FAMILY SUPPORT IN RELATIONS TO THE WELL-BEING OF DIALYSIS PATIENTS

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FAMILY SUPPORT IN RELATIONS TO
THE WELL-BEING OF DIALYSIS PATIENTS

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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
Fabiola Rodriguez
Yesenia Ornelas

June 2020
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THE WELL-BEING OF DIALYSIS PATIENTS

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Approved by:

Dr. Armando Barragan, Faculty Supervisor, Social Work
Dr. Armando Barragan, M.S.W. Research Coordinator
ABSTRACT

When recently diagnosed with a chronic illness, individuals face various challenging events that require social support. Nephrology social workers are expected to increase the psychosocial functioning and adjustment of individuals diagnosed with End Stage Renal Disease (ESRD). Limited studies are available regarding patients with ESRD, social support, and quality of life. This research was intended to explain the effect of familial support on the quality of life of patients diagnosed with ESRD. The research was measured by utilizing a mixed method design with convenience sampling of nephrology social workers employed at inpatient dialysis centers. Participants engaged in the study by completing a questionnaire. Once completed, the data gathered was statistically analyzed through both correlation and content analysis. The findings urged social workers to promote social support in efforts to increase patients’ standard of living.
DEDICATION

Coming into the field, I did not know much about medical social work. Interning at DaVita and working on this research project allowed me to develop a passion in working with patients diagnosed with End Stage Renal Disease.

I was able to expand my knowledge and area of expertise to a vulnerable population, which helped me learn a lot about myself. I am grateful for this experience because I was able to work with patients that demonstrated appreciation, genuineness, and shared their positive outlook on life.

A huge thank you to my number one supporter, my husband, I cannot thank you enough. Thank you for believing in me. Without your support and encouragement, I would not be where I am today. You are my rock! Thank you for editing all my papers! I love you!

To my family, thank you for your unconditional love and support. Los quiero! Gracias mami por enseñarme a luchar por lo que quiero. Todos mis logros son dedicados a ti.

Yesenia, my research partner, what can I say. I am so glad I met you through this program. We are so alike in many ways and I am so fortunate to have you in my life. Thank you for being my partner!

Dr. Barragan thank you for your patience and assistance throughout this journey.

Fabiola Rodriguez
DEDICATION

To my husband, Anthony, thank you for pushing me to be better every single day. You saw potential in me when I failed to do so. You have been a constant source of encouragement and motivation throughout my grad school journey. I love you to the moon and back.

To my mom and dad, thank you for shaping me into the woman I am today and raising me to believe that with hard work anything is possible. Los quiero mucho.

To my uncle, Jesse. I wish there was more I could’ve done throughout your fight with end stage renal disease. Your battle led me to the field of social work and for that I am forever thankful. You have been my source of inspiration for this research project.

To my research partner, Fabiola, I am so glad I got to meet you during orientation! I feel like I have known you forever. I am excited to see you grow and accomplish all your goals as a professional.

Last but not least, to Dr. Barragan, our research advisor. Thank you for your patience and dedication throughout this experience.

Yesenia Ornelas
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CHAPTER ONE
PROBLEM FORMULATION

Introduction

Individuals on dialysis face many challenges throughout their treatment. Getting diagnosed with renal failure and having to start a life filled with various changes gets difficult not just for those affected, but also for their family members (Avşar et al., 2015). Dialysis comes with a variety of life changes including diet, work, travel, activities of daily living, and spending most of their days for hours in the hospital. As such, the patient’s quality of life becomes a significant barrier to the different treatment’s patients can undergo when on dialysis (Li et al., 2016). Although there are home treatments available to the patients, many are afraid of the repercussions that come with getting treated at home and the burden it will cause on their caregivers (Walker et al., 2015).

Given the intensity of dialysis treatment, receiving support from family members or hospital staff is beneficial for the patients who are already facing many challenges (Avşar et al., 2015). There are common mental health disorders associated with a renal failure diagnosis like anxiety and depression amongst both the caregivers and patients (Avşar et al., 2015; Li et al., 2016). Previous research has found that lower family support is often associated with the client’s lower obedience to the prescribed hemodialysis length and staying consistent with diet and other lifestyle changes that are required for the well-being of the
client (Untas et al., 2011). Family members need to be taking care of their own well-being in order to adequately assist and support their affected loved one (Gilbertson et al., 2019). Caregivers experience various levels of mental and emotional burdens when assisting their family member who is on dialysis.

Research has demonstrated the importance of providing support to the families who experience exhaustion in order to appropriately assist their loved ones (Chan et al., 2016). For this reason, understanding the effect familial connectedness has on dialysis patients is important for social work practice. Social workers require awareness of the barriers to treatment in order to alleviate stress and improve the standard of living of their patients. Existent research has focused on older patients who experience dialysis, but there is little information on the challenge’s individuals in middle adulthood face when on dialysis.

A present problem that affects social work practice is the services provided are more inclined towards the patients rather than family inclusion. Clinics are more geared to the physical well-being of the client and lack the encouragement of family integration. This can give the idea that the patients have to go through dialysis on their own. Current social workers provide families and patients with mental and emotional assistance when in a dialysis center. At the micro level, the findings educated social workers on the difficulties patients experience. This enabled social workers to support better policies aimed at improving the quality of life of the patients. Current policies are aimed more
towards challenging California’s dialysis centers rather than focusing on the patients.

