QUALITY OF LIFE AMONG HEMODIALYSIS PATIENTS: EVALUATING THE KDQOL-36 AND ITS UTILITY IN CLINICAL PRACTICE

by

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(Under the Direction of Larry Nackerud)

ABSTRACT

Quality of Life among dialysis patients can have an impact on health outcomes. Patients undergoing hemodialysis face obstacles and intrusions into daily life that can compromise their quality of life. The Kidney Disease Quality of Life (KDQOL) is a popular health-related quality of life survey used with dialysis patients and has undergone several revisions leading to the KDQOL-36. The KDQOL-36 is both a general and disease-specific health quality of life survey and has been identified by the Center for Medicare and Medicaid Services (CMS) as the preferred survey for use by dialysis providers. However, research is limited on the KDQOL-36 and its utility in clinical practice. This dissertation, reported in three manuscripts, provides a review of the KDQOL-36 and attempts to answer if there are patient attributes that contribute to KDQOL-36 scores and if KDQOL-36 scores provide indication of clinical outcomes.

INDEX WORDS: Hemodialysis, KDQOL, KDQOL-36, Dialysis, Quality of life, ESRD, Kidney disease

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DEDICATION

To Donald R. Phillips – the man that once got a credit card that accidently said “Dr.” due to your initials and claimed jokingly to be a doctor. You chose to make me part of your life and your amazing heart taught me love and empathy long before entering Social Work. Your unwavering support throughout my life enabled this moment. Almost a year has passed and I wish more than anything you were here to be celebrate with me.   Here’s to you, “Dr.” Phillips. You will always be my hero.

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The undertaking of a doctoral degree is a journey not taken in isolation. Many contributing factors and people pave the road and assist in countless ways. Time and resources are demanded and often taken from other arenas in life. Sacrifices are made not only by the sojourner, but also by those in their life. While impossible to acknowledge all that have contributed to arriving at this point, several people must be noted.

Though they are both gone, my parents provided a loving home and the support needed to engage in graduate work. First in 1999 when I decided to pursue a MSW degree and again in 2006 when I began my doctoral endeavor. However, life and time march forward outside of the toil of academics and I lost them both during this program. I know that I would not be who I am today without the love they both shared, nor would I have the foundation for the life I am building. There are not enough words to express my love and my thanks for all that they contributed. I wish they could celebrate this occasion with me.

Along with losing both parents, I also went through a divorce during the program. I'm not sure what in life, apart from losing a child, could be more painful. However, I also met an amazing woman and started a new life. Erica graciously gave of her time and often provided the needed encouragement to not drag my feet, or I should say stop dragging my feet, during this dissertation. The occasional push and reminder of why I started the program in the first place kept the train from derailing. I cannot imagine that I would have finally arrived at this point without her love and support.

Occasionally you are lucky enough to connect with the people you work with. During this program, I was working full time and had the pleasure of making friends with David Zablocki. He embodies a quality and true friend. On top of enjoyable times of relaxing and unwinding outside of work, he also lent countless hours to learn a bit about SPSS and assist with data entry. His friendship and aide during this process was invaluable and motivated me to keep pressing forward.

My committee changed several times over the program due to members relocating and developing their careers in academia. Dr. Stacey Kolomer, my first Chair, helped me get prepared for my comprehensive exams and build my committee before moving to UNC. Dr. Brian Bride guided me get through those comps and is now at Georgia State University. Dr. Larry Nackerud graciously agreed to come on board when Dr. Kolomer left and again graciously agreed to serve as Chair when Dr. Bride left. Dr. Nackerud’s laid back personality created a sense of comfort and support as his vast experience in academia provided the guidance needed to complete the program. I also appreciate Dr. Tiffany Washington’s willingness to join the committee shortly after arriving at UGA and her contributions when discussing research with dialysis patients and the direction of this dissertation study.

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Finally, I want to thank Dr. Kirti Shah for allowing me to use data from his dialysis company for the purposes of this study. I hope that the research findings presented here will assist his and other dialysis clinics in their work with ESRD patients. Many others played a role over the years and I want to thank all that have gone unnamed yet provided support and encouragement during this long journey. The journey has finally ended and it is time to celebrate!

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CHAPTER 1

INTRODUCTION AND OVERVIEW

The purpose of this research project was to study the quality of life among hemodialysis patients by evaluating the Kidney Disease Quality of Life-36 (KDQOL-36) and its utility in clinical practice. This introduction and overview will begin by presenting the prevalence of End Stage Renal Disease (ESRD) in the United States and some of the attributes of the dialysis population. Followed by discussing the problem of non-adherence to treatment regimens among hemodialysis patients, quality of life among hemodialysis patients, the role of a nephrology social worker, and the KDQOL-36.

ESRD, Prevalence and Population

End Stage Renal Disease is a chronic illness in which the kidneys have declined in functioning to a point that can no longer sustain life. Once a person has been diagnosed with ERSD they are placed on dialysis, a treatment that performs work normally carried out by the kidneys. While there are two modalities of dialysis, hemodialysis and peritoneal dialysis, this paper will be focusing on the hemodialysis population. Hemodialysis is a treatment for kidney failure in which a dialysis machine performs work the kidneys are normally responsible for, the removal of toxins from the blood stream that accumulate from daily life activity and the removal of excess fluid from body. Treatments are often performed three times per week on a set schedule (Browne, 2006 & NIH, 2006).

The United States Renal Data System (USRDS) is a national data system that collects, analyzes, and distributes information about end-stage renal disease (ESRD) in the United States.

The USRDS is funded directly by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). USRDS staff collaborates with members of Centers for Medicare & Medicaid Services (CMS), the United Network for Organ Sharing (UNOS), and the ESRD networks, sharing datasets and actively working to improve the accuracy of ESRD patient information (USRDS, 2016).

According to the United States Renal Data Systems report from 2016, as of December 31, 2014 there were 678,383 people on dialysis with 63.1% of those individuals on hemodialysis (USRDS, 2016). Of the hemodialysis population, 120,688 were new incidents (USRDS, 2016). Along racial and ethnic demographics for ESRD prevalence, the USRDS (2016) reports that in 2014 the prevalence for black/African Americans was the highest among racial groups being 3.7 times greater than their White counterparts. Hispanics were represented at 35% higher rate compared to non-Hispanics regarding new incidence of ESRD (USRDS, 2016). Though kidney disease effects all racial and ethnic groups, Hispanics and black/African American groups are over represented in the ESRD population, which may be explained by health disparities among minority groups (Phillips, Briggs, & Washington, 2017).

Medical advances have created life sustaining treatments for kidney failure, however individuals on dialysis are faced with regimented treatment and medication schedules, strict diet and fluid restrictions, and symptoms that impose on day to day life.

> Hemodialysis is a complex therapy that regulates electrolytes and removes waste products. To avoid excessive accumulation of electrolytes and waste products, patients are prescribed a therapeutic diet that frequently limits fluid, phosphorus, sodium and potassium. Understandably, nonadherence to these strict fluid and dietary limitations is common in patients on dialysis (Dowell & Welch, 2006, p. 271).

The following section will begin to outlay the problem of nonadherence in dialysis patients by outlining and discussing the following areas where adherence is critical to health outcomes: treatment, treatment duration, renal diet, fluid restrictions, and compliance with phosphorus binders.

Nonadherence

There is little consensus on the definition of adherence. Terms such as ‘compliance’, ‘adherence’, and ‘concordance’ have been used interchangeably (Bosworth, Weinberger, & Oddone, 2006; Hearnshaw & Lindenmeyer, 2006). Adherence is used to describe the extent to which people follow through with agreed or prescribed actions or do what providers expect them to do (Zweben & Zuckoff, 2002). While dialysis treatments can be provided by clinics, it is up to the individual to attend those treatments, stay for their full treatment time, following a renal diet, follow fluid restrictions, and take their medications as prescribed. “Although healthcare professionals provide information about the therapeutic regimen and advise patients to adhere to it, it is patients themselves who have to implement the items included in the regimen. It is therefore important to understand the level of adherence from patients’ perspectives” (Lam, Twinn, & Chan, 2009).

Non-compliance with renal diet, fluid restrictions, treatment schedule, medications and treatment times are an ongoing issue in working with dialysis patients. Dobrof, J., Dolinko, A., Lichtiger, E., Uribarri, J., & Epstein, I. (2001) reported that 27 to 31% of patients missed one treatment per month, 35 to 41% of patients did not receive their full treatment due to signing off early, and 76 to 85% of patients had difficulty following the renal diet. Research suggests that about 50% of dialysis patients are noncompliant with their treatment regimens (Bame, Peterson, & Wray 1993; Sherman, Cody, Matera, Rogers, & Solanchick, 1994; Leggat, Orzol, Hulbert-

Shearon, Golper, Jones, Held, & Port, 1998; Baines & Jindal, 2000). “Compliance problems compromise renal patients’ opportunity to achieve maximal physical well-being on dialysis therapy and may have very serious long-term consequences” (Kutner, 2001, p. 324). Non-adherence can be present in several behaviors critical to successful life on dialysis and it governed by decisions and actions made by the patient. The areas of non-adherence are: 1.) attending scheduled treatments (this is most often three times per week on a set schedule), 2.) remaining at treatment and receiving the full prescribed treatment time (this may range from three to slightly over four hours), 3.) following a renal diet (avoidance of foods that have high phosphorus content), 4.) medication compliance (in this case, specifically phosphorus binders that are taken with each meal to prevent the body from absorbing some of the phosphorus that is present in the food eaten), and 5.) following the fluid restrictions (limiting the amount of fluid that is consumed on a daily basis, so that excess fluid is not being retained in the body) (Baines & Jindal, 2000 & Bleyer, Hylander, & Sudo, 1999).

Treatment

Since the kidneys are no longer functioning at levels high enough to sustain daily life, individuals with End Stage Renal Disease must receive regularly scheduled dialysis treatment. Hemodialysis patients that miss treatments or shorten treatments have an increased risk of mortality (Leggat et al, 1998; Kimmel, Peterson, & Weihs, 1998; Bleyer, Hylander, & Sudo, 1999). Obstacles for attending treatment can be issues with transportation, work or family schedule conflicts, and the desire to skip treatment (Baines & Jindal, 2000 & Bleyer, Hylander, & Sudo, 1999). While both Medicare and Medicaid will provide transportation for qualifying patients (cms.gov), some patients that do not or are unable to drive have to rely on friends and/or family to bring them to their scheduled treatments.

For those patients that do not have Medicaid and do not qualify for Medicare funded transportation, the burden and expense of travel to treatments can be high. The use of self-pay medical transport or taxi services (for ambulatory individuals) can be expensive considering the frequency of treatments. The frequency of treatments can also prove to be a burden on family and friends that agree to transport an individual to treatment and can interfere with their scheduled routines. With many patients on limited or fixed incomes, the family and social network becomes a critical component in the success of their treatments.

Treatment Duration

While getting to treatment is step one, step two is remaining at treatment for the full duration as prescribed by the nephrologist. Treatment duration can vary depending on the height and weight of an individual, their behaviors outside of treatment, and the efficiency of their access (Browne, 2006 & NIH, 2006). Though some individuals may only need three hours of treatment, other can need four hours or more (Browne, 2006, Dobrof et al., 2000 & NIH, 2006). Much like attending treatments, the duration of treatment can impose burdens on the individual and care givers. The treatment schedule and duration may not allow for an individual to maintain their current job or may make it difficult to acquire employment (Brown, 2006).

Renal Diet

Lee & Molassiotis (2002) found rates of non-compliance with fluid and dietary restrictions among dialysis patients were to be 60-65%. Detrimental outcomes can result from non-adherence with dietary and fluid restrictions, such as cardiovascular deterioration, heart failure, hypertension, edema problems, itching, bone pain, and shortness of breath (Brady, Tucker, Alfino, Tarrant, & Finlayson, 1997; Durose, Holdsworth, Watson, & Przygrodzka, 2004; Lee & Molassiotis, 2002). Following a renal diet is also important in individuals with ESRD as it helps to control the amount of phosphorus that accumulates in the blood stream between dialysis treatments (Browne, 2006 & NIH, 2006). Changing dietary patterns can be a burden on both the patient and caregivers (Lubkin & Larsen, 2006, Browne, 2006 & NIH, 2006). This can involve learning to cook new foods and finding alternatives to foods that are enjoyed. Non-adherence to renal diets can be cause by many factors: ability to prepare foods, dependence on others for meals, education level to understand renal diet materials, income level to purchase foods, and access to grocery stores. Those individuals living in a rural location may have less access to options that would be wise choices than those living in more urban locations. Socio-economic status can greatly impact the individual’s ability to spend money on foods and to acquire groceries that are within the guidelines of a renal diet (Bame, Peterson, & Wray, 1993, Browne, 2006 & NIH, 2006). Foods that are inexpensive and prove multiple meals, such as grains and beans, are often items that are high in phosphorus and should be avoided.

Compliance with Phosphorus Binders

Though concise choices when eating and following a renal diet can greatly affect phosphorus levels in the body, the use of medication to further control phosphorus levels is also important (Browne, 2006 & NIH, 2006). Phosphorus binders taken with meals block some of the phosphorus from being absorbed during digestion. These binders are prescribed to be taken with each meal and snack that is consumed. In conjunction with following a renal diet, phosphorus binders assist in keeping phosphorus levels within healthy ranges. Though there is a great benefit to taking these binders as prescribed, there are also obstacles for individuals intending to be compliant: the cost of medications can be expensive even with prescription coverage, getting in the habit and being prepared to take medication with each meal, managing medication for those unable to do so for themselves, having multiple pills to take on a daily basis, and access to pharmacies for refills (Baines & Jindal, 2000, Bleyer, Weinberger, & Oddone, 2006, Brown, 2006).

Fluid Restrictions

Along with strict dietary restrictions, the dialysis patient also must manage how much fluid they take in daily to avoid various health problems and complications during dialysis treatment.

> Because of their inability to effectively produce urine, patients have very strict fluid restrictions, as little as 48 ounces per day. Otherwise, excess liquid will build up and cause the patients' extremities to swell and their lungs to fill with fluid. Extreme weight gains between dialysis treatments can lead to high blood pressure and discomfort during hemodialysis, and removal of excessive fluid results in severe cramping and low blood pressure (Browne, 2006, p. 477-478).

Because the removal of excess fluids from the body is one of the functions that the kidneys would normally perform, individuals on dialysis must be conscious of the amount of fluid they consume daily (Browne, 2006 & NIH, 2006). Educating patients about what is considered fluid intake and the amount that is permissible is an important step, as is helping patients find creative ways to satisfy thirst without consuming large amounts of fluid. Challenges for patients attempting to follow the allowed amount of daily fluids include learning to monitor the amount of fluids they consume, finding alternatives to fluids that have high sodium or phosphorus levels, and being able to monitor fluid intake even during times of physical exertion and during warmer climate (Brady, Tucker, Alinfo, Tarrant, & Finlayson, 1997, Dowell & Welch, 2006).

Discussion

Leggat et al. (1998) reported that patients that were noncompliant in one area had significantly higher odds of being noncompliant in other areas. Though adherence in these areas in largely in the control of the patient and governed by choices they make, some populations and areas may face different challenges (Kimmel, Peterson, Weihs, Simmens, Alleyene, & Cruz, & Brown, 2006). Those individuals living a rural setting may have fewer options for transportation and restaurants, and the local grocery stores may have a more limited selection. Individuals with lower income can find purchasing the groceries or meals that are within a renal diet outside of their budget and can be forced to rely on friends and family for transportation needs. The cost of medications can also be an obstacle to compliance for those without prescription coverage or with limited or low income. It can also be more difficult for those that depend on others for meal preparation to follow a renal diet. With compliance being a vital role in the success of the patient, while also being largely in the patient's control, it is easy to see the importance of the social worker's role. Working with the patients and dialysis staff to encourage compliance, motivate behavioral change, and assist in overcoming barriers to compliance is critical.

Quality of Life

The World Health Organization has defined health as not simply the absence of disease, but a state of well-being physically, socially, and mentally. However, there is a subjective aspect to quality of life as each person's situation, experiences, and values can vary (Lubkin & Larson, 2006). Meaningful existence in the face of suffering, freedom to choose actions, happiness, satisfaction, beliefs, and self-efficacy can all influence an individual's perception of quality of life (Watson, 1985; Benner & Wrubel, 1989; Oleson, 1990; Stuifbergen, Seraphine, & Roberts, 2000).

Lubkin & Larson (2006) note that a patient's overall health and well-being may not be captured by assessments that focus only on clinical values and functioning ability. This concept is supported by research that has found that pain ratings in patients with rheumatoid arthritis corresponded more strongly than physical measures with the patient's perceived quality of life (Kosinki, Zhao, Dedhiya, Osterhaus, & Ware, 2000) and that medication compliance in patients with hypertension can gauged by quality of life assessments (Hollenberg, Williams, & Anderson, 2000). The health and functioning domain of quality of life is characterized by how an individual perceives their health status based on items such as stress levels, pain, self-efficacy, access and use of healthcare, and energy level (Lubkin & Larson, 2006). Compared with the general population, those with a chronic illness are associated with poorer health-related quality of life (Rothrock, Hays, Spritzer, Yount, Riley, & Cella, 2010; Maddigan, Feeny, & Johnson, 2005; Smith, Reeve, Bellizzi, Harlan, Kalbunde, Amsellem, Bierman, & Hays, 2008).

The demanding changes in life associated with a dialysis treatment regimen can create a sense of loss, grief, and feelings of being overwhelmed while the patient is adjusting to being on dialysis. Landsman (1975) defined illness intrusiveness as "the extent to which the illness and/or its treatment interfere with important facets of a patient's life" (p. 328). Illness intrusion is clearly seen in the demands of the dialysis treatment regimen. Sagawa, Oka, Chaboyer, Satoh, & Yamaguchi (2001) reported that treatment regimens, such as dietary and fluid restrictions, interfere with individuals being able to participate in desired social activities. Limitations associated with a dialysis treatment regimen can diminish one's ability to perform tasks required for work, hobbies, or day to day life. Restrictions in diet and fluid intake can force patients to give up foods and beverages they enjoy and at times require learning new recipes and methods for cooking that can be an increased burden on the patient, families, and care providers in the home. Assessing health-related quality of life can provide treatment providers with information on how patients perceive their current health status related to problems associated with an illness.

Measure that assess quality of life can be generic, disease-specific, or both. Generic measures attempt to capture how an individual perceives his/her status regarding health concepts relevant to everyone's health and well-being. The generic measures are more applicable across populations, but may not capture important aspects of a specific population. Specific statuses, such as the perceived burden of an illness or treatment side effects, can be assessed using disease-specific measures. The KDQOL-36 is an example of a measure that includes components of both.

Role of the Nephrology Social Worker

Social workers that practice in dialysis settings are referred to as both renal and nephrology social workers. The social worker assists those individuals on dialysis with overcoming obstacles and barriers that would otherwise compromise the individual's dialysis treatments, resulting in poor health outcomes. This can include adjusting to the treatment regimens, transportation problems, insurance problems, adherence issues, and addressing psychosocial factors that negatively impact treatment. The importance of this function in a dialysis setting is confirmed by a Federal mandate for dialysis clinics to have a social worker on staff. The Code of Federal Regulations §494.140 Condition: Personnel Qualifications:

> (d) Standard: Social Worker. The facility must have a social worker who –
>
> 1. Holds a master's degree in social work with a specialization in clinical practice from a school of social work accredited by the Council on Social Work Education; or

2. Has served at least 2 years as a social worker, 1 year of which was in a dialysis unit or transplantation program prior to September 1, 1976, and has established a consultative relationship with a social worker who qualifies under §494.140(d)(1) (DHHS, 2009).

This is the only area of practice in social work in which there is a Federal mandate for the presence of MSW level social worker.

Organizations, such as the National Kidney Foundation (NKF) and the National Association of Social Workers (NASW), that are specifically engaged in a nephrology or renal setting acknowledge the importance of the social worker on the multidisciplinary team. The mission statement for nephrology social work created by NASW/NKF is as follows:

> Nephrology social work services support and maximize the psychosocial functioning and adjustment of patients who are experiencing end-stage renal disease (ESRD) and their families. These services are provided to ameliorate social and emotional stresses resulting from the interacting physical, social, and psychological concomitants of ESRD, including shortened life expectancy; altered lifestyle with changes in social, financial, vocational, and sexual functioning; and the demands of a rigorous, time-consuming, and complex treatment regimen. Social work functions as a part of the multidisciplinary team and is responsible for fostering a positive treatment environment policy and routines that are attuned to cultural, religious, and ethnic differences among patients and families and show respect for the individuality, independence, and choice of each patient (NASW)

The nephrology social worker provides direct care to patients and their families while collaborating with the other members of the interdisciplinary team (nurse, doctor, and dietitian) to assist individuals on dialysis in reaching positive health outcomes and well-being.

KDQOL-36

With research indicating that higher quality of life is associated with less morbidity and a higher survival rate (Valderrabano, Jofre, & Lopez-Gomez, 2001), health-related quality of life is shown to impact patient's health outcomes and should be reviewed and monitored to optimize patient care. As I wrote in the manuscript, *The KDQOL-36: A health-related quality of life measure*, "Surveying health-related quality of life can provide insights into how an individual perceives his or her physical, mental and social well-being and the extent to which effects, burdens, and symptoms of an illness effect their lives" (p. 24). CMS has mandated that dialysis providers annually assess patients' quality of life and has created a Clinical Performance Measure (CPM) to evaluate compliance. The new CPM for HRQOL will measure the "*number of patients who complete a KDQOL-36 with or without assistance at least once/year out of the number of eligible prevalent dialysis patients (peritoneal dialysis, in-center hemodialysis, home hemodialysis)" (CMS, 2012).*

Originally developed by Hays, Kallich, Mapes, Coons, and Carter in 1994, the Kidney Disease Quality of Life (KDQOL) is a 134 item self-report quality of life survey that is designed to capture patient perspectives related to both disease specific and general health status. Since its development in 1994, two additional versions of the form have been created, the KDQOL-SF (80 items) and the KDQOL-36 (36 items). Each new version of the survey was shorter than the previous, attempting decrease the burden of completing the measure.

