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Caregivers of Dialysis Patients

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CAREGIVERS OF DIALYSIS PATIENTS

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Alyssa Bousquet
Amelia Murillo
May 2024

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ABSTRACT

This study explored the stress and coping skills as it relates to the burden of care experienced by Caregivers of Dialysis patient's. Questionnaires were sent out to 100 caregivers currently caring for dialysis patient's. The surveys explored demographics, stress, self-care, and types of care provided. Questionnaires were designed in order to elicit responses associated with perceived burden of care. These questions were also designed to pinpoint areas of exploration for future research based on the responses of the sample.

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We would like to acknowledge the caregivers associated with the Dialysis Clinic and thank them for taking the time to participate in the study. As a former Intern in the field of Dialysis, we recognize the overwhelming responsibilities, care and time that goes into caring for your loved ones. We would also like to acknowledge the Clinic, and their staff for their assistance, support and guidance; that was able to make this research possible.

DEDICATION

I would like to thank my family for the encouragement and support through this process. My mom , my husband, my sisters, and my grandma. It has been a tough journey and I could have not pushed myself further without your help .

- Alyssa Bousquet

I would like to dedicate this work to my family; especially my Husband, Elias. None of my efforts would have been possible without your continued love and support. To our two handsome boys, Richard and Elias; everything I do, I do for the both of you. I would also like to dedicate this work to all caregivers; who give tirelessly to others regardless of the dynamics of the care.

- Amelia Ramirez (Murillo)

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CHAPTER ONE

PROBLEM FORMULATION

Introduction

According to the American Kidney Fund, “end-stage renal disease (ESRD) or end-stage kidney disease (ESKD), is the fifth and last stage of chronic kidney disease (CKD)” (2021, P. 1). At this stage of the disease, the Kidneys are suffering complete and total failure. Because the Kidneys are a vital organ, the patient's life is threatened, making medical treatment necessary for the patient’s survival. On average, 1 in 7 adults in the United States are diagnosed with End-Stage Kidney Disease; however, approximately 37 million Americans receive or have received dialysis treatments (National Institute of Diabetes and Digestive and Kidney Diseases, 2021). Dialysis treatment is one of three medical treatments offered to patients with ESKD. Dialysis is a medical treatment that requires machines to extract, clean, and then return the filtered blood to the patient's body. Dialysis has demanding requirements that should be considered before treatment, such as a need for a restricted diet, transportation, living expenses, insurance coverage, and coping or support mechanisms (*Your First30 Checklist*, 2022).

Background Definitions to the Problem

There are five stages of chronic kidney disease; understanding glomerular filtration rate levels (GFR) can help caregivers and patients manage and better

understand the stages of care. Glomerular Filtration Rate (GFR) is a blood test that identifies whether your kidneys filter waste and fluid from your body (*Estimated glomerular filtration rate*, 2022). GFR tests are one of many tests that are continuously conducted and monitored upon the diagnosis of kidney disease. Thus, patients who receive dialysis must learn to adjust and manage these lifestyle changes. According to DaVita (2022) the two leading causes of chronic kidney disease are diabetes and high blood pressure. These underlying diagnoses can cause further complications and concerns on top of the lifelong diagnosis of kidney disease.

End-stage kidney disease patients have three options if available to them. They may receive treatments such as dialysis, and surgical transplants or opt for managed care if choosing to decline lifesaving treatments. On average, a patient's life expectancy on dialysis increases by five to ten years in comparison to a kidney transplant which may increase between fifteen to twenty years (American Kidney Fund, 2021). However, according to the U.S Department of Health and Human Services, 71% of ESKD patients are on dialysis treatment, and 29% with a kidney transplant in the year 2020. Dialysis treatment, although burdensome, appears to be the treatment most used in the diagnosis of ESKD. With continued care and lifelong management, ESKD patients and caregivers may be able to live with the lifelong diagnosis of End-Stage Kidney Disease.

Statement of the Problem

Dialysis patients require caregiving and assistance in their daily lives from family members and/or other available supports who need access to vital patient information (Nagasawa et al., 2018). Patient care information and medical transparency are important to provide to the caregiver to ensure continuity of care. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) applies privacy rules that do not require a health care provider or health plan to share information with family or friends (Office of Civil Rights, 2021). Caregivers are met with barriers to patient information, and thus causes barriers to the patient's overall treatment as the family must also navigate the needs of the dialysis patient. Caregivers play a major role in successful and continued treatment; however, caregivers are limited by policies such as HIPAA and confidentiality clauses. The National Center for Biotechnology Information notes that "All other disclosures under the Act are permissive and guided by a principle of minimum necessary disclosure" (Schulz & Eden, 2016). Health providers often exercise caution, and discretion when sharing patient information only providing the bare minimum to these family members and caregivers. These policies create obstacles for caregivers who are active in the dialysis treatment and lifestyle changes of the patient. There are major recommendations and proposals to address the needs of caregivers and family members' access to patient care.

Social Work Implications

Findings from this study will have major implications for social work practice, on both macro and micro levels. At the micro-level, these findings will contribute to the quality of care of dialysis patients and their caregivers. These findings will contribute to a greater understanding and importance of human relationships as they pertain to patient health and wellness in lifelong diagnoses. The potential findings in this study could also identify the support and needs of caregivers assisting with dialysis lifestyle changes. At a Macro level, this study has the potential to identify and recognize areas of improvement in the HIPAA Privacy Rule, by supporting proposed modifications to HIPPA Privacy Rules, such as improving coordinating care and the push to facilitate a family center approach to dialysis care and treatment (Office of Civil Rights, 2022).

Purpose of the Study

This study intends to investigate the question: How do Caregivers of dialysis patients cope with their active/daily role in their family member's care? Patients are not the only ones affected by lifelong diagnoses. Caregivers are often overlooked. However, caregivers often carry the burden of patient care, by facilitating patients' daily activities, as well as managing patients' financial, emotional and physical needs. According to one study caregivers experience negative effects from this burden of care such as social isolation, financial hardships, and employment crises (Azman et al., 2017). Unfortunately, caregivers are not offered adequate resources to allow them to cope and

manage the burdens of care. This study aims to better understand the support systems and resources available to caregivers of Dialysis patients if any. It also aims to draw attention to the need for further research on the topics of Dialysis caregivers.

CHAPTER TWO

LITERATURE REVIEW

Introduction

Dialysis patients experience demanding lifestyle changes. From long and timely doctors' appointments to intensive routine medications and dietary restrictions. As well as patients with underlying diagnoses or other medical conditions may experience more intensive lifestyle changes. It is understood that lifelong diagnoses require various supports and continued care throughout the treatment process. The term caregivers refer to “those who are actively involved in helping patients to cope with and manage their chronic illness during their treatment” (Belasco et al, 2006, P.6). It is important to recognize the role and importance of the caregiver in lifelong diagnoses. The policy often overlooks the importance of the caregivers' role in the patient's continued care. Thus, creating challenges to those essential supportive factors which caregivers provide.

According to one study, the burden among caregivers is often inter-related with sociodemographic such as age, gender, ethnicity, marital status, education, employment, income, and religion/spirituality of both the caregivers and patients; the disease-related factors, including treatment modality, duration and frequency of dialysis, duration of illness, comorbidity, and level of patient's dependency; Other factors mentioned in the study, include situational and relational factors such as the relationship to the patient, and the duration of caregiving

(Alshammari et al, 2021). This literature review will further explore the burdens and challenges that caregivers may face while in this dynamic and demanding role.

