

2020

## Roles of Nephrology Social Workers in Health Literacy

Tiffena Gail Pierce  
*Walden University*

Follow this and additional works at: <https://scholarworks.waldenu.edu/dissertations>



Part of the [Social Work Commons](#)

---

This Dissertation is brought to you for free and open access by the Walden Dissertations and Doctoral Studies Collection at ScholarWorks. It has been accepted for inclusion in Walden Dissertations and Doctoral Studies by an authorized administrator of ScholarWorks. For more information, please contact [ScholarWorks@waldenu.edu](mailto:ScholarWorks@waldenu.edu).

# Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral study by

Tiffena Pierce

has been found to be complete and satisfactory in all respects,  
and that any and all revisions required by  
the review committee have been made.

## Review Committee

Dr. Debora Rice, Committee Chairperson, Social Work Faculty  
Dr. Elizabeth Walker, Committee Member, Social Work Faculty  
Dr. Kristin Richards, University Reviewer, Social Work Faculty

Chief Academic Officer and Provost  
Sue Subocz, Ph.D.

Walden University  
2020

Abstract

Roles of Nephrology Social Workers in Health Literacy

By

Tiffena Pierce

MSW, University of Texas at Arlington, 1992

BS, Ouachita Baptist University 1988

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Social Work

Walden University

May 2020

## Abstract

Health literacy is vital for hemodialysis patients because they need to undergo routine treatments 3 days per week and adhere to medication regimens requiring them to understand complicated health information. The questions for this study focused on a social work practice of their roles when assessing and promoting health literacy in dialysis patients. Nephrology social workers are vital in helping dialysis patients understand their medical information so that they can make better-informed decisions about their healthcare. This study also includes an exploration of the strategies nephrology social workers use to increase health literacy in patients with chronic kidney disease. An ecological framework with social learning theory was used as the foundation to address broader social determinants. An action research design was used to execute the study. Data were collected using a focus group of 5 female social workers, 4 nephrology social workers, and a social worker who previously worked in dialysis. A thematic analysis coding technique was used for data analysis. Key findings include: (a) social workers perceived their crucial role was helping patients understand their treatment plan and condition one step at a time, and (b) ways to engage family and interdisciplinary team patients' care. Recommendations include increased healthcare education screenings and advocating for national social work associations to spread information about healthcare proficiency. These social change recommendations are designed to help increase the overall health literacy of dialysis patients with a result of reduced healthcare costs for people and organizations.

Roles of Nephrology Social Workers in Health Literacy

By

Tiffena Pierce

MSW, University of Texas at Arlington, 1992

BS, Ouachita Baptist University 1988

Project Submitted in Partial Fulfillment  
of the Requirements for the Degree of  
Doctor of Social Work

Walden University

May 2020

## Acknowledgments

From the bottom of my heart, I would like to say a big thank you to my family and support system for all your support. I want to say thanks for listening to me as I vented and even during my crying spells. Thank you all for encouraging me to continue even when my “chemo” brain would not let me be great. A special thanks to Dr. Rice and Dr. Walker for your guidance, and a special thanks to Dr. P and my cohorts for being there for me at residency when I found out that I was diagnosed with cancer without your help and wise guidance this project would not have been the same! To my dear sweet daughter, Lauren, thanks Pumpkin for always being there for me. Thanks for being strong for me and with me. You are truly my shining star. Last but not least, a special thanks to my dear sweet mother. You were one of my biggest supporters, and for that, I am forever grateful. I know that you are looking down on me smiling. Mama, you will forever be in my heart, and I love you. Thanks to my supporters for helping me to live out my motto of I refuse to let my diagnosis determine my destiny.

## Table of Contents

Section 1: Foundation of the Study and Literature Review .....	1
Problem Statement .....	2
Purpose Statement and Research Questions .....	6
Nature of the Doctoral Project .....	7
Significance of the Study .....	9
Theoretical Framework .....	10
Values and Ethics .....	12
Review of the Professional and Academic Literature .....	13
Nephrology and End-Stage Kidney Disease .....	14
Nephrology Social Workers .....	15
Health Literacy Deficits .....	17
Theory of Health Literacy .....	20
Health Literacy as an Asset .....	22
Conventional Social Work Intervention .....	25
Health Promotion Dimensions and Social Workers .....	26
Gaps in the Literature .....	29
Summary .....	29
Section 2: Research Design and Data Collection .....	32
Research Design .....	32
Methodology .....	34
Participants .....	34
Instrumentation .....	35

Data Analysis .....	35
Ethical Procedures .....	37
Summary .....	37
Section 3: Presentation of the Findings .....	39
Data Analysis Procedures .....	40
Limitations .....	42
Findings.....	43
Data Findings .....	43
Unexpected finding.....	54
Summary .....	54
Section 4: Application to Professional Practice and Implications for Social Change .....	56
Application for Professional Ethics in Social Work Practice .....	57
Recommendations for Social Work Practice .....	59
Implications for Social Change.....	64
Summary .....	65
References.....	66
Appendix A: Participant Demographic Questionnaire .....	85
Appendix B: Interview Questions for Focus Group .....	86



## Section 1: Foundation of the Study and Literature Review

In my study, I addressed the gap in social work practice by focusing on the roles of nephrology social workers when assessing and promoting health literacy in dialysis patients. Nephrology social workers are helping end-stage renal disease patients understand medical information in order to make more informed decisions. Social workers know how important it is to meet the patients where they are, and they know the importance of culturally sensitive topics along with listening (Dagefprde & Cavanaugh, 2013). My goal in performing this action research project was to understand nephrology social workers' roles and how they assess the level of health literacy in dialysis patients. Health literacy is the extent that a person has the ability to communicate, process, and understand health information and barriers to make suitable decisions in regards to their health (Centers for Disease Control and Prevention [CDC], 2016). This skill is especially necessary within the growing range of patients with chronic illness and renal disease due to the complexity of the disease, which demands a high level of patient involvement and self-management skills. Patients with kidney disease should follow acceptable dietary restrictions, adhere to advanced medication regimens, build choices regarding treatments, and sustain multiple appointments within the healthcare system (Jain, Sheth, Green, Bender, & Razmaria, 2016). Even despite a patients' knowledge of the various ways to stagnate and delay the progression of many kidney diseases, outcomes are always substantially associated with the hereditary genetic makeup of the specific patient, in addition to the external environmental factors, be it that they are beneficial or detrimental to their overall genetic predispositions (Jain et al., 2016). Although the rate of progression for chronic kidney diseases is somewhat independent, within patients' cases,

there is increasing proof that health literacy plays a vital role within the care of patients with kidney disease (Young, 2013).

Health literacy is as important for social workers as it is for the patients (McCulloch, 2015). To bridge the gap between the medical information provided and its implementation, healthcare professionals are needed to demonstrate an openness to learning in a non-universalized manner and must be brought to the level where they can speak and understand the language and its meaning for the culture of the patients they are dealing with (Purnell, 2014). Health literacy has been associated with positive health outcomes to a higher degree than social and economic status, education, gender, and age (Rikard, Thompson, Mckinney, & Beauchamp, 2016). My goal for this action research project was to promote concise, efficient communication of health literacy information between patient and medical staff. I also hoped to create positive social change in the dialysis community by presenting awareness of the roles that nephrology social workers play by providing psychosocial interventions with the dialysis patients to help improve outcomes by improving patient self-management.

### **Problem Statement**

Patients with chronic kidney disease (CKD) are exposed to multiple physical and psychological stressors as a result of their illness (Untas et al., 2010). Treatment of CKD can involve intense regimens, incorporating potential changes in family relations, social interactions, and activities of daily living (Untas et al., 2010). The biopsychosocial effect of chronic kidney results in poorer personal satisfaction or quality of life contrasted with patients with other chronic illnesses (Loos, Briancon, Frimat, Hanesse, & Kessler, 2003). Dialysis patients have many adjustments to make, along with important health decisions.

They have to learn about dialysis, medications, and about their body. The role a nephrology social worker plays as the patient's advocate is vital because social workers serve as an extension of the patients' support system, which transmits the patient's total medical and nonmedical needs to the healthcare team (Bale et al., 2016).

Social workers are required to advocate and provide means of effective communication with persons of all cultural backgrounds, including people with low literacy skills, with limited English proficiency, and people with disabilities National Association of Social Workers [NASW], 2018. Because of the diverse efficacy of communication techniques, social workers need the skills to help patients who have the limited ability to comprehend medical information.

According to Allen, Auld, Logan, Montes, and Rosen (2017), the importance of health literacy is undervalued, and thus, the common concept of health literacy is often misconstrued and downplayed. Health literacy involves the social and cultural factors along with educational factors that affect the expectations and preferences of dialysis patients and the degree to which those providing health care services can meet those preferences. There is a need to become a more health literate society in the United States. The United States Department of Health and Human Services (United States Department of Health and Human Services [HHS], 2016), stated that social workers can help patients rebuild health literacy skills, especially the 90 million Americans who have below basic health literacy. Further, the Institute of Medicine (2016) defined health literacy as the proficiency for people to obtain, understand, and utilize information built around basic health practices and how to access local medical services to make better informed health

decisions. Health literacy additionally involves oral understanding (speaking and listening skills), numeracy, and cultural and abstract information. Among groups like the elderly, minorities, and people with lower socioeconomic standing, health literacy rates have been found to be very low (Rikard et al., 2016). There is increasing proof that health literacy plays an important role in the care of patients with kidney disease (Young, 2013). Nephrology social workers provide accessible health literacy screening tools, studies of health literacy in patients with kidney disease, and techniques to address health literacy in clinical settings.

Limited health literacy affects 25% of individuals with CKD and may inhibit self-management skills leading to poorer clinical outcomes (Taylor, Oberle, Durlak, & Weissberg, 2017). By disproportionately involving non-White individuals or those with low socioeconomic standing, restricted health skills might exacerbate health inequity (Taylor et al., 2017). Nephrology social workers are learning that the skill set required to teach about health literacy encompasses a greater understanding than merely creating informational pamphlets on health literacy. The key to determining health skills to improve them is to sit down with a patient one-on-one and help the patient pay more attention to their renal disorder. As social workers speak with the patient, social workers can identify areas wherever the language is not clear and revise the discussion of those topics. Social workers must change their approach with the supported feedback from patients, and still be able to modify programs for patients with the ability to point out gaps in communication and practical education (Sørensen et al., 2012).

One-third of U.S. adults do not have adequate health literacy to manage their health care needs; health literacy is grounded in a general understanding of human

communication and also share the goal of improving health outcomes. Low health literacy could be a potential driver of health disparities, and its alleviation is central to the values and issues of the social work profession (Mantwell, Monestel-Umaña, & Schultz 2015). Despite the in-depth information and skills that social workers bring to help patients with low health literacy, understanding and mediating fluency in understanding the medical lexicon of health literacy is often underused in social work (Lietchty, 2011). This gap reflected lost opportunities and missed encounters for social workers to contribute their experience to the evolving field of health literacy and to strategically align their work with structure and national priorities.

Health literacy is especially important for the growing number of patients with CKD, which requires a high level of patient involvement and self-management skills (Young, 2013). Patients with renal failure must follow applicable dietary restrictions, adhere to complex medication regimens, create choices concerning dialysis, and sustain multiple appointments within the health care system (Beto, Schury, & Bansal, 2016). Despite strategies to delay the progression of the disease, kidney outcomes are substandard, partly associated with the patient and their behavioral decisions (Weber, 2013). Of these, there is sufficient evidence to suggest that health literacy plays an important role within the care of patients with kidney disease (Dageforde & Cavanaugh, 2013). Social workers are vital members of the interdisciplinary team and a resource for patients with chronic kidney disease. Social workers supply cost-effective interventions like education, assessment, family, individual, and group therapy, and autonomously

monitor the outcomes of those interventions to confirm their effectiveness (Steketee, Ross, & Glaze, 2017).

The stakeholders and participants of this action research project were the licensed master social workers in the outpatient hemodialysis facilities throughout the regions of Arkansas and Texas. The participants were also those who are the primary social workers involved in the care of the patients. Nephrology social workers employed at dialysis facilities were master's level social workers. They were highly trained individuals who serve as a support system for the patient and their family in adjusting to and understanding CKD. CKD is damage to the kidneys that have gotten worse over time and may result in the kidneys no longer working (Webster, Nagler, Morton, & Masson, 2017). This is known as end-stage renal disease or kidney failure. When this happens, the person will need dialysis or a kidney transplant.

### **Purpose Statement and Research Questions**

The purpose of this study was to identify how nephrology social workers understand their roles in promoting health literacy among CKD patients, how they assess for health literacy, and what strategies they use to promote health literacy, specifically within the regions of southwest rural Arkansas and eastern Texas areas. My action research project may help social workers to have a better understanding of clinical services provided by social workers in the field and may also help enhance their professional development. The distal aim of the study was to promote the improvement of health literacy by providing CKD patients with access to nephrology social workers who have gained a deeper understanding and perspective of their patients and of their needs. The primary research questions for this study were:

Research Question 1 (RQ1): How do nephrology social workers perceive their roles in providing and promoting health literacy among patients with chronic kidney disease?

Research Question 2 (RQ2): How do nephrology social workers assess health literacy skills in patients with chronic kidney disease?

Research Question 3 (RQ3): What strategies do nephrology social workers use to increase health literacy in patients with chronic kidney disease?

For this project, I used the following definitions:

1. *End-stage renal disease* is when chronic kidney disease is at an advanced state, when one's kidneys are no longer able to function at the lowest level of operation in order to meet the minimum basic needs of the human body (Mayo Clinic Staff, 2018).
2. *Health Literacy* is the extent that a person has the ability to communicate, process, and understand health information and barriers to make suitable decisions in regards to their health (CDC, 2016).
3. *Nephrology* is the diagnosis and treatment of those with kidney disease and consists of care for patients by providing kidney replacement, dialysis and transplants (University of Wisconsin, 2019).

### **Nature of the Doctoral Project**

The design of this study was action research. Action research is used to solve an immediate problem or provide a reflective procedure of innovative problem solving. It is led by individuals working with others in teams or community to improve the way they address issues and resolve problems (Glanz, 2014). Meyer (2000) noted that action

research's strength lies in its focus on generating solutions to practical problems and its ability to empower practitioners/social workers, by getting them to get involved in research with a goal of implementation of the activities. Meyer (2000) stated that practitioners can choose to research their own practice, or an outside researcher can be engaged to help to identify any problems, seek and implement practical solutions, and systematically monitor and reflect on the process and outcomes of change. Participatory action social work research places emphasis on systemic social change, especially among adolescents (Anyon, Bender, Kennedy, & Dechants, 2018).

