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Dialysis Social Workers' Perceptions of Strategies to Address Biopsychosocial-Spiritual Barriers to End-of-Life Planning With Black Dialysis Patients

Annette Carol Kestner
Walden University

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College of Social and Behavioral Health

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Annette Carol Stamper Kestner

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Walden University
2025

Abstract

Dialysis Social Workers' Perceptions of Strategies to Address Biopsychosocial-Spiritual

Barriers to End-of-Life Planning With Black Dialysis Patients

by

Annette Carol Stamper Kestner

MSW, Radford University, 2015

BS, Radford University, 1999

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Medical Social Work

Walden University

November 2025

Abstract

Black individuals with end-stage renal disease (ESRD) have an excessive risk of mortality and experience ongoing inequities in end-of-life (EOL) planning. This basic qualitative study, informed by Sulmasy's biopsychosocial-spiritual model, explored social workers' perspectives about approaches that consider the interplay of physical, psychological, social, and spiritual aspects for mitigating barriers to EOL planning among Black dialysis patients. Data were obtained from semi structured interviews with 10 licensed dialysis social workers in Virginia and Maryland. Thematic analysis with descriptive coding, reflexive journaling, and peer debriefing was employed to analyze qualitative data to ensure trustworthiness. Six themes were identified: (a) building trust and rapport, (b) normalizing and integrating EOL discussions, (c) addressing family and cultural influence, (d) overcoming structural and resource barriers, (e) leveraging interdisciplinary collaboration, and (f) adapting communication approaches to enhance EOL planning. These findings highlight the importance of culturally responsive, relationship-based strategies and the routine incorporation of EOL planning into standard care practices. Dialysis social workers and other healthcare professionals may improve equity in EOL care by developing practices that respect Black patients' values, reduce medical mistrust, and enhance quality of life. By applying these strategies, providers may contribute to policies and interventions that strengthen patient-centered care and expand culturally competent support for diverse populations facing ESRD.

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Dedication

I dedicate this dissertation to my late husband, Jason Kestner; son, Chase Kestner; and my parents, Robert and Carolyn Stamper, for all the support they have shown me.

Acknowledgments

I want to thank the faculty who aided in my doctoral journey. Those included my chair, Dr. Pete Meagher, and my second committee member, Dr. Alice G. Yick. I thank all the participants in the research; without them, I could not have obtained my goal. Many thanks and love to my husband, who supported me throughout and encouraged me even while dying of colon cancer. Lastly, I would like to thank my academic advisor, Spanjia Moten, for her support and encouragement.

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Chapter 1: Introduction to the Study

Introduction

Black patients have a disproportionately higher rate of end stage renal disease (ESRD), and many have not heard of advanced care planning (ACP) or had an end-of-life (EOL) discussion, or their medical team has avoided these discussions (Anh et al., 2021; Eneanya et al., 2018; Hing et al., 2016; Jennings & Johanson, 2018; Lazenby et al., 2017). Eneanya et al. (2018) indicated that 23% of patients had not discussed the end of life (EOL) with any healthcare provider. Hing et al. (2016) found that 75% of patients had not heard of ACP. Only 25% had completed ACP forms, if patients had had a conversation (Hing et al., 2016). Black patients are less likely to have received predialysis care, and they are more likely to utilize more aggressive forms of dialysis, aggressive and nonbeneficial medical care at the EOL, and wait longer for transplants than White patients (Anh et al., 2021; Foley, 2018; Harding, 2017; Hilliard et al., 2013; Senteio & Callahan, 2020; Thomas et al., 2013). EOL planning could help decrease these racial disparities.

Disparities in EOL care for Black patients with ESRD or chronic kidney disease (CKD) are a common concern in renal care (Cronin, 2014; Cukor & Kimmel, 2010; Eneanya et al., 2018; Foley et al., 2018; Harding et al., 2017; Song et al., 2010). The disparities relate to patient, clinician, clinical, and systematic factors for Black patients. The known barriers for Black ESRD patients completing EOL planning include physical, psychological, social, spiritual, and historical factors. Foley et al. found that minority patients were less likely to discontinue dialysis, less likely to receive hospice care, and

more likely to die in a hospital than their White counterparts. The National Kidney Foundation (NKF, 2023) and the U.S. Renal Data System (USRDS, 2022) noted that Black patients are 3 times more likely than White patients to have ESRD. Albertus et al. (2016) reported that from birth, the American lifetime risk of ESRD in White males was 3.1%, compared to 8.0% for Black males, 2.0% for White females, and 6.8% for Black females.

This study was needed to understand how dialysis social workers can overcome these biopsychosocial-spiritual barriers to complete EOL planning with Black dialysis patients. Because Black patients are less likely to complete EOL planning than White patients, it is crucial to understand how to overcome these obstacles and improve their care and service provision. This study explored the biological, psychological, social, and spiritual barriers for Black dialysis patients and what strategies dialysis social workers can utilize to overcome these and complete EOL planning. The social implications of the findings of this research are that this could aid dialysis social workers in identifying needs, concerns, and strategies that will assist Black dialysis patients in overcoming these barriers and completing EOL planning. Dialysis social workers and other healthcare professionals can potentially use this research to advocate for and inform dialysis social workers of the need to expand their cultural awareness and understanding of how vital EOL discussions and planning can be. The increased knowledge and awareness among dialysis social workers could improve Black dialysis patients' quality of care and life.

In Chapter 1, I will provide an introduction and discussion of the background to the problem as well as the problem statement. I will also present the purpose of the study

and research question while previewing the theoretical framework, nature of the study, definitions, assumptions, scope and delimitations, limitations, and significance of the study. Finally, there will be a conclusive summary.

Background

The USRDS (2020) reported that at the end of 2018, there were 554,038 individuals on dialysis and that the mortality rate was 131.5 per thousand patient-years. The typical dialysis population is older individuals, though Black patients are overly represented in this population. Albertus et al. (2016) reported that from birth, the American lifetime risk of ESRD in White males was 3.1%, in Black males was 8.0%, in White females was 2.0%, and in Black females was 6.8%. The USRDS also reported that Black patients represent 3.8 times greater numbers than other races in this population. While on dialysis, patients may receive treatment three to seven times a week. Their treatment and care become a dominating factor in their lives, and EOL discussion and ACP become essential. However, most ESRD patients are unfamiliar with the terminology utilized in treatment centers (Eneanya et al., 2018). The patient's knowledge and understanding of their disease and options are limited.

Everyone has ideals regarding care as they age, which are affected by values, preferences, and medical history. EOL discussions and planning are a way to ensure that patients' wishes and preferences are understood. EOL information provision includes ACP, advance directives (AD), do-not-resuscitate (DNR) orders, transplant options, modality options, and hospice and palliative care information. ACP helps individuals provide legal documents outlining their wishes.

O'Riordan et al. (2019) found that nephrologists tended to avoid EOL discussions (see also Amro et al., 2016; Davison, 2010). Hence, dialysis social workers in the dialysis clinic setting are tasked with providing ESRD patients with information about their health, EOL discussions, and assisting with ACP. The dialysis social worker is often the first staff member to talk with the patient about EOL and identify that ESRD is terminal (O'Riordan et al.). Learning about their compromised health status can create anxiety and stress for the patient, making it difficult to listen to and understand further information. Nonetheless, Ladin et al. (2018) noted that EOL discussions among dialysis patients are associated with better patient outcomes. Song et al. (2010) found that African American patients felt that a better quality of communication with more directed EOL discussions would help them feel more comfortable with providers. EOL care and planning are areas where dialysis social workers must know how to provide the best information, services, and referrals (Foley et al., 2018).

There are several barriers to EOL planning for Black dialysis patients, including physical, psychological, social, and spiritual aspects. These barriers include Black patients being told less about their health conditions and their severity, being less open to EOL planning due to conflicts between spiritual beliefs and perceptions of palliative care, and fearing that they are not being offered treatments that other patients might receive, as well as family members' resistance to accepting alternatives to life-sustaining treatments like hospice care and gaps in knowledge on EOL and how to complete forms (Anh et al., 2021; Eneanya et al., 2016, 2018; Saeed et al., 2023). Despite research citing multiple obstacles and reasons for Black dialysis patients not completing EOL planning, there

remains a gap in the literature regarding overcoming these biopsychosocial-spiritual barriers and what dialysis social workers can do to assist in overcoming these barriers.

I examined the dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients. It is crucial to understand how these barriers affect the EOL planning process of Black dialysis patients to serve these individuals more effectively.

Problem Statement

Nearly 800,000 people in the United States receive regular dialysis due to ESRD, and 35% of those individuals are Black. Those with ESRD will have a decreased life expectancy, with most living at least 5 to 10 years on dialysis. The USRDS (2020) reported that, in 2018, dialysis cases rose 0.2% to 131,636 patients beginning dialysis; however, in 2020, the rates decreased by 4.3% though the mortality rate increased by 2% due to COVID-19 (USRDS, 2022). Hence, people with ESRD are greatly affected by the disease and mortality. While on dialysis, patients may receive treatment three to seven times a week. Their treatment and care become a dominating factor in their lives, and EOL discussion and ACP become essential. EOL planning could help decrease these racial disparities. However, Black patients had fewer EOL conversations and were less likely to complete EOL planning.

The disparities in the quality of EOL care for Black patients are well known (Anh et al., 2021; Cronin, 2014; Cukor & Kimmel, 2010; Eneanya et al., 2018; Foley et al., 2018; Harding et al., 2017; Hilliard et al., 2013; Saeed et al., 2023; Senteio & Callahan,

2020; Song et al., 2010; Thomas et al., 2013). The disparities relate to patient, clinician, clinical, and systematic factors for Black patients. The known barriers for Black ESRD patients to completing EOL planning include physical, psychological, social, spiritual, and historical factors. Many have not heard of ACP or had an EOL discussion, or their medical team has avoided these discussions (Eneanya et al., 2018; Hing et al., 2016; Jennings & Johanson, 2018; Lazenby et al., 2017). Eneanya et al. indicated that 23% of patients had not discussed EOL with any healthcare provider. Hing et al. found that 75% of patients had not heard of ACP. Only 25% had completed ACP forms if patients had had a conversation (Hing et al.). Foley et al. found that minority patients were less likely to discontinue dialysis, less likely to receive hospice care, and more likely to die in a hospital than their White counterparts.

Everyone has ideals regarding care as they age, which are affected by values, preferences, and medical history. EOL discussions and planning are a way to ensure that patients' wishes and preferences are understood. EOL information provision includes information regarding ACP, advance directives (AD), do-not-resuscitate (DNR) orders, transplant options, modality options, and hospice and palliative care information. ACP helps individuals provide legal documents outlining their wishes. Dialysis social workers are the primary source of education, advocacy, and support for medical information and EOL planning. However, dialysis social workers continue to struggle with finding ways to help Black patients overcome barriers and complete EOL planning.

Mayeda et al. (2019) completed a literature review of ways to overcome barriers and complete EOL planning with minorities; however, they did not focus on the support

and services that dialysis social workers could offer. Bazargan and Bazargan-Hejazi (2021) completed a cross-sectional longitudinal study that noted the many disparities in EOL care for Black patients but did not address how to overcome these barriers. Several studies have looked at a nephrologist's lack of EOL discussions but have generally found that these discussions are neglected or avoided (Amro et al., 2016; Davison, 2010; O'Riordan et al., 2019). Numerous other researchers have looked at the barriers for Black ESRD patients and found these to be related to multiple factors, including physical, psychological, social, and spiritual-based barriers (Anh et al., 2021; Cronin, 2014; Cukor & Kimmel, 2010; Eneanya et al., 2018; Foley et al., 2018; Harding et al., 2017; Hilliard et al., 2013; Jennings & Johanson, 2018; Lazenby et al., 2017; Saeed et al., 2023; Senteio & Callahan, 2020; Song et al., 2010; Thomas et al., 2013). Although researchers have investigated the barriers and disparities for Black ESRD patients, there has been no work on understanding how dialysis social workers can overcome the biopsychosocial-spiritual barriers for Black dialysis patients in completing EOL planning. The literature has not focused on strategies for dialysis social workers to address the obstacles.

This research was needed to examine how dialysis social workers can overcome these biopsychosocial-spiritual barriers and possibly decrease disparities in EOL planning for Black dialysis patients. By better understanding strategies to complete EOL planning,

dialysis social workers may be better able to serve this population, decrease disparities, and improve healthcare provision for patients.

Purpose

This study's purpose was to explore the perceptions of dialysis social workers on strategies to overcome the biopsychosocial-spiritual barriers for Black patients' EOL planning. These biopsychosocial-spiritual barriers are related to the patient's physical, psychological, social, and spiritual aspects. This was accomplished using a basic qualitative study. I focused on dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients. To my knowledge, such a study has not been completed before in this way

Research Question

The research question for the study was the following: What are dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients?

Theoretical Framework

Sulmasy's (2002) biopsychosocial-spiritual (BPSS) model has been used extensively in palliative and EOL care, as it acknowledges the interaction between a patient's physical, psychological, social, and spiritual aspects of care. The BPSS model is a modern holistic and humanistic view used for health sciences to address the patient as a whole (Saad et al., 2017). The BPSS model is an expansion of the biopsychosocial (BPS)

model (Engel, 1977), which already considers the complex interplay between biological, psychological, and social factors. The spiritual component of the model acknowledges that spiritual well-being can significantly impact mental health and overall quality of life. Additionally, the biological, the psychological, the social, and the spiritual are only distinct dimensions of the person, and no one aspect can be disaggregated from the whole (Sulmasy). Known barriers for Black ESRD patients to completing EOL planning include factors related to their physical, psychological, social, and spiritual needs or concerns. Hence, the BPSS model relates directly to the physical, psychological, social, and spiritual barriers that dialysis social workers encounter with Black ESRD patients when trying to complete EOL planning. The BPSS model aligns with the National Association of Social Workers (NASW) Code of Ethics (NASW, 2021), which states that social workers who practice EOL care are to be mindful of the person and their values and beliefs.

The theoretical framework aligned with this study, as dialysis social workers' roles are to look at the person as a whole and address the biological, psychological, social, and spiritual needs related to the individual. The theoretical framework related directly to the research question as the study aimed to understand how social workers can overcome these physical, psychological, social, and spiritual components to barriers to complete EOL planning with Black dialysis patients.

The framework related to the study approach in that the barriers identified for Black patients relate to biological, psychological, sociological, and spiritual factors and are of a personal nature, which is their experience and perception. Their experiences,

perceptions, and behaviors are best explored through qualitative analysis. For Black patients, this diagnosis affects them as a whole person biologically, psychologically, socially, and spiritually. Some patients may need help understanding how ESRD affects them physically, nutritionally, or medically (USRDS, 2022). Psychologically, they may be unable to understand the information provided, or they may struggle with the emotions of a terminal illness (Ladin et al., 2017). They may need help conveying this information to their social circles or even how they will be able to be involved in their previous social activities (Goff et al., 2015).

Additionally, they may be concerned about how this affects them spiritually and how their choices can correspond with their values and beliefs (Kub et al., 2003). Thus, the research questions revolved around these factors to address the fundamental concepts of the BPSS model. The concept of addressing the overall study through the perception of dialysis social workers is due to the idea that this state of being is a new concept for most patients with ESRD, and the primary source responsible for their health education is dialysis social workers (O'Riordan et al., 2019). Due to dialysis social workers being the primary source, their perceptions of how to overcome these biopsychosocial-spiritual barriers are essential. The BPSS model framework will be outlined and explored further in the literature review in Chapter 2.

Nature of the Study

I used a basic qualitative inquiry to address my research question. The barriers to completing EOL for Black patients are related to personal values and beliefs that support using a qualitative design that examines experience, perception, and behaviors. Basic

qualitative inquiry involves interviewing the individual to understand their experience, perceptions, and behaviors. Percy et al. (2015) noted that understanding this experience, perception, and behavior requires a basic qualitative study. In contrast, a single case study or ethnography would not provide the information this research was conducted to understand. The key concept investigated was dialysis social workers' perceptions of overcoming biopsychosocial-spiritual barriers to EOL planning for Black patients using a biopsychosocial-spiritual lens.

I interviewed dialysis social workers who work with Black dialysis patients and ask specific questions to explore their perceptions concerning the strategies that work in completing EOL planning. I recruited ten social workers who meet the study criteria to participate in the study. Ten respondents are expected to be sufficient to achieve saturation (Hennick & Kaiser, 2022). Inclusion criteria for dialysis social workers included those currently working in dialysis, who have had one year of experience working with Black patients, who have currently or within the last six months attempted EOL planning with Black patients, and who reside in the Renal Network region of the ESRD National Coordinating Center. This region covers Virginia, West Virginia, Maryland, and the District of Columbia. I used purposive sampling and snowball sampling to locate dialysis social workers. I used Saldana's (2021) descriptive coding techniques using first and second-stage coding to analyze the data completed by the computer-aided qualitative data analysis software Dedoose (2023).

Definitions

Throughout this study, I used several terms which are defined here.

Advanced care planning (ACP): Involves discussing and preparing for future decisions about your medical care if you become seriously ill or unable to communicate your wishes (National Institute on Aging, 2022).

Advanced directive (AD): The legal document of an individual's medical directives placed in writing (National Institute on Aging, 2022).

Black and African American: Nomenclature used interchangeably to describe one racial group throughout the literature. Each author's or participant's terms were used for their citation.

Chronic kidney disease (CKD): Means a person's kidneys are damaged and cannot filter blood the way they should (National Kidney Foundation [NKF], 2023).

Dialysis social workers: Social workers who currently work in dialysis centers with a master's degree in social work, are licensed, and have two years of experience in a healthcare setting must be available at every dialysis center by federal law (American Kidney Foundation 2023).

Discrimination: Treating a person or group of people differently because of their race, gender, sexuality, age, religion, etc. (Cambridge University Press, 1999).

Do not resuscitate (DNR): A type of advance directive in which a person states that healthcare providers should not perform cardiopulmonary resuscitation (restarting the heart) if their heart or breathing stops (Medline Plus, 2022).

End-of-life planning (EOL): The process of making decisions and getting your affairs in order in preparation for when you pass away (National Institute on Aging, 2022).

End stage renal disease (ESRD): ESRD is a medical condition in which a person's kidneys cease functioning permanently, leading to a regular course of long-term dialysis or a kidney transplant to maintain life (NKF, 2023).

Transplant: An operation in which a body organ is transplanted (Medline Plus, 2022).

Assumptions

Qualitative inquiries inherently had different assumptions underlying their examination (Pinder, 2020). There were five basic assumptions, which include ontological, epistemological, axiological, methodological, and rhetorical. For this study, I highlighted the two most relevant related assumptions: epistemological and axiological.

Epistemological assumptions refer to the ideas that the researcher interacts with that being researched (Creswell, 1994; Culbertson, 1981). My epistemological assumption was that dialysis social workers were honest about their patient experience. To assist in my goal that the dialysis social workers would be truthful with responses, I assured the participant before the inquiry that all identifying information would remain anonymous. I introduced myself as a medical social worker; this study is part of my Ph.D. program in Medical Social Work, and I was previously a dialysis social worker. I believed these assurances allowed the participants to speak openly and honestly about the perceived knowledge of strategies to overcome the barriers (Surmiak, 2019). This also improved my trustworthiness.

Axiological assumptions refer to the idea that qualitative research is value-laden and biased and that these values must be understood as the critique of ideologies

promotes needed social change (Creswell, 1994; Culbertson, 1981). My axiological assumption was that my bias might surface during the interview. This assumption is necessary as bias could negatively impact the data analysis. I limited this bias by using Saldana's (2021) descriptive coding techniques which involve first and second-stage coding to help decrease the overall chance of bias.

Scope and Delimitations

This research focused on a simple qualitative inquiry of dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients. The study was ultimately intended to identify any effective strategies. This focus was chosen as a strategy to overcome the interaction of biopsychosocial-spiritual components to barriers that had yet to be identified for Black dialysis patients, and this was a gap in the literature. Additionally, the aspect of the study from a social worker's perspective was that dialysis social workers were typically the primary source of EOL information for patients, so their experiences were necessary for identifying strategies (O'Riordan, 2016). Moriarty (2011) indicated that qualitative studies are best utilized for social care, which was the aim of this study.

The scope of this study was limited to dialysis social workers who worked with Black dialysis patients in the Renal Network region of the ESRD National Coordinating Center. This region covers Virginia, West Virginia, Maryland, and the District of Columbia. This excluded other dialysis healthcare providers, patients, and medical social workers who did not work in dialysis. The dialysis social workers were required to

understand and speak English. The scope of this study was focused on strategies to complete EOL planning with Black dialysis patients. Dialysis social workers were legally and morally bound to give quality care to every patient regardless of their personal views (NASW, 2021). I interviewed ten dialysis social workers who were working with Black dialysis patients in the Network region (Vasileiou et al., 2018). However, this created a lack of generalizability as this was from the view of only the dialysis social workers and specifically their work with Black dialysis patients.

The conceptual frameworks most related to the study area that were not investigated include systems theory, biopsychosocial theory, and theories related to racial disparities in EOL care. Systems theory was based on the idea that behavior was influenced by various factors working together as a system; however, my study aimed to seek the intricate details of how to overcome the barriers, not the cause of the barriers. Theories related to racial disparities were not chosen as my study did not solely examine racial disparities but rather how EOL planning could be achieved by overcoming racial disparities in health care. Finally, biopsychosocial theory was not chosen as the more inclusive BPSS model addressed issues related to spiritual needs, which are an essential aspect of EOL planning.

The study might be transferable because it included thick, rich quotes that could apply to chronically ill patients in need of support for EOL planning. However, transferring the results to different populations might have been difficult, as other racial groups might not have similar biopsychosocial-spiritual factors.

Limitations

The limitations of this study relate to the qualitative design that was utilized. The qualitative design of this study was meant to explore the complex perceptions of dialysis social workers. This was considered a limitation as the qualitative study method might not have been transferable to other populations and situations.

The lack of generalizability was another limitation of the qualitative method. However, Cypress (2017) and Percy (2015) indicated that thick and rich reporting throughout this study could have helped improve validity or trustworthiness, which might have led to transferability.

Another limitation was the use of dialysis social workers as participants. The limitation was that I was a part of the population, which might have influenced my perceptions as I viewed EOL planning and transplantation as very important things that were a needed part of kidney disease care. This also limited the population's views to those of dialysis social workers and their values and beliefs. Utilizing the Region network and the snowball sampling method facilitated the identification of necessary interviewees. However, due to time constraints, I was only able to conduct eight interviews with social workers. This limited sample size restricted the overall generalizability, as the perspectives of a small number of social workers might not have fully represented the broader views on overcoming barriers faced by dialysis patients. Additionally, the region encompassed only Virginia, West Virginia, Maryland, and the District of Columbia, further limiting the scope of viewpoints to this specific area.

Notably, responses were only obtained from social workers in Virginia and Maryland, which further constrained the generalizability of the findings.

The bias for the study may have included researcher bias. Researcher bias in qualitative research occurred when the researcher intentionally or unintentionally influenced their results to favor a specific outcome (Creswell, 1994). I was invested in wanting to find ways to overcome barriers and so may have inferred ideas that did not reflect the social workers' intended meaning. I used reflexive journaling, peer debriefers, and member checking to help decrease the issue of bias.

Significance

This study was significant because it filled a gap in understanding by focusing on the dialysis social workers perceptions of strategies that incorporated the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients. The results of this study could have aided dialysis social workers in identifying needs, concerns, and strategies that might have assisted Black dialysis patients in overcoming these biopsychosocial-spiritual barriers and completing EOL planning. Resolving these issues could have created better access to transplants and a better quality of care. The study could have influenced policy in how EOL planning was addressed for all populations to ensure individuals' needs and values were supported and encouraged during this phase of their lives.

Potential implications for positive social change were improved delivery of care and services to Black dialysis patients. With successful EOL planning, biopsychosocial-spiritual barriers for Black patients could have been decreased, and positive social change

could have been made. EOL planning could have helped Black dialysis patients have better health outcomes and met their health values and goals. With successful EOL planning, Black patients might have had better connections with their families and communities as they seek support and understanding and provide their health choices to others. The potential to become part of the transplant list and extend their lives increased with better EOL planning. EOL planning also offered Black patients the opportunity to decrease the aggressive care they received and improved their quality of life. EOL planning could have had a significant impact on the life of a Black dialysis patient.

Summary

Chapter 1 offered a view of Black patients experience with EOL care disparities who have ESRD and CKD. The disparities affected many areas of their care and were related to physical, psychological, social, spiritual, and historical factors. EOL planning could have assisted patients in overcoming these disparities; however, it was well known in renal care that these biopsychosocial-spiritual disparities affected EOL planning for Black patients. Nephrologists tended to avoid EOL discussions, and dialysis social workers became patients' primary purveyors of health information and EOL planning (O'Riordan et al., 2019; see also Amro et al., 2016; Davison, 2010). Dialysis social workers were tasked with understanding and developing strategies to overcome these biopsychosocial-spiritual barriers. However, strategies and perceptions of strategies to overcome these barriers had yet to be discovered. This study's research problem was to identify strategies that incorporated the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis

patients. This was explored through a qualitative study's conceptual framework of the BPSS model. Information was also provided on a synopsis of the conceptual framework, the nature of the study, definitions, and assumptions. Finally, information was provided on this study's scope, delimitations, limitations, significance, and social change.