The initial version of the KDQOL constructed by Hays, et al. (1994), had the SF-36 at its core, a generic 36 item health survey, in conjunction with additional items targeted at disease specific concerns. The KDQOL disease-specific items are: symptoms/problems of kidney disease (34 items), effects of kidney disease (20 items), burden of kidney disease (4 items), work status (4 items), cognitive function (6 items), quality of social interaction (4 items), sexual function (4 items), sleep (9 items), social support (4 items), dialysis staff encouragement (6 items), and patient satisfaction (2 items) (Hays et al., 1994).

The shortened KDQOL-36 version of the survey has the SF-12 as a core generic heath survey and retains the subscales of burden of kidney disease (4 items), symptoms of kidney disease (12 items), and effects of kidney disease (8 items) from the KDQOL-SF. The first twelve questions of the KDQOL-36 are the SF-12 followed by disease specific questions that comprise the three subscales taken from the KDQOL-SF. A Likert type range is used for each disease-specific question: burden of kidney disease subscale items uses the range “definitely true” to “definitely false” and symptoms of kidney disease and effects of kidney disease subscales items use “not bothered at all” to “extremely bothered” range.

Research

This research study aimed to test the psychometric properties of the KDQOL-36 by analyzing existing data composed of demographic information, psychosocial information, clinical values, and KDQOL-36 scores (see variable list). The data was retrieved from the Electronic Medical Records (EMR) at a privately-owned dialysis company that offers in-center hemodialysis and peritoneal dialysis to adult individuals with ESRD.

The Sample

The sample is composed of patients that completed the KDQOL-36 during the period of 7/1/2013 to 6/30/2014 at a privately-owned dialysis company. The company has a cumulative census of roughly 200 hemodialysis patients at six dialysis clinics. There were 120 completed surveys during this period, however four were not used in the study. Since the company only provides treatments to adults, the sample population is individuals 18 years old or older, with ESRD, and on prescribed hemodialysis three times per week.

The Data

The KDQOL-36 is given to all patients that have been on dialysis at least 90 days, with the exception of those that refuse, individuals with cognitive impairment, or in the absence of a survey in the appropriate language for non-English speaking/reading patients. The dialysis company in this study uses KDQOL-Complete (www.kdqol-complete.com) to score the KDQOL-36 in all six of its clinics. All individual answers to the survey are captured and five subscale scores are generated.

Data was collected at two points, the month the patient completed the KDQOL-36 and at a 3-month follow-up. Clinical values for each month include lab work, average interdialytic weight gain, missed treatments, shortened treatments, and hospitalizations. Out of the monthly lab work collected at the dialysis clinic, hemoglobin, adequacy, albumin, and phosphorus were gathered and used for the study. These clinical values will partially serve as indicators of adherence.

Table 1.1

Clinical Values & Treatment Utilization

Indicator	Clinical Value
Treatment	Number of missed treatments
Treatment duration	Number of shortened treatments
Fluid restrictions	Average interdialytic weight gain
Renal diet	Albumin level (lab work)
Renal diet	Phosphorus level (lab work)
Compliance with phosphorus binders	Phosphorus level (lab work)

Patient attribute data contained demographic information about each patient; age at the time the KDQOL-36 was taken, height, weight, race, gender, ethnicity, marital status, religion, employment status, and type of insurance(s). Along with this information, other patient attributes collected were: primary cause of renal failure, if the individual was under the care of nephrologist prior to initiating dialysis, how long the individual had been on dialysis at the time of taking the KDQOL-36, treatment duration, living arrangements, mobility, level of activity, primary language, access type, and co-morbid conditions. The co-morbid conditions that are included in this study are diabetes, hypertension, COPD, CHF, CVA, cancer, and a broader category “other cardiac disease” as labeled on CMS form 2728.

The Research Questions

There has been very limited research conducted on the KDQOL-36. Most of the existing research reports on the validity and reliability of longer versions of the survey, not the 36-question version. Also, though CMS initiated the requirement for dialysis centers to assess quality of life and have identified the KDQOL-36 as the preferred measure with dialysis patients, there has not been any research to provide insight into the clinical utility of the survey or discussion about relationships between patient attributes and KDQOL-36 responses and scores. This research seeks to fill gaps in existing research by critiquing the KDQOL-36 and attempting to answer the following research questions:

1. Do individuals with certain characteristics tend to score in specific ways on the KDQOL-36 subscales?
2. Are there relationships between the KDQOL-36 subscale scores?
3. Does the KDQOL-36 provide clinical utility that could inform hemodialysis staff to better ensure positive health outcomes for patients?

The Manuscripts

This research project is divided into three publishable manuscripts which will be presented over the next three chapters, followed by a chapter with an overall summary and conclusion. The first is a review of the KDQOL-36 survey. The remaining two manuscripts are data-driven pieces using the secondary data collected from the EMR of the dialysis company. One of the data-driven articles researches patient attributes compared to the KDQOL-36 scores and relationships between KDQOL-36 subscale scores. Building on that analysis, the second data-driven manuscript analyzes relationships between patient clinical values and KDQOL-36 scores. All three manuscripts will be submitted for publication post-graduation.

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Supplement 1

Information included in this research was gathered by conducting a review of the literature and prominent organizations in nephrology. The literature review was conducted by using Galileo through the University of Georgia library systems to search databases using key words (e.g. kidney, dialysis, adherence, quality of life, etc…). Databases from which articles were retrieved include: ProQuest, EBSCO, MEDLINE, ScienceDirect, and PsycINFO.

Supplement 2

Variable List:

Primary Cause of Renal Failure: the diagnosed cause that resulted in patients ESRD

Age: patients age at the time of the survey in years

Gender: patients gender at the time of the survey

Race: patient's race

Ethnicity: Hispanic/Not Hispanic

Height: patient's height in centimeters at the time of survey

Weight: patient's weight in kilograms at time of survey

First Date of Dialysis: length of time between first date of dialysis (FDoD) and survey

Treatment Duration: the length of time in minutes the patient dialyzed at time of survey

Living Arrangements: the patient's housing/family support at time of survey; (alone, with spouse and/or children, family member, or friend(s))

Marital Status: patient's marital status in relation to support at time of survey; (single, married, widowed)

Mobility: patient's level of mobility at time of survey; (ambulatory, wheelchair bound, stretcher or with some assistance from a device/person)

Level of Activity: the level of activity indicated by the patient during the time frame of the study and at the time of the survey (1: no activity to once per week, 2: twice to five times per week, and 3: on a regular basis)

Insurance: the insurance carrier that assisted with the payment for treatment at the time of survey (Medicare, Medicare & Medicaid, Medicaid, private or employer insurance, Tricare (military insurance))

Religion: patients declared faith/doctrine at time of survey

Language: patient's primary language spoken

Access Type: the type of access for hemodialysis at time of survey; (AV-Fistula, Graft, or Catheter)

Employment: patient's employment status at time of survey

Under care of Nephrologist: if the patient was seen/treated by a nephrologist prior to onset of ERSD

Co-Morbid Conditions: Diabetic, Hypertension, COPD, CHF, Other Cardiac Disease, CVA, Cancer

Days on dialysis at time KDQOL-36 was taken

KDQOL-36 individual answers

5 Subcategory scores

Categorical subscale scores

Clinical data collected at the month of taking the survey and at 3-month follow-up

Hemoglobin:

Purpose: To determine the amount of hemoglobin in red blood cells and screen for anemia.

Norm Range: In an adult, 12 to 18 grams per deciliter of blood.

Albumin:

Purpose: To detect a protein called albumin in the urine, which may indicate kidney damage.

Norm Range: 3.0 to 4.0

Phosphorus:

Purpose: To measure the levels of electrolytes (sodium, potassium, calcium, phosphorus) in the body that help move nutrients and waste in and out of cells.

Norm Range: 3.0 to 4.5 mg/dL

URR:

Purpose: To measure how much urea was removed during a hemodialysis session.

Norm Range: more than 65 percent.

Number of Missed Treatments

Number of Shortened Treatments

Number of Hospitalizations

Average Interdialytic Weight Gain

CHAPTER 2

THE KDQOL-36: A HEALTH-RELATED QUALITY OF LIFE MEASURE[1]

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[1] Phillips, R. L. (2017). Submitted to *Seminars in Dialysis*.

Abstract

The Kidney Disease Quality of Life (KDQOL) is a 134-question health-related quality of life survey that has been shortened twice resulting in the KDQOL-SF and KDQOL-36. The Medical Outcomes Study Short Form 36 (SF-36) comprises the general health core of both the KDQOL and the KDQOL-SF while the Medical Outcome Study Short Form 12 (SF-12) makes up the general health core of the KDQOL-36. Though the KDQOL-36 is the recommended quality of life survey to be used with dialysis patients, much of the existing research has be conducted using the longer versions. Additional research is need on the KDQOL-36 to better understand its psychometric properties and clinical utility.

Introduction

The Kidney Disease Quality of Life (KDQOL) is a measure designed to capture patient perspectives on their quality of life from a disease-specific and general health standpoint. The measure was first developed in 1994 and consisted of 134 items (Hays, Kallich, Mapes, Coons, & Carter, 1994). Since, the form has been shortened twice, creating the KDQOL-SF (80 items) and the KDQOL-36 (36 items), in an attempt to alleviate some of the burden of completing the measure. All three versions of the measure contain both generic health-related items and disease-specific items.

Health-related quality of life is an important aspect of the patient that should be considered and monitored when providing care to patients. The World Health Organization (WHO) has defined health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. Surveying health-related quality of life can provide insights into how an individual perceives his or her physical, mental and social well-being and the extent to which effects, burdens, and symptoms of an illness affect their lives. Research has found that there is a higher survival rate and less morbidity associated with higher quality of life (Valderrabano, Jofre, & Lopez-Gomez, 2001; Theofilou, 2013).

Quality of life measures can be generic, disease-specific, or both. Generic questionnaires assess health concepts that represent basic human values and are relevant to everyone's health status and well-being. Disease-specific measures assess the special states and concerns of patients with a given illness, for example, disease specific symptoms and/or side effects of treatment (Valderrabano et al., 2001; Theofilou, 2013). Generic measures are widely applicable and allow comparisons between different populations, however they may not be targeted or sensitive enough to capture clinically important changes in specific populations (Carmichael, Popoola, John, Stevens, & Carmichael, 2000). Surveys that utilize both generic and disease-specific components have been recommended by research to best assess quality of life in healthcare settings (Carmichael et al., 2000).

Medical Outcomes Study Short Form 36 (SF-36)

The Medical Outcomes Study Short Form 36 (SF-36) is a generic health-related quality of life measure that is comprised of 36 questions in eight dimensions: physical functioning (PF = 10 items), role limitations attributable to physical problems (RP = 4 items), bodily pain (BP = 2 items), perception of general health (GH = 5 items), vitality (VT = 4 items), social functioning (SF = 2 items), role limitations attributable to emotional problems (RE = 3 items), and mental health (MH = 5 items) (Braizer, Harper, Jones, O'Cathain, Thomas, Usherwood, & Westlake, 1992). Wight, Edwards, Brazier, Walters, Payne, & Brown (1998) found the SF-36 to have Cronbach's α's that range from 0.72 to 0.95 in the eight dimensions, with individuals with end stage renal disease. The SF-36 provides scores in each of the eight dimensions and two summary scores: Physical Component Summary (PCS) and Mental Component Summary (MCS). The

PCS score is created from the PF, RP, BP, and GH dimensions and the MCS score is created from the VT, SF, RE, and MH dimensions. Lii, Tsay, & Wang (2007) reported an $\alpha = 0.91$ for the PCS and $\alpha = 0.88$ for MCS with dialysis patients. Several studies have demonstrated an association between PCS and MCS scores with hospitalizations and death (Mapes, Lopes, Satayathum, McCullough, Goodkin, Locatelli, Fukuhara, Young, Kurokawa, Saito, Bommer, Wolfe, Held, & Port, 2003; DeOreo, 1997). Mapes et al. (2003) found that “patients in the lowest quintile of PCS had a 93% higher adjusted risk of death and 56% higher adjusted risk of hospitalization when compared to those in the highest quintile” (p. 345-346).

SF-12

Ware, Kosinski, & Keller (1996) analyzed data from two sources that used the SF-36, the National Survey of Functional Health Status (NSFHS) and the Medical Outcomes Study (MOS), to shorten the survey to 12 items (SF-12). “Forward-step regression analysis was used to identify a subset of 12 or fewer items from the SF-36 and 2 weighting algorithms for estimating PCS-36 and MCS-36” (Ware et al., 1996, p.221). Scoring the SF-12 results in two summary scales, as with the SF-36, the Physical Component Summary (PCS) and Mental Component Summary (MCS). “Correlations between SF-12 and SF-36 versions of PCS and MCS were 0.951 and 0.969, respectively, on cross-validation, and estimates of group means were consistently within 1 point” (Ware et al., 1996, p. 227).

Lacson, Xu, Lin, Dean, Lazarus, & Hakim (2010) compared the SF-36 and the SF-12 composite scores with patients on dialysis. The authors found that the PCS and MCS scores from the two measures showed excellent linear correlation, both with Pearson coefficients of 0.94 (Lacson et al., 2010). “Each incremental PCS-12 and PCS-36 point was associated with identical 2.4% lower adjusted HR [hazard ratio] of death and 0.4% decline in HR for first hospitalization (both $P < 0.0001$). Corresponding improvement in HR of death for each MCS point was 1.2% for MCS-12 and 1.3% for MCS-36, whereas both had a similar 0.6% lower HR for hospitalization per point (all $P < 0.0001$)" (Lacson et al., 2010, p. 255).

Kidney Disease Quality of Life (KDQOL)

While there are several measures that assess quality of life, the KDQOL is a widely used measure with individuals with kidney failure and on dialysis. Originally constructed by Hays, et al. (1994), the KDQOL is a self-report measure that has at its core the SF-36, a generic 36 item health survey, and is supplemented with items that target disease specific concerns among individuals with kidney disease and on dialysis. The KDQOL disease-specific items target symptoms/problems (34 items), effects of kidney disease (20 items), burden of kidney disease (4 items), work status (4 items), cognitive function (6 items), quality of social interaction (4 items), sexual function (4 items), sleep (9 items), social support (4 items), dialysis staff encouragement (6 items), and patient satisfaction (2 items) (Hays et al., 1994).

Hays et al. (1994) surveyed 165 dialysis patients from nine different dialysis centers using the KDQOL. Internal consistency reliability was reported for each disease-specific subscale and ranged from 0.68 to 0.94 and the SF-36 items had reported internal consistency reliability that ranged from 0.78 to 0.90 (Hays et al., 1994). Relative validity analyses demonstrated that kidney disease-targeted scales were among the most sensitive to known group differences in number of good days and bad days during a typical week (e.g., symptom/problems), rating of self compared to those without kidney disease (burden of kidney disease), and disability days (sleep and symptom/problems) (Hays et al., 1994, p. 337). Hays et al. (1994) recommended the use of the KDQOL as a quality of life measure in the study of patients with kidney disease and estimated the survey to take about 30 minutes to complete.

KQDOL-SF

The Kidney Disease Quality of Life – Short Form (KDQOL-SF) takes 43 kidney disease targeted items from the KDQOL and continues to use the SF-36 as a generic core. The disease-specific items of the KDQOL-SF focus on the concerns of dialysis patients by inquiring about symptoms, effects and burden of kidney disease on daily life, work status, social interactions, cognitive function, sleep, sexual functioning, social support, staff encouragement, and patient satisfaction (Hays, Kallich, Mapes, Coons, Amin, & Carter, 1997). These 43 items and the SF-36, as used in the full length KDQOL, create 79 items. The final item asks individuals to rate their perceived overall health on a scale from 0 - "worst possible" (as bad or worse than being dead), to 10 - "best possible health" (Hays et al., 1997).

Hays et al. (1997) created the subset of items by regressing the KDQOL scale scores on the items composing them and employing Goodnight's maximum R-squared improvement procedure. "This stepwise process was repeated for each scale until enough items were identified to account for approximately 90% of the variance in the long-form scale score" (Hays, et. al., 1997). Content validity was enhanced by adding six additional symptoms, three additional effects of kidney disease, one additional burden of kidney disease, and one item assessing the ability to work full-time. Internal consistency reliability for the disease-specific subscales ranged from 0.61 to 0.90 (Hays et al., 1997). The authors also report modifying some of the items that were selected for the KDQOL-SF. This 80-item version of the KDQOL takes about 16 minutes to complete according to the authors.

Reliability and validity testing of the KDQOL-SF in research has been limited and questioned. Glover, Banks, Carson, Marin, & Duffy (2011) note that the validation for the KDQOL was performed in comparison to the SF-36, providing a limited measure of validity. "Indeed, as the KDQOL is based around the SF-36, its validity can be brought into question" (Glover et al., 2011, p. 26). In their review of measures of quality of life used with patients on dialysis, Danquah, Wasserman, Meiniger, & Berstrom (2010), found that out of six studies using the KDQOL-SF only one reported evidence of reliability and none of the studies reported evidence of validity.

KDQOL-36

The KDQOL-36 uses the SF-12 as a core generic heath survey and the subscales of burden of kidney disease (4 items), symptoms of kidney disease (12 items), and effects of kidney disease (8 items) from the KDQOL-SF. The survey is constructed with the first twelve questions being the SF-12 followed by the three subscales taken from the KDQOL-SF. Each disease-specific subscale is set on Likert type range: burden of kidney disease ("definitely true" to "definitely false") and symptoms of kidney disease and effects of kidney disease ("not bothered at all" to "extremely bothered"). Few reports of internal consistency reliability of the disease-specific items could be found in existing literature using the KDQOL-36, though the three subscales taken from the KDQOL-SF have reported internal consistency reliability of: symptoms of kidney disease (0.84), effects of kidney disease (0.82), and burden of kidney disease (0.83) (Hays et al., 1997).

The KDQOL-36 is a self-report measure that according to Schatell & Witten (2010) takes about 10-15 minutes to complete. Schatell & Witten (2010) also note that the KDQOL-36 cannot be scored by hand because of the complexity of the weighting. Online scoring and reports can be conducted through KDQOL-Compete, which is a scoring service offered to clinics for a fee determined by the number of patients at a clinic (kdqol-complete.org). Each response to the 36 items is entered into the system, then scores and reports can be generated. This service provides a chart report for clinicians and the interdisciplinary team and a patient report that describes the five subscales of the KDQOL-36, the patient's scores, and suggestions for health and quality of life improvements. Patient scores are case-mix adjusted and compare patients to other dialysis patients of the same age, gender, and diabetes status (Schatell & Witten, 2010). The patient scores are reported in tertiles with "above average" being more than one standard deviation above the mean, "average" being within one standard deviation above or below the mean, and "below average" being more than one standard deviation below the mean (Schatell & Witten, 2010). "Each 1-point increase in PCS was associated with a 2% drop in the relative risk of death and hospitalization. Each 1-point increase in MCS was associated with a 2% drop in the relative risk of death and a 1% drop in the relative risk of hospitalization" (as cited, Schatell & Witten, 2010, p. 2).

The validity and reliability of the KDQOL-36 has been evaluated for some populations. Thaweethamchareon, Srimongkol, Noparatataporn, Jariyayothin, Sukthinthai, Aiyasanon, Kitisriworapan, Jantarakana, & Vasuvattakul (2013) found the KDQOL-36 to be satisfactory on construct validity and reliability coefficient (Cronbach's alpha) to be greater than 0.700 for all domains using the survey with Thai patients. In Singapore, the survey was evaluated with hemodialysis patients using the English version and researchers found that internal consistency of the kidney disease scales had "desirable internal consistency (Cronbach's alpha 0.822-0.906) and item-to-scale correlation (range 0.763-0.903)", however, they found the correlation to between the generic and disease specific scales to be low (0.286-0.418) (Yang, Wang, Joshi, Lau, & Lou, 2013, p. 135). Studying the survey's use with a Hispanic population, researchers found the reliability to have a Cronbach's alpha greater than 8.0 for each of the scales and established construct validity by correlating Beck Depression Inventory with the MCS scores ($r = -0.56$ to -0.61, $p < 0.0001$) (Ricardo, Hacker, Lora, Ackerson, DeSalvo, Go, Kusek, Nessel, Ojo, Townsend, Xie, Ferrans, & Lash, 2013).

Schatell & Witten (2010) report that the Center for Medicare and Medicaid Services (CMS) included the requirement health-related quality of life measure to be conducted annually with dialysis patients that are not excluded; those patients under 18, on dialysis less than 3 months, those who refuse, non-English speaking/reading patients (if no translation is available), and those patients that cannot complete the survey based on cognitive impairments, active psychosis, or dementia.

