

LONG-TERM SURVIVAL AMONG INDIVIDUALS DIAGNOSED
WITH END STAGE RENAL DISEASE:
AN EXPLORATORY STUDY

by

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ABSTRACT

Tremendous growth has occurred in the number of individuals diagnosed with end stage renal disease (ESRD) and receiving dialysis treatments for over the past 20 years. This corresponds to growth in the leading causes of ESRD: diabetes and hypertension. The number of individuals being treated for ESRD in 2010 was 593,086; an increase of over 116,946 from 2009. Only about one-half of dialysis patients, and 82% of those who received transplants, lived for more than three years after initiation of treatment for ESRD. Adherence to strict treatment regimens is necessary to achieve optimal health and quality of life, which are often influenced by a range of biological, psychological, social, and spiritual factors.

In this phenomenological qualitative study, the lived experiences of ten individuals diagnosed with and treated for ESRD for more than 20 years were explored through in-depth, semi-structured, audio taped interviews. All were currently receiving in-center hemodialysis treatments but through the years had the opportunity to choose other treatment modalities as well. The primary codes selected from analysis of the data were Initial Diagnosis, Treatment Experiences, Quality of Life, and Vision for the Future. Participants shared challenges and successes of learning how to incorporate time-consuming dialysis treatments, consistent monitoring of medications, and dietary restrictions into their daily lives and still maintain a sense of self and control in achieving optimal quality of life. Participants attributed their long-term survival with ESRD to adherence to the prescribed treatment regimens and faith in God.

The results of this study indicate that additional interventions are needed to address adherence to dialysis treatment regimens. As clinicians, social workers can continuously assess factors that could interfere with adherence and that are unique to each individual, such as employment demands, management of co-morbid conditions, depressive symptoms, lack of understanding of dietary restrictions, and unreliable transportation. Social workers can be involved in pre-ESRD education among populations most at risk for development of ESRD, including African Americans and people diagnosed with diabetes. Social work interventions in these arenas must also be evaluated for effectiveness in increasing quality of life for individuals with ESRD.

DEDICATION

This dissertation is dedicated to individuals living with end stage renal disease, to those who “lost their battle” with this disease, and to the family members and healthcare professionals who dedicate their lives to improving the quality of life among these individuals.

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CHAPTER 1

INTRODUCTION

Every 12 minutes, or about 100 times per day, someone in the United States is diagnosed with end stage renal disease (National Kidney Foundation (NKF), 2013). End stage renal disease (ESRD) prevents the kidneys from cleaning waste products and removing excess fluid from the body. When both kidneys are not functioning properly, an “artificial kidney” is recommended as a way to perform the essential “duties” of the kidneys in a process called dialysis. The two most common forms of dialysis are hemodialysis (HD) and peritoneal dialysis (PD) (NKF, 2013). Although hemodialysis is usually administered in free-standing dialysis facilities, it can also be performed at home. Peritoneal dialysis was designed and intended to be a home-based therapy (NKF, 2013). The only alternative for individuals with ESRD who choose to discontinue dialysis treatments but want to live (because without treatment, the disease will lead quickly to death) is kidney transplantation.

Millions of people around the world have chronic kidney disease that will eventually progress to end stage renal disease and require some form of renal replacement therapy (Alebiosu & Ayodele, 2005). The number of individuals that initiate dialysis for newly diagnosed cases of ESRD in the United States has grown tremendously over the past two decades (Jones et al., 2005). According to the United States Renal Data System (USRDS, 2012), the number of Americans being treated for ESRD in 2010 (at year’s end) was 593,086, an increase of over 116,946 from 2009. In addition, only about one-half of individuals receiving dialysis and 82% of those who received transplants, lived for more than three years after

initiation of treatment for ESRD (USRDS, 2012). Survival rates beyond the first five years of therapy are highest among those in the transplant population and among younger individuals, Blacks/African Americans (compared to Whites), and individuals with a primary diagnosis of glomerulonephritis (compared to those with diabetes or hypertension) (USRDS, 2012).

Leading Causes of Renal Failure

Approximately 40% of all new cases of ESRD in the United States are due to a previous diagnosis of diabetes, thus making it the leading cause of ESRD (USRDS, 2012). Diabetes is a chronic, debilitating disease that affects approximately 18.2 million people in the U.S. (Egede, 2005). African Americans are almost twice as likely to be diagnosed with diabetes as Whites, and many live for years with the disease prior to being diagnosed. Therefore, they are also more likely to be diagnosed in later stages. This, in turn, places African Americans at a higher risk for developing ESRD than any other race (American Kidney Fund [AKF], 2012).

Overall, more than one in three individuals with ESRD in the United States is African American (AKF, 2012). According to the American Kidney Fund (2012), there are three primary reasons for the ESRD “epidemic” among African Americans. As already mentioned, diabetes is the primary cause of ESRD. The second leading cause is hypertension (HTN); 42% of African American adults in the U. S. have been diagnosed with HTN. African Americans are also six times more likely than Whites to develop kidney failure because of uncontrolled HTN. The third leading cause is healthcare access/options. One in five African Americans has inadequate or no health insurance. This makes prevention, early diagnosis, and management of diabetic symptoms, hypertension, and early stages of kidney disease almost impossible (AKF, 2012).

Incidence and Prevalence of ESRD

United States Statistics

On December 31, 2010, there were 383,992 individuals in the U.S. receiving hemodialysis treatments; 29,733 individuals receiving peritoneal dialysis; and 179,361 individuals with functioning kidney transplants. The total ESRD population grew 4% in a period of one year, from 2009 to 2010, to a total of 593,086 (USRDS, 2012). Table 1.1 provides the 2010 incidence and prevalence by modality for the U.S.

Table 1.1

U.S. 2010 Incidence and Prevalence by Modality (USRDS)

Incidence		Prevalence	
Hemodialysis	105,923	Hemodialysis	383,992
Peritoneal Dialysis	7,703	Peritoneal Dialysis	29,733
Transplant	2,863	Transplant	179,361
Other	457		
Total New ESRD	116,946	Total ESRD Population	593,086

Note. Adapted from USRDS, 2012, www.usrds.org.

The information shown in Table 1.2 indicates the prevalence and adjusted rates for ESRD by age, gender, race, ethnicity, and primary diagnosis in the U.S. at the end of 2010.

Table 1.2

Prevalence and Adjusted Rates of ESRD, 2010

Age	Number of Individuals		
	Hemodialysis	Peritoneal	Transplant
0-19	1,355	900	5,094

20-44	49,429	6,007	42,572
45-64	157,520	12,987	90,938
65-74	85,871	5,605	28,275
75+	82,177	3,768	7,257
Male	209,456	15,519	103,554
Female	166,896	13,748	70,582
White	208,434	19,356	126,059
African American	143,862	7,586	35,034
Native American	5,666	351	1,941
Asian	18,390	1,974	11,102
Hispanic	59,294	3,778	21,990
Non-Hispanic	317,058	25,489	152,146
Diabetes	168,582	9,980	41,006
Hypertension	109,265	7,512	28,234
Glomerulonephritis	34,527	4,833	44,958
Cystic Kidney	9,179	1,560	17,170
Other Urologic	6,530	576	5,791
Other Cause	34,334	3,652	26,320
Unknown/ Missing	13,935	1,154	10,657
All	376,352	29,267	174,136

Note. Adapted from USRDS, 2012, www.usrds.org.

Alabama Statistics

Table 1.3 provides a three-year comparison for ESRD dialysis incidence by race in the state of

Alabama (Network 8, 2012). At the end of 2011, there were 5,205 African Americans and 2,557 Whites receiving dialysis treatments in the state of Alabama (Network 8, 2012). From those totals, 1,086 African Americans were newly diagnosed during 2011 compared to 949 Whites.

Table 1.3

Incidence and Prevalence of Individuals Receiving Dialysis by Race

Race	Incidence 2011	Prevalence 2011	Incidence 2010	Prevalence 2010	Incidence 2009	Prevalence 2009
American Indian/ Alaskan Native	3	12	2	12	3	13
Asian	5	28	7	26	7	26
Black or African American	1086	5205	1128	5031	1055	4845
Multi-race	10	6	4	10	5	6
Native Hawaiian/ Pacific Islander	0	7	0	8	2	9
White	949	2557	895	2449	923	2434
Missing	5	3	5	2	0	1
Total	2058	7818	2041	7538	1995	7334

Note. Adapted from Network 8, 2012, www.esrdnetwork8.org.

Table 2. provides a comparison of primary causes of ESRD in Alabama for the past three years (Network 8, 2012).

Table 1.4

Primary Diagnosis Associated with ESRD in Alabama

Primary Diagnosis	Incidence 2011	Prevalence 2011	Incidence 2010	Prevalence 2010	Incidence 2009	Prevalence 2009
Cystic Kidney	46	201	39	199	53	204
Diabetes	945	3412	918	3259	937	3152
Glomerulonephritis	130	706	132	704	111	694

Hypertension	611	2369	598	2270	578	2236
Other	204	737	228	731	220	697
Other Urologic	31	102	34	89	22	75
Missing	9	9	10	4	1	0
Unknown	82	282	82	282	73	276
Total	2058	7818	2041	7538	1995	7334

Note. Adapted from Network 8, 2012, www.esrdnetwork8.org.

Renal Replacement Therapy

When the kidneys are no longer able to remove extra fluid and waste from the body in the form of urine, renal replacement therapy is needed to maintain optimal health (NKF, 2013). This is usually recommended when there is only 10 to 15 percent of kidney function remaining for an individual with CKD. Symptoms such as nausea, vomiting, swelling, and fatigue are often present just prior to the need for treatment. However, many people do not experience any somatic symptoms, while high levels of waste and excess fluid builds up in the blood causing toxicity in the body. This is one cause for late diagnosis and treatment initiation (NKF, 2013). At this point, the individual is considered to have ESRD and will need a kidney transplant (NKF, 2013). If a kidney transplant is not immediately available, there are two forms of dialysis that will sustain an individual’s life, hemodialysis (HD) and peritoneal dialysis (PD).

Hemodialysis

In hemodialysis, a dialysis machine and a special filter called an “artificial kidney”, or “dialyzer,” is used to clean the blood (NKF, 2013). The person requiring dialysis will need to have an “access” to the blood vessel. This is typically a small tube placed directly into the blood vessel through his/ her arm, neck, chest, or leg so that the process of dialysis can take place. During hemodialysis, blood is pumped out of the person’s body from the access (a fistula, graft, or catheter) into a tube connected directly to the dialysis machine and back into the body through

another tube. This process usually takes about four hours per treatment. Three treatments per week are normally recommended for optimal health. A nephrologist (physician who specializes in kidney diseases) prescribes treatment orders on an individual basis dependent upon individual needs (NKF, 2013). Hemodialysis can be performed in the hospital, in a chronic dialysis facility, or in the individual's home.

Peritoneal Dialysis

In peritoneal dialysis (PD), waste is removed by means of cleansing fluid called dialysate. It is placed in and washed out of the abdomen acting as a natural filter (NKF, 2013). This process requires placement of a catheter (tube) into the abdominal wall that allows the transfer of dialysate into and out of the peritoneum cavity. There are two types of peritoneal dialysis: continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). CAPD is a continuous, machine-free, process that is done while a person conducts normal, daily activities such as work or school. In this process, approximately two quarts of dialysate is placed in the abdominal cavity via a catheter and later drained out (NKF, 2013). This process is called an exchange and it is performed three, four, or five times within 24-hours. APD differs from CAPD in that a machine, called a cycler, delivers the dialysate into the body and drains overnight while the person sleeps. The waste is discarded after each treatment. Individuals who choose a home modality are still required to visit their doctor and dialysis team monthly for blood work and monitoring of any health related or psychosocial concerns.

Transplantation

Kidney transplantation can replace a damaged or non-functioning kidney with a healthy kidney. The kidney may come from a cadaver or a living donor (NKF, 2013). Living donors are usually closely related to the individual, but sometimes a non-related person can be a good match

for this procedure. A series of tests to match blood and tissue types are performed with both the recipient and the donor to ensure compatibility. The individual with ESRD, the living donor, and his/ her immediate family members all are required to go through counseling to prepare for this event. The operation itself usually takes about three to six hours, and it requires a hospital stay of about 10 to 14 days. Because the recipient's immune system may try to reject the transplanted kidney, anti-rejection medications must be taken for the rest of the recipient's life (NKF, 2013). Unfortunately, because of insufficient available kidneys, kidney transplants are not performed as often as they are needed or desired. If a living donor is not available, the individual's name is placed on a transplant waiting list. Waiting for a kidney donor could take several years and the individual must continue dialysis treatments during this time (NKF, 2013). In 2010, 16,843 kidney transplants were performed in individuals 20 years of age and older in the United States. However, 86,620 individuals were awaiting kidney transplants and 55,060 of those individuals were listed on active wait lists while 31,560 individuals were inactive for various reasons associated with other co-morbidities (USRDS, 2012).

Medical Management of ESRD without Dialysis

Not all individuals with ESRD choose dialysis as a treatment option. When these individuals feel that the burden of dialysis outweighs the benefits, they may choose not to start dialysis or they may discontinue dialysis at any time after initiating treatment (AKF, 2008). Individuals who choose this option may live only for days or weeks depending on their residual kidney function, their symptoms and their overall medical condition (AKF, 2008). Discontinuation of dialysis is now regarded as a common cause of death among those with ESRD. Ashby (2005), estimated that one in four deaths in the U.S. with ESRD is preceded by a decision to withdraw from dialysis treatments. The desire not to burden others with the rigorous

demands that are required with maintenance dialysis, the fear of a limited quality of life, and religious beliefs are often determining factors in the decision to stop or decline dialysis treatments (AKF, 2008).

Long-term Dialysis

Adherence to treatment regimens remains a challenge for individuals with ESRD, their family members, and their healthcare providers, all of whom have the goals to improve quality of life. In 1976, all Medicare-certified dialysis and transplant centers in the U.S were mandated to recruit and hire Master's prepared social workers to provide interventions to individuals with ESRD. This mandate was established in an effort to decrease depression; improve adherence to dialysis treatments; reduce interdialytic weight gain (fluid gained between treatments) through adherence to dietary guidelines; improve overall quality of life; and decrease the likelihood of premature death (Mazzella, 2004; Browne, 2008). Only 51% of individuals receiving dialysis and 82% of those who received a transplant are still alive three years after the start of ESRD therapy (USRDS, 2012). Survival rates beyond the first five years of therapy are highest among those in the transplant population and among younger individuals, Blacks/African Americans (compared to Whites), and individuals with a primary diagnosis of glomerulonephritis (compared to those with diabetes or hypertension) (USRDS, 2012). Among individuals age 65 and older receiving dialysis, mortality rates are two times higher than for individuals in the general population who have diabetes, cancer, or congestive heart failure (USRDS, 2012).

The primary aim of this study was to explore the experiences of individuals who have been living with ESRD and receiving dialysis treatments for more than 20 years. These individuals seem to have found success and managed to stay alive far beyond many in their cohort. In addition to adhering to dialysis treatments, diet, and medication regimens, individuals

with ESRD must develop skills for managing the lifestyle changes and the depressive symptoms and anxiety often associated with this illness (Browne, 2008).

CHAPTER 2

LITERATURE REVIEW

During World War II, the first artificial kidney machine was invented in Holland by Kolff (Rettig, 2011). In 1947, Kolff visited the United States and a modified version of his machine was developed and used in Boston at the Peter Bent Bringham Hospital. In 1960, Scribner and Quinton invented an arteriovenous shunt that made it possible for an individual to be connected to the machine repeatedly as a treatment for chronic renal failure. This was the beginning of continuous dialysis treatments. The shunt was later replaced by a subcutaneous fistula developed by physicians at the Bronx Veterans Administration (VA) Hospital.

In the 1960s, in addition to dialysis, kidney transplantation was emerging as a viable treatment for chronic renal failure. Both treatments were costly, beyond the means of most individuals, and not covered by health insurance at that time. Access to dialysis was rationed by anonymous “patient selection” committees; early forerunners of medical ethics committees. It was clearly understood that lives could be saved, but there was a high cost to many stakeholders. Only those who were “deemed” to have the most “worth” to society were likely to receive the dialysis treatments; which left out elderly individuals and people with disabilities. In 1963, the VA announced its intention to build dialysis centers within 30 VA hospitals. In addition, from 1964 through 1972, the Public Health Service funded 12 dialysis centers, 12 home dialysis programs, and six organ-procurement programs (Rettig, 2011).

In 1968, about 1,000 people were receiving renal dialysis in the United States. However, thousands more could have benefitted but could not afford to pay privately (Caplan, 1981). In

1972 Congress passed Public Law 92-603 as an amendment to the Medicare and Medicaid provisions of the Social Security Act. Under this bill, individuals with ESRD were guaranteed federal coverage for the costs associated with their treatment. Many people viewed this coverage as form of a National Health Insurance program for those with a specific life-threatening illness (Caplan, 1981). Critics argued that federal reimbursement for health care services was too expensive and too inefficient. Proponents of national health insurance argued that the ESRD program delivered necessary services to those who could not afford them and that thousands of lives had been saved as a result of this government intervention (Caplan, 1981).

By the late 1970s, the number of individuals receiving dialysis treatments had shifted considerably due to the coverage provided by Medicare and Medicaid provisions of the Social Security Act. By 1977, 35,000 people were receiving dialysis in the United States and many had been on dialysis for ten years or more. The average individual on dialysis was middle-aged, male, married, working, and owned his own home (Caplan, 1981). However, many poor individuals and minorities were also able to receive dialysis. In 1981, the ESRD program covered approximately 50,000 individuals with ESRD at a cost of over one billion dollars per year for treatments such as dialysis and kidney transplantation. In 2010, there were approximately 593,086 individuals being treated for ESRD in the U.S. for a total Medicare cost of \$29 billion (USRDS, 2012). According to an analysis by the U.S. Renal Data System (2012), the ESRD population represented 1.3% of all Medicare beneficiaries and used 7.9% of Medicare expenditures. In 2010, the total cost of Medicare and private insurance for individuals with ESRD was \$47.5 billion (USRDS, 2012).

Quality of Life

The development of dialysis was groundbreaking. It is considered a life-sustaining

treatment for individuals diagnosed with ESRD because without it, they cannot survive. However, the long-term physical and psychosocial effects can be quite devastating for the individuals receiving dialysis, as well as for their family members (Curtin, Mapes, Petillo, & Oberley, 2002). Anxiety and depression have been associated with chronic health problems (such as ESRD) and lower health-related quality of life over time (Egede, 2005). Evidence exists that higher quality of life (QOL) is associated with better medical outcomes, including reduced hospitalization and reduced mortality, among individuals with ESRD (Eissa et al., 2010).

Since 1997, the Kidney Dialysis Outcomes Quality Initiative (K/DOQI) of the National Kidney Foundation has included in its guidelines recommendations for the measurement of health-related quality of life (HRQOL), thus viewing it as an important measure of outcomes for individuals receiving dialysis treatments (Devine, Smith, Breen & Patrick, 2003). On April 1, 2008, the Center for Medicare and Medicaid Services (CMS) adopted 26 new clinical performance measures to assess the quality of dialysis care in the United States. CMS included a new requirement for annual measurement of HRQOL in most individuals ([Kidney Disease Quality of Life [KDQOL], 2013). This survey was designed to be administered after the first three months of dialysis treatments and annually thereafter. However, in the case of a significant psychosocial event (loss of a family member or significant other, change in mental or physical health, unstable housing, etc.), a more frequent monitoring is required. The KDQOL-36 became available in 2002 and it is currently the most commonly used KDQOL survey used among dialysis providers in the U.S. (KDQOL, 2013). The 36-item HRQOL survey has five subscales that address: Physical and Mental Functioning (general health, activity limits, depression, anxiety, and social activities); Burden of Kidney Disease (interference of kidney disease with

daily life, feeling of burden on others); Symptoms and Problems (chest pain, cramps, dry skin, shortness of breath, lack of appetite, feeling “washed out” or drained, numbness in the hands or feet, nausea, or problems with dialysis access (fistula, graft or catheter); and Effects of Kidney Disease on Daily Life (fluid limits, diet restrictions, ability to work or travel, feeling dependent on doctors and other medical staff, stress or worries, sex life, and personal appearance), (KDQOL, 2013). A copy of the KDQOL-36 survey can be found in Appendix I.

Treatment Adherence

Non-adherence with prescribed dialysis treatments can influence quality of life outcomes and overall health in both hemodialysis (HD) and peritoneal dialysis (PD). Adherence with prescribed dialysis treatments is a common problem (DiMatteo et al., 2000; Kutner, Zhange, McClennan & Cole, 2002). Non-adherence to dialysis treatments has been associated with increased hospitalizations and mortality rates (Kutner et al., 2002). DiMatteo et al. (2000) studied the relationship between depression and non-adherence in a meta-analysis of research conducted over a 30-year span and found that individuals who were depressed were three times more likely to be non-adherent with medical treatment recommendations compared to individuals who were not depressed. Researchers in many of those studies suggested that depression often involved some degree of hopelessness, and that adherence might be difficult or impossible for individuals who held little optimism that any form of treatment would be worthwhile. Depression also seemed to be often accompanied by considerable social isolation and withdrawal from the individuals or systems that could be essential in providing emotional support and assistance. It was suggested that family and social network systems for those individuals can help them better adhere to medical treatments (Spinale et al., 2008). Having a

choice of treatment modalities available to meet the needs of these individuals may also improve adherence and quality of life (Juergensen et al., 2006; Brown et al., 2010).

Fluid and Dietary Restrictions

Adherence to fluid and dietary restrictions is essential to the long-term health and survival among individuals with ESRD. When the kidneys fail, they make less urine. The less urine the body makes, the less liquid or fluid a person should drink because the excess fluid remains in the body (AKF, 2005). Although dialysis can remove most of the excess fluid from the body, too much fluid in the body can be dangerous. This can cause high blood pressure, tissue swelling, and heart failure (AKF, 2005). Fluid can build up in the lungs, causing shortness of breath. For most individuals receiving dialysis, who no longer urinate, liquids are usually limited to 32 ounces or 1000 ml per day (DaVita, 2013). Some people with ESRD have a small amount of residual kidney function. Fluids for those individuals may even be more restricted. However, too much sodium can increase the amount of fluid in the body and sodium must be monitored as well. A typical renal-restricted diet prescribes no more than about 2000 milligrams of sodium per day; one teaspoon of table salt has about 2300 milligrams of sodium. With the help of a registered dietitian, diet and fluid restrictions and guidelines are tailored to the needs of each individual with ESRD (AKF, 2005).