Purpose of the Study

The overall purpose of this study was to educate social workers, patients, and families about the effect support has on dialysis patients. Past research has demonstrated the benefits of having a support system in helping increase an individual’s well-being (Plantinga et al., 2010). Presenting patients with options on increasing their quality of life with minimal resources is important. Families have the ability to assist in the betterment of their loved ones by just being present. The results of this study are specifically geared towards patients who are on dialysis. The research assisted nephrology social workers better understand the importance of encouraging familial support when patients are recently diagnosed with End Stage Renal Disease (ESRD) and the lifestyle changes that come with this diagnosis.

Given the limited studies available on this topic, the findings attempted to explain the effect of having a supportive family on the patients’ well-being. The best way in going about this research was to receive current nephrology social workers’ input on how they perceived their patient’s health with a good support system in comparison to those who tend to be less supported. By completing a questionnaire and analyzing quantitative and qualitative data the research provided essential knowledge to further improve dialysis treatments. Utilizing this
surveying method allowed for anonymity and it shed light on issues impacting patient well-being. These results yielded knowledge on delivering adequate resources to patients and families.

Significance of the Project for Social Work Practice

This research is necessary to improve patient outcome when being diagnosed with ESRD. The aim of this research was to allow social workers to provide patients with better resources. For example, this can encourage social workers to create support groups within the center to include family members and loved ones to increase patient well-being. The results provided social workers with the knowledge and skills to best support younger dialysis patients who experience mental and emotional burdens while engaging in treatment for their kidney failure. The study provided insight on social worker values which can aid in the enhancement of their programs. Social workers will advocate for better services to their dialysis patients in efforts to minimize the complications faced. Social workers will be better equipped during the entire intervention process as they will learn what questions to ask during the assessment and know what to include during the planning, implementation, and evaluation procedure. Learning about the importance of sustenance will guide social work practice to being family/patient centered.

It is important for professionals working with dialysis patients to acknowledge and encourage social support as a way of promoting well-being.
Social relationships have the power to improve treatment success by decreasing levels of comorbidity, access to medical services, and increasing the willingness of a patient to follow through with their treatment plan (Cohen et al., 2007). The research question “How does family connectedness/ support impact a dialysis patients’ quality of life as perceived by social work professionals?” provided insight to the social work profession and increased awareness on the importance of social support.
CHAPTER TWO
LITERATURE REVIEW

Introduction

This section will present a literature review on current research focusing on ESRD. Although the number of individuals affected with renal failure is rising, there is still a limited amount of research dedicated to this topic. The literature review will center on the diagnosis itself, caregiver support, social support, poverty and racial disparities, and mental health. These topics are needed to further explain the effect of relationships on the standard of living in the perspective of a social worker. Past research has found that the diagnosis of ESRD is interconnected with a reduced quality of life of both the caregiver and the patient by increasing their likelihood of affecting their mental health. As such, it was beneficial to utilize past studies to guide the research on identifying the effect social support has on patients’ quality of life. The theories guiding this research include Person-in-Environment (PIE) Theory and Maslow’s Hierarchy of Needs which will be discussed in this section.

Renal Failure Diagnosis

Renal failure diagnosis is associated with various factors that decrease the well-being of those affected. Individuals are no longer able to enjoy the same activities they did prior to their diagnosis (Li et al., 2016). Those diagnosed with
renal failure are prone to mental health diagnoses such as anxiety and depression (Avşar et al., 2015; Li et al., 2016). They are likely to experience a decreased quality of life associated with the treatment (Avşar et al., 2015). As such, it is beneficial for these individuals to rely on their family members and social supports to undergo dialysis. Unfortunately, this study focused mainly on anxiety and depression and did not account for other illnesses that may arise with kidney failure.

Previous studies have demonstrated that the differences in dialysis treatments may affect the patients and caregivers differently. Home-based dialysis tends to be associated with better quality of life in those affected and their caregivers (Avşar et al., 2015). However, home dialysis also intensifies the amount of patient responsibility on the caregiver (Avşar et al., 2015). For this reason, it is necessary for individuals to be highly educated on the treatments and burdens that come with dialysis.

Dialysis is a huge burden to the patient and families as it requires time, energy, and social support (Gilbertson et al., 2019). Given the intensity of treating renal failure, those involved in the process with the patients suffer from adverse consequences throughout the adjustment period. The high demands that come with caring for the patients increases the likelihood of mental and physical illnesses that impact the caregiver’s well-being (Avşar et al., 2015; Gilbertson et al., 2019). Few factors have been associated with the decrease in caregiver burden including being a spouse, having little education, and being employed
(Gilbertson et al., 2019). The age and gender of the caregiver tend to be risk factors for the caregiving of older patients (Gilbertson et al., 2019). Unfortunately, this study did not account for the necessary support caregivers should receive in assisting someone on dialysis (Gilbertson et al., 2019; Walker et al., 2015).

