried that. I hated that he did that. In fact, he messed up my whole arm. And my body already messed up.

Another participant, 07.08.21_Dialysis_231P, briefly explained the fear of the cannulation by sharing

> I won't say I wasn't afraid at first, because my mother was on dialysis before she died. I guess just the thought of me going on the machine and having needles in my arms and stuff. It's kind of frightening at first.

Other participants expressed similar experiences of being afraid of the treatment and its physical impact on their body, such as cramping, dizziness, fainting, and fatigue. The literature (Farragher, J. et al., 2017; Schatell, D. et al., 2012) supported participants' accounts of their initial experiences undergoing dialysis treatment.

The present study demonstrated how the changes in physical condition also contributed to this form of grief. MacKenzie (2011) agreed that this fear can be rooted in individuals' concerns for how the decline in health or death may impact their loved ones. My findings illustrated how participants were concerned about the fatigue, due to their ESRD diagnosis. Some of the participants narrated how their health issues were negatively impacting their family because of additional dependence or inability to participate in social activities. The fear of becoming more dependent upon their loved ones tended to surface from their stories. Hottensen (2010) revealed similar occurrence in their anticipatory grief case study as well, in which the participant noted that "her body had been betraying her" (p. 106). One of my participants shared similar concerns with the decline by stating "you have to go straight home and you are just bedridden." Another patient expressed fears of being away from her children as a single mother. Although her parents were supportive, she believed it was her ultimate responsibility and feared she would start to decline in health. This finding is vital because the dialysis interdisciplinary teams must not overlook the patient and the fears they face initially by focusing so much on the procedure. The fear of the unknown could impact their ability to understand and cope with their diagnosis and the treatment modality. Han et al. (2019) also concluded that interventions providing education and psychosocial support are essential to address the needs from a holistic approach.

Theme 2: Overwhelmed and Depressed

Symptoms of depression appeared to be predominant theme within the narrative of the initial experiences of the ESRD patients in this study. This finding exemplified a concerning trend that has already been identified among dialysis patients found in previous literature (Bautovich, 2014; Farrokhi, 2012; Silva, 2014), as well as individuals experiencing anticipatory grief (Kostopoulou, 2018; Periyakoil, 2012; Widera, 2012). Chan et al. (2011) emphasized the frequency of depression with ESRD patients and its connectedness to mortality and hospitalization. In this study, the results did not surface based on utilization of standardized depression tools, but simply the initial experiences shared by the participants when hearing of their diagnosis. Hottensen (2010) concluded, from their qualitative case study on anticipatory grief, that the interaction between the patient and healthcare professional about their diagnosis can be extremely emotional and overwhelming.

Several participants from my study indicated there is a heightened sense of feeling overwhelmed and depressed from the initial diagnosis and treatment. Participant 12.10.20_Dialysis_121P verbalized this when they first started, “every time I’d go to dialysis, I would cry. And I had got to a point that I was getting depressed every time I get ready to go to dialysis.” Another participant described themselves as being in a state of shock and said “it really kind of knocked my feet a little bit. It was a lot to take in,” “it kind of winded me a little bit,” and “it was just a lot all at once.” The dialysis patients from my study were consistent in reporting how the initial experience was devastating and greatly impacted their way of life. The participants also conveyed that their emotional state not only affected them but their close family as well, who found it difficult to support, similar to the case study findings of Hottensen (2010). Although the participants did not voice how their families were coping with their diagnosis specifically, they expressed how their families made an effort to comfort and support them.

However, some of the participants also noted that the lack of understanding from their families made them feel isolated. Participant 07.18.21_Dialysis_241P described, “I thought my life was over. I felt very isolated and alone with limited support.” They also stated

> My family don’t talk about things, so I don’t feel supported. They never ask me how I’m doing. They just expect me to take of things including myself. Even when I try to express how I feel, they just shut it down by saying let’s not be negative or let’s have faith. I don’t even think they know a lot about what I’m going through because they are afraid to ask.