Chapter 2 was intended to provide a review of the literature relevant to the background and purpose of this simple qualitative study of dialysis social workers' perceptions of how to overcome EOL planning barriers for Black patients. Chapter 2 included an introduction to the chapter, a literature search strategy, an explanation of the conceptual frameworks used in the study, and a summary.

Chapter 2: Literature Review

Introduction

The problem addressed was that dialysis social workers struggled to identify strategies to help Black patients overcome the physical, psychological, social, and spiritual barriers and complete EOL planning. This study's purpose was to explore the perceptions of dialysis social workers regarding strategies to overcome the biopsychosocial-spiritual barriers to Black patients' EOL planning. Such a study was necessary as the disparities in the quality of EOL care for Black patients due to well-documented disparities (Anh et al., 2021; Cronin, 2014; Cukor & Kimmel, 2010; Eneanya et al., 2018; Foley et al., 2018; Harding et al., 2017; Hilliard et al., 2013; Saeed et al., 2023; Senteio & Callahan, 2020; Song et al., 2010; Thomas et al., 2013), but there was little research addressing these barriers. Mayeda and Ward (2019) completed a literature review of strategies for overcoming barriers to EOL planning with minorities; however, they did not focus on the support and services that dialysis social workers could offer. This research was needed to examine how dialysis social workers could identify strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients.

In this chapter, I reviewed the literature search strategy and the theoretical framework that guided this study. Concepts that were significant to the study were examined in this section, with a focus on how dialysis social workers could identify strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients.

Literature Search Strategy

I used several academic databases and search engines for relevant peer-reviewed articles. These included Google Scholar, Thoreau, SAGE Journals, SocINDEX, ResearchGate, and PsycINFO. Between October 2022 and November 2023, I conducted an exhaustive search for related peer-reviewed literature published within the last twenty years, which focused on overcoming biopsychosocial-spiritual barriers to EOL planning for Black dialysis patients. Initially, I attempted to locate articles limited to the previous five years; however, little research on this topic was found, so I extended the research to ten years, fifteen years, and finally, twenty years. My results indicated that during the last twenty years, existing studies identified barriers to EOL planning and differences between Black and White patients. Still, more research needed to be done to address these differences. More recent articles attempted to pinpoint why there were differences. Still, they had only begun to scratch the surface of overcoming these barriers without addressing how dialysis social workers could assist.

This review also provided information on seminal research related to the conceptual framework. I also utilized completed dissertations located in the Walden University Library. I located research articles using keywords such as *EOL planning*, *dialysis and medical social work*, *Black dialysis patients*, *chronic kidney disease*, *racial discrimination*, *systemic racism*, *advanced directives*, *end-stage renal disease*, *kidney disease*, *death*, *dying*, *BPSS model*, and *advanced care planning*. Various combinations of these key terms were used to search the databases for relevant literature to include in this review.

Sulmasy (2002), BPSS model was used as the theoretical framework for this study. The BPSS model had been used extensively in palliative and EOL care as it acknowledged the interaction between a patient's physical, psychological, social, and spiritual aspects of care (Batstone et al., 2020). The BPSS model provided a context to Black patients' experiences, perceptions, and behaviors by understanding how their overall mind, body, psyche, and spiritual beliefs and values impacted their identity and knowledge of their medical status and EOL needs (Beng, 2004). Saad et al. (2017) stated that the biopsychosocial-spiritual model was a holistic and humanistic approach to the healthcare system and linked this model to the Physician's Pledge on the Declaration of Geneva (Declaration of Geneva, 1948). When applied to patient care, this holistic theory focused on all intrapersonal interactions, including the mind, body, psyche, and spiritual beliefs, along with extra-personal connections such as their environment, family, friends, and community (Galbadage et al., 2020). The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) required spiritual assessment to be part of the plan of care for patients, which had led to routine use of assessments based on a biopsychosocial-spiritual model for chronically ill patients (Chochinov & Cann, 2005; Sheehan, 2005; Woll et al., 2008). The National Association of Social Workers standards and practice of EOL planning (NASW, 2021) also stated that social workers who practice EOL care must be mindful of the person and their values and beliefs, which aligned well with the BPSS model. As such, the BPSS model could be applied to understand better how dialysis social workers grasp the experiences of Black dialysis patients and their families and the

perceptions they have about strategies they used to help when working to overcome biopsychosocial-spiritual barriers to EOL care for the target group.

Sulmasy (2002) noted that healthcare professionals should take a holistic approach to the whole person. The BPSS model comprised of four specific parts or domains: physical, psychological, social, and spiritual. Engel (1977) presented the original biopsychosocial theory for the healthcare profession. As with the expanded BPSS model, his original theory identified that each domain influenced the others. In contrast, White et al. (1996) introduced an ecological model of patient care that also recognized that the patient was influenced by their environment. However, neither of these theories identified the impact of spirituality or addressed a patient's death. Sulmasy's BPSS model identified that the domains are fluid and that the biological, the psychological, the social, and the spiritual are not separable from each other and interact with and influence other aspects of the person.

Applications in the Literature

Song and Hanson (2009) used the BPSS model to examine whether Black dialysis patients' EOL treatment preferences were affected by their psychosocial and spiritual ideals. However, the researchers noted that further research was needed, as the spiritual domain was not the only factor in patient preferences. Additionally, Song et al. (2011) used the theory to explore the awareness of patients' families or surrogate decision-makers of patients' values and beliefs that affected their EOL decision-making. Galbadage et al. (2020) examined how the theory affected patients with COVID-19 who were dying in hospitals alone. The researchers found that all domains were essential to

EOL planning. Galbadage et al. also noted that training for professionals and better connections with families during the EOL planning process was needed. Throughout EOL research, the BPSS model had been used to address disparities for Black patients, minorities, and marginalized patients overall. The 2021 Compassion and Life Research Scan, which reviewed 58 articles about EOL planning for marginalized populations published between 2018 and 2021, highlighted the importance of the BPSS model to address disparities.

End-of-Life Care and Kidney Disease

Overview of End-of-Life Planning

End-of-life (EOL) planning involves various aspects or items that can assist the patient in ensuring their EOL wishes are honored (National Health Services, 2022). The body of literature indicates that the aspects of EOL planning included completion or preparation of advanced directives, living will, will, medical and financial powers of attorney, do not resuscitate orders, other state-related items, and discussions with family or those who will assist in carrying out these wishes (Bansal & Schell, 2018; Cronin, 2014; Cukor & Kimmel, 2010; Eneanya et al., 2018; Foley et al., 2018; Harding et al., 2017; Song et al., 2010). Planning for EOL could have allowed a person, if done in a timely fashion, to make informed decisions (Bansal & Schell, 2018). Items such as advanced directives, living wills, and do-not-resuscitate orders could have provided information about patients' medical care preferences when they cannot communicate their wishes (NHS). The NHS indicated that the powers of attorney items ensured that when a patient cannot make their own decisions, someone was appointed to make their medical

and financial decisions and to take care of items such as bills. A will ensured that once the patient was passed, their personal belongings are cared for in accordance with their wishes.

These items provided the patients, their families, and executors with information about their preferences for care before and after death. Wright et al. (2008) noted that EOL discussions were associated with less aggressive medical care and earlier hospice referrals, which improved quality of life and better bereavement adjustment. Detering et al. (2010) indicated that advanced care planning improved the quality of EOL care and patient and family satisfaction while reducing stress, anxiety, and depression. Davison (2002) noted that quality EOL care needed to be a priority in dialysis facilities but that the limited EOL items that are completed might not have reflected the patient's priorities. Advanced directive and living wills could have included information about patients' preferences for medications, procedures, and support during their last days. Local advanced directive forms in Virginia, included sections related to physical care, mental health care, medications, and donations of body parts after death (Virginia Advanced Directive.org, 2018). All states had their forms and local requirements for these items. To facilitate completion, the Virginia Legal Code on Advance Directives (1983) had determined that advanced care directives did not have to be notarized or prepared by a lawyer.

Forms are widely available, and no specific format is required, allowing individuals easier access to completion. The EOL planning is complex; many wish to avoid considering their final days. However, Ladin et al. (2018) noted that most patients

did not understand EOL terminology and lacked discussions with meaningful content. However, with help, care, kindness, and providing and gathering information, dialysis social workers could successfully assist patients in completing these items. For patients and those with whom they speak, conversations with family, friends, and executors remained difficult as many people struggle with the task. Gerst and Burr (2008) and Hopp and Duffy (2000) noted that White patients were more likely than Black patients to finish EOL planning items and have conversations with their families. Holley (2003) noted that many had conversations with their family but not their care teams, so their preferences were not communicated to care teams. Quill (2000) stated that patients, families, and care teams often resisted these conversations. Hines (1999) noted that patients wanted to engage their families in these conversations to support future decision-making. Song et al. (2010) noted that patients also desired to discuss these with their medical care providers.

Nonetheless, You et al. (2014) noted that though EOL conversations occurred infrequently, specific items were the most essential parts of these talks. These critical items were preferences of care, values, prognosis, fear and concerns, and questions about goals. Discussions that included these items produced better care and higher patient satisfaction. However, several researchers had shown that patients had less EOL planning due to race, ethnicity, geography, and other factors (Du et al., 2015; Huo et al., 2021; Lee et al., 2016), which means that these essential aspects of talks were often omitted in conversations with patients.

Hence, not only was the completion of forms necessary but discussions with care providers and decision-makers were also essential. Mack et al. (2010) reported that when patients had EOL discussions, they received care aligned with their wishes. On the other hand, it was essential to note that maintenance on dialysis did not equal quality of life and that this should have been part of the EOL planning discussion (Castro, 2018; Fassett et al., 2011).

Overview of Kidney Disease and Dialysis

Kidney disease affected hundreds of thousands of people each year. The initial diagnosis for kidney disease may be acute kidney injury (AKI), which, over time, and in the absence of appropriate care or lifestyle changes, could have resulted in chronic kidney disease (CKD) and, ultimately, ESRD (National Institute of Health, 2021). However, many people do not become aware of their kidney disease until they have reached the ESRD stage. The treatment for kidney disease, when it had reached the point that the person had lost 85% to 90% of their kidney function, was known as dialysis (National Kidney Foundation, 2023).

Many kidney disease patients received dialysis to perform the functions typically carried out by healthy kidneys (NKF, 2023). According to the National Kidney Foundation, there are various forms of dialysis. Still, the most utilized form was hemodialysis, where a person was connected to a machine, and their blood was filtered for several hours during multiple sessions a week to replicate kidney function. The typical dialysis schedule was three times a week for approximately three hours at a time.

However, alternatives included no treatment, peritoneal dialysis, and transplants for those who were medically eligible and able to locate a donor.

The NKF (2023) noted that those with acute kidney injury (AKI) might have recover. Still, those with end-stage renal disease (ESRD) had a decreased life expectancy, with most were expected to live at least five to ten years on dialysis. The USRDS (2020) reported that 2018 dialysis cases rose 0.2% to 131,636 patients beginning dialysis. The typical dialysis population was older individuals, though Black patients are overrepresented. Albertus et al. (2016) reported that from birth, the American lifetime risk of ESRD in White males was 3.1%, Black males 8.0%, White females 2.0%, and Black females 6.8%. The USRDS also reported that Blacks patients were 3.8 times more likely than other racial groups to require dialysis.

The USRDS reported that at the end of 2018, 554,038 individuals were receiving dialysis. The mortality rate was 131.5 per thousand patient-years. Hence, people with ESRD experienced significant disease burden and elevated mortality risk. While on dialysis, patients might have received treatment three to seven times a week depending on individual treatment plans. Their treatment and care became a primary concern in their lives, and end-of-life (EOL) discussion and advance care planning (ACP) became essential.

Kidney disease could have been terminal, and EOL planning should have begun with patients at the time of diagnosis; however, many have not had these discussions with their nephrologist. EOL care in the context of kidney disease was shown in the research as an essential and ongoing need within the ESRD community and specifically for Black

patients, as the biopsychosocial-spiritual barriers hindered their completion of EOL planning (Anh et al., 2021; Cronin, 2014; Cukor & Kimmel, 2010; Eneanya et al., 2018; Foley et al., 2018; Harding et al., 2017; Hilliard et al., 2013; Saeed et al., 2023; Senteio & Callahan, 2020; Song et al., 2010; Thomas et al., 2013). Russ et al. (2007) noted the importance of early conversations to ensure patients understood their prognosis and available options (see also Song et al., 2013). Bansal and Schell (2018) noted the importance of beginning EOL planning early once a patient is diagnosed with ESRD and revisiting the topic continually throughout care with patients. Early intervention was preferred for EOL provision throughout the dialysis community for Black patients. Saeed et al. noted that Black patients were less likely to believe that their health would worsen and so did not see a need for EOL planning. Thus, the biopsychosocial-spiritual barriers remained. Hence, many researchers had tried to identify ways to overcome these barriers for Black patients. Davison and Torgunrud (2007) and Jones et al. (2021) worked toward identifying ways dialysis professionals could connect with patients better to enhance the completion of EOL planning. They found that creating relationships with patients and developing education directed toward minorities helped to overcome the biopsychosocial-spiritual barriers. Wright et al. (2008) and Anh et al. (2021) found that EOL discussions were associated with less aggressive medical care, improved quality of life, and better bereavement outcomes when patients had access to information and engaged in conversations with both family and providers.

The practice community noted that initial EOL planning should include information about the patient's understanding of their diagnosis, prognosis, available

options, expected outcomes, and the disease trajectory so that patients can better understand their health (Amro et al., 2016; Bansal & Schell, 2018; Davison, 2010; Eneanya et al., 2018; Hing et al., 2016; Jennings & Johanson, 2018; Lazenby et al., 2017). They agreed that an EOL plan should include the patient's primary support so that all parties could understand the same information (Yang et al., 2016). The next step would be to provide additional support and connections to help individuals communicate their personal preferences—including beliefs and values—regarding their physical (biological and environmental), emotional, and spiritual needs with both family and providers (Jones et al., 2021). Patients and families should also be provided with a list of essential documents to assist and encourage completion. These items should include an advanced directive, living will, will and testament, medical and financial powers of attorney, do-not-resuscitate orders, and other state-specific documents to ensure the patient's wishes are honored (Anh et al., 2021; Eneanya et al., 2016, 2018; Saeed et al., 2023). These discussions and documents may require multiple meetings to complete, but timely completion was essential, as patients and families did not know when the patient's condition might deteriorate and limit their ability to express personal goals and wishes.

Patients with ESRD could survive for years, but because many diagnoses were not caught in the early stages, survival was not guaranteed, and choices needed to be made in an informed and timely manner to ensure that the patient met their personal goals for care (Bansal & Schell, 2018). Yan et al. (2013) noted that Black patients typically survived longer on dialysis than their White counterparts. Most patients were not fully informed of their diagnosis, prognosis, disease course, and available options and

outcomes (Golf et al., 2015; Isenberg & Trisolini, 2008; Song et al., 2013; Tonkin-Crine et al., 2015). Many patients were provided with no other information than that they need dialysis, and at times, they were not told that this disease is terminal (Eneanya et al., 2016). When a patient received dialysis, part of the required service included EOL discussions with the social worker (Saeed et al., 2019). Most facilities that followed the Medicaid and National Kidney Foundation (NKF) guidelines required social workers to talk with patients at least once per quarter (NKF, 2023). Social workers had various techniques to encourage patients and programs to document the requirements and to complete EOL planning. Many dialysis companies had in-house medical records programs that allowed social workers to document completion or attempts to complete EOL planning with the patients (Senteio & Callahan, 2020). Additionally, social workers were allowed the freedom to develop their techniques or strategies to encourage EOL completion, such as through creative bulletin boards, education, and one-on-one talks (NKF, 2023). However, EOL planning requirements only encouraged the completion of advanced directives (NKF, 2014). EOL planning that could have provided quality care and life should have included discussions with medical providers and families that provided information about the patient's values, beliefs, and preferences while completing all forms that could help ensure these preferences are followed (Castro, 2018; Fassett et al., 2011).

Social Workers' Place in Dialysis Patient Support

ESRD was recognized as a terminal illness for which nephrologists did not routinely provide EOL planning to patients and families (Anh et al., 2021; Eneanya et al.,

2018; Hing et al., 2016; Jennings & Johanson, 2018; Lazenby et al. 2017). Due to federal guidelines for dialysis provisions, dialysis social workers were tasked with being the primary providers of EOL planning for patients (NKF, 2014). Wang et al. (2018) noted that dialysis social workers felt that it was their duty to provide and educate patients about EOL planning. However, Berzoff et al. (2020), Heyman & Gutheil (2003, 2006), Kramer et al. (2003), and Taels et al. (2021) noted that dialysis social workers lacked training and education to provide this service confidently and risked inserting their values into patients and families' preferences. Cohen et al. (2020) examined strategies to overcome the primary barrier of the patients not having EOL discussions with providers. They developed training for providers and dialysis social workers on how to have EOL discussions. However, the author noted that the dialysis social workers remained concerned that patients would lose hope even though 71% desired EOL conversations. Taels et al. (2021) found that social workers who utilized a holistic approach provided better support for palliative care patients. However, in general, they were not well prepared. Perry et al. (2005) focused on addressing barriers but looked at peer mentoring rather than social work interventions. They found that peer mentors had the greatest impact on Black patients. However, as the authors noted, this could acknowledge cultural differences and enhance trust but might have been limited by the peer mentor's knowledge. Hence, there was a need to understand how dialysis social workers could overcome the barriers to completing EOL planning for Black dialysis patients.

Eneanya et al. (2015) noted that dialysis social workers may have delayed discussions, or patients may have been less receptive due to a lack of recognition that the

patient was nearing end-of-life. Recognizing impending death might have helped patients become more receptive and allowed dialysis social workers to feel more comfortable initiating EOL planning discussions. Altilio et al. (2008) noted that the additional problem: that often, due to competing requirements, dialysis social workers were unable to dedicate sufficient time to sit with patients and families for EOL discussions in a meaningful way. Goff et al. (2015) noted that barriers to EOL planning for dialysis social workers included the need for more training, support from other staff members, caseloads, and difficulty scheduling time. Additionally, Ladin et al. (2018) noted that most patients did not understand EOL terminology.

Patients continued to desire that dialysis social workers to provide more information and support for EOL planning (Davidson, 2008; Saeed et al., 2023). Dialysis social workers effectively provided supportive services through the use of the Biopsychosocial- spiritual model (Gehlert & Browne, 2019). Reckrey et al. (2014) noted that dialysis social workers played an essential role in supporting patients' EOL planning.

Dialysis social workers utilized a holistic method to address patient concerns (Wang et al., 2018). This approach was needed when addressing a topic such as EOL planning, which affected all domains of a person's life. Heyman and Guthiel (2006) noted that dialysis social workers tended to see the patient issue as the primary barrier to EOL completion. However, EOL planning was essential to patient's lives, and dialysis social workers needed to find ways to address and overcome these barriers (Black, 2007). However, Berzoff et al. (2020) noted that time, training, and cooperative commitment limited dialysis social workers' ability to focus on EOL planning (see also Arthur, 2015;

Christ & Sormanti, 2000; Kwon, 2016). Kwon noted that with a population aging, dialysis social workers needed education to feel confident in providing EOL planning and support. Johnson et al. (2016) noted that dialysis social workers were in a prime position ethically and due to their professional competencies to provide EOL planning.

Black Patients' Experience With End-of-Life Planning and Barriers

In general, Black patients' experience with medical care has historically been less favorable than that of their White counterparts. Ladin et al. (2018) noted that EOL discussions among dialysis patients were associated with better patient outcomes, which was concerning given that many studies found that nephrologists tended to avoid such discussions (O'Riordan et al., 2019; see also Amro et al., 2016; Davison, 2010). Bazargan and Bazargan-Hejazi (2021) completed a cross-sectional longitudinal study that noted the many disparities in EOL care for Black patients but did not address how to overcome these biopsychosocial-spiritual barriers. Several studies examined nephrologists' lack of EOL discussions and have generally found that these conversations were neglected or avoided (Amro et al., 2016; Berzoff et al., 2020; Cohen et al., 2020; Davison, 2010; Goff et al., 2015; O'Riordan et al., 2019).

The research indicated that EOL discussions were not occurring but that Black patients felt that these discussions were needed (Song et al., 2010). There remained several barriers to EOL planning for Black dialysis patients, including physical, psychological, social, and spiritual aspects. These barriers included Black patients being informed less about their health conditions and their severity, being less receptive to EOL planning due to conflicts between spiritual beliefs and perceptions of palliative care, fear

that they were not being offered treatments available to other patients, resistance from family members' to alternatives such as hospice care, and gaps in knowledge about EOL and how to complete related forms (Anh et al., 2021; Eneanya et al., 2016, 2018; Saeed et al., 2023). This section will examine these challenges through the lens of biopsychosocial-spiritual concepts.

Biological and Physical Barriers

Sulmasy (2002) defined the BPSS model as a holistic framework in which each domain influences the other. In health care, EOL planning involved barriers that were affected by each of life domains. The first domain was the biological or physical aspect. Sulmasy noted that the biological domain could be viewed in various ways- through individual body parts, the body, its interaction with the environment, or the disease itself. The research showed that this definition represented the biological or physical barrier experienced by Black patients.

The first aspect of the physical barrier for Black patients was the disease itself. It was well documented that Black people had a disproportionately higher rate of End Stage Kidney Disease (ESRD) (Anh et al., 2021; Eneanya et al., 2018; Hing et al., 2016; Jennings & Johanson, 2018; Lazenby et al., 2017). The National Kidney Foundation (NKF, 2023) and the United States Renal Data System (USRDS, 2022) noted that Black patients were three times more likely than White patients to have ESRD. Albertus et al. (2016) reported that from birth, the American lifetime risk of ESRD in White males was 3.1%, Black males 8.0%, White females 2.0%, and Black females 6.8%.

Beyond being more likely to have ESRD and require dialysis, Black patients were more likely to have been diagnosed with kidney disease at a later stage in life (Lissanu et al., 2019). Many researchers identified this as part of the systemic racism that occurred for Black patients, resulting in less frequent medical services contact (LaVeist et al., 2000). This lack of services, in turn, meant that many Black patients depended on their dialysis center staff for all their medical needs (Davidson, 2010). The result of not having additional medical services- such as a primary care physician, specialty physicians, or other necessary providers- hindered their transplant process, as appointments with these individuals were required to be placed on the transplant list (NKF, 2021). Buford et al. (2023) noted that Black patients were 27% less likely to obtain a transplant than their White counterparts.

Additionally, Black patients were less likely to have received predialysis care, and they were more likely to undergo aggressive forms of dialysis, receive nonbeneficial medical care at the end of life, and wait longer for transplants than White patients (Anh et al., 2021; Foley, 2018; Harding, 2017; Hilliard et al., 2013; Senteio & Callahan, 2020; Thomas et al., 2013). Foley et al. found that minority patients were less likely to discontinue dialysis or receive hospice care, and more likely to die in a hospital. Eneanya et al. (2018) noted that Black patients received more aggressive care, including their selection of dialysis modality. Kwak and Haley (2005) noted that Black patients preferred the use of life support. Shen et al. (2020) noted that Black patients were also 30% less likely than their counterparts to choose less invasive forms of dialysis. The more aggressive care affected their bodies negatively and contributed to a poorer quality of life.

These factors- including a biological predisposition to kidney disease, limited access to medical care, and aggressive treatments they faced- lent an urgency to identifying ways to overcome these barriers and develop EOL planning that could guide and support their medical care. Additionally, this barrier relates to Black patients' need for comprehensive physical care, including early intervention, access to information, and support to ensure their physical needs were met (Cronin, 2014). Overcoming this barrier could have improved the quality of life for Black patients.

Psychological Barriers

The next concept or life domain was that of psychological. This aspect was related to the individual's attitudes, self-esteem, values, coping skills, and personal beliefs (Bergenholtz et al., 2020). These ideas are closely intertwined with the other domains and had historically made it difficult to distinguish these barriers from the others.

In general, psychological barriers stemmed from the patient's values and preferences. Research indicated that values attributed to racial groups might have influenced their EOL preferences. Davison (2017) noted that 61% of Black dialysis patients regretted beginning dialysis. Saeed et al. (2019) noted that most Black patients wanted to have discussions about EOL, regretted starting dialysis, preferred treatments that relieved pain as well as resuscitation. Kwak and Haley (2005) noted that Black patients preferred life support over less invasive EOL measures such as palliative care. Nwamaka et al. (2017) noted that Black patients received a lower rate of palliative care services.

These values and preferences might have been shaped by limited information and a personal desire to preserve life and prolong survival. Janssen et al. (2013) reported that only 30% of patients had EOL discussions, and those Black patients generally felt that their nephrologist had poor communication, though over 50% wanted to have EOL discussions. Because of the lack of discussion, minority patients were less likely to discontinue dialysis or receive hospice care, and more likely to die in a hospital than their White counterparts (Foley et al., 2018; Garrido et al., 2014; Tamura et al., 2010). Ashana et al. (2022) noted that many clinicians often claimed Black patients were unwilling to discuss EOL planning, though patient surveys contradicted this. Patients could not make informed decisions without discussing their prognosis and outcomes, which ultimately shaped their preferences.