My action research project is beneficial to social workers because it aligns with the professional field of social works' ethical principles along with the values and ideals upon which the profession of social work was built and may provide insight for social change agendas. By using action research, social workers participated in a research study in which I addressed potential barriers to presenting health literacy information to patients in a way that they can comprehend.

Focus groups are a useful way for promoting an empowering, action-oriented form of health research (Tausch & Menold, 2016). Using a single focus group, I studied and engaged with nephrology social workers who provide and deliver services to patients with CKD. Chiu (2003) noted that in action research, group processes are central in facilitating change and focus groups are widely used by action researchers. Chiu (2003) also stated that group processes are central because of their potential in engaging participants in research activities.



It was my intent to use a single focus group as a means of facilitating participatory empowerment with the goal of changing, enhancing, or renewing information on the health literacy of the dialysis patients in settings that provide services. I used a focus group for this study to better guide the research process.

I am the regional point social worker for my region. I contacted eight nephrology social workers via email and received six replies for interest in my action research project. After I received responses indicating the social workers' consent for participating in the study, I contacted them by email to request how they present medical information to dialysis patients and asked ways to help patients understand and comprehend with low health literacy levels.

I collected qualitative data from five licensed master's level nephrology social workers that produced insight into barriers regarding how medical information is presented to dialysis patients in a way that they can understand and comprehend in order to make informed decisions. The data was analyzed by breaking the information down into smaller groups of information, then the data was placed into categories, and finally the themes were categorized. I coded and categorized the data through thematic analysis to identify themes, which answered my research questions.

### **Significance of the Study**

My goal for this project was to increase the awareness and knowledge in the field of nephrology social work. The exploratory research could lay the groundwork for helping nephrology social workers improve the transmission of language and their means of presenting medical information to dialysis patients in a way that they can understand to

make better-informed decisions about their medical care. With such information, nephrology social workers may be able to develop and offer evidence-based staff training in health literacy. These trainings may help raise staff awareness about health literacy and address barriers faced by the patients along with identifying those patients with low health literacy. When staff and social workers are fully aware of health conditions and barriers that follow, then information can be presented to the patients in a way that they better understand, and patients may be able to make more informed decisions.

### **Theoretical Framework**

Health literacy is influenced by individual characteristics and the impact of economic, social, and environmental factors (CDC, 2016). I used an ecological framework because it can be used to address broader social determinants of health. Social cognitive theory started as social learning theory in the early 1960s by Bandura (Bandura, 2002). It developed into social cognitive theory in 1986 by Bandura, and viewed that learning occurs in a social context with a dynamic and reciprocal interaction of the person, behavior, and environment (Stokols, 2000). Social cognitive theory places emphasis on social influence and its impact on external and internal social reinforcement (Bandura, 1982; 2002). Social cognitive theory is used to examine the way in which individuals acquire and maintain behavior, also considering the social environment in which individuals perform the behavior. The theory is also used to examine the person's past experiences, which factor into whether behavioral action will occur. These past experiences influence reinforcements, expectations, and expectancies, all of which shape whether a person will engage in a specific behavior and the reasons why a person engages in that behavior. Social cognitive theory is used to consider many levels of the

social ecological model in addressing behavioral changes of people. Social cognitive theory has been widely involved in healthcare, putting the focus on the individual and the atmosphere (Devellis, 1991).

I used social cognitive theory because of its dual focus on the individual and elements in the environment. Incorporating an integrated behavioral health theory that uses self-efficacy and social norms, along with a social planning theory, could possibly result in a strong tool for being effective in helping to improve health literacy. Bandura (1982) defined self-efficacy as a personal judgment of how well someone can carry out actions required to deal with situations. Social planning theory is an effort to provide support and information while addressing social issues within certain communities (Bruzzone, 2019). Social workers could use the social planning theory to assist their patients in determining their goals toward good health. This theory could be used to assist patients with their health immediately and make plans for the future.

Healthcare professionals, including social workers, must consider social circumstances, which can range from playing a small role in a patient's health to being significant determinants of health for patients. These can include the factors that affect health such as health literacy, income, physical environments, and access to quality healthcare services (Montini et al., 2016). Health literacy is the extent to which individuals have the capacity to process, obtain, and understand basic health information to make informed decisions in which fits the theoretical model for the advancement of literate practice (Lesgold & Welch-Ross, 2012). Health literacy interventions can improve adherence to medical treatment, especially for patients following non-

medication regimens or with CKD (Miller, 2016). The teach back method is a useful way to confirm that the information that has been provided is being understood by getting people to “teach back” what has been discussed and presented and what instruction has been given (Tamura-Lis, 2013).

### **Values and Ethics**

The National Association of Social Work’s Code of Ethics (2017) works to enhance the professional growth and development of social workers, to create and maintain professional standards, and to advance sound social policies. In my action research project, I focused on: dignity and worth of the person and service as noted in the National Association of Social Workers Code of Ethics. This information will enhance the ethical practices by social workers. The primary goal of the ethical principle of dignity and worth of the person is to treat each person in a caring and respectful manner while remembering the cultural and ethnic differences. The other ethical principle of service focuses on the social workers’ primary goal of helping people in need and to address social problems (NASW, 2017). Nephrology social workers can show patients that they are there for them by making sure that they are available for the patients when they have psychosocial needs, and that they are there to provide referral sources as needed.

The National Association of Social Workers established a set of core values that includes: (a) social justice, (b) importance of human relationships, (c) integrity, and (d) competence. These principles are the infrastructure of social work professionalism and relevant to nephrology social work practice and other fields of social work (NASW, 2017).

In this action research project, I emphasized these principles and wanted to conduct research and add to the clinical practices of nephrology social workers within the dialysis facilities. I provided the participants the utmost respect. I made sure they felt they were in a warm, secure and open atmosphere in which they were free to share their thoughts and ideas. I complied with the principle of informed consent before I began any conversations. The Code of Ethics was there to serve as a guide for everyday professional conduct of social workers (NASW, 2017).

Social workers play an essential role in the care of patients and families facing end stage renal disease (Peres, 2016). These social workers deal with the presenting concerns and solve problems that are related to renal failure. Such roles include counseling and advocacy, patient and family education, community education as well as the coordination of resources and referrals. Counseling and advocacy roles include addressing marital and family stress, the concerns of death and dying, body image issues such as sexual dysfunction, as well as intimacy. These patients also often face psychological and depressive issues that require counseling. Through coordination of resources, social workers assist with prescription coverage, housing utilities, transportation as well as scholarships. However, an important role of nephrology social workers often pertains to the provision of literacy education about renal failure and dialysis requirements.

### **Review of the Professional and Academic Literature**

My primary literature search strategy included the use of Google Scholar and the various references that were cited in the review articles found thereby. I conducted the literature search using social work databases, and social work research, socINDEX with

full text. The search terms that I used included: *health literacy, functional health literacy, critical health literacy, health literacy assessment, readability, adult education, teaching literacy, patient education, instructional strategies, health literacy and heart disease, health literacy and kidney disease, health literacy and dialysis, health literacy grounded theory and knowledge, health literacy and self-management skills, social cognitive theory health literacy and digital tools, and health literacy, and mobile devices*. Other search terms included: *end-stage renal disease (ESRD), chronic kidney disease (CKD), and hemodialysis and peritoneal dialysis*. The date range for the literature focused on literature published within the last 5 years, and this led to the retrieval of relevant articles that were published between 2014 and 2018. Some earlier literature contained valuable information for the research and was included in the study.

Health literacy deficits, predictors of inadequate health literacy, conventional social work, and health promotion dimensions within the perspective of social work were identified as themes. In addition, I presented the theme of social work advocacy as crucial. In the following sections, I will address each of these topics as they relate to the purpose of this study.

### **Nephrology and End-Stage Kidney Disease**

Nephrology is the study of kidney function. The kidneys serve to filter waste and toxins from the blood, and resupply the veins with clean fluid (Jiang, Fine, & Mottl, 2018). Failure of proper kidney function can lead to imbalances of electrolytes, irregular blood pH, and a build-up of toxins. In extreme adverse physiological cases, the kidneys will not perform their filtering action hardly at all; this is known as kidney failure, which can be acute or chronic, the latter being CKD. Kidney failure also goes by the term end-

stage kidney disease, and mandates a severe form of medical intervention, such as regular blood dialysis (artificial filtering) or organ transplant.

The causes of kidney failure are many and can include physical blockage of the urinary tract or necrosis of kidney cells as a consequence of a pathogen. About three in 1000 Americans are affected by this condition currently (Ferri, 2017). Symptoms of CKD include vomiting, nausea, and too frequent or too infrequent urination. Often, CKD can be associated with diabetes, as the kidney is important in regulating blood sugar and, in many situations, can affect insulin resistance, the causative factor for Type 2 diabetes (Jiang et al., 2018).

### **Nephrology Social Workers**

Nephrology social workers assist patients with CKD by assuming the multifaceted role of standing in for many multidisciplinary medical and non-medical figures that are concerned with renal issues, standards health regimens, and psychosocial factors as well. Renal social workers must be ready in every setting, to address and assist individuals and their respective families to the adjustment and coping needed when one of their family members is diagnosed with renal disease, especially CKD (Green, 2013). As Zengin (2016) noted, nephrology social workers work together with a team that consists of a nephrologist, nutritionists, medical assistants, and psychologists while taking up a diverse position where they can operate in the multiplicity of spheres listed above. Davison, et al. (2015) stressed not only the importance of the role of healthcare workers in general, but here specifically the role of social workers in improving the quality of life for CKD sufferers, especially in terms of palliative care.

There was increasing awareness of the need for a highly interactive exchange between social workers, doctors and the entire nephrology team and their patient regarding key issues such as diet, psychosocial risk factors, comfort, dialysis routines, medical planning and family decision-making (Moorthi, 2019) and illness trajectory. The exchanges highlight the key importance of communication among the social worker(s) team, medical facilities, nurses, doctors, the patient, and their family and close friends (Davison et al., 2015). Further, the Forum of ESRD Networks' Medical Advisory Council (2017), indicated that when staff changes are made, renal dialysis patients may not trust new staff members due to perceived lack of respect, poor communication, or more commonly an overall fear of change which can lead to very anxiety prone situations for patients. Nephrology social workers must console patients when patient-staff insecurity arises and ensure that the communication between the medical clinic, doctors, staff and the patient is clear, proficient, and respectful as to reduce the overall stress and anxiety the patient may be feeling generally or more specifically in relation to any change (ESRD Networks' Medical Advisory Council, 2017).

Canale and Thomas (2018) punctuated the imperative of joint cooperation that needs to happen between doctors, dietitians, and social workers in order to ensure a positive outcome for patients on dialysis treatment. Social workers must assume a multidisciplinary position that entails not only just facilitating the flow of communication between the team, but additionally tasks like nutrition support via feeding tube, addressing wounds within a home care setting, central support services in the home, monthly or bimonthly assessments for psychosocial conditions such as depression.

The health literacy of the patients themselves strongly influences the benefits of



such exchanges (Enworom & Tabi, 2015). The causal relationship between health literacy, discussed in more detail below, and prognosis with patients with CKD is particularly acute because of the nature of the disease itself (Taylor, et al., 2017). When CKD reaches an advanced stage dangerous levels of fluid can put pressure on a patient's heart along with waste build up in their body. This places a unique burden on the relationship between healthcare providers and patients in the case of CKD; the continual maintenance and reinforcement of positive exchanges in this situation is directly correlated to various measures of success and quality of life (Aston, 2017; Peace and Philips, 2016).

### **Health Literacy Deficits**

Inadequate health literacy represents a concern for professionals treating those with chronic renal disease. Martins et al. (2016) carried out quantitative, non-experimental, descriptive, and correlational research with the aim of determining the health literacy among hemodialysis patients with the diagnosis of chronic end-stage renal failure (ESRD). In research that gathered information from 68 patients undergoing treatment at the Tondela/Viseu Hospital Center and the Beirodical Clinic, Martins et al. (2016) realized that higher literacy levels existed only in those patients who had high academic qualifications, as well as those who had higher socioeconomic standings in the society. It also emerged that existence of health literacy significantly impacted the treatment time for this demographic group of patients, and such an attribute could only be obtained through an extensive social worker interaction with patients (Martins et al., 2016). Martins et al. (2016) affirmed that there existed a large number of hemodialysis

patients who had inadequate literacy of their condition, and this was a significant contributor to the emergence of high rates of mortality.

In a similar systematic review conducted by Campbell and Duddle (2010) on the health literacy and CKD (CKD) education, evidence suggested the role of nephrology nursing staff was central in understanding the importance of health literacy in the prevention of adverse outcomes associated with chronic renal failure. The review showed that limited health literacy negatively impacted self-management skills and reduced treatment and medication compliance (Campbell and Duddle, 2010). As a result, patients often experienced severe outcomes and were at the greatest risk of dying because they did not receive the support they needed from social workers and the general neurology care teams (Campbell and Duddle, 2010). As such, Campbell and Duddle (2010) highlighted the need for primary health care education in impacting relevant knowledge of the patients and allowing them to understand how they could successfully manage their health through the use of diet modification, insulin, erythropoietin and fluid restriction. However, such needs could not be met due to a lack of social worker networks and alliances with patients (Lee, Wu & Lee, 2016).

Taylor et al. (2017) expressed the vital importance of health professionals' use of proper communication that patients can understand, and the need to work with patients in developing strategies to manage complications of chronic kidney failure. To this end, social workers could play an important part in linking health literacy and quality improvements deemed necessary for effective management processes.

Young (2013), in an expositional study, tried to understand some of the challenges that CKD patients with limited health literacy face. Young (2013) affirmed

that patients with limited health literacy often develop strategies to avoid demonstrating the limited literacy skills. Therefore, the social worker needs to integrate certain health literacy assessments such as Health Literacy Knowledge and Experience Survey (HI-KES), an instrument designed to rapidly screen patients for potential health literacy problems, which when used in past studies, has shown health literacy rates to be alarmingly low (McCulloch, 2015). Young (2013) emphasized the need for the health system to address the limited literacy as a way of enabling the patients to access renal replacement therapies.

