OCCUPATIONAL PERFORMANCE OF MEXICAN AMERICANS WITH END-STAGE-RENAL-DISEASE LIVING ON DIALYSIS IN THE LOWER RIO GRANDE VALLEY

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DEDICATION

This dissertation is dedicated to my sisters, Cheri and Floydia, who endured living on hemodialysis. Their energy, strength, and love for life have inspired me to help other individuals and families experiencing this life changing condition. This is also dedicated to my family members, friends, and colleagues who without their encouragement, support, and motivation, this would not have been accomplished. Lastly to my mother, Sammie Lee (deceased), for teaching me to love learning and caring for others.
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DISSERTATION
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PREFACE

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There are a number of people that assisted me in the completion of this research study. I am deeply indebted to Vanessa Saldana who not only served as an interviewer, recruiter, translator, and transcriber but also my confidant throughout this project. I would like to especially thank my committee chair, Dr. Belinda Reininger, for without her guidance this study would not have been possible.

I would also like to acknowledge the staff of the DSI in-centered dialysis center and the Ukoli Care Clinic especially Leticia Puga and David Tagliaferri for allowing me to recruit participants from their facility. I would like to thank all the participants in this study who graciously shared their stories and experiences openly and honestly even when it was emotionally painful to do so.

Lastly, I would like to thank the faculty and students of the Occupational Therapy Department at the University of Texas-Pan American for their encouragement, energy, and belief that I could achieve this milestone.
The number of people with end-stage-renal-disease (ESRD) and living with dialysis is a growing public health concern. Most studies about the impact of ESRD on people’s lives have placed attention on the medical and clinical dimension of ESRD. Very few have given attention to the environmental and cultural context in which people with ESRD live, the adaptation that these individuals must make to adjust to living with ESRD and dialysis, or the occupations in which they engage. Additionally these studies have not focused on Mexican Americans who are disproportionately affected by this illness and condition. This qualitative study explores the needs, perceptions, and issues facing Mexican Americans with ESRD living with dialysis as well as their families. Participants were residents of the Lower Rio Grande Valley and included individuals with ESRD, family members, and the healthcare providers who give care to them. The Health Belief Model and Lifestyle Performance Model served as the theoretical frameworks. The study also explored the daily occupations of this population.

In-depth interviews were conducted on 15 Mexican Americans with ESRD living with dialysis, 15 family members, and six dialysis healthcare providers. A video documentary of the day-to-day life of three individuals with ESRD and their families was produced. Such data do not currently exist and will greatly enhance the understanding of the human experience of living with ESRD. The results suggest that a collective effort of the family unit is at work to deal with the demands of dialysis. An imbalance and disharmony exist among the occupational activities, which creates occupational deprivation and
disruption for both the individuals and family members. Implications for practice and recommendations for further research are described.
# TABLE OF CONTENTS

List of Tables .......................................................................................................................... xii

List of Figures ........................................................................................................................ xiii

List of Appendices ................................................................................................................. xiv

CHAPTER I: Introduction ......................................................................................................14
  Statement of the Problem ...................................................................................................14
  Specific Aims .....................................................................................................................18
  Public Health Significance .................................................................................................18
  Literature Review ...............................................................................................................22

CHAPTER II: Method ............................................................................................................33
  Purpose of the Research .....................................................................................................33
  Theoretical Framework ......................................................................................................34
  Constructs Definition .......................................................................................................35
  Sample Design ...................................................................................................................36
  Subject Recruitment .........................................................................................................37
  Data Collection ..................................................................................................................38
  Procedure and Instruments ...............................................................................................39
  Background Information ..................................................................................................44
  Data Analysis .....................................................................................................................45
  Data Preparation ...............................................................................................................45
  Data Analysis .....................................................................................................................46
  Reliability and Validity ....................................................................................................48
  Protection of Human Subjects .........................................................................................49
  Limitations of the Study ...................................................................................................49

CHAPTER III: Results ...........................................................................................................51
  Demographic Characteristics .............................................................................................51
  Individuals with ESRD ......................................................................................................51
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implications and Recommendations</td>
<td>179</td>
</tr>
<tr>
<td>Future Research</td>
<td>182</td>
</tr>
<tr>
<td>Conclusion</td>
<td>184</td>
</tr>
<tr>
<td>Appendices</td>
<td>186</td>
</tr>
<tr>
<td>Literature Cited</td>
<td>225</td>
</tr>
<tr>
<td>Vita</td>
<td>233</td>
</tr>
</tbody>
</table>
LIST OF TABLES