These responses validated the predominance of feelings of being depressed and overwhelmed found in other anticipatory grief case studies, such as Montayo-Juarez et al. (2013) and Cheng et al. (2010).

Further, my research revealed the need for more understanding of these feelings beyond the diagnosis of depression as it relates to anticipatory grief with ESRD patients. Widera and Block (2012) emphasized that grief and loss issues were prominent obstacles when diagnosing depression. They also noted that, due to health professional’s inability to distinguish between major depression with grief and loss, there is a greater need for patient exploration and assessment before determining appropriate intervention. Bennett et al (2008) also emphasized the significance of screening of depression and grief evaluation to provide appropriate supportive and clinical care.

Theme 3: Frustration

The last theme that emerged from the first category describing the initial experience of ESRD was the sense of frustration of the diagnosis and treatment. The participants from my study defined the prevailing aggravation with their health, adherence to diet and treatment regimen, and overall life challenges. My findings corroborated previous evidence by Montoya-Juarez et al. (2013), in which the participants expressed similar emotions because they were consumed with the loss of their current quality of life. Shore et al. (2016) also underscored my results by recognizing frustration and disappointment as a prevalent theme to describe cancer patients' experience with anticipatory grief. Several of the participants from my study found their frustrations to be consistent with initial changes to their life. The frustration was often exacerbated by the symptoms of ESRD prevented them from working and traveling with no restrictions. For example, one participant mentioned that the inability to work was the one of the most frustrating things after being the workforce for over 2 decades. Participant 12.10.20_Dialysis_121P explained how the dialysis treatment and diet regimen was an aggravation:

> I was really frustrated because I was sick a lot. I reckon I had to get used that way of living and that way of eating. Cause I had to eat a whole different way. I was used to eat fries and eating tomatoes. And I was really stressed by this.

Nabolsi et al. (2015) concluded that nonadherence was a frequent occurrence among ESRD patients and increased the probability of mortality and hospitalization. The authors further asserted that how a patient perceived their illness greatly impacted their ability to adhere to the rigorous regimen.

Other participants not only spoke of frustration with treatment and daily activities but also with changes in self-image. MacKenzie (2011) supported these findings by stating a strong correlation between depression and self-image. While Han (2019) also confirmed an undesirable view of themselves was a contributing factor to their distress. The perspective of one's self image is a definitive component of grief and loss. Some of my participants highlighted the changes in their image created frustration. One participant pointed out that people within their spiritual community made comments about the changes in their appearance such as weight and hair loss. Participant 07.08.21_Dialysis_201P spoke of their multiple conditions, "With my self-image issues and with me not wanting to have 'popeye' arm. I refuse to get the fistula at first". As a result, this participant experienced consequences of multiple infections and heart surgery. The participant shared the impact of another medical illness called Hidradenitis Suppurativa (HS), which is an inflammatory condition causes bumps, nodules, abscesses and tunnels on various places on the body (American Academy of Dermatology Association, 2021). These abscesses would smell and drain, which amplified their self-consciousness and frustration with body image. The findings from my study aligned with the quantitative study by Kostopoulou et al (2018), which concluded strong correlations between self-esteem, self-image, and anticipatory grief.

These accounts from my study reiterated the crucial significance of thorough understanding of the dialysis patient's initial feelings about their diagnosis and treatment.

The frustration attributable to multi-faceted loss, which will be explored further in the remaining themes, solidified the presence of anticipatory grief in the dialysis experience. Kostopoulou et al (2018) explained anticipatory grief is an "inner and outer reaction to the perception of loss" (p. 89). Therefore, the interdisciplinary team should take an exploratory, not just an educational approach to beginning of the dialysis journey.