Likewise, Cervantes, Zoucha, Jones, and Fischer (2016), in a thematic synthesis of literature on the management of Latinos with the end-stage renal disease, were able to show that experiences and values of individuals heavily impacted the role of social workers. This study also showed that these individual values, especially for Latinos, while very impactful and could be used extensively in the future development of health literacy skills for managing the condition (Sullivan, Choi, Vazquez, & Neaves, 2019)).

The question remained on how social workers could span the disparities within society to help improve the limited health literacy that has remained common among patients on treatment for CKD (Prieto-Velasco et al., 2015). Logan (2016), in yet another systemic review, expounded on the need for the further development of various conceptual frameworks that will be paramount in development and implementation of real-world collaborative approaches, that will better work with the culture of a social worker's patient. Logan (2016) provided a way the role of social workers can be explained through these collaborative methods, but also a means through which health literacy and health disparities can be explained for policy-making. This can also go a long

way in the improvement of patient health and health-seeking behaviors as presented in the study conducted by Enworom and Tabi (2015).

### **Theory of Health Literacy**

Osterlund, Mendelsohn, Clase, Guyatt, and Nesrallah (2014) identified modifiable factors at the level of the patient, social worker, and healthcare professionals. Some of these barriers included the perception of the complexity of the treatment options, procedures, and insufficient counseling (Harrington, 2015). There emerged a frequent trend that presented the lack of coordination between social workers and CKD patients, and the fact that health literacy education is never imparted to these patients (Narva, Norton, & Boulware, 2015)

As Yu (2015) stated in their systematic review, there is need to use technology in providing all patients with health literacy education. The author emphasized the role of new technology such as mobile phones that can be integrated into the health system models to allow social workers to connect patients with information.

In a separate study conducted by Lim, Yu, Kang, Foo, and Griva (2016) on the quality of life impairments for patients undergoing dialysis for the management of ESRD, the authors used 115 patients to explore the determinants of quality of life. All the patients were asked to complete a Kidney Disease Quality of Life Short Form (KDQOL-SF), and the various indicators were introduced over the duration of the study. Lim et al. (2016) discovered that there existed a significant deterioration in the quality of life especially on the domains of social support and staff encouragement, which played a part in impacting the overall quality of life. Based on these findings, it emerged that just like other quality indicators, social support that is provided by social workers and the rest of

the medical team were paramount for the achievement of best outcomes (Miller et al., 2016).

Pienkos, Sun, Schiller, Czajkowski, and Doss-McQuitty (2018) believed that nephrology social workers are an essential part of the team that manages the patients with ESRD. Skilled psychosocial intervention was then presented as having a positive impact on these patients and the outcome of disease management since it provides for additional educational preparation. Callahan (2011) suggested that is an important intervention that not only improves patient's compliance but also assists in coping with the changes that are part of the disease's manifestation. In a separate mixed method study conducted to improve health literacy in kidney patients, Peace and Philips (2016) hailed nephrology social workers as leaders and affirmed that patients often require more information and support.

The results of a mixed methods research focused on randomized controlled trials on the optimization of care among patients with Type 2 diabetes, Trump and Mendenhall (2017) realized that there was a need for extensive health literacy to help in direct clinical practice. Accordingly, the research expressed the need to integrate community health workers as a means of improving the physical health outcomes on the diabetes knowledge, which goes a long way in preventing long-term outcomes such as CKD (Trump & Mendenhall, 2017). Likewise, Nelson and Rabetoy (2005) explored the need to inform patients about their illnesses in the setting of ESRD. Such information must often be comprehensive. Nelson and Rabetoy (2005) also stated that in some situations, the physicians and dialysis staff members may often be resistant to talk about the issues surrounding the clinical diagnosis of ESRD. Such a problem presents the social worker

with the task of breaking the news and other relevant information to enable the patient cope with the condition.

Brega et al. (2015) indicated that most of the health literacy materials are often beyond the educational level of patients, effectively rendering them useless to these patients who need them the most. In such situations, there is often a need to provide an alternative source of information by allowing interaction between the patients and the social workers. Dickens, Lambert, Cromwell, and Piano (2013), in a cross-sectional study that was performed using various multi-item tools, also concluded that quality healthcare delivery is often tough to get as nurses themselves overestimate patient health literacy. Such findings are also common in various other studies such as that of Goggins, Wallston, Mion, Cawthon, and Kripalani (2016), who provided data from two studies using the Health Literacy Screening (HEALS) tool and found that health literacy scores, as recorded by nurses, could be overestimated. Hence, the outcome could be fatal primarily to patients with chronic illnesses such as ESRD. The following section will focus on health literacy as an asset.

### **Health Literacy as an Asset**

When expressing the difference in health literacy between public and private hospitals, Jessup, Osborne, Beauchamp, Bourne, and Buchbinder (2018) used two cross-sectional surveys, one with 3121 and the other with 384 participants. The study used various instruments that cover nine core health literacy domains to evaluate the performances regarding disease outcomes for all participants. It is interesting to note that in the study, Jessup et al. (2018) present the impact of the delivered health literacy as low for public hospitals as compared to private ones. As such, it emerged that health literacy

remains low in the public hospitals and this significantly affects the outcome of care delivered (Jessup et al., 2018). Further, the study helped to show that certain factors such as practices, values and the environment in which patients are managed are important in improving their health literacy responsiveness, and the social worker must always understand them to allow for effective patient management (Jessup et al., 2018).

Umeukeje et al. (2018), in a separate multi-site cross-sectional study involving adult patients from eight different dialysis units, affirmed the importance of health literacy about healthcare climate, the perceived knowledge of health professionals as well as the autonomy for support of phosphate binders use. The research tried to understand the relationship between adherence to phosphate binders and health literacy as provided by the social workers and the rest of the medical teams (Umeukeje et al. 2018).

Interestingly, autonomy support for patients with the end-stage renal disease, was found to vary in the study; among whites versus non-white, non-whites reported lower HCC scores overall, but HCC support scores between genders was determined to have a pattern of little to no significant at all (Umeukeje et al. 2018). Umeukeje et al. (2016) were able to demonstrate that adherence was an important aspect of health literacy and significantly impacted the role of social workers in end-stage renal disease management.

Mukakarangwa, Chironda, Bhengu, and Katende (2018) conducted a study on adherence to the dialyses procedures for patients which led them to a similar conclusion claiming, that even though adherence issues may often be experienced when managing patients with CKD on dialysis, they need not be blamed but provided with adequate support.

Mukakarangwa et al. (2007) further explicated that if social workers help to better facilitate the patients adhere to fluid restriction and dialysis regimens can more easily be

achieved when social workers themselves, are allowed to conduct effective health literacy and allow the patients to seek clarifications about their own health.

Reilly et al. (2016), in a systemic review of the mixed evidence, examined studies on the lives of indigenous people with CKD. The study showed that various kidney disease management programs must always be integrated when dealing with CKD patients (Reilly et al., 2016). However, the existence of barriers to accessing health information prevents these programs from being effective, and this suggests the failure of social workers as well as other relevant caregivers from advancing patients' roles in maintaining their own health, a finding also expressed by Montini et. al. (2016).

Zala and Rutii (2017), in a thematic analysis interviewed 20 participants in advanced practice nursing regarding CKD management and the role of health literacy in improving outcomes. It emerged that healthcare professionals needed to understand the importance of knowledge acquisition among patients and the need of ongoing guidance in the continuity of care. Llewellyn (2017) affirmed that nephrology nurses often have to develop additional insight that can help care for individuals with ESRD. In this regard, Luckett et al. (2017) found that even though advance care planning in nephrology is advocated widely, it is not always implemented, and this puts patients at a greater risk of developing complications. Hence, in a cross-sectional survey, Luckett et al. (2017) expressed the need to integrate health literacy into everyday patient management to help improve outcomes. However, Montoya (2017), in a systematic review, stated that there is need to heighten efforts through research to ensure that the role of advanced health care practitioners encompasses social work in nephrology especially as pertains to end of life care for patients with chronic kidney failure.



### **Conventional Social Work Intervention**

Lo et al. (2016) conducted qualitative research on the perspectives of patients on health care for co-morbid diabetes and CKD. Using 12 focus groups with eight semistructured interviews and 58 participants, the authors managed to develop an exciting study on patient and health service level factors (Lo et al., 2016). Such factors included socioeconomic situations and patient self-management (Lo et al., 2016). It emerged that poor continuity and coordination of care significantly increased morbidity due to chronic renal failure, a factor that was considered to exist due to lack of effective patient literacy (Lo et al., 2016). Accordingly, Lo et al. (2016) concluded that social workers played a critical role in emphasizing patient empowerment and allowing for the recognition of the need to access health service especially for patients with stage 4 and 5 renal failure.

Wilson, Campbell, Luker, and Caress (2015), in a mixed methods approach, provided a different perspective to the one explored by Lo and counterparts. In the semistructured survey, Wilson et al. (2015) examined 18 adult patients with stage 3-4 CKD (CKD) and concluded that even though patients preferred increased involvement in their own care, referral, and discharge decisions, they needed to have an extensive social work base. Also, the research presented the dire need for adequate health literacy information, and for the CKD specialist to align with social workers to make it happen. Likewise, Kiliś-Pstrusińska et al. (2013), in a cross-sectional national survey consisting of 203 CKD children on hemodialysis and peritoneal dialysis realized the need of special support to improve quality of life. To a large extent, low quality of life ratings was found to render parents unmotivated and adversely affected, and social workers needed to

provide health literacy to ensure that quality care was delivered despite the challenges that these families faced (Kiliś-Pstrusińska et al., 2013); this finding was also supported by Lambert, Mullan, Mansfield, Koukomous, and Mesiti (2017).

### **Health Promotion Dimensions and Social Workers**

Social workers were therefore seen as paramount in the management of patients (Strough, Wime & Wapola, 2014). As part of the health system, social work requires that patients and the whole community, in general, are taught to understand their illnesses as a means of prolonging their lives and embracing health service seeking behavior holistically. In the article written by Lennon-Dearing (2013), social work is emphasized as part and parcel of the delivery of health literacy to the populace. The systemic review provides information from the social worker's perspective and the need to support the well-being of clients while at the same time respecting their inherent dignity and self-worth. In this perspective, Lennon-Dearing (2013) expounded on the link between the social worker and the rest of the medical team in the manner in which they interpret medical experience to clients, providing them with emotional support and also giving critical report on the client's response to various treatments offered by the rest of the medical team. McCulloch (2016) emphasized the position and affirmed that it is the role of social workers to understand the limits of patient's health literacy. Such a move allows them to perform various health literacy assessments as a way of identifying how to work best with the sick and help them embrace their shame and embarrassment that is often associated with the process of health seeking (Young, 2013).

Social workers dealing with CKD patients have the mandate of knowing the right advice to give these patients, and such may often include dietary and salt intake

(Mueleman et al., 2014). According to Mueleman et al. (2014), the strategies for the reduction of sodium intake among these patients are often met with certain challenges. In a qualitative study that informed the effects of self-monitoring on outcomes of CKD (ESMO), purposive sampling was used to identify the effects of self-monitoring in sample size that including 25 patients and 23 healthcare professionals were interviewed (ESMO). Themes that were of importance included lack of practical knowledge and intrinsic motivation from the patients (Mueleman et al., 2014). The researchers concluded that special attention needs to be paid in supporting patients and giving them health education on how to achieve sodium related goals (Mueleman et al., 2014).

Aston (2017) reasoned that increasing social support would improve the disease outcome, which following such a logic lends itself to the possible outcome that affirms why the need to have primary care physicians contact nephrologists whenever the kidney functioning of patients with CKD is declining. Aston (2017) expressed that lack of pre-dialysis nephrology care is an important inhibitor to the whole process of managing these patients, and it is often up to the social worker to create extensive linkage and ensure that appropriate knowledge is imparted to prepare the patients effectively.

It is also important to note that not all patients benefit from the use of dialysis in the chronic end-stage renal failure environment (Wong, McCarthy, Howse, & Williams, 2007). Research carried out by Wong et al. (2007), with a randomized control trial, examined the outcomes of 30 patients with CKD who chose not to undergo dialysis during their renal replacement therapies. Wong et al. (2007) discovered that the best possible quality of life could be achieved when patients were supported to choose their own modalities of therapy, which such support needing to be built upon, with appropriate

health literacy interventions. Lai, Loh, Mooppil, Krishnan, and Griva (2012) could support such findings with finding from a qualitative study that affirmed incident hemodialysis patients often have emotional and informational needs addressed within the various intervention programs to improve outcomes.

In a study conducted by Griva et al. (2013), adherence to hemodialysis regimes often result in the maximization of good clinical outcomes but often adhere to the cultural expectation of patients. In the descriptive and exploratory research study, Griva et al. (2013) used interviews and focus groups to examine some of the factors that created barriers to achieving effective hemodialysis outcomes. It was quite apparent that personal and social barriers, which can be severely compounded by the lack of social worker support and health literacy, were prominent within the sociocultural contexts (Griva et al. 2013).

Likewise, in a study conducted by Quirong-Jones & Glenn (2016) on the successfulness of peritoneal dialysis in the elderly population, it was realized that as much as quality outcomes are often required, patients can always achieve maximal benefit when they are given appropriate knowledge to manage themselves. In the study, Quirong-Jones and Glenn (2016) described their experience with patients on ESRD following the implementation of a 2-hour kidney seminar. It was evident that most of the 83-year old patients in the study who underwent continuous peritoneal dialysis for 124 months had care partners who assisted them partially with the dialysis (Quirong-Jones & Glenn, 2016). The findings also revealed that social work was mandatory for improved outcomes and had the role of ensuring that patients with ESRD stayed active to ensure that their outcomes on peritoneal dialysis were outstanding (Quirong-Jones & Glenn,

2016). Such findings were also reported by Turner (2016), who affirmed the importance of the inductive approach to managing to end-stage renal disease with the help of caregivers and social workers. Also, Turner (2016), through semistructured interviews, affirmed that caregivers faced challenges when managing these patients and needed an extensive support system.

### **Gaps in the Literature**

Following the review of the literature on the role of nephrology social workers and the management of patients on various forms of CKD management such as hemodialysis, dialysis, peritoneal dialysis and non-dialysis therapies, it appeared that health literacy has not been given much priority. Even advanced practice nurses tended to ignore the benefits of imparting patients with knowledge about their management (Turner, 2016).