Caregiver Support

Research suggests that caregivers play a key role in caring for the affected individual (Gilbertson et al., 2019, 340). Irrespective of the type of dialysis patients undergo, caregiver support affects their well-being (Walker et al., 2015). Unfortunately, a lot falls back on the caregiver and patients recognize the burden they place on them when on dialysis (Walker et al., 2015). Prior investigations have urged professionals to increase the amount of resources and support available to the caregivers (Chan et al., 2016). Although these findings are relevant with the significant impact support has on the caregiving process and betterment of patients on dialysis, not enough research has focused on patients having that caregiver with them every step of the way. Future research needs to focus on the social support aspect patients receive from their families and/or friends. An increase in caregiver support is related to a decrease in risk factors accompanying caregiving (Chan et al., 2016). Providing supportive individuals with resources and support groups is found to have led to better physical and mental health outcomes (Chan et al., 2016). Thus, leading to better patient outcomes (Chan et al., 2016).
Social Support

Perceived support from loved ones is believed to have increased benefits on patients’ health. However, the relationship of social support with health outcomes continues to be an understudied problem in relation to dialysis treatment. While other studies have focused on social support with a variety of other health conditions including cancer and heart disease, studies specific to end stage renal disease are limited (Plantinga et al., 2010). A few other studies that have analyzed the impact of social support among dialysis patients have solely focused on the effect of social support by examining mortality rates among patients (Plantinga et al., 2010). By shifting the study’s focus to include other perceived forms of health-related quality of life factors such as hospitalizations and patient satisfaction, health care professionals can aid in the full journey of the patient. Prior research has demonstrated a positive correlation between social support and patient outcomes with lower mortality rates, yet the methods by which it impacts healthcare remain understudied (Cohen et al., 2007). Higher levels of social support in end stage renal disease has previously been associated with higher compliance rates, lower risk for depression, and an increased immune system (Plantinga et al., 2010).

Poverty and Racial Disparities

ESRD is a global health complication that affects individuals of all races and economic backgrounds. However, prior research has found poverty and
racial disparities in regard to both prevalence and mortality rates (Nicholas et al., 2015). Access to prevention care prior to the progression of end stage renal disease seems to be closely associated with lower rates of mortality (Nee et al., 2017). There is a noted relation between lower income patients and less successful outcomes. The relationship may stem from a lack of proper healthcare including the accessibility to insurance (Nicholas et al., 2015). Due to a lack of healthcare support and resources available to the low-income population, it has been discovered that it creates disparities in the kidney transplant wait listing process (Patzer et al., 2009). Kidney failure and end stage renal disease affects individuals of all nationalities and socioeconomic backgrounds, yet higher mortality rates and placement on a kidney transplant list have been linked to low income and among patients of minority groups.

Mental Health in Patients on Dialysis

While kidney failure and end-stage renal disease primarily affect the physical aspect of the patient, the challenges that come with the illness also affects the individual's psychological state. Patients undergoing dialysis face many challenges which increase the probability that they develop depression or anxiety, the most common comorbid illnesses in individuals with kidney failure (Feroze et al., 2010). It is estimated that up to 70% of dialysis patients who experience depression and anxiety symptoms fail to recognize the need for professional help for their mental health condition (Shirazian et al., 2017).
Research has found that a team approach that includes professionals within the medical field and mental health department, in addition to the family, are related to a higher compliance with the treatment of the mental health condition (Feroze et al., 2010). While research on mental health in regard to kidney failure disease is still sparse, there is hope that with the help of a support system, individuals will be encouraged to reach out to receive professional assistance and improve their mental well-being.

Theories Guiding Conceptualization

Two potential theories that guided this research included both the Person-in-Environment (PIE) Theory and Maslow’s Hierarchy of Needs. The Person-in-Environment Theory describes how different aspects of the environment manipulate how a person thinks, feels, or acts (Zastrow & Kirst-Ashman, 2016). Interactions between different systems like friends, family, education, work, and society are factors that affect an individual and influence the person at different levels (Zastrow & Kirst-Ashman, 2016). A study applying the PIE Theory to person-centered care among nursing home residents found that those factors surrounding the patients including relationships between family, staff and other residents were fundamental in improving the patient’s quality of life overall (Koren, 2010). Taking into consideration the different demands that individuals encounter, another study found that protective factors such as family support and resources positively impacted the resilience-stress relationship (Fletcher &
Sarkar, 2013). For the purpose of this research the PIE Theory allowed the focus to be on the interaction people on dialysis have with their support system, main one being their family. This theory allowed social workers to have a perspective on the effect patient interactions with others have on their well-being. The PIE Theory guided this research in addressing any current gaps existent within the various systems dialysis patients interact with that affect their well-being.