Theme 4: Loss of Independence

The next theme delved into response to the second category of living on dialysis, which was the dialysis patient's loss of independence due to ESRD diagnosis and hemodialysis treatment. The participants described how the required time needed for treatment for at least three times a week impacted their daily decisions and family dynamics. This finding was commonly found in other research studies as well (Chilcot, 2012; Nabolsi et al., 2015; Chiang et al., 2015). After Bautovich et al.(2014) reviewed literature concerning depression, they noted adherence to be an ongoing barrier for dialysis patients. Additionally, Velez-Velez and Bosch (2015) acknowledged the patient's ability to cope with the treatment regimen correlated with their adherence. Also, from an anticipatory grief perspective, Cheng et al. (2010) explained how one's autonomy is greatly impacted by the chronic medical condition. The participants from this study had similar views. One participant (07.06.21_Dialysis 171P) described their loss of independence as "I felt trapped". Several participants shared how they tend to decline family or social events because it's too frustrating to rearrange their dialysis treatment. Ultimately, they feel connected to the dialysis machine, even on non-dialysis treatment days. Hottensen (2010) aligned with my findings about loss of independence, when describing the forms of loss experienced by terminal ill patients with anticipatory grief.

The results of my study also uncovered the loss of independence due to physical decline over time. Widera and Block (2012) reinforced my findings by expounding on the impact of compounded loss over a period influenced one's grief. The responses from the study were also strengthened by another qualitative study, which concluded dialysis patients with physical decline experienced more loss of independence (Han et al., 2019). Some of participants from my study communicated how the continued physical changes and deterioration caused them to lose their independence. As a result, they considered themselves burdensome to their loved ones. One participant mentioned the need for spousal support in daily activities, including the care of their disabled son, because of the fatigue. Despite the gratitude of the support, the guilt and burden emerged as subthemes. These findings align with the multiple research studies related to quality of life (Jankowsa-Polanska et al., 2016; Loon et al., 2017; Yarlas et al., 2011). The burden of kidney disease component of the KDQOL survey (Mitema & Jaar, 2016) validated my finding of the correlation between loss of independence and burden.

CMS requires that the KDQOL survey be completed with patients in outpatient dialysis facilities at least annually (Cohen et al., 2019). Therefore, the interdisciplinary team has access to this valuable information to address burden and loss of independence. However, my findings exposed the gap in service delivery, which was to consider the loss from the theoretical lens of anticipatory grief. Therefore, Moon (2016) concluded the need for healthcare professionals to frame the loss experiences for the patients as they journey through the grieving process.

Theme 5: Lack/Loss of Control

The following theme that emerged was the dialysis patient's lack or loss of control. My findings suggested the control factor was also connected to the treatment regimen and limited autonomy. Participants from the study reported being subject to the treatment times given by the dialysis staff, which one has little control over. One participant spoke of their need to be treated for five hours on the dialysis machine for three times a week. As a result, the limited flexibility of the treatment times made it difficult to find a job with satisfactory work hours. These findings were validated by the previous research by Widera and Block (2012), who determined grief was predominant when a person tended to perceive a loss of control. Kostopoulou et al. (2018) had similar findings by identifying various losses found around not only autonomy, but also dependency on others mentioned in previous theme.

Along with the loss of control, the participants identified their autonomy due to persisted with the multiple and growing restrictions. One participant (07.08.21_Dialysis_201P) found the diet restrictions to be the most frustrating with inability to have broader choices. Other participants mentioned similar frustrations related to diet, travel, and every day decisions centered around having kidney failure. With utilization of the Illness Perception Questionnaire, Chilcot (2011) specifically concluded treatment and personal control among ESRD patients was strongly correlated to quality of life and adherence. Widera and Block (2012) noted grieving the loss of control led to individuals avoiding any reminders of illness such as treatment. This emerging theme from my study also aligned with other researchers, who have explored the concept of anticipatory grief (Moon, 2016; Hottenson, 2010; Cheng et al., 2010). Patinadan et al. (2020) re-emphasized one of the resounding contributors of anticipatory grief, which is loss of control and diminished adjustment.

Theme 6: Perception of Own Death

The perception of death was the last theme that materialized from my findings. The dialysis patients in the study mentioned their perspective of impending death from various viewpoints. Most participants tended to respond to these questions with trepidation, as though a locked door had slowly opened within their thoughts. Although in one of the previous themes, several individuals spoke of their fear of death, the topic appeared to be difficulty to introduce into the interview. Sivell et al. (2015) noted similar challenges with qualitative studies exploring end-of-life issues and recommended free formed interviews. They also suggested creating a space for storytelling prompted the most positive results for valuable insight.