The Center for Medicare and Medicaid Services Interpretative Guidelines [S&C-09-01, version 1.1, 10/03/08 (29)] memo accompanying the recently updated Conditions for Coverage for ESRD facilities (42 CFR part 494), identified the KDQOL-36 as the preferred standardized physical and mental assessment tool for psychosocial status, on the basis of recommendations from the National Quality Forum and the Centers for Medicare and Medicaid Services Clinical Performance Measures Work Group, with consideration that the use of the KDQoL-36 is free from royalty fees (Lacson et al., 2010, p. 258). Though the KDQOL-36 is without royalty fees, services that score the measure such as the KDQOL-Complete charge clinics between $100 and $350 for an annual subscription (kdqol-complete.org).

Discussion

The KDQOL-36 is clearly written and the version that can be downloaded from kdqol-complete.org is printed in a large font with clear directions for each section of the survey.

Though the KDQOL-36 has been selected for use by the CMS, the psychometric properties have not been well tested and documented in all populations. The KDQOL-36 derives its reliability and validity from research conducted with previous versions and the SF-36. The three subscales that were taken from the KDQOL-SF and used in the KDQOL-36 are logical, but no documentation could be found that explained the thought process or analysis behind the choice of subscales. Despite research that identifies sleep as an important variable in quality of life among dialysis, the KDQOL-36 fails to capture this; though the two longer versions of the measure do. While subscales may hold up taken from one survey and placed in another, the reliability and validity of the new measure should be adequately tested.

As Schatell and Witten (2010) point out, “dialysis is both life-saving and life-altering” (p. 1). Even though technology and medical advances have created life sustaining treatments for those with kidney failure, patients on dialysis face a huge interruption in life that requires adherence to a regimented treatment and medication schedule, compliance with a strict diet and fluid restrictions, and at times the inability to continue some activities, hobbies, travel, or work (Theofilou, 2011). Due to the use of various accesses (catheters, fistulas, and grafts) to perform dialysis, patients are required to limited behaviors like lifting or other movements that could damage or compromise the access. These limitations can diminish one’s ability to perform tasks required for work, hobbies, or day to day life. Restrictions to diet and fluid intake can force patients to give up foods and beverages they enjoy, and at times require learning new recipes and methods for cooking that can be an increased burden on the patient, families, and care providers in the home. Such demanding changes can create a sense of loss and feelings of being overwhelmed both while adjusting to dialysis and during ongoing treatment.

The National Association of Social Workers (NASW) and the Council of Nephrology Social Workers of the Nation Kidney Foundation (NKF) have detailed the mission of social work in nephrology settings on the NASW website. Within that mission the social worker is charged with providing support to the patients and families to assist in the adjustment to the dialysis regimen and to assist in maximizing psychosocial functioning, alleviating social and emotional stress related to ESRD, and to advocate for the patient to ensure policies and routines are sensitive to differences among patients (NASW, 2016). The renal social worker faces ongoing interactions with patients regarding illnesses and the adjustment to treatment regimens, as well as other psychosocial issues in the patient's history and current life.

Administering the KDQOL-36 gives renal social workers and interdisciplinary team the opportunity to better understand the patient's perspective on their health. Interdisciplinary teams already have a wealth of data available from treatment reports and lab work that can provide insight into a patient's health status. The addition of a health-related quality of life measure adds the patient's perspective on their overall health and the symptoms and burdens created by an illness or treatment, and may help identify those patients at risk for hospitalization or death. "Health related quality of life reflects quality of care to the extent that factors which influence quality of life are amenable to intervention by professional carers" (Wright et al., 1998).

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CHAPTER 3

HEMODIALYSIS PATIENT CHARACTERISTICS AND THEIR EFFECT ON KDQOL-36 SCORES[1]

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Abstract

Kidney disease leading to dialysis is an ongoing health issue in the United States. The quality of life for those on dialysis is challenged daily by the disease and treatment regimens. Quality of life has been linked to health outcomes and the Center for Medicare and Medicaid Services (CMS) has identified the Kidney Disease Quality of Life 36 (KDQOL-36) as the preferred health-related quality of life survey for use with dialysis patients. The purpose of this study was to identify possible relationships between patient attributes and KDQOL-36 scores. Data consisted of patient attributes and KDQOL-36 scores for 116 hemodialysis patients and was analyzed using Chi-square and One-way ANOVA. Relationships between KDQOL-36 subscales was analyzed using Pearson correlation for continuous scores and Chi Square for categorical scores (below average, average, above average). Key findings include relationships between physical activity level and BMI with the Physical Component Summary, between the Mental Component Summary and each of the disease specific subscales, and between each of the disease specific subscales. Encouraging physical activity, managing symptoms, and maintaining mental well-being appears critical in quality of life among dialysis patients and for positive health outcomes.

Introduction

End Stage Renal Disease (ESRD) is an ongoing health issue in the United States. According to the United States Renal Data System, there were 678,383 prevalent cases of ESRD as of December 31, 2014 with 63.1% of those utilizing hemodialysis as their treatment modality (USRDS, 2016). Of those cases of ESRD, Blacks were represented 3.7 times higher prevalence and Asians at 1.5 times compared to their White counter parts in 2014 (USRDS, 2016). End Stage Renal Disease is a terminal disease that requires dialysis to sustain life or a kidney transplant. With the development of a chronic condition, comes implications on an individual's quality of life.

Quality of life, a multidimensional concept that includes subjective perceptions of an individual's life (The WHOQOL Group, 1998; Theofilou, 2013), is affected by kidney disease (Cruz, Andrade, Urrutia, Draibe, Antonio, Nogueira-Martins, & Sesso 2011), and research has shown that comorbid conditions are a determinant in lower quality of life scores among dialysis patients (Mingardi, Cornalba, Cortinovis, Ruggiata, Msoconi, Apolone 1999; Merkus, Jager, Dekker, de Hanan, Boeschoten, Krediet 1999; Baiardi, Degli, Esposti, Cocchi, Fabbri, Sturani, Valpiani 2002). Individuals on dialysis are shown to exhibit impairments on quality of life, including physical symptoms and emotional difficulties, such as depression (Davison, Jhangri, & Johnson, 2006; Unruh, Weisbord, & Kimmel, 2005; Weisbord, Carmody, Bruns, Rotondi, Cohen, Zeidel, & Arnold, 2003; Lopes, Bragg, Young, Goodkin, Mapes, Combe, Piera, Held, Gillespie, & Port, 2002; Theofilou, 2013).

Health-related quality of life is required, by the Center for Medicare and Medicaid Services, to be assessed annually in ESRD patients receiving dialysis, with the Kidney Disease Quality of Life 36 (KDQOL-36) being the preferred survey instrument (Schatell & Witten, 2010; Lacson et al., 2010). The KDQOL-36 is a self-report quality of life measure that contains 36 questions related to both general health and disease specific items, such as symptoms and effects of kidney disease.

Current research suggests that an individual's characteristics such as mobility, BMI, spiritual factors, and social support have implications on quality of life (Kimmel, Emont, Newmann, Danko, & Moss, 2003; Bize, Johnson, & Plotnikoff, 2007; Yan, Daviglus, Liu, Pirzada, Garside, Schiffer, Dyer, & Greenland, 2004). The purposes of this study were to: (1)

identify possible relationships between ESRD patient characteristics and KDQOL-36 scores; and (2) examine relationships between KDQOL-36 subscale scores. Our primary research question of interest was, do individuals with certain characteristics tend to score in specific ways on the KDQOL-36 subscales?

Sample

This study was carried out by collecting existing data from the medical records of hemodialysis patients that received treatments at one of the six dialysis clinics of a privately-owned dialysis company. A convenience sample was generated using existing data on all patients that completed the 36-question version of the Kidney Disease Quality of Life (KDQOL-36) from July 1, 2013 to June 30, 2014. Of the 120 complete records, one was omitted because the mobility level of the patient was a ‘stretcher’ and three were omitted because they lived in a nursing home/skilled nursing facility.

Patient attribute data contain demographic information about each patient; age at the time the KDQOL-36 was taken, height, weight, race, gender, ethnicity, marital status, religion, employment status, and type of insurance(s). Along with this information, other patient attributes collected were: primary cause of renal failure, if the individual was under the care of nephrologist prior to initiating dialysis, how long the individual had been on dialysis at the time of taking the KDQOL-36, treatment duration, living arrangements, mobility, level of activity, primary language, and co-morbid conditions. The co-morbid conditions included in this study are diabetes, hypertension, COPD, CHF, CVA, cancer, and a broader category “other cardiac disease” as labeled on CMS Form 2728.

Of the 116 cases in the study, the age ranged from 25 to 96 with a mean (SD) of 60 ± 14.09 years, with a slightly higher male to female ratio (53.4/46.6). The majority of patients were married (44%), lived with others (88.8%), spoke English (83.6%), and claimed a religion (58.6%). Only 6.9% of the patients were employed, with 44.8% disabled, 36.2% retired, and 12.1% unemployed. African-Americans made up 50.9% of the sample population, while whites made up 29.3%, white Hispanics 10.3%, and Asian or Pacific Islanders 9.5%.

The insurance status was 42.2% Medicare/Medicaid, 25.9% Medicare only, 19% Medicare with supplement/advantage plan or secondary plan, 5.2% Medicaid only, 3.4% with Commercial insurance only, and 4.3% with Tri-care for life or another insurance not commercial comprising the remaining patients. The majority of patients had diabetes (65.5%), were ambulatory without assistance (70.7%), were under the care of a Nephrologist prior to starting dialysis (62.9%), inactive (56.9%), and had Diabetes as their etiology for ESRD (43.1%).

The BMI was calculated using the patient height and weights and ranged from 16.7 to 35.3 with a mean (SD) of 29.19 ± 7.04. How long a patient had been on dialysis upon taking the KDQOL-36 ranged from 90 days to 8523 days with a mean (SD) of 1823.38 ± 1805.23 days. Treatment duration, how long each dialysis treatment was prescribed for, ranged from 150 minutes to 255 mins with a mean (SD) of 208.71 ± 25.22 minutes.

KDQOL-36

The KDQOL-36 is a self-report quality of life instrument that is given to all patients that have been on dialysis at an outpatient dialysis clinic at least 90 days, except for those that refuse, individuals with cognitive impairment, or in the absence of a survey in the appropriate language for non-English speaking/reading patients. The survey is comprised of 12 generic health items (physical component and mental component), 4 burden of kidney disease items, 12 symptoms of kidney disease items, and 8 effects of kidney disease items. The dialysis company gives the KDQOL-36 to qualifying patients to complete annually in their primary language (when available) and uses KDQOL-Complete (www.kdqol-complete.com) to score the KDQOL-36 in all six of its clinics. All individual answers to the survey are captured and five subscale scores are generated. The five subscales of the KDQOL-36 are Physical Component Summary, Mental Component Summary, Burden of Kidney Disease, Symptoms of Kidney Disease, and Effects of Kidney Disease are scored and then categorically identified, based on a case adjusted mean, by the KDQOL-Complete as “below average”, “average”, or “above average”.

This study was approved by the Institutional Review Board (IRB) at the University of Georgia. The data used was existing data that was provided to the researchers in a HIPPA compliant, de-identified format with approval from the Medical Director of the dialysis company.

Statistical Analysis

Data entry and statistical analysis were performed using SPSS version 24 statistical software package (SPSS version 24). To identify possible relationships between patient attributes and KDQOL-36 scores, patient attributes were compared by KDQOL-36 subscale score categorical levels (below average, average, above average) by using Chi Square analysis for categorical patient attributes and One-way ANOVA for continuous variables. The interrelatedness of the KDQOL-36 subscales was examined using Pearson correlation for continuous scores and Chi Square for categorical scores (below average, average, above average). Statistical significance was set at $p < 0.05$.

Results

Patient Personal Characteristics by KDQOL-36 Component

Chi-square statistics were calculated to identify differences in the distribution of patient personal characteristics across KDQOL-36 sub-score categories (Tables 3.1-3.5). There were two patient personal characteristics that were significant, language and employment. A significantly larger proportion of Spanish-speaking patients were represented in the “below average” category of the Burden Component subscale (χ^2 = 10.65, p = 0.031). Patients on disability were represented in a significantly larger proportion on the "above average" category for the Effects Component compared to patients with other employment types (χ^2 = 13.30, p = 0.038).

Patient Medical Characteristics by KDQOL-36 Component

Diabetic patients represented 65.5% of the sample and a relationship between Diabetic status and PCS was found to be significant with 75% of those in the “average” category being diabetic compared to 52.4% in the “below average” and 51.9% in the “above average” categories (p = 0.038). Activity Level was also found to have a positive relationship with PCS that was significant of, those patients identified as inactive represented 81% of the “below average” category compared to 54.4% of the “average” and 44.4% of the “above average” categories, while those that identified as active were represented at 55.6% of the “above average”, 45.6% of the “average”, and only 19% of the “below average” category (p = 0.033).

The Mental Component Summary (MCS) was found to have two significant relationships with the patient medical characteristics, Mobility and BMI. Those patients in wheelchairs represented 25% of the “below average” subscale of the MCS component compared to 9.1% of the “average” and 0% of the “above average” categories (p = 0.029). The average BMI of those in the “below average” was 34.95 (±6.78) compared to 28.49 (±7.04) in the “average” and 28.64 (±6.15) in the “above average” categories (f = 4.78, p = 0.010). Patient medical characteristics by KDQOL-36 component are represented on Tables 3.6-3.10.

KDQOL-36 Component Comparisons

Comparisons among KDQOL-36 continuous subscale scores using Pearson Correlations found eight significant relationships. Table 3.11 shows there was a positive relationship between the continuous score of the PCS with Burden Component ($r = 0.274$, $p < 0.05$) and the Symptoms Component ($r = 0.352$, $p < 0.05$). The MCS had positive relationships with Burden Component ($r = 0.511$, $p < 0.05$), the Symptoms Component ($r = 0.492$, $p < 0.05$), and the Effects Component ($r = 0.511$, $p < 0.05$). Of the disease specific subscale scores, the Burden Component had a positive relationship with the Symptoms Component ($r = .0536$, $p < 0.05$) and the Effects Component ($r = 0.636$, $p < 0.05$) and the Symptoms Component had a positive relationship with the Effects Component ($r = 0.609$, $p < 0.05$).

KDQOL-36 component subscale scores were compared using Chi-square statistics (Tables 3.12-3.15). Several significant differences in distribution were identified. Those scoring “average” on the PCS represented a larger portion of those that scored “below average” or “average” on the Burden Component compared to their counterparts ($\chi^2 = 17.02$, $p = 0.002$). A similar distribution was found for those scoring “average” on the PCS with the Symptoms Component ($\chi^2 = 21.00$, $p < 0.001$). Scores in the “below average” MCS had a higher representation in the “below average” Burden Component ($\chi^2 = 38.20$, $p < 0.001$). On the “below average” MCS 50% scored “below average” on the Symptoms Component compared to 15.6% scoring “average” and 3.7% scoring “above average” ($\chi^2 = 16.65$, $p = 0.002$). A larger percentage of those in the “below average” score on the MCS scored “below average” on the Effects Component, 41.7% compared to 13% “average” and 3.7% “above average” ($\chi^2 = 13.67$, $p < 0.008$). Those scoring “below average” on Burden Component represented higher percentages in the “below average” category for both the Symptoms Component and the Effects

Component compared to the “average” and “above average” categories ($\chi^2 = 56.36$, $p < 0.001$) ($\chi^2 = 63.46$, $p < 0.001$). Individuals scoring “below average” on the Symptoms Component were more heavily represented in the “below average” category of the Effects Component at 57.9% compared to 6.4% “average” and 0% “above average” ($\chi^2 = 42.82$, $p < 0.001$).

Discussion

This study explored patient characteristics in comparison to KDQOL-36 scores among dialysis patients. While the KDQOL-36 is the preferred quality of life survey by CMS, little is known about how patient characteristics might affect how individuals score on the survey. With quality of life being shown to impact health related outcomes, it is important to understand if there are patient characteristics that may influence and individual’s perception of their quality of life. Among patient characteristics collected in this study, only a few showed statistical significance when compared with KDQOL-36 component scores.

As anticipated, the level of physical activity played a role in how patients scored regarding their perception of their health when questioned about physical limitations and physical quality of life status. Individuals that identified on their psychosocial as inactive, engaging in exercise or a physical activity 1 or less times per week, were more likely to score “below average” on the PCS subscale compared to their counterparts. These individuals may be inactive due to physical restraints and thus score low on questions involving physical activities, such as, climbing stairs, vacuuming, playing a port, or working, however 70.7% of the sample population was ambulatory without assistance. Bize, et al. (2007) found a positive association between health-related quality of life and physical activity. Anokye, Trueman, Green, Pavey, & Taylor (2012) also found that that those with higher levels of physical activity scored better on health-related quality of life measures. With diabetes representing a large portion of the sample population, research also indicates how neuropathy can lead to a loss in mobility and thus lead to a decrease in mobility and independence for an individual (Schie, 2008). Encouraging dialysis patients in engaging in physical activities appropriate for their ability could have a positive impact on their perceived quality of life.

Individuals in wheelchairs and those that had higher BMI tended to score poorly on the MCS component, showing a positive relationship between physical status and emotional well-being. Obesity has been identified as a major public health problem that is increasing in prevalence (Baskin, Ard, Franklin, Allison, 2005) and has been shown in some research to impair an individual's social and mental well-being (Jia & Lubetkin, 2005; Doll, Petersen, & Stewart-Brown, 2000; Katz, McHorney, & Atkinson, 2000). Yan, et al. (2004) found that obesity was associated with poorer physical functioning and lower health perception. Using the SF36, a general health quality of life survey, Kalantar-Zadeh, Kopple, Block, & Humphreys (2001) found overweight patients perceived a worse quality of life than their less-obese counterparts. While those individuals in wheelchairs may be more limited in the ability to exercise or engage in physical activities, hemodialysis staff should encourage those patients identified to have higher BMI's to speak with their doctor and renal dietitian to create a plan for weight loss. Based on the findings of this study, both the increase in physical activity and the loss of weight would positively influence the perceived quality of life for the patient.

The Mental Component Summary was found to have positive relationships with all of the disease specific subscales of the KDQOL-36. Those individuals that scored poorly on the MCS were more likely than their counterparts to also score poorly on the Symptoms Component, Effects Component, and Burden Component. Kimmel, et al. (2003) found that symptoms are important determinants of quality of life among ESRD patients. This is an expected interaction since the presence of symptoms or perceived problems due to kidney disease would increase the interference of the disease on daily life for the individual, thus taking an emotional toll. Therefore, emotional well-being, more so than physical aspects, is affected by symptoms and perceived interference of kidney disease on an individual's quality of life. Abdel-Kader, Unruh, & Weisbord's (2009) research that found that depression was strongly correlated with MCS scores. Clinicians should screen individuals that score poorly in these areas for depression and refer as needed since depression likely plays a role in impairments in quality of life in ESRD patients (Merkus et al., 1999; Lopes et al., 2002; Theofilou, 2011).

Lastly, the study found, using both Pearson Correlations and Chi-square analysis, a positive relationship among the disease specific subscales scores of the KDQOL-36. Interference of kidney disease on quality of life for an individual appears to be represented across all three disease specific subscales when perceived to be high in any one area. Therefore, dialysis staff using the KDQOL-36 should be aware that individual scoring poorly in one area are likely to also score poorly in the other areas regarding their kidney disease. By utilizing the interdisciplinary team, working with the nurses, physicians, and dietitians to decrease the symptoms and with social workers to evaluate and alleviate burden imposed by kidney disease, the dialysis staff may be able to assist the patient in improving their perception of quality of life across three dimensions.

The study was limited by the small sample size and the inability to collect additional data to further research identified relationships, such as cultural views and reasons for not engaging in physical activities. This study was also limited in that it did not collect data on status of depression or mental health issues among the sample population.

Conclusion

Research has suggested that perception may be more important that objective data regarding an individual's assessment of their quality of life (Kimmel, Emont, Newmann, Danko, & Moss, 2003). The KDQOL-36 is based on patient perception of their health and scores may at times be incongruent with objective data. Dialysis staff should encourage patients to engage in a level of physical activity within the appropriate range for the individual and screen for depression as the MCS was impacted by the disease specific components of the KDQOL-36. Staff should also note that those speaking a language other than English, particularly Spanish, may experience higher Burden of Kidney Disease than their counterparts; though it is unclear if this is due to additional stress caused by a language barrier or possibly influenced by cultural beliefs.