In addition, Maslow’s Hierarchy of Needs provided guidance on this research. Per Maslow, there are five basic needs that individuals have to meet in order to advance to the next tier: physiological, safety, belongingness and love, self-esteem, and self-actualization (Zastrow & Kirst-Ashman, 2016). In order for someone to climb up the hierarchy to reach self-actualization they first must fulfill their physiological needs, safety, belongingness, and self-esteem (Zastrow & Kirst-Ashman, 2016). This theory related to this research as individuals on dialysis benefit from social support to increase their well-being. Maslow’s theory has been utilized to analyze various topics in research, thus far including treatment of life-threatening diseases and mental health. A study analyzed patients diagnosed with a life-threatening type of cancer under Maslow’s hierarchy as the theoretical lens and found a revolving theme for the need of psychological and social support (love and belonging) during treatment as the two most important aspects to patients (Moore et al., 2013). Further, a study analyzing the intersection between mental health rehabilitation and Maslow’s theory found that patients had in fact a desire to reach self-actualization and
achieve recovery (Henwood et al., 2014). The study found that patients’ basic needs must be first met before undergoing recovery, including that of having current support and improving quality of relationships that already exist (Henwood et al., 2014). These empirical findings support Maslow’s hierarchical theory that love and belonging, including the importance of their support system, is an important aspect in reaching self-actualization in terminally ill patients. Relationships with others are needed to help them achieve well-being. This research intended to understand the effect these relationships have on dialysis patients’ health and promote a supportive environment with the inclusion of family and friends during treatment. Maslow’s theory helped guide this current research in discovering better ways of increasing patient well-being.

Summary

The literature review explored family connectedness in relation to the overall well-being of patients diagnosed with chronic illnesses. Within the context of other terminal illnesses such as cancer, prior research found a positive correlation among social support and increased health of the patient. However, the power of relationships specifically on dialysis patients, remains understudied. Additionally, the literature reviewed suggests that having social support is related to a decrease in mortality among patients; however, further research allowed the exploration on how social support affects quality of life factors including lower rates of mental illness, patient satisfaction and patient compliance to treatment.
CHAPTER THREE
METHODS

Introduction

The purpose of this section is to provide information on how the research was conducted. This part of the paper will review the study design utilized to investigate this topic. Additionally, it will provide information on the sampling method used to recruit participants. Another section will be designated to address the data collection and provide information on the instruments utilized to perform the research. Moreover, the procedure of the study will be discussed by providing further insight on the process of gathering of information. A brief explanation on the protection of the participants will be provided. This section will conclude with the description on how the data will be analyzed.

Study Design

The study sought to explain the relationship between receiving support from family members and the effect on the health of dialysis patients. As such, this was an explanatory study. This study obtained the social workers’ perspective regarding family connectedness and social support with their patients undergoing dialysis.

Given the source of this study, the type of design that best addressed this problem was a mixed methods design. A mixed methods design allowed for the
collection of both qualitative and quantitative data. For this reason, the plan was to provide a scale that measured family connectedness from the social workers' perspective, with a few open-ended questions to further gather information regarding the effect of perceived support on the patients. The questions provided the researchers with a common theme, while the scale offered ratings that determined the urgency and significance of the issue.

A strength of this design was that it allowed social workers to respond truthfully because it was based off their own perception. The social worker’s perspective has not yet been studied within the field of nephrology; therefore, the gathered information provided social workers with insight on family-centered treatment for dialysis patients. A limitation to this research included bias as the research was solely focused on nephrology social workers at DaVita facilities. Being that research participants were recruited at the agency’s semi-annual social worker divisional meeting, there was a possibility of participants not partaking in the study due to the lack of rapport or prior relationship with the researchers.

**Sampling**

The target population for this research was primarily nephrology social workers working with patients diagnosed with end stage renal disease at DaVita clinics within the Counties of Riverside and San Bernardino. Given that the research focused on dialysis patients, social workers became essential in
relaying their perception on familial support and patient health. The sample came from the chosen agency. Approval was requested in advance from the divisional lead social worker at the agency. Social workers interact with the patients and families every day and are aware of the issues that affect patients’ health. As previously mentioned, given the specifics of the study, the sample was chosen through non-probability purposive sampling. With the assistance of the agency, the total number of participants was 45. The data collection and instruments made it feasible for this number of individuals to participate in the research. Since data was collected in the form of a questionnaire, this allowed for easy and fast delivery of the data instruments and allowed participants to answer in a short amount of time.

Data Collection and Instruments

Since the study’s focus is based on the social workers’ perspective, the best data source was collected from them. In this mixed methods study, the independent variable was family connectedness as measured by the score on the Family Connectedness Scale, while the dependent variable was the patient’s quality of life as perceived by the social worker measured by the score on the Family Connectedness Scale. Given that both the independent and dependent variables were measured by the scale, the levels of measurement for both variables were interval. Demographic variables that were measured included gender (nominal), age (ratio), race/ethnicity (nominal), education level (nominal),
years in social work field (ratio), years in current position (ratio), and personal experience with an individual diagnosed with ESRD (nominal). The data collection technique was the Family Connectedness Scale created by the student researchers utilizing a questionnaire.

The questionnaire included demographic information, personal and professional experience, and was designed using a Likert-type scale containing 5 varying responses to choose from in order to get the most accurate results pertaining to the subject being studied. The options included 5-strongly agree, 4-agree, 3-neither agree nor disagree, 2-disagree, and 1-strongly agree. The researchers found this a valuable instrument in order to explain the relationship between social support and quality of life of patients by utilizing social workers’ perception. Both researchers collaborated in the formation of the instrument by coming up with questions pertaining to both social support and quality of life.