To a large extent, the researchers mentioned in this review tended to focus on shortcomings of social workers and the advanced healthcare teams without necessarily presenting the mechanisms that need to be developed to ensure that each patient gets access to the required health literacy information. As such, more research needed to be done to put social workers into the context of health literacy provision, and to develop policies and frameworks that can facilitate such a process.

### **Summary**

Section 1 presented an overview of the study including the problem it will address, the purpose, nature, and significance of the study, the research questions addressed, the theoretical framework, values and ethics, and a review of the literature that also notes the gaps in the literature this study will address. The problem this study

addressed was the lack of health literacy in public hospitals, despite many studies that show there is a need for extensive health literacy to help in direct clinical practice. This significantly affected the outcome of care delivered to CKD patients and adherence to nephrology social workers' recommendations, which significantly impacted the role of social workers in end-stage renal disease management.

The purpose of this study was to assess nephrology social workers' understanding of their role in promoting the health literacy of their CKD patients, the ways they assess for health literacy, and the strategies they use to promote health literacy. The nature of the study was action research, which is geared towards immediate and innovative problem solving. This study will be significant because it will help nephrology social workers improve their ability to provide health literacy to CKD patients so those patients can make more informed decisions about their health care. Social cognitive theory served as the theoretical basis for the study because it focuses both on the individual and their social environment, and emphasizes self-efficacy, something social workers can instill in their CKD patients through by improving health literacy. This research project will help enhance ethical practice by social workers by emphasizing the principles of the dignity and worth of the person and service. While much of the existing literature focuses on the shortcomings of social workers, there was a gap in exploring how these shortcomings might be addressed through access to health literacy information. This is the gap that this study sought to address.

In Section 2, I presented an overview of the manner in which the research was designed, implemented, and its data analyzed. This includes an overview of the

methodology, the participants, instrumentation, and data analysis, as well as the measures taken to make sure the study adhered to ethical procedures.

## Section 2: Research Design and Data Collection

I examined and assessed nephrology social workers perception of their roles in promoting the well-being of their patients. The research found ways to improve nephrology social workers' skill sets. Effective communication between social workers and their patients is vital. I assessed how social workers communicated with their patients and how well their patients received all information shared.

### **Research Design**

The social work practice problem I examined was how nephrology social workers perceived their role in the delivery of health information to patients with end stage renal disease. This action research project was purposeful and research oriented with the intent to explore the best practice that may help improve the way nephrology social workers are presenting information to patients such that they can understand and comprehend. The research questions were:

RQ1: How do nephrology social workers perceive their roles in providing and promoting health literacy among patients with chronic kidney disease?

RQ2: How do nephrology social workers assess health literacy skills in patients with chronic kidney disease?

RQ3: What strategies do nephrology social workers used to increase health literacy in patients with chronic kidney disease?

The problem of low health literacy was used to address how nephrology social workers can present medical information to dialysis patients in order to help the patients make more informed decisions about their health care. I explored how social workers



present information to dialysis patients and what they perceived as their role in presenting information to patients.

I used action research with a semi-structured focus group to collect qualitative data. According to Pettit (2006), action research provides an alternate approach to manage concerning changes in data, practice, and policy. Social workers were presented with the opportunity to participate in this action research methodology to give feedback on their strategies or approaches used to present medical information.

The key definitions:

1. A *focus group* is a research method used to conduct small group interviews with selected participants (Gaižauskaitė, 2012). An interview conducted within a focus group would consist of open-ended questions that allow participants to share experiences with the unison of others who may be experiencing similar issues. Focus groups are utilized to help gather opinions, beliefs, thoughts, experiences, etc., related to a topic (Gaižauskaitė, 2012). In this case, the focus group would consist of a small group of renal social workers that could possibly share their experience of interpreting information for their patients.
2. A *stakeholder* is a person who affects or is affected by a policy or plan (Morphy, 2019). Stakeholders in this action research project could be nephrology social workers. These social workers provide care to dialysis patients in dialysis centers in rural Arkansas and Texas. The stakeholders could also be the patients because they are affected by services provided by the social worker.

## **Methodology**

I conducted an action research study along with a focus group to collect data. Conducting my action research project using a focus group with licensed master's social workers provided insight on how some interact with their population compared to other social workers, where shared information can be useful to others. Social workers have skills in cultural competence (NASW, 2017). Social workers play a vital role in helping patients understand their medical care. Social workers help address health literacy problems on a daily basis and strive to make sure their patients have all the information they need to make informed decisions about their health. Social workers interpret the medical information for the patients along with providing emotional support while interacting with the interdisciplinary team to convey the patient's experience.

### **Participants**

The participants of this action research project were nephrology social workers who aided dialysis patients, patients suffering from CKD and End Stage Renal Disease patients. There were 5 licensed master level social workers with at least 2 years of experience in a dialysis setting. They were located in rural Arkansas and Texas. I initially contacted the social workers via email, followed by a telephone call. Being the regional point social worker, I had access to the social workers' contact information. The sampling strategy I used was convenience sampling. Convenience sampling constitutes non-random, non-probability sampling (Brewis, 2014) and allows a researcher to recruit participants who are easily available and convenient.

## **Instrumentation**

The interview protocol included 10 open-ended questions. I also asked the participants basic information in reference to their years of experience working with dialysis patients, when they graduated, and age range of their patients. I used the open-ended questions to explore what role the social workers play in health literacy of the patients, how they assessed health literacy, and any strategies they use to address the health literacy of their patients. I developed my interview questions from the theoretical framework and literature review.

## **Data Analysis**

Data analysis included coding and identifying themes. I used an audio recorder to collect most of the information shared during the session. The process of transcribing the data took an extended amount of time. It was helpful to listen carefully to the recording before transcribing to restore memory of conversation with patients. I also included all nonverbal cues in the transcript. I reviewed the information collected from the focus group session. I used the interview questions as a means of gathering information on how the social workers feel about their role in health literacy as part of an interdisciplinary team. I read each response carefully and several times. Once complete, the qualitative data collected were coded and analyzed for common responses and content in answering the research question (see below). During the collection process, I used a spreadsheet in Excel to help organize the data carefully prior to formal coding.

For effective data analysis, I used two coding techniques. To begin, I established emergent codes to classify each response provided by the participants regarding the questions raised in the focus group. Categories created through inductive analysis and

reasoning were sorted and organized. I then identified the emergent patterns and themes among participants. Additionally, I also examined data from existing research regarding the question under study and compared to identify the emerging patterns that support or refute findings of these researches.

I used thematic analysis coding to analyze the data, following the methods outlined in Saldaña's (2016) manual as a guide. Thematic analysis is a strategy to identify, and then analyze and report, recurring patterns (i.e., themes) within data. I imported the coded data into the powerful qualitative analysis software MAXQDA. This software is commonly used by social and behavioral scientists to help them collect, organize, analyze, and visualize their data, and can be useful in a subsequent submission for publication if desired (Darling-Hammond, 2020). In particular, MAXQDA is effective in the analysis of data collected from the focus group. I employed the software to detect significant relationships among themes from the coded data in order to draw conclusions to the three research questions posed above. MAXQDA has a built-in theory tester that will allow a rigorous identification of possible connections among the codes. In arriving at these conclusions, I always relied on the social cognitive theory to determine how behavior is acquired.

Credibility is one of many factors that establishes trustworthiness. It is the process of determining if the study measures what is intended. I established credibility through the use of parallel criteria (see Anney, 2014). I did this in several ways: first, by using a method of challenging participants to compare their patients' current situation or health to the past; second, by determining if the results coincide with things that occur in the real world (reality); and, finally, by comparing the results of questions and/or concerns from

patients with information from today's society. This ensured internal consistency and rigor in the data analysis.

### **Ethical Procedures**

I ensured that my action research project had merit and observed research integrity. Using a formal request letter, I sought permission to interview nephrology social workers. Additionally, I was available to ensure that I responded to all the requests and questions raised by the nephrology social workers that I intended to interview and clarified all the details of my action research project. Upon acceptance, I provided the participants with informed consent forms to complete. I advised all the participants to carefully go through the consent form prior to signing it. Additionally, I made myself available to answer any questions and provide further clarification regarding the consent forms. Thereafter, I ensured that the responses provided by my participants were protected and none of their identities were revealed when writing my final action research report. Further, I also ensured that participants were not required to share personal details or identifiers. Finally, I also ensured that none of the participants are harmed in the process of carrying out my action research project and also ensured that all my research findings are accessible to all the participants of the study by providing a summary of the findings to them. All social workers were informed that all information will be confidential and kept on a disk and stored in a secured database.

### **Summary**

I used qualitative measures to carry out the research. I used a semistructured interview guide to gather data and information in this research. The participants in this action research project included social workers who work directly with dialysis patients

while providing health information to enable the patients make informed medical decisions. The methodology included a focus group with six nephrology social workers in an effort to identify the methods and techniques of improving the clinical practice of the social workers working with dialysis patients, patients with CKD and End Stage Renal Disease patients to help improve the way social workers are presenting information to patients in a way that they can understand and comprehend. Finally, I used thematic analysis to code the data and identify themes. The next section will include detail of the data analysis process and a presentation and findings.

### Section 3: Presentation of the Findings

The purpose of this study was to identify how nephrology social workers understand their roles in promoting health literacy among chronic kidney disease patients, how they assess for health literacy, and what strategies they use to promote health literacy, specifically within the regions of southwest rural Arkansas and eastern Texas.

To address this purpose, three main research questions included:

RQ1: How do nephrology social workers perceive their roles in providing and promoting health literacy among patients with chronic kidney disease?

RQ2: How do nephrology social workers assess health literacy skills in patients with chronic kidney disease?

RQ3: What strategies do nephrology social workers use to increase health literacy in patients with chronic kidney disease?

The participants of this action research project were nephrology social workers who aid dialysis patients experiencing chronic kidney failure and end stage renal disease. Convenience sampling was used to identify participants and data were collected through a focus group consisting of five social workers. All participants had knowledge of how to provide emotional support to patients, assist with self-determination, and routinely provided their patients with medical information that patients used to make informed decisions about their care. This experience and knowledge enabled participants to provide qualitative data that answered the research questions and addressed the purpose of this research.

In the first part of Section 3, I will describe the data analysis techniques. In the second part, I will discuss how the findings from the focus group answer the research

question. Finally, I will provide an overall summary and analysis of the findings collected from the participants of the focus group.

### **Data Analysis Procedures**

Once I received Institutional Review Board (IRB) (11-14-19-0573905) approval, I recruited participants during a 5-week timeframe in late 2019 and conducted the focus group in January 2020. and the focus group lasted for 55 minutes. In order to facilitate participation of participants from both Arkansas and Texas, An iPhone plus audio recorder recorded the sessions with the focus group. The credibility of the study was enhanced by combining both collection method. Participants were able to see both me and each other during the focus group. This allowed me to observe non-verbal communication and cues during the focus group. After data collection, I transcribed the audio recording of the focus group within a week by me. I transcribed the session verbatim into a Microsoft Word document. I then sent a transcript of the recording to all participants for participant checking. Participants approved the transcript over the course of 2 days. After transcript approval, I referred to the social workers as participants, and removed their real name from the transcript to protect participant's privacy. Next, I began data analysis. Data analysis took about two weeks to complete. Writing up the findings from the data took approximately 2 weeks.

Thematic analysis coded the data following the methods outlined in Saldaña's (2016) manual as a guide and informed by Braun and Clarke's (2006) six step process. After data collection, I carefully listened to the recording before beginning transcription. I took careful note of nonverbal cues given by the participants. Nonverbal cues were inserted into the transcript that provided greater clarity to the participants' responses. I



transcribed the audio-recording of the meeting verbatim into a Microsoft Word documents to help collect, organize, analyze, and visualize their data. I read the transcript to become even more familiar with the data (Step 1). Emergent codes identified each participant's response regarding the questions raised in the focus group (Step 2). These codes were identified by reading the focus group transcript and coding passages of meaning. The emergent codes were sorted, organized, and refined through inductive analysis and reasoning. After initial refinement, the emergent codes were examined, and the I identified patterns and themes from the codes (Step 3); 23 emergent codes were identified and condensed into six main themes. The themes were then considered and reviewed within the context of the research questions to understand how they informed the research questions and the purpose of the research (Step 4). I then defined the themes and completed the refinement of the codes (Step 5). Finally, I wrote up the findings (step six) and compared the findings to the greater body of literature as a means to confirm and validate findings.

The findings were validated through the use of parallel criteria (Anney, 2014). This was done in two ways: first by using a method of challenging participants to compare their patients' current situation or health to past situations and experiences to ensure that the anecdotes being told by the participants were representative of their greater experience; and second, by determining if the results of the study coincide with things that occur in the real world (reality). This was done by reviewing the findings of the current study with other findings available in the literature. This process of parallel criteria compared participant experiences to each other and to participants' own past

experiences and the overall data to other relevant findings, thereby ensuring internal consistency and rigor in the data analysis.

Each participant reviewed the transcripts to ensure accuracy. After I transcribed the focus group, I sent copies via email to the social workers. The social workers only took a couple of days and reported that the transcript appeared to be correct. I also read the transcript least ten times to check for authentication. I used a peer reviewer to assess the data for researcher bias and to review themes and coding after the transcript was coded and placed into common themes. A licensed certified social worker and former Walden University doctoral candidate reviewed the information. This peer has experience working with dialysis patients in an outpatient setting. There were no new codes reported as needed.

### **Limitations**

The participants addressed the healthcare team/interdisciplinary team frequently in the focus group. A potential limitation is not including other disciplines. There would have been a more diverse group that could have provided a wealth of knowledge to better address the social work practice problem.

Another limitation of this action research project was that it only involved social workers working in rural dialysis facilities in Arkansas and Texas. Findings may have been different in the urban areas. Rural social work tends to be associated with a limited amount of resources, and lack outside referral resources to provide the care that is needed for patients (Zengin, 2016). This may not be the case for nephrology social workers in the urban areas. There may be more resources and opportunities in the cities or other areas

that would allow social workers to be more efficient in assisting patients in the area of health literacy.

I was able to recruit the target number of participants (five) and all participants engaged actively during the focus group. Expected limitations of qualitative data may apply to this study, such as limited sample sizes and the potential fallacy of self-reported data. However, I combated these limitations by collecting the target sample size and ensuring that participants were comfortable during the focus group and encouraged to be honest throughout the discussion.