Fluid restrictions are challenging for most individuals with ESRD as these restrictions often change the way they socialize and interact with others. This can sometimes make these individuals feel “different” and increase their desire to be “like everyone else,” (Tovazzi & Mazzoni, 2012). In order to explore the challenges of fluid restrictions with individuals on hemodialysis, Tovazzi & Mazzoni (2012) conducted a qualitative phenomenological study to explore how individuals with ESRD interpreted their experiences with fluid restrictions. Of the

12 individuals who participated in the study, five were adherent to their fluid restrictions and seven were not, based on measured interdialytic weight gain between treatments. The participants described feelings of “uncontrollable” thirst and a lack of ability to “resist” drinking too much fluid. Most of the participants stated that the strong urges to drink were not present prior to starting dialysis.

In addition to fluid restrictions, individuals with ESRD need to closely limit and monitor their potassium and phosphorus intake. Too much potassium can cause an irregular heartbeat and possible heart attack (AKF, 2005). The renal diet limits potassium intake to about 2000 milligrams of potassium per day. Foods such as bananas, oranges, tomatoes, baked potatoes, and broccoli are high in potassium. Phosphorus is a mineral that can also be very dangerous for individuals with ESRD for several reasons. Too much phosphorus in the blood causes a loss of calcium in the bones, which in turn may make bones frail and cause them to break more easily (AKF, 2005). Phosphorus can also cause a hardening and plaque build-up in the blood vessels and heart. People often complain of itching and bone pain from having too much phosphorus in the body. The renal diet is usually limited to about 1000 milligrams of phosphorus per day (AKF, 2005). Examples of foods high in phosphorus are cheese, biscuits, cornbread, ice cream, chocolate, nuts, and cola.

Many individuals with ESRD take phosphate binders to help control high levels of serum phosphorus, which can lead to cardiovascular-related deaths. According to the USRDS (2012), cardiovascular events are the leading cause of death among individuals with ESRD. Using a meta-analysis of 34 studies, Karamanidou, Clatworthy, Weinman, & Horne (2008) studied the adherence of phosphate binders among individuals with ESRD. The study revealed that non-adherence to phosphate binding medications appeared to be prevalent in ESRD. There was a

wide variation in reported rates of non-adherence (22-74% of individuals were non-adherent, with a mean of 51%). The wide variation may have attributed to the differences in the way adherence was defined in the individual studies. However, several modifiable psychosocial factors were identified as predictors of non-adherence. Health beliefs, social support of friends and family, anxiety and depression, as well as personality traits were all identified as the most promising predictors of non-adherence to phosphate binders.

Nephrology Social Work

Individuals with ESRD often require a range of psychosocial interventions from nephrology social workers that will enable them to manage both physical and psychological challenges associated with ESRD and the treatment process (Browne, 2008). Depression is one of the most common psychological problems that nephrology social workers encounter. If the depression goes undetected and untreated it may progress to termination of treatment or, in some cases, suicide (Mazzella, 2004).

In 1976, nephrology social workers lobbied and gained a mandate for inclusion of licensed, Master's-prepared social workers (MSW) in all dialysis and transplant facilities due to the complex psychosocial needs of the individuals (Browne, 2008). Social workers were primarily hired to help these individuals adjust physically, financially, and psychologically to the demands of their illness. Since that time, social workers in these facilities have provided interventions to individuals with ESRD in an effort to decrease depression; improve adherence to dialysis treatments; reduce interdialytic weight gain (fluid gained between treatments) through adherence to dietary guidelines; improve overall quality of life; and decrease the likelihood of premature death (Mazzella, 2004; Browne, 2008). Social workers have been recognized as leaders in healthcare and they have established a place for the social work

profession in the field of nephrology.

In 2008, CMS developed the Conditions for Coverage (CfCs) for all ESRD facilities and specifically addressed the importance of psychosocial functioning for individuals with ESRD. This placed more emphasis on documentation of clinical outcomes for social workers in dialysis facilities (Browne, 2008). The social worker's documentation includes: (a) honoring the individuals' right to be treated with dignity (as it relates to living wills and medical advance directives); (b) addressing their psychological needs and ability to cope with ESRD; and (c) the development of care plans with the interdisciplinary team and individuals within 30 days of admission. These plans were also to be completed at 90 days after the initiation of dialysis treatments and annually thereafter for stable individuals, or every month for individuals with significant changes in psychosocial needs or who are otherwise deemed unstable (Browne, 2008). The Psychosocial Assessment (Appendix H) used by nephrology social workers usually includes, but is not limited to, five major psychosocial areas of the individual's life: social support, financial stability, housing, medical needs, and transportation.

Social Support

Assessment of social support usually includes a detailed family history. Knowing the dynamics of the individual's relationships to her or his family members can provide insight into the availability of those members when additional support or assistance is needed. Friendships and community activities, such as church, social organizations, and hobbies are also utilized. This area gives the social worker an opportunity to explore available resources for home dialysis and/or possible living transplant donors.

Financial Stability

Each individual is asked to provide a detailed work history. This includes years of service in the military, current employment for the individual as well as her or his spouse, and other means of financial support at the time of the assessment. Having accurate information regarding the individual's work history will allow the social worker to apply for insurance benefits as well as long-term and short-term disability benefits if applicable. The social worker will be able to advise of opportunities for possible job training or vocational rehabilitation services. Having this information available will also give the social worker an opportunity to assess the individual's immediate need for financial assistance.

Housing

Social workers obtain information about the individual's current living arrangements. He or she might live in a house, an apartment, an assistant-living program, a long-term care facility, a skilled nursing facility, or the individual might be homeless. The housing arrangements for all individuals can change over time so this needs to be re-assessed at least quarterly by the social worker.

Medical Needs

The individual's medical history is explored to give the social worker insight as to other co-morbid conditions that the individual is managing. This also gives the individual an opportunity to explain his or her understanding of ESRD and why kidney failure might have occurred. If the individual drinks alcohol, smokes tobacco products, or uses illegal drugs, it will be addressed in this section. The social worker will have the opportunity to address any past or present mental illnesses and treatment methods used to manage these illnesses. The social worker also evaluates the individual's need for durable medical equipment such as a wheelchair,

walker, hospital bed, bedside commode, etc. If the individual remains medically-fragile at the time of assessment, he or she may also need a referral for home healthcare services or hospice care. The social worker will be able to coordinate those services for the individual.

Transportation

Transportation is a common problem for individuals receiving dialysis. Adherence to in-center dialysis treatments often depends upon adequate, reliable transportation. These individuals must have a consistent way to get to and from the dialysis facility. Missed or shortened dialysis treatments are often associated with lack of transportation. The social worker can also assess the individual's need for ambulance transport services or wheelchair accessible transportation services and assist in making arrangements for this service if needed.

Emerging Research

In the late 1970s, the psychosocial issues and challenges faced by individuals receiving dialysis started to emerge in the literature. Research regarding treatment options for individuals with ESRD, transplantation, adherence to treatments, co-morbidities associated with ESRD, ethnicity, and mortality is available in various dialysis and transplantation journals. However, very few studies addressed the factors or skills that may influence long-term survival for individuals with ESRD. Most of the research found in relation to long-term dialysis utilized secondary data analysis through epidemiological, longitudinal studies addressing the causes of death and predictions for mortality associated with various co-morbidities.

Only one qualitative study was found (Curtin et al., 2002); it had a sample of 18 participants who had been treated with dialysis for a cumulative total of 15 or more years, excluding time with transplants. The length of time on dialysis for the participants ranged from 16 to 31 years, with a mean time of 21 years. The results indicated that the participants had to

“modify” the way they viewed themselves in order to adjust to living with ESRD. Curtin (2002) believed that “loss of self” was considered a fundamental consequence of ESRD and a restructuring of the “self” was required to maintain self-integrity and to re-establish that individual’s life. This study was intended to go beyond the ESRD experience and explore psychosocial factors, lifestyle, and decisions that may have contributed to long-term survival of individuals with ESRD.

Theoretical Framework

The Health Belief Model (HBM) is a theoretical model used to understand health behavior and possible reasons for non-adherence with recommended medical treatments (Rosenstock, Strecher, & Becker, 1988). The HBM was developed in the 1950s by a group of researchers of the U.S. Department of Public Health who wanted to explain why people were not participating in health screening and promotion programs in order to detect and possibly prevent disease (National Cancer Institute, 2005). It has been widely used in the healthcare arena and provides a framework to develop an understanding of health behavior and possible reasons for non-adherence with recommended medical treatments (Rosenstock, Strecher & Becker, 1988). Interventions can be developed to encourage adherence to dialysis treatments, dietary and fluid restrictions, and prescribed medication regimens by understanding the health behaviors of individuals with ESRD.

As illustrated in Figure 2.1, the HBM model outlines the desired behaviors for individuals receiving dialysis treatments as a means of sustaining life. This illustration was used to provide a foundation for the present study’s aim of exploring the factors that influence long-term survival among individuals with ESRD. The illustration of the HBM was adapted for

nephrology social workers with individuals who were resistant to dialysis treatments (Cabness, Miller, & Marina, 2007).

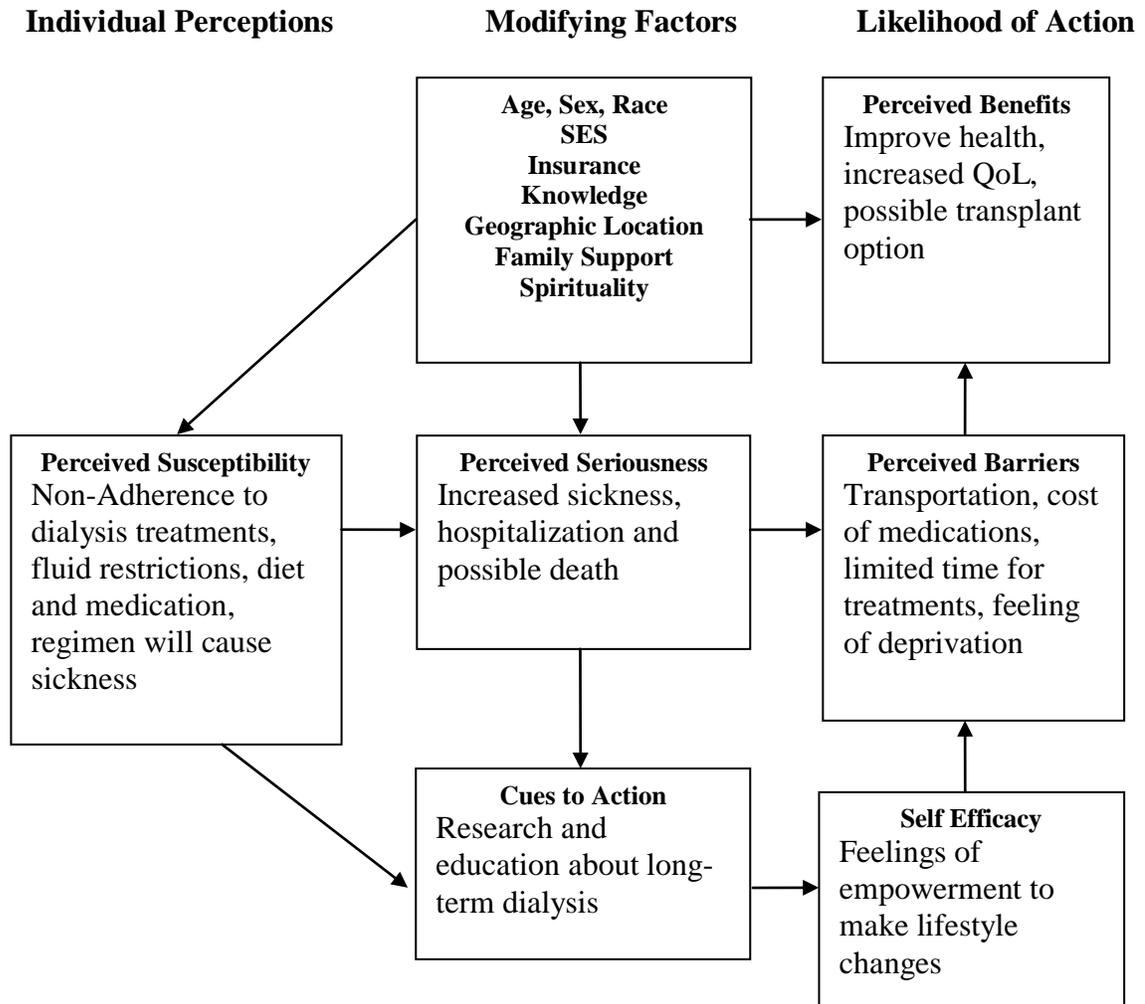


Figure 2.1. Health Belief Model of Motivating Factors for Prediction ESRD Adherence. Adapted from: Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the health belief model. *Health Education and Behavior*, 15(175).

The HBM involves four major constructs: perceived susceptibility, perceived seriousness, perceived benefits, and perceived barriers. Each of these constructs, individually or in combination, can be used to explain health behavior. Perceived susceptibility is a belief about the likelihood of getting sick or having complications associated with ESRD. Perceived

seriousness is a belief about the severity of consequences for one's actions. For example, non-adherence to dialysis treatments can increase the risk of medical complications, increase hospitalizations, and possibly cause death (Egede, 2005). The perceived belief is that the benefits of adhering to dialysis treatments will strongly outweigh the possibility of death. The perceived barriers might include the cost of medications, the time needed to complete the dialysis treatment, or the feeling of deprivation associated with fluid and diet restrictions. These barriers have been identified as contributing factors for increased depression among individuals with ESRD; depression has been shown to lead to non-adherence of dialysis treatments (DiMatteo, Lepper, & Croghan, 2000). Since the development of the original Health Belief Model, the concept of self-efficacy was added to the HBM. Self-efficacy is the belief in one's ability to take action in order to produce desired outcomes. Also added were "cues to action" and "motivating factors," i.e. empirical research, advice from others, or newspaper articles (Rosenstock, Strecher & Becker, 1988). The HBM is one of the most widely used models in nephrology research (Russell, Knowles, & Peace, 2007). It has been used to predict adherence to dialysis treatments for individuals or groups of individuals with ESRD and to help renal professionals identify modifying factors that could improve health-related outcomes for individuals receiving dialysis treatments.

Research Questions

The primary aim of this study was to explore the experiences of individuals who have been living with ESRD and receiving dialysis treatments for more than 20 years. It was anticipated that some insight could be gained into the lives of these individuals and how they managed their daily lives with ESRD over the long-term. Having the ability to gather data from human experiences can be powerful and can have a tremendous impact on the way a particular

situation is viewed. In this study, utilizing a small sample may have been more useful as it was designed to gain a better understanding of the phenomenon. Through in-depth, interviews, the following research questions were explored.

1. What factors facilitate the long-term survival of these individuals with ESRD, including biological (treatment adherence), psychological, and spiritual? For example, treatment adherence generally speaks to the attendance of all dialysis appointments and staying for the entire prescribed time. However, treatment adherence also includes adherence to diet, adherence to fluid restrictions, and adherence to prescribed medications. The psychological factors will include those contributing to mental and emotional well-being.
2. What or who have these individuals relied on for support through the many years of treatment? These factors may include spirituality or religion as well as family or other social support systems.
3. What does quality of life mean to these individuals?
4. What do these individuals see in their future as they continue to live with ESRD?

CHAPTER 3

METHODOLOGY

The research design for this study was qualitative; utilizing a phenomenological approach to explore the experiences of individuals who have lived with ESRD for more than 20 years. Phenomenology is an approach that seeks to understand a “first-person” perspective of those being studied (Cresswell, 1998; Denzin & Lincoln, 1994).

Phenomenology was appropriate to use in this study because the primary aim was to understand the lived experiences of individuals who have survived the challenges of their disease and treatment for more than 20 years. Face-to-face qualitative interviews allowed for in-depth exploration of this phenomenon as experienced by those individuals.

Sample and Procedures

Sample

ESRD Network 8 (governing agency for dialysis and transplant centers in Alabama, Mississippi and Tennessee) reported 7,818 individuals receiving dialysis at the end of 2011 in the state of Alabama (Network 8, 2012). As of December 31, 2011, Network 8 calculated 132 individuals currently receiving dialysis in Alabama who were diagnosed with ESRD and began receiving some form of renal replacement therapy prior to 1992 (over 20 years). The sampling frame for this study included individuals receiving dialysis for 20 years or more in a 7 county area in central/ northeast Alabama. To be eligible for the study, all potential participants needed to be over age 19 (age of consent in Alabama); have been diagnosed with end stage renal disease in 1992 or earlier; and be currently receiving dialysis treatments at DaVita facilities in Greene,

Jefferson, Marengo, Montgomery, Talladega, Tuscaloosa and Walker counties in Alabama. A total of ten individuals participated in this study. According to Creswell (1998), 10 subjects in a phenomenological study represent a reasonable sample size.

Research Setting and Recruitment

Setting

DaVita is the dialysis division of DaVita HealthCare Partners, Inc., a Fortune 500 company, that provides a variety of health care services throughout the United States and abroad. DaVita, which is an Italian phrase for “giving life,” is a leading provider of kidney care to individuals with chronic kidney failure and end stage renal disease. As of March 31, 2013, DaVita operated 1,991 free-standing, chronic dialysis centers in the United States and served approximately 156,000 individuals receiving dialysis treatments. The company also operated 41 chronic dialysis centers located in five countries outside the United States. DaVita employs more than 41,000 teammates (employees) around the nation (DaVita, 2013).

The Vice President of the Southland Division was contacted to discuss an opportunity to conduct a research project involving individuals diagnosed with ESRD for more than 20 years in the Southland Division. The Vice President of Southland approved this request and asked DaVita’s clinical research team to work with me to complete the necessary documentation for the study. DaVita, Inc. granted access to 32 facilities identified in the Southland Division of Alabama for the recruitment of participants for the study. DaVita’s clinical research team provided a letter of support (Appendix A) for this research to be included in the Internal Review Board (IRB) proposal. After the University of Alabama’s IRB approval (Appendix B) was granted, DaVita provided a letter of approval/support for the project (Appendix C). The letter was mailed to the social workers, facility administrators and medical directors in each of those

facilities. With both letters of approval, the researcher included a brief description of the study and requested the assistance of the facility social workers in the recruitment process. I requested to speak with the DaVita social workers in the Southland Division at a regularly scheduled social work staff/peer supervision meeting to explain the purpose of the study. After they learned more about the study and had an opportunity to ask questions, the social workers were asked to assist in identifying eligible participants for the seven identified counties in Network 8. Back at their own centers, they searched, within the treatment database, the “First Date of Dialysis” (FDOD) for each individual in their facility and for those individuals with a FDOD of 1992 and earlier. I contacted each facility social worker by phone to obtain the results of these searches in order to determine the sampling frame. Through the initial search, 15 potential participants were identified for the study.

Recruitment

The social workers met individually with each eligible participant and discussed the study with those individuals according to a script given to them by the researcher (Appendix E). Eligible participants were also given a recruitment flyer that contained brief information about the study and my contact information (Appendix D) in case they wanted to contact me later about participation. If an individual showed interest in participating in the study at that time, the social workers obtained permission to give me the name and phone number of the potential participant. I was provided with contact information for 15 potential participants. However, two of them were not able to participate. I received calls from two social workers that provided updates about the referrals they had provided. One person was hospitalized and was deemed medically-fragile during the time frame when interviews were being scheduled and therefore was not contacted. Another potential participant was not contacted because the medical director of

the facility where he received treatment did not give permission for him to participate. Thirteen individuals were contacted by the researcher who fully described the purpose of the study and arranged an interview date, time and location if the individual agreed. All 13 individuals agreed to participate in the study. The potential participants were also informed that the study was voluntary and their responses would remain confidential. Further, participants were assured that participation would not affect their treatment or relationship with DaVita Dialysis in any way.

DaVita allowed access to its physical facilities as a potential site to conduct interviews for this study. The participants could be interviewed in a private office within the dialysis facility, in their home or another private location of their choosing. Ten participants followed through with the scheduled interviews. One individual scheduled an interview but did not show up for the appointment. Attempts were made to re-schedule another time and date for the interview, however, the individual did not return my calls. Another had a busy work schedule and was unable to confirm a date, time and location after three attempts. The individual was asked to contact me if he would like to be interviewed in the future. The individual agreed but never called. Another potential participant was hospitalized prior to the interview and was sent to a nursing home for rehabilitation. The interview was never rescheduled due to medical/ living situation and the limited time frame of the study.

Data Collection

Interview Procedures

Individual interviews were conducted with the participants that each lasted varying amounts of time (approximately 60-90 minutes). A semi-structured interview guide was used in this study (see further description below in under Measures. The interviews were conducted in private location chosen by the participants. Of the ten participants, five chose to be interviewed

in their homes; four were interviewed in private offices at the dialysis facility in which they received dialysis; and one participant chose to have his interview take place in a private office at his job location.

Each participant received a \$20.00 Wal-Mart gift card as a “thank you” for their time and participation in the study (given prior to beginning the interviews). The interviews were audio-taped and later transcribed verbatim by the researcher. A semi-structured interview guide was constructed specifically for use in this study.

Informed Consent

Informed consent (Appendix F) was obtained from each of the participants prior to beginning the interview. The consent form was read aloud to help the participants understand the content more easily. The purpose of the study and a clear explanation of the risks and benefits of the study were presented to the participants. After the study was explained to the participants, the researcher asked three questions to determine if the participants were oriented to person, place and time: 1. What is today’s date? 2. What city are we in? 3. Who is the president of the United States? After the researcher established that participants were cognitively able to participate in the study, they were encouraged to ask questions regarding the study and purpose and procedures, if they had any, prior to beginning the interview. The participants were also given a copy of the informed consent form which contained the phone numbers, email and street mailing addresses of the principal investigator, faculty advisor, and a representative of the UA IRB committee so that the participant could contact any of these individuals if they had questions or concerns regarding the study after their interview was completed. The participants were informed that their responses would be kept confidential and their names would not be used in

the writing of this study. All of the participants signed the informed consent, including a separate part of the consent for the audio-taping of the interviews.