Stress

One of the essential factors that caregivers face is stress. Caregivers face a variety of stressors while managing patients' day-to-day care. However, the stress felt by caregivers is not only related to the work of caregiving but also related to the grief associated with the decline in their loved one's health (Tunajek, 2010). So not only do caregivers face physical and emotional stress from added work but also emotions such as grief and loss for both the patient and themselves. It is often understood that caregivers may struggle to manage and process these emotions due to the demanding nature of their role as caregivers. According to one study, caregivers who are exposed to stress-making factors may suffer from mental health disorders that stimulate further physiological responses, and illness and may even lead to premature death (Sajadi et al., 2017). Caregivers are exposed to daily stressors such as care management, lifestyle adjustments, lack of communication or understanding, financial burdens, and responsibilities as well as feeling inadequate in their ability to provide proper care. A current example of a stressful experience could be the current situation, of the COVID-19 Pandemic. In this situation, dialysis facilities such as Nephrocare were limiting access to patient care by prohibiting caregivers/family members from entering treatment facilities (Fresenius Medical

Care, n.d.). Family members then must rely on patients to communicate care and treatment as well as navigate medical terminology. This may be difficult after long hours of dialysis which often leaves the patient tired. Vital information may be miscommunicated or left out completely, ultimately affecting the patient's care and the caregivers' ability to provide adequate care to their loved ones. Stress from miscommunication, worry, inadequacy, grief, and overload can affect the overall well-being and performance of dialysis caregivers.

Mental Health

These informal caregivers are often family members and or friends who are willing to take on the tasks of caring for the patient and their daily living. These caregivers are at high risk of developing psychological and chronic diseases (Pereira et al., 2017). According to a UK study on the quality of life in caregivers, It was found that healthy caregivers tend to experience strain, lowered personal health, and anger, regardless of the diagnosis of the patient in which they cared for (Shiue, & Sand, 2016). The overall health of caregivers who care for chronic patients can be dramatically impaired due to the caring process and the worsening of the disease. Studies on caregivers, in general, reported higher levels of depression, estimating between 40 – 70 % of caregivers exhibit clinically significant symptoms (Fordyce, N.D.)

A cross-sectional study on caregivers and chronic kidney disease (CKD) patients found similar results in the prevalence of anxiety, depression, stress, fatigue, social support, and quality of life in both the patients and caregivers.

However, the study also found that caregivers reportedly received less social support than patients (Pereira et al., 2017). Depression was identified as the most common disorder faced by these two groups. The study found that depression negatively influences the quality of life of the subject and their caregivers, decreases treatment adherence, and increases the rate of clinical complications and mortality in patients (Pereira et al., 2017). Ultimately the study summarizes the gaps in understanding the impact of caregivers and their mental health. The study concerns that caregivers are not receiving adequate mental health treatment and resources.

This study addressed concerns and gaps in support services to caregivers by reinforcing the notion that other psychological variables, such as anxiety and depression, must be observed in caregivers to promote their mental health and increase their ability to provide support to patients (Pereira et al., 2017).

Limitations to this study include limited information gathering and limited study duration. The study noted that it did not address the length of time in which caregivers took on the provider role. This information is essential to establish as findings demonstrate that quality of life is affected over time.

Emotional and Physical Demands

Caregivers go through many emotions and struggles as well as patients. In a systematic review of caregivers and their Quality of Life, researchers found that the physical and mental health of family caregivers potentially affects the health, welfare, and successful rehabilitation of patients with chronic diseases

(Sajadi et al., 2017). Current studies have justified the importance of caregivers and have acknowledged the emotional and physical demands they face; however, research has not identified further resources or supports for these caregivers. According to this review, the overreliance on family systems, without taking into consideration the necessary supports, results in adverse effects on the family system and on the caregivers' physical, mental and social health (Sajadi et al., 2017). Despite the negative consequences of being a caregiver, it has positive aspects and benefits for patients. It goes hand in hand with a support system that benefits the individual's health and outcomes. The point is to communicate the lack of support caregivers get from the healthcare system, the patients, or family members. Health professionals and procedures should have methods to help the patients and individuals receive both emotional and physical support.

Limitations to Care

According to another study that focused on understanding Advanced Care Planning by family members, there is a lack of consensus on Advanced Care Planning (ACP). Advanced care planning, as described by CDC, is a plan that provides the health care team and family with information on a patient's health care preferences if ever the patient is unable to make their own decisions (Centers for Disease Control and Prevention, 2018). ACP is often utilized in Dialysis, Alzheimer's patients, and cancer patients. According to the Patient Self-Determination Act (PSDA) of 1990, each person has the right to accept or refuse

medical treatment and to implement advance directives. This is important to note as advanced care directives are not always utilized in inpatient care. In fact, according to the studies, patients, their families, and health care professionals are reluctant to discuss end-of-life treatment preferences or formulate advance directives (Calvin, Engebretson, & Sardual, 2013).

In a similar study, 100 family members of intensive care unit patients participated in a survey study. 13% of these family members reported discussing preferences for life-sustaining treatment with the patient. However, 84% said they felt confident speaking on the patient's behalf (Booth, Doherty, Fairgrieve, and Kinsella, 2008). In another study of caregivers and their patients, Hines et al. were able to identify differences between patients' and caregivers' views of ACP. These views created significant concerns in communicating and understanding care (Hines et al. 2001). This study also identified that over 90% of patients designate a family member as their proxy. Another study of chronic kidney disease patients determined that family members were considered an essential part of the ACP rather than physicians (Davison, 2006). These studies confirmed that social support and trust are crucial factors when determining or making end-of-life decisions with family members, even if they are not on the same page.

In a study of cancer patients and their caregivers, family members and caregivers reported that they often felt neglected and disempowered in the health care settings (Meeker, 2004). Meeker's finding suggested that healthcare providers should work to understand the needs of the caregivers better. In fact,

according to the study, caregivers often did not desire direct help when it came to decision-making or discussing ACP due to feelings of mistrust, misunderstanding, and a perceived threat from health care providers. Meeker states, "although advance directives (ADs) are regarded as "the next best way" of honoring patient self-determination when the patient cannot exercise that self-determination directly, there remain many barriers to the creation and implementation of legally valid and effective advance directives" (2004). Overall, Meeker's findings highlighted the frequent neglect of the caregivers by health care providers and helped identify limitations of AD regarding the apparent disconnect between family members as the providing caregivers and health care providers.

Ultimately the family proves to be a support system when facing chronic medical conditions. However, unlike Alzheimer's and Cancer, Dialysis treatment utilizes the practice of ACP rather than Power of Attorney. According to an article titled Health Care Power of attorney, Advanced Directives (AD) work to apply an attorney-in-fact, which has limited decision-making access and does not have access to medical records (n.d.). Comparison to California's Health and Safety Code 123100, which states that representatives under Power of Attorney have access to patient medical records and medical information (the State of California, 1995). With limited access to healthcare plans and records under ACP, it is difficult for caregivers to make educated and confident decisions when creating an end-of-life plan. Ultimately, Limited access and care overload lead

caregivers to manage patients and their dialysis care independently and with limited access to accurate information. This reinforces the previous study that families and caregivers feel neglected in the caring process and inadequately informed about patients' care and future planning (Sajadi et al., 2017).

Importance of Family Involvement

Studies have shown the importance and success that has followed Patient-and-Family-Centered-Care practices. In one study they found that acknowledging family members roles in the patient's care, and exploring their strengths and weakness, improved both the patient health and health care practices (Clay & Parsh, 2016). Patient and Family-Centered Care aims to promote communication and collaboration, promote health literacy, and include patients and families for better relationships and outcomes. The purpose is to discuss the benefits of such practice in hospitals or medical facilities. The goal is to involve the patients in their health care but having family members or caregivers present and vocal in such meetings and treatment discussions. Not to take away any power from the patient but to create better communication of care and relieve some stressors for caregivers.