### **Findings**

The participants of this action research project were four nephrology social workers, and one social worker who now works in the home health industry but previously worked as a nephrology social worker for 3 years. The social workers, located in Arkansas and Texas, aid dialysis patients, patients suffering from chronic kidney failure and end stage renal disease patients. All participants had between 2 and 4 years of experience working as a social worker specializing in renal care, and all participants held a master's in social work. All but one participant, Shelia, worked at a dialysis center. Shelia worked as a home health social worker who visited dialysis patients at home to assess psychosocial needs. All participants were female. Of the five participants, two were African American and three were Caucasian.

### **Data Findings**

The purpose of this study was to identify how nephrology social workers understand their roles in promoting health literacy among CKD patients, how they assess for health literacy, and what strategies they use to promote health literacy, specifically

within the regions of southwest rural Arkansas and eastern Texas. Participants were given pseudonyms to assist with data presentation. There were several themes that emerged from the data during data analysis that can be used to address this purpose. While each participant told a unique story and reported unique experiences, there were patterns and themes that emerged from the participants. The themes included in this study are patient assistance, care team support, assessment, care team communication, engaging content, and involving families. These themes can be used to inform the research questions and purpose.

**Research question one.** Research question one asked how nephrology social workers perceive their roles in providing and promoting health literacy among patients with CKD. Themes from the data that inform this research question included engaging with patients and care team support. Participants indicated that they perceived their roles providing and promoting health literacy as providing assistance to the patient as well as by supporting the larger care team to ensure a good outcome for each patient.

***Engaging with Patients.*** Participants reported that their role promoting health literacy involved directly engaging with patients to help them understand their medical needs, the doctor's suggestions, and navigating a sometimes-daunting medical system. Sometimes the engagement could take the form of impressing the importance of sticking to their, the patient's, treatment plans and sometimes even dispensing tough love.

In the most basic sense, participants expressed that they were the front lines of education to patients. Sarah indicated that she often found that patients did not understand their medical history, or what ultimately led to their renal failure, and that her role

providing health literacy often started by walking through a patient's chart with them.

Sarah said,

The intake process involves reviewing their [the patient's] chart, figuring out what it is, and seeing how diabetes, hypertension, or whatever it might be is related to renal disease, because many of them aren't aware of that prior to that discussion. So, I use [the chart] and the other materials to kind of go through that process and what can lead to renal failure.

Shelia indicated that she often encountered patients who may have had a lot of information, and were able to communicate that information, but did not understand what it meant to them, or did not engage with the information on a meaningful level. Shelia found that by engaging with her patients, she was able to get them to better connect the information to their own health. According to Shelia,

They [the patients] have heard the transplant speech, and the modality speech a thousand times, and could quote it back to you better. The hard part is how to get them engaged, and how to keep them interested, and still learning new things. Because either they're bored or they think they know it all, or it goes in one ear and out the other.

Laura and Sarah agreed with Shelia and continued the conversation by saying that often patients did not engage until their health started to decline. Laura said, "It usually takes them getting sick for them to even engage and start listening to what you are trying to tell them. That's especially true for the young ones." Sarah indicated that the process of engaging the patient was vitally important, because otherwise patients would not

follow their care plan once they left the dialysis center and returned to the normal routines. According to Sarah,

When they go back to their social environment, when they go back home, and they are eating what they're not supposed to eat and drinking too much, and it's like you're starting back over when they're come in again [to the dialysis center] and you have to talk to them again about fluid overload, and different things like that, because you can't control their social and home environment.

Laura continued this conversation by saying sometimes the only way to reach patients was by deploying tough love. Laura recounted a story about a patient she worked with who had a hard time following his care plan. Laura addressed this issue head on by dispensing well meaning, tough love. According to Laura,

I saw a patient this morning who probably comes to treatment twice in a month. We saw him a couple of weeks ago but then he stopped coming to treatment and we didn't see him again for a couple of weeks. So, I walked in this morning and I told him, 'I don't know if I need to shout or fuss.' And so my question was to him was, 'How do you want to live the rest of your life?' Because now he's starting to feel bad because he was one of those ones that didn't really believe they needed treatment. He thought, 'Oh I'm fine, I feel fine. I could miss two weeks.' And he'll miss two weeks, come back and won't have any fluid on.

Participants indicated that perhaps the largest role that played in promoting health literacy was engaging with patients and helping them understand their treatment plan and condition one step at a time. While each participant had a different communication style,

all indicated that engaging with patients as at the center of their role supporting health literacy.

*Care team support.* While participants did discuss the roles they played supporting health literacy, they also indicated that they were a small part of a larger team, and that the larger team was also critical to supporting a patient's health literacy. Sarah indicated this by saying,

I think it [health literacy] is very much partnership with the doctor, the nurse, and the dietician. Like we [as social workers] have a small portion that we can help reiterate things that they [the rest of the team] has said, and directions that they're going with education. So, I think it is, it's not our sole responsibility, but I think it's very important, and it is that partnership with the other aspects of treatment that they do.

Laura agreed with Sarah and indicated that she believed she was an important component in supporting the rest of the care team. She believed her input was a valuable part of the team's greater feedback and instructions to the patient, and her role as a social worker was to connect with the patient and inform the care team of the patient's needs in a way the rest of the care team may not be able to do. Laura said,

I feel like I get that support from the rest of the interdisciplinary team and that I have a say when we have team meetings to discuss a patient. As social workers we have that skill and knowledge of cultural competency, you know, we're able to identify more with the patients, and help the patients to make a more informed decision about their, about their health care.

While participants indicated that they played a role in directly educating their patients, social workers also indicated that their role providing health literacy to patients was to be a part of a larger team designed to treat the patient and support them in their care. Together, these two themes (engaging with patients and care team support) summarized the focus group data that informed research question one.

**Research question two.** Research question two asked how nephrology social workers assess health literacy skills in patients with CKD. Themes from the data that inform this research question include direct assessment and care team communication. Much like the themes that informed research question one, the themes that informed research question two indicated that participants believed that they had an individual direct role in assessing health literacy skill in patients (direct assessment) and another role as a part of a larger team that assessed health literacy skill (care team communication).

***Direct assessment.*** Participants indicated that direct assessment was often one of the first things they did when new patients came into their clinics and that direct assessments were also one of their greatest strategies to assess health literacy skills in patients. Sarah explained the assessment process by saying,

We do an initial assessment with the patients. When they're brand new to dialysis they usually have a lot of questions about what dialysis is, different modalities, different ways to get dialysis, and like financial questions.

Sandra indicated that the assessments they performed was different from simply filling out an intake sheet. The assessment involved questioning patients about their



health and gauging each patient's level of education and understanding. According to Sandra and Natalie,

Also, besides assessments, just starting where they [the patients] are, just trying to see how much they understand about their own health condition. Because you may find some, you ask them, 'how did you come about being on the dialysis', and some of them are like, 'I don't know.' So just really starting to see what all they [the patients] understand, and then making sure they have the right person to talk to about what they don't understand. Just starting where they are, asking them what they understand, what they don't understand, what the doctor has explained to them, and just going from there, connecting them with the right resources, documentation wise, or referral wise to the dietician or a doctor.

While it may not be the most innovative or cutting-edge strategy for assessing health literacy skills in patients with CKD, participants indicated that direct assessment was still one of the most important tools in their toolbox when it came to health literacy assessment. Participants indicated that they used this technique to ensure that they got an accurate idea of patient's education level, and gave patients an opportunity to ask questions and voice their fears.

***Care team communication.*** Participants also indicated that they had a role to play assessing patient's health literacy as a part of a larger team as well as individuals. Participants indicated this team approach to assessment was effective, as some members of the care team had more face-to-face time with patients than others. Participants indicated that nurses and dialysis techs saw the patients a lot and were well situated to

assess a patient's understanding about their care plan and treatments. Sarah indicated that they commonly used this technique at her clinic. Sarah said,

We do like a team education approach. I make one of my coworkers talk to them [the patient's] about something. The techs know when to talk to the patients because the techs are close to the patients. Maybe they [the patients] feel more comfortable asking them questions, more questions. We have those daily homeroom meetings where we just like talking to the techs and say, 'Hey Mr. so and so is interested in this, can you maybe mention it to him? He likes you a lot. He's comfortable with you, he knows you.' And I think maybe that helps in being comfortable with somebody.

Shelia agreed with Sarah and added her own experience into the discussion. According to Shelia,

I liked what Sarah said because when I worked in a smaller clinic, the techs were awesome. They would pick upon all the gossip and tell me, 'Hey, this person is struggling with this, can you talk to them about it?' And then in turn I'd also say, 'Hey, this person's really forgetting to bring this in. Will you show them what we need?' But really involving the techs because they that have that relationship built with the patients and the nurses too.

These anecdotes from Sarah and Shelia indicated that while the participants did their assessments of the patient's health literacy, they also relied on input from the rest of their care team to understand where patients struggled. By combining their information and opinions about a patient with the doctor's, nurse's, and tech's understanding,

participants could better serve their patients and accurately assess which patients needed more support to strengthen their health literacy.

**Research question three.** Research question three asked what strategies do nephrology social workers use to increase health literacy in patients with CKD. Themes pulled from the data related to this research question included engaging education and involving families. Participants indicated that they used both these strategies to engage patients in education and to keep them invested in learning more and preserving their health.

**Engaging education.** Participants reported that often the best strategy to educate patients was to educate them in a way that was engaging and did not rely on material they may have heard many times before or that was boring to them. Shelia explained that even while in the midst or aftermath of kidney failure, patients do not always know even the basic information and that the best way to provide them with that information was to do it face to face and empathetically. Sandra said that she and her clinic take the time to explain it to patients, sometimes starting at the very beginning. According to Sandra,

Basically, anybody who's in the stages of kidney failure, you sit down, and they literally go over everything that we've been talking about, about the toxins in your body, what your kidneys actually do, it starts from the very beginning. And like Sarah said, it's simple for even me to understand or somebody with less education, but it can be confusing. Your kidneys do a lot more than we realize.

Sarah, Natalie agreed with Sandra and said that her clinic formalized the process of engaging in this direct education by creating a Kidney Smart class. Sandra indicated this class is very popular among the patients. According to Sandra,

I also used to help with the Kidney Smart class. And so that was amazing, seeing the people that were on the journey to dialysis at different stages, but weren't quite there [education wise], and all their questions. And a lot of them were just completely clueless about one why they're in the situation they're in, what got them there, and what the future was like. So that class was amazing even for me as a social worker who worked there for years, sitting through one of those really helped me out.

Sarah and Shelia both agreed that their clinics had a similar Kidney Smart class and they found it to be an engaging way of educating participants. Shelia even said, "I learned a lot from that class." Sarah agreed by saying, "I did too when I took it." Shelia went on to describe other ways she found to engage patients in health education that was not boring or tedious. According to Shelia, one strategy she found particularly engaging was playing educational games. Shelia said,

We did a lot of bingo, and they [the patients] loved it and they got prizes to wear. We did different games, and they loved it. I think like one of them was naming high potassium foods, and so then you get them engaged in shouting out answers, and it made it fun.

By using games and face-to-face education to engage patients in health education, participants found that they were able to achieve deeper learning with their patients than by using other forms of less direct education. Participants indicated that these methods were more effective than some traditional education materials, like the distribution of informational brochures or handouts. However, participants also indicated that they had

discovered other effective ways of engaging patients in health education, such as by getting the patient's families involved.

*Involving families.* Participants indicated that they often involved family members in the education process when patients first came to their clinic or become enrolled in treatment for renal failure. By doing this, patients felt more supported in the process, and there was another educated individual watching out for patient's health. Shelia indicated that, in her experience, patients often did not immediately notice the nuances of renal health education, and that by involving families in the education process, more information was likely to be absorbed. According to Shelia,

I've noticed that some things, maybe the patient didn't pick up on, but the family could pick up on. And so, when they [the patient] went home the family member would say, 'Hey, did you remember blah, blah, blah.' And so, to me, it was beneficial to have more than one person there [during the education process]. Because they probably caught one of every five things, and then if their family member caught one of every five things, and you could have two of five.

Other participants agreed with this statement, and recounted times when family members were beneficial to patients during the education process. Laura said that they often encouraged family to come to their Kidney Smart classes, and that family members were a real support to patients during the education process. According to Laura,

I remember there were so many family members who were scared [during the Kidney Smart class]. To have that safe environment where patients were able to ask questions but then they were allowed to bring their family members. And I noticed that the family members became very engaged in it. And I don't know if

the family member was engaged before the class, but during the class they were asking questions. It was just a beautiful process.

The themes that emerged from the data indicated that patients and social workers worked as individuals and as part of a larger team to assess patient's health literacy and improve patient's health literacy. Participants indicated strategies and practices used individually by the participants to assess and promote health literacy could often be used on a larger scale by the rest of the care team or by the patient and the patient's family.

### **Unexpected finding**

When or if a patient did not show for an appointment, participants of the study thought the healthcare team needed to make phone calls to see what was going on, and also ask if the patient would like to re-schedule their treatment. The participants in the study stated that they had homeroom meetings with the staff explaining the importance of treatment adherence. The staff stressed that they felt like the patients were adults and old enough to make their own decisions, but they also stated that they were willing to do their part in educating patients on treatment modalities, and the importance of dialyzing as prescribed in order for the patients to make better-informed decisions about healthcare. This was a finding that was not expected by the researcher and represents an area of discussion and potential future research that will be discussed in Section 4.

### **Summary**

The purpose of this study was to identify how nephrology social workers understand their roles in promoting health literacy among CKD patients, how they assess for health literacy, and what strategies they use to promote health literacy, specifically within the regions of southwest rural Arkansas and eastern Texas. The data was gathered

from a focus group that included five participants working as social workers in dialysis care centers or in-home health. To address the purpose of the study, three main research questions were asked.

Themes related to how nephrology social workers perceive their roles providing and promoting health literacy included engaging with patients and care team support. Themes related to assessment skills included direct assessment and care team communication. The research question related to strategies used to increase health literacy in patients with CKD elicited themes of engaging education and involving families.

Section 3 presented the results of the study, including data analysis procedures and findings from the data. Section 4 will include a discussion of this research's application in professional ethics and social work practice. In that section the researcher will also make recommendations for social work practice and discuss the implications this research has for social change.

## Section 4: Application to Professional Practice and Implications for Social Change

### **Introduction**

The purpose of this study was to help understand the roles of nephrology social workers in health literacy and how they relay health information to their patients in the healthcare industry. The findings may aid in the identification of how nephrology social workers understand their roles in promoting health literacy among CKD patients, how they assess for health literacy, and strategies they use to promote health literacy. Data were collected through a focus group with participants from southwest rural Arkansas and eastern Texas. The purpose of the study and research questions were answered by five themes. The themes were care-team support, patient assistance, content engagement, care-team communication and assessment, and family involvement.