Many researchers showed that Black patients desired EOL discussions and preferred they involved their families (Anderson et al., 2019; Ceckowski et al., 2017). Anderson et al. (2019) emphasized the importance of support from caregivers, as they help shape the patient's preferences and values. However, Saeed et al. (2023) noted that Black patients were less likely to believe their health would worsen over the next twelve months. Jones et al. (2021) noted that this related to systematic racism in medical care, as the mistrust that Black patients had in the medical system was reflected in their personal beliefs about their health. This belief is one of the primary psychological barriers to EOL planning, rooted in the perception that planning was unnecessary for something not seen as imminent.

Social Barriers

Social barriers also played a role in the completion of EOL planning for Black patients. Social barriers related to the environment that surrounds the patient and how this affected them (Han et al., 2019; Ladin et al., 2018). Ladin et al. (2018) noted that patients tended not to complete EOL planning due to socially constructed rules, including those of their family, friends, and community circle. Wicher and Meeker (2012) noted that Black patients rated their care poorer and reported concerns regarding family support. Saeed et al. (2019) noted that 71 percent of patients wanted their quality of life discussed with the medical staff, and 50 percent wanted assistance with their social needs. Han et al. (2019) identified that part of the social barrier was patients' increasing dependence on family for care and support, which led to a loss of social engagement. Over 85 percent of patients relied on their families for support and to make choices for them about their quality of life (Saeed et al.). This loss of autonomy and increased dependence made obtaining care more difficult, as Black dialysis patients tended to be predominately poorer and lacked adequate support (Nair et al., 2021). Sanders et al. (2019) noted that patients and their communities expressed a desire to understand and control the end of life, but without clear discussions with healthcare providers, this could not occur. This lack of support created challenges across multiple aspects of care.

Black patients lacked the emotional, financial, and social support often available to other patient groups (Han et al., 2019). Additionally, they required social support, including necessary support such as transportation to and from dialysis (Pham et al., 2019). One of the primary barriers to EOL planning was the basic ability to access

necessary care appointments- including dialysis, nephrology, and other medical services (Cervantes et al., 2020; Powathil & Kr, 2023; Tian et al., 2023). Transportation remained a widespread issue for dialysis patients nationwide, as they typically attend dialysis sessions three times a week for several hours (NKF, 2023). EOL discussions could not occur if patients were unable to attend their appointments. Mayeda and Ward (2019) reported that access to healthcare was a primary barrier for Black patients. This seemingly basic barrier posed a significant obstacle to both EOL planning and general care for Black dialysis patients. Support from friends, family, and the broader community was essential to help patients overcome these challenges, access services, and complete EOL planning- ultimately improving their quality of life and ensuring care aligned with their personal goals and values.

Spiritual Barriers

The final concept of the BPSS model is the spiritual domain. Saad et al. (2017) noted that this domain is fluid and dynamic. For the purposes of this analysis, the spiritual domain is defined as “the search for ultimate meaning, purpose, and significance, concerning oneself, family, others, community, nature, and the sacred, expressed through beliefs, values, traditions and practices” (Puchalski et al., 2014, p. 10). This definition effectively captures the overarching themes presented in the current body of research.

Gordon (2001) and Salter et al. (2015) noted that for Black patients, their fears were influenced their spiritual beliefs. Saaed et al. (2023) noted that racial differences existed in beliefs about future health and the belief that death was not imminent. This

belief might have been detrimental to their decision to complete EOL planning. Rhodes et al. (2015 & 2017) noted that Black patients feared EOL planning might hasten their death or cause providers to deliver lesser care. Carr (2011) reported that they did not complete EOL forms due to their belief that God controlled their death. Torke et al. (2005) reported that Black patients found it unnecessary though they were willing to talk about their EOL plans, but there were several barriers, including the belief that their death is not imminent, and God was in control. Garrido et al. (2014) and Salter et al. (2015) noted that Black patients were more likely to desire treatment that prolonged their lives, which might have directly related to their belief in divine control over the timing of death.

Hence, spiritual care remained problematic as healthcare providers continued to struggle with the implementation of this aspect of care even though spirituality played an essential role in EOL planning, especially for Black patients (Delgado-Guay, 2014; Puchalski, 2001; Puchalski et al., 2009; Saad et al., 2017; Williams, 2006). However, Black patients, along with others, identified spiritual aspects as essential to their decision-making. Kub et al. (2003) noted that they were concerned with how their decisions aligned with their spiritual values and beliefs.

Overall, these biopsychosocial-spiritual barriers negatively impacted Black dialysis patients, and dialysis social workers should seek strategies to overcome them. Additionally, Sulmasy (2002) noted that these domains or concepts were difficult to distinguish from one another as they flowed, connected, and influenced each other. Hence, the BPSS model related to the barriers that affected Black patients, as all of these interconnected domains affect the individual. Overall, ESRD and dialysis created a

reduced quality of life for Black patients, and with the completion of EOL planning, their care and values were met, and the quality of their lives could be improved.

Medical Care and Black Patients

Throughout history, the treatment for White and Black patients had differed significantly, leading to an underlying fear among Black patients toward the medical system. This systemic bias stemmed from multiple concerns, such as prior abuse and current racial discrimination. Odonkor et al. (2021) noted that Black patients received care inconsistent with current clinical guidelines. Egede (2006) noted that Black patients generally received a lower level of care. Chapman et al. (2013) and Penner et al. (2014) also noted an implicit physician bias, adding to the racial disparities that patients experienced. Mebane et al. (1999) examined whether there was a difference in care related to the physician's race. They found that White physicians were more likely to find physician-assisted suicide an acceptable treatment and tube-feeding a heroic measure than their Black counterparts. Jha et al. (2007) also noted that hospitals that provided care for larger populations of Black patients had worse performance scores. This systemic fear prevented many Black patients from seeking medical care and affected them in many other ways. Penner et al. (2009) and Dovidio et al. (2008) showed that this historical discrimination had created a systematic bias that deterred Black patients from adhering to recommendations made by their doctors, which in turn created ongoing health concerns. Odonkor et al. noted that Black patients had health disparities across multiple conditions, including stroke, traumatic brain injury, spinal cord injury, hip/knee osteoarthritis, fractures, and cardiovascular and pulmonary disease. These disparities, including

socioeconomic status (SES), was a contributing factor to disparities for Black patients' care and health outcomes.

In kidney disease, race was a significant factor in determining an individual's diagnosis. Kidney disease was found to be significantly more common among Black individuals (USRDS, 2020). Racial disparities in CKD were caused by inequities in major social determinants of health, such as education, employment, housing, criminal justice, and access to health insurance and care. In particular, the estimated glomerular filtration rate (eGFR) equations involved a race-based coefficient (Eneanya et al., 2022). The idea is that Black patients are more muscular, an idea based on historical beliefs rooted in slavery-era assumptions, and thus they have higher levels of serum creatine. This idea created a bias in renal disease as Black patients were not diagnosed as early as their White counterparts, leading to longer wait times for treatment and transplants. Gadegbeku et al. (2002) noted that this difference could be seen in managing Black patients' anemia and their treatment decisions regarding dialysis modality.

Systemic discrimination had created a system in which Black patients were less likely to receive transplants. Numerous researchers found that Black patients were less likely to receive a transplant due to fears related to medical care and support (Anh et al., 2021; Foley, 2018; Gordon, 2001; Harding, 2017; Hilliard et al., 2013; Salter et al., 2015; Senteio & Callahan, 2020; Thomas et al., 2013; Wentlandt et al., 2017). Wachterman et al. (2015) noted that Black patients were less likely to receive transplants due to mistrust, misperceptions, and miscommunication from their healthcare providers. Maleek et al. (2010) noted that Black patients had poorer transplant outcomes, such as graft failure and

mortality, due to these systemic fears and racial disparities in healthcare. In 2021, a joint task force between the NKF and American Society of Nephrologists called for removing race as a determinant for diagnosing kidney disease.

Abuse of Black Patients in Medical Care

Historical abuse of Black individuals had affected their trust in the medical system. LaVeist et al. (2000) noted that Black patients and other minorities had not benefited from medical advances and that racism persisted in training, medical practice, medical decision-making, the work environment, and research. This racism had led to systemic mistrust, as Black patients were wary of modern medical care due to a legacy of mistreatment (Jindra et al., 2021). Historically, Black people were abused and mistreated in the name of advancing science.

There were numerous incidents of Black people used for research without their consent not afforded to their White counterparts. A notable example was observed in the work of Dr. J. Marion Sims. Between 1846 and 1859, Dr. J. Marion Sims, considered the father of modern gynecology, operated on ten enslaved women (Wall, 2006). He performed surgery without anesthesia, based on the false belief that Black people could not feel pain. One specific woman underwent more than 30 surgeries to address her condition. The research was intended to develop surgical techniques to treat vesicovaginal fistula.

This racism throughout American history created multiple care denials for Black patients, as seen in the 1918 Influenza Pandemic (Krishnan et al., 2020). During the epidemic, persistent racism caused hospitals to turn away Black patients, leading to

significant loss of life. This discriminatory response was similar to during the 1862-1867 Smallpox outbreak and 1792-1793 Yellow Fever outbreak.

These ethical violations were also seen in the Tuskegee Syphilis Study, in which 600 Black men were promised free health care in exchange for participation (Lewis, 2018). In 1929, Black men diagnosed with syphilis were studied to determine if they exhibited different disease progression. In what is known as the Tuskegee Syphilis Study, the participants were unaware of their diagnosis, treatment options, or the study's purpose. Even after a treatment was identified, the men continued to receive no treatment and were observed without intervention. According to Lewis (2018), this study was the primary reason for the National Research Act of 1974 which established formal protections for humans' subjects in research.

Other experiments that supported concerns by Black patients about their medical care and the intentions of those providing it were seen in recent decades. Between 1960 and 1971, Dr. Eugene Saenger led experiments that exposed Black patients to whole-body radiation (Egilman et al., 1998). The patients were poor and did not provide consent; many were still otherwise healthy and employed when the experiments were completed. However, many of the experiments resulted in fatal or near-fatal outcomes. From the early 1950s to the mid-1970s, non-consensual medical research was conducted on Philadelphia's Holmesburg Prison inmates. Included testing for "herpes, staphylococcus, cosmetics, skin blistering chemicals, radioactive isotopes, psychoactive drugs, and carcinogenic compounds such as dioxins" (Hornblum, 1998). As was common at the time, the inmates were predominantly Black men.

These were just a few of the egregious research practices completed on Black patients. These and the many other research abuses conducted on Black patients had created a widely held mistrust of the medical community among Black individuals. Even recently, during the COVID pandemic, Black individuals were less likely to receive the COVID-19 vaccine, possibly due to the history of systemic racism (Rusoja & Thomas, 2021). Throughout history, Black people had learned that to trust the medical community was potentially harmful.

Disparities for Black Patients With Kidney Disease

There were multiple disparities affecting for Black patients with kidney disease. These disparities include biological, psychological, social, and spiritual. The primary biological disparity is that Black patients experienced ESRD and the need for renal replacement therapy or dialysis at a higher rate than their White counterparts. The USRDS (2020) reported that the number of dialysis cases in 2018 rose 0.2% to 131,636 patients beginning dialysis. The typical dialysis population was older individuals, though Black patients were overrepresented this population. Albertus et al. (2016) reported that based on lifetime risk from birth, the American lifetime risk of ESRD in White males was 3.1%, Black males 8.0%, White females 2.0%, and Black females 6.8%. The USRDS also reported that Black individuals were 3.8 times more likely to be represented than other races in this population.

There were also complicated psychological and social barriers that are intertwined for Black patients, including systemic and interpersonal racism and bias that had left many Black patients wary of engaging with the medial system (Ashana et al., 2021;

Bailey et al., 2017; Eneanya et al., 2022; Hauff et al., 2017; Laury et al., 2019; Saeed et al., 2023). Cultural differences and mistrust in doctors, and have resulted in Black patients having fewer conversations about EOL planning and lower rates of completion (Amro et al., 2016; Beach et al., 2010; Berzoff et al., 2020; Carr, 2011; Carr, 2012; Cohen et al., 2020; Cooper et al., 2003; Davison, 2010; Eneanya et al., 2016; Goff et al., 2015; Huskamp et al., 2009; Johnson et al., 2007; O'Riordan et al., 2019; Saeed et al., 2023; Siminoff et al., 2006).

Finally, spiritual concerns for Black patients also affected their care and decision-making (Bazargan & Bazargan-Hejazi, 2021; Eneanya et al., 2016; Perry et al., 2005; Song et al., 2009 & 2016; True et al., 2005). True et al. (2005) noted that Black patients were more likely to use spiritual coping methods and were less likely to have completed EOL planning. Rhodes et al. (2017) reported that Black patients perceived EOL planning as conflicting with their faith and religious beliefs. To fully address the needs of Black patients, dialysis social workers should consider the complex connection between ethnicity and spirituality in EOL decision-making. De Vries (2019) noted the importance of spirituality and religiosity for EOL planning with minorities and the potential role of church to help promote advanced care planning.

These overall biological, physiological, social, and spiritual intersecting disparities for Black patients needed to be considered to ensure their needs were met for them. Without understanding these domains, dialysis social workers struggled to identify strategies to address barriers to completing EOL planning for Black patients. However,

acknowledgment and support that addressed all these domains was considered a pathway for dialysis social workers to address these challenges.

Support for Method Chosen

Basic qualitative research focused on experience, perception, and behaviors, which is why the study selected this method. Studies that examined the experience of Black patients typically relied on understanding their experience through a qualitative method, whether this was a case study or phenomenological designs. This was demonstrated in Washington et al.'s (2016) which explored barriers to disease self-management among dialysis patients. Other qualitative studies that used interviews to identify barriers to end-of-life planning for Black patients included Anh et al. (2021) and Hilliard et al. (2013). However, studies examining barriers to EOL planning also employed quantitative methods to support barrier identification. Quantitative methods were used in studies such as Washington et al. (2016) that examined the need for social work interventions to address these barriers.

Additionally, Cukor & Kimmel (2010), Eneanya et al. (2016), Eneanya et al. (2018), Foley et al. (2018), Saeed et al. (2023), Song et al. (2010), and Thomas et al. (2013) used quantitative methods to identify the barriers for Black patients to EOL completion. Alternatively, studies relied on literature reviews to determine barriers, as were evident in Cronin (2014), Eneanya et al. (2017), Harding et al. (2017), and Senteio and Callahan (2020). Similar qualitative and quantitative methods were used to assess the Black experience and the role of dialysis social workers in renal care. However, studies that examined experience, perception, and behaviors relied on interviews. This supported

the use of interviews in the present study to explore how dialysis social workers addressed barriers faced by their Black patients. Heyman and Guthiel (2006), Kimura et al. (2020), and Nedjat-Haiem et al. (2022) utilized interviews to explore dialysis social workers' perceptions of the barriers to EOL planning, but they emphasized the need for continued efforts to overcome these challenges. Nedjat-Haiem et al. (2023) further found that dialysis social workers actively build relationships with patients to facilitate EOL planning. Their study also supported the notion that dialysis social workers served as the primary source of EOL planning and that their expertise contributed to overcoming these barriers. Thus, this study aimed to continue that line of inquiry by exploring dialysis social workers' perceptions through a qualitative interview-based approach. As Sandelowski (2000) noted, the goal of basic qualitative studies is to provide comprehensive description- an aim that guided this research.

Summary and Conclusion

At this time, research had not addressed how dialysis social workers could identify strategies that integrated physical, psychological, social, and spiritual components to address barriers to completing EOL planning for Black dialysis patients from the lens of the BPSS model, leaving no existing literature for comparison. Previous studies had identified disparities in EOL planning for Black patients, their desire to engage in EOL discussions, and the potential for improved quality of life through enhanced information and support (Anh et al., 2021; Foley, 2018; Harding, 2017; Hilliard et al., 2013; May et al., 2016; Senteio & Callahan, 2020; Thomas et al., 2013). These disparities contributed to mistrust in the medical community and heightened

psychological and social concerns (Ashana et al., 2021; Baily et al., 2017; Eneanya et al., 2022; Hauff et al., 2017; Laury et al., 2019; Saeed et al., 2023). Understanding these disparities was considered essential for developing strategies to address and overcome biopsychosocial-spiritual barriers. The BPSS model has been recognized as a useful framework for identifying various barriers to EOL planning (Song & Hanson, 2009). Clinicians needed to understand how Black patients could receive EOL information and planning while being supported across all life domains, in alignment with patient preferences (Gehlert & Browne [Chapter 2], 2019). There has been little research into overcoming these biopsychosocial-spiritual barriers, and dialysis social workers had the potential to meet this challenge (Reckrey et al., 2014). This gap highlighted the need for further research.

This chapter provided an overview and discussion of the study's related literature and theoretical basis. Chapter three included an introduction, the researcher's role, and the methodology chosen for the study. The next chapter included an explanation of the participant selection logic, the instrumentation, the procedures for recruitment, participation, and data collection, the data analysis plan, and a summary.

Chapter 3: Research Method

Introduction

Chapter 3 outlined the procedures and methods used in this study. It presented information about the study's purpose, the research design, and the rationale for selecting the design. Chapter 3 presented the researcher's role, the methodology employed, and the instrument used for data collection. Additional topics included the research question and the corresponding interview protocol. Finally, Chapter 3 detailed the data analysis plan, explained how trustworthiness was established, and described the measures taken to uphold the highest ethical standards.

The purpose of this study was to explore the perceptions of dialysis social workers' ability to identify strategies that incorporated the interaction of physical, psychological, social, and spiritual components that addressed barriers to completing EOL planning with Black dialysis patients. This was accomplished using a basic qualitative study through the lens of the BPSS model that helped overcome the physical, psychological, social, and spiritual components of these barriers.

Research Design and Rationale

This study focused on dialysis social workers' perceptions of strategies that incorporated physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients. To guide the study, the following research question was used: What are dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients?

A basic qualitative research design was selected to examine dialysis social workers' perceptions of their ability to identify strategies that incorporated physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients. Studies that explored the experiences of Black patients typically relied on understanding their experience through a qualitative method. Other qualitative studies, such as those by Anh et al. (2021) and Hilliard et al. (2013), used interviews to identify barriers to EOL planning for Black patients; however, quantitative methods were also employed in related research. Qualitative research aimed to deepen understand first-hand experience through observation and interviews in natural settings (Bengtsson, 2016). Given the study's focus on the challenges to completing EOL planning for Black dialysis patients, a qualitative method was considered appropriate.

Basic qualitative research was selected as a design to explore people's experiences, perceptions, and behaviors (Merriam, 2009; Worthington, 2013). Lambert and Lambert (2012) noted that a basic qualitative design is valuable. The experiences of others help provide valuable information and knowledge, which is why I choose the qualitative research approach.

A basic qualitative design served as the foundational approach to qualitative research and later evolved to encompass traditions such as phenomenology, case studies, and ethnography. The core aim of qualitative research was to capture the lived experiences and cultural contexts of individuals (Jacob, 1987; Polkinghorne, 2010). Collectively, these traditions facilitated the examination of human nature and interpersonal interactions.

Role of the Researcher

The researcher's role included being an observer, identifying and selecting all participants, and collected data through digital interviews through teleconferencing technology (e.g., Zoom) or via in-person interviews. As the researcher, I was responsible for data analysis, including transcription, coding, and identifying emerging themes. I attempted to create an atmosphere where participants felt free to share personal details of their experiences by maintaining confidentiality and ensuring privacy and allowed participants to stop the interview and participate in the study whenever they chose

However, there may have been bias, as this was the subjective value or belief I held about something (Merriam & Tisdell, 2016; Ravitch & Carl, 2021). Researcher bias was a potential issue. Researcher bias in qualitative research occurred when the researcher intentionally or unintentionally influenced their results to favor a specific outcome (Creswell, 1994). I used reflexive journaling, peer debriefers, and member checking to help reduce the issue of bias. Polit and Beck (2020) noted that any bias that could influence the study needed be identified. Acknowledging, accounting for, and approaching my bias was an ethical necessity in qualitative research (Ravitch & Carl, 2021). Researcher bias may also have stemmed from my experiences as a social worker providing EOL planning and as a patient with similar experiences. The personal biases that I had to be aware of included that I was a Caucasian medical social worker who previously worked in dialysis with Black patients and found that it was harder to complete EOL planning with this group of patients and that fewer Black patients made it to transplantation as shown by the reports I received from the Renal Network dialysis

transplant reports. This led to my decision to study the topic and understand better why there was a difference. Additionally, I had chronic kidney disease and was on the transplant list for a kidney, so I experienced the process. During this experience, I was aware that there were fewer Black patients. However, I had a transplant for my liver, which was the primary source of my CKD, so I understood the benefits and costs of receiving a transplant. Given my positive perception of transplants, I remained cognizant of my biases during the interviews, data analysis, and reporting of results. Among my biases were the belief in the critical importance of end-of-life (EOL) care and transplantation, and the observation that Black patients often received lower quality medical care and support. In the dialysis clinics where I worked, I noticed that Black patients were less likely to complete EOL planning, be on the transplant list, and more likely to undergo prolonged invasive dialysis rather than gentler methods like peritoneal dialysis. These observations may have influenced my interpretation of the interviewees' responses. My desire to identify and overcome barriers for Black patients may have led me to perceive answers that were not explicitly given.

Methodology

Participant Selection

I used purposeful sampling strategies for the selection criteria, including time and location sampling and saturation. Purposeful sampling involved deliberately recruiting participants for the study based on specific criteria (Campbell et al., 2020). Purposeful sampling involved selecting participants from a specific setting based on preliminary methodological dimensions (or delimitations) to meet the study's needs. Time/location

sampling involved choosing participants who were available at the time sampling occurred and within the location identified, which was the Renal Network for the purpose of this study (Karon & Wejnert, 2012). To meet the criteria for selection for this study, the study population included individuals who (a) were Masters of Social Work (MSW) dialysis social workers, (b) worked currently or within the last six months with Black patients currently on dialysis, (c) had worked in dialysis for at least one year, and (d) had worked in Renal Network region. These criteria were selected due to the Medicare ESRD dialysis social workers standards that were mandated, which included that they must have held an MSW from an accredited university, had two years of social work experience in a healthcare setting (including hospital, outpatient, or other settings not necessarily dialysis), demonstrated kidney care competencies, were licensed within the state as applicable, and maintained ongoing education in the field (NKF, 2014). Saturation was defined when no new information was yielded from the study, and it was noted to be approximately ten interviews as the sample size (Hennick & Kaiser, 2022). I sought ten dialysis social workers to complete interviews. This study utilized purposeful sampling to obtain participants through e-mails to the Renal Network region dialysis social workers to identify and recruit potential participants for the study who met the population inclusion. I requested permission from the Renal Network region to email their members twice with an email invitation and flyer. I also used snowball sampling by working with the participants who were recruited through the e-mail process and those who responded to flyers and invitations on social media such as Facebook and Instagram (Dosek, 2021; Leighten et al., 2021). Snowball sampling helped to obtain an adequate number of

participants who met the inclusion criteria by identifying those who meet the inclusion criteria. Achieving a sufficient sample size to reach saturation was the aim. Moser and Korsten's (2018), argued that ten or less interviews were required to reach saturation.

Instrumentation

The data collection instruments included an interview protocol (see Appendix B), and a demographic checklist (see Appendix A) created by the researcher, Zoom video and audio recordings, and a digital voice recorder. Interview questions were open-ended to allow for the description of the experiences of participants. The interview protocol was designed to be consistent with the ideals of qualitative research and to address the research question of the perceptions of dialysis social workers' ability to identify strategies that incorporated the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients. I utilized resources that guided the creation of interview questions, such as Roberts' (2020), along with the expertise of my committee, to ensure that the questions were consistent with the application of ideals. To help ensure my questions asked the information I was seeking and were understandable, I also tested questions out on a colleague. The demographic checklist provided demographic information about the sample without collecting any personally identifiable information other than for verification of being a participant who meets the inclusion criteria.

Procedures for Recruitment, Participation, and Data Collection

For this research, data collection was conducted through interviews on Zoom that were recorded on Zoom and a digital voice recorder due to the Renal Network covering

multiple states. I conducted local interviews that allowed the participants to choose whether to do it by Zoom or in person; however, all participants choose to be via Zoom. A digital camera and a voice recorder were used to record the interviews. I asked participants to complete this interview with the camera on initially so that I could verify that they were not imposter participants trying to do more than one interview for the appreciation gift (Roehl & Harland, 2022). I requested permission from the Renal Network region to send an email to their members, and since this did not yield ten complete interviews, I recruited additional participants with flyers and invitations on Facebook and Instagram for participants who met the inclusion criteria. Additionally, I encouraged those I interviewed to invite their colleagues to participate in the study.

Once identified, a preinterview was conducted through a telephone conversation to complete the demographic checklist and identify eligibility. The requirement of a phone preinterview helped initiate the process of identifying possible imposter participants (Roehl & Harland, 2022). During this preinterview, I obtained the participant's place of current employment to verify that the participant were a dialysis social worker at a dialysis center. I provided information about the study process and purpose and obtained informed consent at that time. I also advised the interviewees of the voluntary nature and that they could choose not to answer questions or not be a part of the interview. I scheduled the interview at that time and collected their e-mail addresses to send a consent form for their review and confirmation. Consent forms were converted into PDFs and emailed to willing participants during the preinterview for their initial review. Consent was attained by having participants review then sign the informed

consent document via the program *eSign PDF*. Data were collected through semi structured interviews and carried out through interviews conducted on Zoom (Gray et al., 2020). Before beginning the interview, I confirmed their desire to continue and that they were comfortable. I recorded the interview on Zoom and with a digital recording device to ensure I captured the information thoroughly. I then transcribed the information with the use of the program *Otter.ai* and provided a copy to the interviewee for review and clarification via e-mail.