Studies Focused on Dialysis Caregivers

Few studies have addressed the concerns that face informal caregivers of dialysis patients and their coping mechanisms. There are, however, various studies that focus on caregivers of disabled or elderly patients (Abernathy, 2020; Callum et al., 2012; Zither & James, 2014). This study will identify the gaps in

research to further address the coping mechanisms and quality of life of caregivers of dialysis patients. The study will focus on caregivers' vital role in coordinating the care of dialysis patients and the effects on the caregiver's quality of life. Our study will build on current research that identifies both physical and psychological risks associated with caregivers, the limitations to patient access and involvement as the providing caregiver, and the impact on the quality of life of caregivers as it relates to patient's health and treatment. Our study will identify gaps in services and concerns facing informal caregivers.

Quality of Life and Care

Studies are finding various risks and concerns that affect caregivers' overall quality of life. There is an apparent lack of studies that define the obligations of caregivers; however, we can assume they play a vital role in coordinating care and daily living. Because "daily living" can be defined differently by each patient, it is hard to fully understand what functions, tasks, and obligations these caretakers uphold. One article by Shiue and Sand attempts to close the gap in understanding caregivers' health related to patient care. Although Shiue and Sand were trying to find the gap in understanding the impact of caregiver health conditions, they found that caregivers overall report a lower quality of life, which affects the quality of care provided to patients. The study determined that caregivers with and without chronic disease experience emotional problems such as anxiety and depression (Shiue & Sand, 2016). Another study reported that 40-70% of caregivers have clinically significant

depression, with one-quarter of these caregivers meeting the criteria for major depression (Fordyce, n.d.).

An estimated 44 million Americans ages 18 and older provide unpaid assistance and support to older people and adults with disabilities (Fordyce, n.d.). The Family Caregivers Alliance FCA research has shown that caregivers are often ill-prepared for their new role and provide care to patients with little to no support themselves (Fordyce, n.d.). Caregivers with higher stress are more susceptible to substance and alcohol use, increased rates of physical ailment, and diminished immune systems. Depression and anxiety have been shown to negatively influence the quality of life of caregivers and decrease adherence to treatment and increase the rate of clinical complications and mortality in patients (Pereira et al., 2017).

These limited studies draw attention to the health and well-being of caregivers concerning patient well-being, but little is known about the relative influence on the burden of care and the quality of life of caregivers of dialysis patients, supporting the need for further research. Ultimately these studies support the idea that poor quality of life in caregivers affects the patients for which they are being cared. According to social support models, patients need to have solid and supportive systems while dealing with the uncertainties of chronic diseases.

Theories Guiding Conceptualization

A guiding theory in this research was the Family Stress Theory, utilizing the Double ABC-X model. The purpose is to look at the impact of the crisis on families. "It states that the combination of stressors (A), the family's resources (B), and the family's definition of the event (C) will produce the family's experience of a crisis (X) (Ballard et al.,2020). Understanding the family surroundings will help identify the issue among the family and how best to go about it. Not every family goes through the same transition; some family members may have had a long-term illness that progressively worsened, an individual whose health declined suddenly or rapidly, and an individual who may have been diagnosed but did nothing to prevent its progression.

Another potential theory that will guide this research is The Person-In-Environment Theory. The person-in-environment theory describes "how different aspects of the environment manipulate how a person thinks, feels, or acts; you can better understand an individual by understanding the environment surrounding them" (Kondrat, 2017). How might the different aspects of their environment affect all individuals who are involved? Looking at dialysis patients' history of who is surrounding them, their support system, where they are located, either at home or in a nursing facility, and how they ended up on dialysis. Patients who have a caregiver should be a part of the equation. Understanding the caregiver's environment is also essential to help provide a healthy and productive life and the patient they are providing for. It will help with the quality of life and care crucial for both individuals.

The Family Systems Theory will help to guide and explore how family systems manage the diagnosis of end-stage kidney disease. This theory will help to better understand possible patterns of interactions, stability and change within the family and supportive systems. According to the Journal of Advanced Nursing, health issues increases family stress, requires constant adaptation and challenges health care professionals to meet the greater needs of the patient and family (Neighbour, 1985). Focusing on the family system will give insight in to the adaptions, challenges and stresses that undergo the patient's family system. This theory may also help to identify stressors that impact the burden of care for those in the caregiving role. Ultimately this theory will help to better understand how the family system adapts, changes and adjusts to chronic kidney disease and Dialysis treatment.

CHAPTER THREE

METHODS

Introduction

The intentions of this study was to describe and understand how caregivers of dialysis patient cope and manage their active/daily role as a caregiver. The study helped to identify the caregiver's self-care, burden of care and social support in hopes to improve or expand services for dialysis caregivers. This chapter will discuss the details of how this study was conducted. Sections discussed in this chapter will be, study design, sampling, data collection and instruments, procedures, protection of human subjects, and data analyst.

Study Design

The purpose of this study is to identify and explore how caregivers manage and cope with the demands of patient care and their own personal lives. Due to the limited data surrounding this topic, the project will be exploratory. This exploratory study utilized a quantitative, descriptive research design. The study surveys used scaling methods such as the burden of care (ZBI) scale, the self-care inventory, and the social support scale. This focus helped to identify, observe and measure the data surrounding caregivers and coping methods.

A strength in using a surveying method with an exploratory, quantitative approach, is that the data can be collected from a large sample size. Surveys

were offered digitally through various platforms, as well as physically, through paper forms to increase the range of participants. The survey process is cost efficient, fast, and allows for anonymity. Survey methods allowed for the subjects to respond while in their own natural environments. Allowing surveyors to remain in the comfort of their own environment increases honesty and disclosure. In addition, the research refrains from manipulating variable in the study, which increases external validity.

A disadvantage of this descriptive study is that the data collected cannot explain cause. Although the data will be able to help better understand the problem, it will not be able to explain why the problem exists. The study relied heavily on the true and accurate responses of the participant, thus there is a risk of false responses. These untrue responses would compromise the study validity. There is always the possibility that the survey is completed with false information or misunderstandings. These situations can create major concerns regarding the legitimacy of the data. This study also carries the risk of sampling error as the study largely employs the use of random sampling.

This study seeks to better understand the caregiver's role in dialysis patient's care, the burden of care of caregiving and how these caregivers manage and cope with their active roles in dialysis patient's care.

Sampling

The study used non-probability sampling of caregivers who are currently caring for dialysis patients, diagnosed with end state renal disease. Utilizing purposive sampling; the authors of this study were able to select dialysis patients who have active caregivers, a vital criterion for the study. The participants were recruited for the study based on a participating location; a Southern California Dialysis clinic. The approval of these surveys were requested from the supervisor of this agency. Random sampling was conducted through online surveys posted to dialysis support groups on public social media networks and/or forums. These surveys used voluntary response sampling obtained through Qualtrics survey links. Approximately one-hundred subjects are anticipated to participate in this study not including incomplete or nonresponsive participants.

Data Collection

Quantitative data was collected through online surveys and physical paper surveys, over the span of 8 months. The surveys included an introduction and description of the study and purpose using a research flyer (see appendix C). The survey included demographic information as well as questions from an adapted tool that contained Self-care and stress scaling (See appendix A). Demographic questions such as age, ethnicity, house-hold income, employment status, average hours worked in a week, number of dependents, and medical insurance coverage. For the patient section in the survey, two added questions were included to address competence and number of years in dialysis treatment.