An essential finding in the study was an increasing need for high interaction and engagement between social workers, doctors, and the whole nephrology team with their patients. Interaction and engagement should focus on issues regarding their dialysis routines and medical planning. This finding indicates the need for a team approach instead of only the social worker carrying out the duties of each discipline of the interdisciplinary team. The finding also may be used to encourage social workers to continue to seek continuing education on health literacy in order to educate patients and empower them to be more active in their care. Social workers can also take the lead to educate the healthcare team and other healthcare personnel on health literacy.

The findings also could be used to focus on what was needed to address limited health literacy. One key was making educational materials that address limited health literacy widely available. Another key included assessing health literacy upon admission



to a dialysis facility, and before being discharged from the hospital. This process would require more defined roles and responsibilities for assessment.

This section includes recommendations on how nephrology social workers can promote health literacy among patients suffering from CKDs and how they can assess the disease in the future. The section also includes the limitations that were encountered in the process of carrying out this research project and provides additional suggestions and recommendations on how future research in this area of study can be improved.

### **Application for Professional Ethics in Social Work Practice**

There are two principles from the NASW code of ethics that relate to how nephrology social workers understand their roles in promoting health literacy among CKD patients, how they assess for health literacy, and what strategies they use to promote health literacy, specifically within the regions of southwest rural Arkansas and eastern Texas. One of the ethical principles that nephrology social workers must hold is to respect the inherent dignity and worth of the person (NASW, 2017). In nephrology social work, social workers have the ability and resources to be initiate change in a patient's life and to make a significant difference. The core value of dignity and worth of the person (NASW, 2017) holds a social worker accountable for doing what is right and in the best interest of patients. As stated previously, it is essential to note that many nephrology social workers will encounter patients of different ages, ethnicities, religious backgrounds, etc., which could impact the level of understanding the patient has of their renal failure and medical history. Although many of the patients in renal care may be different, it is vital that social workers treat each patient with dignity and respect as they care for them in the healthcare setting. As a social worker, it is also essential to be

mindful and educated on the differences among the patient population. Social workers must also be knowledgeable on how to make modifications if necessary, to educate patients on their renal failure and other health conditions. Social workers must present current and updated information in regard to patients' health.

Social workers must value the dignity of each patient while honoring the patient's right to self-determination. Social workers must allow patients to make their own decisions as they relate to their care or treatment. During decision making, nephrology social workers have the responsibility to educate and guide patients and to give each patient a sense of empowerment. Empowering patients helps them find their dignity and worth as an individual.

The second relevant ethical principle is competence (NASW, 2017). Nephrology social workers must work to continue to expand their knowledge of the factors that could impact a patient's treatment outcome as well as the updates of the transplant process. While nephrology social workers have the responsibility to constantly expand their knowledge within the field of renal failure, they must also remain practical and practice within their area of understanding. With renal patients who may often be more vulnerable and unable to advocate for themselves adequately, it is vital that social workers serve as a voice for them. Nephrology social workers must continue to seek to build on their knowledge and expertise and apply this to their practice in renal care. Social workers must also participate in continuing education training related to social work practice and ethics of social work.

The NASW code of ethics guides the clinical social work practice of nephrology social work and reflects their core values. Nephrology social workers must provide

patients with treatment options before their start of renal care. Providing options reflects the idea of social workers promoting clients' right to self-determination. Social workers work as part of a treatment team to make contributions to patients' outcomes as they relate to patient engagement, medical history, and adequacy of dialysis treatment.

Nephrology social work encourages and promotes quality of life as recognized by the patient, their family, and caregivers by honoring their originality, freedom, and decisions.

Social workers promote general well-being through all phases of care: prevention, diagnosis, management of their chronic illness, treatment, and end-of-life care.

Nephrology social workers must always practice with responsibility, confidentiality, ethical principles, and without conflict.

### **Recommendations for Social Work Practice**

Nephrology social workers are often presented with opportunities to broaden their knowledge of renal health to improve their patients' outcomes and to make a difference within their lives. The findings may also impact the practice of nephrology social workers by promoting the importance of their role as an advocate for any policy improvements to meet the needs of patients. The practice of nephrology social workers may shift more towards a focus of providing interventions for emotional distress that, if untreated or unaddressed, would lead to the prevention of patient's health improving.

According to the NASW (2017, p. 2), "social workers seek to enhance clients' capacity and opportunity to change and to address their own needs." Nephrology social workers working in a renal care facility should work to help address any emotional issues that patients may have during their time of treatment. To improve treatment or health outcomes, social workers need to address the well-being of patients, so patients can self-

manage. Nephrology social workers work hard as members of the interdisciplinary team to support patients in their phase of treatment. Social workers have an essential set of skills and knowledge to provide interventions for patients who may be experiencing negative feelings as a result of their current health state. Social workers should continue to use evidence-based approaches while working with all patients to address any signs of depression or negative feelings. These are feelings that may occur as a patient is attempting to cope or adjust to their renal failure.

I recommend two action steps for nephrology social workers to take while working with patients with renal failure. One action step is to research and become more knowledgeable on the resources such as support groups or financial/emotional sources that could help improve patients' quality of life. Improving patients' quality of life could be accomplished by providing supportive counseling to patients and those around them. Supportive counseling includes providing a patient's family with valuable information as it relates to the patient's diagnosis. "Family psychoeducation is the most effective type of intervention used in working with families who have a member with a chronic illness" (Callahan, 2011, p.445). If a nephrology social worker does their part on educating the family about health literacy, this could improve the possibility of a patient complying with the medical attention that they need. A patient's compliance depends upon their understanding, perception of treatment outcome, and how vulnerable they allow themselves to become during this troubling time. A healthy family system can promote a patient's quality of life and support the patient in following through with their treatment plan. The goal of including family is to help patients start the process of healing and returning to activities they once enjoyed before their diagnosis.

The second action step that I would recommend for nephrology social workers to focus on would be the idea of assisting patients with understanding the rights and responsibilities that they have as a patient. There are specific things within the situation that a patient may not have control over, but they can control the amount of effort they put into their care. “Social workers seek to enhance clients' capacity and opportunity to change and to address their own needs” (NASW, 2017, p.6). Nephrology social workers must respect patients' rights to make choices based on informed consent.

It is recommended that social workers incorporate the use of information technology to provide detailed information to patients diagnosed with CKDs. Information technology solutions for communication and education are useful in hospitals because of their ease of use and brevity. According to Dageforde and Cavanaugh (2013), low health literacy is associated with less use of information technology devices such as computers to research medical conditions associated with kidneys and related medical conditions. For instance, patients can use mobile phones with programs that assist them in tracking their medicine use and diet changes. Patients that use technology in their healing process may report changes in medical plans that will help improve health literacy.

There is a need for boosting of doctor-patient relationships before initiating medical interventions. The relationship between patients and doctors is significant in the treatment process and the outcome of patients. According to Campbell et al., (2016), good doctor-patient relationships are imperative because they help increase the knowledge of patients regarding kidney diseases and how they can be managed and treated. Therefore, it is recommended that social workers form good relationships with patients in the healing process.

As a licensed master social worker, I will be better prepared to take a more active role within the dialysis facility to get involved in projects to help patients become better educated and better able to make more informed decisions in their healthcare, to help limit hospital admissions and readmissions. The findings from this project will also motivate me to learn more about health literacy and become a more informed advocate for patients with low health literacy. It will also help me to advocate for screening tools for health literacy upon admission to the dialysis facility. I will also be better prepared to consult more with patients during kidney smart classes before the patient is admitted.

Transferability depends on the degree to which findings are useful to people in different settings, is not like other aspects of research in that readers determine how relevant the findings are to their situations (Connelly, 2016). Personal views expressed in focus groups would interchange according to the social worker framework of the focus group representation. The findings of the study could be transferred to the field of social work practice by focusing on experiences in a way that other clinical social workers can consider the problem. Focusing on how important the public health issue of improving health literacy provides the foundation for transitional care interventions to help improve this public health issue of low health literacy. Clinical social workers can be the voice of reason for the patients by being advocates as well as gaining knowledge on improving health literacy that will, in return, help enhance their practice.

The broader area of social work can use the results of this project to recognize that health literacy is a social problem that affects communities and individuals. Social workers need to recognize that in the hospital or dialysis setting, the detection of inadequate health literacy can occur. Social workers can help improve communication

skills with patients to help alleviate some of the deficits. Social work is committed to community-level evidenced-based intervention that includes community organizing and advocacy, added is the skills and values needed to implement effective health practices related to health literacy. Social workers need to engage in ongoing work and efforts to create programs related to raising awareness of functional health literacy that include guidelines for public health information. Social workers can use education, counseling, and advocating to address health literacy issues with the social work boards and the Council of Social Work Education to include information about addressing health literacy in the educational curricula.

A limitation of the study is that the focus group recruited social workers in only two closely related regions, and there was only one focus group conducted. Opening the focus groups to other areas would have allowed for a comparison of how health literacy is addressed in other areas and could have gained insight from other regions. There is the possibility that if there have been more focus groups conducted, it could have yielded a variety of answers and responses. Generally, focus groups are vulnerable to biases because some participants may be unwilling to discuss the real situations that they experience with their patients. The reliance on focus groups as a data collection tool is based on the participant's prejudice. In this case, the responses issued by participants to the researcher may fail to give the real answers to the questions administered to them, thereby failing to achieve the overall objective of the research project. Some participants may resort to giving responses that do not provide a clear reflection of the happenings in their line of work. Therefore, it is highly recommended that researchers seeking to carry

out related studies in the future should adopt structured questionnaires to reduce potential for subjectivity and bias in their research studies.

One way to disseminate the findings of this project is by speaking at a conference or making a poster presentation at the local Council of Nephrology Social Workers meeting. Another way to disseminate information could be through publishing a journal article through the *Journal of Social Work*. The process of disseminating information through these avenues may allow me to reach other social workers and have a more significant impact on policy and programming.

### **Implications for Social Change**

Perceiving constraints in clinical social work practice and overcoming these restrictions can affect positive social change. Recognizing challenges and hindrances to people with low health literacy can influence constructive change at the micro, mezzo, and macro levels of social work practice. On the micro-level, social workers can identify people with low healthcare literacy and provide interventions to overcome difficulties in obtaining maximum health outcomes. Identifying people with low healthcare literacy can impact their healthcare results and enable people to assume individual responsibility for their welfare, which over some time can assist them with overcoming chronic disease health-related problems. On the mezzo level, social workers can advocate inside their associations for positive social change by pushing for healthcare education screenings (Schulz & Northridge, 2004). Changes in healthcare literacy screening policies can reduce expenses to the healthcare facilities and the individual, reduce hospital admissions and hospital readmissions. On the macro level, social workers can advocate for national social work associations to spread information in regards to healthcare proficiency. They



may also require knowledge in the social work educational program and proceed with training and work with other healthcare experts to enhance skills for healthcare literacy. Each degree of engagement can reduce healthcare costs significantly for people and organizations.

### **Summary**

Health literacy is vital to the care and outcome of approximately 350,000 hemodialysis patients across the United States due to the compound nature of kidney failure and end-stage renal disease. This research project aimed at investigating how nephrology social workers in the dialysis setting provide and promote health literacy to patients with CKDs. Social workers play an essential role in patients' health literacy by working together with larger teams known as interdisciplinary teams to direct psychosocial assessment of the dialysis patients. Direct communication of social workers with their patients as part of a care-team communication was an integral part of promoting and providing patient health literacy and the promotion of health literacy by carrying out engagement education of patients to equip them with primary health education. These findings summarize the significant roles of social workers in providing and promoting health literacy. Also, these findings may raise medical awareness for patients, thus helping them to adhere to the required treatment plans and understand their medical conditions. The findings gathered through this research project provide solutions that are used by nephrology social workers to raise awareness by providing and promoting health literacy for patients with CKDs.

## References

- Allen, M. P., Auld, E., Logan, R., Montes, H., & Rosen, S. (2017). *Improving collaboration among health communication, health education, and health literacy*. Retrieved from <https://nam.edu/improving-collaboration-among-health-communication-health-education-and-health-literacy>.
- Anney, V. N. (2014). Ensuring the quality of the findings of qualitative research: Looking at trustworthiness criteria. *Journal of Emerging Trends in Educational Research and Policy Studies (JETERAPS)*, 5(2), 272-281. doi: 10.2307/3594403
- Anyon Y., Bender, K., Kennedy, H., & Dechants, J. (2018). A systematic review of youth participatory action research (YPAR) in the United States: Methodologies, youth outcomes, and future directions. *Health Education & Behavior*, 45(6), 865-878. doi:10.1177/1090198118769357
- Aston, G. (2017). The renal treatment: Finding patients at risk for kidney disease and convincing them they're sick is a major task. *H&HN: Hospitals & Health Networks*, 91(7), 46–50.
- Bale, C., Douglas, A., Jegatheesan, D., Pham, L., Huynh, S., Mulay, A., & Ranganathan, D. (2016). Psychosocial factors in end-stage kidney disease patients at a tertiary hospital in Australia. *International Journal of Nephrology*. 2016. doi.org/10.1155/2016/2051586
- Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, 37(2), 122–147. <http://dx.doi.org/10.1037/0003-066X.37.2.122>.
- Bandura, A. (2002). Social foundations of thought and action. In D. F. Marks (Ed.), *The health psychology reader* (pp. 94-106). Thousand Oaks, CA: Sage.