Table 1: Constructs Operational Definition.................................................................35
Table 2: Summary of Sample Selection......................................................................38
Table 3: Data Collection Matrix .................................................................................44
Table 4: Summary of Data Collected..........................................................................48
Table 5: Demographic Characteristics of Individuals with ESRD ..............................53
Table 6: Demographic Characteristics of Family Members .........................................54
Table 7: Demographic Characteristics of Healthcare Providers.................................56
Table 8: Major Concerns, Issues & Needs.................................................................129
Table 9: Areas of Significant Occupational Changes and/or Adaptation...............148
LIST OF FIGURES

Figure A: Interconnectedness of the Lifestyle Performance Domains & Areas of Dissatisfaction

........................................161
LIST OF APPENDICES

Appendix A: Background Information and Interview Questions ...........................................187
Appendix B: Graphical Networks ..........................................................................................200
Appendix C: IRB Approval and Consents .............................................................................209

CHAPTER I: INTRODUCTION

Statement of the Problem

It is estimated that approximately 7.4 million adults aged 20 years and older have moderate or severe chronic kidney disease (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2004). Nearly 400,000 of these individuals will progress to end-stage-renal failure requiring dialysis or a kidney transplant to stay alive (United States Renal Data System [USRDS], 2005). Forecasts indicate that by the year 2010 there will be over 650,000 people with end-stage-renal-disease (ESRD) in the United States (Xue, Thomas, & Collins, 2001). By 2015 there will be 136,166 new cases of ESRD patients per year, 712,290 prevalent patients, and 107,760 ESRD deaths annually. The financial and human resources that will be needed to care for these patients in 2015 will be considerably greater than in 2005 (Gilbertson, et al., 2005).

ESRD has a disproportionate impact on certain racial and ethnic groups. It is 5 times more likely to occur in African Americans, 3.6 times more likely in American Indians/Alaska Natives and 1.6 times more likely in Asian Americans than White Americans (American Society of Nephrology [ASN], 2004; Healthy People 2010, 2000). Although there is incomplete data nationally, evidence indicates that Hispanics have 2 times the risk of developing ESRD, particularly due to diabetes and high blood pressure (US Department of Health and Human Services [HHS], 2002, USRDS, 2005). Given that these population groups are significantly more susceptible and have higher rates of diabetes, high blood pressure and obesity, they are also at greater risk for developing kidney failure as well. The
disproportionately higher rates of chronic kidney failure among these ethnic groups result in a greater burden in these communities.

In Texas the data show not only a high incidence rate but also an increasing prevalence rate of treated ESRD among Mexican Americans. According to the Kidney Health Care Program (KHC) in 2005 the incidence rate for Hispanics (235 per million) was almost twice the rate for the general Texas White population (195 per million) and the prevalence rate was three times larger (1,395 per million) than the rate of the White group (544 per million) (KHC, 2005). By 2007, the Hispanic group comprised 41% of newly eligible recipients as compared to African Americans (27%) and Whites (30%). More than 40% of all active recipients of KHC funds were Hispanic (KHC, 2008).

For Cameron County in 2005, the incidence was 2.18 per 10,000 and the prevalence was 16.53 per 10,000 for ESRD. In 2007, 32 received home peritoneal dialysis and 755 underwent in-center hemodialysis. In Brownsville 34 received home peritoneal dialysis and 350 experienced in-center hemodialysis (ESRD Network, 2008). The rapid growth among the Hispanic population itself means that Hispanic patients with ESRD are likely to represent an ever-increasing proportion of the total population with ESRD in Texas.

Medical expenditure for dialysis and transplant creates a financial burden not only for individuals with ESRD but also for the community. Under the Chronic Renal Disease (CRD) program, Medicare covers allowable medical costs for dialysis and transplant for those individuals who are fully or currently insured under Social Security (KHC, 2006). This has made treatment more accessible and has increased the number of ESRD patients receiving therapy – more than 36,000 of whom are Texas patients. If the current trend continues, the ESRD program will cost the U.S. Medicare program $28.3 billion by 2010 (Xue, Thomas, & Collins, 2001).