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Table 3.1

Patient Personal Characteristics by KDQoL Physical Component

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
Age	60.0 (±14.09)	58.76 (±14.38)	61.85 (±12.64)	56.30 (±16.84)		
Sex					1.51	0.470
Male	53.4%	61.9%	54.4%	44.4%		
Female	46.6%	38.1%	45.6%	55.6%		
Race					6.53	0.367
African American	50.9%	47.6%	47.1%	63.0%		
White	29.3%	28.6%	33.8%	18.5%		
White Hispanic	10.3%	9.5%	13.2%	3.7%		
Asian or Pacific Islander	9.5%	14.3%	5.9%	14.8%		
Language					4.00	0.406
English	83.6%	85.7%	80.9%	88.9%		
Spanish	10.3%	4.8%	14.7%	3.7%		
Other	6.0%	9.5%	4.4%	7.4%		
Marital Status					3.04	0.551
Married	44.0%	47.6%	48.5%	29.6%		
Single	33.6%	33.3%	30.9%	40.7%		
Widowed	22.4%	19.0%	20.6%	29.6%		
Living Arrangement					1.90	0.387
With Others	88.8%	90.5%	91.2%	81.5%		
Alone	11.2%	9.5%	8.8%	18.5%		
Employment					6.25	0.396
Disabled	44.8%	52.4%	45.6%	37.0%		
Retired	36.2%	33.3%	36.8%	37.0%		
Unemployed	12.1%	4.8%	14.7%	11.1%		
Employed	6.9%	9.5%	2.9%	14.8%		
Religion					0.55	0.760
No Religion	41.4%	47.6%	41.2%	37.0%		
Has Religion	58.6%	52.4%	58.8%	63.0%		

Table 3.2

Patient Personal Characteristics by KDQoL Mental Component

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
Age	60.0 (±14.09)	57.83 (±13.90)	58.81 (±13.94)	64.37 (±14.24)		
Sex					2.36	0.308
Male	53.4%	33.3%	54.5%	59.3%		
Female	46.6%	66.7%	45.5%	40.7%		
Race					5.30	0.506
African American	50.9%	41.7%	53.2%	48.1%		
White	29.3%	33.3%	27.3%	33.3%		
White Hispanic	10.3%	25.0%	7.8%	11.1%		
Asian or Pacific Islander	9.5%	0.0%	11.7%	7.4%		
Language					0.47	0.346
English	83.6%	75.0%	84.4%	85.2%		
Spanish	10.3%	25.0%	7.8%	11.1%		
Other	6.0%	0.0%	7.8%	3.7%		
Marital Status					5.43	0.246
Married	44.0%	75.0%	41.6%	37.0%		
Single	33.6%	16.7%	35.1%	37.0%		
Widowed	22.4%	0.3%	23.4%	25.9%		
Living Arrangement					5.15	0.076
With Others	88.8%	100.0%	90.9%	77.8%		
Alone	11.2%	0.0%	9.1%	22.2%		
Employment					4.53	0.605
Disabled	44.8%	33.3%	48.1%	40.7%		
Retired	36.2%	41.7%	32.5%	44.4%		
Unemployed	12.1%	16.7%	10.4%	14.8%		
Employed	6.9%	8.3%	9.1%	0.0%		
Religion					6.00	0.050
No Religion	41.4%	25.0%	49.4%	25.9%		
Has Religion	58.6%	75.0%	50.6%	74.1%		

Table 3.3

Patient Personal Characteristics by KDQoL Burden Component

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
Age	60.0 (±14.09)	57.80 (±16.85)	60.67 (±12.80)	59.35 (±16.28)		
Sex					1.32	0.516
Male	53.4%	40.0%	54.7%	57.7%		
Female	46.6%	60.0%	45.3%	42.3%		
Race					8.07	0.233
African American	50.9%	40.0%	48.0%	65.4%		
White	29.3%	20.0%	33.3%	23.1%		
White Hispanic	10.3%	26.7%	9.3%	3.8%		
Asian or Pacific Islander	9.5%	13.3%	9.3%	7.7%		
Language					10.65	0.031
English	83.6%	60.0%	85.3%	92.3%		
Spanish	10.3%	33.3%	8.0%	3.8%		
Other	6.0%	6.7%	6.7%	3.8%		
Marital Status					2.29	0.683
Married	44.0%	60.0%	41.3%	42.3%		
Single	33.6%	20.0%	34.7%	38.5%		
Widowed	22.4%	20.0%	24.0%	19.2%		
Living Arrangement					4.77	0.092
With Others	88.8%	93.3%	92.0%	76.9%		
Alone	11.2%	6.7%	8.0%	23.1%		
Employment					9.29	0.158
Disabled	44.8%	20.0%	49.3%	46.2%		
Retired	36.2%	40.0%	34.7%	38.5%		
Unemployed	12.1%	26.7%	12.0%	3.8%		
Employed	6.9%	13.3%	4.0%	11.5%		
Religion					2.69	0.260
No Religion	41.4%	26.7%	46.7%	34.6%		
Has Religion	58.6%	73.3%	53.3%	65.4%		

Table 3.4

Patient Personal Characteristics by KDQoL Symptoms Component

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
Age	60.0 (±14.09)	62.16 (±14.83)	59.55 (±14.02)	59.68 (±14.25)		
Sex					0.02	0.992
Male	53.4%	52.6%	53.8%	52.6%		
Female	46.6%	47.4%	46.2%	47.4%		
Race					4.41	0.621
African American	50.9%	52.6%	48.7%	57.9%		
White	29.3%	15.8%	34.6%	21.1%		
White Hispanic	10.3%	15.8%	9.0%	10.5%		
Asian or Pacific Islander	9.5%	15.8%	7.7%	10.5%		
Language					0.80	0.938
English	83.6%	78.9%	84.6%	84.2%		
Spanish	10.3%	15.8%	9.0%	10.5%		
Other	6.0%	5.3%	6.4%	5.3%		
Marital Status					2.84	0.586
Married	44.0%	47.4%	41.0%	52.6%		
Single	33.6%	21.1%	37.2%	31.6%		
Widowed	22.4%	31.6%	21.8%	15.8%		
Living Arrangement					3.22	0.200
With Others	88.8%	78.9%	92.3%	84.2%		
Alone	11.2%	21.1%	7.7%	15.8%		
Employment					7.36	0.289
Disabled	44.8%	26.3%	50.0%	42.1%		
Retired	36.2%	47.4%	33.3%	36.8%		
Unemployed	12.1%	15.8%	12.8%	5.3%		
Employed	6.9%	10.5%	3.8%	15.8%		
Religion					3.91	0.142
No Religion	41.4%	47.4%	44.9%	21.1%		
Has Religion	58.6%	52.6%	55.1%	78.9%		

Table 3.5

Patient Personal Characteristics by KDQoL Effects Component

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
Age	60.0 (±14.09)	59.56 (±18.28)	60.90 (±13.21)	56.75 (±14.08)		
Sex					4.47	0.107
Male	53.4%	37.5%	60.0%	40.0%		
Female	46.6%	62.5%	40.0%	60.0%		
Race					9.47	0.149
African American	50.9%	50.0%	46.3%	70.0%		
White	29.3%	12.5%	35.0%	20.0%		
White Hispanic	10.3%	25.0%	8.8%	5.0%		
Asian or Pacific Islander	9.5%	12.5%	10.0%	5.0%		
Language					4.65	0.325
English	83.6%	68.8%	85.0%	90.0%		
Spanish	10.3%	25.0%	8.8%	5.0%		
Other	6.0%	6.3%	6.3%	5.0%		
Marital Status					5.21	0.266
Married	44.0%	31.3%	50.0%	30.0%		
Single	33.6%	43.8%	27.5%	50.0%		
Widowed	22.4%	25.0%	22.5%	20.0%		
Living Arrangement					1.69	0.430
With Others	88.8%	81.3%	91.3%	85.0%		
Alone	11.2%	18.8%	8.8%	15.0%		
Employment					13.30	0.038
Disabled	44.8%	31.3%	41.3%	70.0%		
Retired	36.2%	31.3%	38.8%	30.0%		
Unemployed	12.1%	31.3%	11.3%	0.0%		
Employed	6.9%	6.3%	8.8%	0.0%		
Religion					4.33	0.115
No Religion	41.4%	56.3%	35.0%	55.0%		
Has Religion	58.6%	43.8%	65.0%	45.0%		

Table 3.6

Patient Medical Characteristics by KDQoL Physical Component

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
Insurance					13.71	0.187
Medicare/Medicaid	42.2%	42.9%	45.6%	33.3%		
Medicare	25.9%	33.3%	26.5%	18.5%		
Medicare +	19.0%	9.5%	17.6%	29.6%		
Medicaid	5.2%	9.5%	4.4%	3.7%		
Commercial	3.4%	4.8%	0.0%	11.1%		
Else	4.3%	0.0%	5.9%	3.7%		
Diabetic					6.54	0.038
No	34.5%	47.6%	25.0%	48.1%		
Yes	65.5%	52.4%	75.0%	51.9%		
Primary Cause of Renal Failure					3.93	0.416
Diabetes	43.1%	33.3%	50.0%	33.3%		
Hypertension	29.3%	28.6%	27.9%	33.3%		
Other	27.6%	38.1%	22.1%	33.3%		
Mobility					5.24	0.264
Ambulatory	70.7%	76.2%	67.6%	74.1%		
Ambulatory with Assistance	20.7%	9.5%	22.1%	25.9%		
Wheelchair	8.6%	14.3%	10.3%	0.0%		
Under Care of Nephrologist Prior					3.18	0.528
Yes	62.9%	66.7%	57.4%	74.1%		
No	31.0%	28.6%	36.8%	18.5%		
Unknown	6.0%	4.8%	5.9%	7.4%		
Activity Level					6.83	0.033
Inactive	56.9%	81.0%	54.4%	44.4%		
Active	43.1%	19.0%	45.6%	55.6%		
Number of Chronic Conditions					12.08	0.440
Zero	3.4%	4.8%	1.5%	7.4%		
One	19.0%	19.0%	13.2%	33.3%		
Two	34.5%	28.6%	36.8%	33.3%		
Three	26.7%	33.3%	29.4%	14.8%		
Four	8.6%	4.8%	11.8%	3.7%		
Five	6.0%	9.5%	5.9%	3.7%		
Six	1.7%	0.0%	1.5%	3.7%		

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
BMI	29.19 (±7.04)	27.02 (±5.98)	30.31 (±6.87)	28.07 (±7.85)	2.25	0.110
Days of Treatment before Dialysis	1823.38 (±1805.23)	2559.90 (±2256.68)	1644.90 (±1562.70)	1700.04 (±1914.84)	2.19	0.117
Treatment Duration	208.71 (±25.22)	207.14 (±28.70)	211.10 (±23.08)	203.89 (±27.68)	0.84	0.435

Table 3.7

Patient Medical Characteristics by KDQoL Mental Component

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
Insurance					15.09	0.129
Medicare/Medicaid	42.2%	50.0%	42.9%	37.0%		
Medicare	25.9%	16.7%	28.6%	22.2%		
Medicare +	19.0%	33.3%	15.6%	22.2%		
Medicaid	5.2%	0.0%	6.5%	3.7%		
Commercial	3.4%	0.0%	5.2%	0.0%		
Else	4.3%	0.0%	1.3%	14.8%		
Diabetic					0.61	0.736
No	34.5%	25.0%	36.4%	33.3%		
Yes	65.5%	75.0%	63.6%	66.7%		
Primary Cause of Renal Failure					471.00	0.976
Diabetes	43.1%	41.7%	41.6%	48.1%		
Hypertension	29.3%	33.3%	29.9%	25.9%		
Other	27.6%	25.0%	28.6%	25.9%		
Mobility					10.80	0.029
Ambulatory	70.7%	75.0%	71.4%	66.7%		
Ambulatory with Assistance	20.7%	0.0%	19.5%	33.3%		
Wheelchair	8.6%	25.0%	9.1%	0.0%		
Under Care of Nephrologist Prior					3.16	0.532
Yes	62.9%	41.7%	66.2%	63.0%		
No	31.0%	50.0%	27.3%	33.3%		
Unknown	6.0%	8.3%	6.5%	3.7%		
Activity Level					0.11	0.948
Inactive	56.9%	58.3%	55.8%	59.3%		
Active	43.1%	41.7%	44.2%	40.7%		
Number of Chronic Conditions					8.99	0.704
Zero	3.4%	8.3%	3.9%	0.0%		
One	19.0%	16.7%	20.8%	14.8%		
Two	34.5%	25.0%	35.1%	37.0%		
Three	26.7%	41.7%	20.8%	37.0%		
Four	8.6%	8.3%	10.4%	3.7%		
Five	6.0%	0.0%	7.8%	3.7%		
Six	1.7%	0.0%	1.3%	3.7%		

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
BMI	29.19 (±7.04)	34.95 (±6.78)	28.49 (±7.04)	28.64 (±6.15)	4.78	0.010
Days of Treatment before Dialysis	1823.38 (±1805.23)	1188 (±1262.17)	1806.94 (±1663.62)	2152.67 (±2313.11)	1.20	0.305
Treatment Duration	208.71 (±25.22)	202.50 (±19.71)	208.83 (±25.38)	211.11 (±27.26)	0.48	0.618

Table 3.8

Patient Personal Characteristics by KDQoL Burden Component

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
Insurance					10.60	0.390
Medicare/Medicaid	42.2%	46.7%	42.7%	38.5%		
Medicare	25.9%	20.0%	29.3%	19.2%		
Medicare +	19.0%	33.3%	16.0%	19.2%		
Medicaid	5.2%	0.0%	6.7%	3.8%		
Commercial	3.4%	0.0%	2.7%	7.7%		
Else	4.3%	0.0%	2.7%	11.5%		
Diabetic					3.00	0.223
No	34.5%	20.0%	33.3%	46.2%		
Yes	65.5%	80.0%	66.7%	53.8%		
Primary Cause of Renal Failure					2.50	0.645
Diabetes	43.1%	53.3%	45.3%	30.8%		
Hypertension	29.3%	26.7%	28.0%	34.6%		
Other	27.6%	20.0%	26.7%	34.6%		
Mobility					3.94	0.414
Ambulatory	70.7%	60.0%	73.3%	69.2%		
Ambulatory with Assistance	20.7%	20.0%	18.7%	26.9%		
Wheelchair	8.6%	20.0%	8.0%	3.8%		
Under Care of Nephrologist Prior					5.29	0.259
Yes	62.9%	46.7%	66.7%	61.5%		
No	31.0%	46.7%	25.3%	38.5%		
Unknown	6.0%	6.7%	8.0%	0.0%		
Activity Level					1.90	0.386
Inactive	56.9%	66.7%	58.7%	46.2%		
Active	43.1%	33.3%	41.3%	53.8%		
Number of Chronic Conditions					10.51	0.571
Zero	3.4%	6.7%	2.7%	3.8%		
One	19.0%	13.3%	16.0%	30.8%		
Two	34.5%	26.7%	36.0%	34.6%		
Three	26.7%	26.7%	30.7%	15.4%		
Four	8.6%	13.3%	9.3%	3.8%		
Five	6.0%	6.7%	5.3%	7.7%		
Six	1.7%	6.7%	0.0%	3.8%		

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
BMI	29.19 (±7.04)	31.71 (±7.53)	28.94 (±7.10)	28.46 (±6.52)	1.15	0.321
Days of Treatment before Dialysis	1823.38 (±1805.23)	1175 (±1079.76)	1891.60 (±1835.16)	2000.65 (±2017.49)	1.15	0.321
Treatment Duration	208.71 (±25.22)	205 (±21.71)	209.40 (±26.15)	208.85 (±25.07)	0.19	0.829

Table 3.9

Patient Medical Characteristics by KDQoL Symptoms Component

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
Insurance					14.91	0.135
Medicare/Medicaid	42.2%	47.4%	43.6%	31.6%		
Medicare	25.9%	10.5%	32.1%	15.8%		
Medicare +	19.0%	31.6%	14.1%	26.3%		
Medicaid	5.2%	0.0%	6.4%	5.3%		
Commercial	3.4%	5.3%	1.3%	10.5%		
Else	4.3%	5.3%	2.6%	10.5%		
Diabetic					5.54	0.063
No	34.5%	31.6%	29.5%	57.9%		
Yes	65.5%	68.4%	70.5%	42.1%		
Primary Cause of Renal Failure					1.44	0.836
Diabetes	43.1%	42.1%	46.2%	31.6%		
Hypertension	29.3%	31.6%	26.9%	36.8%		
Other	27.6%	26.3%	26.9%	31.6%		
Mobility					4.38	0.356
Ambulatory	70.7%	63.2%	73.1%	68.4%		
Ambulatory with Assistance	20.7%	21.1%	17.9%	31.6%		
Wheelchair	8.6%	15.8%	9.0%	0.0%		
Under Care of Nephrologist Prior					5.75	0.219
Yes	62.9%	52.6%	65.4%	63.2%		
No	31.0%	31.6%	32.1%	26.3%		
Unknown	6.0%	15.8%	2.6%	10.5%		
Activity Level					2.06	0.357
Inactive	56.9%	57.9%	60.3%	42.1%		
Active	43.1%	42.1%	39.7%	57.9%		
Number of Chronic Conditions					13.33	0.345
Zero	3.4%	5.3%	2.6%	5.3%		
One	19.0%	15.8%	16.7%	31.6%		
Two	34.5%	21.1%	35.9%	42.1%		
Three	26.7%	31.6%	28.2%	15.8%		
Four	8.6%	21.1%	7.7%	0.0%		
Five	6.0%	5.3%	7.7%	0.0%		
Six	1.7%	0.0%	1.3%	5.3%		

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
BMI	29.19 (±7.04)	29.75 (±6.53)	29.52 (±7.41)	27.30 (±5.87)	0.83	0.438
Days of Treatment before Dialysis	1823.38 (±1805.23)	1356.11 (±956.77)	2064.46 (±1897.89)	1300.95 (±1930.34)	2.17	0.119
Treatment Duration	208.71 (±25.22)	205.26 (±21.24)	209.42 (±26.64)	209.21 (±23.70)	0.21	0.811

Table 3.10

Patient Medical Characteristics by KDQoL Effects Component

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
Insurance					8.86	0.545
Medicare/Medicaid	42.2%	50.0%	40.0%	45.0%		
Medicare	25.9%	12.5%	27.5%	30.0%		
Medicare +	19.0%	31.3%	18.8%	10.0%		
Medicaid	5.2%	0.0%	6.3%	5.0%		
Commercial	3.4%	0.0%	5.0%	0.0%		
Else	4.3%	6.3%	2.5%	10.0%		
Diabetic					0.09	0.958
No	34.5%	31.3%	35.0%	35.0%		
Yes	65.5%	68.8%	65.0%	65.0%		
Primary Cause of Renal Failure					1.24	0.871
Diabetes	43.1%	50.0%	42.5%	40.0%		
Hypertension	29.3%	31.3%	30.0%	25.0%		
Other	27.6%	18.8%	27.5%	35.0%		
Mobility					3.75	0.442
Ambulatory	70.7%	62.5%	72.5%	70.0%		
Ambulatory with Assistance	20.7%	25.0%	17.5%	30.0%		
Wheelchair	8.6%	12.5%	10.0%	0.0%		
Under Care of Nephrologist Prior					5.40	0.249
Yes	62.9%	62.5%	67.5%	45.0%		
No	31.0%	25.0%	27.5%	50.0%		
Unknown	6.0%	12.5%	5.0%	5.0%		
Activity Level					1.06	0.588
Inactive	56.9%	68.8%	55.0%	55.0%		
Active	43.1%	31.3%	45.0%	45.0%		
Number of Chronic Conditions					9.82	0.632
Zero	3.4%	6.3%	2.5%	5.0%		
One	19.0%	18.8%	18.8%	20.0%		
Two	34.5%	25.0%	31.3%	55.0%		
Three	26.7%	25.0%	31.3%	10.0%		
Four	8.6%	18.8%	7.5%	5.0%		
Five	6.0%	6.3%	6.3%	5.0%		
Six	1.7%	0.0%	2.5%	0.0%		

Characteristic	Total	Below Average	Average	Above Average	χ^2 or f	P
BMI	29.19 (±7.04)	28.50 (±5.23)	29.73 (±7.73)	27.59 (±5.07)	0.83	0.440
Days of Treatment before Dialysis	1823.38 (±1805.23)	1183.94 (±991.49)	1826.71 (±1793.85)	2321.60 (±2227.83)	1.79	0.172
Treatment Duration	208.71 (±25.22)	205.31 (±21.72)	209.63 (±26.79)	207.75 (±21.91)	0.21	0.811

Table 3.11

Pearson Correlations KDQoL Components

	1	2	3	4	5
1	1.00	-0.03	.274**	.352**	0.18
2		1.00	.511**	.492**	.511**
3			1.00	.536**	.636**
4				1.00	.609**
5					1.00

1= PCS Physical Component Summary
2= MCS Mental Component Summary
3= K1 Burden of Kidney Disease (subscore)
4= K2 Symptoms and Problems (subscore)
5= K3 Effects of Kidney Disease on Daily Life (subscore)

Table 3.12

KDQoL Mental Component Comparisons

Component	Below Average	Average	Above Average	Total	χ^2	P
Physical Component					7.65	0.105
Below Average	4.8%	14.7%	3.7%	10.3%		
Average	85.7%	57.4%	74.1%	66.4%		
Above Average	9.5%	27.9%	22.2%	23.3%		
Mental Component						
Below Average						
Average						
Above Average						
Burden Component						
Below Average						
Average						
Above Average						
Symptoms Component						
Below Average						
Average						
Above Average						

Table 3.13

KDQoL Burden Component Comparisons

Component	Below Average	Average	Above Average	Total	χ^2	P
Physical Component					17.02	0.002
Below Average	14.3%	14.7%	7.4%	12.9%		
Average	85.7%	66.2%	44.4%	64.7%		
Above Average	0.0%	19.1%	48.1%	22.4%		
Mental Component					38.20	<0.001
Below Average	66.7%	6.5%	7.4%	12.9%		
Average	33.3%	72.7%	55.6%	64.7%		
Above Average	0.0%	20.8%	37.0%	22.4%		
Burden Component						
Below Average						
Average						
Above Average						
Symptoms Component						
Below Average						
Average						
Above Average						

Table 3.14

KDQoL Symptoms Component Comparisons

Component	Below Average	Average	Above Average	Total	χ^2	P
Physical Component					21.00	<0.001
Below Average	23.8%	16.2%	11.1%	16.4%		
Average	71.4%	75.0%	44.4%	67.2%		
Above Average	4.8%	8.8%	44.4%	16.4%		
Mental Component					16.65	0.002
Below Average	50.0%	15.6%	3.7%	16.4%		
Average	50.0%	70.1%	66.7%	67.2%		
Above Average	0.0%	14.3%	29.6%	16.4%		
Burden Component					56.36	<0.001
Below Average	60.0%	13.3%	0.0%	16.4%		
Average	40.0%	80.0%	46.2%	67.2%		
Above Average	0.0%	6.7%	53.8%	16.4%		
Symptoms Component						
Below Average						
Average						
Above Average						

Table 3.15

KDQoL Effects Component Comparisons

Component	Below Average	Average	Above Average	Total	χ^2	P
Physical Component					3.20	0.525
Below Average	19.0%	13.2%	11.1%	13.8%		
Average	76.2%	67.6%	66.7%	69.0%		
Above Average	4.8%	19.1%	22.2%	17.2%		
Mental Component					13.67	0.008
Below Average	41.7%	13.0%	3.7%	13.8%		
Average	58.3%	71.4%	66.7%	69.0%		
Above Average	0.0%	15.6%	29.6%	17.2%		
Burden Component					63.46	<0.001
Below Average	66.7%	8.0%	0.0%	13.8%		
Average	33.3%	82.7%	50.0%	69.0%		
Above Average	0.0%	9.3%	50.0%	17.2%		
Symptoms Component					42.82	<0.001
Below Average	57.9%	6.4%	0.0%	13.8%		
Average	42.1%	76.9%	63.2%	69.0%		
Above Average	0.0%	16.7%	36.8%	17.2%		

CHAPTER 4

KDQOL-36 SCORES AND CLINICAL OUTCOMES IN HEMODIALYSIS

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Abstract

Hemodialysis is a life sustaining treatment and is also accompanied by a demanding treatment regimen. Nonadherence is an ongoing problem among dialysis patients and can result in poor health-related outcomes. Dialysis providers are charged with assisting patients to reach positive health outcomes by providing quality treatment and needed support. The Center for Medicare and Medicaid Services (CMS) requires dialysis providers to annually assess quality of life among its patients and has identified the KDQOL-36 as the preferred survey. Existing research has shown a relationship between quality of life and health-related outcomes. The purpose of this study was to identify relationships between patient clinical values and treatment utilization with KDQOL-36 scores. The sample consisted of 116 hemodialysis patients that completed the KDQOL-36. Data was clinical data was collected at the month the survey was taken and at a 3-month follow-up. One-way ANOVA was uses to analyze clinical data compared to KDQOL-36 subscale categorical scores and paired sample t-tests were used to analyze changes over time. Delta scores were created and then analyzed using Chi-square analysis to evaluate KDQOL-36 categorical scores relatedness to clinical improvement. Results showed a relationship between good Physical Component Summary (PCS) and Mental Component Summary (MCS) scores with shortened treatments. Poor MCS scores were also associated with higher rates of hospitalization and missed treatments. Research has shown that depression is a risk factor in adherence to treatment and this study would concur that mental well-being plays a significant role in positive health-related outcomes in hemodialysis patients.