Measures

I used a semi-structured interview guide that was designed specifically for this study to address the research questions. This was to ensure that some similar information would be solicited from each participant in order to address the aim of the study. The questions for the interviews were open-ended, evolving, and non-directional (Cresswell, 1998). The interview guide was developed based on findings from the literature, preliminary studies, and my own practice experience. These questions were supplemented with follow-up questions that were guided by each individual's interview and experiences that were shared.

The guide included the following questions:

1. Tell me about your initial experiences with dialysis treatment?
2. Tell me how you felt when you were first told your kidneys were failing?
3. What treatment options were explained to you when you were diagnosed with ESRD?
4. What changes (if any) have occurred in dialysis treatment since you started?
5. How did your family react to your diagnosis?
6. What are your family's feelings about your treatment now?
7. Describe your typical day (and typical dialysis day).
8. How do you ensure that you are following the treatment regimen (i.e. diet, meds)?
9. What challenges have you faced in adherence to treatment regimens and treatment?
10. Who or what do you rely on for support? (Friends, organizations, church, etc.)
11. How do you define *Quality of Life*?
12. If you knew 20 years ago what you know now about managing ESRD, what would you do differently?

13. What have you learned about yourself through this experience?
14. What do you imagine your life will be like in five years?
15. What advice would you give to someone just starting dialysis?

The interview guide can also be found in Appendix G. Questions were open-ended and simple, but when the participants had difficulty understanding the questions, the researcher rephrased the questions in a way so that the participants may be able to better understand what was being asked. After the interviews were completed, the participants who did not mention their age, marital status and cause of renal failure during the interview were specifically asked those questions. This information was used to develop profiles of each participant and describe the overall demographics of the sample.

Data Protection and Maintenance

The data collected and managed for this study, included written consent forms, micro-cassette (audio) recorded interview files, transcribed interview document files and documents containing field notes from each interview are kept in a locked file cabinet. To protect the participants, each was assigned a pseudonym rather than using his/ her actual name prior to beginning the interviews. The pseudonyms were used consistently throughout the interviews. The participant's actual names appear only on the informed consent form and only I can identify the pseudonyms linked to each participant. The data analysis was conducted without use of identifying information. All 'hard' copies of documents were kept in a locked file cabinet in my home office and will be retained in a locked file cabinet for a minimum of three years (as required by the University IRB). After the minimum required time for retaining this information has passed, the above mentioned documents will be destroyed.

Data Analysis

Role of the Researcher

I occupied roles as both an “insider” and an “outsider.” The insider role was evident due to the familiarity with the phenomenon under this study. I have 23 years of practice experience as a social worker, including 13 years and current employment (at the time of data collection) in nephrology social work. Furthermore, I was an employee of DaVita at the time of the study. Because of my close connection with direct practice experience with ESRD, the insider and outsider roles needed to be recognized. In recruitment for the study, gaining consent, and conducting the interviews, I was able to step into the “outsider” role and be seen as an “outsider” by the participants (even though I was acquainted with some of the individuals interviewed through my employment). I personally conducted each of the interviews. During this process, I was aware that I might have been anticipating certain responses from the participants because of my knowledge of treatment regimens and the common problems that individuals with ESRD often face during dialysis treatments. I had to constantly be aware of my reactions and responses to the participants. The participants seemed to readily accept my “outsider” role. However, because the participants also knew I had an insider role as well, this could have either enhanced the interview process and style of interaction or it may have also served to discourage participants from answering honestly. It is believed because of the similarities seen in the “stories” of the participants, that having experience in the field made the participants feel comfortable and willing to share the experiences freely. Acknowledgement of the insider/outsider role was an important part of the interviewing process since it was not possible to separate these roles from one another.

The diagram in Figure 3.1 illustrates my “roles” as the researcher during study development, data collection, analysis and interpretation of the findings. It is noted that the space between insider/outsider that allows researchers to occupy both roles rather than forcing one or the other (Dwyer and Buckle, 2009).

Figure 3.1

Role of the Researcher

Insider	Researcher	Outsider
<ul style="list-style-type: none"> • DaVita Employee • Have access to the ESRD population • Worked professionally with participants • Knowledgeable about ESRD and terminology 	<ul style="list-style-type: none"> • Designed a study based on empirical literature • Used procedures developed by experts in the field of qualitative research methods to collect, analyze and interpret data 	<ul style="list-style-type: none"> • No experience receiving dialysis treatments • Connected with staff and participants as a researcher • Explorer of a phenomenon

Qualitative Software in Data Analysis

The ATLAS.ti 7 (2012), software program was initially used to organize the qualitative data collected in this study. The qualitative software program helped to organize the text files transcribed from the audio-recordings, create and organize codes, search meaningful quotes, and develop themes. The codes, quotes and themes were color-coded and transferred to a Microsoft Word document for easy access during data analysis.

Analysis Process

I referred to Creswell’s *Qualitative inquiry and research design choosing among five traditions* and various sections of Moustakas’ *Phenomenological Research Methods* as a guide to

analyze the data. Table 2.3 illustrates Creswell’s guide to analyzing data from the phenomenological tradition. These steps were used to organize the data for this study.

Table 2.3

Creswell’s Data Analysis and Representation (Phenomenology)

-
1. Create and organize files for data.
 2. Read through text, make margin notes, form initial codes.
 3. Describe the meaning of the experience for researcher.
 4. Find and list statements of meaning for individuals. Group statements into meaning units.
 5. Develop a textural description, “What happened” and “How” the phenomenon was experienced. Develop an overall description of the experience, the “essence.”
 6. Present narrative of the “essence” of the experience; use tables or figures of statements and meaning units.
-

Note. Adapted from *Data Analysis and Representation by Research Traditions* by Creswell, J.W. (1998). *Qualitative inquiry and research design choosing among five traditions*. Thousand Oaks, CA: Sage Publication.

Table 2.4 below, is Moustakas’ modification of the Van Kaam method of analysis of phenomenological data (Moustakas, 1994). Appendix J includes a detailed description of this model. This model was used to create a visual interpretation of the participants’ experiences by using graphs to show the clustering of primary codes.

Table 2.4

Modification of the Van Kaam Method of Analysis of Phenomenological Data

-
1. Listing and preliminary grouping – List every expression relevant to the experience (Horizontalization).
 2. Reduction and Elimination – Test each expression for significance.

3. Clustering and thematizing the invariant constituents: Cluster the invariant constituents of the experience that are related into a thematic label.
 4. Final identification of the invariant constituents and themes by application: Validation.
 5. Construct an *Individual Textural Description* of the experience.
 6. Construct an Individual Structural Description of the experience based on the Individual Textural Description and Imaginative Variation.
 7. Construct a Textural-Structural Description of the meanings and essences of the experience.
-

Note. Adapted from Modification of the Van Kaam Method of Analysis of Phenomenological Data by Moustakas, C. (1994). In *Phenomenological Research Methods*. Thousand Oaks: Sage Publications.

I transcribed all of the interviews verbatim. This allowed me to “experience” the interviews for a second time. After the data (transcripts) were entered into the ATLAS-ti7 program, the transcripts were read and re-read in order to become more immersed in the data. I was able to recognize common words and phrases used by the participants. The words, phrases and statements that were relevant to understanding the participants’ ESRD experiences were coded, highlighted and grouped into categories. I also referred to my field notes for patterns of words and phrases that emerged during each interview. Moustakas (1994) refers to this process as “horizontalization.” The information that was extracted from the transcripts was categorized according to primary codes from the participants' responses. The primary codes were not pre-selected so that researcher bias could be eliminated as much as possible and to enhance the trustworthiness of the research. The primary codes, and thus some participants’ responses were based on the research and interview questions and were to a certain extent, expected from the data. These primary codes were used to cluster similar words and statements from each

participant into categories and subcategories. I began interpreting the data when I could discern no new categories or subcategories. An outline was used to interpret and explain the data. Quotes and descriptive examples were identified that illustrated and gave depth to the interpretations of the participants' experiences.

Using Moustakas (1994) Modification of the Van Kaam Method of Analysis of Phenomenological Data, I was able to share the experiences for each of the participants. First, I constructed an individual textural description of her or his experience. This allowed me to describe clear images of what happens in the life of someone diagnosed with ESRD and follows them over a 20 year or more life span. The stories began with a description of the symptoms associated with ESRD and follows the journey through each person's struggles, challenges, triumphs and decisions that were made through the present day. I then constructed individual structural descriptions of each participant's experience by providing a vivid account of how hers or his feelings and thoughts connected with the experience of living with ESRD. These structural descriptions included the participants' feelings of denial, acceptance and each viewed her or himself as someone living with ESRD. Verbatim quotes from the transcripts were used to add depth to these experiences. Finally, I constructed a textural-structural description of the meanings and essences of the experience by incorporating the primary codes that were used to describe these experiences. This process allowed me the ability to share the experiences of the group as a whole.

Trustworthiness and Rigor

Trustworthiness and rigor is sometimes more difficult, but not impossible, to demonstrate in a qualitative study (Padgett, 2004). The researcher became familiar with qualitative methodology in order to address possible biases before the study began. This was especially

necessary since the researcher works directly with individuals receiving dialysis treatments and knew some of the participants through her professional practice. Trustworthiness refers to the methodological sufficiency of the study and was enhanced through the use of bracketing, field notes, peer debriefing and member checking. I used these methods to reduce bias and ensure credibility.

Bracketing

Creswell (1998), explained the concept of *epoche* as occurring when the researcher “brackets”, or “sets aside”, his or her own preconceived ideas about the phenomenon so that it can be understood through the voices of the participants. In this study, bracketing was used to address researcher biases throughout the process in order to minimize personal feelings, preconceptions, beliefs and previous knowledge about ESRD and the perceived dialysis experience in order to focus on the lived experiences of the participants. Throughout each of the interviews, I attempted to set aside any preconceived ideas I had about dialysis and allowed the participants to share their personal experiences without judgment. I wanted to experience the stories without anticipating any of the responses or outcomes. Although I have many years of experience as a nephrology social worker who works directly with individuals receiving treatment for ESRD, I was able to ask questions as an outsider because I have no personal knowledge of being diagnosed with ESRD or living with this experience. I allowed each of the participants to describe her or his experiences in great detail in order to better understand the feelings each of them expressed and shared as someone living with ESRD. I was able to identify my role as an insider and an outsider and kept a journal of my personal feelings throughout the study.

Field Notes

Field notes were used as an audit trail to document the experience from start to finish. Padgett (2004), discussed the importance of self-reflection. During the interviews, I “jotted” down words or short phrases that may have “triggered” the need for further exploration in a particular area. This allowed me to explore “deeper” into the experiences by asking follow-up questions based on the thoughts and feelings that were evoked by some of the words or phrases expressed by the participants. Within an hour of each interview, I reflected on my feelings about the challenges of obtaining the information. It was sometimes difficult to imagine living the experiences that each of the participants shared. A short journal entry was added to my field notes after completion of each interview as a way to bring closure to that experience for me. For example, I interviewed a woman who was diagnosed with CKD her senior year of high school. Her mother was reluctant for her to go away to school but the doctors encouraged her to continue with her plans to attend college and to enjoy her life. She said they told her that because they didn’t expect her to live more than a few years. As I listened to her talk about that experience, I couldn’t help but imagine myself in her situation. I imagined what my life would have been like in college while living with this disease. I imagined myself as her mother and having to let my young daughter leave home thinking she might only live a few more years. As I reflected on that experience throughout the day it was very difficult to imagine the experience as a personal one but I feel that it was necessary to fully understand her experience. I wrote about my feelings and I was able to bring closure for myself by reconnecting with the beautiful life this individual lives today. Knowing that she survived and continues to be happy with her life provided a happy ending to the journey I took with her.

I was also able to reflect on these experiences as an insider and made notes regarding the things that surprised me during each interview. For example, I was surprised and pleased to know that each of the participants was very knowledgeable about her or his treatment regimen. These realizations gave me an opportunity to recognize what may be important pieces of the overall experience for these individuals.

Peer Debriefing

Peer debriefing was used throughout this process through consultation with an experienced professor in the area of qualitative research methodology. DaVita's clinical research team also served as a resource to answer questions as they related directly to end stage renal disease. Through this process, the "vision" of the research was enhanced as I was able to "see" aspects of the research that may have been evident to someone not as close to the phenomena. For instance, while consulting with an experienced professor about the early onset of ESRD and the treatment options that were available, she immediately began to ask questions about how these individuals' choice of treatment affected their personal life in terms of marriage, intimacy and ability to have children. This experience helped me think as an outsider and focus on questions and information that might be important to someone outside of the field of nephrology.

Member Checking

Member checking was conducted through telephone calls to the participants after completion of all interviews and a summary of major findings was formulated. This was done in order to determine the accuracy of the transcripts and to summarize the findings from their perspective. Moustakas (1994), often referred to participants in a qualitative study as "co-researchers." I contacted each participant within one month of hers or his interview to review

the initial transcripts and to clarify accuracy. I discussed with each participant the primary codes that were selected from all of the interviews and asked them if those codes accurately represented hers or his experience. I reviewed specific comments made by the individual with whom I was speaking, as they were relevant to the selected codes. Each of the participants agreed that the selected codes represented the experience shared with me. I also asked for feedback regarding the recruitment and interviewing process. No issues or concerns were addressed and each of them stated that they were pleased with the organization of the process. In summary, each participant seemed glad to know that her or his experience might be used to help others manage their illness and to inspire them to want to live the best life possible.

CHAPTER 4

RESULTS

This chapter presents data collected from the study's participants. First, the participants' characteristics and profiles are presented in order to introduce those who shared their experiences and life stories for this research. In the second section, the results of the data analysis, including primary codes, patterns, and interpretations are described. In the third section, individual textural and individual structural descriptions are included to show aspects of the analysis process that led to the construction of the composite textural and structural descriptions that follow. These composite descriptions highlight the themes that emerged from the analysis. These themes represent concepts that seemed to represent the everyday experiences of these participants over their time in treatment and may be viewed as possible underlying strengths in long-term survival with ESRD.

Introduction of Participants

Individuals who were diagnosed with end stage renal disease for twenty years or longer within the Southland Division of DaVita Dialysis were the target population for this study. DaVita's Southland Division is located in central Alabama and includes Greene, Jefferson, Marengo, Montgomery, Talladega, Tuscaloosa, and Walker counties. The facility social workers assisted me in identifying potential participants for the study by searching their facility data base for individuals diagnosed with ESRD in 1992 or earlier. Ten participants agreed to participate and followed through with the interviews. Six males and four females participated in face-to-face interviews with me in March 2013. Four interviews took place in private conference rooms

at various DaVita facilities where the participants receive in-center hemodialysis treatments. One interview took place at the participant’s place of employment (private office) and the remaining five interviews were conducted in the individuals’ homes.

Participant Characteristics and Profiles

General Participant Characteristics

The participants ranged in age from 42 to 68. There were nine Black participants and one White participant. Six of them were male and four were female. Six of the participants were single, two were married, and two were divorced. According to the preliminary research, the sample was consistent with incidence and prevalence of ESRD cases in Alabama. According to Network8 (2012), there were 5,205 African Americans and 2,557 Whites receiving dialysis treatments in the state of Alabama on December 31, 2011. The demographic information for each participant is found in Table 4.1.

Table 4.1

Participant Demographics

#	Pseudo Name	Age	Gender	Race*	Marital Status
1	Gates	42	M	B	Divorced
2	Shelby	57	M	B	Married
3	Richardson	68	M	W	Married
4	Stephens	42	M	B	Single
5	Cook	62	F	B	Divorced
6	Flowers	58	F	B	Single
7	White	53	F	B	Single
8	Brock	42	M	B	Single
9	Rowe	60	F	B	Single
10	Duncan	53	M	B	Single

*Note: Race: W= White; B= Black

The overall makeup of the sample revealed that hypertension was the most common cause of renal failure among the participants. Two participants had a primary diagnosis of glomerulonephritis and one participant had a primary diagnosis of diabetes. Among the ten participants in this study, the years since onset of ESRD diagnosis ranged from 20 to 45 years as indicated in Table 4.2

Table 4.2

*Diagnosis of ESRD and Treatment Type **

#	Pseudo Name	Year of Diag	Age at Diag	Years since Diag	Primary Cause of ESRD	Txp	Current Modality
1	Gates	1991	21	22	Hypertension	2	ICHD
2	Shelby	1991	35	22	Hypertension	1	ICHD
3	Richardson	1993	48	20	Hypertension	1	ICHD
4	Stephens	1987	17	26	Glomerulonephritis	0	ICHD
5	Cook	1968	17	45	Glomerulonephritis	2	ICHD
6	Flowers	1985	31	28	Diabetes	2	ICHD
7	White	1985	25	28	Hypertension	2	ICHD
8	Brock	1987	16	26	Hypertension	1	ICHD
9	Rowe	1985	32	28	Hypertension	0	ICHD
10	Duncan	1984	23	29	Hypertension	0	ICHD

Note: Current Modality: ICHD = In-center hemodialysis; Txp = Transplant; Diag = Diagnosis
 * At time of study interview

Participant Profiles

1. Mr. Gates is a 42 year-old, African American male who was diagnosed with end stage renal disease in 1991 at age 21. He had two transplants. The first transplant occurred about six months after being diagnosed with ESRD with a kidney donated by his mother. This lasted about 3 ½ years. He stated that his first kidney was rejected because he did not adhere to the medication regimen. After this rejection, he restarted in-center hemodialysis (at age 24) and

remained on dialysis until 2000 when he received a second transplant. His second transplanted kidney was from a cadaver; it lasted for 12 years. He restarted dialysis in 2012 and continues to receive in-center hemodialysis.

2. Mr. Shelby is a 57 year-old African American male who was diagnosed with end stage renal disease in 1991 at age 35. He received a transplant, with a cadaver kidney, one year after starting dialysis. After seven months, rejection occurred due to unknown reasons. He has remained on in-center hemodialysis since then and has never missed a treatment.

3. Mr. Richardson is a 68 year-old White male who began having symptoms of renal failure in 1992, at age 47. However, he was not diagnosed with end-stage renal disease until early 1993. He received a transplant with a cadaver kidney after eight months on dialysis. The transplant lasted 13 years and rejection occurred after complications associated with a heart attack. He re-started in-center hemodialysis and he continues to receive these treatments three days per week.

4. Mr. Stephens is a 42 year-old African American male who was diagnosed with end stage renal disease in 1987 at age 17. He began peritoneal dialysis immediately and continued this treatment for 10 years. After several life-threatening episodes with peritonitis, he decided to start in-center hemodialysis. He decided to forgo a kidney transplant due to the pain associated with the surgery and the required medication regimen. He remains on in-center hemodialysis at this time.

5. Ms. Cook is a 62 year-old African American female who was diagnosed with chronic kidney disease in 1968 at age 17. She was able to avoid dialysis for nine years but her disease continued to progress toward ESRD and she began in-center hemodialysis in 1977 at age 26. One year after starting chronic, in-center hemodialysis, she received a cadaver kidney transplant;

it lasted for 2 ½ years. Afterwards, she did peritoneal dialysis for approximately nine years and home hemodialysis for ten years. She had a second transplant, also with a cadaver kidney, in 2001 and rejection occurred in 2010. She is currently receiving in-center hemodialysis.

6. Ms. Flowers is a 58 year-old African American female who was diagnosed with end stage renal disease in 1985 at age 31. One year after starting dialysis, she received a transplant with a cadaver kidney that lasted six years. A second transplant with a cadaver kidney was received in 2001 which also lasted about six years. She is currently receiving in-center hemodialysis.

7. Ms. White is a 53 year-old African American female who was diagnosed with end stage renal disease in 1985 at age 25. She started with peritoneal dialysis for about two years and then switched to in-center hemodialysis. She's had two transplants, both with cadaver kidneys. The first transplant lasted six months; rejection occurred in the second one almost immediately. She now remains on in-center hemodialysis.

8. Mr. Brock is a 42 year-old African American male who was diagnosed with end stage renal disease in 1987 at age 16. He immediately began training for peritoneal dialysis and continued this treatment for approximately one year prior to receiving a kidney transplant. The transplanted kidney was with a cadaver kidney and lasted 21 years. He felt that the transplanted kidney rejected due to a minor infection, stress, and the natural lifespan of a transplanted kidney. He started in-center hemodialysis in 2012.

9. Ms. Rowe is a 60 year-old African American female who was diagnosed with ESRD in 1985 at age 32. She began in-center dialysis immediately and continues with this type of treatment. She refused to be evaluated for a kidney transplant after being told that she would have to limit her physical contact with her children in order to minimize her risk of infection and

other childhood diseases her children might have. Even though this information was incorrect, she stated that she never regretted this decision.

10. Mr. Duncan is a 53 year-old African American male who was diagnosed with ESRD in 1984 at age 23. He did peritoneal dialysis for six years and he has been receiving in-center hemodialysis for the past 23 years, for a total of 29 years without transplantation. He stated that he was evaluated and received a call that a kidney was available for transplant. However, he did not have transportation to the hospital (about 50 miles away from his home) at the time it was available.

Participants' Experiences

The four primary codes that were selected from the participant's stories were: Initial Diagnosis, Treatment Experiences, Quality of Life, and Vision for the Future. The first code, Initial Diagnosis, included five categories encompassing symptoms, medical confirmation, prior knowledge about ESRD, individual reactions, and family reactions. Participants shared how they found out that their kidneys had failed and that they would require lifelong renal replacement therapy along with their and their families' initial reactions. The participants' narratives related to Treatment Experiences provide insight as to how they made their initial choices for treatment, the challenges they faced to adhere to those treatments, and the ongoing daily decisions that ensure they follow their prescribed treatment plans. Quality of Life included two categories: daily life and self-efficacy. These pertain to the intimate details of the individual's life. Managing the challenges associated with ESRD can be life altering. The participants in this study shared those challenges but also gave insight as to what made them stay positive and remain encouraged while trying to live the best life possible. They shared stories of love and support from their family members and friends. They talked about their faith in God and about

an inner strength that they discovered within themselves as they began to make decisions to achieve a higher quality of life. Within the last code, Vision for the Future, participants shared their hopes for the future and offered advice to individuals that were newly diagnosed with ESRD.