Despite the Medicare CRD program, the impact and cost of ESRD on Texans is enormous. Since Medicare does not cover the initial three months of dialysis and most drugs and travel expenses associated with the treatment of ESRD, the Texas Legislature created the Kidney Health Care program to help ease the financial burden on people with ESRD. This provides financial assistance for dialysis treatment, surgery for access, hospitalization,
medication, and transplantation costs incurred in the treatment of ESRD for those patients whose gross income is less than $60,000 per year (KHC, 2006). In fiscal year 2007 KHC spent over $20 million for client services expenditures – 44.1% for drugs, 7.2% part D premiums, 33.9% for travel, and 14.8% for medical services (KHC, 2008). Of these funds $3 million was for those individuals receiving in-center hemodialysis. In 2004 the expenditure for ESRD was $411,734 in Cameron County alone (KHC, 2005).

With the rising prevalence and awareness of the stressors of this disease, understanding the daily challenges and occupations of Mexican Americans with ESRD are important. The impact of ESRD on people’s lives has been studied since the 1980’s. Investigators have used the term “quality of life” in their assessments. However, in actuality; they have placed attention on the medical or clinical dimensions of ESRD (Rebollo & Ortega, 2002). Very few have explored “quality of life” as defined by the World Health Organization (as cited in Rebollo & Ortega, 2002):

…The personal perception of a person, of his/her situation in life, and within the cultural context in which he/she lives, and in relationship with his/her objectives, expectations, values and interests. (p.196)

Even fewer studies have given attention to non-medical factors such as patient satisfaction, spirituality, social support, self-maintenance, societal contribution, interpersonal relationships, and the assessment of social status and occupational performance. Nor has attention been given to the environmental and cultural context in which people with ESRD live.

Although quantitative studies on quality of life among patients with ESRD have been done, relatively few have been directed at the adaptation that these individuals must make to adjust to living with ESRD and dialysis. According to the ESRD Workgroup Final Report Summary (Robert Wood Johnson Foundation, 2003), “The quality of life instruments in use are largely objective and provide little information regarding the patient’s perception of his/her quality of life” (p. 60). Even fewer studies have explored what it is like living with someone with ESRD and dialysis, the meaning given to everyday life with this debilitating disease and treatment, or the impact it has on their family members.
To focus and guide this study, quality of life is viewed as an individual’s engagement in daily occupations. Everyday life is carried out through a myriad of occupations embedded in a variety of contexts - cultural, physical, social, personal, temporal, and spiritual realities. The active process of occupation is a basic human need and is fundamental to human existence and to the organization of societies (Christiansen & Townsend, 2004). Human occupation reflects time use according to both individual and cultural characteristics. Biological, ecological, and psychological factors also influence occupational choices. Consequently involvement in occupations enables humans to develop as individuals and members of society (American Occupational Therapy Association [AOTA], 2002).

The term occupational performance as defined in this study is the ability or perceived ability to engage or participate in meaningful everyday life whether related to self-care, leisure or work. Occupational performance entails the domains of self-care and self-maintenance, intrinsic gratification, societal contribution and reciprocal interpersonal relatedness (Velde & Fidler, 2002). It is the intertwining of self, motivation, lifestyle, society and environment. Yet, when an individual experiences a life changing illness such as ESRD and dialysis that is beyond their immediate control, occupational deprivation can occur. Persons with disabilities are often exposed to a scarcity of occupational opportunities imposed by the human and nonhuman environment (Whiteford, 2004). Therefore the central question to explore is whether various types of disabilities or medical conditions in themselves are barriers to participation in occupations or whether human and physical environment are the real impediments to occupational performance.

With the rising national epidemic of obesity and diabetes which can lead to ESRD cases especially among Hispanic populations, increasing financial burden of this condition and human resources that will be needed to care for individuals with ESRD, and the potential for occupational deprivation, it would behoove us to explore and understand the challenges and meaning this disease has for those who suffer and try to live with it. Investigating the lived experiences of Mexican Americans with ESRD receiving dialysis and their families as well as examining their day-to-day lives from their own perspectives may provide guidance
to advance participation in daily occupations and reduce occupational deprivation as well as improve the quality of life for all patients receiving dialysis treatment.

**Specific Aims**

The specific aims of this study are

1) To identify the most prominent needs, perceptions and issues related to the occupational performances of Mexican Americans with ESRD living on dialysis in the Rio Grande Valley of Texas from the points of view of the individuals with ESRD who have lived with dialysis for 6 months or more, their families, and the healthcare providers who serve them.