For the purpose of exploring the caregivers perceived stress levels. The questionnaire contained 10 items derived from Cohen and Williamson's Perceived Stress Scale (PSS) (1988). The questionnaire also contained an adapted version of the Mindful Self-Care Scale (Cook, 2015). The questions included in this adapted tool include a Likert scale, with 5 scores (see appendix A). The scoring is listed as 1-never, 2- rarely, 3-sometimes, 4-often and 5-regularly. These questions and scales were used to explore how caregivers cope with stress, as well as if there are any supportive factors for the caregiver.

Procedures

The questionnaire was handed out with a brief printed explanation/ purpose of the survey and blank envelope. Patient's and caregivers who walked into the facility were presented with a QR code to the online Qualtrics version for participants convenience. Nurses and staff on the treatment floor of the Sothern California Dialysis Clinic, were given both the physical survey and the QR code to patient's caregivers, during inhouse and regularly scheduled dialysis day treatment/checkups. These surveys were then placed in blank envelope and returned to designated drop box. Peritoneal dialysis patient and caregivers were given both physical and digital QR code during their scheduled monthly clinic and were instructed to return the survey by end of treatment. All physical surveys were received through a locked drop box at the nurses stations. Surveys online were made available to Facebook groups using QR code or Qualtrics survey link.

These surveys also included a brief explanation of the survey purpose, qualifications for the survey participation, and directions. Qualifications for this research study specified that the survey is for caregivers of patients with end stage renal disease and patient's with ESRD. All participants who choose to participate via digitally or through physical forms, were included in the data collection.

Protection of Human Subjects

The identity and confidentiality of the participants was safe guarded through various procedures. Identity was made anonymous on all survey's forms. The in-person surveys were returned to a locked drop box located at the facility. The lock box was provided to increase patient confidentiality and ensure anonymity. The paper surveys were entered at a later date into the anonymous online survey system, Qualtrics. Patients were instructed at the beginning of the survey that there should not be any names or identifying information listed on the survey. QR code to the survey were made available to those who prefer a digital version. All electronic data was shared between the authors of this study through a password protected google document. There was no emailing, phone sharing or discussing in public regarding research. All conversations were conducted in a private room with only the involved research party. All paper surveys will be stored and preserved in a locked filing cabinet for up to three years after completion of study and will be shredded after its stated use.

Data Analysis

All data collected and processed from this research was produce through SPSS. The data collected through paper survey were transferred to the Qualtrics data system. Researchers imputed data by hand and preserve originals to ensure and dispute possible human error or mis entry. After imputing of data into the system, researchers downloaded and transferred data to SPSS, for analyzation. The data was run through descriptive statistics to record central tendencies and dispersion. A separate analysis was ran to examine bivariate correlations.

Summary

This study survey explored how caregivers cope with their active roles in dialysis patient's. By evaluating perceived stress, self-care and demographics of these patient's and caregivers. The survey helped to better understand and address the demographic circumstances surrounding these caregivers and patients. It assisted in exploring the perceived stress and coping abilities in order to discover and investigate possible barriers, needs and recommendations for future studies of caregivers of dialysis patients. The Quantitative data collected in this study was used to best facilitate and represent the research project.

CHAPTER FOUR

RESULTS

Introduction

Chapter four provides visual illustrations of the data collected from the research surveys. The researchers performed the following test, Pearson's Correlation, descriptive statistics and frequencies based on the demographic variables of household income, number of dependents, employment status, and weekly employment hours. Tables 1-7 present the most significant and noteworthy correlations and findings which will be further analyzed in Chapter Five. Tables 8-15 identify frequencies of Independent variables and demographic variables utilized in the data correlation. The Independent variables address the following, number of coping skills reported, current stress levels, and self-care score.

Table 1 illustrates Pearson Correlation of household income and number of coping skills utilized by dialysis care givers. This data utilized SPSS and the data collected from the surveys. The Sample size consisted of 31 caregivers and identifies variable of household income and the number of coping skills utilized by the caregiver. This table indicates that there is a strong negative correlation between household income and coping techniques used by caregivers. The results are significant, with Sig (2-tailed) reporting at .042.

Table 1. Household Income and Number of Coping Skills Utilized by Caregivers.

Correlations			
		What is your household Income?	NmbrCoping
What is your household Income?	Pearson Correlation	1	-.367*
	Sig. (2-tailed)		.042
	N	31	31
NmbrCoping	Pearson Correlation	-.367*	1
	Sig. (2-tailed)	.042	
	N	31	31

*. Correlation is significant at the 0.05 level (2-tailed).

Table 2 presents significant relationship between Caregivers confidence in patient's care plan, and the number of dependents reported. The data table identifies the p-values as .011 This table indicates that there is a strong positive correlation, identifying that caregivers reporting higher confidence in patient's care plan, also report having more dependents.

Table 2. Caregiver's Confidence in Patient Care Plan and Number of Dependents Reported.

Correlations			
		How confident do you feel in understanding the patients care plan?	How many dependents do you have?
How confident do you feel in understanding the patients care plan?	Pearson Correlation	1	.450*
	Sig. (2-tailed)		.011
	N	31	31
How many dependents do you have?	Pearson Correlation	.450*	1
	Sig. (2-tailed)	.011	
	N	31	31

*. Correlation is significant at the 0.05 level (2-tailed).

Table 3 illustrates the Pearson's Correlation coefficient between the number of services provided to the patient and the number of hours spent caregiving each week. The Sample size remains at N=31 with Sig (2-tailed) reporting at .008. As anticipated there is a positive correlation between the number of hours spent caregiving and the number of services provided to the patient. Caregivers who spend more time caring for patient, the more services they provide to the patient.

Table 3. Number of Services Provided to the Patient and Number of Hours Providing Care

Correlations			
		NmbrServices	HoursWeek2
NmbrServices	Pearson Correlation	1	.471**
	Sig. (2-tailed)		.008
	N	31	31
HoursWeek2	Pearson Correlation	.471**	1
	Sig. (2-tailed)	.008	
	N	31	31

** . Correlation is significant at the 0.01 level (2-tailed).

Table 4 demonstrates the correlation between the number of coping skills utilized by caregivers and the caregivers confidence in medical terminology. This is displayed using Pearson's Correlation coefficient. The data ran through SPSS, indicated a positive relationship with both variables, resulting in a Sig(2-tailed) of .001. This data table indicates that caregivers who feel confident in understanding medical terminology, also report utilizing more coping techniques.

Table 4. Number of Coping Skills and Caregivers Confidence in Medical Terminology.

Correlations			
		NmbrCoping	How confident do you feel in medical terminology?
NmbrCoping	Pearson Correlation	1	.555**
	Sig. (2-tailed)		.001
	N	31	31
How confident do you feel in medical terminology?	Pearson Correlation	.555**	1
	Sig. (2-tailed)	.001	
	N	31	31

** . Correlation is significant at the 0.01 level (2-tailed).

Table 5 displays Pearson Correlation between caregivers confidence in understanding patient's care plan and the Caregivers confidence in understanding medical terminology. This table indicates that there is a strong positive correlation between understanding patient's care plan and understanding medical terminology. The results are significant, with Sig (2-tailed) reporting at <0.001. This data indicates that the more confidence reported by caregiver in understanding the patient's care plan, relates to their confidence in understanding medical terminology .

Table 5. Caregiver’s Confidence in Understanding Patient's Care Plan and Medical Terminology.