Initial Diagnosis

The first code selected from the participants' interviews was associated with their initial diagnosis with end stage renal disease (ESRD). Each interview with the participants began with general questions that invited them to talk about their initial diagnosis with end stage renal disease. They described the events that led to their diagnosis with ESRD. Each participant described the symptoms that caused them to seek medical attention. Upon reflection, they realized that those symptoms were present for an extended amount of time, but at the time, they did not realize that they would lead to a serious illness. Initial thoughts and reactions to their diagnosis were shared as well as their perceptions of the reactions of their family members.

Symptoms

As the participants described the details of their initial diagnosis, they shared the symptoms they had experienced.

.... when I went in the hospital, my blood pressure was like 2 something over 1 something [200/100] and I had started experiencing headaches and my eyes was going blurry. They were surprised I even walked in there with that kind of blood pressure. And then they started working on me and as it got later and later it started messing with my kidneys. (Mr. Shelby)

I swelled up like a big old basketball. My face was swollen. I couldn't walk a few feet without being out of breath. (Mr. Duncan)

I remember when I was 12 or 13, my ankles would swell up. I remember that but I didn't do anything about it. Being so young I thought maybe I wasn't drinking enough water or I'm drinking too much water but I went on playing and never thought too much about it. When I turned 17, that's when it hit me. That's when I had hypertension and kidney disease; that's when I found out. (Mr. Stephens)

These early signs and symptoms of renal failure are very common and are often mistaken for those associated with many other diseases. Participants related that they often ignored the symptoms, especially if they were not persistent or ascribed them to some other ‘minor’ illness. Some used home remedies passed down from their mother or grandmother to address symptoms rather than seek out a “diagnosis.” Several of the participants discussed their lack of regular visits to the doctor as they were growing up and in early adulthood until their diagnosis.

Medical Confirmation

Nine of the participants were diagnosed with renal failure in the emergency room after recurring symptoms of headaches, dizziness, and “blackouts.” They were admitted to the hospital with acute symptoms of renal failure. After lab tests confirmed the diagnosis, hemodialysis was begun immediately via a catheter. The participants were presented with the treatment options for in-center hemodialysis or peritoneal dialysis (PD). Six participants began in-center hemodialysis and three began training for and utilized PD after discharge from the hospital.

I had a real bad headache so I told my mom to take me to the emergency room. She got me in the car and took me to the emergency room and when I got there my pressure was 270/170. I remember telling her that I wanted some water and she got me up and helped me to the fountain and when I pulled the trigger to get the water, I just remember everything going white and I got up a day and a half later, they told me my kidneys was gone. They were destroyed because of my blood pressure. (Mr. Stephens)

Only one participant was diagnosed with CKD by her primary care doctor and had nine years before it progressed to ESRD.

My general practitioner put me in the hospital and I had a kidney biopsy. I remember so clearly, he had his assistant there with him and they took a little piece of it and put it in the solution right there and he said, “it sank.” I felt the weight of the whole world in those two words. I knew whatever test they were performing, I didn’t pass. (Ms. Cook)

Prior knowledge about ESRD

Five of the participant's had prior knowledge of ESRD from family members who were diagnosed with it. The remaining five participants stated that they had no knowledge about ESRD.

My mom, before she passed, her kidneys were failing. But she passed though [died] (before she started dialysis). (Mr. Shelby)

I was about 32 (years old) and I had never heard of anybody around me with kidney failure. I didn't know what that was. People ask me all the time, how did you know you had kidney failure? (Mr. Richardson)

I had 3 brothers. Two of 'em dead now. So it was 4 of us on dialysis. (Ms. Rowe)

Individual's Reaction

Although their initial reactions ranged from immediate acceptance to denial, each participant explained how they came to terms with their illness. Over varying amounts of time, and most often after periods of non-adherence to different aspects of the treatment regimen, all ten participants decided to make the necessary changes to their lifestyle in order to live with the best quality of life possible.

I was the youngest person there. Everybody was like 60 years-old. I was sitting around these old folks looking like, why am I here? Why am I even here? You see all these old folks with like high blood pressure, diabetes, heart conditions and I'm like, what happened to me? Before I even turned 25, before I even got married, before I had kids....I got to go through all this? (Mr. Gates).

They [the doctors] said, "you're the fullest I've ever seen anybody." He said, I still can't understand how you still living. He said, "most people would have died"....(starting to cry)....I said...it's the good Lord's will.... He got something for me to do...(crying). (Mr. Richardson)

Well, I kind of...well tell you the truth, I kind of like brought it on myself. 'Cause you know, I had been drinking and carrying on and stuff like that and I kind of brought it on myself and then like when they told me about it and had to take it like...well, if that's what I got to do to live then that's what I got to do. (Mr. Shelby)

...they were trying to get my (blood) pressure down and they zoomed it down. When they zoomed it down it shut my kidneys off and I was out about two or three days. Then, I finally woke up and that's when they told me...you on dialysis. Your kidneys failed. I was in shock. (Mr. White)

Family's Reaction

All of the participants expressed how important their family members were and still are to them. They expressed the sadness they shared together after the initial diagnosis and how their family members stepped in to support them and to help them make the best of the situation. All of the participants had family members who volunteered to become kidney donors, although only one participant chose to receive a kidney from his mother. According to this participant, after having asked his mother to hold off on giving him a kidney because he also had a younger brother and sister, she told the doctor 'I'm giving him one (a kidney) and that's that'. The other six participants who received transplants waited for cadaver kidneys.

All of these people were coming to see me...and I kept asking...why are all these people coming to see me? I was happy because I'm crazy about my family. I was enjoying it and then they finally told me that they were told this might be the last time they see me. (Ms. White)

At the time, when I got sick, I had a lot of people, you know, I had two sisters and one brother that matched with me but I didn't want them to do it at the time. My sister was the baby girl and she's married now and her son is in college. So, she said, "if you still want to do it just let me know." But I'm still thinking about it. (Ms. White)

I'll be 69 years old...I'm still on the transplant list. I've had numerous people said, "Let me go and be tested" and I said, no. I would take it from somebody that dies but I won't take one from nobody living. And my kids have tried to give me one...I said, nope. I would feel bad if somebody gave me a kidney and I found out years later that the only one you had done quit and now you're on dialysis. That would make me feel bad. So, I just want it from a cadaver or I don't want it at all. (Mr. Richardson)

Treatment Experiences

One of the most prominent factors that affects the lives and treatment experiences of individuals with ESRD is the type of treatment utilized for management of the disease. When the

participants for this study were first diagnosed with ESRD over 20 years ago, they had fewer options available to them than individuals starting renal replacement therapy in 2013. However, most had experienced each of the three main types of treatment modalities (hemodialysis, peritoneal dialysis, and kidney transplantation) and all ten were receiving hemodialysis at the time of the interviews. Each type of treatment has its own unique medical regimen that must be followed by the individuals. The regimens normally include adherence to proper medication administration and keeping to a strict dietary plan, which will be discussed in more detail in the section titled, “quality of life.”

Social workers are required to educate all individuals diagnosed with ESRD regarding various modality choices within the first 90 days of initiating dialysis treatments. Six of the individuals who participated in this study received transplants within the first year of initiating dialysis.

Hemodialysis

All ten participants have experienced in-center hemodialysis treatments. Each of them was receiving in-center hemodialysis at the time of the interview. One participant described one of her earliest memories of in-center treatment as follows.

(30 years ago) Everybody around you threw up. Everybody threw up. Everybody passed out. Everybody’s blood pressure dropped. Half the time, patients’ heads were down to the floor. It was awful. You felt bad going on; you felt bad coming off. Somebody talked about highs and lows...I never experienced any highs. I was always just like this (bending over with her head in her lap)...in fact, one time I was in a wheelchair ‘cause I just couldn’t walk. (Ms. Cook)

Adherence.

I used to miss one every now and then because of a ride situation but I don’t miss any more...I don’t miss anymore. It’s too important, this our lifeline and I found out that missing treatments will catch up with you so I don’t want to go through that no more. It’s good to come. (Mr. Stephens)

Social Aspect.

(Laughing)...I just come up here and have a good time. To me, that's life. I don't want to bother no body. I don't want to upset nobody. But, I cut up with people like that all the time. I don't mean nothing bad about it. I don't want nobody to take it wrong or crazy but I cut up with them back there all the time. To me, that's life. That makes life fun. 'Cause you got to keep your shoulders up here. Have a good time while you're living. Make people laugh. I'm not no comic but I'll say some old off the wall something you know. I like when somebody get tickled about it and we have a good laugh. (Mr. Richardson)

Peritoneal Dialysis

All ten of the participants in this study were receiving hemodialysis at time of their interview. However, five of the participants had tried PD in the past. Of those five participants, two of them were adolescents and the other three worked full time jobs at the time of diagnosis. PD provided them with a more flexible schedule to work and attend school. PD is a self-administered dialysis treatment that takes place in the home. One of the adolescents discontinued PD after receiving a transplant. The other four participants who tried PD, discontinued this modality due to severe infections and problems with their access site. At that point, the only option available was in-center hemodialysis. They all continued to work after changing modalities. One of them has since retired and the other two continue to work part-time jobs. The participants in this study preferred hemodialysis over PD. Most thought that PD kept them isolated and they preferred the interaction with other patients in the center. Each of them also described how the interactions they had with other patients and staff has made their dialysis experience more enjoyable. The quote below was stated by one participant who had to start in-center hemodialysis due to infection. He describes his first hemodialysis experience after being on PD for 10 years.

So I went in and had my first dialysis...I think I cried the whole time. It was painful. I didn't know, when they said I had to get needles in my arm, I had just underestimated the

size of the needles. I was in shock. I didn't know it would hurt as bad as it did. (Mr. Stephens)

Adherence.

When I was on CAPD, I taught French and I would take my class to France and they would commit to carrying the boxes (of supplies). We were on the train to Nice and I remember putting on a mask and they watched me do an exchange. (Ms. Cook)

I did that (PD) for about 2 years. I kept working. I did my treatment in the bathroom and so forth. (Ms. White)

Five participants did not want to use PD because of the type of access (a catheter in the peritoneum) used during treatment; this modality has a high risk of infection. The PD catheter is surgically-inserted directly into the stomach and requires extreme sterilization and cleanliness as the line is open directly into the body. This is often the entrance for infectious bacteria. Another issue with this modality is body image. Several of the participants "shook their heads" to say no when asked about PD as an options for dialysis treatments. They did not even want to consider PD because of this reason.

Access.

PD was just never an issue. I just couldn't see myself at 23, 24 years-old and I'm walking around with tubes hanging out of myself I was like, I know I'm gonna have this thing in my arm vibrating but that tube hanging out of my stomach just wouldn't be too attractive. (Mr. Gates)

Social Aspects.

I like to interact with people but if I do dialysis at home, I wouldn't ever leave home. What would be the purpose? I would never get out. (Mr. Gates)

I try to get out as much as I can because if you don't do that, you gone get depressed and stuff if you just stay around the house all the time. It helps to talk to other people because other people have much more problems than you have and it's amazing. (Ms. Cook)

Kidney Transplantation

Six of the ten participants in this study had previous kidney transplants. Three of these individuals had received two kidney transplants and all were back on in-center hemodialysis.

Surgery.

I really don't want one. I've been cut on so much. I see a lot of people that get transplants and end right back up in here. I don't know why but I just decided in my mind that I didn't want to go through all that surgery and taking all that medicine. I'll just live my life out like I am. And I'm in the best shape I've ever been in my whole life. I'm in good shape. (Mr. Stephens)

Adherence.

I wasn't treating my body like I was supposed to. I can't even tell no story. I was hanging out. I might get 2 hours of sleep here and 3 hours of sleep there. I was drinking, just...what a 23 year old person would do. I was having fun. I would take my medicine...I may take it Monday through Friday but that weekend, because I'm partying so hard....I'd be like...Oh, I forgot to take my medicine or did I take my medicine...I'm not really sure, I don't want to double up, aw, I'll take it later on...and then end up not taking it. (Mr. Gates)

Social Aspect.

(Transplant lasted)...Seven months. Yeah, I enjoyed it. I mean, I didn't have to go get stuck with no needles and stuff like that. (Mr. Shelby)

When I first got on dialysis they told me, "If you get a kidney, you can't be around your son because if he catches a cold..." I wasn't going to allow that because that was my baby. (Ms. Rowe)

Quality of Life

Each participant described a typical day, including days they had to attend dialysis appointments, and their overall treatment regimen in relation to their personal choices. Social and other support in their daily lives was seen as important to their overall quality of life.

Daily Life

The consensus among the participants was that their responsibility to take care of themselves was like a "full time job." They have a responsibility to attend all dialysis treatments

at a certain time and they understood that the consequences for missing treatments could mean further medical complications or death. Participants were also able to share stories of the challenges they have faced over the past twenty years. Each of them had a particularly good understanding of the need to closely monitor their diet as a major factor that would increase their likelihood for a good quality of health. This, however, was the source of much of the discussion of their struggles; many times they related how they “managed” their dietary restrictions in a joking manner.

Management of ESRD.

It’s like...just like a job. To me, it’s just like a job. Just like getting up going to work. And I know if I had a job and I had to get up and go, I look at it just like that. That’s why I have never missed a treatment...never. (Mr. Shelby)

Dietary restrictions I don’t have any chocolate in my house. I don’t have any peanuts in my house...and I love peanuts and I love chocolate...but if it’s here, you gone be tempted...you’ll wake up in the middle of the night...(whispering)...there’s some Hershey’s kisses in there...(laughter). So you go in there to eat 1 and 1 turns to 3 and 3 turns to 10...so you know, I just don’t have the stuff around. (Mr. Gates)

I make sure I take my medication. I make sure I come to dialysis and stay the whole treatment. It has just become a habit to me. And talking to other patients helps a lot. (Ms. Flowers)

I just do what my doc tell me. You know, I stay within the guidelines they set for me. Don’t go outside the line too bad and you’ll be alright. You know, that’s really the key to me. (Mr. Stephens)

Social Support

Health-related quality of life has been associated with perceptions of social and spiritual support and long-term survival among patients with ESRD (Spinale et al., 2008). All ten of the participants in this study were able to identify a strong network of family members and friends that they could call on in times of need. They also expressed a strong belief in God and talked about how their faith in God brought them through many difficult situations. Nine of the ten

participants spoke of their active membership in the church. They spoke of God as part of their organized religion and they also spoke of God in a spiritual sense. These nine participants discussed at many times throughout the interview how their faith in God helped them deal with difficult times in their lives, including with their management of ESRD.

Family and Friends.

God and my family...they have been wonderful. My wife, my sisters, all of 'em. They've been wonderful. They have supported me through all of this. (Mr. Shelby)

I'm good...I got my sister, my brother, my mom, I got family members, church members...you know...they've always been there. (Mr. Gates)

A lot of people that's on dialysis...they have family members that's there to try to support them but because they are so angry and mad at the world...they're going down. I mean, "You don't know what I'm going through. How can you..." It's not the fact they know what you going through, they just want to be there to help you. So, even as a patient, you have to learn as much as you can so you can teach whoever it is that's there for support...so they will understand. (Mr. Gates)

In-center Peers and Staff.

My family...friends, the one's I be around the most; the techs, you know most of them are very inspirational. They're always helping us and you know, making sure we feeling alright...talking to us during our treatment. They are a big part of the staff to me and my family. (Mr. Stephens)

Faith in God.

I realized that I knew or felt that modern medicine and prayer would help and when it is absolutely your time to go, it is your time to go. And, um, I am so thankful to the people that were treating me and having a strong faith in God and really helped me become stronger along with my strong will. (Mr. Brock)

He (the doctor) didn't predict that I would live over a couple of years, and of course you see God brought me through. (Ms. Cook)

My doctor said I might only live 3 years on dialysis but my sister kept telling me, "He's not God. You got to have faith in God 'cause those doctors just like us." (Ms. Rowe)

My doctor told my son that I might make it and I might not. It was a 50/50 chance so I just prayed and left it in God's hands. But when I woke up all I saw was white and I had to climb up, it seems like steps I was climbing up but when I got to the top I opened my

eyes and they said, “it’s over.” I said, huh? They said your surgery is over. Everybody had on white...(laughing)...I thought I had died... (Ms. Flowers)

Self-efficacy

The participants were asked questions regarding the decisions they have made about their illness and what they had learned about themselves in dealing with ESRD. All of the participants described an “inner strength” within them that they didn’t know they had until faced with the challenges associated with ESRD.

Inner Strength.

Don’t look at yourself as being sick. It’s just another hurdle you have to go over...and it’s not a hurdle...it’s just a little ant hill. Cause life goes on, you can’t just sit back and say, “oh, I’m on dialysis and my life has ended now.” No, it’s just started a new chapter. That’s all it is, it’s just a new chapter. And that chapter might have some hills and turns, good weather, bad weather, you just got to deal with it and keep on going. (Mr. Gates)

I did CAPD and I had to do exchanges but with a bit ingenuity, you can do a lot more than you think you can. I’ve learned that if I make one step, I need to just make two. I just push myself a little bit further than I think I can go and it always helps. (Ms. Cook)

Participants also responded to what they might do differently if they had to do this experience from the beginning all over again. Many participants expressed that they would have taken better care of themselves in the earlier years. They would have followed their diet and fluid restrictions so they could have avoided the experience of major complications associated with non-adherence to learn that lesson. All of the patients stated that they have learned things through trial and error and if they could do it all over again, they would educate themselves more about their illness.

Ooooh.....when I first got on dialysis and I got my first transplant...when I first got on dialysis, I would have tried to learn as much as I could. When I got my first transplant, it would have lasted longer and I would have become a tech and by now, I would have been a nurse...in dialysis. (Mr. Gates)

I mean, I was really ignorant and now that I think about it...at that age...at 17, ignorance was bliss. Because I think if I had been overwhelmed with a lot of information, knowing the resources that was out there at that time, there was nothing. I would have just crawled into a corner. But I didn’t know and I just went about my life

just like everybody else...and then got the consequences.....Now, I have learned so much about policy and Medicare; that opportunity just wasn't there back then. My doctor suggest I do it (get involved). If you just push yourself out of your comfort zone and do a little bit more than you would normally do. That's what I've learned that I can do. I don't say no to opportunities. I try to open myself up to doing different things. (Ms. Cook)

Vision for the Future

The participants shared how they had watched many others in the centers on dialysis become very sick and die because of non-adherence issues. They recalled and related many "stories" from their over 20 years of experience with their disease and treatments. Some of the participants shared how they had unsuccessfully tried to help these individuals get on the right track. They shared how it hurt them emotionally to see others lose their battle with ESRD. In this section, the participants offered advice to newly diagnosed individuals with ESRD.

Vision for Self

Each of the interviews was positive and upbeat. There were tears shed as well as laughter. I found myself laughing with the participants as they shared things they had learned throughout the years. There was a feeling of joy and peace during each interview. The participants were happy to share their stories and each of them hoped to help other dialysis patients through sharing what they had experienced with their stories of survival.

Enjoying Life.

You know, as a patient, you have to have that attitude that this is not the end of the world. This is not going to be my stop. I could be 80 years old, this is not gone be my stop, my last stop, I'm gone have a good time. (Mr. Gates)

Newly Diagnosed Individuals

The participants offered their observations about what has changed in ESRD treatment over time and advice they would give to individuals newly diagnosed with ESRD. Each participant made reference to the improvements made to the dialysis machines. They were also

very pleased with the educational materials that are currently offered prior to starting dialysis, and continue to be made available on a monthly basis for each dialysis patient.

Changes in ESRD Treatments. There have been many changes in ESRD treatments since the ten participants in this study started dialysis over 20 years ago. There are new policies and procedures in place to protect each person receiving treatment for ESRD. There is much more oversight and monitoring from governing agencies to make sure dialysis companies provide quality services for the individuals receiving care in their facilities. Education is an important component in helping an individual on dialysis have a sense of control regarding her or his life while managing the day-to-day challenges associated with ESRD and dialysis treatments. These changes were intended to encourage and empower individuals living with ESRD.

Besides the dialysis process, the way they keep the patient informed. I love that. I mean, every month they give us a sheet with our lab values. It explains exactly what the labs are, what your ranges should be, what you could do to improve. If my albumin is low, then it says you need to eat more of this...oh, the patient is so empowered...if he chooses to be. The patient is so empowered. They are encouraged to ask questions, they're encouraged to get information. (Ms. Cook)

Advice to New Patients. Each participant was asked what advice they would give to someone newly diagnosed with ESRD. All of them shared how they felt a sense of responsibility for new and mostly younger individuals receiving dialysis treatments at their facilities.

Learn everything you can about the way your access is placed. You know where the loop is and there's a curve here and it drops down (outlining his access). Know everything you can about your dialysis. Learn as much as you can about...not just dialysis...heart treatment [things that could come up as complications], whatever you going through, learn what you can about it. (Mr. Gates)

I would tell them to take their medication, follow their diet and come to dialysis. The hardest thing they have with new patients is they don't come. They hate coming to

dialysis but I always tell them, “look, this is an option for you to live. There is no other option other than a transplant; you can die if you don’t come.” (Ms. Flowers)

Always do your treatment all the time. I’ve seen a lot of ‘em come in there and they just want to get off (the dialysis machine) and I recommend you stay on your treatment and do all your time and always come. Always come to your treatment. (Mr. Shelby)

I’d tell them to go...and to not miss none. Don’t start going and get discouraged and start skipping...that’s the worst. Now, I’ve never, as long as I’ve done it, I’ve never skipped. I’ve always come. I get here and do my dialysis and I go back to the house. (Mr. Richardson)

The number one issue is, be compliant. It’s going to make your dialysis life so much easier. It’s going to avoid so many problems down the road. (Ms. Cook)

Individual Textural Descriptions and Individual Structural Descriptions

Moustakas (1994) states that individual textural descriptions are used to evoke clear images of what happens during a phenomenon. Individual structural descriptions are constructed to provide a vivid account for “how” feelings and thoughts connect with the phenomena. In this study, the participants provided accounts of how they viewed themselves and their lives while living with ESRD. These descriptions are told in story form. Verbatim examples from the transcribed interviews are used to capture the essence of each individual’s experience. From this analysis and construction of the individual textural descriptions and individual structural descriptions, composite textural and structural descriptions of the experience of the group as a whole were developed. Themes and patterns representing the overall experience emerged from this part of the analysis and are highlighted in these composite descriptions.