In order to ensure the survey instrument produced data that was reliable and valid, researchers analyzed the inter-rater reliability of the data collection instrument. Researchers did this by seeking the evaluation from a mentor working within the field of nephrology and their research supervisor. This was done to verify that both raters agreed in the quality of the instrument created and that it allowed for precise representations of the variables measured. Some issues that arose with these collection techniques included social desirability, acquiescence bias, and leading questions. The participants may believe there is a better way to respond to questions and end up answering that way. Others may
not be reading the questions and just answer in a pattern. The questions asked may also appear to be guiding the participant to respond a certain way. However, in order to combat these issues, the researchers varied the questions and asked open-ended questions for the participants to fill out. This allowed social workers to answer truthfully which is a strength of this instrument.

Some questions that were asked included: How do you value family support? What effect does family connectedness/support have on the patients’ health? How can social workers encourage social support within a dialysis center? Confidentiality was the number one priority and was addressed by having anonymous questionnaires.

Procedures

As aforementioned, the data was gathered in the form of a paper questionnaire that was given to the participants. The participants were solicited at the semi-annual divisional social worker meeting that took place on December 9, 2019. At this meeting, the social workers at DaVita were asked to participate in this research and received the informed consent as well as the questionnaire. Participants were informed that partaking in this study was optional and they were able to skip any question they did not feel comfortable answering. The questionnaire took no more than five to ten minutes to complete including the informed consent. The responses were collected by the researchers once the participants completed them.
Protection of Human Subjects

For the purpose of this study, the participants within this research design was limited to only include social workers employed at outpatient dialysis clinics within the chosen agency. Participants were provided with a document explaining the topic discussed, the potential risks and benefits of participation and the purpose of the research study. Likewise, participants were allowed to refrain from the study at any point, if needed, by submitting their questionnaire. Furthermore, each participant read and signed an informed consent explaining that anonymity would be guaranteed. For the purpose of maintaining the confidentiality of the participants, an “X” was required instead of a signature. In addition, no participant identifiers were collected throughout the research study. The questionnaire was taken in person and participants were given time to complete the forms anonymously. Once finished, the questionnaires were collected by the researchers themselves. To conclude the survey, participants were thanked for their time and cooperation and were provided with a short statement on the purpose of the study and impact within the nephrology field. The gathered data was maintained and protected in a locked cabinet at one of the researcher’s residence. The data was saved on an excel spreadsheet within the University’s Google Drive, which features password encryption and can only be accessed using the student’s login information. Research data will be stored for one year upon completion of the study, after which, the data will be deleted.
Data Analysis

The data collected was analyzed using mixed method measures. For the quantitative data, correlation analysis was used to examine if there was a relationship between the independent and dependent variable. A correlation between the independent variable identified as family connectedness and the dependent variable being quality of life of the patient was analyzed, thereby answering the research question. Furthermore, descriptive statistics was conducted to identify the demographic profile of respondents including gender, age, race/ethnicity, education level, years in social work field, years in current position and personal experience with an individual diagnosed with ESRD.

For the qualitative data, content analysis was utilized to identify major themes or keywords. Examples of concepts that arose as factors that contribute to the well-being of the patients are family support, financial support and legal status.

Summary

This study analyzed the perception amongst social workers pertaining to the relationship between social support and the impact on the well-being of dialysis patients. For optimal results, the research study utilized a mixed methods design through non-probability purposive sampling using a paper survey. Data collected enhanced the field of nephrology by providing a better understanding of the effect of a positive family relationship for dialysis patients during the
treatment process. The findings of the study contributed to possible integration of family support groups or increased family inclusion into the patients’ care plan.
CHAPTER FOUR
RESULTS

Demographics

Descriptive Statistics

Descriptive statistics were analyzed including gender, age, race/ethnicity, education level, months in social work field, months in current position, and personal experience with an individual diagnosed with ESRD. The participants included 50 social workers working with dialysis patients in Riverside and San Bernardino Counties. The mean age of the respondents were 36.7 years (SD=8.24), with 107.3 months in the social work field (SD=81.70) and 53.38 months in their current position (SD=43.34). The participants consisted of 46 females and 5 males. Participants had diverse ethnic and racial backgrounds including Hispanic/Latino, Caucasian, African American, and Asian American. Each participant had a master's in social work. 66% of study participants identified as having had a personal experience with a loved one being diagnosed with ESRD. From those who had a personal experience related to ESRD, 93% believed that having family support improved the well-being of the individual diagnosed with ESRD. The participants had an average of 107 months (9 years) working within the field of social work and an average of 53 months (4 years) working in their current position as nephrology social workers.
Presentation of Quantitative Findings

The research question explored in the study was how family connectedness, as perceived by nephrology social workers, affect the quality of life of dialysis patients. Given that the data collected was both qualitative and quantitative, it was necessary to utilize mixed method measures. A bivariate Pearson correlation analysis was utilized for the quantitative data which examined the relationship between family connectedness and quality of life of the patient. A Pearson correlation coefficient found a strong, positive relationship between family connectedness and quality of life of a patient, $r=0.610$, $n=47$, $p=0.00$, with high levels of family connectedness associated with high quality of life of a patient. These findings indicate that per social workers’ perceptions, the higher family support and connectedness is associated with higher quality of life among patients.