Correlations			
		How confident do you feel in understanding the patients care plan?	How confident do you feel in medical terminology?
How confident do you feel in understanding the patients care plan?	Pearson Correlation	1	.755**
	Sig. (2-tailed)		<.001
	N	31	31
How confident do you feel in medical terminology?	Pearson Correlation	.755**	1
	Sig. (2-tailed)	<.001	
	N	31	31

** . Correlation is significant at the 0.01 level (2-tailed).

Table 6 demonstrates the Pearson’s correlation between caregivers reported employment status and the caregivers current reported stress related to their roles as a caregiver of a family member receiving dialysis treatment. The table below indicates a negative correlation of -.412, and Sig (2-tailed) of .021 which determines significance. In this study employment status was ranked as the following, 1-fulltime, 2-part-time, 3-seeking opportunities, 4- retired and 5- never worked. Based on the data, as employment status ranked higher (i.e retired) the stress level associated with caregiving was reported as lower.

Table 6. Caregiver’s Employment Status and Stress Levels Related to Caregiving.

Correlations			
		What is your employment status?	What is your current stress level as it relates to being a caregiver of a family member on dialysis treatment.
What is your employment status?	Pearson Correlation	1	-.412*
	Sig. (2-tailed)		.021
	N	31	31
What is your current stress level as it relates to being a caregiver of a family member on dialysis treatment.	Pearson Correlation	-.412*	1
	Sig. (2-tailed)	.021	
	N	31	31

*. Correlation is significant at the 0.05 level (2-tailed).

Table 7 identifies a significant and positive correlation between Caregivers current stress as it relates to caring for a family member receiving dialysis treatment, and the average hours worked weekly by the caregiver (i.e. fulltime, or part time). The data table reads a Sig (2-tailed) rating of .022 and Pearson’s correlation as $p = .411$. This data indicates that the more work currently doing (i.e fulltime employment) the more likely to express stress as it relates to being a caregiver of a family member receiving dialysis treatment.

Table 7. Caregiver's Stress Levels and Their Average Weekly Employment

Correlations			
		What is your current stress level as it relates to being a caregiver of a family member on dialysis treatment.	On average, how many hours do you work a week?
What is your current stress level as it relates to being a caregiver of a family member on dialysis treatment.	Pearson Correlation	1	.411*
	Sig. (2-tailed)		.022
	N	31	31
On average, how many hours do you work a week?	Pearson Correlation	.411*	1
	Sig. (2-tailed)	.022	
	N	31	31

*. Correlation is significant at the 0.05 level (2-tailed).

Table 8 indicates the age groups of participants who participated in the study. The sample comprised of (N=31), 6 between the ages of 21 and 40 years old (19.4%), 14 between the ages of 41 and 60 (45.2%), and 11 reporting between the ages of 61 and 80 (35.5%).

Table 8. Age Frequency .

What is your age?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	21-40	6	19.4	19.4	19.4
	41-60	14	45.2	45.2	64.5
	61-80	11	35.5	35.5	100.0
	Total	31	100.0	100.0	

Table 9 indicates the ethnic groups which participants identified with during the study. The sample size consisted of (N=31), 16 white/Caucasian (51.6%), 5 African American (16.1%), 9 Hispanic (29%), and 1 Native American or Pacific Islander (3.2%).

Table 9 . Ethnicity Frequency

		What is your ethnicity?			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Caucasian/White	16	51.6	51.6	51.6
	African American	5	16.1	16.1	67.7
	latino/Hispanic	9	29.0	29.0	96.8
	Native American or Pacific Islander	1	3.2	3.2	100.0
	Total	31	100.0	100.0	

Table 10 indicates the household income reported by participants. The sample included 2 reporting income as \$13,590 or less (6.5%), 8 reporting between \$13,591 and \$23,030 (25.8%), 13 reporting between \$23,031 and \$33,000 (41.9%), 4 reporting between \$33,001 and \$43,000 (12.9%), and 4 report having \$43,001 or higher (12.9%) household income.

Table 10. Income Frequency

What is your household income?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	13,590 or Less	2	6.5	6.5	6.5
	13,591-23,030	8	25.8	25.8	32.3
	23,031-33,000	13	41.9	41.9	74.2
	33,001-43,000	4	12.9	12.9	87.1
	43,001 Plus	4	12.9	12.9	100.0
	Total	31	100.0	100.0	

Table 11 illustrates participants employment status as reported in the surveys. This sample includes (N=31), with 11 reporting fulltime employment (35.5%), 8 as part-time (25.8%), 2 as seeking opportunities (6.5%), and 10 retired (32.3%).

Table11. Employment Frequency

What is your employment status?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Full-Time	11	35.5	35.5	35.5
	Part-Time	8	25.8	25.8	61.3
	Seeking Opportunities	2	6.5	6.5	67.7
	Retired	10	32.3	32.3	100.0
	Total	31	100.0	100.0	

Table 12 indicates number of coping techniques identified by participants. The data indicates the following, 4 report not using any coping techniques (12.9%), 11 reported using at least one coping technique (35.5%), 8 reported using 2 different coping techniques (25.8%), 7 reported utilizing 3 different coping techniques (22.6), and 1 identifying 5 different coping techniques (3.2%).

Table 12. Coping Skills Frequency

		NmbrCoping			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	4	12.9	12.9	12.9
	1.00	11	35.5	35.5	48.4
	2.00	8	25.8	25.8	74.2
	3.00	7	22.6	22.6	96.8
	5.00	1	3.2	3.2	100.0
	Total	31	100.0	100.0	

Table 13 indicates stress level frequencies. Data reports current stress levels rating from 1 to 10 with one representing lowest levels of stress to 10 indicating highest levels of stress. The data collected from 31 participants indicated that 2 report stress rankings of 2 (6.5%), 3 reporting a 3 on the scale of stress (9.7%), 5 reported feeling at a level 4 scaling (16.15), 6 reported as a level of 5 (19.4%), another 6 reported feeling at a level 6 (19.4%), 4 participants reported higher levels of stress, indicating a score of 7(12.9%), 3 reported level 8

(9.7%) 1 reported with a level 9 (3.2%) and 1 reported feeling the highest levels of stress at 10 (3.2%).

Table 13. Stress Scale Frequency

What is your current stress level as it relates to being a caregiver of a family member on dialysis treatment.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2	2	6.5	6.5	6.5
	3	3	9.7	9.7	16.1
	4	5	16.1	16.1	32.3
	5	6	19.4	19.4	51.6
	6	6	19.4	19.4	71.0
	7	4	12.9	12.9	83.9
	8	3	9.7	9.7	93.5
	9	1	3.2	3.2	96.8
	10	1	3.2	3.2	100.0
	Total	31	100.0	100.0	

Table 14 addresses the question, does the caregiver receive training? This table illustrates the results utilizing two direct options, of either yes or no. The results yielded the following data; 71% 22 participants out of total (n=31) responded with no, they have not received training in order to become a caregiver, and 29% or 9 of the remaining participants responded with yes, they did receive training.

Table 14. Training Frequency.

Did you receive training to become a caregiver ?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	22	71.0	71.0	71.0
	Yes	9	29.0	29.0	100.0
	Total	31	100.0	100.0	

Table 15 indicates self-care scores as determined by the sum of four self-care questionnaires with ranked responses of 1- never, 2-rarely, 3-sometime, 4-often and 5-regularly. These scores indicate 1 score of 7(3.2%), 2 scores of 8 (6.5%), 2 scores of 9 (6.5%) 4 scoring 10 (12.9%), 2 scores of 11 (6.5%), 2 scores of 12 (6.5%), 2 scores of 13 (6.5%), 2 scores of 14 (6.5%), 2 scores of 15 (6.5%), 5 scores of 16 (16.1%0, 4 scores of 17 (12.9%), 2 scores of 19 (6.5%), and lastly 1 score of 20 (3.2%).