Each interview was conducted within an approximately 60-minute timeframe. Participants were sent transcripts by e-mail for review and clarification, a process known as member checking. I then provided each participant who completed the full interview and member check with a \$10 Amazon or Starbucks gift card as an incentive.

Participants were allowed to discontinue or withdraw from the interview at any point; however, none chose to do so. They were informed of their rights during the preinterview and again before the start of the interview. The participants were debriefed at the interview's close and advised of the possible uses of the study. They were asked to respond to follow-up for review and clarification.

I submitted the study to the Walden University IRB to gain approval for the study protocol and instruments before recruiting participants through purposeful and snowball sampling methods and it was approved on 2/27/2024 under study number 02-27-24-1009070.

Data-Analysis Plan

In this study, I analyzed the transcripts of 8 individual interviews using thematic coding for the data analysis and a computer-aided qualitative data analysis software, Dedoose (2023). The procedure for data analysis was applied to the transcripts followed Saldana's (2021) inductive thematic method. The BPSS model and its component domains- biological/physical, psychological, social, and spiritual- informed this study and throughout the analysis these components generated themes and sub-themes that interacted and overlapped. Saldana used a mixture of first and second cycles in his data analysis method to find patterns and themes. The procedure or cycle for thematic coding by Saldana (2021) included: (a) familiarization, (b) generating codes, (c) searching themes, (d) reviewing themes, (e) defining and naming themes, and (f) finally repeating this process again to ensure that categorization is accurate. Razi et al. (2023) noted that thematic coding could develop patterns and themes for research problems.

Utilizing the Dedoose (2023) program's tools for creating memos, excerpts, code highlighting and creating themes, I applied Saldana's (2021) thematic coding to identify themes, patterns, and their significance within the context of the study and theoretical framework.

Issues of Trustworthiness

The goal of basic qualitative research was to convey trustworthiness. Trustworthiness referred to the idea that the material provided conveyed a sense of confidence in what was reported (Stahl & King, 2020). The essential elements of trustworthiness were credibility, transferability, dependability, confirmability, and

authenticity (Rose & Johnson, 2020). I applied trustworthiness with thick and rich reporting of the data and the process.

Credibility

Credibility examined how congruent findings were with reality (Stahl & King, 2020). The alignment of theory, methods, analytical techniques, and assumptions was encouraged in qualitative studies to support credibility (Rose & Johnson, 2020). I ensured credibility through thick and rich reporting (Cypress, 2017; Percy, 2015). I used reflexive journaling, peer debriefers, and member checking to help reduce bias.

Lastly, I ensured credibility through member checking in which participants reviewed the interview transcript to confirm their accuracy (Motulsky, 2021). Transcripts were emailed to participants for review and comment; however, none submitted changes.

Transferability

Transferability was the extent to which the results could be transferred to other circumstances, conditions, or settings (Nassaji, 2020). Maxwell (2021) noted the importance of external transferability for qualitative research, as this was an area where quantitative research was considered less valuable. To aid in transferability, I ensured that a description of participants' experiences were thick and rich in the reporting. Those reading qualitative investigative studies should have been able to determine whether the results from a study were applicable to other situations, circumstances, or settings (Cypress, 2017; Nassaji, 2020; Percy, 2015).

Dependability

Dependability, or consistency, was essential for establishing the trustworthiness of a qualitative study (Janis, 2022). Achieving dependability involves providing comprehensive and detailed reporting. In this study, dependability was established through an audit trail, member checking, and triangulation.

The audit trail involved systematic data archiving and documenting the researcher's thought process throughout the study (Carcary, 2020). This was accomplished by recording interviews, which were securely stored in a password-protected file on my computer. Additionally, I tracked my thought process by taking notes during and after interviews, including brief notations of perceptions or ideas that I wanted to be mindful of in subsequent interviews.

Member checking involved participants reviewing the transcripts of their interviews and a summary of the findings to ensure accuracy (Motulsky, 2021). After transcription, I sent a copy of the transcript to each interviewee for verification. No changes were requested by the participants.

Triangulation was achieved through the data analysis process (Farquhar et al., 2020). I employed Saldana's (2021) descriptive coding techniques, utilizing both first and second-stage coding to analyze the data. By adopting an inductive approach, I allowed the codes to emerge organically from the data. The initial round of coding was conducted using Dedoose. Subsequently, I reviewed and refined the codes to ensure they represented the data. Through an iterative process, I revisited the codes multiple times,

further refining them and organizing them into themes. This approach ensured a robust and transparent analysis of the qualitative data.

Confirmability

Confirmability demonstrated how the researchers arrived at their findings through thick and rich reporting (Stenfors et al., 2020). Confirmability was ascertained by keeping a reflexive journal and double-checking the data through member checking (Cypress, 2017; Percy, 2015). A reflective journal was commonly utilized in a qualitative investigation to explain the investigator's perspective and potential (Olmos-Vega et al., 2023). Reflective journaling allowed me to reduce bias and describe my thought process through written reflection, as I was able to identify when my personal desire to see themes did not align with the interviewee's actual statements.

Authenticity

Authenticity was a more recent and less widely used set of criteria for considering the influence of context (Amin et al., 2020; Rose & Johnson, 2020). Authenticity was demonstrated through five components: fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity. Fairness meant that all opinions were considered, even if they were conflicting. Ontological authenticity occurred when participant's views or changes in views were considered, which took place during the member-checking phase of the data analysis. Educative authenticity referred to the appreciation of the participant's enhanced understanding or acceptance of others' viewpoints, which was supported through peer debriefing or the audit trail. Catalytic authenticity addressed how the results were used and if they could be sustained over time.

Tactical authenticity focused on how the participants were empowered to act after the interview. These items were addressed through informed consent, member checking, thick and rich reporting, peer review, and conclusions identified strategies for overcoming the barriers to completing EOL planning for Black dialysis patients.

Ethical Procedures

Walden University's philosophy and the approval of the Institutional Review Board (IRB) were followed to ensure the ethical principles of this study. This investigator sought participants only after receiving IRB's approval to complete the study. As previously mentioned, permission to post flyers, obtain email addresses, and utilize social media was obtained from the appropriate authorities. Informed consent was obtained from every participant through a detailed consent form. The rights of all participants were safeguarded. Their identities were protected by using pseudonyms in place of their names. Participants had the right to withdraw from the study at any time and choose not to answer any of the questions. Confidentiality was maintained through a password-protected computer and data bank for the next five years. Lastly, the study was conducted online using the teleconferencing platform Zoom, which was password-protected. The recordings were downloaded to a computer that was also password-protected.

Summary

In this chapter, I outlined the study's methodology. It included the introduction, design, the researcher's role, and issues related to trustworthiness. This chapter also addressed the data analysis plan and ethical considerations. Chapter 4 presents findings

from the completed study, including an introduction, setting, demographics, data collection and analysis procedures, evidence of trustworthiness, and the study's results.

Chapter 4: Data Analysis

Introduction

The purpose of this basic qualitative study was to explore the perceptions of dialysis social workers on strategies to overcome the biopsychosocial-spiritual barriers to Black patients' EOL planning. By examining dialysis social workers' experiences with EOL planning, this study illustrated how the Biopsychosocial-Spiritual Model could inform strategies to overcome barriers for Black dialysis patients. This research study addressed the following research question: What are dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients? Lastly, this chapter discussed the research setting, demographics, data collection, data analysis, evidence of trustworthiness, results, and summary.

Setting

A purposeful sample of dialysis social workers who had been working in the Renal Network, with Black dialysis patients for at least one year were recruited from emails sent out by the Renal Network and snowball sampling. Interested individuals contacted the researcher directly from the distributed flyers and email invitations.

Demographics

The sample included eight participants, all current dialysis social workers from the Region Renal Network. The age range was between 37 and 51 years. As it related to years of experience, all participants had 2.5 years of experience or longer, with one having 26 years of experience. All self-identified their races or ethnicity, as shown in

Table 1 below. During the Zoom interviews, all participants initially reported they were comfortable with EOL planning and documented their activities in some form of an electronic health record. However, during the interviews, two social workers realized and acknowledged that they were not as comfortable with EOL planning as they had originally thought.

Table 1

Demographic Characteristics of Participants

Pseudonym	Age	Years of experience	Race (self-identified)
Daphne	44	7	Caucasian
Anthony	40	5	African American
Eloise	51	26	White
Francesca	37	3	African American
Violet	45	4	Caucasian
Charlotte	42	2.5	Half Irish/Korean
Hyacinth	38	2.5	Caucasian
Edwina	43	9	Caucasian

- Daphne was a Caucasian American woman who had worked in dialysis for 7 years and was 44 years of age. Daphne reported that she was a hospice social worker previously and so expressed strong comfort with EOL planning. She works in a small rural dialysis center that she described as rural with fewer Black patients. Daphne was known to me before the interviews, as I met her professionally as a dialysis social worker.
- Anthony was an African American man who had worked in dialysis for five years and was 40 years of age. Anthony reported that he was comfortable with EOL planning. He worked in a large urban dialysis center predominantly comprised of Black patients. Anthony's interview was complicated by the

Zoom video not working. Only the phone and audio recorder captured his interview.

- Eloise was a White woman who had worked in dialysis for 26 years and was 51 years of age. Eloise reported that she was comfortable with EOL planning describing it as a routine part of social work. She worked in two small rural clinics in the Renal network and had only a few Black patients in her clinics.
- Francesca was an African American woman who had worked in dialysis for three years and was 37 years old. Francesca reported that she was comfortable with EOL planning as her family, specifically her father, regularly discussed EOL planning and made sure his and all the family's plans were settled early in life. She worked in two larger urban clinics and reported that her patient population was primarily Black, with only five non-Black individuals out of 94 patients.
- Violet was a Caucasian woman who had worked in dialysis for four years and is 45 years old. Violet reported that she was comfortable with EOL planning as it was just part of her job that she was used to doing; however, during the interview, she changed her statement, reporting that maybe she was not as comfortable as she thought. She worked in four small rural clinics and reports that about 40% of her patients were Black. Violet was known to me before the interviews when I met her professionally as a dialysis social worker.
- Charlotte was a Half Irish/ Half Korean (as identified by herself) woman who has worked in dialysis for 2.5 years and was 42 years of age. Charlotte

reported that she was comfortable with talking about EOL planning as her mother worked in a nursing home and talked about life and death regularly. She worked in a large urban clinic and reported that her patient population had numerous Black patients.

- Hyacinth was a Caucasian woman who had worked in dialysis for 2.5 years and was 38 years of age. Hyacinth reported that she was comfortable talking about EOL planning. However, during the interview, she acknowledged that she had received no training and did not know how to provide EOL planning information. She explained that she had learned more about how she should have approached this in her most recent dialysis job. She worked in one large urban clinic and reported that she only had approximately seven patients who were not Black. Her interview stood out as she shared from the beginning that her experience as a dialysis social worker had not been positive until recently due to a lack of social work supervision.
- Edwina was a Caucasian woman who had worked in dialysis for nine years, and she was 43 years of age. Edwina reported she was comfortable with EOL planning, though recently, she had become less comfortable as she was going through this with her mother, which made her more reflective about how she communicated with people. She worked in a large urban clinic and reported that her clinic consists of about 40% of Black patients.

Data Collection

Recruitment of participants began in March 2024 and ended in May 2024. With approval from the Renal Network and Walden IRB, an invitation was posted electronically via the Renal Network mailing list. Interested social workers contacted me directly via email. Seven participants were interviewed via Zoom, and one was interviewed by phone with a Zoom and audio recording used as backup. All participants were provided with the informed consent agreement to review and confirm before the interviews, which were signed electronically. Data were collected from 8 participants through electronic real-time interviews using the teleconferencing platform Zoom. Demographic information was collected during the telephone call during the pre-interview. All participants' interviews in Zoom were recorded on a digital recording device and transcribed using the Otter.ai computer program, along with the researcher's review, and then uploaded into the qualitative analysis software Dedoose by the researcher. A limited number of questions were presented, with additional follow-up probing questions asked when needed for clarity.

The interviews averaged between 30 and 55 minutes in length and were completed over a period of eight weeks. Most interviews were of a longer nature, but one interview was shorter as the respondent primarily spoke about her lack of knowledge and training, and that she did not feel prepared for her role in discussing EOL. Data were recorded on a Zoom video recording and a digital audio recorder. I created margin notes during the interview process. Member checking took place via email. Each participant received the transcript and a summary of the interview. Member checking allowed

participants to ensure that their ideas and descriptions during the interview were represented accurately. No participants made corrections to the context of their statements. No unusual circumstances were encountered in the collection of data or variations that were previously presented.

Data Analysis

In this study, I analyzed the transcripts of 8 individual interviews using thematic coding for the data analysis and a computer-aided qualitative data analysis software, Dedoose (2023). The procedure for the analysis of data that was applied to the data was Saldana (2021) inductive thematic method. The BPSS model and its component domains of biological/physical, psychological, social, and spiritual informed this study and throughout the analysis these components created themes and sub-themes that interact and overlapped. Saldana used a mixture of first and second cycles in his data analysis method to find patterns and themes. The procedure or cycle for thematic coding by Saldana (2021) includes (a) familiarization, (b) generating codes, (c) searching themes, (d) Reviewing themes, (e) defining and naming themes, and (f) finally repeating this process again to ensure that categorization is accurate. Razi et al. (2023) noted that thematic coding can develop patterns and themes for research problems. During the interviews, I noticed that the participants stated similar ideas when being interviewed. I noted this in the margins to begin to listen for these or similar ideas in the other interviews. This created some of the initial codes that were developed.

I then began to the first cycle of thematic coding analysis. The initial phase of analysis was to familiarize myself with the data. I read and reread the data in full during

transcription, again to verify the transcription was accurate, once again after moving the data to the data analysis software, and then repeatedly to ensure that the interviews had been fully and accurately entered.

I then began to generate codes by coding interesting features such as the ideas or phrases that I had noticed during the interviews that I had noted in the margins. Employing an inductive approach, I allowed the codes to emerge organically from the data. The first round of coding was completed using Dedoose. I assigned codes by identifying words or concepts that appeared repeatedly and marked these within the program. Dedoose would then add up the number of times that codes appeared and that these coincided with the other identified codes. Subsequently, I meticulously reviewed and refined the codes to ensure they accurately represented the data. I was able to make memos within the program itself about the points of interest such as repeated ideas and keywords from which codes might be developed. I was also able to take excerpts that expressed similar meanings from the interviews in the program to be able to cluster these for identification as possible codes. For instance, Daphne spoke about the need to normalize talking about death saying, “start the conversation there and just normalize it as in none of us are guaranteed tomorrow,” and Eloise spoke about how the conversation needed to be routine “that it is routine, education and routine information that we are providing.” Both responses indicated that the participants recognized the importance of normalizing discussions about death with patients. However, they also noted the challenges associated with these conversations, as patients often hesitate to engage in such discussions. Consequently, both responses were categorized under the theme

“Ongoing conversations with patients and their families.” (see Table 3). Following my analysis in Dedoose, I then entered all 8 interviews with identifying information removed into ChatGPT and asked for identification of themes and subthemes to help me clarify the information I had identified in Dedoose and my results. As I am not as knowledgeable in qualitative analysis this helped me to clarify my themes and subthemes. I also asked ChatGPT to identify a codebook for the interviews and compared this with my results from Dedoose utilizing both to further refine my codes. The analysis yielded a total of 240 response excerpts, which were organized into 29 distinct codes. Table 2 presents the initial codes along with the corresponding number of excerpts assigned to each code, illustrating the code frequencies.

Table 2*Initial Code Frequencies*

Initial code	Frequency
Demonstrating empathy	13
Establishing consistency	8
Cultural sensitivity	11
Relational disclosure	6
Creating safe spaces	9
Routine introduction	10
Early integration	7
Revisit discussions	8
Destigmatizing	6
Framing as standard of care	9
Family resistance	12
Cultural beliefs	10
Faith/spirituality	9
Patient-family dynamics	5
Adjusting for literacy	7
Visual/alternative formats	6
Plain language	9
Modes of engagement	6
Cultural language framing	8
Team-based planning	8
Medical provider communication	6
Shared responsibility	6
Chaplain/nurse/physician input	7
Spiritual care integration	5
Respecting readiness	13
Rechecking and follow up	11
Avoiding pressure	10
Recognizing emotional timing	9
Letting patients initiate	6

Note. This table exhibits the frequency of the initial codes and number of response

excerpts assigned to each code.

The next phase of thematic analysis entails grouping the codes to form themes. Through an iterative process, I revisited the codes multiple times, refining them further and organizing them into themes as viewed through the lens of the BPSS model. Codes included ideas such as demonstrating empathy, routine introduction of EOL planning, family resistance, adjusting for literacy, team-based planning, and respecting readiness. Throughout the process, every participant identified that they felt more training as part of their role as a social worker was needed to better understand the role of and how to complete EOL planning. Additionally, all the participants were able to identify that EOL conversations were had less with Black patients as shown by Charlotte's statement that "they just aren't being brought to me as often by Black patients as much as Caucasian ones." The importance of interdisciplinary collaboration was brought forth, as can be seen in Daphne's declaration, "So, I can then incorporate that with the IDT, we use an IDT approach as far as how we're navigating through the next steps." Themes were revealed to address the research question through the lens of the biopsychosocial-spiritual theoretical framework. These themes and the associated responses of the participants are discussed separately in the results using verbatim examples to provide an in-depth understanding and powerful insight into the participants' experiences and support theme development. In total, the 29 codes initial codes were clustered into 6 themes.

Using the BPSS model as a guiding framework provides a holistic lens to understand how biological, psychological, social and spiritual factors influence patients' engagement in EOL planning. Themes emerged through the interviews with the dialysis social workers, who described both challenges and strategies they employ to address

these barriers. As the codes were developed from words and contexts, I separated these into themes by identifying codes that fit into these categories and started to develop a story of how they applied to the theory. In Table 3, the reader can view how I broke down the codes into themes to visualize the theming process.

The next phase of the thematic analysis involved a comprehensive review of the identified themes. I cross-checked and refined the themes to ensure that their underlying ideas did not overlap. Additionally, I compared the themes to the original data to ensure they accurately reflected patterns in participant's responses and aligned with the and the theoretical framework. In the fifth phase, the themes were defined and named (Saldana, 2021). I also utilized ChatGPT to ensure that the themes identified did answer my research question. For a preliminary overview of the results, Table 3 illustrates how the initial codes were organized to create the finalized five themes. Finally, I reviewed the codes and themes again to ensure that finalized themes addressed the research question through the theoretical lens.

Table 3*Grouping of Codes Into Finalized Themes*

Themes	Initial codes clustered to identify each theme
Building trust and rapport	<ul style="list-style-type: none"> • Demonstrating empathy • Establishing consistency • Cultural sensitivity • Relational disclosure • Creating safe space
Normalizing and integrating EOL discussion	<ul style="list-style-type: none"> • Routine introduction of EOL planning • Early integration into care • Revisiting discussion regularly • Destigmatizing conversations
Addressing family and cultural influences	<ul style="list-style-type: none"> • Family resistance • Cultural beliefs and practices • Patient-family dynamics • Deference to family decision-making
Adjusting communication approaches	<ul style="list-style-type: none"> • Adjusting for literacy • Visual aids and alternative formats • Speaking plainly • Multiple modes of engagement • Cultural language framing
Leveraging interdisciplinary collaboration	<ul style="list-style-type: none"> • Team-based planning • Communication with medical providers • Shared responsibility in EOL planning • Consultation with chaplains, nurses, and physicians
Allowing patients to set the pace	<ul style="list-style-type: none"> • Integration of spiritual care • Respecting readiness • Rechecking and following up • Avoiding pressure • Recognizing emotional timing

Note. This table demonstrates how codes were grouped to form finalized themes.

In developing the themes, I categorized the codes into themes and sub-themes using an inductive thematic analysis approach informed by the BPSS model. For Theme 1, I focused on codes that related to timing, repetition, routine integration and early introduction of conversations. For Theme 2, I focused on codes that reflected relational depth, such as “cultural humility,” that fostered trust and creating openness in discussions. For Theme 3, I drew from codes that referenced family involvement, deference to relatives, spiritual beliefs, cultural norms around death, and fears of burdening loved ones. For Theme 4, was formed from codes that captured collaboration with medical teams, chaplains, and community organizations. For Theme 5, the codes reflected ties to systemic issues such as “lack of time,” “high caseload,” and “limited privacy.” Finally, Theme 6 were formed by codes describing flexible, patient-centered strategies for discussing EOL care. Each of these themes integrates biopsychosocial-spiritual elements, illustrating how social workers navigate complex patient realities with intentional, culturally responses strategies.

Evidence of Trustworthiness

Trustworthiness in qualitative research is supported by evidence of credibility, transferability, dependability, confirmability, and authenticity (Rose & Johnson, 2020). Credibility looks at how congruent findings are with reality (Stahl & King, 2020). I ensured credibility through member checking, in which participants reviewed the interview transcript to confirm its accuracy and ensure that I captured the perceptions they were trying to convey (Motulsky, 2021). Transferability is the extent to which the results can be transferred to other studies or settings (Nassaji, 2020). I tried to ensure

transferability by detailing every aspect of my research and through documenting the statements made by interviewees relating to each topic. Dependability refers to the concept of ensuring consistency and reliability of the research findings (Janis, 2022, Stahl & King, 2020). Dependability was achieved through detailed explanations of the research methods, verbatim examples, member checking, and an audit trail that included audio recordings, transcription, and field notes. During the data collection process, I kept a short field notebook in which I noted concerns and observations. I primarily kept notes during the initial phase reporting about my concerns with finding interviewees and then my observations when I interviewed individuals I knew from my work in dialysis. Confirmability refers to the degree to which findings of a study can be confirmed and this can be done by providing thick and rich reporting (Stenfors et al., 2020). I utilized member checking to help ensure that the participants' perspectives were accurately reflected and that I remained neutral in my reporting along with providing thick and rich reporting throughout this study to the extent possible to ensure confirmability.

Results

This study was conducted to address the following research question: What are dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients? All participants described their work experience with EOL planning with Black patients. They expressed their perspectives on how they overcame barriers to biological, psychological, social, and spiritual barriers while working with Black patients.

Throughout the analysis, I identified six major themes related to EOL planning with their Black patients which were (a) building trust and rapport, (b) normalizing and integrating EOL discussions, (c) addressing family and cultural influence, (d) overcoming structural and resource barriers, (e) leveraging interdisciplinary collaboration, and (f) adapting communication approaches to enhance EOL planning. These six themes arose throughout the interviews that answered the research question of what dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients.

Table 4

Research Question and Corresponding Themes and Subthemes

Research question	
What are dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients?	
Theme	Subtheme
Building trust and rapport	<ol style="list-style-type: none"> 1. Using self-disclosure selectively 2. Demonstrating cultural humility 3. Providing consistency in presence
Normalizing and integrating EOL discussions	<ol style="list-style-type: none"> 1. Incorporating EOL planning early and routinely
Addressing family and cultural influence	<ol style="list-style-type: none"> 1. Addressing family resistance to EOL planning 2. Personalizing discussions with real-life scenarios
Overcoming structural and resource barriers	
Leveraging interdisciplinary collaboration	
Adapting communication approaches to enhance EOL planning	<ol style="list-style-type: none"> 1. Allowing patients to set the pace

Note. This table demonstrates the themes and subthemes that addressed the research question.

Throughout the analysis, I identified six major themes related to EOL planning with their Black patients which were (a) building trust and rapport, (b) normalizing and integrating EOL discussions, (c) addressing family and cultural influence, (d) overcoming structural and resource barriers, (e) leveraging interdisciplinary collaboration, and (f) adapting communication approaches to enhance EOL planning. These six themes arose throughout the interviews that answered the research question of what dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients.