Included in the questionnaire were questions regarding social worker perception on how a strong support system affects a patient's wellbeing. Respondents were given a scale (1-5) ranging from strongly disagree to strongly agree for each statement. For the statement “Patients with a strong support system have a better quality of life than those lacking support”, an astounding 47 out of 50 (94%) participants answered strongly agree (50%) or agree (44%). Social workers were then asked how having a strong support system affects the compliance rate of a patient undergoing dialysis treatments. In the statement “Having a strong support system leads to client compliance with treatment”
nearly three fourths of the respondents (74%) chose strongly agree (32%) or agree (42%). Student researchers were interested in obtaining the social workers' perspective on the inclusion of Family Integrated Care within dialysis centers and the benefit this may pose to patients. The related statement “Patients would benefit from Family Integrated Treatment” resulted in the majority (84%) of respondents answering strongly agree (38%) or agree (46%). In closing, social workers were asked how they may value social support if they were in their patients’ shoes, with the statement “If I were in the patient role, I would highly value social support.” An impressive 96% of respondents selected strongly agree or agree. Data findings allow student researchers to conclude that nephrology social workers in fact do believe family connectedness is essential in the care and success of their patients.

Presentation of Qualitative Findings

Factors contributing to the well-being of patients

Content analysis was utilized to distinguish the major factors that contribute to the quality of life of patients with ESRD. Taken from the qualitative portion of the data, some factors that were found to contribute to the well-being of the patient include support, resources, education, and self-motivation.

Support

Out of the 50 survey’s collected, 43 participants (86%) responded to the question about factors that contribute to the well-being of the patient. Out of the
43 respondents, 29 (67%) believed that support was a main contributor to the well-being of the patients. Support was defined in various forms including social, family, community, caregiver, financial, friend, and clinical staff support. Social workers from the agency deemed it necessary for patients to have someone they can rely on to help with their ESRD diagnosis.

*Resources*

Resources came in second with a total of 21 of participants (42%) reporting that patients should receive some form of assistance while on dialysis. Patients should receive appropriate access to certain things they lack in order to improve their well-being. Such resources included “mental health services, in-home support services, transportation, and no to low cost resources.”

*Education and Self-Motivation*

Furthermore, 16 (32%) of the participants believed that education and self-motivation helped improve the quality of life of the patients. Social workers perceived “having appropriate insight, awareness, and control of their feelings” allows for them to understand more about their diagnosis. These factors, plus being educated on ESRD gives patients the appropriate tools to make well-informed decisions on their care and treatment which leads to medication adherence, diet/ treatment compliance and the ability to cope through this process. Patients having “positive coping mechanisms” leads them to have a better quality of life.

*Family Involvement*
Similarly, out of the 50 responses received, only 38 (76%) of individuals provided feedback on the areas where patients should receive some form of support during their treatment. Although a third of the participants, 10 (26%) perceived support as very important for patients diagnosed with ESRD, they did not provide feedback in regard to the area they should be involved in during treatment.

*Entire treatment*

The findings established that the participants believe family involvement should happen throughout the entire patient’s treatment. The majority of participants 29 (76%) believed that support is needed during the entire treatment process including “medical appointments, care plans, the initial treatment, and when discussing any medical/treatment options like modality, transportation, dietary restrictions, fluid restrictions, transplant, and medications.”

*Education phase*

From the 38 participants, 9 (24%) argued that involvement is necessary during the education phase of the diagnosis. Family members become the support for many patients on dialysis and it is important to involve them throughout the education process to help patients feel supported and cared for. The patient’s support system should “understand the diagnosis and receive ESRD education.”
CHAPTER FIVE

DISCUSSION

Introduction

This section will offer a brief discussion on the results presented by the research study regarding the significance familial support has on patients’ well-being. There will be a succinct explanation on whether the results are in line with past studies. The paper will then provide a concise description on the limitations of this research study. The section will conclude with recommendations for social work practice, policy, and further research.

Discussion

The research question offered a new perspective to nephrology social workers who are dedicated to serve ESRD patients. Granted the results of this study, familial support is believed to have a positive impact on the quality of life of individuals diagnosed with a chronic illness. Through this research, it was established that there is a strong positive correlation between familial connectedness and a patients’ quality of life. These results indicated the significance of patients having some type of support to adjust and cope with their illness. The purpose of this research was to explain the relationship between familial connectedness and the well-being of patients. Per the social workers who
participated in the study, it was determined that patients rely on their support system to manage their diagnosis.

This research paved the way and expanded on prior ideas that encourage familial support for patients experiencing a chronic illness in order to positively impact their well-being. Prior research has focused mainly on cancer patients and there was minimal information regarding patients diagnosed with ESRD (Plantinga et al., 2010). Furthermore, this study corresponded with other findings that demonstrated the benefits of having familial support for patients in regard to their medication/treatment compliance, their mental health and increased well-being (Plantinga et al., 2010). Current social workers have realized the significance of family integration in patient treatment to lead to an increase in the quality of life of patients. These social workers have recommended family members or supports to be there with the patient throughout the entire treatment process.