Table 15. Self-Care Scale Frequency.

		SelfCareScore			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	7.00	1	3.2	3.2	3.2
	8.00	2	6.5	6.5	9.7
	9.00	2	6.5	6.5	16.1
	10.00	4	12.9	12.9	29.0
	11.00	2	6.5	6.5	35.5
	12.00	2	6.5	6.5	41.9
	13.00	2	6.5	6.5	48.4
	14.00	2	6.5	6.5	54.8
	15.00	2	6.5	6.5	61.3
	16.00	5	16.1	16.1	77.4
	17.00	4	12.9	12.9	90.3
	19.00	2	6.5	6.5	96.8
	20.00	1	3.2	3.2	100.0
	Total		31	100.0	100.0

Summary

The explore section of this study presented the findings of the survey, designed to explore how caregivers cope with their active roles in dialysis patient's. Researchers utilized quantitative data analysis to present the responses of the study participants. The data collected evaluated perceived stress, self-care and demographics of dialysis caregivers. The respondents reported wide ranges of age, and income with the majority of respondents reporting to be between the ages of 41 and 60 and incomes between \$23,031 and \$33,000. Data collected has identified the diverse and unique dynamics of

dialysis caregivers. According to the results participants identified both negative and positive correlation related to independent variable, such as income, confidence in understand client care plan, and confidence in medical terminology. These areas showed direct correlation to the caregiver abilities to utilize coping techniques, and reported stress and self-care.

CHAPTER FIVE

DISCUSSION

Introduction

Chapter five will further explore the data analysis presented from the quantitative study. This final chapter provides a summary discussion of significant findings and limitations. In addition, this chapter provides recommendations for future social work practice, policy and implications to improve quality of research in the area of Dialysis Caregivers. The purpose of this study was to explore and investigate how caregivers of dialysis patients cope with their active and daily role in their family members care.

This study focused its investigation on the burden of care, that dialysis caregivers experience. Focusing on data correlations that yielded significant findings on areas that related to income, dependents, reported stress levels, coping skills, ethnicity, and competing interests; as these areas help to illustrate the burden of care experienced by dialysis caregivers.

Discussion

Some of the outcomes of this study confirmed existing qualitative and quantitative research. Existing research has found that caregivers often face multiple responsibilities, and experience high levels of stress. The data collected further confirms both existing literature and supports the findings of this research

study. Outcomes of this study also recognized limitations, that suggest that further exploration and research should take place to fully comprehend the extent of the matter.

This study successfully explored the importance of the household income as it relates to the caregivers ability to use or identify personal use of coping skills (Table 1). The findings of this study identified a strong negative correlation between the two variables. This means that caregivers who report higher incomes, report lower use of coping skills. This study found that 61% of caregivers utilize only one to two coping skills. The data in this study identified only 1 participant, out of the 31 participants who reported the use of five different coping skills (Table 12). The data collected in this study implies that money cannot buy coping skills, and that instead the circumstances surrounding higher incomes may take away from caregivers abilities to engage or utilizing coping techniques/skills. It can be further speculated that higher incomes require more from caregivers such as work obligations and greater work hours. This further suggests that although money is necessary for caregivers to function in their roles, it is not sufficient in addressing the needs of the caregiver. These findings seem to suggest that caregivers require more than financial assistance to effectively and adequately care for dialysis patient's/ family members.

Findings from table 2 refers to the correlation between Caregiver's dependents and the caregivers confidence in understanding patients care plan. The data collected on the N=31 participants identified a positive correlation

between the number of dependents and the caregivers confidence in understanding patient's care plan. This study found that caregivers who reported having more dependents also reported having higher confidence in the patient's care plan. The results of this study suggest that caregivers with multiple dependents, may already be equip with the skills necessary to care for other individual's. The study also suggests, that caregivers with more dependents, may have increased time management skills and natural supports within the home as a result of these dependents. This study recognizes that having more dependents, positively relates to the caregivers confidence in understanding and administering the patient's care plan. This study suggests that research should be conducted to further explore the importance of supportive family structures and family dynamics among dialysis caregivers.

The results obtained in this study confirm current and historical literature, that identifies high stress in caregiving populations (table13). The study identifies stress by utilizing a scaling method (1-10), with one being the lowest and 10 being the greatest amount of stress. The results of this scale found that 19.4% of caregivers feel moderate to severe stress, ranking themselves at either a 6 or 7 on the stress scale. Additional uncovering that 68% of caregivers rank themselves at or above a level 5 rating (moderate stress) with zero participants reporting low to no stress, 0 or 1. This study found that the dialysis caregivers feel some level of stress with more than half reporting moderate to severe stress. The results from this study, imply that stress in undeniable among dialysis

caregivers. The data also suggests that further studies should be conducted to explore the continued implications of stress on dialysis caregivers

Data results from this study confirms and absence of skills with in the population of dialysis caregivers. Further supporting current literature that suggest that caregivers of dialysis patient's lack coping technique and skills (table 12). This study implies that, caregivers may lack skills due to, lack of time, age, and employment. Many of the participants reported to be retired or working full time (table 11) and a large percent reported to be over 60 years (table 8). This study further implies, that there is a lack of education within the caregiving population, regarding feasible coping skills and techniques. This study further suggests that future research should be done to better understand what coping mechanisms can be utilized within this dynamic population. It also suggests that actions should be taken to explore future implications for training opportunities among dialysis caregivers.

Out of the 31 participants, 51.6% identified as Caucasian/white (table 9). The numbers expressed in this study implies that more Caucasian/white participants were willing to participate in the study, than those of their counterparts. This study implies that Caucasian/white express a willingness to disclose personal information for the purpose of research. This study suggests that African Americans, Hispanics and other ethnic minorities who chose not to participate, may have questions, uncertainties and worries as to the outcome of participation. The study further suggests that future research should be

conducted to explore race and ethnic barriers to participation. It also suggests that future researchers should work to improve research tactics in order to include reluctant caregivers/possible participants.

When looking at caregivers employment status as it relates to stress we found a surprising correlation. As employment increased in rankings (1-fulltime, 2-part-time, 3-seeking opportunities, 4-retired), stress levels decreased (table 6). This means that there is a direct relationship between less work and stress triggers, among caregivers. Those participants who reported as retired or unemployed reported experiencing less stress as it relates to the patients care. This data that caregivers may have competing interests, as there employment because more demanding (ie. Fulltime), the stress associated with the patient's care rises. The findings in this study seem to suggest that caregivers can reduce stress if able to be free from employment obligations. Further studies should be conducted to explore how agencies and supportive services can address caregivers who demonstrate competing interests such as employment or careers. The study further suggests that competing obligations of caregiver should be further explored as it directly effects the stress reported and associated with the patient, by the caregiver.

Limitations

One limitation of this study is the small sample size. Although 100 surveys were anticipated and handed out, only 31% (31) surveys were returned. The

findings from this study, although consistent with previous literature, the small sample size may prevent the study from being extrapolated.

Another limitation associated with this study is that the participants were recruited from one particular agency. This may lead to limitations on population representation. The study population may not accurately represent the general population of dialysis caregivers. This may also affect the studies demographics information such as income, employment, age, ethnicity, etc. based on the location in which the study was conducted.