2) To compare the points of view between individuals with ESRD who have lived with dialysis for 6 months or more, their families, and the healthcare providers who serve them regarding most prominent needs, perceptions and issues related to the occupational performances of Mexican Americans with ESRD living on dialysis.

3) To describe the day-to-day impact of living on dialysis from the point of view of the individual with ESRD who have lived with dialysis for 6 months or more and his or her family members.

**Public Health Significance**

The escalation of ESRD to an urgent public health concern is a consequence of the current and anticipated disease burden on the American population. With the number of new cases of ESRD growing steadily and the tremendous impact this condition has on society in terms of treatment costs for its victims and their concomitant loss of productivity and years of life, chronic kidney disease is a focus area in Healthy People 2010 (Healthy People 2010, 2000). ESRD is the 9th leading cause of death nationally (USRDS, 2005).

End-stage renal disease is a progressive, debilitating, chronic illness that requires medical interventions that include dialysis, education on lifestyle alternations, and dietary and fluid restrictions. When kidney function has deteriorated and is no longer adequate to sustain life and the process is considered irreversible, renal replacement therapy (RRT)—
dialysis or transplantation—becomes necessary to maintain life. Unless people experiencing kidney failure are treated, they can die within days (Kronkosky Foundation, 2004). Chronic or permanent kidney failure is the result of years of chronic kidney disease (CKD) caused by inherited conditions, an injury to the kidneys or, most commonly, a medical condition such as diabetes and/or hypertension. It is the final stage of a slow deterioration of the kidneys (KHC, 2005).

In Texas, the number of people with ESRD has increased 106% in the past ten years. The incidence and prevalence rates are above the national average and trending upward for many years until 2007 when the incidence rate decreased from 379 per million in 2006 to 369.9 per million. The prevalence rate has followed the same upward trend and continues to rise. The prevalence rate have climbed to 1,352 per million (ESRD Network, 2008). A large portion of the continuing growth was in the age groups 45-54 years (24.6%) and 55-64 years (28.3%) and among males (58.6%). The most notable increase within the ethnic distribution has been the high percentage (41.6%) of Hispanics with ESRD (KHC, 2008). Within Cameron County, 787 individuals are living with ESRD with 384 persons in Brownsville, TX (ESRD Network, 2008).

Nineteen percent of all new ESRD patients placed on hemodialysis will die within the first year (USRD, 2005). According to the Kidney Health Care (2005) report, in 2003, 10% of the 1,094 African Americans and of the 1,736 Hispanics who initiated dialysis, died within the first year as compared to 16% of the 1,006 Whites. The lower mortality rate among the racial/ethnic groups’ newest ESRD patients was considered to be due to improvements in treatment procedures while the increased rate for white patients might be due to the later age of ESRD onset.

Another method for viewing mortality is by viewing the remaining years of survival. Owen (2003) stated that survival of a “59 yr. old with ESRD is worse than that of an equivalent patient with a diagnosis of prostate or colon cancer (4.3 versus 13 and 8 years respectively)” (p. 876). The overall expected remaining life years from 2003 for an ESRD patient on dialysis were 5.5 years and 15.1 for a patient obtaining a transplant (USRDS, 2005). The probability of surviving past 5 years decreases with each year. The mortality rate
can be affected by multiple factors, such as age of entry into the program, primary diagnosis, disease severity, and other co-morbid conditions (KHC, 2005). The burden of cardiovascular disease seen in older patients is possibly one of many contributing factors to the high mortality rates seen in this population (Gilbertson, et al., 2005; KHC, 2005).

Diabetes is the most common cause and predictor of kidney failure in both Texas and the United States followed by hypertension and glomerulonephritis (KHC, 2005; Ohmit, Flack, Peters, Brown, & Grimm, 2003; Stengel, Tarver-Carr, Powe, Eberhardt, & Brancati, 2003; USRDS, 2005). In 2005, diabetes accounted for 51% of all ESRD cases (ESRD Network, 2006). Type 2 diabetes is a dominant cause of ESRD. A high percentage of patients with Type 1 diabetes may develop ESRD, but because the Type 2 population is larger, it contributes the larger number of cases (Benabe & Rios, 2004; Pugh, Medina, Cornell, & Basu, 2003). Diabetes is particularly common among Mexican Americans and Puerto Rican Americans (Benabe & Rios, 2004). According to Ohmit et al. (2003), “The risk of developing diabetic nephropathy and ESRD increases with the duration of diabetes, poor glycemic control, comorbid hypertension, hyperlipidemia, and a family history of diabetic kidney disease (p. S117).” Type 2 diabetes is becoming increasingly prevalent in younger individuals across all racial groups due to inactivity and obesity (Ohmit, et al., 2003; Pugh, et al., 2003).