- Bass, P. F., Wilson, J. F., & Griffith, C. H. (2003). A shortened instrument for literacy screening. *Journal of General Internal Medicine*, *18*(12), 1036–1038.  
Doi:10.1111/j.1525-1497.2003.10651.
- Berkman, N. D., Davis, T. C., & McCormack, L. (2010). Health literacy: What is it? *Journal of Health Communication*, *15*(S2), 9–19.  
<http://dx.doi.org/10.1080/10810730.2010>.
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine*, *155*(2), 97–107. DOI: 10.7326/0003-4819-155-2-201107190-00005.
- Beto, J. A., Schury, K. A., & Bansal, V. K. (2016). Strategies to promote adherence to nutritional advice in patients with chronic kidney disease: A narrative review and commentary. *International Journal of Nephrology and Renovascular Disease*, *9*, 21-33.
- Brainard, J., Loke, Y., Salter, C., Koós, T., Csizmadia, P., Makai, A., & Szepes, M. (2016). Healthy ageing in Europe: Prioritizing interventions to improve health literacy. *BMC Research Notes*, *9*(1), 270. doi: 10.1186/s13104-016-2056-9 .
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.  
<http://dx.doi.org/10.1191/1478088706qp063oa>.
- Brega, A. G., Freedman, M. G., LeBlanc, W. G., Barnard, J., Mabachi, N. M., Cifuentes, M., ... West, D. R. (2015). Using the Health Literacy Universal Precautions Toolkit to improve the quality of patient materials. *Journal of Health*

- Communication*, 20(S2), 69–76. doi: 10.1080/10810730.2015.1081997.
- Brewis, J. (2014). The ethics of researching friends: On convenience sampling in qualitative management and organization studies. *British Journal of Management*, 25(4), 849–862. <https://doi.org/10.1111/1467-8551.12064>
- Bruzzo, V. (2019). The moral limits of autonomous democracy for planning theory: A critique of Purcell. *Planning Theory*, 18(1), 82–99. <https://doi.org/10.1177/1473095218776042>
- Callahan, M. B. (2011). The role of the nephrology social worker in optimizing treatment outcomes for end-stage renal disease patients. *Dialysis & Transplantation*, 40(10), 444–450. <https://doi.org/10.1002/dat.20618>
- Campbell, S., & Duddle, M. (2010). Health literacy in chronic kidney disease education. *Renal Society of Australasia Journal*, 6(1), 26–31. doi: 10.3310/hsdr03120
- Campbell, Z. C., Stevenson, J. K., Mccaffery, K. J., Jansen, J., Campbell, K. L., Lee, V. W., & Webster, A. C. (2016). Interventions for improving health literacy in people with chronic kidney disease. *Cochrane Database of Systematic Reviews*, 2016(2), CD012026. <https://doi.org/10.1002/14651858>
- Canale, S. B. (2018). Calciphylaxis: The role of the dietitian and social worker in a multidisciplinary treatment. *Journal of Renal Nutrition*, 28(2), 140. doi:10.1053/j.jrn.2018.01.006
- Centers for Disease Control and Prevention (CDC). (2016). *What is health literacy?* Retrieved from <https://www.cdc.gov/healthliteracy/learn/index.html>
- Cervantes, L., Zoucha, J., Jones, J., & Fischer, S. (2016). Experiences and values of

- Latinos with end stage renal disease: A systematic review of qualitative studies. *Nephrology Nursing Journal*, 43(6), 479–493.
- Chiu, L. F. (2003). Transformational potential of focus group practice in participatory action research. *Action Research*, 1(2), 165–183.  
<https://doi.org/10.1177/14767503030012006>
- Choi, J. N. (2012). Context and creativity: The theory of planned behavior as an alternative mechanism. *Social Behavior and Personality: An International Journal*, 40(4), 681–692. <https://doi.org/10.2224/sbp.2012.40.4.681>
- Connelly, L. M. (2016). Trustworthiness in qualitative research. *Medsurg Nursing*, 25(6), 435–437. doi:10.4324/9780203118863.
- Curtin, R. B., Walters, B. A., Schatell, D., Pennell, P., Wise, M., & Klicko, K. (2008). Self-efficacy and self-management behaviors in patients with chronic kidney disease. *Advances in Chronic Kidney Disease*, 15(2), 191–205.  
doi: 10.1053/j.ackd.2008.01.006.
- Dageforde, L. A., & Cavanaugh, K. L. (2013). Health literacy: Emerging evidence and applications in kidney disease care. *Advances in Chronic Kidney Disease*, 20(4), 311–319. doi: 10.1053/j.ackd.2013.04.005
- Davison, S. N. (2010). End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clinical Journal of the American Society of Nephrology*, 5(2), 195–204. doi: 10.2215/CJN.05960809
- Davison, S. N., Levin, A., Moss, A. H., Jha, V., Brown, E. A., Brennan, F., Obrador, G. T. (2015). Executive summary of the KDIGO controversies conference on supportive care in chronic kidney disease: Developing a roadmap to improving

- quality care. *Kidney International*, 88(3), 447-459. doi:10.1038/ki.2015.110
- Devellis, R. F. (1991). *Scale development: Theory and applications*. Thousand Oaks, CA: SAGE Publications.
- Dewalt, D. A., Broucksou, K. A., Hawk, V., Brach, C., Hink, A., Rudd, R., & Callahan, L. (2011). Developing and testing the health literacy universal precautions toolkit. *Nursing Outlook*, 59(2), 85–94. doi: 10.1016/j.outlook.2010.12.002.
- Dickens, C., Lambert, B. L., Cromwell, T., & Piano, M. R. (2013). Nurse overestimation of patients' health literacy. *Journal of Health Communication*, 18(S1),62–69. doi: 10.1080/10810730.2013.825670.
- End-stage renal disease. (2018, March 08). Retrieved from <https://www.mayoclinic.org/diseases-conditions/end-stage-renal-disease/symptoms-causes/syc-20354532>
- Enworom, C. D., & Tabi, M. (2015). Evaluation of kidney disease education on clinical outcomes and knowledge of self-management behaviors of patients with chronic kidney disease. *Nephrology Nursing Journal*, 42(4), 363–372.
- Fals-Borda, O., & Rahman, M. A. (Eds.). (1991). *Action and knowledge: Breaking the monopoly with participatory action research*. New York, NY: Intermediate Technology/Apex.
- Ferri, F. (2017). *Ferri's clinical advisor, e-book 5*. Amsterdam, Netherlands: Elsevier.
- Gaižauskaitė, I. (2012, April). The use of the focus group method in social work research. Retrieved from <https://www3.mruni.eu/ojs/social-work/article/view/503/466>
- Glanz, J. (2014). *Action research: An educational leader's guide to school improvement*. Rowman & Littlefield.

- Goggins, K., Wallston, K. A., Mion, L., Cawthon, C., & Kripalani, S. (2016). What patient characteristics influence nurses' assessment of health literacy? *Journal of Health Communication, 21*(S2), 105–108.  
doi: 10.1080/10810730.2016.1193919.
- Green, J. A., Mor, M. K., Shields, A. M., Sevick, M. A., Palevsky, P. M., Fine, M. J., ... & Weisbord, S. D. (2011). Prevalence and demographic and clinical associations of health literacy in patients on maintenance hemodialysis. *Clinical Journal of the American Society of Nephrology, 6*(6), 1354-1360. doi: 10.2215/CJN.09761110
- Griva, K., Ng, H., Loei, J., Mooppil, N., McBain, H., & Newman, S. (2013). Managing treatment for end-stage renal disease – A qualitative study exploring cultural perspectives on facilitators and barriers to treatment adherence. *Psychology & Health, 28*(1), 13–29. DOI:10.1080/08870446.2012.703670
- Hanson, L., Haynes, L. K., & Turiano, L. (2014). Chronic kidney disease in Central America: The big picture. *American Journal of Public Health, 104*(7), e9.  
<https://doi.org/10.2105/AJPH.2014.301984>
- Harrington, M. (2015). Health literacy in children with chronic kidney disease and their caregivers. *Nephrology Nursing Journal, 42*(1), 53–57.  
doi: 10.3310/hsdr03120.
- Health Literacy. (2016, December 13). Retrieved from  
<https://www.cdc.gov/healthliteracy/learn/>
- Healy, K. (2001). Participatory action research and social work. *International Social Work, 44*(1), 93–105. <https://doi.org/10.1177/002087280104400108>
- Hu, Y. (2015). Health communication research in the digital age: A systematic review.

*Journal of Communication in Healthcare*, 8(4), 260–288.

DOI: 10.1080/17538068.2015.1107308

Jahagirdar, D., Kroll, T., Ritchie, K., & Wyke, S. (2012). Using patient reported outcome measures in health services: A qualitative study on including people with low literacy skills and learning disabilities. *BMC Health Services Research*, 12, 431.

Jain, D., Sheth, H., Green, J. A., Bender, F. H., & Razmaria, A. A. (2015). Health literacy in patients on maintenance peritoneal dialysis: Prevalence and outcomes.

*Peritoneal Dialysis International*, 35(1), 96–98.

doi: 10.3747/pdi.2013.00211.

Jessup, R. L., Osborne, R. H., Beauchamp, A., Bourne, A., & Buchbinder, R. (2018).

Differences in health literacy profiles of patients admitted to a public and a private hospital in Melbourne, Australia. *BMC Health Services Research*, 18(1), 134.

Jiang, Y., Fine, J. P., & Mottl, A. K. (2018). Competing risk of death with end-stage renal disease in diabetic kidney disease. *Advances in Chronic Kidney Disease*, 25(2),

133-140. doi:10.1053/j.ackd.2018.01.008

Kammerer, J., Garry, G., Hartigan, M., Carter, B., & Erlich, L. (2007). Adherence in patients on dialysis: Strategies for success. *Nephrology Nursing Journal*, 34(5),

479–486. doi:10.1159/000254388.

Kanj, M., & Mitic, W. (2010). Health literacy and health promotion. In, *Proceedings of the 7th Global Conference on Health Promotion, “Promoting Health and Development: Closing the Implementation gap”*.

Katzung, B. G. (2007). *Basic and clinical pharmacology (10th ed.)*. New York, NY:



McGraw Hill Medical.

- Kickbusch, I. S. (2001). Health literacy: Addressing the health and education divide. *Health Promotion International, 16*(3), 289–297.  
<https://doi.org/10.1093/heapro/16.3.289>.
- Kiliś-Pstrusińska, K., Medyńska, A., Chmielewska, I. B., Grenda, R., Kluska-Józwiak, A., Leszczyńska, B., & ... Zwolińska, D. (2013). Perception of health-related quality of life in children with chronic kidney disease by the patients and their caregivers: Multicentre national study results. *Quality of Life Research, 22*(10), 2889–2897.
- Kuhn, T. S. (2012). *The structure of scientific revolutions*. Chicago: University of Chicago Press.
- Kutner, M., Greenberg, E., & Baer, J. (2006). *A first look at the literacy of America's adults in the 21st century*. NCES 2006-470. Washington, DC: National Center for Education Statistics.
- Kutner, M., Greenburg, E., Jin, Y., & Paulsen, C. (2006). *The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy*. NCES 2006-483. Washington, DC: National Center for Education Statistics.
- Lai, A. Y., Loh, A. P., Mooppil, N., Krishnan, D. P., & Griva, K. (2012). Starting on haemodialysis: A qualitative study to explore the experience and needs of incident patients. *Psychology, Health & Medicine, 17*(6), 674–684.  
[doi.10.1080/13548506.2012.658819](https://doi.org/10.1080/13548506.2012.658819).
- Lambert, K., Mullan, J., Mansfield, K., Koukomous, A., & Mesiti, L. (2017). Evaluation of the quality and health literacy demand of online renal diet information. *Journal*

*of Human Nutrition and Dietetics*, 30(5), 634–645.

- Lee, Y., Wu, W., & Lee, Y. (2014). Explanatory style differences in health literacy: A survey among young adults in Taiwan. *Psychology, Health & Medicine*, 21(2), 189–197.
- Lennon-Dearing, R. (2013). Health literacy for social workers: A cross-cultural approach. [https://www.researchgate.net/publication/277718481\\_Health\\_literacy\\_for\\_social\\_workers\\_A\\_cross-cultural\\_approach](https://www.researchgate.net/publication/277718481_Health_literacy_for_social_workers_A_cross-cultural_approach)
- Lesgold, A. M., & Welch-Ross, M. (2012). *Improving adult literacy: Options for practice and research*. Washington, DC: Committee on Learning Sciences: Foundations and applications to adolescent and adult literacy. National Research Council. National Academy of Sciences.
- Liao, M.-T.; Sung, C.-C.; Hung, K.-C., Wu, C.-C., Lo, L., & Lu, K.-C. (2012). Insulin resistance in patients with chronic kidney disease. *Journal of Biomedicine and Biotechnology*, 2012, 1–5.
- Liechty, J. M. (2011). Health literacy: Critical opportunities for social work leadership in healthcare and research. *Health & Social Work*, 36(2), 99–107..  
DOI: 10.1093/hsw/36.2.99
- Lim, H., Yu, Z., Kang, A., Foo, M., & Griva, K. (2016). The course of quality of life in patients on peritoneal dialysis: A 12-month prospective observational cohort study. *International Journal of Behavioral Medicine*, 23(4), 507–514.
- Llewellyn, S. (2017). Concept clarification: Uncertainty in individuals with chronic kidney disease. *Nephrology Nursing Journal*, 44(6), 513–539.
- Lo, C., Ilic, D., Teede, H., Cass, A., Fulcher, G., Gallagher, M., & ... Zoungas, S. (2016).