A further limitation to this study; is that the study failed to provide survey options in different languages. By providing the survey only in English, the authors of this study may have effected, the participants willingness to participate, and the participants understanding of the survey questions. This is a limitation that can be adjusted for future research in order to improve access and willingness to participate. This limitation also can be addressed with future ethical and cultural considerations.

Lastly, we found that our study relied solely on the willingness to participate and the participants honesty when self-reporting. Depending on the caregivers understanding of the question, their honesty, and their willingness to participate; the study findings could be skewed.

Implications for Social Work
Practice, Policy and Research

Results obtained from this study identifies a need for further research into services and resources available to dialysis caregivers. The study acknowledges a need for agencies to develop educational workshops, to assist caregivers in developing coping skills and strategies. By developing these programs, caregivers will have the opportunity to gain a better understanding of coping techniques. The development of coping techniques and strategies unique to the complex dynamics of dialysis caregivers will help to relieve the stress associated with “caregivers burden”.

Current literature has consistently identified stress as an overwhelming factor in regards to caregivers burden. This study further supports the need for social work involvement in dialysis patient care, that includes addressing the caregiver as part of the family system. The study acknowledges stress as a dynamic factor that effects quality of care, work/employment, understanding and confidence of the caregiver. Social Workers should consider services and resources that can further address caregivers stress that relates to caregivers competing obligations, such as work/employment.

Future research should begin to address the differences between caregivers needs. Current literature is beginning to uncover the unique needs that come with terminal diseases and the effects it has on the caregivers and the patient relationship. Future social work research should continue to focus on end stage renal disease and other terminal disease to pinpoint needs and identify patterns and themes. Future research should also focus of developing and

exploring possible interventions, that continue to support the support systems of the client and patient utilizing family systems theory and by expanding on the patient and family centered care models.

Conclusions

Results from this study suggest that caregivers of dialysis patients, do experience stress related burdens associated with their active roles. This study further suggests that caregivers have limited means to support themselves through coping skills, techniques or strategies. It was also determined that dependents and family systems aid in supporting caregivers confidence and understanding in the patient's care plan. Ultimately this study identified the needs and strengths of dialysis caregivers and identified further suggestions for future research and studies.

APPENDIX A
QUESTIONNAIRE

Survey for caregivers of dialysis patients who are family members

Please circle your answers

For the caregiver:

What is your age?

18-20

21-40

41-60

61-80

81+

What is your ethnicity?

Caucasian/white

African American

Asian/Asian American

Latino/Hispanic

Native American or Pacific Islander

Other.....

Prefer not to say

What is your household income?

\$13,590 or less

\$13,591-\$23,030

\$23,031-\$33,000

\$33,001-\$43,000

\$43,001 Plus

What is your employment status?

Full-time

Part-time

Seeking opportunities currently

Retired

Never worked

Prefer not to say

On average, how many hours do you work a week?

0

1-10

11-20

21-30

31-40

40+

How Many dependents do you have?

- None
- 1-2
- 3-4
- More than 4
- Prefer not to say

On a scale rate, your stress level?

1-10

What services do you provide?

Check all that apply.

Housekeep/Laundry/Shopping/Meal prep/ Medication reminders/Personal hygiene
Transportation/Attend Doctor Visits/Phones calls/ Medical Advocacy/ Medical Decisions/Help with mobility/Companionship/Financial accountability/reporting and monitoring/ making appointments/

Did you receive training for becoming a caregiver?

Yes or no

How confident do you feel in medical terminology?

- Extremely confident
- Somewhat confident
- In-between
- Not confident

How confident do you feel in understanding the patient's care plan?

- Very Confident
- Confident Neutral
- Less Confident
- Not confident at all

How much care do you provide for the patient in hours?

Fill in the blank

How do you cope with the stress of being a caregiver? Ex: reading, naps, playing sports

Fill in.

Do you get days off to relax to take time for yourself?

Yes or no

About the Patient:

Does the patient have insurance?

Yes

No

Do not qualify

Are they mentally capable of making their own decisions?

Yes or no

Does the patient work?

Yes or no

Does the patient work?

Full-time

Part-time

Seeking opportunities currently

Retired

Never worked

Disabled

How long has the patient been on dialysis?

Less than a year

1-5 years

6-10 years

11-20 years

21+ years

Self-Care Scale

For Caregiver:

Scale 1-4

1-Never

2-Rarely

3-Sometimes

4-Often

5-Regularly

1. I permitted myself to feel my feelings. Ex: I allowed myself to cry.
2. I experience meaning and/or a larger purpose in my work/home life.
3. I spent time with people who were good to me. Ex: Support, encourage, and believe in me.
4. I feel supported by people in my life.

Cook-Cottone, C.P.(2015).Mindfulness and yoga for embodied self-regulation: A primer for mental health professionals. New York, NY: Springer Publishing.

APPENDIX B
INFORMED CONSENT

Informed Consent

The study in which you are asked to participate is designed to examine seeks a better understand the caregiver's role in dialysis patient's care, the burden of care of caregiving and how these caregivers manage and cope with their active roles in dialysis patient's care. The study is being conducted by Amelia Murillo and Alyssa Bousquet, graduate students, under the supervision of to be determined, in the School of Social Work at California State University, San Bernardino (CSUSB). The study has been approved by the Institutional Review Board at CSUSB.

PURPOSE: The purpose is to examine This study seeks to better understand the caregiver's role in dialysis patient's care, the burden of care of caregiving and how these caregivers manage and cope with their active roles in dialysis patient's care

DESCRIPTION: Participants will be asked of a question about services they provide, personal information and brief description of daily tasks provided.

PARTICIPATION: Your participation in the study is totally voluntary. You can refuse to participate in the study or discontinue your participation at any time without any consequences.

CONFIDENTIALITY: Your responses will remain confidential, and data will be reported in group form only.

DURATION: It will take 5 to 10 minutes to complete the survey.

RISK: Although not anticipated, there may be some discomfort in responding to some of the questions. The respondents are not required to answer all the questions and have the option to skip any questions that are perceived to be uncomfortable to the participant. The participant will not be reprimanded for choosing to skip a question.

BENEFITS: There will not be any direct benefits to the participants. However, findings from the study will contribute to our knowledge in this area of research.

CONTACT: If you have any questions about this study, please feel free to contact Dr.

Thomas Davis via email: tomdavis@csusb.edu

RESULTS: Results of the study can be obtained from the Pfau Library ScholarWorks database (<http://scholarworks.lib.csusb.edu/>) at California State University, San Bernardino after July 2024.

APPENDIX C
PARTICIPATION FLYER

RESEARCH PARTICIPANTS NEEDED



ELIGIBILITY

Eligible participants are caregivers of dialysis patients, who are currently caring for patient's receiving or have received dialysis treatment while under their care.

DESCRIPTION OF STUDY

This study seeks to better understand the caregiver's role in dialysis patient's care, the burden of care of caregiving and how these caregivers manage and cope with their active roles in dialysis patient's care. The data collected from this research project will help provide a better understanding of how to best support caregivers and help to explore how policies can be made more effective.