Table 5*Themes and Corresponding Definitions and BPSS Domains*

Theme/Subtheme	Definition	BPSS domains addressed
Theme 1: Building trust and rapport	Ongoing relational process in which social workers build authentic connections with Black dialysis patients to reduce medical mistrust and create a safe space for EOL conversations	Psychological—fosters emotional safety and reduces fear Social—builds relational connection and mutual respect Spiritual—honors dignity and personal meaning
– Using self-disclosure selectively	Sharing limited, intentional personal information to humanize the interaction and foster mutual understanding	Psychological—reduces anxiety and builds comfort Social—strengthens relational connection
– Demonstrating cultural humility	A reflective practice that acknowledges cultural differences and invites patients to lead with their experiences and values	Psychological—reduces anxiety through respectful, patient-led engagement Social—fosters mutual respect, validating lived experiences, and addressing relational imbalances Spiritual—honoring the dignity and values of patients whose mistrust may stem from cultural and historical marginalization
– Providing consistency in presence	Maintaining regular contact and emotional availability over time to foster trust and safety	Psychological—fosters a sense of stability and reduces uncertainty in emotionally difficult conversations Social—builds relational trust and demonstrates reliability over time, which supports patient openness
Theme 2: Normalizing and integrating EOL discussions	Incorporating EOL planning as a routine and expected part of dialysis care to reduce stigma and avoid crisis-based decision-making	Psychological—reduces anxiety through familiarity Social—destigmatizes death-related conversations Biological—enhances proactive care alignment Spiritual—allows time for reflection and articulation of values
– Incorporating EOL planning early and routinely	Introducing EOL conversations early in treatment and revisiting them regularly to promote familiarity and acceptance	Psychological—reduces anxiety through repeated, noncrisis conversations and allowing patients time to process emotionally Social—normalizes EOL discussions within ongoing care relationships, reducing stigma and avoidance Spiritual—gives patients opportunities to reflect on values, meaning, and beliefs over time rather than under pressure Biological—integrates planning alongside ongoing treatment discussions, ensuring alignment with medical care and prognosis

Theme/Subtheme	Definition	BPSS domains addressed
Theme 3: Addressing family and cultural influence	Recognizing and working within family dynamics and cultural beliefs that shape decision-making around EOL planning for Black patients	Social—acknowledges family dynamics and cultural norms Psychological—reduces emotional resistance Spiritual—supports culturally grounded values Biological—improves informed decision-making
– Addressing family resistance to EOL planning	Offering education and reframing to help family members overcome fear or denial and support the patient’s autonomy	Psychological—reduces patient anxiety through reframing and reassurance Social—mediating family dynamics and fostering supportive communication Spiritual—when addressing cultural or faith-based reluctance that shapes resistance
– Personalizing discussions with real-life scenarios	Using concrete and relevant examples to illustrate the importance of EOL planning and encourage informed decisions	Psychological—reduces abstract fear and helping patients process mortality in concrete, relatable terms Social—frames EOL planning within real-world contexts that resonate with patients’ lived experiences and family dynamics
Theme 4: Overcoming structural and resource barriers	Identifying and mitigating institutional obstacles (e.g., limited time, privacy, and training) that restrict social workers’ ability to facilitate meaningful EOL conversations	Biological—addresses infrastructure needs affecting quality of care Social—ensures equitable access and privacy Psychological—reduces stress from rushed or constrained contexts Spiritual—protects dignity of EOL conversations
Theme 5: Leveraging interdisciplinary collaboration	Coordinating EOL planning across care team members and community partners to ensure consistent messaging and culturally responsive support	Social—shared messaging and collaborative care Psychological—reduces confusion through consistency Spiritual—engages trusted community supports Biological—integrates EOL planning across treatment trajectory
Theme 6: Adapting communication approaches to enhance EOL planning	Tailoring tone, language, pacing, and delivery to align with patient readiness and cultural context to support engagement in EOL planning	Psychological—promotes emotional readiness Social—aligns communication with cultural preferences Spiritual—honors patient values and beliefs Biological—enhances clarity and understanding of care options
– Allowing patients to set the pace	Adjusting conversations to the individual’s emotional readiness and revisiting topics over time rather than pushing for immediate decisions	Psychological—reduces pressure, allowing patients to process mortality gradually, and creating emotional readiness for difficult conversations Social—reinforces respect for autonomy, fostering mutual trust, and ensuring that patients feel heard and valued in decision-making

Note. Mapping of themes and subthemes to the four domains of the biopsychosocial-spiritual model.

Theme 1: Building Trust and Rapport

Building trust and rapport emerged as the primary strategy that social workers in this study identified as effective in overcoming barriers to engaging Black patients in EOL planning, framed within the BPSS model. They described trust as not something won in one meeting, but as a dynamic and relational process that evolved, shaped by ongoing emotional connection, cultural understanding, and respect for patient autonomy. Establishing rapport was seen as instrumental to addressing barriers rooted in medical mistrust, cultural disconnection, and the emotional weight of EOL discussions. Three interrelated practices—using self-disclosure selectively, demonstrating cultural humility, and providing consistency in presence—were repeatedly described as essential to fostering meaningful relationships. These strategies allowed social workers to connect with patients as themselves as trusted partners. Participants emphasized that allowing patients to guide when and how EOL conversations occurred was critical to establishing trust. This patient-led approach conveyed respect for personal readiness and acknowledged the impact of prior negative healthcare experiences. As Daphne explained:

I have had to really first, before I get into deep conversations or the topics, really establish a rapport with the patient, let them get to know me more, maybe do some self-disclosure... to help them see me as a person versus, you know, a White female coming in to try to... tell them what to do or take care of them.

Similarly, Hyacinth described honoring patients' emotional boundaries when they were not ready to talk; "There are days they'll say, 'I don't want to talk about it today.' And that's okay. You respect that and come back another time." Francesca underscored

the relational payoff of this approach; “I would say my ability to build rapport has played a good part in me being able to facilitate some of these conversations... I feel like my patients, they trust me.”

This trust was not built overnight. Violet described how one patient took nearly a year before she was willing to discuss EOL matters openly; “It must have been a year for me to build rapport with her and get her to talk to me.” Edwina reinforced the importance of listening without rushing to complete a task; “It’s very, very important to sometimes just listen and not... have it checked off like, ‘Okay, I had that conversation.’ Because then you can miss a lot... If you just ask them what makes them not want to look into it, maybe that could actually be addressed.”

In some cases, rapport was strengthened by acknowledging the patient’s spiritual worldview and creating space for that within the relationship. One participant shared, “Some of my patients are very devout in their faith and want to pray before we talk about anything. She starts us with a prayer, and that builds a level of trust” (Charlotte). These moments of spiritual recognition helped foster emotional safety and contributed to the development of deeper trust.

For these social workers, relationship-building was not an introductory step to EOL planning—it was the ongoing foundation that allowed for honest, values-based conversations about care preferences. Trust created a safe space in which patients could voice fears, clarify misconceptions, and explore their options without feeling pressured or judged. This highlights how important the relational process is and that how the conversation is had is just as important as the conversation itself.

Subtheme 1: Using Self-Disclosure Selectively

Although earning trust often took time, patience, and consistent presence, some participants identified that sharing small, personal details could help speed up the connection worked to overcome barriers. When used thoughtfully, self-disclosure became a way to break down walls and make the relationship feel more genuine from the start. The process of developing trust was multidimensional; some social workers found that sharing carefully chosen aspects of their own experiences helped humanize them in the eyes of their patients. In addition to quieter strategies like listening and allowing space, sharing personal experiences helped shorten the emotional gap between social worker and patient. It made the relationship feel more real—especially in cases where patients were understandably cautious or hesitant because of past negative experiences in the healthcare system. Daphne shared how she used this approach, explaining:

So I have had to really first before I get into deep conversations, or the topics, really just establishing a rapport with the patient, let them get to know me a little bit more, maybe do some self-disclosure a little bit, when it's appropriate, to help them see me as a person versus, you know, a White female coming in to try to like, save them or tell them what to do or take care of them.

Daphne's insight shows how deliberate she was in using self-disclosure—not to draw attention to herself, but to break down barriers and challenge assumptions that patients might hold about her role. She found that showing up as a person first, rather than leading with her professional title, helped her connect more authentically across racial and cultural lines. This way of relating—as one human being to another—came up

in many participants' stories. For Daphne, sharing parts of her own experience also helped her build culturally meaningful connections with the patients she served. She noted:

A lot of the African American Black population I've run into in our area are more Pentecostal, or Baptist. And that's right up my alley, because I'm Pentecostal myself. So, like, I think that surprises several of my Black patients, because I love a lively church, we can kind of bond over that and have bonded over that.

Other participants used self-disclosure to highlight their own caregiving experiences or vulnerabilities. Edwina shared how she personalized conversations around family and trust:

I put myself in it, because I'm dealing with health issues with my mom... Can you trust that [your family] is going to follow your decisions? Or because they love you so much... are they going to do what you want versus what their heart is trying to tell them to do?

In this instance, self-disclosure created space for patients to reflect on emotionally complex EOL decisions from a relational, not just clinical, perspective.

Violet offered a poignant example of how long-term consistency and informal self-disclosure (e.g., a shared name) could eventually lead to deep trust:

There was this one lady—she had the same name as me, so I always loved talking with her. It took forever to build rapport with her and to get her to talk to me, but once she did, she would text me, she'd talk to me at home, she'd reach out to me.

Charlotte, meanwhile, described using a form of collective disclosure—sharing patient-to-patient stories (with anonymity) to help normalize and validate the experiences of others:

I often try to act as a reporter... I have the privilege of talking to a lot of different folks... sharing from patient to patient, like different perspectives from real accounts of people that have been exactly where that person is.

Eloise took a slightly different approach by acknowledging moments when patients questioned her understanding due to perceived socioeconomic differences. She responded by reaffirming her role and redirecting the conversation, “I always try to just do some redirection when that happens... and assure them that, as their social worker and as their advocate, I do have their best interest at heart.”

These stories show that when social workers shared parts of their own experiences, it often helped build trust in multiple ways. Thoughtful self-disclosure made them more relatable, strengthened cultural connections, helped bridge emotional and experiential differences, and made patients feel understood. Still, participants were clear that this strategy wasn't used lightly. It was always intentional—rooted in an awareness of the unequal power dynamics that exist in both medical settings and racially charged interactions.

Subtheme 2: Demonstrating Cultural Humility

The second subtheme the participants identified was that of demonstrating cultural humility to overcome barriers with Black dialysis patients. Rather than acting as experts, social workers described approaching each patient with a willingness to listen,

learn, and follow the patient's lead. They recognized that every patient brings unique life experiences and cultural perspectives—knowledge that could not be assumed or generalized. This kind of humility required looking inward, acknowledging their own biases, and being mindful of how racism and past trauma might influence how patients experience healthcare.

Daphne reflected on her personal growth in finding empathy for patients who had experienced incarceration or substance use. She admitted that building those connections took time and effort. Edwina and Charlotte also shared how they understood their limitations when working across cultures. Rather than assuming understanding, they allowed their patients to educate them. Edwina explained:

“I will just have them educate me on what the implications are for them... just because overall that's what that particular race or culture believes doesn't mean that that particular person falls into that.” Charlotte echoed this sentiment, especially when working with African patients, admitting, “I'm not very educated on their particular culture... I'm learning as I go.”

Several participants also identified how race and perceived identity shaped the relational dynamics in care. Violet described an initial mistrust from patients who questioned her motives as a White social worker. Anthony provided a nuanced reflection, explaining that while being African American sometimes fostered connection, it could also result in skepticism from patients who didn't feel their experiences were fully understood—even by someone of the same race.

Demonstrating humility also involved adapting to patient readiness and communication preferences. Hyacinth recounted offering patients ample time and space to engage in EOL planning without pressure, respecting their pace, “I don’t want to rush you making these decisions. You can take it home; you can talk to your family about it.” Francesca called for broader “cultural sensitivity training for all providers,” stressing that knowledge of historical trauma was critical to providing compassionate care. Eloise reinforced the value of standardized, non-targeted approaches, stating that routine education across all racial groups helps prevent any one group from feeling singled out,

I think it’s really important that, as a social worker, we make it a factor known that it is routine education and routine information that we are providing to all persons of race, color, whomever, so that no one race feels like they are being targeted.

Together, these narratives reflect a deep commitment to cultural humility—not as a one-time act, but as a sustained practice of curiosity, respect, and co-learning. Participants identified that building trust and having meaningful conversations around EOL decisions required being mindful of the lived realities of their patients. While cultural humility opened the door to deeper connections with patients, participants pointed out that it could not stand alone—it had to be backed by consistent action and genuine follow-through. Trust had to be nurtured and sustained through ongoing, consistent presence—a relational strategy that created space for patients to engage with emotionally complex decisions at their own pace.

Subtheme 3: Providing Consistency in Presence

Participants described the value of showing up repeatedly and reliably—both formally through scheduled assessments and informally through casual check-ins—as essential to building trust over time. These repeated encounters allowed patients to become more comfortable, revisit difficult topics when ready, and view the social worker as a steady, trustworthy presence. Rather than relying on one-time conversations, social workers emphasized the importance of low-pressure, ongoing engagement that unfolded gradually and respectfully, reinforcing relational safety and emotional readiness.

Many social workers spoke about the structured yet flexible routines they developed for revisiting EOL planning. Hyacinth explained that she raised the topic at intake, then again after 90 days, and annually thereafter, giving patients multiple opportunities to engage at their own pace. Francesca and Eloise echoed this practice, emphasizing routine and regular follow-up to keep the door open for future conversations. Francesca noted, “For sure, annually during the assessment and then pretty much as needed whenever somebody wants to talk about it.”

This steady rhythm of engagement allowed patients to process difficult topics without pressure. Violet described how critical it was to meet patients where they were, stating, “It really can take time... If they want to talk with me, then they come back. If they want to talk, I just sit there and listen.” Similarly, Edwina focused on adapting to patient readiness and listening for cues, reinforcing that genuine presence—not just checklists—made a difference.

Anthony's approach added another layer, as he intentionally made himself visible on the clinic floor multiple times a week—not always to talk, but to be seen and accessible. “Sometimes people see you... and then they walk away like hey, I've got to tell them something right. So, I make it my duty... to be out there for hours.” Daphne, too, emphasized the importance of letting the patient lead, saying that consistency in presence “gave me a framework on how to approach him and how to let Him lead.” This de-centering of the social worker's agenda allowed space for authentic, patient-directed dialogue.

Together, these narratives underscore that presence itself—especially when consistent, non-threatening, and attuned to patient needs—served as a therapeutic strategy. This approach gave social workers the opportunity to build trust over time, offer a sense of emotional security, and make difficult conversations feel more routine and less intimidating. It worked hand in hand with practices like cultural humility and thoughtful self-disclosure, further supporting a more personal and well-rounded approach to EOL planning with Black dialysis patients.

Theme 2: Normalizing and Integrating End-of-Life Discussions

Throughout the interviews, participants described the perception of the strategy that making EOL planning a natural and routine part of dialysis care—rather than waiting for emergencies or late-stage decline—was essential to helping patients move past common barriers. Social workers shared that when these conversations were introduced early and returned to consistently, they became less overwhelming and more familiar to patients and their families. Many reflected that EOL planning should not feel like an

isolated event or a box to check, but rather a gradual, ongoing process built through trust, regular engagement, and genuine connection. From their perspective, there was a clear push to take the stigma out of EOL conversations by making them a routine part of care. This approach helped patients feel more at ease and more in control when thinking about and preparing for the future.

Participants described a shared commitment to making EOL planning a routine part of dialysis care rather than a crisis-driven intervention. Daphne explained that she introduces the subject early by “starting with advanced medical directives,” documenting each discussion in the electronic health record as she would any other aspect of care. For her, treating EOL planning as a standard element of practice underscores that these conversations are not emergencies but part of providing quality, comprehensive care.

Francesca emphasized the importance of making these conversations part of ongoing care and not a single event. She explained that “talking about it more frequently and making it less of a taboo thing” helps patients see EOL planning as a natural part of treatment. She also noted that choices made in advance are far more effective than those made under crisis pressure.

Consistency was a theme across several interviews. Edwina explained that she introduces EOL planning when first meeting with patients, reminding them that “planning for end of life does not mean we’re planning for it to happen tomorrow.” In her clinic, documentation requirements mean that she must record an activity related to advanced care planning each quarter, which ensures the subject is addressed. Violet described a similar structure in her facility, where she is expected to revisit EOL

discussions at the 30-day, 90-day, and annual marks, which helps to keep the conversations from being forgotten.

Other participants identified the importance of putting EOL planning into the larger context of patients' lives. Charlotte reflected that beginning dialysis marks a major adjustment: "You have a chronic illness... You have to think about what that means." For her, EOL planning was about the whole person, not only their medical condition. Eloise added that providing this education to all patients is essential to prevent any group from feeling targeted. She also felt strongly that the conversation should begin even earlier in the healthcare system, ideally at the primary care level, so patients are better prepared once dialysis begins.

These accounts demonstrate how social workers work to normalize EOL planning by introducing it early, revisiting it regularly, and embedding it into routine care. Their emphasis on consistency, context, and cultural sensitivity reflects an effort to make the conversations less intimidating and more meaningful for patients.

Anthony shared a similar view, explaining that EOL conversations begin with admission in his clinic, where patients are asked about living wills and offered information right away. But he also pointed to a larger issue: "We don't talk about end-of-life planning... until they get sick, and it is not meaningful." For him, the goal is to "start to speak earlier about death" and help people plan when they are still well enough to engage fully.

Subtheme 1: Incorporating EOL Planning Early and Routinely

A key strategy identified by participants for normalizing EOL conversations was to integrate them consistently into the rhythm of care rather than waiting for a crisis. Social workers reported initiating discussions during intake, incorporating them into scheduled assessments, and reintroducing them at pivotal health moments such as hospitalizations. This approach reflected a shared belief that routine engagement reduces the likelihood of rushed, crisis-driven decisions and allows patients space to reflect and plan over time.

Daphne explained her process as beginning with education: “My approach is to start off talking about the initial assessments, are they aware of what an advance directive is?” She often found that patients mistakenly assumed they had one when it had only been discussed verbally with family. Clarifying these misconceptions early provided an opportunity to offer education and ensure the topic was addressed at the outset of care. Hyacinth described a similar practice, making Medical Orders for Life-Sustaining Treatment (MOLST) discussions a standard part of every new patient interaction: “Whenever a new patient would come in... I would always do a MOLST with them.” She emphasized giving patients time and flexibility: “Wherever pace you're moving at is fine.” For her, routine check-ins at 90-day and annual reviews ensured that the conversation remained part of ongoing care without becoming coercive.

Others reinforced this structured but flexible approach. Francesca noted that she raises EOL planning annually and then as needed, particularly after hospitalizations: “Maybe they may come out of the hospital... and it’s something that

they bring up.” Edwina also viewed health changes as natural openings, sharing, “If they’ve been going through maybe some medical challenges... I might say, ‘Has anyone been asking you...?’” She added that she flagged charts to prompt intentional follow-up months later.

Violet described a similar rhythm, explaining, “Probably once a year, and then we have those initial kinds of things the first 30 days and 90 days, then annually.” Charlotte likewise blended scheduled and situational check-ins: “Whether those are happening... 60 days, 90 days, and then annually or if they are unstable... I always approach [it] like they’re the MOLST and advanced care plan.” In Eloise’s setting, this structure was formalized as policy: “That is per policy for us.”

Anthony summarized the collective view by stressing the importance of timing: “If I were to say, at the very beginning, and as their health starts to deteriorate...” He cautioned that waiting too long diminishes the value of the discussion: “Because when I think about it, we don’t talk about end-of-life planning... until they get sick, and it is not meaningful.”

Taken together, these perspectives illustrate how dialysis social workers use structured, routine engagement—anchored in intake, periodic reviews, and health transitions—to normalize EOL conversations. By embedding these discussions into the ongoing course of care, social workers foster familiarity, reduce resistance, and ensure that patients have the time and support needed to make meaningful decisions.

Theme 3: Addressing Family and Cultural Influences

The third overarching theme to emerge as a perception of strategies to overcome barriers was the importance of addressing family and cultural influences in EOL planning for Black dialysis patients. Participants shared a variety of strategies they used to acknowledge and work within the family, cultural, and spiritual contexts that influence how patients view and approach EOL decisions. Their insights reflected the core ideas of the BPSS model, which emphasizes understanding how personal beliefs, relationships, and cultural backgrounds intersect in shaping healthcare choices.

Many participants shared the perception that family beliefs, cultural norms, and community traditions can serve both as motivators and barriers to EOL planning. Several participants shared that cultural resistance often surfaced during EOL conversations. They observed that some patients were more comfortable with verbal agreements rather than written directives, frequently relied on family to make decisions, or steered clear of the topic altogether to avoid causing distress to their loved ones. Eloise explained, "Some of the patients are... hesitant to have that conversation because... the families are not the ones that are ready to hear that discussion. They're not ready to let go."

Other participants emphasized the importance of meeting patients where they are by using empathy, shared cultural connections, or spiritual understanding to reframe discussions. Daphne shared, "Some individuals may have resistance or concerns or stigmas associated with hospice."

Participants also reported the need to navigate complex family dynamics. Charlotte described how caregiving responsibilities within families can shape a patient's

willingness to engage in EOL discussions: "The mother has expressed time and time again that she doesn't want to continue dialysis. But her daughter interprets it as her mom being tired." In this case, the patient's autonomy appeared constrained by her daughter's emotional readiness. Others, like Anthony, highlighted how decision-making hierarchies in some families often placed authority in the hands of an elder or designated figure, which could override a patient's preferences; "Yes, in the sense that there is somebody that's the head of the house, it might not be the person that's the patient... they're just trying to make the best decisions. As a family."

Across narratives, participants described using culturally responsive strategies such as involving pastors, inviting families to join care planning conversations, reframing EOL planning as an act of empowerment, and emphasizing that planning is not about "giving up" but about respecting one's values and wishes. These efforts were rooted in a desire to break down stigma, acknowledge the weight of historical mistrust in the medical system, and foster trust through care that felt culturally respectful and grounded.

Several social workers also noted that family resistance was sometimes rooted in religious beliefs (e.g., "God will decide when it's time"), which required sensitive reframing. Hyacinth explained, "I've had them say, 'God will decide the time.' So, I have to gently say, 'Planning doesn't interfere with your faith.'" This reflects how spiritual values intersect with cultural and emotional readiness and underscores the importance of culturally and spiritually attuned engagement.

Subtheme 1: Addressing Family Resistance to EOL Planning

Many social workers shared that family pushback often made EOL planning more difficult. They spoke about how relatives sometimes shut down or steered away from the conversation—driven by fear, denial, or cultural unease. In response, they leaned on education, patience, and reframing to help families see the value of planning ahead. Several participants noted that they had to help patients and families understand what EOL planning entailed. Francesca emphasized the importance of reframing: "This is the opportunity for you to have control over what things look like... Sometimes I do say, 'God created these, these documents, these things, and if you know, I know this is his plan, but you can plan have a plan also.'" This approach demonstrates how spiritual language can be used to align EOL planning with religious values, making it more acceptable to resistant families.

Social workers emphasized the importance of adapting their approach to family dynamics, recognizing that some patients hesitated to express their wishes independently. Edwina described offering joint meetings with patients and families to support decision-making, while Eloise noted that many patients delayed choices, such as stopping dialysis, out of concern for upsetting loved ones. To address this resistance, participants stressed the value of consistent education and framing EOL planning as a routine aspect of care. As Eloise explained, presenting EOL discussions as standard practice helps reduce stigma and ensures that no group feels singled out. Together, these strategies illustrate how social workers balance cultural sensitivity with patient advocacy, creating space for patients' preferences to be voiced while easing family concerns.

Through these approaches, social workers aimed to create safer spaces for patients to express their values, while also reducing fear and misunderstanding among families. The perception of this strategy was that it allowed for a more inclusive, family-centered, and culturally grounded approach to EOL planning.

Subtheme 2: Personalizing Discussions with Real-Life Scenarios

Another key strategy identified by participants was the use of personalized, real-life examples to illustrate the importance of EOL planning. This included scenarios that patients could relate to emotionally or socially, such as unexpected illness, medical crises, or family dynamics that could lead to undesired outcomes if preferences were undocumented. Francesca described using legal examples to emphasize the urgency of documenting wishes to create an emotional and psychological understanding of the importance:

They're like still technically married to someone else, but in a relationship with someone else... I'm like, well technically, your wife would be the one that makes the decisions because she is your legal next of kin. And they're like, 'Oh no,' then they're more like, 'Let me do this documentation.'

Other social workers used hypothetical clinical scenarios. Edwina recounted how she would say,

Maybe your kids love you. Can you trust that they're going to follow your decisions? Or are they going to say, 'Do everything to keep her alive' because they love you so much and are not ready to say goodbye?

These personalized narratives helped patients visualize the potential consequences of leaving EOL decisions unspoken or undocumented.

This subtheme demonstrates the perception that personalizing discussions can reduce emotional distance, clarify legal or ethical complexities, and increase the likelihood that patients will engage in meaningful planning. As Daphne reflected, "None of us are guaranteed tomorrow... what would that look like for you? What would your wishes be?" Taken together, the strategies within this theme reveal a deep commitment to culturally attuned, patient-centered practice that leverages relational insight, real-world examples, and family systems knowledge to overcome barriers in EOL planning with Black dialysis patients.

Theme 4: Overcoming Structural and Resource Barriers

Another dominant theme that emerged as a perceived strategy to overcome barriers for Black dialysis patients was the need to address the structural and resource-related barriers. Participants described how systemic issues such as staffing shortages, high caseloads, unclear policies, physical and cognitive limitations, poverty, lack of social supports, and medical mistrust intersect to create tangible barriers. These findings reflect the broad range of institutional and environmental challenges that social workers must navigate when facilitating EOL conversations with their patients.

This theme included the perception that institutional time constraints and high caseloads made it difficult to provide personalized and ongoing EOL planning. Participants described how documentation requirements, competing job roles, and short-

staffed clinics often left little room for meaningful conversations about patient values and wishes.

Daphne described juggling multiple roles: “I’m the social worker, and a facility administrator... it’s challenging to have genuine conversations.” Hyacinth admitted, “I’m already behind... Everyone needs a quarterly note and I’m behind all these KDQOLs and care plans.” Violet noted that EOL planning only happened “probably once a year,” while Anthony stated, “We have to do a lot, I would call short solution-focused therapy.”