Many narratives provided from the dialysis patients exposed their concerns for their family after their death, as well as their spiritual beliefs related to afterlife. One participant (12.17.20_Dialysis_151) spoke openly, once given time to ponder, and began how they consider how they want to be remembered by their children and grandchildren. While another participant (12.10.20) mainly shared their concerns with care of their disabled child, who required total care. These findings were reinforced by Molzahn et al.

(2018), whose narrative inquiries comparatively identified the theme of potential of death due to kidney failure and the impact on their loved ones.

More interestingly, despite the fear mentioned initially of death, by the end of interviews, several participants shared their resolve of little to no fear of death. The common subtheme rested within their faith or previous death experiences of loved ones. One participant (12.10.20_Dialysis_121P) noted:

> Well, no, it's kind of weird, but I'm not afraid to die. Because I feel like I've lived a good life. I feel that if I do die. I feel like I haven't done anybody wrong. Well, I tried to people like, I wanted to be treated. I tried to be good to everybody. So, I'm no afraid, because I know that I'm not here to stay, I'm on borrowed time. I already know here to stay, I'm just passing through.

On the other hand, three other participants expressed their familiarity and resolution with death was attributed to the passing of their loved ones. A participant from the study shared in-depth the occurrence of her mother, a previous ESRD patient, who died from multiple seizures. These responses were consistent with several research studies, which substantiated the willingness to face death within their process of their own grief and loss (Molzahn et al., 2012; Montoya-Juarez et al., 2013; Molzhan et al., 2018).

Lastly, although the commonality of not fearing death was previously recognized, several participants alluded they had made no legal preparations such as advance directives or living wills. Only one of the 10 participants had stated an advanced directive was in place after discussion with their son. The remaining dialysis patients in the study shared various reasons for little to no action to address the matter of their death. They either believed their family were aware of their wishes, even with no discussions, or they planned to address in the indefinite future. The limited use of end-of-life care planning found in the study were aligned with a referenced study provided by Molzahn et al (2012), which noted less than 15% of dialysis patients had advance directives. A more recent study concluded more dialysis patients were willing to discuss end-of-life planning, if the healthcare team discussed more in-depth their prognosis (Saeed et al., 2019). Therefore, my findings support the need for more interdisciplinary discussions with patients about advance directives and living wills.

Findings in Relation to the Conceptual Framework

I used the anticipatory grief theory for this study, which was originally introduced by Lindeman (1944) and later expanded by Kubler-Ross (Moon, 2016) and Rando (1986, as cited in Patinadan et al., 2020). I discovered several commonalities that were consistent with the defining factors of anticipatory grief, while analyzing the data. The participants provided a rich descriptive narrative, which gave more understanding into their initial experience and continued journey as an ESRD patient on hemodialysis. The findings from the study presented a consideration of dialysis patients experience of anticipatory grief. The indicators of this form of grief defined by Kubler-Ross (1969, as cited in Patinadan et al., 2020) of denial, anger, and depression aligned with the initial experiential themes within the study of depression and frustration. The findings demonstrated that this grief phenomenon can be experienced by ESRD patients. The participants communicated about their experiences similarly found with the stages of grief and loss presented by Kubler-Ross. Their responses were supported by the research delineated in the previous sections that illustrated cancer patients processed their diagnosis through anticipatory grief. A similar qualitative case study found comparable findings of depression (Hottensen, 2010). Cheng et al. (2010) revealed the fear faced by a terminal diagnosis reinforced the emergent theme of fear of the unknown. The dialysis patients in the study continued to express the pervasive fear for what would happen to their health, family, and careers. The shock and denial overshadowed their abilities to process the information and support given by the physicians and dialysis staff.