Introduction

Kidney disease and kidney failure is a prevailing issue in the United States with roughly half million individuals on currently on dialysis (USRDS, 2016). Dialysis is demanding treatment regimen that is utilized when an individual's kidney function drops below levels that can sustain life (Brown, 2006). The treatment regimen includes attendance to treatment for a prescribed amount of time, adherence to a specific diet and fluid intake restrictions, and compliance with prescribed medications. Research shows that compliance with treatment regimens is an ongoing and prevalent problem with about 50% of dialysis patients not adhering to aspects of their prescribed treatment (Bame, Peterson, & Wray 1993; Sherman, Cody, Matera, Rogers, & Solanchick, 1994; Leggat, Orzol, Hulbert-Shearon, Golper, Jones, Held, & Port, 1998; Baines & Jindal, 2000; Theofilou, 2011).

Attendance to each dialysis treatment and staying for the full duration of each treatment is critical as research shows that shortened and missed treatments can lead to higher risk of mortality (Leggat et al, 1998; Kimmel, Peterson, & Weihs, 1998; Bleyer, Hylander, & Sudo, 1999). Nonadherence to dietary and fluid recommendations can lead to detrimental health outcomes including bone disease, calcification of blood vessels, heart failure, edema problems, hypertension, shortness of breath, and cardiovascular deterioration (Brady, Tucker, Alfino, Tarrant, & Finlayson, 1997; Brown, 2006; Durose, Holdsworth, Watson, & Przygrodzka, 2004; Lee & Molassiotis, 2002). There are higher odds of an individual being nonadherent in multiple areas when the individual is nonadherent is one area (Leggat et al., 1998). Therefore, even though several aspects of adherence are up to the individual, it is a concern of dialysis centers and critical in achieving positive health outcomes.

Quality of life is concept that is multidimensional and includes subjective perceptions of various aspects of life both positive and negative (The WHOQOL Group, 1998). Health-related Quality of Life is considered to provide insight into unmet needs and health-related outcomes by evaluating the patient's perceptions on physical and mental aspects of their life (Dominick, Ahern, Gold, & Heller, 2002; DeSalvo, Bloser, Reynolds, & Muntner, 2006; Theofilou, 2013). Higher quality of life is associated with higher survival rates and less morbidity (Valderrabano, Jofre, & Lopez-Gomez, 2001; Theofilou, 2013). Disease specific symptoms, side effects of treatment, and concerns regarding an individual's specific illness are often captured using a disease-specific measure, while general questions are used to survey basic health status and sense of well-being (Valderrando et al., 2001; Theofilou, 2013). Carmicheal et al. (2000) recommend using a combination of general and disease specific components when surveying quality of life.

The Center for Medicare and Medicaid Services (CMS) established a requirement for dialysis clinics to conduct annual health-related quality of life surveys with all patients that meet criteria (Schatell & Witten, 2010) and selected the KDQOL-36 as the preferred survey (Lacson et al., 2010). The KDQOL-36 is a self-report 36 question survey that is comprised of both generic and disease specific questions. The KDQOL-36 is shortened version of the KDQOL, which contained 134 items. The SF-12 comprises the first 12 questions of the survey and captures the individual's perception of their general health and sense of well-being resulting in two summary scales, the Physical Component Summary (PCS) and Mental Component Summary (MCS) (Ware, et al., 1996). The other 24 questions of the KDQOL-36 comprise the disease specific portion of the survey and are scored into three subscales; Burden of Kidney Disease, Symptoms of Kidney Disease, and Effects of Kidney Disease. The purposes of this study were to: (1) identify possible relationships between KDQOL-36 subscale scores and patient clinical data; and (2) compare changes in clinical data over time compared to KDQOL-36 subscale scores. Our primary research question of interest was, does the KDQOL-36 provide clinical utility that could inform hemodialysis staff to better ensure positive health outcomes for patients?

Sample

Data for this study were collected from the medical records of hemodialysis patients at a privately-owned dialysis company, consisting of six clinics, that both took the KDQOL-36 and received dialysis treatment from July 1, 2013 to June 30, 2014. Of the 120 patients that completed the KDQOL-36 survey, four were omitted from the study, three lived in a nursing home or other skilled nursing facility and one patient due to mobility level being ‘stretcher’.

The majority of patients were diabetic (65.5%) and there were slightly more males in the study compared to females (53.4%/46.6%). The age ranged from 25 to 96 with an age mean (SD) of 60 ± 14.09 years, with African-Americans comprising the 50.9%, whites 29.3%, white Hispanics 10.3%, and Asian/Pacific Islanders 9.5% of the sample population. The average age at the time the KDQOL-36 was taken was 60 and ranged from 25 to 96, average BMI was 29.19 and ranged from 16.7 to 52, average number of days on dialysis at the time of taking the KDQOL-36 was 1823.38 days and ranged from 90 to 8613 days, and the average treatment duration was 208.71 with a range of 150 to 255 minutes (Table 4.1).

KDQOL-36

Quality of Life is surveyed at the dialysis clinics by using the KDQOL-36. The survey is a self-report measure that is given to all patients that do not refuse the survey and meet the criteria (have been at the dialysis clinic receiving treatments at least 90 days, do not have cognitive impairment). In the absence of a survey in the appropriate language for non-English speaking/reading patients, the survey is not given. The survey is comprised of both generic health questions and disease specific questions. The SF-12 makes up the first 12 items on the survey and generate two subscale scores, the Physical Component and Mental Component. The Burden of Kidney Disease, the Symptoms of Kidney Disease, and the Effects of Kidney Disease components make up the disease specific subscales of the KDQOL-36. The KDQOL-Complete (www.kdqol-complete.com) is used to score the KDQOL-36 in all six of clinics of the company. The responses marked on paper copies of the instrument are input into the program and five subscale scores are generated in both a continuous number score and identified with a categorical score of “below average”, “average”, and “above average” based on the case adjusted mean.

Clinical values at the month the patient completed the KDQOL-36 and at a 3-month following were captured. Clinical values for each month include lab work, average interdialytic weight gain, missed treatments, shortened treatments, and hospitalizations. Out of the monthly lab work collected at the dialysis clinic, hemoglobin, urea reduction ratio (URR), albumin, and phosphorus were gathered and used for the study. In order to determine positive health outcomes, cut-off for clinical values were selected using KDOOQI guidelines and CMS standards: Hemoglobin >10gm/dl, URR >65%, Phosphorus <5.5gm/dl, Albumin ≥4.0gm/dl (NKF KDQOI Guidelines). The number of shortened treatments, defined as stopping dialysis treatment prior to achieving the prescribed duration of treatment, for each month was calculated for each patient, as was the number of hospitalizations for each month.

Interdialytic weight gain is defined as, “the amount of fluid that is ultrafiltrated during the subsequent hemodialysis treatment (ie, the difference between the prehemodialysis [wet] and posthemodialysis [dry] weight) is equivalent to the magnitude of weight gain immediately before the treatment” (Kalantar-Zadeh, et al. 2009, p. 672). The average interdialytic weight gain was calculated for each patient based on the number of treatments received at the clinic and weight gained between those treatments for each month studied. While there is not a set guideline for what is considered excessive interdialytic weight gain, research suggests between 1.0 kg and 2.0

kg to be normal weight gain (NKF KDOQI Guidelines, 2006 & Kalantar-Zadeh, et al. 2009); therefore, for the purpose of the study, a cut-off of 2.0kg was chosen.

Statistical Analysis

SPSS statistical software package (SPSS version 24) was used for data entry and statistical analysis. In order to compare clinical values and healthcare utilization by KDQOL-36 subscale categorical scores, one-way ANOVA was used. Paired sample t-tests were used to identify changes over time from the clinical values and healthcare utilization at the month the KDQOL-36 was taken and clinical values and healthcare utilization at three months following. Paired sample t-tests were also used to identify changes in clinical values and healthcare utilization over time by KDQOL-36 categorical scores for each subscale component. Clinical values and healthcare utilization for the month at the time KDQOL-36 was taken and at three months following were also categorized based on positive health outcome cut-off values and used to calculate Delta scores in order to evaluate KDQOL-36 categorical scores relatedness to clinical improvement. Chi Square tests were then used to compare Delta scores by KDQOL-36 subscale categorical score. Statistical significance was set at $p < 0.05$.

Results

Changes in Clinical Values Over Time (n = 116)

Independent sample t-tests were conducted to compare changes of clinical values over time (Table 4.2-4.4). A comparison of clinical values at the time of taking the KDQOL-36 (baseline) and at the three-month follow-up revealed four significant differences between the groups. Hemoglobin increased significantly from baseline (M = 9.77, SD = 0.69) to 3-month follow-up (M = 9.97, SD = 0.62) showed (t = -2.60, p = 0.011). Albumin increased from baseline (M = 3.71, SD = 0.34) to 3-month follow-up (M = 3.83, SD = 0.27) showed (t = -3.28, p

= 0.001). Urea Reduction Ration (URR) decreased from baseline (M = 79.47, SD = 3.63) to 3-month follow-up (M = 78.25, SD = 4.18) showed (t = 2.33, p = 0.021). The number of shortened dialysis treatments increased from baseline (M = 0.21, SD = 0.55) to 3-month follow-up (M = 0.54, SD = 0.58) showed (t = -4.29, p < 0.001).

Clinical Values by KDQoL Component

Clinical values and healthcare utilization, at baseline and 3-month follow up, were compared by KDQOL subscale category scores using one-way ANOVA (Tables 4.5-4.9). Hospitalizations at baseline was significantly different among Mental Component Scores, Symptoms Component, and Effects Component with a higher frequency of hospitalization among those scoring “below average” on MCS (f = 3.41, p = 0.36), Symptoms Component (f = 3.14, p = 0.047), and Effects Component (f = 6.59, p = 0.002). Phosphorus at baseline was significantly different among Effects Component scores with those scoring in the “above average” having higher Phosphorus levels (f = 3.96, p = 0.022). At the time of the 3-month follow-up, Hospitalizations and Missed treatments were significantly different among MCS scores with a higher frequency of hospitalizations (f = 3.99, p = 0.021) and a higher frequency of missed treatments (f = 3.52, p = 0.033) among those that scored in the “below average” categories.

Changes in Clinical Values Over Time based on KDQoL at Baseline (n = 116)

Using paired sample t-tests, changes over time in clinical values and healthcare utilization were analyzed by KDQOL-36 categorical scores for each subscale component (Tables 4.9-4.17). Those that scored “average” on the PCS subscale had significant increases from baseline to follow-up in Albumin (t = -2.25, p = 0.028), URR (t = 2.04, p =0 .046), and Shortened treatments (t = -2.57, p =0 .012). There was also an increase in Shortened treatments from baseline to follow-up for those that scored “above average” on the PCS (t = -5.38, p < .0001).

In the MCS subscale, those that scored in the “below average” category had a decrease in Phosphorus levels from baseline to follow-up (t = 2.55, p = 0.027). And those scoring in the “average” category had an increase in Hemoglobin levels (t = -2.39, p = 0.019), Albumin levels (t = -2.37, p = 0.021) and Shortened treatments (t = -3.50, p = 0.001), and a decrease in URR (t = 2.12, p =0 .037). Those in the “above average” category had increases in Albumin (t = -2.81, p = 0.009) and Shortened treatments (t = -3.24, p =0 .003).

Among those scoring in the “average” category on the subscale of the Burden Component there was an increase in Hemoglobin levels (t = -2.61, p = 0.011), Albumin levels (t = -3.17, p = 0.002), and Shortened treatments (t = -3.49, p = 0.001) from baseline to follow-up. Those in the “above average” category had an increase in Shortened treatments also (t = -2.74, p = 0.011). In the Symptoms Component subscale, those scoring in the “average” category had an increase in Albumin levels (t = -2.06, p = 0.043) and Shortened treatments (t = -3.01, p = 0.003) and a decrease in URR (t = 2.90, p = 0.005). Those scoring in the “average” and “above average” categories of the Effects Component subscale had in increase in Shortened treatments from baseline to follow-up (t = -3.35, p = 0.001) (t = -2.46, p = 0.024) and the “average” category also had an increase in Albumin levels (t = -2.63, p = 0.010).

Clinical Changes by KDQoL Component at Baseline

Chi-square analysis identified four relationships between clinical changes and KDQOL-36 components at baseline (Tables 4.18-4.22). A relationship between Phosphorus levels and MCS was found with 58.3% of those scoring in the “below average” category showing improvement compared to 19.5% in the “average” and 29.6% in the “above average” categories.

There was also a larger percentage of those in the "average" category getting worse (24.7%) compared to the 8.3% in the "below average" category and 3.7% in the "above average" category. The relationship between Phosphorus levels and MCS was significant (p = 0.010).

Phosphorus and Symptoms Component showed a significant relationship with a higher percentage of those in the "above average" category had poor phosphorus levels at baseline and at the 3-month follow-up (42.1%) compared to 20.5% in the "average" and 10.5% in the "below average" categories. Those in the "below average" were more likely to get worse (31.6%) in comparison to the "average" (16.7%) and "above average" categories (10.5%) (p = 0.024).

The Physical Component and Hospitalizations relationship showed that 9.5% of those in the "below average" category had hospitalizations at baseline and at 3-month follow-up compared to 0% in both the "average" and "above average" categories. In the "average" category 10.3% got better (had a hospitalization at baseline, but not at follow-up) compared to 0% in the "below average" and "above average" categories. The PCS and Hospitalizations relationship is significant (p = 0.016).

No members of the "average" or "above average" categories in the Symptoms Component missed treatments at both baseline and at the 3-month follow-up, while 10.5% of those in the "below average" category did miss treatments at both recorded points. However, those in the "below average" category also showed a higher percentage of improvement with 21.1% not missing a treatment at follow-up compared to 15.4% "average" and 5.3% "above average". The "above average" category showed the most compliance with 84.2% not missing treatments, while the "average" category had 71.8% and the "below average" category had 57.9%. Missed Treatments and Symptoms Component was significant (p = 0.044).

Discussion

When looking at how the KDQOL-36 scores might relate to a patient's clinical data, this study found several significant relationships. Both the general health and disease specific quality of life subscales had at least one clinical value that could guide approaches to dialysis treatment and interactions with the patient. We will discuss the physical aspect of the general health quality of life findings first, followed by the mental and kidney disease specific findings.

The Physical Component Summary surveys how an individual is feeling about their health in general and physical abilities/activity. Those scoring "average" on PCS had an increase in albumin levels at the follow-up, however this group and those scoring "above average" displayed an increase in shortened treatments. This might indicate that those feeling physically able and not physically hindered by their health status are more likely to eat well or have more ability regarding meal preparations and meal choices, but also to "cheat" regarding their treatment schedule by choosing to one or more shorten treatments. Those without physical limitations may also continue to be employed and thus feel the need to shorten treatments to address work or personal issues on top of a demanding treatment regimen. This study was not able to look at the reasons behind treatments that were shortened and thus limited in understanding this phenomenon. It is important for dialysis staff to communicate the importance of each treatment and the full duration of each treatment with patients as research has identified associations nonadherence with treatment schedules and poor health outcomes, including mortality (Saran, Bragg-Gresham, Rayner, Goodkin, Keen, Van Dijik, Kurokawa, Piera, Saito, Fukuhara, Young, Held, & Port, 2003). Future research should gather data that includes the reason that each treatment was shortened and the amount of time each treatment was shortened by to better understand how scoring regarding physical aspects of quality of life relates to nonadherence with the individual's dialysis treatment schedule.

The Mental Component Summary evaluates an individual's perception regarding their sense of well-being and emotional status. Previous research indicated a relationship between MCS scores and hospitalization (Schatell & Witten, 2010). This study found those scoring poorly on the MCS component had a higher frequency of hospitalization at both the month the KDQOL-36 was given and at the 3-month follow-up. Those that scored poorly on the MCS also had a higher frequency of missed treatments at the time of the 3-month follow-up. These findings are consistent with research that identifies depression as a risk factor regarding nonadherence with medical treatments (Theofiliou, 2011; DiMatteo, Heidi, Lepper, & Croghan, 2000).

The Burden, Symptoms, and Effects Components comprise the kidney disease specific sections of the KDQOL-36. These sections include questions related to the perceived impact of kidney disease on an individual's life and the presence of symptoms. These subscales were found to have a positive relationship with the Mental Component Summary (Phillips & Smith, 2017). Individuals that scored well on MCS and disease specific subscale scores were associated with an increase in Albumin levels, possibly indicating that a sense of well-being goes hand-in-hand with eating well. Kalantar-Zadeh, Kopple, Block, & Humphreys (2001) found that low albumin was associated with lower quality of life scores in individuals on hemodialysis. However, these scores were also associated with an increase in shortened treatments which could indicate that a sense of well-being or healthy mental status leads to one feeling more comfortable "cheating" on their prescribed dialysis treatment regimen; this was also evident as those with an "average" score on the MCS had phosphorus levels exceeding goal at the 3-month follow-up, however those that scored “below average” had improvement on their phosphorus levels at follow-up possibly indicating an attempt to follow the renal diet or medication compliance regarding phosphorus control leads to an increased negative impact on perceived quality of life from being required to forsake desired foods and increased pill burden.

Since the KDQOL-36 is a self-report survey based on the individual’s perceptions of their health, it holds the possibility of not reflecting objective health outcomes and to be influenced by aspects such as other medical conditions without capturing this information. However, the Symptoms of Kidney Disease section of the survey can provide beneficial information to medical staff regarding the extent to which an individual is bothered by specific health and disease related symptoms, such as feeling washed out, cramps, numbness, and shortness of breath, possibly leading to changes or recommendations in the treatment regimen or medications. Symptoms in ESRD patients have been identified by research as important determinants of quality of life, therefore, managing and reducing these symptoms is critical to quality care and directly impacts a patient’s quality of life (Kimmel, Emont, Newmann, Danko, & Moss, 2003; Frank, Auslander, & Weissgarten, 2004). Other research has shown that not just the presence of symptoms, but also the intensity of the symptoms affects quality of life (Hudson, Kirksey, & Holzemer, 2004). It is recommended that social workers report to medical staff those symptoms that patients identify as “moderately bothered by” or higher regardless of the overall subscore of the Symptoms Component.

The sample size of this study was small and there were only two points of clinical data captured on each patient. A larger sample and additional points of data collection would allow for a more in-depth analysis of what information the KDQOL-36 could provide for clinical utility. Additional collection points of the survey would allow for a better understanding of what is changing over time with individuals on dialysis. The KDQOL-36 is not an intervention and there is not a standard delivery method of the results to the patients. Utilization of a standard approach when speaking with patients about their individual results and methods to improve their quality of life could potentially improve the utility of the survey.