Participant 1: Mr. Gates

Individual Textural Description

Initial diagnosis. Mr. Gates was 21 years-old when he was diagnosed with end stage renal disease. He was in the military at the time and serving in Desert Storm. He was feeling tired and had frequent headaches but didn’t give it much thought. He attributed his headaches to

the stress of being in Desert Storm and “brushed it off.” During a visit with his family for Thanksgiving, he developed symptoms that resembled the flu. He decided to seek medical attention to alleviate the symptoms and so that he might to enjoy his visit with his family. In the emergency room, he was told his blood pressure was 220/180. His blood pressure was at stroke level and with this high reading, the doctors were surprised that he was still able to walk. He recalled being given several glasses of water in an effort to make him use the restroom. He had not noticed that he wasn’t urinating. He had not given it much thought. After several blood tests were taken, Mr. Gates was told he would have to be admitted to the Medical Intensive Care Unit for further testing. He didn’t understand why he needed to be in intensive care for the flu but he agreed and within hours he received startling news.

He [the doctor] came back in and told me, “well your kidneys have totally shut down, not one but both.” I was like, wait, hold up, slow down, slow down... Wait a minute, you moving too fast.

Treatment experience. He was shocked to learn that he would now be required to undergo dialysis treatments for the rest of his life unless he received a kidney transplant. Mr. Gates described his first dialysis treatment.

My first initial dialysis treatment was kind of scary because I didn’t know what to expect...you’re like, what is all this and nobody could really tell me the whole details. They give you bits and pieces here and there.

Mr. Gates had a kidney biopsy taken and had a follow-up meeting with a nephrologist who explained the process of dialysis while in the hospital. The biopsy indicated that he had glomerulonephritis. The nephrologist also informed him that he would require regular dialysis treatments until he received a kidney transplant. Mr. Gates’ mother immediately stepped up and offered her kidney but he didn’t want to take a kidney from his mother knowing that he had

younger siblings who might suffer the same fate. Later, when stabilized and back in the military, he had treatment in base hospitals; this was a challenge for him.

I was the youngest person there. I was sitting around these old folks looking like, why am I here? Why am I even here? You see all these old folks with like high blood pressure, diabetes, heart conditions and I'm like, what happened to me? before I even turned 25, before I even got married, before I had kids....I got to go through all this?

He refused peritoneal dialysis because he didn't want a catheter placed in his stomach. It took only five months for Mr. Gates to decide that he wanted to follow through with the kidney transplant his mother had offered. It lasted 3 ½ years.

I was 22. I wasn't treating my body like I was suppose to....I was hanging out. I might get 2 hours of sleep here and 3 hours of sleep there. I was drinking, just...what a 23 year old person would do. I was having fun....

The kidney that his mother gave him did not last because he didn't adhere to his medication regimen and he didn't take care of his body. After starting dialysis again, Mr. Gates made a decision to find out everything he needed to know about his treatments and taking care of his body.

Quality of life. After learning how to take care of himself and adhering to his treatments, Mr. Gates received another transplant five years later with a cadaver kidney. It lasted 12 years. Although he is on hemodialysis again, Mr. Gates learned some valuable lessons.

I just took my time and asked questions about the machine and about being on dialysis and what it took to do dialysis...I just took the time to learn about what I needed to do to make me feel better. I ended up, about a year later...learning how to stick myself. I learned how to set my machine up. I learned everything I could about dialysis. Because it wasn't just affecting [me] physically, I had to live with it....not let it take over my life.

Mr. Gates continues to be was adherent to his dialysis treatments, diet and fluid restrictions. He shared how he measures his fluid limits with a 16 oz. cup. He talked about having cravings for food and never allowing those foods in his home because he knows that they are triggers for him. He decided to choose life over an unhealthy lifestyle. He visits with his friends and no longer

drinks alcohol. In addition, he allows his body to rest when needed. These are strategies that work for him.

Vision for the future. As Mr. Gates reflected on the time when he was first diagnosed with ESRD, he wished he had done things differently. He now uses his experiences as an opportunity to help other patients learn about dialysis and how to take care of themselves.

...when I first got on dialysis, I would have tried to learn as much as I could. When I got my first transplant, it would have lasted longer.

I tell every patient that come in there to learn how to stick yourself. Even if you don't stick yourself, learn how to do it.

At the time of the interview, Mr. Gates was no longer in the military. He had retired. He maintains an active lifestyle with his family, friends, and church members. He remains active on the transplant list.

Individual Structural Description

Mr. Gates struggled with how this happened. How did he lose function of both kidneys? He had a full physical five months prior to his diagnosis and the doctors didn't find anything wrong with him. He searched for answers. He also struggled with wanting to have fun and enjoy his life without taking his medical needs seriously. Mr. Gates had a strong family support system. He learned about his illness and then he was able to help his family members understand how ESRD was affecting his life. He learned what he could about his illness and he applied what he had learned to his own lifestyle choices. He worked with others to teach them what he had learned about taking care of himself. He shared stories about his inner strength and the love and support he receives from his family members. His church family and his faith in God were also very important to him. Although he continues to require hemodialysis treatments three days per week while awaiting his third transplant, he keeps a positive attitude about life.

Participant 2: Mr. Shelby

Individual Textural Description

Initial diagnosis. Mr. Shelby was 35 years old when he was diagnosed with ESRD. He had been experiencing headaches and blurred vision for a while. He knew he had high blood pressure but never expected to lose function of his kidneys. He found out about ESRD when he was hospitalized for dangerously high blood pressure. As his blood pressure continued to increase, his kidneys began to fail. The doctors informed him during that time that he would require dialysis treatments in order to survive. In spite of the evidence linking his high blood pressure to loss of kidney function, he believed that he brought this situation on himself due to years of abusing alcohol.

Well, I kind of...I kind of like brought it on myself...I had been drinking and carrying on and stuff like that and I kind of brought it on myself.

Treatment Experiences. Various treatment options were discussed with Mr. Shelby and he decided that in-center hemodialysis was most appropriate for him at that time. However, approximately one year after starting dialysis, Mr. Shelby received a kidney transplant from a cadaver. The transplanted kidney lasted seven months. Mr. Shelby did not look at this situation as something negative. He enjoyed seven months of freedom from his dialysis routine.

Seven months. Yeah, I enjoyed it. I mean, I didn't have to go get stuck with no needles and stuff like that.

Quality of life. Mr. Shelby stated that his lifestyle is really no different from anyone not on dialysis. He maintains an active lifestyle with his family and he is active in his church.

I go to dialysis and after that I can do just about anything I want to. And then on non-dialysis days I ummm, like in the summer time, I got a lawn service. I do lawns. And, I do just about anything I want to do.

I've learned I can do a lot of stuff...since I've been on dialysis, I haven't been too much sick. It's just like it's nothing wrong with me. It's just my kidneys. Other than that, I feel fine. Nothing bothers me.

Vision for the future. As Mr. Shelby reflected over his past decisions, he shared his regret of abusing alcohol; believing that this caused his life to change. Mr. Shelby stated that he maintains an active lifestyle and he offered advice to individuals who are newly diagnosed with ESRD.

Always, always, always (getting louder) do what you're supposed to do. And the main thing is, always come to treatment. Always do your treatment all the time.

Individual Structural Description

Mr. Shelby has not missed a dialysis treatment in over 22 years. He attributes his long-term survival with ESRD to his adherence to treatments, his family, and his strong faith in God. Mr. Shelby has also never missed a doctor's appointment and gives his family credit for that because they typically provide transportation. He stated that his wife and sisters take him wherever he needs to go. All he has to do is ask one of them. Mr. Shelby enjoys having an active lifestyle but considers his health a priority over everything else in his life. He never takes his health for granted and he serves as a mentor to newly diagnosed individuals with ESRD. His advice to anyone who wants to be successful on dialysis and have the best possible quality of life is to always adhere to the treatment regimen and give this top priority in life.

Participant 3: Mr. Richardson

Individual Textural Description

Initial diagnosis. Mr. Richardson was 48 years old when he was diagnosed with ESRD. For several months, he had been coughing up large amounts of water and his skin was turning yellow. Mr. Richardson very "bloated" and did not know why his body was retaining so much fluid. Because of this, he began to isolate himself from some family members and friends. He

did not want these coughing spells to occur around anyone outside of his immediate family. As his body became weaker, he decided to finally go to the emergency room to find out what was going on with his body. The doctors in the hospital explained to Mr. Richardson that he had not been urinating for quite some time and this was the cause of his symptoms. He had not noticed. After extensive testing they also informed him that he was in renal failure and would require dialysis. Mr. Richardson did not know what that meant. He had never heard of dialysis and did not understand how renal failure would affect his life. He stated that he was later told that the medication he was taking to control his high blood pressure had caused his kidneys to fail.

Treatment experiences. Mr. Richardson began dialysis in the hospital. He did not choose peritoneal dialysis due to his fear of peritonitis. He decided that in-center hemodialysis was most appropriate for him and his family. About eight months after he was initially diagnosed with ESRD, Mr. Richardson received a kidney transplant from a cadaver. Fourteen years after his transplant, Mr. Richardson had a heart attack and had to make a decision to allow his doctors to inject a medical dye into his body that would possibly cause his kidney to reject. Without this procedure, he knew it was possible to have another heart attack that would possibly be fatal. Mr. Richardson agreed to allow the doctors to use the dye in order to save his life, but he lost the transplanted kidney in the process.

I was between a rock and a hard place. If I didn't have it done, I was going to have another heart attack and if I did, I was going to lose my kidney. I thought, well, I'll go back on dialysis because if I don't get something done to this heart, it's going to take me out of this world.

Quality of life. Mr. Richardson restarted in-center hemodialysis and continues to enjoy socializing with other patients and staff during his treatments.

I just come up here and have a good time. To me, that's life. I don't want to bother nobody. I don't want to upset nobody...I cut up with people like that all the time....that makes life fun.

Mr. Richardson also enjoys hunting and fishing with his sons and grandsons. He stated that he knows he can't live forever but he thanks God for allowing him this time with his family.

Vision for the future. Mr. Richardson remains active on the transplant list. He has had family members who wanted to give him a kidney but he does not want to take a donation from a family member. He was 69 years old at the time of our interview and he was not planning to consider transplantation as an option for much longer. Mr. Richardson shared how adhering to his treatments has made a difference in his life and shared advice he would give to individuals newly diagnosed with ESRD.

I'd tell them to go...and to not miss none. Don't start going and get discouraged and start skipping...that's the worst. Now, I've never, as long as I've done it, I've never skipped. I've always come.

Individual Structural Description

For Mr. Richardson, adherence to his dialysis treatments and the strict diet regimen was very important to him, especially given his chronic heart disease. He shared the struggles he had with the diet regimen in the past but he and his wife learned new recipes that have made sticking to it much easier to manage. Mr. Richardson seems to enjoy a positive outlook on life that he attributes to his faith in God and the love and support he receives from his family.

Participant 4: Mr. Stephens

Individual Textural Description

Initial diagnosis. Mr. Stephens was diagnosed with ESRD at age seventeen. He was diagnosed after an emergency room visit due to a severe headache. His blood pressure was 270/170 when he arrived at the hospital. He passed out in the emergency room and woke up a day and a half later. The doctors informed him that he had severe hypertension and that had

caused his kidneys to fail. Mr. Stephens stated that he had symptoms of swollen ankles since age 12 but never thought much about what might have been causing it.

Treatment experiences. Due to his age and his school schedule at the time of diagnosis, Mr. Stephens chose peritoneal dialysis as his treatment option. He did peritoneal dialysis for ten years. He was forced to start in-center hemodialysis after several episodes of peritonitis. The adjustment was hard for him at first.

They introduced me to hemo(dialysis). I was scared at first. Seeing the needles and seeing peoples' blood, I was scared.

Mr. Stephens did not want to be evaluated for a kidney transplant. At the time of the interview, Mr. Stephens had been receiving dialysis treatments for almost 26 years He has never received a transplant; he did not want to have the surgery. He stated that he felt healthy and he had chosen to make the best of his dialysis treatments. Besides, he felt that dealing with a possible kidney rejection would probably be harder on him than having the surgery.

Quality of life. Mr. Stephens stated that he is in the best shape of his life. He stated that his body is healthy and he has no medical complications. When asked questions about how he felt after dialysis treatments, Mr. Stephens stated that he did not have any problems.

I feel good most of the time. I would say, 90% of the time I feel good 'cause most of the time I walk right out. I don't have any problems. But every now and then I might get a little headache or something...but other than that, no problems at all.

Vision for the future. Mr. Stephens stated that he maintains an active lifestyle. He stated that would advise individuals who are new to dialysis treatment not to be afraid and to do what her or his doctor tells them to do.

I would try to tell them not to be so scared because I was real scared. It's not a death sentence because you're on dialysis. That's what I thought, I'm gonna end up dead but I found out you could still live a good life.

Individual Structural Description

Mr. Stephens attributed his good quality of life to adherence to his treatments and to his diet regimen. Mr. Stephens stated that he used to miss dialysis treatments in the past due to transportation issues. After dealing with some medical complications associated with missed treatments (fluid overload and cramping), he realized that his treatments were vital to his health. Now he does whatever is needed to maintain his healthy lifestyle. He sometimes walks to dialysis because he knows that missing his treatments is no longer an option for him. Mr. Stephens commended the staff at his dialysis clinic for educating him about his dialysis treatments and his diet. He found that the monthly blood test results were very valuable tools for helping him manage his diet and fluid intake. Mr. Stephens also shared that the love and support of his family has made dealing with ESRD a lot easier.

Participant 5: Ms. Cook

Individual Textural Description

Initial diagnosis. Ms. Cook is a 62 year old woman who was first diagnosed with renal failure at age 17. It was 1968 and she was a senior in high school. She shared stories of how “sickly” she had been for many years. She described episodes in which she “passed out” but she had no idea what was causing her to feel so poorly. She recalled a visit to her primary care doctor that changed her life. Due to the results of her lab tests, her doctor requested a kidney biopsy that revealed signs of renal failure. She had no prior knowledge of kidney disease and she was told “the bare minimum.” Looking back on it, she was glad that she didn’t know much about her illness because she was not sure she could have handled it at her young age. At that time, with few treatment options, she was not expected to live very long, but she was relatively healthy for nine years before she required regular dialysis treatments.

Treatment experiences. Ms. Cook began in-center hemodialysis in 1977. It was the only option offered to her at that time. She described the treatments as “horrible.” She described the process as being painful and crippling to her body. She didn’t remember anything good about the experience. It was a very difficult adjustment for her. Ms. Cook received her first kidney transplant from a cadaver approximately one year after starting dialysis. The transplant lasted 2 ½ years. She eventually tried peritoneal dialysis and home hemodialysis. She worked full-time and those options were most appropriate for her work schedule. Ms. Cook received another kidney transplant over twenty years later which lasted nine years. She was receiving in-center hemodialysis at the time of the interview.

Quality of life. Ms. Cook did not immediately accept responsibility for her health. She shared stories of how she tested the limits and did things “her way,” which was always against medical advice. She drank more fluid than she was allowed. She did not adhere to her treatment regimen as prescribed and she refused to accept this dramatic change in her young life. Ms. Cook was married shortly after college and her husband had a negative view of her illness as well. He referred to her as “nothing but a doctor’s bill.” The marriage did not last and Ms. Cook decided to change her life and start learning more about her illness. She eventually became a mentor for newly diagnosed individuals with ESRD. Her life experience with ESRD has helped other individuals locally and nationally through various organizations.

Vision for the future. Ms. Cook is close to her family and professes a strong faith in God. She is engaged in activities in her local community. She remains active on the transplant list. Ms. Cook is very knowledgeable about ESRD and the dialysis process and serves as a mentor to individuals around the country who are having difficulty adjusting to ESRD. She hopes that her experiences with ESRD will help other individuals live a higher quality of life.

During the interview she shared advice she would give to others who may be struggling with this life change as she did early on in coping with ESRD.

...be as compliant as possible, because it will make things so much easier. You will feel better, dialysis will go better, your chances for a transplant will be better, I mean your life in general will be better. You'll live longer...compliance.

Individual Structural Description

Ms. Cook attributed her good quality of life to the educational materials that were made available to her through her dialysis facility, the internet, and many organizations that have been developed to help individuals who want to live better while managing ESRD. She is retired but remains active as a volunteer mentor for several kidney organizations around the country. She has a strong family support system and a strong faith in God.

Participant 6: Ms. Flowers

Individual Textural Description

Initial diagnosis. Ms. Flowers was 31 years old when she was diagnosed with ESRD. She took the medical advice of doctor and had a shunt placed in her arm, but she did not understand why she needed it. Her doctors explained to her that her kidneys had failed and she needed dialysis. She had no prior knowledge of the dialysis process or why the treatments were necessary. Ms. Flowers did remember being sick a lot as a teenager and being told that she had problems with her kidneys in her 20s, but she did not understand what that meant. There were no dialysis units where she lived and she did not know anyone with kidney problems. After the doctors explained to her that she would require dialysis treatments in order to stay alive, she agreed to start hemodialysis immediately.

Treatment experiences. Ms. Flowers was offered in-center hemodialysis. She later explored peritoneal dialysis as a treatment option but she was not able to have a catheter placed

in her stomach due to scar tissue. Ms. Flowers received a transplant approximately one year after she began in-center hemodialysis. It was a cadaver kidney that lasted six years. She went back to in-center hemodialysis and, ten years later, she received a second kidney transplant. It was also a cadaver kidney that lasted six years. Ms. Flowers was receiving in-center hemodialysis at the time of the interview.

Quality of life. Ms. Flowers remains active on the transplant list. She has had other medical problems that may prevent her from receiving another kidney transplant. However, she does not worry about it. She tries to eat right and adhere to all of her dialysis treatments and doctor's appointments. Ms. Flowers sometimes becomes tired after dialysis treatments but does all she can to remain active in her community. She fears becoming depressed if she does not stay busy. She enjoys talking to other individuals who receive dialysis treatments. They help each other through the hard times.

I make sure I take my medication. I make sure I come to dialysis and stay the whole treatment...it has just become a habit to me...doing what I need to do to deal with dialysis. And talking to other patients helps a lot.

Vision for the future. Ms. Flowers wished she had taken better care of herself when she was younger. She did not go to the doctor when she was sick. She used a lot of home remedies and she did not eat foods that were healthy for her. Since accepting the diagnosis and the life changes that needed to be made, she still struggles from time-to-time but enjoys now and looks forward to a future with a good quality of life.

Individual Structural Description

At the time of her interview, Ms. Flowers had been living with ESRD for more than 28 years. Her journey was not always easy. She believes that adherence to her diet and her dialysis treatments have kept her alive this long. She experienced many health problems, as well as

psychological challenges in acceptance, along the way but expressed an inner strength that kept her fighting to live. She believes that the love of her son and her faith in God keep her going when times are hard.

Participant 7: Ms. White

Individual Textural Description

Initial diagnosis. Ms. White was diagnosed with ESRD at age 25. She was going to her doctor quite often for blurred vision and fatigue. Even though numerous medical tests had been conducted throughout this time a clear diagnosis was not made. As her symptoms became more intense, her sister took her to the emergency room for further evaluation. Ms. White's blood pressure was so high that she lost consciousness while in the ER. When she woke up three days later, she was told that her high blood pressure had caused her kidneys to fail and she would need dialysis treatments to stay alive. She was shocked. She knew she had high blood pressure at a very young age but never knew anything was wrong (or could go "wrong") with her kidneys.

Treatment experiences. Ms. White chose to do peritoneal dialysis because she worked full-time and wanted to continue working. She had to discontinue peritoneal dialysis after two years due to a serious infection; she then started in-center hemodialysis. About two years later, she received her first transplant from a cadaver; it lasted six months. Two years after that, she received another cadaver kidney; this transplant failed almost immediately. She remains active on the transplant list. She continues to do in-center hemodialysis three days per week and feels good after her treatments.

...when I first started [dialysis], people used to tell me, "when you get off dialysis, you just need to go home and lay down." And I did it...for about a week or two. Then I said, why am I laying down...I am not tired...(laughing)...that's when I went back to work.

Quality of life. Ms. White continues to work and she maintains an active lifestyle. Several of her family members have offered to become kidney donors for her but she refused. She is happy with her life and does not want to put her family through any unnecessary medical procedures and risk future problems for them. She is grateful for their unconditional support.

Vision for the future. Ms. White tries to have a positive attitude in about life. She explained that while she does struggle and “every day is not easy,” she does not let others see this. She chooses to stay positive. She has learned over the years that she is stronger than she thought. She would advise individuals new to dialysis to stay positive and adhere to what her and his doctor tells them to do. She also wants to help in a larger way by restarting a mentoring group in her clinic.

I was the one who started the kidney club. It was big for a while and we want to get it back going. We would go to the hospitals when they start dialysis and introduce ourselves and let them know we were dialysis patients and answer their questions... you got to keep a good mind because it's hard...you see people really, really suffering. I try to cheer them up and let 'em know it's gonna get better...

Individual Structural Description

Ms. White shared that she has not always followed her treatment regimen as prescribed. She did not follow the fluid restrictions as recommended until her medical complications began to outweigh her need to drink water. She began to rely on her faith in God to help her through the difficult times. She prayed about her health and always tried to treat people right. The love of her family has always been her primary focus for staying healthy. She never married nor had children. Her nieces became the world to her and she wanted to see them grow up healthy and happy. They are grown now and they remain the center of her joy.

Participant 8: Mr. Brock

Individual Textural Description

Initial diagnosis. Mr. Brock is a 42 year old who was diagnosed with ESRD at age 16. He was on a trip with his high school chorus when he started experiencing flu-like symptoms. After his return, he made several visits to his doctor, and after many medical tests, Mr. Brock was told that the test results indicated that he was in renal failure. He was hospitalized and began hemodialysis immediately. A neighbor, who was already on dialysis, talked to him and explained what he could expect during dialysis treatments.