After the original thought of anticipatory grief by Lindemann, Rando (1986, as cited in Patinadan et al., 2020) expanded the concept by adding the of loss of self-sufficiency and disability. The data I presented suggested ESRD patients receiving dialysis treatment had similar experiences within the themes of loss of independence and loss of control. The participants within the study expressed shared experiences of losing control due to treatment and diet regimen, as well as physical decline. With utilization of the preparatory grief advanced cancer (PGAC) standardized tool, Kostopoulou et al. (2018) validated my findings related to loss. While Cheng et al. (2010) again supported dominating occurrences of various losses, which arose in similar forms as with my themes.

Finally, the responses related perception of death and dying were paralleled with the body of research of anticipatory grief. This element found among individuals diagnosed with cancer has been explored and validated in quantitative and qualitative studies. Although Mozahn et al. (2018) does not address this phenomenon, the authors explored the end-of-life discussion among ESRD patients and concluded these patients have a heightened awareness of their mortality. Therefore, my findings are validated with similar themes of thoughts of impending death. Shore (2016) concluded individuals faced with these feelings welcomed an opportunity share their thoughts. Several of the participants in the studies communicated the need to share thoughts of death and dying with loved ones and the frustration when their family were not open to the discussion. Overall, the research of anticipatory grief undergirded my findings experienced by ESRD patients.

Limitations of the Study

A limitation of this study was addressing researcher bias while interviewing the research participants. As a nephrology social worker, I expected to hear certain responses based on my years of experience serving dialysis patients, which created bias. Therefore, I took the time to document my thoughts and feelings about their responses as they occurred after each interview, especially when reviewing the audio recordings. During the interview, I remained cognizant of the bias by not offering any suggestions to resolve their concerns related to barriers to transplant, dialysis access concerns, and psychosocial issues related to adherence. During the responses related advance directives and death, I had to resist the desire to interject when they had no end-of-life care planning. Instead, I redirected the participants to speak to their nephrology social worker about any issues or concerns discussed during the interview by referring them to their informed consent. When interviewing end-of-life issues, Sivell et al. (2015), instructed researchers to steer away from the interview becoming a therapeutic session, which is unethical. I found this guidance to be helpful during the entire interview.

Another limitation was the sample size and gathering data from a small group of dialysis facilities. Malterud et al. (2016) theorized that qualitative studies with established theories with limited research should have a larger sample size. The anticipatory grief theory has historically been applied to cancer patients, with little to no focus on individuals with ESRD. Therefore, it will be beneficial to expand the sample into other geographical areas to determine generalization of the theoretical framework in future studies. However, the information power was strengthened by my knowledge of the dialysis patient journey (Malterud et al., 2016). I was familiar with the end-of-life discussion, which helped to create a safe space for them to share comfortably.

Recommendations

The purpose of the study was to explore the dialysis patient's experience of anticipatory grief. The research questions brought forth data with emerging themes aligned with the definitive conceptual framework. The findings from the data collection confirmed that dialysis patients exhibited indications of this form of grief and loss. Therefore, there is a significant gap in social work service delivery to expand the assessment beyond depression to address anticipatory grief. Based on the themes, which surfaced from the respondent's initial experience of diagnosis and treatment, there is a recommendation to evaluate current educational programs to minimize their fears and concerns. Dialysis providers can use these findings to customize interventions tailored to address palliative care and end-of-life planning. However, this recommendation would also propose proper palliative care training for the entire interdisciplinary team, including nephrologists. Nephrology social workers in the chronic kidney disease can apply these findings to gain insight into how anticipatory grief may impact their quality of life and adherence to treatment. In addition, these preliminary findings should serve as a catalyst for further exploration into the dialysis patient narrative of grief and loss. It would be beneficial to expand this research to identify standardized tools for assessment and existing interventions that could be utilized with this population of patients.