Since the clinical data does always capture why an individual missed or shortened a treatment, and this information was not available to the researcher, it is impossible to draw implications regarding the survey and missed or shortened treatments, as one could speculatively shorten or miss a treatment for feeling well, feeling poorly, transportation issues, or other obligations. Therefore, future research would benefit from collecting this additional data to better understand the relationship between missed and shortened treatments and patient's perception of their health. This study also did not have the socioeconomic status of each patient to better understand possible relationships with eating habits and medication compliance that would affect phosphorus levels, as well as access to exercise opportunities.

It is also important to note that due to health protected information and the data being deidentified, the researcher was not able to assess the impact of the timing of the KDQOL-36. It is reasonable to assume that dialysis patients would potentially have changes in behaviors during holiday times, especially religious or family oriented times of celebration. Negative changes in diet, fluid intake, medication compliance, and/or treatment schedule adherence could increase symptoms and influence the perception of how demanding and intrusive the treatment regimen is on daily life. During these times, dialysis staff may also increase education efforts regarding aspects of compliance, such as dietary restrictions and suggestions during Thanksgiving. Since the survey is given throughout the year and not during a specific month, it is important for clinicians to take this into consideration when evaluating the results and to consider providing the survey again at a later date.

Conclusion

The KDQOL-36 provides insight into the patient's perception of their health, quality of life, and symptoms related to kidney disease. However, being a self-report survey based on perception, it may not capture the whole picture of the patient's health status. Aligning the survey with clinical data can provide additional guidance for dialysis staff to assist the patient in reaching positive health outcomes. As a Condition for Coverage, CMS requires dialysis providers to utilize the interdisciplinary team (IDT) to assess patients and provide care that leads to positive health outcomes (DHHS, 2009). Social workers are uniquely qualified to gather qualitative information during interactions with patients that can inform the IDT beyond lab values and other quantifiable data such as missed or shortened treatments. As a critical part of the interdisciplinary team, social workers can present findings from the KDQOL-36 and advocate for the patient so that the other disciplines can be further informed when making treatment decisions, providing services, and developing care plans to foster positive health-related outcomes and patient quality of life.

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Table 4.1

Patient Characteristics (n=116)

Characteristic	Mean	SD	Range	Min	Max
Age at time of KDQoL	60.00	14.09	71	25	96
Number of chronic conditions (0 to 7 possible)	2.43	1.26	6	0	6
BMI	29.19	7.04	35.3	16.7	52
Number of Dialysis Days before KDQoL	1823.38	1805.23	8523	90	8613
Treatment Duration (minutes)	208.71	25.22	105	150	255

Table 4.2

Changes in Clinical Values Over Time – Baseline (n = 116)

Component	Mean	SD	Range	Min	Max
Hemoglobin	9.77	0.69	4	7.1	11.1
Phosphorus	5.66	0.67	2.7	4.1	6.8
Albumin	3.71	0.34	1.4	3.1	4.5
URR (Urea Reduction Ratio)	79.47	3.63	18.9	69.2	88.1
Hospitalizations	0.09	0.35	2	0	2
Shorted Treatments	0.21	0.55	3	0	3
Missed Treatments	0.23	0.60	3	0	3
Monthly Average Interdialytic Weight Gain	2.62	0.34	2	2	4

Table 4.3

Changes in Clinical Values Over Time - 3-Month Follow-Up (n = 116)

Component	Mean	SD	Range	Min	Max
Hemoglobin	9.97	0.62	2.4	8.8	11.2
Phosphorus	5.59	0.74	2.5	4.3	6.8
Albumin	3.83	0.27	1.1	3.2	4.3
URR (Urea Reduction Ratio)	78.25	4.18	15	70.2	85.2
Hospitalizations	0.16	1.22	13	0	13
Shorted Treatments	0.54	0.58	2	0	2
Missed Treatments	0.27	1.27	13	0	13
Monthly Average Interdialytic Weight Gain	2.59	0.26	0.9	2.1	3

Table 4.4

Changes in Clinical Values Over Time - Paired Sample T-Tests (n = 116)

Component	t	P	Lower	95% CI Upper
Hemoglobin	-2.60	0.011	-0.36	-0.05
Phosphorus	0.90	0.370	-0.09	0.23
Albumin	-3.28	0.001	-0.19	-0.05
URR (Urea Reduction Ratio)	2.33	0.021	0.18	2.25
Hospitalizations	-0.59	0.560	-0.30	0.17
Shorted Treatments	-4.29	<0.001	-0.49	-0.18
Missed Treatments	-0.26	0.796	-0.30	0.23
Monthly Average Interdialytic Weight Gain	0.54	0.588	-0.06	0.10

Table 4.5

Clinical Values by KDQoL Physical Component

Component	Total	Below Average	Average	Above Average	f	P
BASELINE						
Hemoglobin	9.77 (±0.69)	9.66 (±0.55)	9.77 (±0.76)	9.86 (±0.60)	0.46	0.631
Phosphorus	5.66 (±0.67)	5.45 (±0.61)	5.73 (±0.65)	5.64 (±0.73)	1.51	0.226
Albumin	3.71 (±0.34)	3.62 (±0.37)	3.73 (±0.34)	3.73 (±0.32)	0.87	0.421
URR (Urea Reduction Ratio)	79.47 (±3.63)	80.11 (±2.74)	79.33 (±3.90)	79.32 (±3.59)	0.39	0.676
Hospitalizations	0.09 (±0.35)	0.10 (±0.30)	0.13 (±0.42)	0 (±0.0)	1.41	0.250
Shorted Treatments	0.21 (±0.55)	0.29 (±0.72)	0.22 (±0.54)	0.11 (±0.42)	0.64	0.530
Missed Treatments	0.23 (±0.60)	0.24 (±0.70)	0.26 (±0.61)	0.15 (±0.46)	0.37	0.693
Monthly Average Interdialytic Weight Gain	2.62 (±0.34)	2.59 (±0.33)	2.64 (±0.32)	2.57 (±0.40)	0.49	0.615
FOLLOW-UP						
Hemoglobin	9.97 (±0.62)	9.95 (±0.62)	9.96 (±0.64)	10.03 (±0.61)	0.14	0.869
Phosphorus	5.588 (±0.74)	5.5 (±0.64)	5.56 (±0.77)	5.73 (±0.77)	0.66	0.517
Albumin	3.83 (±0.27)	3.78 (±0.34)	3.83 (±0.27)	3.86 (±0.23)	0.54	0.582
URR (Urea Reduction Ratio)	78.25 (±4.18)	79.34 (±4.55)	77.87 (±4.08)	78.39 (±4.10)	1.02	0.365
Hospitalizations	0.16 (±1.22)	0.10 (±0.30)	0.24 (±1.59)	0.04 (±0.19)	0.29	0.748
Shorted Treatments	0.54 (±0.58)	0.48 (±0.60)	0.50 (±0.56)	0.70 (±0.61)	1.37	0.259
Missed Treatments	0.27 (±1.27)	0.24 (±0.54)	0.32 (±1.61)	0.15 (±0.46)	0.19	0.828
Monthly Average Interdialytic Weight Gain	2.59 (±0.26)	2.50 (±0.27)	2.61 (±0.26)	2.61 (±0.27)	1.47	0.234

Table 4.6

Clinical Values by KDQoL Mental Component

	Total	Below Average	Average	Above Average	f	P
BASELINE						
Hemoglobin	9.77 (±0.69)	9.575 (±1.07)	9.76 (±0.65)	9.87 (±0.58)	0.77	0.466
Phosphorus	5.66 (±0.67)	6.04 (±0.69)	5.57 (±0.66)	5.75 (±0.62)	2.99	0.054
Albumin	3.71 (±0.34)	3.78 (±0.34)	3.71 (±0.36)	3.68 (±0.30)	0.40	0.674
URR (Urea Reduction Ratio)	79.47 (±3.63)	78.8 (±3.99)	79.80 (±3.33)	78.82 (±4.28)	0.96	0.385
Hospitalizations	0.09 (±0.35)	0.33 (±0.65)	0.08 (±0.32)	0.04 (±0.19)	3.41	0.036
Shorted Treatments	0.21 (±0.55)	0.42 (±0.67)	0.21 (±0.52)	0.11 (±.058)	1.28	0.282
Missed Treatments	0.23 (±0.60)	0.42 (±0.79)	0.19 (±0.54)	0.26 (±0.66)	0.75	0.473
Monthly Average Interdialytic Weight Gain	2.62 (±0.34)	2.53 (±0.28)	2.64 (±0.34)	2.60 (±0.37)	0.50	0.610
FOLLOW-UP						
Hemoglobin	9.97 (±0.62)	10.08 (±0.76)	9.97 (±0.61)	9.94 (±0.61)	0.20	0.817
Phosphorus	5.588 (±0.74)	5.39 (±0.76)	5.58 (±0.71)	5.70 (±0.84)	0.70	0.497
Albumin	3.83 (±0.27)	3.77 (±0.31)	3.81 (±0.29)	3.89 (±0.21)	1.16	0.316
URR (Urea Reduction Ratio)	78.25 (±4.18)	77.57 (±3.85)	78.41 (±4.45)	78.11 (±3.55)	0.23	0.798
Hospitalizations	0.16 (±1.22)	1.08 (±3.75)	0.05 (±0.22)	0.07 (±0.27)	3.99	0.021
Shorted Treatments	0.54 (±0.58)	0.42 (±0.52)	0.52 (±0.60)	0.67 (±0.56)	0.96	0.387
Missed Treatments	0.27 (±1.27)	1.17 (±3.74)	0.16 (±0.40)	0.19 (±0.56)	3.52	0.033
Monthly Average Interdialytic Weight Gain	2.59 (±0.26)	2.48 (±0.24)	2.61 (±0.27)	2.60 (±0.25)	1.18	0.312

Table 4.7

Clinical Values by KDQoL Burden Component

	Total	Below Average	Average	Above Average	f	P
BASELINE						
Hemoglobin	9.77 (±0.69)	9.55 (±0.91)	9.76 (±0.64)	9.93 (±0.67)	1.48	0.232
Phosphorus	5.66 (±0.67)	5.73 (±0.67)	5.64 (±0.66)	5.7 (±0.70)	0.16	0.853
Albumin	3.71 (±0.34)	3.65 (±0.29)	3.7 (±0.35)	3.77 (±0.34)	0.75	0.475
URR (Urea Reduction Ratio)	79.47 (±3.63)	79.76 (±3.33)	79.55 (±3.66)	79.06 (±3.83)	0.23	0.795
Hospitalizations	0.09 (±0.35)	0.27 (±0.59)	0.08 (±0.32)	0.04 (±0.20)	2.28	0.107
Shorted Treatments	0.21 (±0.55)	0.4 (±0.74)	0.2 (±0.49)	0.12 (±0.0)	1.29	0.280
Missed Treatments	0.23 (±0.60)	0.53 (±0.83)	0.19 (±0.51)	0.19 (±0.63)	2.25	0.110
Monthly Average Interdialytic Weight Gain	2.62 (±0.34)	2.56 (±0.27)	2.61 (±0.33)	2.66 (±0.41)	0.39	0.676
FOLLOW-UP						
Hemoglobin	9.97 (±0.62)	9.79 (±0.65)	9.99 (±0.64)	10.04 (±0.57)	0.85	0.430
Phosphorus	5.588 (±0.74)	5.45 (±0.69)	5.53 (±0.73)	5.83 (±0.79)	1.88	0.158
Albumin	3.83 (±0.27)	3.72 (±0.32)	3.84 (±0.28)	3.84 (±0.21)	1.31	0.274
URR (Urea Reduction Ratio)	78.25 (±4.18)	78.35 (±3.72)	78.18 (±4.34)	78.4 (±4.08)	0.03	0.970
Hospitalizations	0.16 (±1.22)	0.13 (±0.35)	0.23 (±1.51)	0 (±0.0)	0.33	0.717
Shorted Treatments	0.54 (±0.58)	0.53 (±0.64)	0.53 (±0.60)	0.58 (±0.50)	0.06	0.946
Missed Treatments	0.27 (±1.27)	0.2 (±0.56)	0.33 (±1.55)	0.12 (±0.33)	0.31	0.737
Monthly Average Interdialytic Weight Gain	2.59 (±0.26)	2.55 (±0.23)	2.59 (±0.27)	2.62 (±0.27)	0.39	0.676

Table 4.8

Clinical Values by KDQoL Symptoms Component

	Total	Below Average	Average	Above Average	f	P
BASELINE						
Hemoglobin	9.77 (±0.69)	9.68 (±0.89)	9.74 (±0.66)	9.98 (±0.57)	1.16	0.318
Phosphorus	5.66 (±0.67)	5.5 (±0.61)	5.74 (±0.67)	5.52 (±0.70)	1.51	0.225
Albumin	3.71 (±0.34)	3.64 (±0.35)	3.72 (±0.34)	3.71 (±0.36)	0.44	0.644
URR (Urea Reduction Ratio)	79.47 (±3.63)	78.45 (±4.43)	79.74 (±3.48)	79.39 (±3.39)	0.97	0.382
Hospitalizations	0.09 (±0.35)	0.26 (±0.56)	0.08 (±0.31)	0 (±0.0)	3.14	0.047
Shorted Treatments	0.21 (±0.55)	0.26 (±0.65)	0.24 (±0.59)	0 (±0.0)	1.62	0.202
Missed Treatments	0.23 (±0.60)	0.47 (±0.77)	0.22 (±0.60)	0.05 (±0.23)	2.52	0.085
Monthly Average Interdialytic Weight Gain	2.62 (±0.34)	2.65 (±0.27)	2.61 (±0.33)	2.6 (±0.46)	0.10	0.903
FOLLOW-UP						
Hemoglobin	9.97 (±0.62)	10.06 (±0.56)	9.90 (±0.64)	10.19 (±0.59)	1.87	0.160
Phosphorus	5.588 (±0.74)	5.55 (±0.66)	5.54 (±0.74)	5.84 (±0.85)	1.28	0.283
Albumin	3.83 (±0.27)	3.78 (±0.30)	3.82 (±0.29)	3.91 (±0.17)	1.17	0.314
URR (Urea Reduction Ratio)	78.25 (±4.18)	79.41 (±4.25)	77.82 (±4.30)	78.88 (±3.43)	1.38	0.255
Hospitalizations	0.16 (±1.22)	0.11 (±0.32)	0.22 (±1.48)	0 (±0.0)	0.27	0.767
Shorted Treatments	0.54 (±0.58)	0.32 (±0.58)	0.55 (±0.57)	0.74 (±0.56)	2.59	0.079
Missed Treatments	0.27 (±1.27)	0.21 (±0.42)	0.31 (±1.51)	0.16 (±0.50)	0.13	0.880
Monthly Average Interdialytic Weight Gain	2.59 (±0.26)	2.53 (±0.26)	2.61 (±0.26)	2.59 (±0.27)	0.68	0.511

Table 4.9

Clinical Values by KDQoL Effects Component

	Total	Below Average	Average	Above Average	f	P
BASELINE						
Hemoglobin	9.77 (±0.69)	9.47 (±0.84)	9.85 (±0.63)	9.70 (±0.74)	2.17	0.119
Phosphorus	5.66 (±0.67)	5.44 (±0.55)	5.62 (±0.66)	6.01 (±0.69)	3.96	0.022
Albumin	3.71 (±0.34)	3.63 (±0.33)	3.73 (±0.35)	3.69 (±0.32)	0.60	0.553
URR (Urea Reduction Ratio)	79.47 (±3.63)	79.8 (±3.95)	79.35 (±3.60)	79.71 (±3.67)	0.15	0.859
Hospitalizations	0.09 (±0.35)	0.38 (±0.72)	0.05 (±0.22)	0.05 (±0.22)	6.59	0.002
Shorted Treatments	0.21 (±0.55)	0.31 (±0.60)	0.19 (±0.51)	0.2 (±0.70)	0.34	0.713
Missed Treatments	0.23 (±0.60)	0.44 (±0.73)	0.2 (±0.54)	0.2 (±0.70)	1.10	0.336
Monthly Average Interdialytic Weight Gain	2.62 (±0.34)	2.61 (±0.33)	2.63 (±0.36)	2.57 (±0.26)	0.25	0.778
FOLLOW-UP						
Hemoglobin	9.97 (±0.62)	9.92 (±0.58)	9.99 (±0.63)	9.95 (±0.67)	0.12	0.889
Phosphorus	5.588 (±0.74)	5.33 (±0.57)	5.63 (±0.76)	5.64 (±0.79)	1.11	0.335
Albumin	3.83 (±0.27)	3.76 (±0.38)	3.84 (±0.26)	3.81 (±0.23)	0.63	0.537
URR (Urea Reduction Ratio)	78.25 (±4.18)	78.79 (±3.97)	78.32 (±4.14)	77.54 (±4.58)	0.43	0.652
Hospitalizations	0.16 (±1.22)	0.19 (±0.40)	0.2 (±1.46)	0 (±0.0)	0.22	0.807
Shorted Treatments	0.54 (±0.58)	0.56 (±0.73)	0.49 (±0.55)	0.75 (±0.55)	1.66	0.194
Missed Treatments	0.27 (±1.27)	0.13 (±0.34)	0.34 (±1.51)	0.1 (±0.31)	0.39	0.676
Monthly Average Interdialytic Weight Gain	2.59 (±0.26)	2.48 (±0.26)	2.60 (±0.27)	2.65 (±.023)	2.17	0.120

Table 4.10

Changes in Hemoglobin Clinical Values Over Time based on KDQoL at Baseline (n = 116)

	Baseline	3-Month Follow-Up	Paired Sample T-Tests			
					95% CI	
	Mean (SD)	Mean (SD)	t	P	Lower	Upper
Physical Component						
Below Average	9.66 (±0.55)	9.95 (±0.62)	-1.741	0.097	-0.62795	0.05653
Average	9.77 (±0.76)	9.96 (±0.64)	-1.782	0.079	-0.40847	0.02318
Above Average	9.86 (±0.60)	10.03 (±0.61)	-1.078	0.291	-0.50606	0.15791
Mental Component						
Below Average	9.58 (±1.07)	10.08 (±0.76)	-1.341	0.207	-1.32086	0.32086
Average	9.76 (±0.65)	9.97 (±0.61)	-2.394	0.019	-0.38068	-0.03491
Above Average	9.87 (±0.58)	9.94 (±0.61)	-0.405	0.689	-0.40519	0.27186
Burden Component						
Below Average	9.55 (±0.91)	9.79 (±0.65)	-0.698	0.496	-0.9501	0.48343
Average	9.76 (±0.64)	9.99 (±0.64)	-2.608	0.011	-0.40922	-0.05478
Above Average	9.93 (±0.67)	10.04 (±0.57)	-0.724	0.475	-0.42862	0.20554
Symptom Component						
Below Average	9.68 (±0.89)	10.06 (±0.56)	-1.502	0.151	-0.89647	0.14911
Average	9.74 (±0.66)	9.90 (±0.64)	-1.805	0.075	-0.34509	0.01689
Above Average	9.98 (±0.57)	10.19 (±0.59)	-1.115	0.279	-0.59201	0.18149
Effects Component						
Below Average	9.47 (±0.84)	9.92 (±0.58)	-1.603	0.13	-1.04845	0.14845
Average	9.85 (±0.63)	9.99 (±0.63)	-1.654	0.102	-0.32226	0.02976
Above Average	9.70 (±0.74)	9.95 (±0.67)	-1.302	0.208	-0.63876	0.14876

Table 4.11

Changes in Phosphorus Clinical Values Over Time based on KDQoL at Baseline (n = 116)

	Baseline	3-Month Follow-Up	Paired Sample T-Tests			
					95% CI	
	Mean (SD)	Mean (SD)	t	P	Lower	Upper
Physical Component						
Below Average	5.45 (±0.61)	5.50 (±0.64)	-0.233	0.818	-0.47381	0.37857
Average	5.73 (±0.65)	5.56 (±0.77)	1.576	0.12	-0.04584	0.38996
Above Average	5.64 (±0.73)	5.73 (±0.77)	-0.558	0.582	-0.38176	0.2188
Mental Component						
Below Average	6.04 (±0.69)	5.39 (±0.76)	2.551	0.027	0.08918	1.21082
Average	5.57 (±0.66)	5.58 (±0.71)	-0.094	0.925	-0.20176	0.18358
Above Average	5.75 (±0.62)	5.70 (±0.84)	0.303	0.764	-0.29999	0.40369
Burden Component						
Below Average	5.73 (±0.67)	5.45 (±0.69)	1.148	0.27	-0.23743	0.78409
Average	5.64 (±0.66)	5.53 (±0.73)	1.037	0.303	-0.09712	0.30779
Above Average	5.70 (±0.70)	5.83 (±0.79)	-0.822	0.419	-0.47177	0.20253
Symptom Component						
Below Average	5.50 (±0.61)	5.55 (±0.66)	-0.239	0.814	-0.46365	0.36892
Average	5.74 (±0.67)	5.54 (±0.74)	1.926	0.058	-0.00675	0.40419
Above Average	5.52 (±0.70)	5.84 (±0.85)	-2.313	0.033	-0.61272	-0.02938
Effects Component						
Below Average	5.44 (±0.55)	5.33 (±0.57)	0.559	0.584	-0.31639	0.54139
Average	5.62 (±0.66)	5.63 (±0.76)	-0.103	0.918	-0.20383	0.18383
Above Average	6.01 (±0.69)	5.64 (±0.79)	1.806	0.087	-0.05952	0.80952