Treatment experiences. Mr. Brock began training for peritoneal dialysis immediately after he was discharged from the hospital. He did peritoneal dialysis for one year and then received a kidney transplant from a cadaver. The transplant lasted 21 years. A small pimple on his leg became infected and triggered the events that led to kidney rejection, and afterwards he started in-center hemodialysis while he continues to await another transplant. Although Mr. Brock was not receiving dialysis for 21 years, he was still responsible for taking his medications and following a strict diet.

Quality of life. Mr. Brock maintains an active lifestyle. He does well with his dialysis treatments and he adheres to his diet. He stays away from certain trigger foods that may jeopardize his chances of getting another transplant. He has good family support but they don't always understand his struggles. He no longer has the support of his close friends because he recently moved out-of-state to be closer to family. He misses his friends and might consider moving back to be closer to them if he receives another transplant.

Vision for the future. Mr. Brock expressed that he was looking forward to going back to work full-time. He stopped working after he went back on dialysis. He offered advice to individuals who are just starting dialysis.

Follow your treatment carefully. Do as best as you can. You will need to do what you are told to do. Don't miss any treatments and keep your stress level to an absolute minimum.

Individual Structural Description

Mr. Brock was very young when he was diagnosed with ESRD. Even at a young age, he said he always had a strong will and he knew he could do anything he “set his mind to”. He has a strong faith in God and talked very openly about his faith being the source of his strength. He lives a “Christian lifestyle.” He treats people the way he wants to be treated and he seeks the guidance of God for all decisions in every aspect of his life.

Participant 9: Ms. Rowe

Individual Textural Description

Initial diagnosis. Ms. Rowe was 32 years old when she was diagnosed with ESRD. She had been experiencing severe headaches due to high blood pressure. She had three siblings with ESRD so she was not surprised when she was told she would have to start dialysis. However, she was surprised to learn, after a kidney biopsy, that she was born with only one kidney. That kidney was removed due to possible cancer cells. Therefore, she no longer has a kidney in her body.

Treatment experiences. Ms. Rowe had three young children at the time of her diagnosis. She was told by “someone” that it would not be wise for her to have a transplant. She was told that she would not be able to take care of her children if they were sick because she would become ill herself and this would cause her kidney to reject. After receiving that (inaccurate) advice, she made a decision to never be evaluated for a kidney transplant. She also did not want to try peritoneal dialysis. At the time of her interview, Ms. Rowe had been receiving in-center hemodialysis for more than 28 years.

Quality of life. Ms. Rowe has a strong family history of ESRD. She had three siblings already receiving dialysis treatments when she was initially diagnosed with ESRD. Even being familiar with the dialysis treatment regimen from her siblings' experiences, she did not always adhere to her own treatment regimen. The first 18 years were very difficult for her as she did not consistently follow the strict diet or attend treatments. She also admitted to not taking her medications as prescribed. Ms. Rowe became very sick due to complications associated with non-adherence and decided to make positive changes in her lifestyle.

I was hard-headed and didn't care. I had told my sister, "if something happen to me I want you to take care of my boys." Cause, I was upset about all this and my doctor said I might only live 3 years on dialysis but my sister kept telling me, "He's not God."

...my sister kept talking to me and I thought about it one day and I put God in front. I thought about my children. I started watching my fluid. I started eating right. And I did good.

She now looks forward to getting her monthly report card from the center's dietitian and bragging to everyone about how well she is doing. Ms. Rowe has also learned that her dialysis treatments do not go very well if she drinks too much fluid. The cramping becomes very intense and she is very tired after her treatments. If she adheres to her fluid restrictions, the treatment is usually complication-free and she feels good afterwards.

Ms. Rowe has a strong faith in God and she has a very supportive family. She admitted that her children "spoil" her and overall they "take good care of her." At the time of her interview, she was also in a healthy romantic relationship with someone who really seemed to care about her.

Vision for the future. As Ms. Rowe reflected over the past 28 years, she the difficulty for her to adhere to her treatments after she began dialysis was clearly evident.

I'mma tell you the truth. I thought I was gone die any day. I didn't have no hope for myself. I didn't have no hope. I said, well if I die, I just die...you know. My sister kept telling me, "You got to have faith in God."

Ms. Rowe also offered advice to others who may be just starting their "journey" with ESRD.

I would tell them one thing about dialysis, you got to take your treatment. You can't miss your treatments and you got to eat the stuff you're supposed to eat.

...you just have to learn how to take care of yourself because if you don't look out for yourself, nobody else will.

Individual Structural Description

Ms. Rowe had a family history of ESRD and she had prior knowledge about the affects of her illness. However, she did not adhere to her treatment, diet, and fluid restrictions until she almost died. She gives credit and thanks for her change in lifestyle to God and to the love and support of her family. Ms. Rowe tries to stay within the guidelines that her medical team has set for her and advises others to do the same. She has learned that her quality of life is much better and she is much happier when she follows her treatment plan.

Participant 10: Mr. Duncan

Individual Textural Description

Initial diagnosis. Mr. Duncan was 23 years old when he was diagnosed with ESRD. His face was swollen and he could not walk more than a few feet without becoming short of breath. A family member witnessed him taking two steps backwards for every step he attempted to take forward while walking up a slight incline. Mr. Duncan was taken to the emergency room, where upon arrival, he had cardiac arrest. His blood pressure was high and he was at great risk of having a stroke. Mr. Duncan was diagnosed with ESRD and began dialysis immediately. He had a family history of ESRD but he was not aware that his own kidneys were failing because of hypertension.

Treatment experiences. He started in-center hemodialysis and later switched to peritoneal dialysis. He did peritoneal dialysis for six years before switching back to in-center hemodialysis. Mr. Duncan was evaluated for a kidney transplant and placed on the list. At the time a kidney was available for transplant he did not have transportation to the hospital in order to undergo the surgery. He has never had a transplant and is no longer interested in this option.

Quality of life. Mr. Duncan stated that his lifestyle did not change that much from before being diagnosed with ESRD. He continues to “hang out” with his friends. He does not drink alcohol with them as he used to and he takes good care of his body. He has good family support and a girlfriend who takes good care of him. Mr. Duncan has learned not to take life “too seriously.” He is employed and he enjoys having fun.

I guess that’s what keeps me going most of the time. I sit around and joke with them. If I’m not joking with them, they think something’s wrong with me.

Vision for the future. Mr. Duncan says he just takes one day at a time. He has learned how to manage his diet and fluid restrictions.

I’ve been doing this 29 years. I learned that I can’t have everything I see. Now, I can walk by it. I ain’t got to have it.

He has tried to help others get on the right path to better health. He says it is frustrating to see young people coming to the center (or not coming/skipping treatments) and know that they are dying because they do not take care of themselves. He makes himself available if anyone wants help but he does not push them into accepting a lifestyle that they are not ready to embrace.

Individual Structural Description

Mr. Duncan joked throughout the entire interview. He believes that life is short and he has to enjoy every minute of it. He continues to work full-time and he remains active in his church. His friends and family are supportive. Mr. Duncan feels that adherence to his dialysis

treatments has been one of the reasons for his success with ESRD. Another reason he has been successful on dialysis is because he live stress free.

Composite Textural Description

The challenges individuals face each day while living with end stage renal disease can only be described by someone who has lived with this experience. There are certain characteristics one must possess to endure a life-threatening, chronic illness. Such conditions may seem hopeless and individuals may believe that there is no one in their immediate circle of family and friends that can truly relate to her or his experience. The participants in this study displayed common behaviors, attitudes, and beliefs that may have influenced their long-term survival with ESRD.

“Knowledge” emerged as a theme that may have contributed to the long-term success of the participants. Having the knowledge to make informed decisions about their health provided each with a sense of control and the power that they could improve their quality of life. The medical and technical terminology alone can be quite intimidating for most people. However, these individuals were able to accurately articulate the functions of the dialysis machines and how the machines were actually set up. When asked what had changed over the past twenty years, each of them discussed the changes that have occurred with the dialysis machines to make the process less cumbersome and more effective.

Their knowledge also extended to the restrictive renal diet regimen. Several of the participants actually stated that they knew the diet “like the back of my hand.” They knew the purpose of every medical laboratory blood test performed and used their monthly lab values to gauge adjustments needed to maintaining or improve these values (indicators of overall health). They then made these changes in order to stay within the recommended guidelines prescribed by

their physicians. They looked forward to receiving their monthly “report cards” as a way of validating their own self-efficacy. They were able to provide extensive details about their dialysis access site and the importance to taking care of their “lifeline.”

The participants found it helpful to educate their family members as well. They used the resources provided by the dialysis staff members in addition to other sources. They used the internet as a tool for locating information about specific issues that are not always addressed in the facilities. In addition, many of them attended conferences specifically for individuals with ESRD. They used their knowledge to make wise choices that would ultimately enhance their lives.

A second theme that emerged from the data was the *realization that “I had to do it.”* Each of the participants discussed the challenges they faced with adherence to the treatment regimen, in one aspect or another, after their initial diagnosis with ESRD. They did not always make the best choices regarding their health but were able to come to the realization that they needed to make better choices in order to survive. The choice to attend all dialysis treatments might not seem difficult to someone who has never “sat in that chair” for 4 hours a day/3 days per week. However, no matter what was going on in their lives, each of the participants made this life-saving commitment to adhere to their dialysis treatments. They provided details about their daily activities and each of them remained active without experiencing extreme fatigue after treatments. They attributed the good quality of their health to adherence to treatment. Adherence was a major factor in their success and they felt that it ultimately improved their quality of life overall.

They all confirmed that their bodies accepted the dialysis treatments better when they followed their diet and fluid restrictions as prescribed. The most difficult challenge for most of

the participants was the renal diet and fluid restrictions. It was sometimes difficult for them to stay away from certain “trigger” foods that would cause them to binge. In order to satisfy the cravings, each of them had developed a “system” of either having a small amount and taking extra binders or using their inner strength to resist all together. They all agreed that the consequences for having certain foods or too much fluid, was not worth giving up the ability to receive a transplant or the loss of their own lives. Some of the participants shared that this realization came to them very early in their treatment, but this was not the case for all.

Having a strong support system was a key factor for the participants in this study. They all had family members and friends that they could rely on to take them to appointments and to be with them while in the hospital. They had friends they could spend time with and who continued to support them when they could no longer physically do the things they used to do. It was especially important for them to have support in the area of food. Certain kinds of food that was restricted on the renal diet were “not allowed” in their homes and their family members understood the importance of avoiding temptation, and even adapted their recipes to include healthy choices that everyone in the family could enjoy. Getting “through” each day for these participants was not necessarily easy. They sometimes struggled with medical complications and even worried about dying. They related stories that at their weakest moments, family members prayed for them and reminded them that “God was in control, not the doctors.”

“*Spirituality*” was another important theme that likely influenced the participants’ long-term survival. They described a connection to a power greater than themselves. They explained how they prayed for strength and often turned their situations over to God and allowed Him to take control when they felt like giving up. When times were hard and they felt that no one else could understand what they were going through, they turned toward God. They described God’s

grace for seeing them through difficult times and were thankful that this may have allowed them to live as long as they have with ESRD. They talked about the “power” of God and the “presence” of God during surgeries and how the doctors were just “normal” people led by God. When they had nowhere else to turn, they knew God was there with them. Many were also active in their churches, and this provided an additional social connection for them as well.

Composite Structural Description

All participants shared what they felt was important to them as they were going through treatment over the years and what they thought contributed to their long-term survival with ESRD. Since the participants began dialysis more than 20 years ago, they were able to observe other patients that were not successful in managing their illness. Some of what they observed may have been similar to their own experiences, prior to “deciding” that they wanted to live life to the fullest as healthy individuals. They shared stories of sadness, severe medical complications associated with ESRD, and death. They shared their own struggles and the incidents in which they attempted to “counsel” others who were not adherent with treatment, perceived to have refused help, and lost their battle with end stage renal disease. Frustration was expressed with the difficulty of convincing these individuals to follow the path to health that they had.

In spite of the challenges and obstacles the participants faced each day, they all exuded a joy and peacefulness during their interviews. There were tears of joy and much laughter during each of the interviews. The participants have learned to enjoy life despite their challenges. They take the management of their health very seriously but they balance this with other important aspects of their lives. They described a quality of life that that they believed was no different from someone who was not diagnosed with ESRD. They all had an inner strength that they

learned to utilize when things got tough, and they knew that no matter what happened in life, everything would work out fine for them in the end.

CHAPTER 5

DISCUSSION, IMPLICATIONS, AND CONCLUSION

In this chapter, the major findings of the study will be further discussed and applied to the Health Belief Model (HBM) that was introduced and illustrated in Chapter 2. This model provides a foundation for beginning to understand the health behaviors and experiences of the participants in this study who have been treated for ESRD for more than twenty years. Statements made by the participants will be used to link the constructs from the HBM to the findings of the study. Implications for social work as it relates to nephrology social work practice, policy, and education will be discussed.

Discussion

The primary aim of this study was to explore the experiences of individuals living with ESRD for more than 20 years. These individuals shared their experiences through in-depth interviews. I utilized a semi-structured interview guide (Appendix G) to ensure some basic information was gathered from each in open-ended questions designed to explore the psychosocial and spiritual aspects of the experience that may facilitate long-term survival and optimal quality of health and life among individuals with ESRD. The open-ended nature of the exploration also allowed the participants to share information that was important for them to tell me about their experience.

After reviewing the transcripts, four primary codes were selected that were essentially based on the interview questions, in conjunction with the transcripts of the participants' interviews. These codes were: Initial Diagnosis, Treatment Experiences, Quality of Life, and

Vision for the Future. The individual textural and individual structural descriptions were written to reflect my interpretation of participants' experiences based on the interview statements. Taken together, composite textural and composite structural descriptions of the experiences were constructed that highlight the themes that emerged from the participants' stories. These themes may be viewed as possible underlying reasons for the long-term success of the individuals in this study. The themes included knowledge about the ESRD process (more than expected), the realization that I "had to do it," and spirituality.

Each of the participants exuded an inner strength that allowed them the courage to overcome many adversities in their lives. They shared stories of how the love of their family members, their church family, and their faith in God helped them get through very difficult times, and how their faith in God also keeps them positive about the future. According to White (2013), spirituality helps individuals with chronic illnesses to maintain a positive outlook on life. Spirituality offers hope and comfort during difficult times. She also indicated that spirituality and spiritual support, such as support from members of the church, were viewed as coping mechanisms for individuals with chronic illnesses. Many of the participants in this study identified members of their church as "church family."

Active involvement and participation within the church was an important factor in the lives of the participants. Spinale et al. (2008), conducted a study utilizing quantitative methods with 166 individuals who had ESRD and were treated with hemodialysis. The participants completed questionnaires that measured various psychosocial issues, perceptions of quality of life, and religious and spiritual beliefs. Social support was assessed using the Multidimensional Scale for Perceived Social Support. The findings of this study indicated there was a relationship between religion and increased perception of social support. People who

identified themselves as spiritual or religious were often involved in religious communities and typically reported higher social support scores compared with individuals who did not self-identify as religious. The findings from this study implied that there is a need for further investigation into the association between spirituality and survival in individuals with ESRD.

Another important factor that may have influenced the success of the individuals in this study was their increased knowledge about ESRD. It was expected that these individuals be knowledgeable about their treatment options and dietary needs. However, the knowledge that each of the participants shared during their interviews went far beyond the basic information that is provided to each individual on dialysis to help them monitor their health outcomes, which was surprising. Each of them took on the responsibility of learning about the dialysis machines and its functions. They shared how important it was for them to ask questions and to keep their medical team informed of changes in their body. They used their monthly lab results to gauge their progress and their effectiveness in monitoring their outcomes. With this increased knowledge, the individuals in this study also became aware of certain behaviors and decisions they were making that could keep them from becoming healthier and could possibly limit their quality of life. As each of them became more aware of various aspects of adherence to treatment, they realized that adherence was a key factor in living a longer, healthier life. This theme, realization that “I had to do it,” in regard to adherence, can be developed for possible interventions to help other individuals connect with their inner strength and use this knowledge to make better choices about their healthcare needs.

Health Belief Model Applied to ESRD

The findings in this study were applied to the Health Behavior Model in an effort to understand behaviors of individuals with ESRD and to develop interventions that will

produce positive outcomes. The participants in this study have lived successfully with ESRD for more than 20 years. They shared stories about how their behaviors were not always “good” in the earlier years after initiating dialysis, as they did not believe that were susceptible to the negative consequences. However, they learned positive behaviors that work for them and they were willing to share their experiences that may help others who might be struggling to manage the challenges associated with ESRD.

The Health Belief Model (HBM) is one of the most widely used models in nephrology research (Russell, Knowles, & Peace, 2007). It has been used by nephrology professionals to predict adherence to dialysis treatments for individuals ESRD. This model has also been used to assist renal professionals identify modifying factors that could improve health-related outcomes for individuals receiving dialysis. The HBM involves four major constructs: perceived susceptibility, perceived seriousness, perceived benefits, and perceived barriers. Self-efficacy and “cues to action” were also included as they have been shown to increase individuals’ motivation for change. The constructs of this model will be examined as they relate to the findings of this study.

Perceived Susceptibility

Perceived susceptibility is a belief about the likelihood of getting sick or having complications associated with ESRD. Non-adherence to dialysis treatments has been associated with increased hospitalizations and mortality rates (Kutner et al., 2002). The participants in this study all agreed that adherence to dialysis treatments, diet, and fluid restrictions, and the prescribed medication regimen, would reduce an individual’s chances of getting sick or having serious medical complications. Many of them explained that they did not always adhere to their dialysis treatments, diet, and fluid restrictions. Many of them experienced

a potentially life-threatening complication at some point which made them choose to adhere to their prescribed dialysis treatments, diet, and fluid restrictions. They were all in agreement that their decision to make the necessary changes to get back to optimal health and to continue with their prescribed treatment regimen had a direct impact on their overall health and allowed them a better quality of life.

In the beginning, I did horribly with the fluid restriction. I mean, that was so hard for me. You know, you're in the south and it gets awfully warm but I got into trouble a couple of times and had to be hospitalized for putting too much fluid on. And so, if you go through those sorts of things a couple of times, you will learn from it. So I did it by trial and error. I mean, if they told me to only drink 32 oz, I couldn't do just 32 oz, I had to have 35 (laugh) but if you get sick enough a couple of times and make it through that, you will change your ways. And so that's what worked for me. And now somebody can tell me...do this or do that, I am so compliant because I know the consequences. When I was younger I might have done a few things that weren't necessarily in the regimen but now, I'm following it because I know the consequences. (Ms. Cook)

Perceived Seriousness

Perceived seriousness is a belief about the severity of consequences for one's actions. For example, non-adherence to dialysis treatments can increase the risk of medical complications, increase hospitalizations, and possibly lead to death (Egede, 2005). All ten participants shared their personal experiences with non-adherence to treatment, diet, and fluid restrictions that caused them to change their ways in order to live a healthier life. The participants found it difficult to watch other individuals go through the same mistakes they had made. They learned from their mistakes and found it difficult to watch others who were not aware, or did not believe in, the seriousness, of the long-term consequences of not adhering to her or his prescribed treatment.

The hardest thing they have with new patients is they don't come. They hate coming to dialysis but I always tell them, "look, this is an option for you to live. There is no other option other than a transplant; you can die if you don't come." (Ms. Flowers)

I had problems when I first started, I really did. I like drinking water. Some people like drinking drinks but I like drinking water. I had problems in my early years and then you get to the point when you get on the machine and you start cramping and they have to pull you so hard you have muscle spasms and you get uncomfortable. You get to the point where you say, "I've got to do better." You know, they give you the measurements of what you can drink but I've been doing this so long I can tell when I need to stop. (Ms. White).

Perceived Benefits

The concept of perceived benefits is the belief that the benefits of adhering to dialysis treatments will strongly outweigh the consequences of not following the treatment regimen (due to possibility of serious complications and death). All ten of the participants in this study believed that adherence to dialysis treatments as prescribed was a major, contributing factor to their long-term survival. They wished to live as long as possible in good health.

I'm living for my family and my new great-grandson. I want to see him grow up and teach him to fish and hunt. He's only two weeks old, so I plan to be around for a while (laughing). (Mr. Richardson)

Perceived Barriers

The perceived barriers to adherence to the treatment regimen might include: transportation, the cost of medications, time needed to complete the dialysis treatment, or the feeling of deprivation associated with fluid and diet restrictions. Also, these participants expressed the difficulty of adjusting socially when they were first diagnosed with ESRD. Managing ESRD requires many hours of dialysis treatments per week as well as planning for meals, medications, and other doctor's appointments. Due to the intense scheduling of appointments, maintaining full-time employment is often difficult, but many do. One's social activities (outside of work and home life) can also be limited due to additional barriers such as fatigue. Most of the participants had to develop a new outlook about what was possible over time and were able to negotiate a balance in their social lives.

I used to miss one [treatment] every now and then because of a ride situation but I don't miss any more...I don't miss anymore. It's too important, this our lifeline and I found out that missing treatments will catch up with you so I don't want to go through that no more. It's good to come. (Mr. Stephens) [He continues to work hard to find transportation through family, friends, or even walks to the treatment facility.]

...in the beginning, when you're so young and start dialysis, and I was newly married when I started and my main thought was not to take care of myself. I just wanted to be like everybody else. If everybody else was at the club, I wanted to be at the club. If everybody else was drinking, I wanted to drink. I mean, I didn't want people to look at me and see disability. I didn't want people to look at me and see kidney machine and I tried to hide it. I tried to deny it as best I could and I think a lot of the decisions I made when I was younger, God just kept me and maybe my good sense just kicked in. But, you know, there were some things that I did was contrary to what...you know the overload of fluid...I just wanted people to see that I could do anything anybody else could do and I think that's a problem with young people. And when you see other young people who are handling it in a different way, that makes a difference. (Ms. Cook)

Self-Efficacy

Self-efficacy is the belief in one's own ability to take action in order to produce desired outcomes. The participants expressed that the monthly lab blood test results are helpful to them in monitoring their diet. At least once per month, each individual receiving dialysis has their blood drawn to monitor a wide range of health indicators. The values obtained are used to monitor the individual's adherence with the dietary guidelines that they had been given by the dietitian. The facility dietitian and the medical director review the findings during "rounds" and share them with each individual. They discuss the optimal value ranges for each individual's particular health condition and offer guidance about how to get "back on track" if the values are not where they should be or encourage them to continue to make healthy choices, if lab values are good. The participants expressed the sense of empowerment they felt in the ability this allowed them to take control of their health and their lives. They learned to utilize the information to stay within the guidelines to maintain optimal health.