- The perspectives of patients on health-care for co-morbid diabetes and chronic kidney disease: A qualitative study. *PLoS ONE*, *11*(1), e0146615.
- Logan, R. A. (2016). Seeking an expanded, multidimensional conceptual approach to health literacy and health disparities research. *Information Services & Use*, *36*(3/4), 217–241.
- Luckett, T., Clayton, J. M., Lam, L., Spencer, L., Pollock, C. A., Morton, R. L., & ... Tong, A. (2017). Advance care planning in chronic kidney disease: A survey of current practice in Australia. *Nephrology*, *22*(2), 139–149.  
doi: 10.1111/nep.12743.
- Mantwill, S., Monestel-Umaña, S., & Schulz, P. J. (2015). The relationship between health literacy and health disparities: A systematic review. *PLoS ONE*, *10*(12), e0145455.
- Marshall, V.W., & Altpeter, M. (2005). Cultivating social work leadership in health promotion and aging: Strategies for active aging interventions. *Health & Social Work*, *30*(2), 135–144. DOI:10.1093/hsw/30.2.135.
- Martins, C., et.al. (2016). Health literacy among dialysis patients. In, Proceedings of the 18th International Scientific Conference on Economic and Social Development – “Building Resilient Society” –Zagreb, Croatia, 9-10 December 2016, 270–275.
- Mayo Clinic Staff (2018). *End-stage renal disease*. Retrieved from <https://www.mayoclinic.org/diseases-conditions/end-stage-renal-disease/symptoms-causes/syc-20354532>
- McCulloch, E. C. (2015). Health literacy knowledge and experiences of social workers at north shore-LIJ health system (Doctoral dissertation, Fordham University)

[Abstract]. (UMI No. AAI3702560)

- Meppelink, C. S., Weert, J. C., Haven, C. J., & Smit, E. G. (2015). The effectiveness of health animations in audiences with different health literacy levels: An experimental study. *Journal of Medical Internet Research*, *17*(1), e11. doi:10.2196/jmir.3979.
- Meuleman, Y., Brinke, L., Kwakernaak, A., Vogt, L., Rotmans, J., Bos, W., & ... Dijk, S. (2015). Perceived barriers and support strategies for reducing sodium intake in patients with chronic kidney disease: A qualitative study. *International Journal of Behavioral Medicine*, *22*(4), 530–539. doi: 10.1007/s12529-014-9447-x.
- Meyer, J. (2000) Using qualitative methods in health-related action research. *British Medical Journal*, *320*, 178–181. <https://doi.org/10.1136/bmj.320.7228.178>
- Miller, M. D., Valenti, M., Schettler, T., & Tencza, B. (2016). A story of health: Filling a gap in environmental health literacy for health professionals. *Environmental Health Perspectives*, *124*(8), A133–A136. doi: 10.1289/EHP222.
- Montini, G., Edefonti, A., Galán, Y. S., Sandoval Díaz, M., Medina Manzanarez, M., Marra, G., & ... Sereni, F. (2016). Non-medical risk factors as avoidable determinants of excess mortality in children with chronic kidney disease. A prospective cohort study in Nicaragua, a model low income country. *PloS: Public Library of Science ONE*, *11*(5), e0153963. <https://doi.org/10.1371/journal.pone.0153963>
- Montoya, V. (2017). Advanced practice nurses and end-of-life care for patients with progressive chronic kidney disease and end stage renal disease. *Nephrology Nursing Journal*, *44*(3), 256–259.

- Moorthi, R. N. (2019). Does and apple (or many) each day, keep mortality away? *Clinical Journal of the American Society of Nephrology*, *14*, 180–181.  
<https://doi.org/10.2215/CJN.15001218>.
- Morphy, T. (2019). *Definition - What is a stakeholder?* Retrieved from  
<https://www.stakeholdermap.com/stakeholder-definition.html>
- Mukakarangwa, M. C., Chironda, G., Bhengu, B., & Katende, G. (2018). Adherence to hemodialysis and associated factors among end stage renal disease patients at selected nephrology units in Rwanda: A descriptive cross-sectional study. *Nursing Research and Practice*, *2018*, 1-8. doi:10.1155/2018/4372716
- Narva, A. S., Norton, J. M., & Boulware, L. E. (2015). Educating patients about CKD: The path to self-management and patient-centered care. *Clinical Journal of the American Society of Nephrology*, *11*(4), 694–703. doi: 10.2215/CJN.07680715.
- National Association of Social Workers. (2017). *NASW code of ethics*. Accessed April, 2019. Retrieved from: <https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English>
- Nelson, M., & Rabetoy, C. P. (2005). Giving hope through information. *Nephrology Nursing Journal*, *32*(4), 440–441.
- Nielsen-Bohlman, L. T., Panzer, A. M., Hamlin, B., & Kindig, D. A. (2004). *Health literacy: A prescription to end confusion*. Committee on Health Literacy, Board on Neuroscience and Behavioral Health. Washington, DC: National Academies Press.
- Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st

century. *Health Promotion International*, 15(3), 259–267.

<https://doi.org/10.1093/heapro/15.3.259>

Office of Disease Prevention and Health Promotion (2015). Social determinants of health. *Healthy People 2020*. Retrieved from

<https://www.healthypeople.gov/2020/about/foundation-health-measures/Determinants-of-Health>

Osterlund, K., Mendelsohn, D., Clase, C., Guyatt, G., & Nesrallah, G. (2014).

Identification of facilitators and barriers to home dialysis selection by Canadian adults with ESRD. *Seminars in Dialysis*, 27(2), 160–172. doi: 10.1111/sdi.12183.

Otis-Green, S. (2013, June 11). Health care social work. *Encyclopedia of Social Work*. Retrieved from

<https://oxfordre.com/socialwork/view/10.1093/acrefore/9780199975839.001.0001/acrefore-9780199975839-e-176>.

Parker, R. M., Wolf, M. S., & Kirsch, I. (2008). Preparing for an epidemic of limited health literacy: Weathering the perfect storm. *Journal of General Internal Medicine*, 23(8), 1273–1276. <https://doi.org/10.1007/s11606-008-0621-1>

Peace, L., & Philips, M. (2016). Improving health literacy in kidney patients: Nephrology social workers as leaders. *National Kidney Foundation Journal of Nephrology Social Work*, 39(2), 32–37.

Peres, J. (2016). A time and place: The role of social workers in improving end-of-life care. *Journal of Social Work in End-of-Life & Palliative Care*, 12(3), 185–194. doi: 10.1080/15524256.2016.1200522.

Pettit, J. (2006). Power and pedagogy: Learning for reflective development practice. *IDS*

*Bulletin*, 37(5). Brighton, UK: Institute of Development Studies.

Pienkos, S., Sun, S., Schiller, B., Czajkowski, T., & Doss-McQuitty, S. (2018).

Predialysis nephrology care and incident atrial fibrillation in older patients with ESRD initiating dialysis. *American Journal of Kidney Diseases*, 71(4), 576-577.

doi:10.1053/j.ajkd.2018.02.250

Pleasant, A., Cabe, J., Patel, K., Cosenza, J., & Carmona, R. (2015). Health literacy

research and practice: A needed paradigm shift. *Health Communication*, 30(12),

1176–1180. doi: 10.1080/10410236.2015.1037426.

Prieto-Velasco, M., Quiros, P., Remon, C., & Spanish Group for the Implementation of a

Shared Decision Making Process for RRT Choice with Patient Decision Aid

Tools (2015). The concordance between patients' renal replacement therapy

choice and definitive modality: Is it a utopia? *PloS ONE*, 10(10), e0138811.

Purnell, L. D. (2014). *Guide to culturally competent health care* (3rd ed.). Philadelphia,

PA: FA Davis.

Quirong-Jones, N. & Glenn, J. (2016). Successful peritoneal dialysis in elderly patients.

*Nephrology Nursing Journal*, 43(2), 167.

Razmaria, A. A. (2016). Chronic kidney disease. *Journal of the American Medical*

*Association*, 315(20), 2248. doi: 10.1016/j.pop.2008.01.008

Reilly, R., Evans, K., Gomersall, J., Gorham, G., Peters, M. J., Warren, S., & ... Brown,

A. (2016). Effectiveness, cost effectiveness, acceptability and implementation

barriers/enablers of chronic kidney disease management programs for Indigenous

people in Australia, New Zealand and Canada: a systematic review of mixed

evidence. *BMC Health Services Research*, 16, 119.

- Rikard, R. V., Thompson, M. S., McKinney, J., & Beauchamp, A. (2016). Examining health literacy disparities in the United States: A third look at the National Assessment of Adult Literacy (NAAL). *BMC Public Health, 16*(1). doi:10.1186/s12889-016-3621-9
- Saldaña, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). Thousand Oaks, CA: SAGE Publishing.
- Sanabria-Arenas, M., Tobón Marín, J., Certuche-Quintana, M. C., Sánchez-Pedraza, R., & Marín, J. T. (2017). Validation of an instrument for measuring satisfaction of patients undergoing hemodialysis. *BMC Health Services Research, 17*, 321. <https://doi.org/10.1186/s12913-017-2251-y>.
- Santos Pereira, B. d., Silva Fernandes, N. D., de Melo, N. P., Abrita, R., Santos Grincenkov, F. D., & Silva Fernandes, N. M. (2017). Beyond quality of life: a cross sectional study on the mental health of patients with chronic kidney disease undergoing dialysis and their caregivers. *Health & Quality of Life Outcomes, 15*(1), 74. doi: 10.1186/s12955-017-0646-4.
- Schulz, A., & Northridge, M. E. (2004). Social determinants of health: implications for environmental health promotion. *Health education & behavior, 31*(4), 455-471.
- Sørensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health, 12*(1), 80.
- Steketee, G., Ross, A. M., & Wachman, M. K. (2017). Health outcomes and costs of social workers services: a systematic review. *American journal of public health, 107*(S3), S256-S266. doi: 10.2105/AJPH.2017.304004



- Stokols, D. (2000). Social ecology and behavioral medicine: Implications for training, *health*, 107(S3), S256-S266. doi: 10.2105/AJPH.2017.304004
- Strough, H., Wimer, J., & Wapola, J. (2014). Health literacy: Implications for athletic trainers and therapists. *International Journal of Athletic Therapy & Training*, 19(1), 32–35. <https://doi.org/10.1123/ijatt.2012-0099>.
- Sullivan, J. E., Choi, N. G., Vazquez, C. E., & Neaves, M. A. (2019). Psychosocial depression interventions for dialysis patients, with attention to Latinos: A scoping review. *Research on Social Work Practice*. doi:10.1177/1049731518820134
- Tamura-Lis, W. (2013). Teach-back for quality education and patient safety. *Urologic Nursing*, 33(6), 267–271. doi:10.7257/1053-816X.2013.33.6.267.
- Tausch, A. P., & Menold, N. (2016). Methodological aspects of focus groups in health research: Results of qualitative interviews with focus group moderators. *Global Qualitative Nursing Research*, 3. <https://doi.org/10.1177/2333393616630466>
- Taylor, D. M., Fraser, S., Dudley, C., Oniscu, G. C., Tomson, C., Ramanan, R., & Roderick, P. (2017). Health literacy and patient outcomes in chronic kidney disease: A systematic review. *Nephrology Dialysis Transplantation*. doi:10.1093/ndt/gfx293
- Taylor, R. D., Oberle, E., Durlak, J. A., & Weissberg, R. P. (2017). Promoting positive youth development through school-based social and emotional learning interventions: A meta-analysis of follow-up effects. *Child Development*, 88(4), 1156–1171. doi: 10.1111/cdev.12864.
- The Forum of ESRD Networks' Medical Advisory Council, (MAC) (2017). Transitions of care toolkit. Retrieved from <http://esrdnetworks.org/resources/toolkits/mac->

toolkits-1/new-toolkit-transitions-of-care-toolkit/transitions-of-care-toolkit/view

Trump, L. J., & Mendenhall, T. J. (2017). Community health workers in diabetes care: A systematic review of randomized controlled trials. *Families, Systems, & Health*, 35(3), 320–340. doi: 10.1037/fsh0000283 PMID: 28639794.

Turner, C. (2016). The lived experience of being a caregiver for a family member dependent upon hemodialysis. *Nephrology Nursing Journal*, 43(2), 167.

Umeukeje, E., Merighi, J., Browne, T., Wild, M., Alsmann, H., Umanath, K., & ... Cavanaugh, K. (2016). Health care providers' support of patients' autonomy, phosphate medication adherence, race and gender in end stage renal disease. *Journal of Behavioral Medicine*, 39(6), 1104–1114. doi: 10.1007/s10865-016-9745-7.

United States Department of Health and Human Services. (2016). *Quick guide to health literacy fact sheet: Health literacy basics*. Retrieved from:

<https://health.gov/communications/literacy/quickguide/factsbasic.htm>

University of Wisconsin (2019). *Nephrology*. Retrieved from [www.uwhealth.org/kidney-disease/conditions-and-treatments/10409](http://www.uwhealth.org/kidney-disease/conditions-and-treatments/10409)

Untas, A., Thumma, J., Rascole, N., Rayner, H., Mapes, D., Lopes, A. A., ... & Pisoni, R. L. (2010). The associations of social support and other psychosocial factors with mortality and quality of life in the dialysis outcomes and practice patterns study. *Clinical Journal of the American Society of Nephrology*, 6(1), 142–152. doi: 10.2215/CJN.02340310.

Webster, A. C., Nagler, E. V., Morton, R. L., & Masson, P. (2017). Chronic kidney disease. *The Lancet*, 389(10075), 1238–1252.

- White, S. (2008). *Assessing the nation's health literacy: Key concepts and findings from the National Assessment of Adult Literacy (NAAL)*. Retrieved from [www.ama-assn.org/ama1/pub/upload/mm/367/hl\\_report\\_2008.pdf](http://www.ama-assn.org/ama1/pub/upload/mm/367/hl_report_2008.pdf)
- Wilson, C., Campbell, S. M., Luker, K. A., & Caress, A. (2015). Referral and management options for patients with chronic kidney disease: perspectives of patients, generalists and specialists. *Health Expectations, 18*(3), 325–334. doi: 10.1111/hex.12025.
- Wong, C. F., McCarthy, M., Howse, M. P., & Williams, P. S. (2007). Factors affecting survival in advanced chronic kidney disease patients who choose not to receive dialysis. *Renal Failure, 29*(6), 653–659.
- Yin, R. K. (2015). *Qualitative research from start to finish*. New York, NY: Guilford Publications.
- Young, B. A. (2013). Health literacy in nephrology: Why is it important? *American Journal of Kidney Diseases, 62*(1), 3–6. doi: 10.1053/j.ajkd.2013.04.003.
- Yu, Y., Liu, Z. W., Hu, M., Liu, X. G., Liu, H. M., Yang, J. P., ... & Xiao, S. Y. (2015). Assessment of mental health literacy using a multifaceted measure among a Chinese rural population. *BMJ Open, 5*(10), e00905. doi: 10.1136/bmjopen-2015-009054.
- Zala, P. (2017). Experiences of patients with chronic kidney disease and their family members in an advanced practice nurse-led counseling service. *Nephrology Nursing Journal, 44*(6), 521–543.
- Zengin, O. (2016). Nephrology social work: Social work intervention in chronic kidney disease. *Turkish Nephrology Dialysis Transplantation, 25*(03).

doi:10.5262/tndt.2016.1003.01

### Appendix A: Participant Demographic Questionnaire

1. What is your employment status?
2. How long have you been a nephrology social worker?
3. What is your level of education?
4. What other titles or roles do you possess at the dialysis facility?

### Appendix B: Interview Questions for Focus Group

1. How do you engage patients in learning more about their health condition?
2. What are the most difficult parts of educating patients?
3. How do you perceive your role as a social worker related to health literacy education?
4. How do you assess your patients' health literacy?
5. What strategies do you use to help patients grow in their health literacy?
6. What improvements do you think if any can be made to help patients better understand the transmission of health literacy, and health care information?