Implications

The study was intended to create social change within the dialysis provider service delivery. First, I wanted to gain understanding of the initial and ongoing experience of anticipatory grief among ESRD patients receiving hemodialysis treatment. The findings from the study established the need for dialysis providers to develop clear staff training and patient education to facilitate end-of-life discussions. The pervasive culture of taboo around conversations of death and dying in the dialysis centers could be a silent barrier to treatment adherence. With the understanding that poor adherence and low quality of life scores are predictors of increased hospitalization and mortality among ESRD patients. Therefore, as my social change initiative, I intend to bring awareness to this gap among dialysis providers and ensure further research, both qualitative and quantitative, are performed to better support our ESRD patients and ultimately improve their quality of life. In the initial phase of my social change goal, I will circulate my research findings to the medical office, research department, and clinical services departments of the large dialysis company organization, in which I am employed. Patient experience and engagement are closely monitored by governmental agencies and insurance companies. Next, I will disseminate my findings at professional conferences and the renal research communities. These findings are beneficial to stimulate further discussion and promote awareness of an anticipatory grief and loss among dialysis patients. It my desire to add to ever-growing renal research in exploration to barriers to ESRD patient's adherence and quality of life.

Conclusion

I believe ESRD patients are faced with complex challenges on their dialysis journey and it is imperative that we seek to not only understand their quality of life but also how they face the quality of their death. Grief and loss are the elephants in the room that are present from the time they are diagnosed with ESRD. Dialysis providers must be willing to partner with our patients on their journey to support as they cope with their loss and prevailing changes in their health, family dynamics, and financial stability. With continued research, there is an opportunity to develop end-of-life care planning patient education, ensure substantial training is provided to the patient care staff, and provide evidence-based social work interventions. The findings from my study should generate the changes needed to improve service delivery to ESRD patients receiving dialysis treatment.

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Appendix A: Interview Questions

Introduction

Thank you for agreeing to speak with me today. I am interested in learning about the experience of hemodialysis patients who are facing end-stage renal disease, and hearing about what their thoughts and feelings are at this period in their lives.

I hope that understanding your experience will help other care providers better address the needs and concerns of patients. The interview is entirely open-ended questions and the duration of the interview is entirely up to you. If at any time in the conversation you feel uncomfortable continuing, please let me know. I will be recording the interview, and the recording as well as its transcript will be available to you if you would like to have them. The materials will remain confidential, and any of the content used in our research will use your initials only.

Do you have any questions now? Please feel free to ask me any questions during the interview. We can begin wherever you would like to start.

Interview Questions:

1. How long have you been on dialysis?
2. Do you remember what caused your kidney failure?
3. What do you understand about having kidney failure?
4. Do you have any other medical conditions that you would like to share?
5. Tell me your initial thoughts when you were told you have to start dialysis.
6. Can you share with me your initial concerns about having kidney failure?
7. Can you share with me what it is like to live with kidney failure?

    a. Tell me what has changed in the last five years

8. Describe your quality of life before you started dialysis?
    a. Has it changed since then?
9. How has this illness influenced your life?
10. Have you experienced any loss of independence since you started dialysis?
    a. In what way?
11. Describe a time when you were frustrated about having kidney failure?
12. How do you describe your relationships with your family before your diagnosis?
    a. Have your relationships changed since you started dialysis?
    b. How do they cope with your illness?
13. Have you completed an advance directive?
    a. If yes, why?
        i. Can you share with me what your wishes are now?
            1. Were those your wishes when you first started dialysis?
    b. If no, why?
14. Tell me about a time you talked about end of life or death with a loved one.
15. Were you afraid of the possibility of dying when you were first diagnosed?
    a. If yes, what were your thoughts and feelings?
16. If you were in the end of life and were possibly dying, what would be important to you?

Appendix B: Recruitment Poster

- Topic: Dialysis Experience and End of Life Issues
- Patient Criteria:
- Must have been on dialysis for at least three months
- Must have been on dialysis less than 15 years
- What’s the Need:
- Interview by Phone or Virtually for 1 hour
- Who Do I Contact:
- Felicia Speed, Walden Student Researcher at [redacted]
- or at felicia.speed@waldenu.edu
- This study is being conducted for my PhD Dissertation Study