I've gotten more smarter and more wiser as far as learning about my labs and what everything means on my flow sheet. I don't just come, I want to know what's going on.

I look at my blood work and I always keep tabs on everything. When the machine go off or I'm always looking around and asking what they doing, that kind of stuff. I stay interactive with the techs and stuff. (Mr. Stephens)

...the way they keep the patient informed. I love that. I mean, every month they give us a sheet with our lab values. It explains exactly what the labs are, what your ranges should be, what you could do to improve. If my albumin is low, then it says you need to eat more of this...oh, the patient is so empowered...if he chooses to be. The patient is so empowered. They are encouraged to ask questions, they're encouraged to get information. (Ms. Cook)

Cues to Action

Cues to action are also known as the “motivating factors” for change. This includes current research about advances in ESRD treatments, educational materials/resources, and advice from others that may provide awareness about ESRD to individuals and the community. All of the participants agreed to be interviewed in the hope that their stories would help others who may be having a hard time with the changes that having a diagnosis of ESRD means in their lives on many levels: physically, psychologically, socially, and spiritually. Many offered advice, even one-on-one directly with these “new” individuals.

It's just...we need more patients that have been on dialysis a long time to interact with the new patients. (Mr. Gates)

I try to pull 'em aside and say, “you got to come to treatment. That's the only way you gonna' make it. 'Cause if you don't, you ain't gone make it. You ain't gone make it.” (Mr. Shelby)

There's Network 8, I'm on the board of directors, I work with them a lot. And there's the National Kidney Foundation, I work a lot with them. You know, I do a little mentoring and I help put out the magazine. So, there are so many opportunities for the patients to get involved and not just come and sit in a chair and go back home. I just love that the patients are informed and they have so many occasions to get involved. And they've got all these seminars and workshops and meetings. You don't have to make all of them, just one every now and then, you know, and some patients never go to any of them. I know the problem with transportation for some but some of the younger ones are just not interested. (Ms. Cook).

Summary

The Health Belief Model has four constructs that were used in an attempt to explain and predict the attitudes and beliefs of individuals with ESRD. The constructs were designed to predict the individual's readiness for change and to offer strategies to achieve positive outcomes. Perceived Susceptibility accounted for the individual's risk of getting sick (non-adherence to dialysis treatments, fluid restrictions, diet, and medication regimen will cause sickness). Whether they believed it could happen to them or not, the behavior was present. The Perceived Seriousness accounted for the individual's perception of the significance of the problem for them (increased sickness, hospitalization, and possibly death). Perceived Benefits accounts for one's belief that the benefits will outweigh the consequences (living a long healthy life outweighs sickness and possibly death). Perceived Barriers were identified as obstacles that can reduce positive outcomes (transportation issues, cost of medications, feelings of deprivation regarding fluid restrictions). Self-Efficacy is the confidence in one's ability to take action (attending seminars and getting involved in their own treatment to build self-confidence). "Cues to action" was added as a strategy to provide guidance (monthly labs, advice from others who have been successful, research, educational materials).

Study Implications

Implications for Social Work Practice

Nephrology social workers are available in all dialysis and transplantation centers to assist individuals with ESRD to manage psychosocial challenges, coordinate services and resources, and implement interventions to assist in managing the challenges associated with ESRD (Browne, 2008). Social workers have been recognized as leaders in healthcare and they have established a place for this profession in the field of nephrology. Additional interventions

are needed to address adherence to dialysis treatments, diet, and fluid restrictions as seen through the findings of this study. Social workers can and should focus on anxiety and depression as they are linked to issues of adherence to treatment. Anxiety and depression have also been associated with chronic health problems and lower health-related quality of life (DiMatteo, Lepper, & Croghan, 2000). There is evidence that higher perceived quality of life can produce better medical outcomes, including reduced numbers and lengths of hospitalizations and reduced mortality among individuals with ESRD (Eissa et al., 2010). Social workers are beginning to utilize Motivational Interviewing (Rollnick, Miller, & Butler, 2008) techniques to help individuals make positive choices about their healthcare.

Nephrology social workers also continue to function in an educational role to help reduce the progression of CKD and ESRD. As the incidence of individuals diagnosed with ESRD continues to increase, the need for pre-ESRD education remains a major concern. The USRDS (2012) reported that 43% of newly diagnosed individuals in 2010 had not seen a nephrologist prior to beginning ESRD therapy. The Centers for Disease Control and Prevention (CDC, 2013) reported that more than 20 million (more than 10%) U.S adults are estimated to have CKD and most are undiagnosed. Most participants in this study had no knowledge of ESRD before being diagnosed and started dialysis by way of visits to the emergency room. Social workers can influence these outcomes by becoming more involved in CKD education in doctor's offices and hospitals, but most importantly in the community. Three of the participants in this study were diagnosed with ESRD while they were in high school. Starting early education programs in high school would allow adolescents to become aware of the signs and symptoms associated with ESRD. These preventive type programs would also make young people aware of the risk factors associated with ESRD. Knowing the signs, symptoms, and risk

factors for ESRD could make prevention and early detection possible for youth.

The Council of Nephrology Social Workers and the CDC are working to bring awareness about CKD to communities that are most affected by and at-risk for this disease. The CDC has developed a Chronic Kidney Disease (CKD) Surveillance System that documents the burden of CKD and its risk factors over time. This system will provide a means for evaluating, monitoring, and implementing quality improvement efforts for individuals with CKD (CDC, 2013). The CDC has partnered with federal agencies, academia, and national organizations to disseminate information about the burden of CKD in the U.S. This includes data about prevalence by race and ethnicity. Nephrology social work practitioners have an opportunity to become involved in CKD prevention particularly in the communities surrounding the centers in which they are employed.

Another area of interest in prevention and increasing quality of life that was mentioned throughout the interviews was the potential for development of peer mentoring programs or support groups at each of the facilities. However, due to the Health Insurance Portability and Accountability (HIPAA) Act of 1996 (USD[HHS], 2013), many dialysis centers may be reluctant to establish groups designed for individuals to openly discuss their medical concerns at the risk of a possible breach of confidentiality which could actually drive those individuals farther away. Yaldez (2003), discussed the need for mentoring programs as a possible intervention for individuals who are non-adherent to dialysis treatments. Social workers should explore alternative ways of engaging and linking individuals who are non-adherent with those who are considered to be successful with their treatment regimen. This could offer inspiration and motivation from people who have lived this experience and have overcome some of the same challenges as those who are struggling to adhere to their treatments. Since CMS (Centers for

Medicare and Medicaid Services) is using strict criteria to evaluate a center's overall adherence for purposes of reimbursement, this could be evaluated as a company-wide project to ensure all avenues are explored in an effort to increase adherence among individuals receiving dialysis treatments. These programs could be monitored by the facility social workers in order to protect sensitive information about the individuals from others who should not be privy to such information. Social workers would also be available to handle any emotional distress that may become a factor during the meetings. The groups could possibly provide an option for social support for those with limited social outlets. Having access to these programs could improve the quality of life for individuals who are non-adherent and possibly improve their long-term outcomes.

Federal and Facility Policies and Implications

In 1972 Congress passed an amendment to the Medicare and Medicaid provisions of the Social Security Act. Under this bill, individuals with ESRD were guaranteed federal coverage for the costs associated with their dialysis treatments. This amendment guaranteed that any individual who required dialysis treatments or kidney transplantation "shall be deemed disabled" and therefore entitled to Medicare Parts A and B (Rettig, 2011). The total Medicare expenditures for ESRD reached \$33 billion in 2010; more than 6% of the total Medicare budget. According to an analysis by the U.S. Renal Data System, ESRD beneficiaries represented 1.3% of all Medicare beneficiaries and used 7.9% of Medicare spending. Medicare costs for ESRD were \$75,000 per patient per year (USRDS, 2012; CDC, 2013).

Individuals on dialysis are being encouraged to continue working if possible. However, due to the challenges these individuals face trying to maintain employment and attend scheduled dialysis treatments and doctor's appointment, it is very difficult. Social workers are responsible

for discussing job training programs with patients if they are physically able to work. However, the job hours often interfere with the individual's dialysis schedule. Some individuals on dialysis have difficulty performing any type of activity (even daily living skills such as cooking) on "dialysis days" and state that their body will usually require another day to recover from treatment. The participants in this study stated that they felt "good" after treatment. They were all asked to describe a typical dialysis day and a non-dialysis day. No one mentioned problems with fatigue, and three of the participants have decided to continue working. One stayed at home to raise her children; the other six were retired. They all described very active lifestyles and expressed how good it felt to remain active.

On July 26, 2010, the Centers for Medicare and Medicaid Services released the final rules for the prospective payment of dialysis services (aka, "the bundle") (Mayne, 2010). The bundling of dialysis services took effect January 1, 2011. Dialysis clinics were given the option of opting into the new bundled payment system 100% on November 1, 2010, or phasing in over four years. According to the CMS ruling, the base rate for payment of hemodialysis treatments was set at \$229.63. Home training treatments were set at \$33.38 per treatment. In addition, this rule will reduce the bundled payment by up to 2% to facilities that score poorly in quality indicators.

In 2012, CMS began reviewing each dialysis facility's performance on 3 basic indicators: low hemoglobin, high hemoglobin, and urea reduction rate (URR). Failure to meet the targeted performance measures will result in a payment reduction of up to 2%. CMS has indicated that future performance indicators would include: Kt/V, vascular access, vascular access infections, hospitalization, measures of bone and mineral metabolism, patient satisfaction, and patient

reported quality of life. The prospective “pay for performance” system has changed the way dialysis providers do business and will ultimately affect how patients receive services.

With dialysis providers being reimbursed for quality services and patient outcomes as opposed to being paid solely for services rendered, the providers are now placing more responsibility and expectations on the individuals for whom they provide care. Social workers have taken on key roles in making sure these performance areas are meeting their company’s objectives. They are serving as “access coordinators” and monitor access surgeries as well as tracking infections. They take the lead in administering and tracking patient satisfaction surveys and use them as guides for improving services and offering quality care. Social workers also administer the KDQOL surveys and track incidents that may affect the patients’ quality of life.

As the ESRD providers continue to move toward “pay-for-performance” models, social workers and others are concerned that self-interest could lead those providers and nephrologists toward “cherry-picking” dialysis patients. Cherry-picking is morally problematic because it treats patients as a means of reimbursement rather than as individuals who deserve dignity and respect. For example, older, sicker patients in the hospital with multiple co-morbidities may be encouraged to forego dialysis when otherwise dialysis may have been recommended. Social workers have an opportunity to intervene before decisions to withhold dialysis treatments to these types of patients who are not likely to survive very long despite receiving dialysis. The idea that patients should not always receive the most aggressive possible medical interventions remains both unpopular and controversial (Parker, 2011), but also at times the treatment may indeed be futile.

A Canadian nephrologist, D. J. Hirsch (1997), developed a set of guidelines to identify patients who, due to medical complications, should be advised to refuse the offer of dialysis

support. This list included: dementia; metastatic malignant disease; severe liver, heart, or lung failure that limits the patient to bed or chair; irreversible severe neurological diseases that prevent performance of activities of daily living; multisystem organ failure; and a need to restrain or sedate patients in order to provide dialysis treatments. Ethical judgments as well as legal regulations could call for additional policies to address under what circumstances dialysis treatments should be forgone.

Social work organizations are offering increased training opportunities to ensure that the most recent policies and best practices are being used to provide optimum care. Nephrology Social workers have a pivotal role in ensuring individuals continue to have adequate access to needed treatments and other services. They assist individuals, families, and healthcare professionals with understanding treatment plans and changes in medical conditions over time, and treatment modalities and options. There are opportunities for social workers to become more involved with legislation that directly affects their patients. Many nephrology social workers work closely with the National Council of Nephrology Social Workers, as well as the local chapters, to stay informed about national and local policies that will have a direct impact on those with ESRD. By becoming more involved in local, state, and federal agencies and organizations, social workers will have a platform to make their concerns known while building relationships that could help with advocacy efforts and, in turn, influence healthcare policies.

Study Strengths and Limitations

This study had several strengths and limitations. The goal of qualitative research is to gain an in-depth perspective about a particular phenomenon of interest. Since the phenomenon of long-term survival on dialysis treatment has been understudied, utilizing a qualitative approach was appropriate in order to begin to identify factors that could make long-

term survival possible.

The methodology for this study was useful as it allow for in-depth exploration with only ten participants. Even though participants were few, but adequate for a phenomenological study, diversity could be seen along a range of demographic factors. For example, as a group, they had received various types of treatments for ESRD, including in-center-hemodialysis, home hemodialysis, peritoneal dialysis, and kidney transplantation over the years. They included African Americans and Caucasians, had varying employment situations and socioeconomic statuses, and varied in terms of age and gender. The sample was a clear representation of the individuals most affected by ESRD. While each participant had some unique experiences, some common ones could be seen as well.

One limitation of this study was that the sample was limited to one small geographic area in a rural state. The experiences of people with ESRD from urban areas may be different and could also be different among these individuals across the country. Unlike quantitative research (conducted with large random samples), it is not possible to generalize the findings of a qualitative study to a broader population. This is true of the results from this study. The experiences of these participants may not be similar to others who have been treated for ESRD for more than 20 years. Another limitation of the study was the inclusion of individuals from one specific dialysis provider only. Individuals receiving dialysis treatments with other providers may have different experiences related to quality of care, education, and treatment options. Although it may also be viewed as a strength, I was an “insider” and had prior knowledge about ESRD. I used bracketing and peer consultation throughout the data collection to strengthen the trustworthiness of the study results. Overall, the strengths far out-weighed the limitations in this study, especially as long-term survival on dialysis remains understudied, and

this study revealed strategies that may lead to increased quality of life for individuals receiving this life-extending treatment.

Future Research

By using qualitative methodology in this study that explored the experiences of individuals with ESRD over the course of twenty years of treatment, identification of factors that contributed to their long-term success has begun. Still further qualitative studies could be conducted specifically among high-risk groups that do not have such long-term survival rates in order to understand the challenges and complications faced by these individuals and to continue to identify factors important in management of ESRD. Future studies should take a more in-depth look at quality of life using larger samples. For instance, the CDC and USRDS have large national datasets that can be used for larger scale studies. Typically, across the country, the enterprise of dialysis is run by large corporations (such as DaVita). Therefore, nephrology social work practitioners have access to large dialysis patient populations that also could be used to obtain random national samples. Other large datasets include the DOPPS (Dialysis Outcomes and Practice Patterns Study) that social workers can use to study psychosocial issues that relate to quality of care and quality of life for their patients.

In addition, there are opportunities for research at the local level, including partnerships between multidisciplinary team members to conduct quantitative research on a phenomenon of interest at their particular facility. Quality of life should be examined in future quantitative studies with larger samples from some of the national databases that were mentioned above, particularly in the age group of 65 and older as the long-term survival rates are lower and the presence of other medical conditions are more likely (McKevitt et al., 2007). Studies conducted with individuals who have been in treatment for varying lengths of time could expose the “root

of the problem” for younger, newly diagnosed-individuals receiving treatment. Longitudinal studies could then identify what changes are made over time and discern patterns of behaviors. Samples of individuals with diabetes only as the cause of the ESRD could be studied because this is the fastest-growing cause of diagnosis and because they have the shortest survival expectancy. Religion and spirituality are topics that are increasingly being investigated in relation to health outcomes. The association between spirituality and survival among individuals receiving treatment for ESRD should be further explored. The opportunities for social workers in nephrology research are endless.

Conclusion

This study focused on understanding the day-to-day experiences, challenges, and triumphs for people diagnosed with ESRD. The stories shared by the participants offered insight into the dedication that is necessary each day in an effort to maintain optimal health when options are few. Participants discussed concerns regarding treatment options offered and lifestyle choices they have made over time. These individuals are faced with choices each day that will affect their health and overall quality of life. They have managed to live successfully with these challenges for more than 20 years. Ten individuals, six males and four females, allowed me to explore their personal stories in an effort to gain knowledge into their daily lives with ESRD. The findings for this study yielded a rich description of the challenges individuals with ESRD face each day in order to maintain optimal health.

The participants in this study explained how difficult it was to manage their illness 20 years ago, as dialysis was a relatively new option for individuals with renal failure. Modality choices were minimal and the machines were not as well-designed as they are today. They shared how difficult it was to adhere to their diet and fluid restrictions. They found it difficult to

maintain intimate relationships as all of them were relatively young at the onset of their diagnosis. Each of them shared how important their family, friends, and faith in God were to them when times got hard, but in the mist of all the challenges, each of these individuals managed to find a way to survive. Most of them realized through trial and error that there were consequences for not adhering to these prescribed regimens. They were all interested in helping others find ways to manage living with ESRD and they offered advice to newly diagnosed individuals. Each of them ended their stories by sharing their plans for continuing to live full and productive lives with ESRD.

Ten individuals assisted me in an effort to explore the lifestyle, treatment experiences, and challenges of individuals with ESRD. Each participant shared intimate details about the challenges they have faced while trying to survive an illness where the outcomes are not always in their favor. Each individual laughed, cried, and shared her or his plans for the future. This exploration revealed that these participants were able to live a daily life that they perceived as being no different than others without an ESRD diagnosis and they had a quality of life that they enjoyed.

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Appendix A: DaVita's Letter of Support



Minneapolis Office
825 South Eighth Street
Suite 300
Minneapolis, MN. 55404
(612) 852-7000 phone
(612) 852-3241 fax

September 28, 2012

Jacqueline Williams

Re: Letter of Support – “Factors that Influence Long-term Survival Among Individuals Diagnosed with End Stage Renal Disease: An Exploratory Study”

Dear Jacqueline,

This letter acknowledges support by DaVita Clinical Research (DCR) for the above-referenced study. We look forward to supporting you and your research team on this study that involves 10-15 patients from the potential of 30 facilities located in the Southland Region (facility numbers: #2931, 3343, 2604, 2601, 3380, 2601, 3380, 2614, 2371, 3382, 5081, 5084, 5097, 3377, 3379, 5082, 5083, 2932, 2616, 3205, 3204, 3619, 2615, 3206, 1647, 1649, 1646, 1648, 3862, 3383, 2249, 6858).

Once you receive approval from the IRB, our clinical research team will assist you in completing the necessary DaVita paperwork required for research studies in the DaVita facility and obtaining the final approvals.

We look forward to collaborating with you on this project.

Sincerely,

Amy Young
Vice President, Clinical Services
DaVita Clinical Research

Appendix B: IRB Approval



March 1, 2013

Jacqueline Williams
School of Social Work
The University of Alabama
Box 870314

Re: IRB # 13-OR-075: "Long-term Survival among Individuals Diagnosed with End Stage Renal Disease: An Exploratory Study"

Dear Ms. Williams,

The University of Alabama Institutional Review Board has granted approval for your proposed research.

Your application has been given expedited approval according to 45 CFR part 46. Approval has been given under expedited review Category 7 as outlined below:

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your application will expire on February 28, 2014. If the study continues beyond that date, you must complete the IRB Renewal Application. If you modify the application, please complete the Modification of an Approved Protocol form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants. When the study closes, please complete the Request for Study Closure (Investigator) form.

Please use reproductions of the IRB-stamped consent form.

Should you need to submit any further correspondence regarding this application, please include the assigned IRB application number.

Good luck with your research.

Sincerely,



358 Rose Administration Building
Box 870127
Tuscaloosa, Alabama 35487-0127
(205) 348-8401
fax (205) 348-7189
TOLL FREE (877) 920-3066

Carpamato T. Myles, MSM, CIM
Director & Research Compliance Officer
Office for Research Compliance
The University of Alabama

Appendix A:

UNIVERSITY OF ALABAMA

Individual's Consent to be in a Research Study

You are being asked to be in a research study. This study is called "Long-term Survival Among Individuals Diagnosed with End Stage Renal Disease: An Exploratory Study." The study is being done by Jacqueline Trask Williams. She is a doctoral student in the School of Social Work at the University of Alabama. Mrs. Williams is being supervised by Dr. Ellen L. Csikai.

The research study is being done for the completion of a dissertation. The information collected may be used for future publications. Mrs. Williams is not receiving financial compensation for this work.

What is this study about?

Millions of people around the world suffer from end stage renal disease (ESRD) and require dialysis treatments. This study is exploring ESRD and dialysis treatments through the experiences of the individuals diagnosed with ESRD for more than 20 years. Specifically, the investigator would like to know how you managed the challenges of living with ESRD. You will also be asked about the your adherence to treatments and quality of life.

Why is this study important—What good will the results do?

The findings may be able to help other individuals with ESRD develop good habits that will improve their quality of life and live longer.

Why have I been asked to take part in this study?

You have been asked to participate because you are someone who has been living with ESRD for 20 years or more.

How many other people will be in this study?

For this study, the investigator hopes to interview 10-15 people living with ESRD for 20 years or more in the state of Alabama.

What will I be asked to do in this study?

If you agree to be in this study, Jacqueline Williams will interview you in your home or a place of your own choosing about your experiences as an individual living with ESRD for more than 20 years. The interviewer would like to tape record the interview to be sure that all your words are captured accurately. If you do not wish to be audio-taped, you will not be able to participate in the study.

How much time will I spend being in this study?

The interview is expected to last about an hour, depending on how much information about your experiences you choose to share.

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EXPIRATION DATE: 2/28/2014

Will being in this study cost me anything?

The only cost to you from this study is your time.

Will I be compensated for being in this study?

In appreciation of your time, you will receive a \$20 gift certificate to Wal-Mart.