Table 4.12

Changes in Albumin Clinical Values Over Time based on KDQoL at Baseline (n = 116)

	Baseline	3-Month Follow-Up	Paired Sample T-Tests			
	Mean (SD)	Mean (SD)	t	P	Lower	95% CI Upper
Physical Component						
Below Average	3.62 (±0.37)	3.78 (±0.34)	-1.676	0.109	-0.3527	0.03842
Average	3.73 (±0.34)	3.83 (±0.27)	-2.25	0.028	-0.19703	-0.0118
Above Average	3.73 (±0.32)	3.86 (±0.23)	-1.662	0.109	-0.2817	0.02985
Mental Component						
Below Average	3.78 (±0.34)	3.77 (±0.31)	0.181	0.86	-0.18577	0.2191
Average	3.71 (±0.36)	3.81 (±0.29)	-2.365	0.021	-0.19618	-0.01681
Above Average	3.68 (±0.30)	3.89 (±0.21)	-2.806	0.009	-0.37217	-0.05746
Burden Component						
Below Average	3.65 (±0.29)	3.72 (±0.32)	-0.827	0.422	-0.26341	0.11674
Average	3.70 (±0.35)	3.84 (±0.28)	-3.167	0.002	-0.23676	-0.0539
Above Average	3.77 (±0.34)	3.84 (±0.21)	-0.872	0.391	-0.23271	0.09425
Symptom Component						
Below Average	3.64 (±0.35)	3.78 (±0.30)	-1.924	0.07	-0.2973	0.01309
Average	3.72 (±0.34)	3.82 (±0.29)	-2.055	0.043	-0.18174	-0.00287
Above Average	3.71 (±0.36)	3.91 (±0.17)	-2.062	0.054	-0.41442	0.00389
Effects Component						
Below Average	3.63 (±0.33)	3.76 (±0.38)	-1.331	0.203	-0.34146	0.07896
Average	3.73 (±0.35)	3.84 (±0.26)	-2.632	0.01	-0.20196	-0.02804
Above Average	3.69 (±0.32)	3.81 (±0.23)	-1.367	0.188	-0.31639	0.06639

Table 4.13

Changes in URR Clinical Values Over Time based on KDQoL at Baseline (n = 116)

	Baseline	3-Month Follow-Up	Paired Sample T-Tests			
					95% CI	
	Mean (SD)	Mean (SD)	t	P	Lower	Upper
Physical Component						
Below Average	80.11 (±2.74)	79.34 (±4.55)	0.606	0.551	-1.88385	3.42671
Average	79.33 (±3.90)	77.87 (±4.08)	2.038	0.046	0.03011	2.90519
Above Average	79.32 (±3.59)	78.39 (±4.10)	1.033	0.311	-0.92801	2.80209
Mental Component						
Below Average	78.80 (±3.99)	77.57 (±3.85)	0.665	0.52	-2.85035	5.31702
Average	79.80 (±3.33)	78.41 (±4.45)	2.123	0.037	0.08607	2.70614
Above Average	78.82 (±4.28)	78.11 (±3.55)	0.739	0.466	-1.25341	2.66082
Burden Component						
Below Average	79.76 (±3.33)	78.35 (±3.72)	1.112	0.285	-1.30537	4.1187
Average	79.55 (±3.66)	78.18 (±4.34)	1.914	0.059	-0.05624	2.80291
Above Average	79.06 (±3.83)	78.4 (±4.08)	0.814	0.423	-1.01195	2.33503
Symptom Component						
Below Average	78.45 (±4.43)	79.41 (±4.25)	-0.651	0.523	-4.07167	2.14535
Average	79.74 (±3.48)	77.82 (±4.30)	2.903	0.005	0.6035	3.24009
Above Average	79.39 (±3.39)	78.88 (±3.43)	0.89	0.385	-0.69475	1.7158
Effects Component						
Below Average	79.80 (±3.95)	78.79 (±3.97)	0.748	0.466	-1.87224	3.89724
Average	79.35 (±3.60)	78.32 (±4.14)	1.601	0.113	-0.24903	2.29403
Above Average	79.71 (±3.67)	77.54 (±4.58)	1.735	0.099	-0.44704	4.77704

Table 4.14

Changes in Hospitalization Clinical Values Over Time based on KDQoL at Baseline (n = 116)

	Baseline	3-Month Follow-Up	Paired Sample T-Tests			
						95% CI
	Mean (SD)	Mean (SD)	t	P	Lower	Upper
Physical Component						
Below Average	0.10 (±0.30)	0.10 (±0.30)	--	--	--	--
Average	0.13 (±0.42)	0.24 (±1.59)	-0.512	0.61	-0.504	0.298
Above Average	0 (±0)	0.04 (±0.19)	-1	0.327	-0.113	0.039
Mental Component						
Below Average	0.33 (±0.65)	1.08 (±3.75)	-0.664	0.52	-3.235	1.735
Average	0.08 (±0.32)	0.05 (±0.22)	0.63	0.531	-0.056	0.108
Above Average	0.04 (±0.19)	0.07 (±0.27)	-1	0.327	-0.113	0.039
Burden Component						
Below Average	0.27 (±0.59)	0.13 (±0.35)	0.807	0.433	-0.221	0.488
Average	0.08 (±0.32)	0.23 (±1.51)	-0.82	0.415	-0.503	0.21
Above Average	0.04 (±0.20)	0 (±0.0)	1	0.327	-0.041	0.118
Symptom Component						
Below Average	0.26 (±0.56)	0.11 (±0.32)	1.143	0.268	-0.132	0.448
Average	0.08 (±0.31)	0.22 (±1.48)	-0.82	0.414	-0.483	0.201
Above Average	0 (±0.0)	0 (±0.0)	--	--	--	--
Effects Component						
Below Average	0.38 (±0.72)	0.19 (±0.40)	0.899	0.383	-0.257	0.632
Average	0.05 (±0.22)	0.20 (±1.46)	-0.909	0.366	-0.479	0.179
Above Average	0.05 (±0.22)	0 (±0.0)	1	0.33	-0.055	0.155

Table 4.15

Changes in Shortened Treatments Clinical Values Over Time based on KDQoL at Baseline (n = 116)

	Baseline	3-Month Follow-Up	Paired Sample T-Tests			
						95% CI
	Mean (SD)	Mean (SD)	t	P	Lower	Upper
Physical Component						
Below Average	0.29 (±0.72)	0.48 (±0.60)	-0.94	0.358	-0.613	0.232
Average	0.22 (±0.54)	0.50 (±0.56)	-2.574	0.012	-0.496	-0.063
Above Average	0.11 (±0.42)	0.70 (±0.61)	-5.38	0	-0.819	-0.366
Mental Component						
Below Average	0.42 (±0.67)	0.42 (±0.52)	0	1	-0.664	0.664
Average	0.21 (±0.52)	0.52 (±0.60)	-3.496	0.001	-0.489	-0.134
Above Average	0.11 (±.058)	0.67 (±0.56)	-3.238	0.003	-0.908	-0.203
Burden Component						
Below Average	0.40 (±0.74)	0.53 (±0.64)	-0.564	0.582	-0.64	0.374
Average	0.20 (±0.49)	0.53 (±0.60)	-3.489	0.001	-0.524	-0.143
Above Average	0.12 (±0)	0.58 (±0.50)	-2.739	0.011	-0.809	-0.114
Symptom Component						
Below Average	0.26 (±0.65)	0.32 (±0.58)	-0.325	0.749	-0.392	0.287
Average	0.24 (±0.59)	0.55 (±0.57)	-3.013	0.003	-0.511	-0.104
Above Average	0 (±0.0)	0.74 (±0.56)	-5.715	0	-1.008	-0.466
Effects Component						
Below Average	0.31 (±0.60)	0.56 (±0.73)	-1.168	0.261	-0.706	0.206
Average	0.19 (±0.51)	0.49 (±0.55)	-3.346	0.001	-0.478	-0.122
Above Average	0.20 (±0.70)	0.75 (±0.55)	-2.463	0.024	-1.017	-0.083

Table 4.16

Changes in Missed Treatments Clinical Values Over Time based on KDQoL at Baseline (n = 116)

	Baseline	3-Month Follow-Up	Paired Sample T-Tests			
	Mean (SD)	Mean (SD)	t	P	Lower	95% CI Upper
Physical Component						
Below Average	0.24 (±0.70)	0.24 (±0.54)	0	1	-0.432	0.432
Average	0.26 (±0.61)	0.32 (±1.61)	-0.277	0.783	-0.483	0.365
Above Average	0.15 (±0.46)	0.15 (±0.46)	0	1	-0.269	0.269
Mental Component						
Below Average	0.42 (±0.79)	1.17 (±3.74)	-0.66	0.523	-3.25	1.75
Average	0.19 (±0.54)	0.16 (±0.40)	0.491	0.625	-0.119	0.197
Above Average	0.26 (±0.66)	0.19 (±0.56)	0.42	0.678	-0.289	0.437
Burden Component						
Below Average	0.53 (±0.83)	0.20 (±0.56)	1.234	0.238	-0.246	0.913
Average	0.19 (±0.51)	0.33 (±1.55)	-0.766	0.446	-0.528	0.235
Above Average	0.19 (±0.63)	0.12 (±0.33)	0.527	0.603	-0.224	0.378
Symptom Component						
Below Average	0.47 (±0.77)	0.21 (±0.42)	1.316	0.205	-0.157	0.683
Average	0.22 (±0.60)	0.31 (±1.51)	-0.475	0.636	-0.466	0.286
Above Average	0.05 (±0.23)	0.16 (±0.50)	-0.809	0.429	-0.379	0.168
Effects Component						
Below Average	0.44 (±0.73)	0.13 (±0.34)	1.576	0.136	-0.11	0.735
Average	0.20 (±0.54)	0.34 (±1.51)	-0.752	0.454	-0.502	0.227
Above Average	0.20 (±0.70)	0.10 (±0.31)	0.567	0.577	-0.269	0.469

Table 4.17

Changes in Average Interdialetic Weight Gain Clinical Values Over Time based on KDQoL at Baseline (n = 116)

	Baseline	3-Month Follow-Up	Paired Sample T-Tests			
						95% CI
	Mean (SD)	Mean (SD)	t	P	Lower	Upper
Physical Component						
Below Average	2.59 (±0.33)	2.50 (±0.27)	0.923	0.367	-0.10204	0.26395
Average	2.64 (±0.32)	2.61 (±0.26)	0.499	0.62	-0.08387	0.13975
Above Average	2.57 (±0.40)	2.61 (±0.27)	-0.44	0.666	-0.21	0.14
Mental Component						
Below Average	2.53 (±0.28)	2.48 (±0.24)	0.445	0.665	-0.19756	0.29756
Average	2.64 (±0.34)	2.61 (±0.27)	0.519	0.605	-0.0773	0.13185
Above Average	2.60 (±0.37)	2.60 (±0.25)	-0.044	0.965	-0.17595	0.16855
Burden Component						
Below Average	2.56 (±0.27)	2.55 (±0.23)	0.147	0.885	-0.18062	0.20729
Average	2.61 (±0.33)	2.59 (±0.27)	0.389	0.698	-0.08241	0.12241
Above Average	2.66 (±0.41)	2.62 (±0.27)	0.349	0.73	-0.16941	0.23864
Symptom Component						
Below Average	2.65 (±0.27)	2.53 (±0.26)	1.167	0.258	-0.09261	0.32419
Average	2.61 (±0.33)	2.61 (±0.26)	0.05	0.961	-0.10053	0.10566
Above Average	2.60 (±0.46)	2.59 (±0.27)	0.111	0.913	-0.18943	0.21048
Effects Component						
Below Average	2.61 (±0.33)	2.48 (±0.26)	1.183	0.255	-0.10523	0.36773
Average	2.63 (±0.36)	2.60 (±0.27)	0.505	0.615	-0.07721	0.12971
Above Average	2.57 (±0.26)	2.65 (±.023)	-1.021	0.32	-0.24396	0.08396

Table 4.18

Clinical Changes by KDQoL Physical Component at Baseline (n=116)

	Total	Below Average	Average	Above Average	Total	x2	P
Hemoglobin						1.924[a]	0.927
Comply Both Times	19.80%	14.30%	22.10%	18.50%	19.80%		
Got Better	33.60%	42.90%	29.40%	37.00%	33.60%		
Got Worse	16.40%	14.30%	16.20%	18.50%	16.40%		
Non-Compliant Both Times	30.20%	28.60%	32.40%	25.90%	30.20%		
Phosphorus						12.229[a]	0.057
Comply Both Times	33.60%	42.90%	30.90%	33.30%	33.60%		
Got Better	25.90%	19.00%	32.40%	14.80%	25.90%		
Got Worse	18.10%	33.30%	14.70%	14.80%	18.10%		
Non-Compliant Both Times	22.40%	4.80%	22.10%	37.00%	22.40%		
Albumin						1.198[a]	0.977
Comply Both Times	8.60%	4.80%	8.80%	11.10%	8.60%		
Got Better	21.60%	23.80%	20.60%	22.20%	21.60%		
Got Worse	13.80%	9.50%	14.70%	14.80%	13.80%		
Non-Compliant Both Times	56.00%	61.90%	55.90%	51.90%	56.00%		
URR (Urea Reduction Ratio)						-	-
Comply Both Times	100.00%	100.00%	100.00%	100.00%	100.00%		
Got Better	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Worse	0.00%	0.00%	0.00%	0.00%	0.00%		
Non-Compliant Both Times	0.00%	0.00%	0.00%	0.00%	0.00%		
Hospitalizations						15.668[a]	0.016
Comply Both Times	87.90%	90.50%	83.80%	96.30%	87.90%		
Got Better	6.00%	0.00%	10.30%	0.00%	6.00%		
Got Worse	4.30%	0.00%	5.90%	3.70%	4.30%		
Non-Compliant Both Times	1.70%	9.50%	0.00%	0.00%	1.70%		

	Total	Below Average	Average	Above Average	Total	x2	P
Shorted Treatments						7.369[a]	0.288
Comply Both Times	37.90%	42.90%	36.80%	37.00%	37.90%		
Got Better	12.10%	14.30%	16.20%	0.00%	12.10%		
Got Worse	46.60%	38.10%	45.60%	55.60%	46.60%		
Non-Compliant Both Times	3.40%	4.80%	1.50%	7.40%	3.40%		
Missed Treatments						3.023[a]	0.806
Comply Both Times	71.60%	66.70%	70.60%	77.80%	71.60%		
Got Better	14.70%	14.30%	16.20%	11.10%	14.70%		
Got Worse	12.10%	19.00%	10.30%	11.10%	12.10%		
Non-Compliant Both Times	1.70%	0.00%	2.90%	0.00%	1.70%		
Monthly Average Interdialytic Weight Gain						-	-
Comply Both Times	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Better	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Worse	0.00%	0.00%	0.00%	0.00%	0.00%		
Non-Compliant Both Times	100.00%	100.00%	100.00%	100.00%	100.00%		

Table 4.19

Clinical Changes by KDQoL Mental Component at Baseline (n=116)

	Total	Below Average	Average	Above Average	Total	x2	P
Hemoglobin						6.556[a]	0.364
Comply Both Times	19.80%	16.70%	22.10%	14.80%	19.80%		
Got Better	33.60%	41.70%	31.20%	37.00%	33.60%		
Got Worse	16.40%	8.30%	13.00%	29.60%	16.40%		
Non-Compliant Both Times	30.20%	33.30%	33.80%	18.50%	30.20%		
Phosphorus						16.711[a]	0.01
Comply Both Times	33.60%	16.70%	37.70%	29.60%	33.60%		
Got Better	25.90%	58.30%	19.50%	29.60%	25.90%		
Got Worse	18.10%	8.30%	24.70%	3.70%	18.10%		
Non-Compliant Both Times	22.40%	16.70%	18.20%	37.00%	22.40%		
Albumin						5.283[a]	0.508
Comply Both Times	8.60%	16.70%	10.40%	0.00%	8.60%		
Got Better	21.60%	16.70%	19.50%	29.60%	21.60%		
Got Worse	13.80%	8.30%	15.60%	11.10%	13.80%		
Non-Compliant Both Times	56.00%	58.30%	54.50%	59.30%	56.00%		
URR (Urea Reduction Ratio)						-	-
Comply Both Times	100.00%	100.00%	100.00%	100.00%	100.00%		
Got Better	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Worse	0.00%	0.00%	0.00%	0.00%	0.00%		
Non-Compliant Both Times	0.00%	0.00%	0.00%	0.00%	0.00%		
Hospitalizations						10.986[a]	0.089
Comply Both Times	87.90%	66.70%	89.60%	92.60%	87.90%		
Got Better	6.00%	25.00%	5.20%	0.00%	6.00%		
Got Worse	4.30%	8.30%	3.90%	3.70%	4.30%		
Non-Compliant Both Times	1.70%	0.00%	1.30%	3.70%	1.70%		

	Total	Below Average	Average	Above Average	Total	x2	P
Shorted Treatments						11.079[a]	0.086
Comply Both Times	37.90%	25.00%	41.60%	33.30%	37.90%		
Got Better	12.10%	33.30%	11.70%	3.70%	12.10%		
Got Worse	46.60%	41.70%	41.60%	63.00%	46.60%		
Non-Compliant Both Times	3.40%	0.00%	5.20%	0.00%	3.40%		
Missed Treatments						4.314[a]	0.634
Comply Both Times	71.60%	66.70%	72.70%	70.40%	71.60%		
Got Better	14.70%	16.70%	13.00%	18.50%	14.70%		
Got Worse	12.10%	8.30%	13.00%	11.10%	12.10%		
Non-Compliant Both Times	1.70%	8.30%	1.30%	0.00%	1.70%		
Monthly Average Interdialytic Weight Gain						-	-
Comply Both Times	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Better	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Worse	0.00%	0.00%	0.00%	0.00%	0.00%		
Non-Compliant Both Times	100.00%	100.00%	100.00%	100.00%	100.00%		

Table 4.20

Clinical Changes by KDQoL Burden Component at Baseline (n=116)

	Total	Below Average	Average	Above Average	Total	x2	P
Hemoglobin						3.721[a]	0.714
Comply Both Times	19.80%	6.70%	21.30%	23.10%	19.80%		
Got Better	33.60%	46.70%	33.30%	26.90%	33.60%		
Got Worse	16.40%	13.30%	14.70%	23.10%	16.40%		
Non-Compliant Both Times	30.20%	33.30%	30.70%	26.90%	30.20%		
Phosphorus						7.233[a]	0.3
Comply Both Times	33.60%	26.70%	37.30%	26.90%	33.60%		
Got Better	25.90%	40.00%	26.70%	15.40%	25.90%		
Got Worse	18.10%	20.00%	17.30%	19.20%	18.10%		
Non-Compliant Both Times	22.40%	13.30%	18.70%	38.50%	22.40%		
Albumin						3.864[a]	0.695
Comply Both Times	8.60%	6.70%	8.00%	11.50%	8.60%		
Got Better	21.60%	20.00%	24.00%	15.40%	21.60%		
Got Worse	13.80%	6.70%	12.00%	23.10%	13.80%		
Non-Compliant Both Times	56.00%	66.70%	56.00%	50.00%	56.00%		
URR (Urea Reduction Ratio)						-	-
Comply Both Times	100.00%	100.00%	100.00%	100.00%	100.00%		
Got Better	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Worse	0.00%	0.00%	0.00%	0.00%	0.00%		
Non-Compliant Both Times	0.00%	0.00%	0.00%	0.00%	0.00%		
Hospitalizations						6.291[a]	0.391
Comply Both Times	87.90%	73.30%	88.00%	96.20%	87.90%		
Got Better	6.00%	13.30%	5.30%	3.80%	6.00%		
Got Worse	4.30%	6.70%	5.30%	0.00%	4.30%		
Non-Compliant Both Times	1.70%	6.70%	1.30%	0.00%	1.70%		

	Total	Below Average	Average	Above Average	Total	x2	P
Shorted Treatments						4.784[a]	0.572
Comply Both Times	37.90%	33.30%	38.70%	38.50%	37.90%		
Got Better	12.10%	20.00%	13.30%	3.80%	12.10%		
Got Worse	46.60%	40.00%	44.00%	57.70%	46.60%		
Non-Compliant Both Times	3.40%	6.70%	4.00%	0.00%	3.40%		
Missed Treatments						5.233[a]	0.514
Comply Both Times	71.60%	60.00%	72.00%	76.90%	71.60%		
Got Better	14.70%	26.70%	13.30%	11.50%	14.70%		
Got Worse	12.10%	6.70%	13.30%	11.50%	12.10%		
Non-Compliant Both Times	1.70%	6.70%	1.30%	0.00%	1.70%		
Monthly Average Interdialytic Weight Gain						-	-
Comply Both Times	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Better	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Worse	0.00%	0.00%	0.00%	0.00%	0.00%		
Non-Compliant Both Times	100.00%	100.00%	100.00%	100.00%	100.00%		

Table 4.21

Clinical Changes by KDQoL Symptoms Component at Baseline (n=116)