Francesca similarly noted,

There are so many responsibilities that I have as a social worker, that end of life, or advanced care probably isn’t necessarily at the top of my list... They need more social workers in health care... so we can actually make meaningful impact.

Edwina noted the burden of system triggers in documentation: “I can’t finalize my quarterly note until I complete an activity on the advanced care plan.” Charlotte added, “It would be good to have more of a structured approach,” reflecting a lack of clarity and support around EOL planning workflows. Eloise emphasized the limited setting for EOL conversations: “Unfortunately, the majority of those conversations are... by chairside. Out on the treatment floor. That’s just how things are with dialysis, unfortunately.”

These quotes reflect the systemic pressures that prevent social workers from spending sufficient time with patients to engage in holistic planning that addresses the physical, psychological, social, and spiritual aspects of EOL care. This subtheme reinforces the broader structural challenges social workers face and illustrates how institutional capacity and workload policies must be addressed in order to improve EOL

planning outcomes for Black dialysis patients. This subtheme reinforces the broader structural challenges social workers face and illustrates how institutional capacity and workload policies must be addressed in order to improve EOL planning outcomes for Black dialysis patients.

Participants also reported that EOL conversations often occurred in noisy, public spaces lacking privacy. Edwina noted, “Most of the time it is on the treatment floor, which is not ideal... surrounded by everyone else.” Violet echoed this, stating, “You're sitting on the floor with a bunch of people around you. It's not like it's private. And you're going to ask these people about their plans for end of life.” These constraints made it difficult to establish the trust and emotional space needed for these sensitive conversations.

Many social workers described institutional constraints that prevented them from completing EOL documents with patients. Hyacinth explained, “At my last job, I would sit chairside with a patient normally... but then the company doesn't even want me to have a conversation with a patient. It says no, the doctor has to do it.” Edwina described witnessing restrictions: “You need witnesses... and the amount of times I've had to be like, I'm sorry, we can't be a witness... That can be a challenge sometimes.”

In addition to institutional constraints such as time and training, social workers highlighted the broader structural barriers that disproportionately affect Black dialysis patients—particularly those living in under-resourced communities. Limited access to basic services, low health literacy, and chronic underinvestment all contributed to the difficulty of completing EOL documentation. As Charlotte observed, “I didn't go to the

pharmacy. I didn't have \$25 for my medicine," underscoring how financial hardship can make conversations about future care feel secondary to more immediate needs. Francesca made a similar distinction when comparing her two clinics, noting that one group of patients was already familiar with advance directives, whereas in her urban clinic, "it's not a foreign concept to these people... But here in the city, it's very different."

Social workers also described situations in which patients lacked the social support necessary to appoint a health proxy or complete the required paperwork. Eloise explained, "I have certainly had some patients who just simply don't have family or don't have any support to appoint someone as their medical power of attorney." Others, like Edwina and Charlotte, shared examples of patients living with visual impairments or limited literacy, which made the forms difficult to read or complete without assistance. Taken together, these accounts reflect the ways that structural inequities—economic instability, limited social networks, and inadequate access to supportive services—create additional barriers to equitable engagement in EOL planning.

Another recurring structural barrier was distrust of the medical system, which several participants identified as rooted in both personal and historical experiences. Anthony explained, "They don't want to maybe take their medication regimen because they don't really believe in medicine the way everybody else does." Hyacinth shared that some patients conflated EOL planning with resource barriers for finances: "I did have patients say to me stuff like... 'I got no money to leave nobody.'"

Despite these challenges, participants described ways to bridge these gaps such as by offering follow-up conversations, clarifying misconceptions, advocating for workflow

improvements, and using informal resources like techs or translators to support communication. While the structural barriers to EOL planning are significant, social workers continue to find creative and compassionate ways to meet patients where they are.

Theme 5: Leveraging Interdisciplinary Collaboration

A central theme that surfaced across participant interviews was the strategic use of interdisciplinary collaboration to support Black dialysis patients through EOL planning. Social workers described how they coordinated with physicians, nurses, administrative staff, dietitians, technicians, mental health professionals, and even family members to offer holistic, culturally sensitive, and effective support. Their perceptions of this strategy emphasized the necessity of integrated teamwork to address the physical, psychological, social, and spiritual components of care.

Social workers consistently discussed their roles within interdisciplinary teams (IDTs) and the ways these teams functioned in supporting EOL readiness. Daphne explained, "We use an IDT approach as far as how we're navigating through the next steps," indicating that coordinated team planning was a standard approach. Similarly, Francesca emphasized the shared responsibility: "I as well as kind of the rest of the IDT team is responsible for educating the patients about their options for care." This sentiment was echoed by Eloise, who said, "It would be something that could be done as an IDT setting. So that you're addressing it as part of just their routine care, education."

Documentation and communication across disciplines were also seen as essential tools. Edwina shared that when inconsistencies arose between patient wishes and

documented MOLST forms, she would "alert [the] doctor or nurse practitioner to see if they can follow up," illustrating her role in flagging concerns for medical colleagues. Francesca described entering her educational efforts into shared records: "I may put in a separate note, outside of the assessment, of me doing more education or providing resources."

Participants identified specific moments where collaboration made EOL planning more culturally responsive. Hyacinth described working with a patient's family: "His daughter was a nurse... he was like, 'I can't just tell him myself. It has to come from another male in the family.'" This example illustrates how cultural awareness was integrated through informal collaboration with family members. Similarly, Charlotte recounted a situation where an IKC nurse practitioner helped facilitate a complex conversation with a patient's daughter, showing the value of medical-social work partnerships.

Education and training within and across disciplines were frequently cited as strategies to improve interdisciplinary EOL planning. Anthony described educating non-clinical staff about behavioral health symptoms, stating, "I try to have homeroom meetings... to educate them about some of the symptomologies." Hyacinth noted that when only the social worker leads EOL discussions, patients may disengage: "If it's literally just the social worker bugging you about it... you're definitely not going to talk about it." She implied that shared messaging across the team could normalize and reinforce the importance of planning.

Participants also highlighted role-specific contributions, such as working with dietitians to support health-related EOL issues. Violet noted, "The nutritionist and I had worked on making sure to get him supplements to help him." Charlotte described partnering with pharmacy staff to support a patient with low literacy: "I've worked with the pharmacy to try to do like bubble packs... considering he can't read the labels."

While participants regarded interdisciplinary collaboration as a critical component of effective EOL planning, several also acknowledged existing limitations within their organizations. In some cases, role confusion or policy constraints reduced the effectiveness of team-based efforts. Hyacinth explained that her nursing supervisor misunderstood the scope of social work, stating, "She was like... we think that you should be the patient's therapist. And I was like, no, I can't do that." Francesca similarly noted institutional restrictions that prevented deeper involvement in the planning process, commenting, "My company needs to change their policy and let their social workers go through the forms." These examples highlight how unclear expectations, and organizational policy can undermine otherwise well-intended collaboration.

At the same time, participants stressed that meaningful EOL planning often required partnerships that extended beyond the traditional care team. Several social workers described involving trusted faith leaders when patients expressed spiritual concerns, thereby reinforcing the connection between interdisciplinary support and culturally responsive practice. As Edwina noted, "I've had pastors come in and sit with the patient during the conversation because they're the person the patient trusts most."

Despite the barriers, participants repeatedly emphasized that interdisciplinary collaboration was essential—not optional—for addressing the full range of patients’ needs. Anthony pointed to the importance of coordinated messaging among team members, explaining, “The dietician and I collaborate well... we try to talk about what it's like to be overloaded with fluid.” Eloise echoed this sentiment, stating, “It shouldn’t only come from a social worker... everybody should have that on their radar.” For these social workers, collaboration served as the backbone of a more holistic and culturally responsive approach to EOL planning—particularly important in supporting Black dialysis patients whose needs often extend across biological, social, psychological, and spiritual domains.

Theme 6: Adapting Communication Approaches to Enhance End-of-Life Planning

Social workers in this study consistently described that what worked best in engaging Black dialysis patients in EOL planning was adapting their communication style to meet patients where they were—emotionally, culturally, and psychologically. They emphasized that this was not a one-size-fits-all process but rather a flexible, patient-led approach that evolved over time. By adjusting tone, pacing, language, and format to match a patient’s readiness, social workers aimed to reduce anxiety, dismantle myths, and normalize EOL planning as a routine part of care.

Participants reported that one of the most effective strategies was weaving EOL planning into everyday care conversations rather than presenting it as an isolated or crisis-driven event. Daphne explained, “I try to incorporate [advance directive conversations] into all of my treatment planning... just normalize it... and incorporate

that into just a normal everyday—we're all going to have to go through that." Similarly, Edwina shared that once she became more comfortable with the topic, she could blend it seamlessly into other discussions: "It's just like, you know, we're talking about transportation, and now we're talking about end-of-life planning." Francesca reinforced that normalizing the topic reduced its taboo nature: "Not waiting until someone is ill to start having these conversations... just making this like a normal thing to talk about."

Another method participants found effective was explicitly framing EOL planning as universal, not targeted toward any one group, which helped address perceptions of racial bias. As Eloise noted, "We must... make it known that it is routine information that we are providing to all persons of race, color... so that no one race feels like they are being targeted." A few social workers also adapted their communication to reflect patients' spiritual perspectives, using language that aligned with faith-based understandings of illness and mortality. Anthony noted, "Sometimes they respond better when I use language like 'your wishes in God's timing' instead of medical language. It meets them where they are." This suggests that adapting communication is not only a cultural or emotional task, but also a spiritual one, reflecting an integrated use of the BPSS model.

Social workers also described pacing as central to their success. Meeting patients at their own level of readiness allowed for gradual engagement. Daphne shared, "I want to meet the patient where they're at, find out what their thoughts are, what their goals are..." Charlotte echoed, "I often find myself like starting where the patient is with those conversations..." and Edwina described how she sometimes waited months before

introducing the topic in depth: “Once I get them a little bit more comfortable... three months, six months, a year down the line, then I’ll have that conversation. “Violet added that in some cases, “It must have been a year for me to build rapport with her and get her to talk to me.”

Providing information in multiple formats also proved helpful. Daphne noted, “We do have videos... That’s important to know, what is their education style? Do they prefer to read it themselves? Do they like videos?” She also made herself available for private follow-ups: “I always let my patients know that if they ever want to talk one-on-one, I can schedule some office hours.” Hyacinth observed that showing materials visually was often more effective than using medical jargon: “Sometimes showing them what you’re talking about is easier than... throwing acronyms around.” Anthony described using Google Translate to bridge language gaps: “Sometimes they are excited that I even tried to reach people where they are.”

Participants also addressed and corrected common misconceptions that hindered engagement, particularly the belief that EOL planning was solely about wills or possessions. Francesca noted, “As soon as you say anything about a will... the first thing they say is ‘I ain’t got none to leave nobody.’ But that’s not what it is... This is about your healthcare.” Hyacinth emphasized reframing these discussions: “It’s about... their end-of-life wishes.” Daphne described actively working to “bust any myths or preconceived notions that that individual patient has.”

Trust-building was woven through all of these approaches. Daphne stated, “If they can see that I’m coming from a very nonjudgmental place, and that I’m sincere

about it... I think especially a minority can tell if you are being genuine.” She also acknowledged the role of historical racism in shaping patient perceptions: “There’s racism that has run rampant generational[ly]... So, I have had to really first... establish rapport... maybe do some self-disclosure.” Francesca noted that her shared identity and relatability often opened doors: “Because I’m Black, because I’m young, because I’m educated... that allows me to have some of these conversations more so than maybe someone else.” Edwina described adapting her body language to create privacy in public treatment spaces: “I do tend to be closer to the patient... leaning forward... just to create a little bit more of a sense of privacy.”

Collectively, these accounts demonstrate that what worked for social workers was not simply what they said about EOL planning, but how they said it—integrating the topic naturally, pacing it according to patient readiness, using multiple communication formats, correcting misconceptions, and fostering trust through cultural sensitivity and relational consistency. These strategies reflect the interconnected physical, psychological, social, and spiritual considerations outlined in the Biopsychosocial-Spiritual model, and underscore the central role of adaptive communication in reducing barriers to EOL planning for Black dialysis patients.

Subtheme 1: Allowing Patients to Set the Pace

Participants emphasized that patience and timing were crucial to ensuring that discussions about EOL planning were well received. Hyacinth explained, “I can do this with you right now, chairside. I don’t want to rush you making these decisions. You can take it home; you can talk to your family about it.” She later reiterated, “Wherever pace

you're moving at is fine... you can have a little more time.” Similarly, Edwina described her practice of intentionally revisiting conversations, stating, “I have flagged for myself to follow up in a few months... Have they thought more about it?”

Charlotte reflected on the limits of introducing planning during crisis moments, observing, “When someone’s in crisis, they’re not really thinking about this kind of journey toward end of life. They’re just living moment to moment, day to day.” Eloise added that readiness was shaped by emotional state, noting, “It also depends on the mindset and the emotional well-being of the patient as well.”

The dynamic and evolving nature of rapport-building was further illustrated by Violet, who shared, “She’ll tell me, ‘I don’t wanna talk to you today...’ but she will sit there and talk to me for a long time [on other days].” Francesca echoed this perspective, remarking, “When patients really don't want to... I don't try to push it.” Violet also recalled how denial or avoidance was common, as some patients would say, “Nope, I don't want to think about that. I’m not dying.” Rather than pressuring patients, she emphasized the value of revisiting the discussion over time: “I just let it go at that moment, but I always try again later.” This persistent yet patient-centered strategy reflects a respectful approach that reduces psychological resistance while allowing space for readiness to develop.

Collectively, these communication strategies highlight how dialysis social workers balance patience, persistence, and responsiveness in order to navigate complex barriers to EOL planning. Their adaptive approaches demonstrate a holistic and culturally attuned practice that supports the nuanced needs of Black dialysis patients and fosters

more accessible, meaningful planning conversations. To illustrate these connections more systematically, Table 5 organizes the findings within the BPSS framework. This mapping underscores that the strategies identified are not limited to any single domain of care but instead intersect across psychological, social, biological, and spiritual dimensions. For instance, building trust and rapport primarily addresses psychological and social domains, while overcoming structural barriers extends into the biological and systemic. In this way, Table 5 provides a conceptual synthesis that situates the findings within the guiding theoretical model and offers a foundation for the interpretive discussion that follows.

Summary

Chapter 4 provided the detailed findings of the analysis of data collected from the research question: What are dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients? Findings revealed six key themes that included: normalizing and integrating EOL discussions, building trust and rapport, addressing family and cultural influences, leveraging interdisciplinary collaboration, overcoming structural and resource barriers, and adapting communication approaches.

These themes reflect the multifaceted barriers and strategies identified by dialysis social workers in their efforts to facilitate EOL planning with Black dialysis patients. The responses from participants provide rich, verbatim examples that offer a deeper understanding of how social workers perceive and navigate the challenges of incorporating the physical, psychological, social, and spiritual aspects of care in the

context of EOL planning. Through these findings, the study sheds light on the complexities and nuances that impact social workers' ability to engage in effective EOL discussions.

As shown in Table 5, the study's findings extend beyond descriptive themes by explicitly aligning strategies with the domains of the BPSS model. This framework serves as a bridge between the empirical results and the broader theoretical and practical implications. The themes presented in this chapter will be further explored and analyzed in Chapter 5, where the findings are interpreted in relation to the existing literature and the conceptual framework. This chapter will provide a synthesis of the results, examining how the strategies identified by dialysis social workers both reinforce and extend prior literature while providing fresh insight into the multidimensional challenges and opportunities in EOL planning for Black patients while highlighting the implications of these findings for practice, policy, and future research.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This chapter presents the key findings from a study that explored how dialysis social workers perceive and implement strategies to address the complex barriers Black patients face in completing EOL planning. Using the BPSS model as a guiding framework, this qualitative research focused on understanding how social workers navigate the intertwined physical, emotional, social, and spiritual elements that influence patients' decision-making.

The study involved in-depth interviews with eight dialysis social workers who had worked directly with Black patients within the past year in the Renal Network. Each participant completed a demographic form and participated in a semi structured interview, which was recorded, transcribed verbatim, and returned for participant review to ensure accuracy and completeness. This member-checking process helped to affirm the credibility and trustworthiness of the data.

Through careful thematic analysis, six primary themes emerged from the interviews: (a) building trust and rapport, (b) normalizing and integrating EOL discussions, (c) addressing family and cultural influence, (d) overcoming structural and resource barriers, (e) leveraging interdisciplinary collaboration, and (f) adapting communication approaches to enhance EOL planning. These themes reflect how social workers intentionally respond to the multifaceted needs of their patients, tailoring their approaches to honor individual values, build rapport, and reduce barriers to planning.

As illustrated in Table 5, these themes do not stand alone but intersect with the BPSS domains. This alignment demonstrates social workers strategies operate simultaneously across psychological, social, biological, and spiritual dimensions, underscoring their work's holistic and multidimensional nature. By situating the results within the BPSS model, the findings provide descriptive accounts of practice but and a theoretical map for understanding how holistic care is operationalized in dialysis settings.

In this chapter, I will examine these findings alongside existing research and discuss how they align with or diverge from prior literature. The interpretation of results will be grounded in the BPSS model, offering insights into social workers unique role play in supporting culturally responsive, patient-centered EOL planning. The chapter concludes with a discussion of limitations, implications for practice and policy, and directions for future research.

Interpretation of the Findings

This section will present the findings and how they confirm, challenge, or extend existing knowledge of overcoming barriers for EOL planning with Black dialysis patients. Six primary themes emerged from the interviews: (a) building trust and rapport, (b) normalizing and integrating EOL discussions, (c) addressing family and cultural influence, (d) overcoming structural and resource barriers, (e) leveraging interdisciplinary collaboration, and (f) adapting communication approaches to enhance EOL planning. The themes identified by the dialysis social workers as strategies to overcome the biological, psychological, social, and spiritual barriers faced by Black dialysis patients provide

valuable insights into addressing these challenges. These findings contribute empirically to the research on overcoming barriers to EOL planning for Black dialysis patients.

Guided by Sulmasy's (2002) BPSS model the themes reflect a holistic understanding of patient-centered care, encompassing physical, psychological, social, and spiritual dimensions. The BPSS framework views individuals as whole beings whose health and decision-making are shaped by interconnected physical, psychological, social, and spiritual factors. Using this framework, the themes identified in the research study reflect dimensions that overlap in shaping patients' experiences with EOL planning. In this way, the findings align with a holistic, patient-centered approach that recognizes the importance of addressing all aspects of the person's life.

The BPSS model has long informed palliative and EOL care by acknowledging that clinical encounters must integrate physical symptoms, psychological needs, relational supports, and spiritual beliefs (Batstone et al., 2020; Beng, 2004). Recent literature continues to affirm its use in patient care. A 2024 scoping review emphasized that biopsychosocial–spiritual interventions improve EOL outcomes, fostering peace, acceptance, and meaning for patients with advanced illness (Prieto-Crespo et al., 2024). Similarly, Sleeth et al. (2025) noted that spiritual assessment tools such as the HOPE framework guide the application of the BPSS model, providing clinicians with skills to put into practice. These contemporary findings reinforce the model's applicability to dialysis settings, where patients' medical decisions are deeply entwined with psychological resilience, family relationships, and spiritual identity.

The model aligns with the complex realities faced by Black dialysis patients, whose decisions and experiences around EOL care are shaped by intertwined medical, emotional, relational, and cultural factors. Research shows that integrating holistic care approaches can help mitigate disparities and foster trust, particularly by validating cultural and spiritual values alongside medical concerns (Chuang et al., 2022; Saeed et al., 2023) Saad et al. (2017) noted that the BPSS model is a holistic and humanistic approach to the healthcare system and applied this to the Physician's Pledge in the Declaration of Geneva (Declaration of Geneva, 1948). The BPSS model provides a critical foundation for interpreting how social workers described strategies to overcome barriers to EOL planning in this study.

The BPSS model comprises four specific parts or domains- physical, psychological, social, and spiritual. Engel's (1977) original biopsychosocial theory laid the groundwork for integrating multiple health domains into medical care. Sulmasy's extension of this framework into the BPSS model—and its subsequent application to ethical standards such as the Declaration of Geneva (Saad et al., 2017)—has further emphasized its humanistic and relational orientation. As reflected in Table 5, the study's findings extend beyond descriptive themes by explicitly aligning strategies with the domains of the BPSS model. This framework serves as a bridge between the empirical results and the broader theoretical and practical implications. The discussion that follows builds on this synthesis, examining how the strategies identified by dialysis social workers both reinforce and extend prior literature while providing fresh insight into the multidimensional challenges and opportunities in EOL planning for Black patients.

Theme 1: Building Trust and Rapport

The theme of building trust and rapport emerged as a cornerstone in facilitating EOL planning with Black dialysis patients. Participants emphasized that rapport was not a preliminary step but an ongoing process essential for entering into difficult conversations about mortality, prognosis, and care preferences. This theme reflects the psychological and social dimensions of the BPSS model, showing how the interpersonal relationship between social worker and patient shapes the ability to engage meaningfully in EOL discussions.

Participants described trust-building as intentional and grounded in culturally responsive communication. One strategy they used was selective self-disclosure. Several social workers noted that limited, purposeful sharing allowed patients to see them as professionals and people with shared human experiences. Charlotte reflected, “I might say, ‘You know, my mom went through something similar,’ and that helps them see me not just as a social worker but as someone who understands.” Similarly, Edwina observed, “Sometimes I share just enough about my own experience to let them know I understand—then they open up.” These disclosures were deliberate and patient-centered, designed to reduce emotional distance and open space for honesty. Prior research shows that, self-disclosure can strengthen rapport and foster emotional openness (Beach et al., 2010). More recent work suggests that such relational approaches can also help bridge mistrust and foster engagement in EOL care among dialysis patients (Saeed et al., 2023; Perry et al., 2005). My findings build on this by showing that self-disclosure can affirm cultural understanding and credibility, particularly in systemic mistrust.

Cultural humility also played a key role in trust-building. Rather than presenting themselves as “culturally competent,” participants described humility as a posture of openness, reflection, and willingness to be guided by the patient. Daphne illustrated this by saying, “I had to work on finding empathy for patients with histories very different from mine. That took intentional effort.” This reflects Tervalon and Murray-García’s (1998) conceptualization of cultural humility as a lifelong process of learning and self-reflection. Later scholarship supports this approach, identifying humility as essential to patient-centered care (Foronda et al., 2016) and showing that it fosters relational safety while reducing stereotyping in palliative contexts (Chuang et al., 2022; Saeed et al., 2023). This study adds to that work by showing how social workers actively translated humility into practice—validating cultural concerns, centering patient voices, and allowing patients to shape their EOL conversations.

Consistency in presence was another way trust was strengthened. Participants emphasized that being reliable, showing up consistently, and checking in regularly helped patients feel safe enough to engage. Violet explained, “If I’m the one who always shows up, who checks in, then they begin to open up.” Even brief interactions carried weight because they signaled commitment that went beyond tasks. Prior research shows that sustained engagement helps reduce power imbalances and build credibility (Penner et al., 2014), and recent nephrology studies confirm that continuity enhances patient confidence and supports EOL discussions (Anderson et al., 2019; Winterbottom et al., 2024). Senteio and Callahan (2020) similarly emphasized that relational continuity is essential for creating the emotional safety needed for sensitive dialogue. My findings suggest that

consistency is more than good practice for Black patients—it also serves as a corrective to the disenfranchisement many have historically experienced.

Importantly, participants did not frame rapport to gain compliance but as an ethical commitment to honoring patient voice and dignity. For Black patients, whose preferences have often been ignored or minimized, creating a sense of relational safety was essential. Edwina noted, “If social workers felt uncomfortable and kind of treat it as a taboo, people will also feel that way and feed into it.” Her words highlight the reciprocal nature of communication: provider attitudes directly shape patient openness. Avoidance or discomfort on the part of providers risks reinforcing silence and stigma around death and dying.

Although cultural norms and social taboos can make EOL conversations difficult, participants consistently emphasized that Black patients do want to engage in these discussions. However, they need is a safe, respectful, and culturally aware environment in which to do so. Studies have shown that Black patients often desire to discuss EOL preferences but may hold back if they perceive provider discomfort or lack of cultural understanding (Anderson et al., 2019; Fisher et al., 2023; Saeed et al., 2023). My study extends these findings by showing how social workers used relational strategies—humility, consistency, and self-disclosure—to reduce hesitation and normalize dialogue.

These findings resonate with the broader literature on trust and health communication. Rapport has been shown to reduce resistance and foster openness in treatment planning (Chapman et al., 2013; Jindra et al., 2021), while reviews of EOL disparities identify trust as a central factor shaping outcomes (Chuang et al., 2022). By

situating these dynamics within the specific experiences of Black dialysis patients, this study strengthens understanding of how culturally responsive practices can be applied in nephrology social work. This approach is echoed in the work of Cáceres-Titos et al. (2025), who found that managing cultural diversity in EOL care requires clinicians to build trust gradually through ongoing, respectful dialogue. Their qualitative study emphasizes that culturally responsive care is not achieved through one-time interventions, but through sustained engagement, that honors patients' spiritual, and relational needs.

Building trust and rapport is not a preliminary step but the foundation upon which all EOL care depends. For Black dialysis patients, relational approaches rooted in humility and presence may be particularly powerful in addressing historical inequities and fostering true partnership in decision-making. Viewed through the BPSS model, trust functions as a psychosocial intervention that helps patients face mortality honestly, engage fully with their care, and voice their goals at the end of life.