What are the risks (problems or dangers) from being in this study?

The chief risk to you is that you may find the discussion of your experiences to cause discomfort as you review past life events. If this occurs, you may choose not to answer a particular question or discontinue your involvement in the study. You may wish to talk with your center social worker further about these distressing thoughts.

What are the benefits of being in this study?

There are no direct benefits to you unless you find it pleasant or helpful to describe your experience living with ESRD. You may also feel good about knowing that you will help other individuals with ESRD deal with the long-term challenges of this disease.

How will my privacy be protected?

The interview will be conducted at a location of your choosing. If in the center, a private office will be secured for the interview. Mrs. Williams will also visit you in the privacy of your home or in another place that is convenient for you.

How will my confidentiality be protected

Your name will appear on this informed consent. This form and all other identifying information will be kept in a locked file drawer in Mrs. Williams' office (locked when she is not there). She will not use a name-number list so there is no way to link a consent form to an interview. When she records the interview, she will not use your name, so no one will know who you are on the tape. After the interview, Mrs. Williams will listen to the tape and type out the interview. When all of her interviews have been typed, the tapes will be destroyed. Research reports from the data in this study will be writing with no identifying information about you. No one will be able to recognize you.

What are the alternatives to being in this study?

The only alternative is not to participate.

What are my rights as a participant?

Being in this study is totally voluntary. It is your free choice. You may choose not to be in it at all. If you start the study, you can stop at any time. Not participating or stopping participation will have no effect on your care and treatment at the DaVita Dialysis Center. Also, this will have no effect on your relationship with the University of Alabama.

The University of Alabama Institutional Review Board is a committee that looks out for the ethical treatment of people in research studies. They may review the study records if

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CONSENT FORM APPROVED: 3/1/2013
EXPIRATION DATE: 2/28/2014

they wish. This is to be sure that people in research studies are being treated fairly and that the study is being carried out as planned.

Who do I call if I have questions or problems?

If you have questions about this study right now, please ask them. If you have questions later on, please call me, Jacqueline Williams at 205-835-8540 or you may contact my faculty advisor, Dr. Ellen Csikai at 205-348-4447. If you have questions, concerns, or complaints about your rights as a research participant, you may contact Ms. Tanta Myles, the Research Compliance Officer of the University at 205-348-8461 or toll-free at 1-877-820-3066.

You may also ask questions, make a suggestion, or file complaints and concerns through the IRB Outreach Website at http://osp.ua.edu/site/PRCO_Welcome.html. After you participate, you are encouraged to complete the survey for research participants that is online there, or you may ask Mrs. Williams for a copy of it. You may also e-mail us at participantoutreach@bama.ua.edu.

I have read this consent form. I have had a chance to ask questions.

Signature of Research Participant _____ Date _____

Signature of Investigator _____ Date _____

Audio Taping Consent

With your permission, the researcher would like to audio-tape the interviews for research purposes in order to accurately capture our conversations. The tapes from these sessions will be stored in a locked file cabinet in a locked room and only available to the researcher. The tapes will be destroyed after they have been transcribed.

I have been informed that part of my participation in this research study will be audio-taped and I give my permission to the researcher to record our sessions.

_____ **Yes, my participation can be audio-taped.**

_____ **No, I do not want my participation to be audio-taped.**

Future Contact Consent

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CONSENT FORM APPROVED: 3/1/2013
EXPIRATION DATE: 2/28/2014

With your permission, the researcher would like to call you after the interviews have been reviewed to find out if the information in the study is the same as what you shared during your interview.

Yes, I give my permission for the researcher to contact me for follow questions.

No, I do not give permission to be contacted after the interview.

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CONSENT FORM APPROVED: 3/1/2013
EXPIRATION DATE: 2/28/2014

Appendix C: DaVita’s Letter of Approval



Study Approval Terms

Study Code
007-2013

Principal Investigator	Principal Investigator’s Institution
Jacqueline Trask Williams, MSW, LGSW	University of Alabama
Study Title	Protocol
“Long-term Survival Among Individuals Diagnosed with End Stage Renal Disease: An Exploratory Study”	3949
Criteria	Comments
Approval Date	March 6, 2013
Length of the Study	60-90 minute interviews/1 follow-up call
Facility(s) Approved (name and number)	<ul style="list-style-type: none"> Southland Region (Facility #s: 3380, 2614, 2371, 3382, 5081, 5084, 5097, 3377, 1962, 3379, 5082, 5083, 2932, 3598, 6052, 5891, 6281, 5878, 6284, 6281, 2932, 2616, 3205, 3204, 3619, 2615, 3206, 1647, 1649, 1646, 1648, 3862, 3383, 2249, 6858, 1859)
Number of Patients	10-15 patients
Staff Tasks/Responsibilities	<ul style="list-style-type: none"> According to the attached Charge Master, DaVita Staff will not be asked to perform any study related tasks. All activities related to the study, must be performed by Investigator as she serves as a DaVita teammate. Per applicable state and or federal laws as well as any DaVita policy and procedure, written or verbal physician orders must be obtained prior to ending or starting any agents and/or study drugs or related therapies. Any protocol amendments after initial study approval must be reported and sent to DCR for review Any ICF revisions made after initial study approval must be sent to DCR for review If the PI plans to exceed the anticipated number of patients referenced on this form, DCR must be notified prior to enrolling additional patients Any SAE’s that are probably or possibly related to the study article must be reported to DCR as soon as is practicably possible. A signed copy of the patient’s ICF must be placed in patient’s chart as well as any amended ICF’s or HIPPA release forms. A copy of the protocol must be made available to the dialysis unit staff
Research Staff	The following are the research staff: <ul style="list-style-type: none"> Jacqueline Trask Williams, MSW, LGSW

Enrollment Process	Principal Investigator will use the following forms: <ul style="list-style-type: none">• Patient ICF
Accounting for Disclosures	N/A

Appendix D: Recruitment Flyer

Title of Research Study: Long-term Survival Among Individuals Diagnosed with End Stage Renal Disease: An Exploratory Study

Who is Eligible:

1. Patients diagnosed with ESRD in 1992 or earlier (20 years or longer).
2. Must be currently receiving hemodialysis or peritoneal dialysis at a DaVita facility in Alabama.

What exactly is involved:

Participation in a face-to-face interview (lasting approximately one hour). The interviews will take place in a private office within the dialysis facility or in the participant's home.

Compensation:

\$20 Wal-Mart gift card.

Contact:

Your facility social worker or researcher, Jacqueline Trask Williams, (205-835-8540).

Appendix E:

Social Worker/ Researcher Sample Script for Patient Participation

Social workers employed by DaVita, Inc. in the state of Alabama will be asked to search the “First Date of Dialysis” for each patient in their facility from the *Reggie* data system and identify patients with FDOD from 1992 and earlier. Because of their previous relationships with the potential participants, the social workers will be able to determine if the patients are cognitively capable to communicate independently for the purpose of the interview. The social workers will also be able to provide the information sought regarding the phenomena of interest in the study.

All eligible patients will be approached about participation during a dialysis clinic visit using the following script...

I would like to talk to you about participating in a research study that involves people who have been diagnosed with ESRD for 20 years or longer. The main topic of the study will focus on the factors that influenced your long-term survival as a patient with ESRD. The researcher is a doctoral student in the School of Social Work at the University of Alabama. If you are interested in participation, I will give her your contact information so that she can contact you directly to further describe the study and schedule an interview time and location of your choosing. Participation is voluntary and your name will not be provided to the researcher if you choose not to participate. Would you like to participate?

After the social worker receives permission from the patient to provide the researcher with their name and phone number, the researcher will initiate contact within 1-2 days. The researcher will fully describe the purpose of the study and arrange an interview date, time and location.

Sample script for the researcher...

My name is Jacqueline Trask Williams and I was given your name and phone number by your social worker _____ as someone who might be interested in participating in a research study I am conducting. The purpose of the research is to explore your experiences with long-term dialysis treatment. You will be asked questions about your dialysis experience over the past 20 years and things that have been challenging as well as rewarding about his experience. I would like to arrange a time and location for us to meet. The interviews will last approximately one hour. The interviews will be audio-taped with your permission. Participation in the research is voluntary and you can withdraw at any time without penalty. In addition, you will receive a \$20 Wal-Mart gift card for your time and participation in the study.

If you are still interested, when can we meet and where? Do you have any other questions? Thank you for agreeing to participate in the study. I look forward to meeting you.

Appendix F:

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Individual's Consent to be in a Research Study

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Millions of people around the world suffer from end stage renal disease (ESRD) and require dialysis treatments. This study is exploring ESRD and dialysis treatments through the experiences of the individuals diagnosed with ESRD for more than 20 years. Specifically, the investigator would like to know how you managed the challenges of living with ESRD. You will also be asked about the your adherence to treatments and quality of life.

Why is this study important—What good will the results do?

The findings may be able to help other individuals with ESRD develop good habits that will improve their quality of life and live longer.

Why have I been asked to take part in this study?

You have been asked to participate because you are someone who has been living with ESRD for 20 years or more.

How many other people will be in this study?

For this study, the investigator hopes to interview 10-15 people living with ESRD for 20 years or more in the state of Alabama.

What will I be asked to do in this study?

If you agree to be in this study, Jacqueline Williams will interview you in your home or a place of your own choosing about your experiences as an individual living with ESRD for more than 20 years. The interviewer would like to tape record the interview to be sure that all your words are captured accurately. If you do not wish to be audio-taped, you will not be able to participate in the study.

How much time will I spend being in this study?

The interview is expected to last about an hour, depending on how much information about your experiences you choose to share.

Will being in this study cost me anything?

The only cost to you from this study is your time.

Will I be compensated for being in this study?

In appreciation of your time, you will receive a \$20 gift certificate to Wal-Mart.

What are the risks (problems or dangers) from being in this study?

The chief risk to you is that you may find the discussion of your experiences to cause discomfort as you review past life events. If this occurs, you may choose not to answer a particular question or discontinue your involvement in the study. You may wish to talk with your center social worker further about these distressing thoughts.

What are the benefits of being in this study?

There are no direct benefits to you unless you find it pleasant or helpful to describe your experience living with ESRD. You may also feel good about knowing that you will help other individuals with ESRD deal with the long-term challenges of this disease.

How will my privacy be protected?

The interview will be conducted at a location of your choosing. If in the center, a private office will be secured for the interview. Mrs. Williams will also visit you in the privacy of your home or in another place that is convenient for you.

How will my confidentiality be protected

Your name will appear on this informed consent. This form and all other identifying information will be kept in a locked file drawer in Mrs. Williams' office (locked when she is not there). She will not use a name-number list so there is no way to link a consent form to an interview. When she records the interview, she will not use your name, so no one will know who you are on the tape. After the interview, Mrs. Williams will listen to the tape and type out the interview. When all of her interviews have been typed, the tapes will be destroyed. Research reports from the data in this study will be written with no identifying information about you. No one will be able to recognize you.

What are the alternatives to being in this study?

The only alternative is not to participate.

What are my rights as a participant?

Being in this study is totally voluntary. It is your free choice. You may choose not to be in it at all. If you start the study, you can stop at any time. Not participating or stopping participation will have no effect on your care and treatment at the DaVita Dialysis Center. Also, this will have no effect on your relationship with the University of Alabama.

The University of Alabama Institutional Review Board is a committee that looks out for the ethical treatment of people in research studies. They may review the study records if they wish. This is to be sure that people in research studies are being treated fairly and that the study is being carried out as planned.

Who do I call if I have questions or problems?

If you have questions about this study right now, please ask them. If you have questions later on, please call me, Jacqueline Williams at 205-835-8540 or you may contact my faculty advisor, Dr. Ellen Csikai at 205-348-4447. If you have questions, concerns, or complaints about your rights as a research participant, you may contact Ms. Tanta Myles, the Research Compliance Officer of the University at 205-348-8461 or toll-free at 1-877-820-3066.

You may also ask questions, make a suggestion, or file complaints and concerns through the IRB Outreach Website at http://osp.ua.edu/site/PRCO_Welcome.html. After you participate, you are encouraged to complete the survey for research participants that is online there, or you may ask Mrs. Williams for a copy of it. You may also e-mail us at participantoutreach@bama.ua.edu.

I have read this consent form. I have had a chance to ask questions.

Signature of Research Participant Date

Signature of Investigator Date

Audio Taping Consent

With your permission, the researcher would like to audio-tape the interviews for research purposes in order to accurately capture our conversations. The tapes from these sessions will be stored in a locked file cabinet in a locked room and only available to the researcher. The tapes will be destroyed after they have been transcribed.

I have been informed that part of my participation in this research study will be audio-taped and I give my permission to the researcher to record our sessions.

_____ **Yes, my participation can be audio-taped.**

_____ **No, I do not want my participation to be audio-taped.**

Future Contact Consent

With your permission, the researcher would like to call you after the interviews have been reviewed to find out if the information in the study is the same as what you shared during your interview.

_____ **Yes, I give my permission for the researcher to contact me for follow questions.**

_____ **No, I do not give permission to be contacted after the interview.**

Appendix G:

Interview Guide

1. Tell me about your initial experiences with dialysis treatment?
2. Tell me how you felt when you were first told your kidneys were failing?
3. What treatment options were explained to you when you were diagnosed with ESRD?
4. What changes (if any) have occurred in dialysis treatment since you started?
5. How did your family react to your diagnosis?
6. What are your family's feelings about your treatment now?
7. Describe your typical day (and typical dialysis day).
8. How do you ensure that you are following the treatment regimen (i.e. diet, meds).
What challenges have you faced in adherence to treatment regimens and treatment?
9. Who or what do you rely on for support? (Friends, organizations, church, etc.)
10. How do you define *Quality of Life*?
11. If you knew 20 years ago what you know now about managing ESRD, what would you do differently?
12. What have you learned about yourself through this experience?
13. What do you imagine your life will be like in five years?
14. What advice would you give to someone just starting dialysis?

Appendix H:

Social Worker Psychosocial Assessment

PSYCHOSOCIAL ASSESSMENT

Patient: _____ **Physician:** _____

DOB: _____ **AGE:** _____ **Gender:** M F **Ethnicity:** _____

Address: _____ **SS#:** _____

_____ **Phone:** _____

Primary Language Spoken: _____ **Interpreter Needed:** Y N

Emergency Contact #1: _____ **Relationship:** _____ **Phone:** _____

Emergency Contact #2: _____ **Relationship:** _____ **Phone:** _____

MEDICAL INFORMATION:

Initial Date of Dialysis: _____ **First Date at Facility:** _____

Current Modality: In-Center Hemo Home Hemo CAPD CCPD

Medical

Diagnoses: _____

FAMILY BACKGROUND/CURRENT LIVING SITUATION

Parent's Marital Status: M S D W **Separated Comments:**

Level of Family Involvement:

Primary Caregiver(s): _____

Current Living Situation: House Apartment Mobile Home

With: _____

Religious Preference and level of involvement: _____

Hobbies/Leisure Interests: _____

TRANSPORTATION:

Family Friend Public Transportation: _____

Van: _____ Phone Number: _____

Transportation Comments/Concerns: _____

INSURANCE/FINANCIAL INFORMATION:

Does the patient have any financial concerns? Yes No

Primary Insurance: _____ Effective Date: _____

Secondary Insurance: _____ Effective Date: _____

Medicare Effective Date: Part A: _____ Part B: _____

Prescription Coverage: Yes No N/A

Insurance/Financial/Education Comment(s): _____

CURRENT LEVEL OF FUNCTIONING:

Ambulatory Cane Walker Wheelchair Gurney

Visual Impairment? Yes No Hearing Impairment? Yes No

Cognitive Impairment? Yes No Other Impairment? _____

Does Patient have an exercise regimen? Yes No

Exercise Comments: _____

ASSESSMENT:

History of substance abuse? Yes No Comments: _____

Mental Status: _____

____ Cooperative _____ Insightful _____ Hopeful
____ Positive Interactions _____ Realistic _____ Difficult to engage
____ Combative _____ Easily Agitated _____ Denial
____ Appears Angry _____ Anxious _____ Verbally abusive

Identified Coping Mechanisms: _____

Level of Motivation: _____

SUMMARY/IMPRESSION:

PROBLEMS IDENTIFIED:

PLAN OF ACTION:

Social Worker Signature

Date

Your Health – *and* – Well-Being

Kidney Disease and Quality of Life (KDQOL™-36)

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.



Thank you for completing these questions.

Why Should I Take the KDQOL-36™?

The KDQOL-36 survey lets you rate your quality of life with kidney disease. Hundreds of studies have found that how you view your physical and mental function is vital. People who had a poor view of their lives were more likely to need hospital care and less likely to live a long time.

You are the only one who can tell us how you feel about your life.

In fact, how you rate your quality of life is one of the best ways to know how you are doing. The *Dialysis Outcomes and Practice Patterns Study (DOPPS)* looks at people who are on dialysis around the world. The DOPPS found a strong link between how people feel, their quality of life, and how well they do on dialysis.

We ask you to take this survey so you can share things that may affect how well you feel while you receive dialysis treatment. At the end of the survey, we will provide a report that will tell you information about:

- Your scores on each of 5 subtests
- How your scores compare to others like you with regard to age, sex, and diabetic status
- Things you can do to improve your scores

Over time, tracking your scores will help you learn how taking care of yourself affects how you feel.

Help us to help you feel your best with kidney failure.

Your Health

This survey includes a wide variety of questions about your health and your life. We are interested in how you feel about each of these issues.

1. In general, would you say your health is: [Mark an in the one box that best describes your answer.]

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/>				

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? [Mark an in a box on each line.]

Yes, limited <u>a lot</u>	Yes, limited <u>a little</u>	No, not limited <u>at all</u>
---------------------------------	------------------------------------	-------------------------------------

2. Moderate activities, such as moving a table,
pushing a vacuum cleaner, bowling, or
playing golf..... , z..... ,
3. Climbing several flights of stairs..... , z..... ,

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

Yes	No
▼	▼

4. Accomplished less than you would have liked..... , ,
5. Were limited in the kind of work or other activities..... , ,

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

Yes	No
▼	▼

6. Accomplished less than you would like , ,
7. Didn't do work or other activities as carefully as usual..... , ,

8. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> ,				

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...

All of the time ▼	Most of the time ▼	A good bit of the time ▼	Some of the time ▼	A little of the time ▼	None of the time ▼
----------------------------	-----------------------------	--------------------------------------	-----------------------------	---------------------------------	-----------------------------

9. Have you felt calm and peaceful? , , , , , ,
10. Did you have a lot of energy? , , , , , ,
11. Have you felt downhearted and blue? , , , , , ,

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time ▼	Most of the time ▼	Some of the time ▼	A little of the time ▼	None of the time ▼
<input type="checkbox"/> ,	<input type="checkbox"/> ,	<input type="checkbox"/> ,	<input type="checkbox"/> ,	<input type="checkbox"/> ,

Your Kidney Disease

How true or false is each of the following statements for you?

	Definitely true ▼	Mostly true ▼	Don't know ▼	Mostly false ▼	Definitely false ▼
13. My kidney disease interferes too much with my life.....	<input type="checkbox"/>				
14. Too much of my time is spent dealing with my kidney disease.....	<input type="checkbox"/>				
15. I feel frustrated dealing with my kidney disease.....	<input type="checkbox"/>				
16. I feel like a burden on my family.....	<input type="checkbox"/>				

During the past 4 weeks, to what extent were you bothered by each of the following?

Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
▼	▼	▼	▼	▼

17.	Soreness in your muscles?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
18.	Chest pain?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
19.	Cramps?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
20.	Itchy skin?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
21.	Dry skin?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
22.	Shortness of breath?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
23.	Faintness or dizziness?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
24.	Lack of appetite?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
25.	Washed out or drained?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
26.	Numbness in hands or feet?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
27.	Nausea or upset stomach?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
28^a.	(Hemodialysis patient only)									
	Problems with your access site?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						
28^b.	(Peritoneal dialysis patient only)									
	Problems with your catheter site?.....	<input type="checkbox"/>	,	<input type="checkbox"/>						

Effects of Kidney Disease on Your Daily Life

Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
	▼	▼	▼	▼	▼
29. Fluid restriction?	<input type="checkbox"/>				
30. Dietary restriction?	<input type="checkbox"/>				
31. Your ability to work around the house?	<input type="checkbox"/>				
32. Your ability to travel?	<input type="checkbox"/>				
33. Being dependent on doctors and other medical staff?	<input type="checkbox"/>				
34. Stress or worries caused by kidney disease?	<input type="checkbox"/>				
35. Your sex life?	<input type="checkbox"/>				
36. Your personal appearance?	<input type="checkbox"/>				

Appendix J:

Modification of the Van Kaam Method of Analysis of Phenomenological Data

<p>1. Listing and preliminary grouping – List every expression relevant to the experience (Horizontalization).</p>
<p>2. Reduction and Elimination – To determine the invariant constituents: test each expression for two requirements:</p> <p>a) Does it contain a moment of the experience that is a necessary and sufficient constituent for understanding it?</p> <p>b) Is it possible to abstract and label it? If so, it is a horizon of the experience. Expressions not meeting the above requirements are eliminated. Overlapping, repetitive, and vague expressions are also eliminated or presented in more exact descriptive terms. The horizons that remain are the invariant constituents of the experience.</p>
<p>3. Clustering and thematizing the invariant constituents: Cluster the invariant constituents of the experience that are related into a thematic label. The clustered and labeled constituents are the core themes of the experience.</p>
<p>4. Final identification of the invariant constituents and themes by application: Validation. Check the invariant constituents and their accompanying theme against the complete record of the research participant. (1) Are they expressed explicitly in the complete transcription? (2) Are they compatible if not explicitly expressed? (3) If they are not explicit or compatible, they are not relevant to the co-researcher's experience and should be deleted.</p>
<p>5. Using the relevant, validated invariant constituents and themes, construct for each co-researcher an <i>Individual Textural Description</i> of the experience. Include verbatim examples from the transcribed interview.</p>
<p>6. Construct for each co-researcher an Individual Structural Description of the experience based on the Individual Textural Description and Imaginative Variation.</p>
<p>7. Construct for each research participant a Textural-Structural Description of the meanings and essences of the experience, incorporating the invariant constituents and themes.</p>