In 2004 for Texas, diabetes was the leading cause of ESRD for those ages 33 or over while glomerulonephritis was the leading cause for those under the age of 21. Hypertension was the leading cause of ESRD among individuals aged 21-34 years. The median age of ESRD was 64.8 years. While Hispanics were disproportionately affected by diabetes as the primary diagnosis of ESRD, African Americans were disproportionately affected by hypertension. The percentage of females with a primary diagnosis of diabetes was higher than that of males, but males with a primary diagnosis of hypertension outnumbered females (KHC, 2005). Co-morbid conditions common to ESRD include peripheral nerve damage and cardiovascular disease.

Uncontrolled or poorly controlled high blood pressure is the second leading risk factor for chronic kidney disease (Benabe & Rios, 2004; Stengel, et al., 2003). Failure to
lower blood pressure to normal over several years results in irreversible changes in the left ventricular hypertrophy and diastolic function. Hypertension is the highest risk factor for coronary artery disease and cerebro-vascular disease. Hypertension is both a cause and a consequence of kidney disease (Consensus Development Conference Panel, 1994; Ohmit, et al., 2003).

At the end of 2007, 41,607 persons were receiving renal replacement therapy (dialysis and transplant combined). Hemodialysis is the predominant treatment modality among Texans. In 2007, 32,383 individuals received either hemodialysis or peritoneal dialysis and 9,224 were transplanted. Of the newly diagnosed persons with ESRD, 8,840 begin receiving dialysis, a <1 % increase over 2006 (ESRD Network, 2008). In Cameron County 32 received home peritoneal dialysis and 755 underwent in-center hemodialysis. In Brownsville 34 received home peritoneal dialysis and 350 experienced in-center hemodialysis (ESRD Network, 2008). Over 8,000 Hispanics in Texas received in-center hemodialysis (KHC, 2006). This type of dialysis requires patients to commit a considerable amount of time to their treatment, to comply with strict dietary and fluid restrictions, and to take medication on a regular basis. Hemodialysis must be performed three times a week with each session lasting between three to five hours.

Due to the large and growing number of patients faced with long-term dependence on dialysis, ESRD is among the most expensive diseases to treat on a per capita basis. The cost for the ESRD program is $22.8 billion in public and private spending with an annual Medicare cost of $63,000 and employer group health plan cost of $126,000 for dialysis (ESRD Network, 2006; USRDS, 2005). By primary diagnosis, per person per year expenditures are highest for patients whose ESRD is caused by diabetes. For instance, spending exceeded $68,000 in 2003 – nearly 13% higher than for patients with hypertension and almost 30% higher than for patients with glomerulonephritis. Per person per year expenditures are also higher for those patients who have been on dialysis for less than two years (USRDS, 2005). These increases in cost are due to both the increase in patients and the cost of newer, more effective medications and treatment processes.
Living with ESRD and dialysis is a complex affair that poses challenges for policy makers, healthcare providers, and financial planners. According to Gilbertson et al. (2005), “The aging of the baby boomers, changing racial distributions, increasing prevalence of diabetes, increasing probability of surviving to ESRD before dying, and changing life expectancy of patients with ESRD” (p. 3736) will all contribute significantly to the future number of patients living with ESRD on dialysis. The insight to be gained from examining the life of Mexican Americans with ESRD living on dialysis will be critical in shaping public health policy and health care planning related to the treatment of kidney disease as well as formulating rational public health strategies to reduce the increasing number of Mexican Americans with ESRD living with dialysis.

Literature Review

ESRD programs currently serves more than 400,000 patients and they are expected to serve over 712,000 by 2015 in the U.S. (Gilbertson, et al., 2005). From a patient-specific focus, a gauge of success of an intervention like dialysis is patient reduced mortality. Transplantation is the primary choice of care because it offers the longest survival time but access to this modality is limited especially for the economically disadvantaged and ethnic populations. Although dialytic therapy is life saving, it clearly does not restore normal health and well-being to patients (Kinchen, et al., 2002).