Implications for Building Trust and Rapport

This study points to the central role of relational trust in helping Black dialysis patients engage in EOL planning. While cultural and social taboos often made conversations about death difficult, participants emphasized that many patients were willing—and in some cases eager—to talk once a foundation of trust was in place. Trust was not something assumed; it was built over time through genuine connection, humility, and consistency. Within the BPSS framework, these practices supported the

psychological domain by creating emotional safety, the social domain by fostering respectful relationships, and the spiritual domain by affirming dignity and values.

Trust was often cultivated through intentional, culturally responsive communication, including the careful use of self-disclosure. Several social workers described how limited, purposeful sharing helped patients see them as more than professionals and opened space for mutual understanding. Charlotte reflected, “I might say, ‘You know, my mom went through something similar,’ and that helps them see me not just as a social worker but as someone who understands.” Edwina added, “Sometimes I share just enough about my own experience to let them know I understand—then they open up.” These disclosures were never casual; they were deliberate, patient-centered choices that reduced emotional distance and encouraged honesty. Earlier work shows that thoughtful self-disclosure can strengthen rapport (Beach et al., 2010), and more recent studies highlight how relational approaches can help reduce mistrust and foster engagement in EOL care among dialysis patients (Saeed et al., 2023; Perry et al., 2005). My findings illustrate how social workers used disclosure not only to connect but also to affirm cultural understanding and credibility.

Cultural humility also emerged as essential. Rather than positioning themselves as “culturally competent,” participants described humility as an openness to learning, reflection, and allowing patients to guide the conversation. Daphne noted that she had to work intentionally to find empathy with patients whose backgrounds were different from her own. This reflects Tervalon and Murray-García’s (1998) view of humility as a lifelong process rather than a single skill. Subsequent research has reinforced this

perspective, identifying humility as a core component of patient-centered care (Foronda et al., 2016) and showing its importance for fostering safety and avoiding stereotyping in palliative settings (Chuang et al., 2022; Saeed et al., 2023). My findings build on this literature by showing how social workers operationalized humility in practice—validating cultural concerns, centering patient voice, and making space for patients to shape their own EOL discussions.

Consistency in presence was another way participants-built trust. Regular check-ins, reliability, and emotional availability created a sense of safety that made hard conversations less intimidating. Violet explained, “If I’m the one who always shows up, who checks in, then they begin to open up.” Even brief gestures signaled to patients that their social worker’s commitment extended beyond task-based care. Prior research shows that sustained engagement helps reduce power imbalances and build credibility (Penner et al., 2014). More recent nephrology studies confirm that continuity strengthens patient confidence and supports EOL conversations (Anderson et al., 2019; Winterbottom et al., 2024). Senteio and Callahan (2020) likewise point to relational continuity as critical for creating the emotional safety required for these discussions. My findings suggest that for Black patients, consistency is more than good practice; it is a corrective to histories of neglect and disenfranchisement.

Taken together, these findings underscore that building trust and rapport is not secondary but foundational to effective EOL planning. For Black patients who may carry experiences of bias or systemic neglect, strong, trusting relationships open space for them to share preferences, ask questions, and take part in shared decision-making. Relational

trust in turn reinforces all four domains of the BPSS model—helping patients prepare emotionally, strengthening respect and autonomy, affirming dignity and meaning, and ensuring that care aligns with individual needs and wishes.

Although cultural taboos can make EOL conversations challenging, participants emphasized that Black patients are willing to engage when the environment is safe, respectful, and culturally responsive. Prior studies echo this, showing that while Black patients often wish to talk about their goals of care, they may hesitate if they sense discomfort or lack of cultural awareness from providers (Anderson et al., 2019; Fisher et al., 2023; Saeed et al., 2023). This study adds new evidence by showing how humility, consistency, and selective self-disclosure can reduce this hesitation and normalize dialogue.

Finally, these findings extend the broader literature on trust and health communication. Rapport has been shown to reduce resistance and increase openness in treatment planning (Chapman et al., 2013; Jindra et al., 2021), and reviews of EOL disparities consistently identify trust as a key mediator between patient values and outcomes (Chuang et al., 2022). By grounding these insights in the lived experiences of Black dialysis patients, this study adds to our understanding of culturally responsive practice in nephrology social work.

Ultimately, trust and rapport are not preliminary steps but the ground on which all other aspects of EOL care rest. For Black dialysis patients, relational approaches rooted in humility and presence may be especially powerful in addressing historical inequities and creating genuine partnership in decision-making. Viewed through the BPSS model,

trust emerges as a psychosocial intervention—one that allows patients to face mortality with honesty, engage fully with their care, and voice their goals at the end of life.

Theme 2: Normalizing and Integrating End-of-Life Discussions

Despite the cultural and emotional barriers that can accompany EOL conversations, participants in this study highlighted the importance of making EOL planning a normalized, expected part of care rather than something only addressed during moments of crisis. Several social workers noted that integrating these discussions early—often soon after the patient begins dialysis—and revisiting them periodically helped reduce anxiety and fostered openness over time. Daphne explained, “We don’t just bring it up once and never again. It becomes something we revisit, just like any other part of their treatment.”

This proactive and routine approach to EOL conversations is especially significant when working with Black dialysis patients, who may face compounded emotional, cultural, and historical barriers to discussing death. The findings underscore that when EOL planning is introduced early and discussed in a consistent, non-threatening manner, it can begin to shift the narrative from avoidance to acceptance. Social workers who engaged patients in low-pressure, ongoing conversations created space for patients to think, reflect, and revisit their preferences over time, rather than being forced into rushed decisions during moments of medical crisis.

This finding supports research by Bansal and Schell (2018), who argue that introducing EOL conversations early in the course of chronic illness and revisiting them regularly helps patients process the reality of their condition and understand their options.

Likewise, Russ et al. (2007) and Saeed et al. (2023) suggest that consistent, ongoing conversations enable patients to engage with their prognosis more meaningfully, which in turn supports better decision-making. My study builds on this work by examining the specific ways social workers adapt their communication strategies to build culturally relevant momentum around EOL planning with Black patients, offering concrete methods for normalizing these discussions that go beyond general recommendations in the literature. Jawed and Comer (2024) emphasize that systemic mistrust and cultural stigma often prevent Black patients from engaging in EOL planning, and they advocate for strategies that build relational trust and normalize these conversations over time.

Participants echoed this sentiment, describing how frequent, non-threatening touchpoints around EOL planning helped normalize the subject. Rather than presenting the discussion as an isolated event, social workers integrated it into care conversations, reinforcing its relevance. Melissa noted, “Sometimes I’ll just check in—‘Has anything changed with how you’re feeling about your advance directive?’—and that alone keeps it from being a scary or taboo topic.” These brief but meaningful check-ins allowed patients to remain in control of their planning process while building familiarity with the subject. While prior studies have recommended revisiting EOL topics periodically, my study adds to the literature by illustrating how these checks reduce cultural stigma, support autonomy, and affirm patient identity within the clinical relationship. Similar findings are noted in dialysis research, where high-quality advance care planning has been shown to reduce unwanted high-intensity interventions and better align treatment with patient values when discussions are iterative and patient-led (see Song et al., 2016; Adenwalla et

al., 2024). These findings are also echoed in Tamura et al. (2010) research which highlights high-quality advanced care planning can reduce unwanted high-intensity interventions and better align care with patient values—especially when clinicians use low-pressure, iterative approaches.

This strategy aligns with the psychological and spiritual aspects of the BPSS model. From a psychological standpoint, early and regular EOL discussions can reduce fear and anxiety associated with mortality. Spiritually, these discussions honor the patient’s values, beliefs, and preferences over time, allowing them to make decisions aligned with their sense of dignity and personal meaning.

Furthermore, the repeated nature of these conversations allowed for a relationship-centered approach, where trust could build gradually, and patients could engage at their own pace. This aligns with the cultural considerations raised by Anderson et al. (2019) and Ceckowski et al. (2017), who emphasize that Black patients may want to engage in EOL conversations but prefer to do so within the context of a trusting, established relationship. My findings deepen this understanding by showing how social workers fostered trust not through one-time interventions, but through consistent, culturally responsive dialogue. This helps address well-documented disparities in EOL care, where Black patients are more likely to receive aggressive care due to gaps in communication and mistrust (see Wicher & Meeker, 2012; Johnson et al., 2016). Belisomo (2018) argue that Black patients often receive more aggressive care at EOL due to poor communication and lack of trust, underscoring the need for culturally sensitive,

relationship-centered approaches like those described by participants in this study. This relational rhythm is particularly vital in addressing racial disparities in EOL care.

Implications for Normalizing and Integrating EOL Discussions

The implications of this theme are substantial. By normalizing and integrating EOL discussions into standard care, dialysis social workers can disrupt long-standing taboos around death and foster deeper, more meaningful planning. Recent evidence shows that in dialysis and ESRD populations, early, integrated ACP leads to better patient preparedness and satisfaction. (Adenwalla et al., 2024). As Violet summarized, “Starting that conversation early and having it be throughout the lifetime” allows patients to prepare with confidence. These findings reflect the core tenets of the BPSS model by attending to emotional well-being, honoring spiritual values, and promoting social and psychological readiness. Just as Golsorkhi et al. (2025) notes that these communication practices of normalization influence psychological/spiritual readiness.

Ultimately, integrating EOL planning as a continuous, compassionate practice helps ensure that Black patients—who may have previously experienced rushed, impersonal, or culturally insensitive care—receive thoughtful and empowering support throughout their healthcare journey. My study contributes novel insights by demonstrating how early, sustained communication access, both an educational and therapeutic intervention, fostering psychological preparedness while creating space for cultural affirmation and personal control. This contrasts with Li et al. (2025) who noted that clinicians had early barriers and that ongoing conversations as their illness trajectories changed was needed. In this way, the work adds depth to existing literature

and provides actionable guidance fostering EOL discussions into everyday practice for marginalized populations. Which is supported by Crooks et al. (2023) which indicates that formal documentation and integrating ACP into routine care records matters for equity.

Theme 3: Addressing Family and Cultural Influence

Social workers in this study repeatedly emphasized that EOL planning is rarely an individual endeavor. For Black dialysis patients in particular, the attitudes and expectations of family members, close friends, and community members play a powerful role in shaping openness to EOL discussions. This theme explores two key subthemes: addressing family resistance and personalizing discussions using real-life scenarios.

Participants described how family members' fear, denial, or discomfort with the topic of death frequently hindered patients' ability or willingness to complete EOL documentation. In many cases, even when patients expressed interest in planning, they hesitated to move forward due to anticipated or actual opposition from loved ones. As Amy stated, "Sometimes the patient is ready, but the family isn't. They'll say, 'Don't talk about that, Mom. You're not dying.' And then the patient backs off." This finding reinforces existing literature, such as Ladin et al. (2018) and Batstone et al. (2020), which highlights how house, social and familiar expectations significantly influence patient engagement with EOL care.

However, this study extends prior work by examining how social workers navigate these familiar dynamics and culturally responsive ways. Rather than approaching resistance as minor, noncompliance, participants sought to reframe EOL

planning as a form of advocacy and empowerment. Jill shared, “I try to help the family see that planning isn’t giving up. It’s making sure their loved one’s wishes are respected.” This approach mirrors the psychosocial domain of the BPSS model by addressing relational barriers to care and highlights the clinical utility every interpreting resistance as protectiveness, born from cultural and emotional ties. The literature similarly supports this view, with Beng (2004) and Ahn et al. (2021) emphasizing the critical role that families play in shaping the cultural acceptability of EOL care decisions.

Another strategy social workers used to overcome resistance was to personalize discussions using real-life examples relevant to the patient’s circumstances. Rather than relying on abstract language, they described practical consequences of not having an advance directive. As Francesca explained, “I might say something like, ‘Right now, your estranged spouse would be your legal decision-maker. Is that what you want?’ That gets their attention.” This aligns with Senteio and Callahan (2020), who advocate for grounding EOL discussions in culturally and personally relevant scenarios. My study builds on this work by providing concrete dialogue, examples and illustrating how personalization builds, cognitive clarity, strengthens autonomy, and addresses these psychosocial hesitations that emerge in collectivist cultural contexts.

Personalized and scenario-based communication also enhances psychological engagement. This aligns with prior research showing that communication framed in concrete, relevant scenarios increase patient comprehension and decision-making capacity (Senteio & Callahan, 2020). Patients are often more willing to reflect on their choices when they can envision the implications in real terms. Ramakrishnan et al. (2024)

highlighted that patient, and their families found scenario-based dialogue useful for navigating dialysis withdrawal and EOL choices. This finding not only supports earlier status on the importance of relevance and health communication, but also contributes a culturally specific lens by showing how Black patients may benefit from storytelling or situational framing that connects with their lived experience and familial structures.

Implications

The strategies described in this theme illuminate how social workers must serve not only as educators but also as mediators within complex family systems. Their ability to reframe EOL planning as a form of empowerment rather than defeat, and to illustrate its importance with relatable examples, underscores their central role in overcoming social and cultural barriers. These findings reinforce the value of culturally responsive care, as highlighted by LaVeist et al. (2000), and demonstrate how personalized, respectful engagement can shift conversations around death from fear to empowerment.

Ultimately, the findings suggest that addressing familial and cultural influences is not a peripheral task but a core function of effective EOL planning. By honoring cultural norms while gently challenging misinformation and fear, social workers can help patients and families navigate these critical conversations with greater clarity, autonomy, and support. My study contributes, new knowledge to this area by articulating specific interventions that bridge, family influence, and patient autonomy offering practical guidance for EOL work with culturally diverse populations. These insights help expand the current literature by illustrating health social workers act as relational facilitators-

balancing empathy, authority, and advocacy to move EOL discussions forward within complex family and cultural landscapes

Theme 4: Overcoming Structural and Resource Barriers

A persistent thread across the interviews was the presence of structural and institutional barriers that limited the capacity of dialysis social workers to engage in meaningful EOL planning with their Black patients. These obstacles—ranging from time constraints and high caseloads to limited privacy, inadequate training, and professional discomfort—collectively constrained the depth and frequency of EOL conversations. Similar concerns have been documented in prior work, where nephrology providers reported that heavy caseloads and institutional culture often limited their ability to initiate or sustain goals-of-care discussions (Nair et al., 2021; Senteio & Callahan, 2020). Despite their commitment to providing compassionate care, participants often found themselves navigating systems that made it difficult to fully fulfill their professional responsibilities.

Many social workers expressed frustration over the lack of private space in dialysis units, making it difficult to broach sensitive topics. Eloise shared, “We don’t have private rooms. So, trying to talk about death with eight other people hooked up to machines—that’s not ideal.” Violet echoed this concern, stating, “Sometimes it’s just too loud or busy to have a real conversation. Patients will shut down if they think others are listening.” These experiences mirror findings from Holley (2003), who noted that patients frequently share EOL preferences with family members but often lack a safe, confidential setting to communicate these wishes to their care team.

My study extends existing research by showing how the lack of privacy not only impedes disclosure, but also erode the sense of dignity and control that patients need when facing EOL decisions. Participants emphasize that without intentional space for these conversations, patients may avoid or delay crucial planning. These findings reinforce the importance of environmental factors in EOL readiness and add nuance to the current literature by connecting physical space constraints to broader systemic inequalities that disproportionately impact Black patients.

In addition to spatial limitations, several participants acknowledged their own discomfort or uncertainty when initiating EOL discussions—particularly when these involved cultural nuances or when they felt unprepared. Hyacinth candidly admitted, “I’m not comfortable with it at all... I think it’s something I still need to work on.” This professional vulnerability reflects a common concern in the literature. Berzoff et al. (2020), Heyman and Gutheil (2003, 2006), and Taels et al. (2021) have all documented the widespread gaps in EOL-specific training for nephrology social workers, particularly as it relates to engaging with diverse populations. Recent evidence further highlights that insufficient communication skills training for nurses and social workers remains a major barrier to integrating palliative approaches in nephrology care (Cheung et al., 2021).

Although previous studies have identified the need for better training, this study contributes additional insight by capturing how the absence of culturally, relevant mentorship and institutional support compounds this problem. As Daphne noted, “It’s not that I don’t want to talk about it—I just feel like I could do it better with more training or mentorship.” These reflections demonstrate that EOL discomfort is not simply an

individual issue but a product of larger systemic deficits in workforce preparedness. de Sosa et al. (2025) showed that when provided training and guidance social workers felt more skillful in addressing ACP.

Compounding these individual challenges were systemic issues like overwhelming caseloads and limited time. Nearly every participant described the tension between administrative duties and the emotional labor of patient care. These concerns echo findings from de Sosa et al. (2025), whose evaluation of the HIGHWay ACP initiative found that while structured programs improved confidence, competing clinical demands continued to restrict the time that staff could dedicate to meaningful end-of-life discussions. Francesca remarked, “There are days I can barely catch my breath. How can I have an hour-long talk about end-of-life planning when I have 90 patients?” This concern is echoed by Altilio et al. (2008) and Goff et al. (2015), who highlight the impact of time constraints and institutional expectations on the ability to engage in comprehensive EOL planning.

However, this study extends those discussions by explicitly connecting administrative burden to ethical challenges. Participants expressed that not having time for meaningful EOL planning created a sense of moral distress, particularly when working with Black patients who have historically been denied opportunities to engage in transparent, dignified care. This aligns with broader findings that structural constraints not only reduce the feasibility of ACP but also raise ethical concerns about equitable patient outcomes (Metzger et al., 2021; Senteio & Callahan, 2020). These findings

expand the literature by framing institutional limitations not only as logistical hurdles but as justice-related concerns that undermine equitable patient outcomes.

Despite these barriers, social workers remained committed to finding ways to advocate for their patients. Some spoke of intentionally carving out time during documentation, collaborating with team members to share the burden, or partnering with community resources to extend support beyond the clinic walls. These small but intentional efforts reflected a shared belief that patients—particularly Black patients navigating systemic inequities—deserved the opportunity to plan for their future with dignity and clarity.

The findings affirm what Davidson (2008) and Saeed et al. (2023) have found in broader research: patients value EOL conversations and look to social workers as trusted allies in navigating them. However, this study moves beyond prior research by illustrating how social workers actively resist institutional limitations through creative adaptations and quiet forms of advocacy. Their efforts demonstrate how professional ethics, cultural commitment, and relational insight converge to create space for patient-centered care in structurally constrained settings.

Implications

The findings from this theme point to the urgent need for structural and institutional reforms that support the ability of dialysis social workers to engage in meaningful, culturally responsive EOL planning—particularly with Black patients who already face compounded disparities within the healthcare system. While the participants in this study demonstrated deep commitment and professional integrity, they also

revealed the extent to which their efforts were constrained by systemic limitations far beyond their control.

The absence of private, dedicated space for EOL conversations is a significant barrier that must be addressed at the organizational level. Discussing mortality in open, noisy, or crowded settings not only hinders communication but also diminishes the dignity of the conversation for patients. Policies that prioritize the allocation of private space for sensitive discussions could significantly improve patient comfort and disclosure. Supporting this, Metzger et al. (2021) reported that clinicians frequently noted that clinical areas lack suitable private rooms, which impaired their ability to hold meaningful end-of-life conversations in dialysis settings. Furthermore, this aligns with the ethical imperative of offering safe, respectful, and confidential environments for care planning.

Equally pressing is the need for more robust, standardized training in EOL planning for dialysis social workers. Participants expressed a lack of confidence in initiating conversations about death—particularly with patients from different cultural backgrounds—and many indicated that their graduate education and workplace training did not sufficiently prepare them for the complexities of this work. Cheung et al. (2021) found that nephrology social workers and nurses often feel unprepared for advance care planning due to gaps in communication training and lack of protocols, and that structured workshops increase preparedness. Training that includes culturally informed communication strategies, trauma-informed approaches, and practical tools for navigating

EOL options could better equip social workers to fulfill their roles, as defined by both federal policy and professional ethics.

In addition to improved education and physical space, systemic attention must be paid to caseload size and time allocation. Nearly all participants described the sheer volume of tasks and patients as a major impediment to providing individualized, holistic care. The implications here are not just logistical but ethical. If social workers are tasked with supporting patients through some of life's most difficult decisions, then the institutional framework in which they operate must allow them the time to do so effectively. Revisions to staffing models, workload distribution, and performance metrics may be necessary to facilitate this shift. Ramakrishnan et al. (2024), where healthcare providers reported being 'very busy' and lacking 'the time needed for in-depth end-of-life or withdrawal discussions.' Revisions to staffing models, workload distribution, and performance metrics may be necessary to facilitate this shift.

Despite the limitations imposed by their environments, participants found creative ways to advocate for patients—highlighting a persistent ethic of care that deserves institutional backing. The data suggest that even small structural changes—like designated time for EOL conversations, interdisciplinary support, or collaboration with community-based services—can empower social workers to provide more complete and compassionate care. These modes of advocacy align with findings in Anderson et al. (2019), which showed social workers often lead innovative efforts within constrained systems to integrate supportive care and advance care planning despite time and role constraints. These efforts are not only clinically sound but socially just, particularly for

Black patients who may otherwise encounter rushed or dismissive care due to systemic inequities.

Ultimately, this theme highlights that the barriers to effective EOL planning are not rooted in unwillingness or lack of compassion among social workers, but in the systems that fail to support their responsibilities. For EOL planning to become truly patient-centered and equitable, the dialysis care infrastructure must reflect the values of time, presence, and preparation that social workers strive to uphold. This means redesigning systems with human needs—not just administrative efficiency—in mind. It is only through such structural investments that social workers will be fully empowered to walk alongside patients in the meaningful, deliberate planning of their final chapter. My study expands existing literature by documenting how these structural reforms are not merely idealistic goals, but urgent necessities supported by frontline experiences.

Theme 5: Leveraging Interdisciplinary Collaboration

A central theme that emerged from participants' experiences was the essential role of interdisciplinary collaboration in effectively supporting Black dialysis patients through EOL planning. Social workers emphasized that EOL care could not be achieved in isolation and that coordinated efforts across healthcare professionals, patients, families, and external resources were necessary. For instance, Vahlkamp et al. (2023) implemented a nephrology-palliative care collaboration, including social work, that dramatically increased goals-of-care documentation in outpatient dialysis settings—from 27% to 81%—underscoring how team approaches can overcome systemic inertia. This theme

reflects not only the structural complexities of dialysis care but also the importance of teamwork in addressing the biopsychosocial-spiritual needs of patients.

Participants underscored that collaboration within the dialysis team—comprising nephrologists, nurses, dietitians, and social workers—was instrumental in delivering consistent, holistic messaging about EOL care. This is echoed by the HIGHway project (de Sosa et al., 2022/2025), which found that engaging nurses, social workers, and nephrologists together in structured ACP conversations improved the consistency of communication and the acceptability of EOL planning processes in dialysis centers.

Violet emphasized,

I definitely think having the whole team be a part of this conversation is important. It shouldn't just be left to the social worker. The doctors should be talking about it too. The nurses should be saying that. The dietitians—everyone should be involved.

This emphasis on multidisciplinary integration mirrors findings from Mesa-Gresa et al. (2023) and Rhodes et al. (2017), who have shown that interdisciplinary collaboration improves care outcomes, especially among marginalized or underserved populations. Johns et al. (2022) showed that among racial and ethnic minority patients with end-stage kidney disease, interdisciplinary care was associated with better preparedness compared to usual nephrology care alone. The present study extends those findings by demonstrating how unified team messaging not only improves communication but also reinforces trust and reduces cultural resistance in EOL planning among Black patients—a nuance not previously centered in the literature.

Several participants described how the interdisciplinary team could act as a unified front to normalize EOL discussions, especially when patients were hesitant. Similarly, in interviews with clinicians across nephrology, primary care, and palliative care, Ernecoff et al. (2022) identified inter-clinician communication and workflows as key levers for enabling collaborative, team-based palliative approaches in CKD care. Charlotte shared, "When patients hear the same thing from all of us—not just me—it sinks in more. It doesn't feel like just one person trying to push it." This collective reinforcement helped dismantle fears and misperceptions, EOL planning as a standard part of care rather than a distressing or stigmatized topic. The present findings contribute to existing research by highlighting the cumulative power of team reinforcement in facilitating, culturally sensitive, patient-centered communication.

Beyond the internal dialysis team, participants noted that partnerships with community agencies, mental health providers, chaplains, and transportation services were essential to ensuring continuity of care. Eloise highlighted this approach, saying, "I try to see if they are hooked up with any mental health resources within the community, if they might have mental health case managers." These collaborative efforts were particularly effective in addressing patients' non-medical barriers and promoting continuity of care.

The value of connecting with trusted community institutions has been underscored by Senteio and Callahan (2020), who argue that such partnerships can help mitigate mistrust and improve patient engagement—especially in populations historically marginalized by the healthcare system. This study affirms those conclusions and adds new depth by showing how dialysis social workers operationalize these partnerships to

meet patients' spiritual and social needs within the Biopsychosocial-Spiritual (BPSS) framework.

Participants also pointed to the importance of peer-to-peer education in EOL planning. Francesca explained, "Sometimes I give out handouts, or I pass out flyers for events in the community, like seminars on EOL planning." These peer-led efforts helped reduce anxiety and normalize planning by demonstrating lived experiences. Prior research by Perry et al. (2005) and Adenwalla et al. (2024) supports the effectiveness of peer mentoring, but this study extends their work by illustrating how social workers actively connect patients to those experiences as part of a holistic strategy grounded in interdisciplinary and cultural collaboration.