Limitations

There were several limitations that were faced throughout the process of the research study including sample size, sample convenience, social desirability and method. The total number of participants was determined on the location the research was conducted. All social workers were employed within Riverside and San Bernardino Counties, which may affect the degree of the generalizability of the findings and may not be representative of social workers working in other
geographical locations. Given that the focus was on nephrology social workers at a specific out-patient agency the study failed to include other social workers who work with ESRD patients in other medical settings including hospitals and clinics.

Another limitation of this study is the possibility of participant and researcher bias. In regard to the student researchers, it is possible that when creating the Family Connectedness Scale, the questions were formulated in a way that could have led the participants to respond in ways that were favorable to the results. Concerning participant bias, the questionnaire allowed the participants to remain anonymous, however it is possible that they felt inclined to answer with responses that are socially acceptable and favorable.

The method of collecting data was paper based which also limited the number of respondents. Additionally, the paper-based questionnaire included two short answer questions to collect qualitative data, however participants could have limited their answers in writing versus speaking in an in-person interview.

Recommendations for Social Work Practice, Policy, and Research

The intent of this research was to identify changes that out-patient dialysis centers can implement with their patients diagnosed with ESRD. Current services provide patients with the necessary tools to adjust and cope with their diagnosis. However, even though support is expected, agencies are not very inclusive with families. For example, families are not expected to be included throughout the entire treatment. They are not required to be present or make decisions for a
patient who is fully capable of understanding and making decisions. In addition, family members are not educated in the lifestyle changes the patient will endure while on dialysis. However, the findings demonstrate the importance of having a family member there with the patient throughout the entire process.

The results have provided nephrology social workers and other agencies who work with patients diagnosed with ESRD with information on bettering their services provided. The hope of these results was to allow social workers to understand the need to advocate for and encourage more family involvement in healthcare settings and provide patients/families with better resources. One recommendation is to establish support groups for families and patients to assist when recently diagnosed with ESRD. There are limited support groups focusing on ESRD patients and it would be beneficial for out-patient agencies to consider creating such groups. Another recommendation is to encourage social workers to include family members throughout the entire treatment planning, assessment, implementation, and evaluation phases in order best address patient needs and increase their well-being. Family integration is very important and necessary for the well-being of chronic patients.

Future research should consider patient perspectives. While the perspective of nephrology social workers provided valuable insight and guidance into the effect of family connectedness on a patient’s wellbeing, direct patient feedback would allow for more accurate findings. Additionally, it would be a
valuable asset to further explore social support from the patient’s family perspective.

Conclusion

This study was conducted to further understand social workers’ perceptions on the effect of family connectedness on the quality of life of dialysis patients. A mixed study was conducted in which researchers gathered data from 50 social workers working in the dialysis field using the Family Connectedness Scale.

The findings revealed that family connectedness and support are in fact important in enhancing a patient’s quality of life while on dialysis. These results can aid in the improvement of care and services offered by dialysis clinics, by promoting family integrated care. Additionally, dialysis patients can greatly benefit from the incorporation of support groups and education classes for family members. It is important to acknowledge that the inclusion of social support in the treatment plan process can lead to increased physical and mental well-being of dialysis patients. The findings of this study pave the road for future research examining the influence of family connectedness and support to the well-being of dialysis patients.
APPENDIX A

DATA COLLECTION INSTRUMENT
1. What is your gender?
   a. Female
   b. Male
   c. Other

2. What is your age?
   __________

3. What is your race/ethnicity? (Circle all that apply)
   a. White
   b. Black or African American
   c. Hispanic/Latino
   d. American Indian or Alaskan Native
   e. Asian American/Pacific Islander
   f. Other (please specify) __________________________

4. What is the highest degree you have received?
   a. Master of Social Work (MSW)
   b. Doctor of Social Work (DSW)
   c. Other (please specify) __________________________

5. How long have you been working in the social work field?
   __________

6. How long have you been working in your current position?
   __________

7. I have had a personal experience with at least one individual (family member, friend, self) who has been diagnosed with End Stage Renal Disease.
   a. Yes
   b. No

8. If yes, I/the individual had a support system who helped me/them adjust and cope with the diagnosis?
   a. Yes
   b. No

9. If yes, having support allowed for my/their well-being to increase?
   a. Yes
   b. No

For the following questions please indicate how much you agree with the statements below utilizing the scale where 1=Strongly Disagree, 3=Neither Agree Nor Disagree, and 5=Strongly Agree.
<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree (1)</th>
<th>Disagree (2)</th>
<th>Neither Agree Nor Disagree (3)</th>
<th>Agree (4)</th>
<th>Strongly Agree (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. My Social Work education has prepared me to work with End Stage Renal Disease (ESRD) patients.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. My agency has prepared me to work with ESRD patients.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. I do not feel prepared to work with patients diagnosed with ESRD.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. It is important for me to have support in times of need.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I feel like a burden on my family when I ask for assistance.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. My patients receive all the support and care needed to cope with their diagnosis from their families.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. My patients do not receive adequate support and resources.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. The agency provides patients with the necessary resources to support them and increase their quality of life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Patients with a strong support system feel less of a burden on their families.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Patients with a strong support system have a better quality of life than those lacking support.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. Patients would benefit from Family Integrated Treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21. Having a strong support system leads to client compliance with treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
22. Feeling supported decreases the likelihood of patients feeling depressed or anxious.