	Total	Below Average	Average	Above Average	Total	x2	P
Hemoglobin						4.541[a]	0.604
Comply Both Times	19.80%	21.10%	17.90%	26.30%	19.80%		
Got Better	33.60%	42.10%	32.10%	31.60%	33.60%		
Got Worse	16.40%	10.50%	15.40%	26.30%	16.40%		
Non-Compliant Both Times	30.20%	26.30%	34.60%	15.80%	30.20%		
Phosphorus						14.559[a]	0.024
Comply Both Times	33.60%	31.60%	30.80%	47.40%	33.60%		
Got Better	25.90%	26.30%	32.10%	0.00%	25.90%		
Got Worse	18.10%	31.60%	16.70%	10.50%	18.10%		
Non-Compliant Both Times	22.40%	10.50%	20.50%	42.10%	22.40%		
Albumin						5.253[a]	0.512
Comply Both Times	8.60%	15.80%	6.40%	10.50%	8.60%		
Got Better	21.60%	10.50%	23.10%	26.30%	21.60%		
Got Worse	13.80%	5.30%	16.70%	10.50%	13.80%		
Non-Compliant Both Times	56.00%	68.40%	53.80%	52.60%	56.00%		
URR (Urea Reduction Ratio)						-	-
Comply Both Times	100.00%	100.00%	100.00%	100.00%	100.00%		
Got Better	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Worse	0.00%	0.00%	0.00%	0.00%	0.00%		
Non-Compliant Both Times	0.00%	0.00%	0.00%	0.00%	0.00%		
Hospitalizations						7.781[a]	0.255
Comply Both Times	87.90%	73.70%	88.50%	100.00%	87.90%		
Got Better	6.00%	15.80%	5.10%	0.00%	6.00%		
Got Worse	4.30%	5.30%	5.10%	0.00%	4.30%		
Non-Compliant Both Times	1.70%	5.30%	1.30%	0.00%	1.70%		

	Total	Below Average	Average	Above Average	Total	x2	P
Shorted Treatments						12.357[a]	0.054
Comply Both Times	37.90%	63.20%	33.30%	31.60%	37.90%		
Got Better	12.10%	10.50%	15.40%	0.00%	12.10%		
Got Worse	46.60%	21.10%	47.40%	68.40%	46.60%		
Non-Compliant Both Times	3.40%	5.30%	3.80%	0.00%	3.40%		
Missed Treatments						12.946[a]	0.044
Comply Both Times	71.60%	57.90%	71.80%	84.20%	71.60%		
Got Better	14.70%	21.10%	15.40%	5.30%	14.70%		
Got Worse	12.10%	10.50%	12.80%	10.50%	12.10%		
Non-Compliant Both Times	1.70%	10.50%	0.00%	0.00%	1.70%		
Monthly Average Interdialytic Weight Gain						-	-
Comply Both Times	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Better	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Worse	0.00%	0.00%	0.00%	0.00%	0.00%		
Non-Compliant Both Times	100.00%	100.00%	100.00%	100.00%	100.00%		

Table 4.22

Clinical Changes by KDQoL Effects Component at Baseline (n=116)

	Total	Below Average	Average	Above Average	Total	x2	P
Hemoglobin						2.121[a]	0.908
Comply Both Times	19.80%	18.80%	20.00%	20.00%	19.80%		
Got Better	33.60%	43.80%	32.50%	30.00%	33.60%		
Got Worse	16.40%	6.30%	18.80%	15.00%	16.40%		
Non-Compliant Both Times	30.20%	31.30%	28.70%	35.00%	30.20%		
Phosphorus						5.867[a]	0.438
Comply Both Times	33.60%	50.00%	32.50%	25.00%	33.60%		
Got Better	25.90%	25.00%	23.80%	35.00%	25.90%		
Got Worse	18.10%	18.80%	20.00%	10.00%	18.10%		
Non-Compliant Both Times	22.40%	6.30%	23.80%	30.00%	22.40%		
Albumin						3.198[a]	0.784
Comply Both Times	8.60%	12.50%	8.80%	5.00%	8.60%		
Got Better	21.60%	25.00%	22.50%	15.00%	21.60%		
Got Worse	13.80%	6.30%	16.30%	10.00%	13.80%		
Non-Compliant Both Times	56.00%	56.30%	52.50%	70.00%	56.00%		
URR (Urea Reduction Ratio)						-	-
Comply Both Times	100.00%	100.00%	100.00%	100.00%	100.00%		
Got Better	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Worse	0.00%	0.00%	0.00%	0.00%	0.00%		
Non-Compliant Both Times	0.00%	0.00%	0.00%	0.00%	0.00%		
Hospitalizations						12.165[a]	0.058
Comply Both Times	87.90%	62.50%	91.30%	95.00%	87.90%		
Got Better	6.00%	18.80%	3.80%	5.00%	6.00%		
Got Worse	4.30%	12.50%	3.80%	0.00%	4.30%		
Non-Compliant Both Times	1.70%	6.30%	1.30%	0.00%	1.70%		

	Total	Below Average	Average	Above Average	Total	x2	P
Shorted Treatments						5.138[a]	0.526
Comply Both Times	37.90%	37.50%	41.30%	25.00%	37.90%		
Got Better	12.10%	18.80%	12.50%	5.00%	12.10%		
Got Worse	46.60%	37.50%	43.80%	65.00%	46.60%		
Non-Compliant Both Times	3.40%	6.30%	2.50%	5.00%	3.40%		
Missed Treatments						4.950[a]	0.55
Comply Both Times	71.60%	62.50%	71.30%	80.00%	71.60%		
Got Better	14.70%	25.00%	13.80%	10.00%	14.70%		
Got Worse	12.10%	6.30%	13.80%	10.00%	12.10%		
Non-Compliant Both Times	1.70%	6.30%	1.30%	0.00%	1.70%		
Monthly Average Interdialytic Weight Gain						-	-
Comply Both Times	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Better	0.00%	0.00%	0.00%	0.00%	0.00%		
Got Worse	0.00%	0.00%	0.00%	0.00%	0.00%		
Non-Compliant Both Times	100.00%	100.00%	100.00%	100.00%	100.00%		

CHAPTER 5

SUMMARY AND CONCLUSION

Literature Review Summary

End Stage Renal Disease is a chronic illness in which the kidneys no longer function at a level capable of sustaining life and requires an individual either partake in dialysis or receive a kidney transplant. With over half of a million people on dialysis in the United States (USRDS, 2016), ESRD is a prevalent health problem. Data collected by USRDS in 2014 also shows that Blacks and Asians have a higher prevalence of ESRD than their White counterparts (USRDS, 2016). Imperative to positive health outcomes in dialysis is compliance with prescribed treatment schedules, medication compliance, following recommended fluid restrictions, and adherence to a renal diet. Each of these items has a direct effect on the life of the individual on dialysis and requires active participation on their part.

According to Bosworth et al. (2006), ‘compliance’, ‘adherence’, and ‘concordance’ are often used interchangeably. Zweben & Zuckoff (2002) state that adherence is used to describe the extent to which an individual follows prescribed actions or treatment recommendations. Nonadherence to treatment regimens can lead to medical problems and an increased risk of mortality (Leggat et al, 1998; Kimmel, Peterson, & Weihs, 1998; Bleyer, Hylander, & Sudo, 1999; Theofilou, 2011). Dobrof et al. (2001) found that 27 to 31% of dialysis patients missed one treatment per month, treatment was cut short by 35 to 41% of patients, and 76 to 85% of patients struggled with adhering to the renal diet. With nonadherence to treatment recommendations being an ongoing problem with individual on dialysis, it is important for clinical staff to understand the best ways to encourage and assist patients toward positive health outcomes.

The WHOQOL (1998) identified Quality of Life as multidimensional and including subjective perceptions regarding life. Valderrabano et al. (2001) found higher survival rates and less morbidity were associated with higher quality of life. Researchers have also recommending using surveys that capture both general and disease specific aspects of the individual's perceived health status and sense of well-being (Carmichael et al., 2000). Quality of Life can be compromised by intrusion of chronic illness on daily life. Individuals on dialysis are subjected to a regimented treatment program that demands several life style changes in order to maintain health. To best treat those on dialysis, CMS requires that dialysis clinics annually evaluate quality of life among patients with the KDQOL-36 being the preferred survey (Schatell & Witten, 2010; Lacson et al., 2010).

The Kidney Disease Quality of Life short form 36 (KDQOL-36) is a thirty-six question, self-report quality of life survey that captures an individual's perceptions on both general health and disease specific items. This survey scores into five subscales, Physical Component, Mental Component, Burden of Kidney Disease, Symptoms of Kidney Disease, and Effects of Kidney Disease and is to be given to each dialysis patient once they have been at the clinic 90 days and then annually. While the KDQOL-36 is not scorable by hand, there are companies that provide services that will score the survey and provide reports for both the patient and the medical record.

In reviewing the literature, it became clear that studies using the KDQOL-36 version of the survey were limited. This dissertation was designed to better understand the KDQOL-36 and the survey's use in clinical practice. The first manuscript in the is study provides a review of the

KDQOL-36 so that the origin and properties of the survey could be better understood. The two manuscripts that followed were data driving using patient characteristics, clinical lab values, and KDQOL-36 scores. The manuscript titled “Hemodialysis Patient Characteristics and Their Effect on KDQOL-36 Scores” was designed to (1) identify possible relationships between ESRD patient characteristics and KDQOL-36 scores; and (2) examine relationships between KDQOL-36 subscale scores. The primary research question of interest for this second manuscript was, do individuals with certain characteristics tend to score in specific ways on the KDQOL-36 subscales? The manuscript titled “KDQOL-36 Scores and Clinical Outcomes in Hemodialysis”, sought to (1) identify possible relationships between KDQOL-36 subscale scores and patient clinical data; and (2) compare changes in clinical data over time compared to KDQOL-36 subscale scores. The primary research question of interest was, does the KDQOL-36 provide clinical utility that could inform hemodialysis staff to better ensure positive health outcomes for patients?

Methods Summary

The sample for this study was drawn from existing data on hemodialysis patients that received dialysis at one of six clinics belonging to a privately-owned dialysis company. The convenience sample consisted of patients that had completed the KDQOL-36 from July 1, 2013 to June 30, 2014. There were 120 complete records during this collection time, however, the decision was made to remove four patients form the study; one due mobility level (stretcher) and three due to living arrangements (nursing home). For each patient, their KDQOL-36 individual answer responses, subscale scores, and subscale categorical scores were collected. In addition to patient attributes, clinical values were also collected for the month the individual took the KDQOL-36 and at three months following.

The sample of 116 patients was comprised of slightly more males (53.4%) than females (46.6%) with an age range from 25 to 96 (mean age, 60). The majority of patients were diabetic (65.5%), ambulatory without assistance (70.7%), married (44%), spoke English (83.6%), lived with others (88.8%) and claimed a religion (58.6%). African-Americans comprised the largest group (50.9%), followed by Whites (29.3%), Hispanics (10.3%), and then Asian/Pacific Islanders (9.5%). The sample patients had BMI ranging from 16.7 to 35.3 and with prescribed dialysis treatments ranging from 150 minutes to 255 minutes. The majority were under the care of a Nephrologist prior to starting dialysis (62.9%) and the range of time on dialysis at the time of survey ranged from 90 to 8523 days.

To attempt to answer the research question, “do individuals with certain characteristics tend to score in specific ways on the KDQOL-36 subscales?”, Chi Square and ANOVA analysis were used to identify possible relationships between patient attributes and KDQOL-36 categorical subscores. The decision was made to use the categorical levels of the subscale scores because those scores place individuals in groups based on standard deviations from the mean scores and those patients in the “below average” category of any subscale are identified for further support and education. Interrelatedness of the KDQOL-36 subscales was also analyzed using Pearson correlation.

The second data driven manuscript attempted to answer, “does the KDQOL-36 provide clinical utility that could inform hemodialysis staff to better ensure positive health outcomes for patients?” by looking at clinical data compared to KDQOL-36 subscale categorical scores using ANOVA, Chi Square, and Paired sample t-tests. Clinical values by KDQOL-36 subscale categorical scores were compared using one-way ANOVA, and Paired sample t-tests were used to identify changes over time in clinical values by KDQOL-36 subscale categorical scores.

Positive health outcome cut-off values, determined by KDQOI guidelines, were used to create Delta scores for the two points of data collection (month of taking survey and three months following) so the KDQOL-36 subscale categorical scores could be compared to clinical improvement. Chi Square tests analyzed the comparison of the Delta scores by KDQOL-36 subscale categorical scores.

Results Summary

There were several significant findings that are worth reviewing from the two data driven manuscripts. In comparing patient attributes by KDQOL-36 components, higher percentages of Spanish speaking patients were represented in the "below average" category of the Burden Component. The Burden Component contains questions relating to interference of kidney disease in life, time spent dealing with disease, and feeling like a burden to family which might have a greater impact on an individual's perceptions based on cultural views.

It was anticipated that physical activity would play a role in Physical Summary Component and it was found that those individuals that identified as "inactive" on their psychosocial were represented at higher percentages in the "below average" category of the PCS. Further data would be needed to determine the reason for inactivity, however, the majority of patients were ambulatory without assistance. This finding was consistent with research that has shown that higher physical activity levels are associated with better quality of life scores (Bize, et al., 2007; Anokye, et al., 2012). It is possible that diabetic complications influenced physical activity with loses in mobility and independence (Schie, 2008) since the majority of patients in the study were diabetic. Encouraging and promoting increases in physical activity by staff to dialysis patients appears to have promise in improving perceived quality of life. High scores on the Physical Component were associated with increases in Albumin levels, but also with shortened treatments at follow up. Those that are more “physically” able may have more choices in meal preparation or eating options and may also have more obligations, work or personal, that make “cheating” by shortening treatments seem an acceptable option. This study was not privy to the reason treatments were missed or shortened, but a sense of physical well-being may contribute to feeling that shortening a treatment would be acceptable. It is important for dialysis staff to stress and educate patients on the importance of each treatment for full duration to avoid poor health outcomes (Saran et al., 2003).

The Mental Component had positive relationships with all disease specific subscales of the KDQOL-36 and with BMI. Research has shown that obesity is a public health problem, can impair social and mental well-being, and is associated with lower health perception (Baskin et al., 2005; Doll et al., 2000; Katz et al., 2000; Yan et al., 2004; Kalantar-Zadeh et al., 2001). This study found that individuals with higher BMI tended to score poorly on the MCS component, agreeing with current research. Scoring poorly on the MCS was associated with poor scores on the disease specific components. This association is logical considering the experience of symptoms and disease related problems would increase the interference of the disease on daily life and result in additional emotional toll; and is supported by existing research (Kimmel et al. 2003; Theofilou, 2011). Research has indicated that depression is a risk factor involved in nonadherence with treatments (Theofilou, 2011; DiMatteo et al., 2000) and that poor MCS scores are associated with hospitalizations. Comparing KDQOL-36 MCS scores with clinical data found that poor MCS scores were associated with higher frequencies of hospitalization at both data collection points, and a higher frequency of missed treatments at follow up. It appears critical that dialysis staff screen patients for depression as mental aspects of quality of life are related to the intrusion of kidney disease on life (Theofilou, 2011; Abdel-Kader et al., 2009; Merkus et al., 1999; Lopes et al., 2002).

In analyzing the KDQOL-36 components subscales scores using Pearson Correlations and Chi square, positive relationships were identified among the disease specific components. Medical conditions, such as ESRD, can intrude on daily life and this interference appears to be represented across the disease components when and individual perceives poor effects on quality of life in one disease component. Dialysis staff should be aware that low scores in one disease specific arena likely is indicative of an individual’s poor perception about their kidney disease and treatment in other areas and should work to alleviate symptoms and to reduce the burden on of kidney disease on the daily life of the patient.

Methodological and Conceptual Concerns

This research project was limited in several ways. First, the sample size was small at only 120 data sets prior to the removal of four from analysis. A larger data set would have allowed for more in-depth analysis with more individuals falling into each category for investigation. It is also notable that the individuals were not receiving dialysis at the same clinic, however, the clinics were all in the same state and part of the same organization. The clinics were located in three different counties in the state. The individuals dialyzing at one of the four clinics in a suburban area would potentially have the most comparable environment outside of the dialysis days, such as work opportunities and access to other healthcare, transportation resources, grocery stores, restaurants, and leisure activities. While those in one of the more rural areas might have more limited resources. There is also a chance that staff interaction, education, and support with patients varied from clinic to clinic.

The KDQOL-36 is a self-report survey and is solely based on the individual's perception of their health at the time of taking the survey. Since it is based on perception, the person's actual health may vary for better or worse compared to how they answer questions on the survey. For example, a person could perceive their quality of life to be poor while still having positive health outcomes and clinical labs. Individuals could also be limited physically, such as being in a wheelchair, but still respond that they are not bothered by limitations on questions regarding physical activity. Likewise, some individuals might have a higher sensitivity to symptoms and respond with "extremely bothered" on questions, as opposed to individuals that are experiencing a symptom, but are not bothered by it. However, perception has been identified by research as possibly being more important than objective data in an individual's evaluation of their quality of life (Kimmel et al., 2003).

Due the high number of categorical data, many of the analysis were limited to Chi square tests. While these tests can identify significant relationships, it does not offer information on the strength of the relationship. Using the continuous subscale scores would have allowed for different statistical analysis, however, these scores have no current clinical meaning beyond if how many standard deviations they fall from the mean. A score of 50 versus 65 on the Burden of Kidney Disease component has little meaning compared to if the score falls in the "below average" or "average" category. Clinical staff is directed to further educate and support patients that fall into "below average" on any component subscale. Therefore, the categorical scores were chosen, but did limited the type of statistical analysis that could be utilized.

This study used existing data that included KDQOL-36 data, patient attributes, and clinical values, which at times was insufficient to fully understand the dynamics of a phenomena. There was no ability to further investigate results that were significant to better understand and explain the relationship, such as an individual’s reason for missing or shortening a treatment. Likewise, available information such as living arrangements do not communicate if living with others is a supportive environment or simply a status. Though there were no significant findings related to comorbid conditions, this data was limited in that it was collected from the CMS form 2728 which is generated at the time an individual started dialysis.

Another limitation to the study was the clinical data was collected for the month the individual took the KDQOL-36 and at a three-month follow-up, therefore these dates were not consistent for all patients. Poor clinical values at a collection point could be attributed to the time of year at which the data was collected, for example eating habits and obligations can change during holiday seasons. It is also unclear if there were staffing changes during these various points, changes in clinical operations, or educational focuses on the staff’s part. The researcher is also unaware of the level of review and education provided to each patient after taking the KDQOL-36 and being provided the patient report generated by kdqol-complete.org. It is possible that any intervention or education provided post KDQOL-36 influenced future clinical values and may not have been consistent across all patients.

While there is research using the KDQOL, there are not many studies that specifically use the KDQOL-36 as the survey of study. Any research that contributes to the field using the KDQOL-36 would be beneficial, especially those that could combine KDQOL-36 data with clinical information. Recommendations for future research would be to design a study that collects data for one year since the KDQOL-36 is given annually. This would allow for clinical data to be evaluated for twelve months and would provide two data point of KDQOL-36 scores for analysis. In conjunction with a larger sample size, this would allow for comparison of KDQOL-36 score changes by clinical values over time. There would be greater opportunity to catch missed or shortened treatment, hospitalizations, and mortalities over a year period. It would also be important to have a consistent response or intervention post KDQOL-36 for all patients and to have nurses make notations regarding the reason an individual missed or shortened a treatment to better understand the phenomena compared to KDQOL-36 scores, patient attributes, and clinical values. Being able to compare changing in KDQOL-36 scores over time in light of clinical values would be invaluable to the field and clinical practice in dialysis.

Physical activity level in this study was associated with better quality of life. However, the amount, type, and duration of physical activity was not part of the data collected. Future research should focus on better understanding the benefits of activity level in dialysis patients including recommendations for exercise/activity regimens, suitable for all mobility levels and age groups, that would have a positive influence on health outcomes.

Depression screenings in conjunction with the administration of the KDQOL-36 would provide a better understanding of Mental Component scores and disease specific components in relation to depression among dialysis patients. Also, having some qualitative understanding of patient attributes would also improve understanding for clinical utility, such as if living with others provides support, level of engagement with religion, access to resources, and culture values.

Since the is study was based on existing data that is common in the field of Nephrology, replicating this study would also be recommended. Standards in the field involve the KDQOL-36 being given annually and clinical values, reviewed in this study, collected monthly. Companies that are larger, such as DaVita or US Renal Care, should easily have access to thousands of dialysis patients KDQOL-36 and the clinical data to replicate this study.

Conclusions

Quality of life involves the perceived experience of the individual and is considered at time more important than objective data (Kimmel et al., 2003). This study was designed to better understand the KDQOL-36 and its use in clinical practice by attempting to answer the following two questions; (1) do individuals with certain characteristics tend to score in specific ways on the KDQOL-36 subscales? and (2) does the KDQOL-36 provide clinical utility that could inform hemodialysis staff to better ensure positive health outcomes for patients? The two data driven manuscripts contribute the field of nephrology by providing some insight into these questions.

Both this study and existing research has identified mental components of quality of life as playing a critical role in health outcomes. It is recommended that in regular practice that depression screens are conducted to assess the emotional status of dialysis patients. From these screenings and information form the KDQOL-36, dialysis staff should provide appropriate treatment or referral to ensure the best patient care. It was also apparent form this study that increases in physical activity have benefits across the spectrum of quality of life and health outcomes. Therefore, it is critical to stress these benefits to patients and for staff work with patients to increase physical activity level among patients.

The nephrology social worker plays a critical role in the care of dialysis patients and are often on the front line of assessing quality of life and depression among individuals on dialysis. Tools like the KDQOL-36 can provide valuable insight into the patient’s perception of their health and quality of life. As an important part of the interdisciplinary team, it is encouraged that social workers continue to take a leading role in educating both patients and colleagues on existing research that can guide practice and assist in achieving positive health outcomes.

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