Taken together, these findings demonstrate that interdisciplinary collaboration is not merely a logistical necessity, but a strategic and ethical imperative for promoting equity in EOL care. Tsalouchos et al. (2024) describe a specialized multidisciplinary model in Europe—including psychologists and palliative care specialists—that addressed emotional and psychological needs alongside medical management, demonstrating how EOL planning can be more holistic when multiple professional roles are integrated. When care teams align their messaging and extend their network into trusted community institutions, they increase patient confidence and participation in EOL planning. The integration of this collaborative model within the BPSS framework ensures that patients' biological, psychological, social, and spiritual dimensions are considered in a cohesive, respectful manner.

Implications

The findings from this theme position interdisciplinary collaboration as a foundational pillar of equitable and effective EO planning, particularly for Black dialysis patients while prior research has acknowledged the utility of team-based approaches, this study provides new evidence that a collaborative model rooted in culturally, responsive, biopsychosocial-spiritual care is essential for overcoming systemic, mistrust, and fragmented care. When nephrologists, nurses, dietitians, and social workers engage as a unified front, EOL conversations become normalized, coordinated, and more likely to reflect patient values. This reduces confusion and helps shift EOL planning from an uncomfortable, isolated task to an integrated and expected part of holistic care. Institutions must therefore prioritize shared training, structured communication protocols, and team alignment in the delivery of EOL messaging. For example, Johns et al. (2022) found that in racial and ethnic minority patients with end-stage kidney disease, interdisciplinary care was associated with significantly better preparedness for kidney failure than usual nephrology care alone. This provides strong empirical support for the benefit of team-based models

This study expands upon existing literature by offering concrete examples of how interdisciplinary teams within dialysis settings engage patients through collaborative care processes such as the HIGHWay project (de Sosa et al., 2025), which shows that when dialysis social workers and nurses receive structured training and integrated coaching, their confidence addressing ACP topics improves, overcoming reluctance and fragmented care. More importantly, it highlights the ways in which external partnerships—

particularly with faith-based groups and community mental health services—are indispensable in meeting the needs of Black patients who may place greater trust in culturally familiar sources. These findings support calls by Eneanya et al. (2018) and Anh et al. (2021) for a more community-embedded model of EOL care and extend them by showcasing how frontline social workers actively implement such models. Programs like 'My Dialysis Plan' (Dorough et al., 2021) illustrate how an interdisciplinary plan-of-care approach, involving multiple team members and patient input, can help align treatment with patient priorities. This model shows how unified messaging and patient-centered care plans can make EOL discussions feel more integrated rather than isolated tasks.

The implications are clear: dialysis centers must invest in infrastructures—both internal and external—that facilitate team-based, culturally grounded approaches to EOL planning. Barriers such as lack of institutional support, training deficits, and disjointed provider roles are well documented in Chiu et al. (2025), who found that providers require clearer structures and more interprofessional cooperation to embed ACP successfully. These findings mirror what participants in this study described, reinforcing the need for structural change. This includes developing formal partnerships, establishing clear interprofessional communication standards, and supporting social workers with the time and resources needed to serve as both team collaborators and community liaisons. These structural commitments are not just best practices—they are ethical obligations in pursuit of equitable, person-centered care.

Ultimately, interdisciplinary collaboration expands the reach and depth of EOL care. It ensures that patients receive not only clinical guidance but also emotional

validation, spiritual respect, and social empowerment. For Black patients navigating complex medical systems often marred by inequity, this model provides a pathway toward dignity, trust, and autonomy at the end of life. This study contributes to the growing body of research by illustrating how dialysis social workers operationalize this model in real-world settings, offering a replicable framework for culturally responsive, team-based EOL care.

Theme 6: Adapting Communication Approaches to Enhance End-of-Life Planning

A consistent finding across interviews was the importance of adapting communication strategies to meet patients where they are—emotionally, culturally, and psychologically—when introducing EOL planning. Social workers emphasized that Black dialysis patients, in particular, often face layered emotional and historical challenges that may make conversations about mortality more complex. For instance, Golsorkhi et al. (2025) note that in advanced kidney disease, patients are more receptive to discussions when providers slow down, allow for questions, and tailor framing based on observable cues and emotional readiness. Participants described how emotional unpreparedness, coupled with cultural and systemic barriers, can lead to resistance or disengagement when the topic of EOL care is introduced too abruptly or without sufficient trust.

To address these challenges, participants adopted flexible, patient-led approaches that allowed individuals to engage at their own pace. Selman et al. (2024) found that when older patients with advanced kidney disease are given opportunities to ask questions and have treatment options presented without pressure, they report greater

clarity and feeling less overwhelmed. Rather than relying on formal, one-time conversations, social workers intentionally created multiple opportunities for patients to reflect, ask questions, and express concerns. This slower, more deliberate process helped reduce the emotional weight of the topic and allowed patients to gradually build readiness to engage. Similarly, Aryal et al. (2024) in their scoping review of hemodialysis care describe how clinicians who adapt communication style—slowing pace, using culturally relevant metaphors, ongoing check-ins—are more effective in engaging patients emotionally and allowing them to own their EOL preferences. As Charlotte explained, “Sometimes you just start with listening. You give them room to speak, to ask something small. And from there, you build.”

This approach often required social workers to read nonverbal cues, adjust their tone, and revisit the conversation over time. In doing so, they created an emotionally safe environment that supported patient autonomy and trust. This aligns with the psychological dimension of the BPSS model, which recognizes that processing mortality can be an ongoing and emotionally complex journey. For many patients, especially those facing racial disparities or systemic mistrust, communication must be tailored with sensitivity and cultural awareness.

The findings built on existing literature while extending its application. While Sanders et al. (2015) and Taylor et al. (2019) have previously highlighted the need for sensitivity and cultural humility in EOL conversations, this study adds nuance by illustrating how social workers operationalize these principles overtime. For Black dialysis patients specifically, adaptive communication strategies served as a means of honoring lives

experiences shaped by medical mistrust, grief, and historical marginalization- factors that have been under explored in prior research.

Several participants also emphasized the integration of emotional support and counseling into EOL planning efforts. Patients who appeared emotionally overwhelmed or avoidant were often referred to mental health professionals or provided additional time and space to process their feelings. Eloise highlighted the value of this approach, noting, “I try to see if they are hooked up with any mental health resources within the community, if they might have mental health case managers.” these practices demonstrate a broader, holistic strategy that supports, patient decision-making across emotional and relational domains.

This finding aligns with and expands on the work of Senteio and Callahan (2020), who advocate for wraparound models that address emotional and cultural readiness in EOL engagement. Simultaneous, Saeed et al. (2022) show that racial differences in health beliefs, prognostic expectations, and engagement in ACP are substantial; for Black patients, emotional readiness and culturally congruent communication are key mediators. This study contributes additional insight by showing how dialysis social workers identify, connect, and coordinate these resources as part of culturally responsive care, particularly for Black patients navigating EOL decisions within racially complex systems.

By allowing patients to guide the pace and depth of EOL discussions, social workers were better equipped to address fear, uncertainty, and cultural taboos. Fisher et al. (2024) found that informal, family-based conversations were preferred and far more

common than formal written directives. This aligns with the strategy described by participants in this study of beginning with listening and small conversations to build trust and engagement. This not only supported psychological readiness but also fostered a stronger therapeutic alliance, reinforcing the importance of trust and timing in patient engagement. The strategy of tailoring communication to fit emotional and cultural needs reflects an ethos of relational practice central to social work and aligned with the BPSS framework.

Implications

The findings from this theme highlight that emotional flexibility, cultural humility, and patient-centered pacing are not optional techniques—they are core competencies in EOL communication with Black dialysis patients. Social workers in this study consistently reported that allowing patients to set the tone, timing, and depth of conversations created the conditions for trust and sustained engagement. These approaches stand in contrast to standardized; checklist-driven models that may inadvertently overlook the relational dynamics essential to meaningful dialogue.

Participants described adapting communication styles as a deliberate, ongoing process grounded in attentiveness to the patient's psychological and emotional state. This aligns with the findings by Golsorkhi et al. (2025), who report that in advanced kidney disease contexts, patients benefit when clinicians' slow communication, allow repeat conversations, adapt to emotional cues, and avoid checklist-style interactions that press for immediate decisions. This included reading nonverbal cues, offering information in multiple formats, and revisiting conversations gradually rather than pressing for

immediate decisions. As the interviews illustrated, pressuring patients into premature choices often heightened resistance and undermined trust, whereas pacing discussions over time fostered a greater sense of control, respect, and openness. This reinforces the value of repeated touchpoints, emotional availability, and relational continuity as integral to EOL planning.

Within the Biopsychosocial-Spiritual (BPSS) framework, these communication strategies engage multiple domains. Psychologically, they help reduce anxiety and enhance readiness to engage with sensitive topics. Socially, they promote respectful, individualized interaction. Spiritually, they honor dignity and personal meaning, while biologically, they ensure that care plans align with the patient's evolving needs and values. For Black patients navigating cumulative stressors, racialized healthcare encounters, or cultural silence around death, adaptive communication can function as both an engagement tool and a healing mechanism.

These findings extend prior research by Anderson et al. (2019) and Ladin et al. (2018), which emphasize the need for cultural sensitivity in EOL care, by providing specific examples of *how* social workers operationalize adaptability in real-world dialysis settings. While existing studies have underscored the importance of cultural humility, this study adds nuance by demonstrating how social workers calibrate their tone, language, and pacing to align with patient readiness—often over weeks or months—thereby embedding EOL discussions into the normal rhythm of care rather than isolating them as singular, high-stakes events. Notably, Saeed et al. (2023c) found that for Black patients, communication that includes cultural humility and emotional availability, especially

across multiple touchpoints, supports trust and improves uptake of advance care planning.

The implications for social work practice are clear. Social workers and interdisciplinary teams must be equipped with advanced training in trauma-informed, emotionally intelligent communication that incorporates culturally grounded strategies. Such training should extend beyond clinical content to include techniques for sustaining rapport over time, navigating complex cultural contexts, and accommodating individual preferences for receiving and processing information. At the institutional level, policies should prioritize relationship-based care by allocating time and flexibility for multiple patient touchpoints, rather than expecting immediate outcomes from a single conversation. Trauma-informed care frameworks, such as those described by de Groot et al. (2023), further highlight how patients with histories of trauma or systemic marginalization require patience, emotional safety, and pacing rather than being rushed into conversations about mortality.

Ultimately, adapting communication approaches to the emotional and cultural realities of each patient enhances the inclusivity, dignity, and effectiveness of EOL planning. By framing communication as a relational and iterative process rather than a transactional exchange, social workers can address barriers rooted in mistrust and create space for authentic, patient-led decision-making. Lanini et al. (2022) also point out that multidisciplinary palliative care in kidney disease must include flexible, evolving communication that honors changing patient values over time rather than fixed, one-time presentations. This study contributes to the growing body of literature calling for a more

relational, culturally attuned approach to EOL care, while offering practical insights into how such strategies can be enacted in the daily realities of dialysis practice.

Limitations of the Study

While this study offers important insights into how dialysis social workers engage in EOL planning with Black patients, several limitations must be acknowledged. First, the sample size was relatively small, with only eight participants. Although qualitative research values depth over breadth, the limited number of interviews may not fully reflect the diversity of experiences among dialysis social workers across different settings. Most participants were also female and identified as White, which may have shaped how certain themes—particularly those related to race, cultural humility, and trust-building—were discussed or understood. Research indicates that cultural differences in beliefs, rituals, and expectations surrounding death can significantly influence trust and communication in EOL care (Caceres-Titos et al., 2025). A more culturally and gender-diverse sample may have produced a wider range of perspectives on how best to engage Black patients in these sensitive conversations.

Secondly, the findings are drawn solely from the perspectives of social workers. While the intention of this study was to better understand how social workers perceive and address the barriers to EOL planning, the absence of direct input from Black dialysis patients means that some patient-specific experiences and beliefs may not have been fully captured. As the APA notes, cultural identity profoundly shapes how individuals approach serious illness and EOL decisions (American Psychological Association, 2025). Their voices are central to a more complete understanding of how race, culture, and

structural inequities shape EOL engagement, and future research should consider incorporating their perspectives more directly.

Another limitation relates to geographic representation. Half of the participants were from smaller, more rural areas in Virginia, while the other half were from more urban areas in Maryland. These regional differences may have influenced access to resources, support for interdisciplinary collaboration, or community-level cultural attitudes around EOL care, which limits the transferability of findings to other regions.

Researcher bias must also be considered. I approached this study not only as a researcher but also as a former dialysis social worker and someone with personal experience navigating chronic illness. While I engaged in self-reflection throughout the process and aimed to remain objective, my prior professional experiences and personal connections to the topic may have shaped both the way I conducted the interviews and how I interpreted the data. Additionally, two participants were professional colleagues, which may have influenced how candidly they responded or how I perceived their input.

Finally, while Sulmasy (2002) BPSS model provided a helpful lens for organizing and interpreting the data, it had some limitations. The model was useful for highlighting how social workers addressed the physical, psychological, social, and spiritual needs of Black dialysis patients, but it does not fully account for the systemic or institutional barriers that emerged as significant in this study. Boomer et al. (2024) emphasizes that understanding cultural attributes and structural inequalities is essential for meaningful EOL engagement, especially in diverse populations. For example, high caseloads, lack of training, and limited privacy—factors deeply embedded in organizational structures—are

not easily addressed within the BPSS framework. In hindsight, a theory that more directly incorporates structural competence or culturally responsive care might have been a stronger fit for capturing the full complexity of the barriers identified. Similarly, had the study focused more on the lived experiences of Black dialysis patients themselves, the spiritual and cultural dimensions of the BPSS model might have been more fully engaged.

Recommendations

To advance equitable and comprehensive EOL care for all patients—particularly Black dialysis patients who face longstanding structural and cultural barriers—it is critical that training for all healthcare professionals, including social workers, be rooted in culturally informed, evidence-based approaches. Training should go beyond generic instruction and include in-depth exploration of state-specific policies and practices related to EOL planning, including diagnosis, prognosis, disease trajectory, treatment options, and legally recognized tools such as advance directives, living wills, and health care proxies. Furthermore, it is essential that education address palliative care, hospice, transplant eligibility, and other EOL pathways so that patients can make informed choices aligned with their values and goals.

The findings of this study suggest a strong need for more targeted training and ongoing support for dialysis social workers, particularly in how to engage in culturally sensitive and psychologically safe EOL conversations. Participants consistently emphasized that building rapport, using selective self-disclosure, demonstrating cultural humility, and providing a consistent presence are foundational to creating trust and

openness. Without adequate preparation, social workers may avoid these conversations altogether or enter them with uncertainty, inadvertently reinforcing the very barriers they hope to dismantle.

Additionally, there is a clear need for dialysis centers to support social workers in carrying out their EOL responsibilities effectively. This includes offering not only regular training but also supervision, interdisciplinary collaboration, and protected time for rapport-building conversations. Institutions should consider embedding EOL discussions into the standard of care early in the patient's dialysis journey, allowing space for the dialogue to evolve naturally over time rather than being reserved for moments of crisis. Participants demonstrated that when EOL planning is normalized as part of routine care, patients are more likely to feel empowered, informed, and ready to engage.

From an educational perspective, social work curricula would benefit from more comprehensive instruction on death, dying, and culturally responsive EOL planning. These topics remain underrepresented in many MSW programs, yet they are central to the work of nephrology social workers. Expanding this content could prepare emerging practitioners to meet the complex psychological, spiritual, and social needs of patients navigating chronic illness and terminal care.

Although this study focused on social workers' perceptions, its use of Sulmasy (2002) BPSS model helped illuminate how physical, psychological, social, and spiritual needs intersect in the context of EOL planning for Black patients. While the model was a useful framework, future research might benefit from integrating theories that explicitly

address structural barriers or systemic racism to better contextualize the institutional limitations that participants described.

Given the small and regionally bound sample of this study—limited to dialysis social workers in the Renal Network region spanning three eastern U.S. states—it is recommended that future research expand the scope both geographically and methodologically. A larger, nationwide quantitative study could provide valuable insight into how widespread the identified barriers are, while also improving the generalizability of findings. In addition, further qualitative work would be beneficial in capturing the perspectives of Black dialysis patients themselves, whose voices are essential to fully understanding the nature of the barriers and the effectiveness of proposed strategies.

While such studies may pose ethical and logistical challenges due to the medical vulnerability of this population, the insight gained would be invaluable. Comparing the perspectives of social workers and Black dialysis patients could help identify alignment or disconnect between provider intentions and patient needs. This could open new pathways for culturally responsive practice and better-informed care models that integrate patient voice at every level.

Finally, future research should include clinics and providers from other regions of the country. Several potential participants outside of the Renal Network declined to participate in this study, which highlights the need to explore regional variations in practice, resource availability, and cultural approaches to EOL planning. Expanding the study population may help uncover broader patterns and promising interventions that could improve EOL outcomes for Black patients across diverse communities.

Implications

The results from this study have some implications for positive social change. Ensuring the quality of healthcare for all groups of patients, especially those from vulnerable populations such as Black dialysis patients, requires a systemic approach to overcoming barriers related to EOL planning. For example, researchers have identified a range of challenges impeding social workers' ability to provide EOL planning, including physical, psychological, social, and spiritual barriers (Amro et al., 2016; Bansal & Schell, 2018; Davison, 2010; Eneanya et al., 2018; Hing et al., 2016; Jennings & Johanson, 2018; Lazenby et al., 2017). The findings of this study align with the BPSS model, which highlights the importance of addressing not only the physical and psychological needs of patients but also their social and spiritual needs. The theory underscores the need for a holistic approach to patient care, where social workers engage with patients to understand their concerns and facilitate EOL discussions that reflect their values and beliefs (Gehlert & Browne, 2019). The literature also underscores the essential role of dialysis social workers in EOL planning, with Reckrey et al. (2014) noting that they are integral to the process of helping patients navigate complex decisions at the end of life. This study emphasizes the critical need for comprehensive training for social workers and healthcare providers that is grounded in scientific knowledge, cultural competence, and a commitment to open, ongoing discussions about EOL planning. Training programs must cover not only the clinical aspects of EOL planning—such as diagnosis, prognosis, available options (e.g., palliative care, hospice, transplant), and disease trajectory—but also include culturally informed strategies for engaging patients in these sensitive

conversations. This is essential for improving comprehension, facilitating informed decision-making, and ensuring that all patients, regardless of cultural background, have access to the support they need during this critical time.

Black patients may be uncomfortable with talking about EOL, but they desire conversations (Anderson et al., 2019; Ceckowski et al., 2017), but with utilizing the IDT and community resources, helping patients be more prepared for EOL discussions with therapeutic supports, having regular conversations with patients and their families, social workers who represent, understand, and connect with patients, and training and support for social workers, these barriers can be overcome. By understanding that racism and discrimination contribute to health disparities, social workers can provide more culturally competent services and information to their Black patients. This can improve Black patients' quality of life overall and, in turn, that of their families and communities.

There are various ways that this can be achieved, such as presentations at conferences with all types of healthcare professionals and lunch and learning with targeted audiences such as dialysis social workers. Additionally, working with the National Association of Social Workers to create an EOL planning training program would help to achieve this goal. Finally, dialysis workers need targeted training on EOL with consistent information about their states practices and requirements to help social workers feel more confident and comfortable with these discussions.

Additionally, a potential positive social change is incorporating more education for social workers within their core MSW programming regarding EOL, which could assist with improving outcomes. Nonetheless, this training should also extend to all

healthcare providers to ensure that the information is known across disciplines and can be successfully applied to patients to help normalize the topic and support patients.

Results from this investigation contribute to the existing literature on overcoming barriers to EOL planning with Black dialysis patients. This study demonstrates the need for culturally competent and sensitive professional practices to promote informed decision-making and respect for patient preferences to enhance the quality of life of Black patients. The BPSS model offers a comprehensive framework for overcoming barriers to EOL planning with Black dialysis patients. The theoretical implications include a holistic understanding of patients, addressing health inequalities, cultural sensitivity, and competence, enhancing communication, supporting psychological and spiritual well-being, building trust and rapport, and empowering patients and families. By utilizing the theory, social workers can create a more inclusive and supportive environment for Black dialysis patients, ultimately improving their EOL care experiences.

The findings suggest improved training for dialysis social workers on EOL discussions, planning, and utilizing the healthcare team and other supports. Advocating for education and training changes that increase EOL knowledge and cultural competency within social work are strong implications from the findings of this study. Additionally, training for all IDT members would help improve support for Black patients. Promoting awareness of the need for EOL discussions throughout life and cultural competency in social work practices that provide services to diverse populations may provide supportive information required for the continuance of EOL and cultural

competency training. Improvements in education could be made by creating a specific learning goal for EOL planning that is part of the required curriculum of accredited social work programs. This can be done through work with the National Association of Social Workers and the Counsel of Social Work Education to ensure that all information is included in educational programs. Additionally, dialysis centers could ensure that their staff are all trained similarly with thorough information and knowledge by developing a consistent training and checklist to ensure that staff have and know the information and how to have EOL conversations during onboarding.

Conclusion

This study of the experiences of dialysis social workers with EOL planning may help to understand better how the BPSS model may serve to aid or hinder in understanding how to overcome physical, psychological, social, and spiritual barriers with Black dialysis patients. To understand this experience, eight dialysis social workers who currently work with Black dialysis patients were interviewed about their experiences in providing EOL discussions and planning with their Black patients. The findings revealed that participants felt it was important to build trust and rapport, normalize and integrate EOL discussion, address family and cultural influences, overcome structural and resource barriers, leverage interdisciplinary collaboration, and adapt communication approaches to enhance EOL planning. This research serves as a call to action for further studies surrounding the barriers to EOL planning for Black dialysis patients. It prepares clinicians to successfully engage and support Black patients' EOL journey and improve discussion rates. This research also supports the need for change in the education and

training of social workers. This exploration into EOL planning can help to provide better services and support to Black dialysis patients and all individuals by creating a plan of action for training social workers and other healthcare providers in EOL planning and ensuring that all individuals are provided with appropriate, accurate, and timely information and support. For my part, I will share my results with the Renal Network that I utilized and ensure that the students and professionals I work with know these barriers and how to address them.

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Appendix A: Demographic Checklist

Name _____

Participant pseudonym _____

Phone Number _____

Email address _____

Race/Ethnicity _____

Age _____

Dialysis center/company in which you are currently employed

Years/Months of Service _____

Do you work with Black dialysis patients currently? _____ Yes _____ No

Have you worked with patients who identify as Black within the last six months?

_____ Yes _____ No

Do you complete EOL planning at work? _____ Yes _____ No

Do you document it? _____ Yes _____ No How _____

Are you comfortable with EOL planning? _____ Yes _____ No

Appendix B: Interview Protocol

Thank you for taking the time out of your busy schedule to participate in this study. My name is Annette Kestner, and I am a doctoral candidate at Walden University. This research is being completed to fulfill my degree requirements, but it is a topic of interest and passion for me. I am researching dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients. My definition of EOL planning is explaining to the patient their disease and prognosis, their options for care and treatment, and the completion of forms that convey to providers their preferences for care and treatment, such as advanced directives, do-not-resuscitate orders, power of attorney documents, and wills. I will only take up a little of your time. This interview will likely take approximately 60 minutes, give or take a few minutes. Are you ok with the amount of time you have in case we run over a few extra minutes if needed? Ok, thank you for that feedback. I will do my best to be timely. I am going to ask you a few questions, and I ask you to respond to the best of your ability. If there is a question you do not understand, please do not hesitate to let me know, and I will rephrase it for you. Let me know if any questions make you uncomfortable, and I will stop the questions. I will end the session at any time at your request. Do you have any questions for me? Ok, let us begin.

RQ: What are dialysis social workers' perceptions of strategies that incorporate the interaction of physical, psychological, social, and spiritual components to address barriers to completing EOL planning with Black dialysis patients?

Interview Protocol:

- I. Tell me about your experience with being a dialysis social worker.
- II. Tell me about your responsibilities regarding EOL planning with your Black patients.
 - a. Do you have to document this in some way, and how?
 - b. How often do you have discussions with your patients about EOL planning?
 - c. How did you learn to talk about EOL planning?
 - d. Do you feel comfortable having these talks? How comfortable?
 - e. Tell me about the place and environment where you have these conversations.
- III. Tell me about your experience with EOL planning with Black patients.
 - a. Tell me about any difficulties and successes and how you handled them.
 - b. Tell me about any biological or physical barriers you encountered and how you overcame these.
 - c. Tell me about any psychological barriers you encountered and how you overcame these.
 - d. Tell me about any social barriers you encountered and how you overcame these.
 - i. Tell me about cultural or historical barriers and how you overcame them.

- e. Tell me about any spiritual barriers you encountered and how you overcame these.
- f. Tell me how your race, gender, age, socioeconomic status, or other personal features impact your effectiveness in EOL planning with Black patients.

IV. What other things do you do to educate your Black patients on EOL planning or needs?

- a. What other things do you feel need to be or could be done to make EOL planning easier or better?
 - i. What things could be done before, during, or after that could also help with the EOL planning process?

V. Are there any other things you would like to share with me about your experience in EOL planning with your Black patients?