23. If I were a in the patient role, I would highly value social support.

24. Patients and families would benefit from support groups within the agency.

For the following questions please let us know what you think about those topics.

25. What factors do you think contribute to the well-being of the patients?

26. What areas do you consider important for a patient's support system to be actively involved in during treatment?
APPENDIX B

INFORMED CONSENT
INFORMED CONSENT

The study in which you are asked to participate is designed to examine the perception social support has on dialysis patients as perceived by social workers in a dialysis center. The study is being conducted by Fabiola Rodriguez and Yesenia Ornelas, graduate students, under the supervision of Dr. Armando Barragan, Assistant Professor 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. You have been selected to participate because you have been identified as a DaVita Dialysis social worker attending the semi-annual social worker divisional meeting.

PURPOSE: The purpose of the study is to examine the perception familial support has on dialysis patients.

DESCRIPTION: Participants will be asked a few questions on topics including demographics, the perceived effect of familial support on patient health and outcomes, and current resources offered to patients.

PARTICIPATION: Your participation in the study is completely 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.

RISKS: Although not anticipated, there may be some discomfort in answering some of the questions. You are not required to answer and can skip the question or end your participation.

BENEFITS: There will not be any direct benefits to the participants. Your participation will help improve the understanding of how familial support impacts the health and quality of life of patients, and the importance of the incorporation of a patient’s support system to his or her treatment.

CONTACT: If you have any questions about this study, please feel free to contact Dr. Barragan at (909) 537-3501.

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 2020.

I understand that I must be 18 years of age or older to participate in your study, have read and understand the consent document and agree to participate in your study.

Place an X mark

Date
APPENDIX C

IRB APPROVAL LETTER
December 6, 2019

CSUSB INSTITUTIONAL REVIEW BOARD
Administrative/Exempt Review Determination
Status: Determined Exempt
IRB-FY2020-94

Fabiola Rodriguez-Gonzalez Armando zzzDELETED_Barragan, Yesenia Ornelas
CSBS - Social Work
California State University, San Bernardino
5500 University Parkway
San Bernardino, California 92407

Dear Fabiola Rodriguez-Gonzalez Armando zzzDELETED_Barragan, Yesenia Ornelas

Your application to use human subjects, titled “FAMILY SUPPORT IN RELATIONS TO THE WELL-BEING OF DIALYSIS PATIENTS” has been reviewed and approved by the Chair of the Institutional Review Board (IRB) of California State University, San Bernardino has determined that your application meets the requirements for exemption from IRB review Federal requirements under 45 CFR 46. As the researcher under the exempt category you do not have to follow the requirements under 45 CFR 46 which requires annual renewal and documentation of written informed consent which are not required for the exempt category. However, exempt status still requires you to attain consent from participants before conducting your research as needed. Please ensure your CITI Human Subjects Training is kept up-to-date and current throughout the study.

The CSUSB IRB has not evaluated your proposal for scientific merit, except to weigh the risk to the human participants and the aspects of the proposal related to potential risk and benefit. This approval notice does not replace any departmental or additional approvals which may be required.

Your responsibilities as the researcher/investigator reporting to the IRB
Committee the following three requirements highlighted below. Please note failure of the investigator to notify the IRB of the below requirements may result in disciplinary action.

- Submit a protocol modification (change) form if any changes (no matter how minor) are proposed in your study for review and approval by the IRB before implemented in your study to ensure the risk level to participants has not increased,
- If any unanticipated/adverse events are experienced by subjects during your research, and
- Submit a study closure through the Cayuse IRB submission system when your study has ended.

The protocol modification, adverse/unanticipated event, and closure forms are located in the Cayuse IRB System. If you have any questions regarding the IRB decision, please contact Michael Gillespie, the Research Compliance Officer. Mr. Michael Gillespie can be reached by phone at (909) 537-7588, by fax at (909) 537-7028, or by email at mgillesp@csusb.edu. Please include your application approval identification number (listed at the top) in all correspondence.

If you have any questions regarding the IRB decision, please contact Michael Gillespie, the Research Compliance Officer. Mr. Michael Gillespie can be reached by phone at (909) 537-7588, by fax at (909) 537-7028, or by email at mgillesp@csusb.edu. Please include your application approval identification number (listed at the top) in all correspondence.

Best of luck with your research.

Sincerely,

Donna Garcia

Donna Garcia, Ph.D., IRB Chair
CSUSB Institutional Review Board

DG/MG
REFERENCES


ASSIGNED RESPONSIBILITIES

This research project was completed as a joint effort by student researchers Fabiola Rodriguez and Yesenia Ornelas. The composition of the questionnaire and data collection were completed collaboratively by both researchers. The composition of the 5 chapters: introduction, literature review, methods, results and discussion were evenly divided among both members. Each section was divided into equal responsibilities and completed by the assigned member. Both student researchers participated in any revisions and agreed to the submission of the final copy.