- Participants will be asked to complete a 30-minute survey.
- The survey is anonymous. No identifying information will be obtained or used in the survey.
- Participation is completely voluntary. Participants may choose not to answer questions, and may skip over questions. Participants can withdrawal participation at any time.
- This research study has been approved by both the CSUSB Institutional Review Board (IRB#) and the primary investigator/research supervisor, Dr. Tom Davis

INTERESTED

If interested please see link bellow to participate.

https://csusb.az1.qualtrics.com/jfe/form/SV_bD6f77eOrxemu7Y

If you have any further questions regarding this research study please contact Amelia Murillo (003943146@coyote.csusb.edu) or Alyssa Bousquet (005511996@coyote.csusb.edu). Should you have a further questions regarding this project, please contact the project's supervisor and primary investigator Dr. Tom Davis (909-537-3839 or tomdavis@csusb.edu)

APPENDIX D
IRB APPROVAL

Date: 11-5-2023

IRB #: IRB-FY2023-50

Title: Caregivers of Dialysis patients among family members

Creation Date: 9-13-2022

End Date:

Status: **Approved**

Principal Investigator: Thomas Davis

Review Board: Main IRB Designated Reviewers for School of Social Work

Sponsor:

Study History

Submission Type	Initial	Review Type	Exempt	Decision	Exempt
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Key Study Contacts

Member Alyssa Bousquet	Role Co-Principal Investigator	Contact alysb303@coyote.csusb.edu
Member Amelia Murillo	Role Co-Principal Investigator	Contact muria305@coyote.csusb.edu
Member Thomas Davis	Role Principal Investigator	Contact tomDavis@csusb.edu
Member Thomas Davis	Role Primary Contact	Contact tomDavis@csusb.edu

REFERENCES

- Alshammari, B., Noble, H., McAneney, H., Alshammari, F., & O'Halloran, P. (2021, September 14). *Factors associated with burden in caregivers of patients with end-stage kidney disease (a systematic review)*. Healthcare (Basel, Switzerland). Retrieved September 21, 2022, from <http://www.ncbi.nlm.nih.gov/pubmed/34574986>
- Azman A, Jamir Singh PS, Sulaiman J. The mentally ill and their impact on family caregivers: A qualitative case study. *International Social Work*. 2019;62(1):461-471. doi:10.1177/0020872817731146
- Ballard, J., Wieling, E., Solheim, C., & Lang, D. (2020, May 18). The double ABC-X model of family stress. In *Parenting and family diversity issues*. (pp. 93-94). Iowa State University Digital Press. DOI: <http://doi.org/10.31274/isudp.8>
- Belasco, A., Barbosa, D., Bettencourt, A. R., Diccini, S., & Sesso, R. (2006). *Quality of life of family caregivers of elderly patients on hemodialysis and peritoneal dialysis*. American journal of kidney diseases: the official journal of the National Kidney Foundation. Retrieved September 21, 2022, from <http://www.ncbi.nlm.nih.gov/pubmed/17162150>
- California Medical Power of attorney form (HCPOA)*. California Medical Power of Attorney Form | CA MPOA (HCPOA). (n.d.). Retrieved May 18, 2022, from <https://powerofattorneycalifornia.net/medical-power-of-attorney-form-california/>

Calvin, A. O., Engebretson, J. C., & Sardual, S. A. (2013). Understanding of advance care planning by family members of persons undergoing hemodialysis. *Western Journal of Nursing Research*, 36(10), 1357–1373. <https://doi.org/10.1177/0193945913514637>

Centers for Disease Control and Prevention. (2018, April 30). *Advance Care Planning and Chronic Disease Management*. Centers for Disease Control and Prevention. Retrieved May 19, 2022, from <https://www.cdc.gov/aging/advancecareplanning/index.htm>

Clay, A. M., & Parsh, B. (2016, January 1). Patient- and family-centered care: It's not just for Pediatrics anymore. *Journal of Ethics | American Medical Association*. Retrieved May 16, 2022, from <https://journalofethics.ama-assn.org/article/patient-and-family-centered-care-its-not-just-pediatrics-anymore/2016-01>

Cohen, S. and Williamson, G. *Perceived stress in a probability sample of the united states*. Spacapan, S. and Oskamp, S. (Eds.) *The Social Psychology of Health*. Newbury Park, CA: Sage, 1988.

Cook-Cottone, C. P. (2015). *Mindfulness and yoga for embodied self-regulation: A primer for mental health professionals*. New York, NY: Springer Publishing.

Estimated glomerular filtration rate (egfr).(2022). National Kidney Foundation. Retrieved September 21, 2022, from <https://www.kidney.org/atoz/content/gfr>

- Fordyce, M. (Ed.). (n.d.). *Caregiver health*. Caregiver Health - Family Caregiver Alliance. Retrieved May 18, 2022, from <https://www.caregiver.org/resource/caregiver-health/>
- Fresenius Medical Care. (n.d.). *At the Dialysis Center*. Nephrocare. Retrieved September 21, 2022, from <https://www.nephrocare.com/about-us/covid-19-update/at-the-dialysis-centre>
- Health Care Power of attorney*. Centers for Dialysis Care. (n.d.). Retrieved May 18, 2022, from <https://www.cdcare.org/patient-resources/health-care-power-of-attorney/>
- Kidney disease*. Kidney Disease | Education | DaVita Kidney Care. (2022). Retrieved March 10, 2022, from <https://www.davita.com/education/kidney-disease>
- Kidney failure, end-stage kidney disease (ESKD) or end-stage renal disease (ESRD)*. American Kidney Fund. (2021, November 17). Retrieved March 11, 2022, from <https://www.kidneyfund.org/all-about-kidneys/kidney-failure-end-stage-kidney-disease-eskd-or-end-stage-renal-disease-esrd>
- Neighbour RH. (1985). The family life-cycle. *Journal of the Royal Society of Medicine Supplement*, 78(8), 11-15.
- Newby, N.M. (1996), Chronic illness and the family life-cycle. *Journal of Advanced Nursing*, 23: 786-791. <https://doi-org.libproxy.lib.csusb.edu/10.1111/j.1365-2648.1996.tb00052.x>

- Pereira, B.S., Fernandes, N.S., Pires de Melo, N., Abrita, R., Grincenkov, F. and 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 and Quality of Life Outcomes*, 15(1), 74–74. <https://doi.org/10.1186/s12955-017-0646-4>
- Sajadi, S. A., Ms, Ebadi, A., PhD, & Moradian, S. T., PhD (2017). Quality of life among family caregivers of patients on hemodialysis and its relevant factors: A systematic review. *International Journal of Community-Based Nursing and Midwifery*, 5(3), 206–218.
- Schulz, R., & Eden, J. (2016). Appendix H. In *Families caring for an aging america* (pp. 339–340). The National Academies Press.
- State of California Health and Safety Code. (1995). *Patient Access to Health Records*. (123100-123149.5). Chapter 415, section 8. https://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?lawCode=HSC§ionNum=123100.
- Shiue I, Sand M. (2016). Quality of life in caregivers with and without chronic disease: Welsh Health Survey, 2013. *Journal of Public Health*, 39 (1), 34-44. doi: 10.1093/pubmed/fdv210.
- Tunajek, S. (2010). Understanding Caregiver Stress Syndrome. *AANA Journal*, 64(10), 22–23.
- U.S. Department of Health and Human Services. (n.d.). *Kidney Disease Statistics for the United States*. National Institute of Diabetes and Digestive and

Kidney Diseases. Retrieved September 21, 2022, from
<https://www.niddk.nih.gov/health-information/health-statistics/kidney-disease>

Your FIRST30 checklist - american kidney fund. American Kidney Fund. (n.d.).

Retrieved September 22, 2022, from
<https://www.kidneyfund.org/sites/default/files/media/documents/new-to-dialysis-checklist.pdf>

Zastrow, C. H. and Kirst-Ashman, K. K. (2016). *Understanding human behavior and the social environment.* Boston: Cengage Learning.