Personal Lifestyle Risk Factors

Major risk factors for the development, progression and survival of ESRD have been identified and studied. Risk factors that can lead to chronic kidney disease and ESRD occur commonly throughout the adult population. Individual risk factors for the development of ESRD include diabetes mellitus, hypertension, elevated cholesterol levels, family history of chronic kidney disease, older age, male gender, and being a member of an ethnic group (Benabe & Rios, 2004). Yet, several risk factors of kidney disease are directly attributed to personal lifestyle choices including diet, use of tobacco, substance abuse, physical activity, obesity, and lack of adherence to a medical care plan.
Stengel et al. (2003) found in their nonconcurrent cohort study of adults, aged 30-74, that those individuals who were inactive when compared to very active persons had more than twice the risk of developing chronic kidney disease. Those with morbid obesity had more than twice the risk of developing chronic kidney disease than normal-weight persons. Alcohol consumption, however, was not related to the risk of chronic kidney disease. The authors also found that physical activity had a stronger association with the risk of diabetic or hypertensive nephropathy than with other types of kidney disease. Other risk factors that have been mentioned specifically related to the Hispanic population but lack sufficient studies include genetic predisposition, socioeconomic status, racial disparities, cultural differences, and access to medical care (Benabe & Rios, 2004).

Non-Compliance

Providing appropriate preparation, support and intervention for compliance among those on renal replacement therapy is necessary in order for patients to adapt to dialysis (Boyer, Chlouverakis, & Kaloyanides, 1990). Hemodialysis requires patients to commit considerable time to treatment, to comply with strict dietary and fluid restrictions, and to take medication on a regular basis. They must come to all scheduled treatment sessions and stay the entire 4-6 hours. They must limit their protein, sodium and potassium intake. They must limit their fluid intake due to the kidney’s inability to excrete fluids. Excess fluids can lead to muscle cramping, congestive heart failure, edema, vomiting and death. Failure to comply with the medication regimen can lead to high levels of serum phosphate in the body, which causes a decrease in calcium and eventual bone demineralization (Consensus Development Conference Panel, 1994; Hailey & Moss, 2000; Kutner, 2001). Hemodialysis is not a cure for ESRD but it can significantly prolong someone’s life therefore noncompliance with these activities has significant impact on patients’ survival and outcome.

Non-compliance with the hemodialysis treatment regimen leads to complications and even death in patients already suffering from a chronic condition. Non-compliant behaviors are depended upon how it is defined and assessed. Much of the literature use dietary, fluid and medication along with skipping and shortening of the treatment session as measurements of non-compliance. Missing one or more sessions or shortening one session by more than ten
minutes foretell a decrease in survival and an increased risk of death (Hailey & Moss, 2000; Kutner, 2004; Sehgal, 2002). Hailey and Moss (2000) found that predictors of noncompliance especially for missing or skipping sessions were the patient age and length of time on dialysis. Younger patients and those relatively new to dialysis were more likely to miss scheduled sessions and made significant errors in adhering to the treatment regimen (Curtin, Oberley, & Sacksteder, 1997). Younger patients may consider themselves less vulnerable to negative health outcomes and are likely to highly value a sense of independence. Younger patients are typically less compliant than older patients (Kutner, 2001).

Noncompliance with dietary, fluid and medication regimen was found among those patients who considered family and staff unsupportive or supportive only out of sense of duty (Boyer, Chlouverakis, & Kaloyanides, 1990; Christensen, et al., 1992). Kimmel, Emont, Newmann, Danko, and Moss (2003) found that low levels of social support, decreased behavioral compliance with dialysis regimen, and increased negative perception of the effects of illness were independently associated with increased mortality in ESRD patients on hemodialysis.

Psychosocial factors have been involved in relating non-compliant behaviors and high mortality in hemodialysis patients. Kimmel, Emont, Newmann, Danko, and Moss (2003) found pain along with psychosocial and spiritual factors as important determinants for noncompliance among hemodialysis patients. Schneider, Friend, Whitaker, and Wadhwa (1991), who looked at cognitive and emotional factors in noncompliance, concluded that compliance was a function of self-control. They suggested that interventions to increase compliance should focus on increasing motivation and attributions of personal power and success rather than treating negative emotional states in patients. Christensen et al. (1992) concluded in their study of dialysis patients that perceived health competence was an important determinant of noncompliance for patients with predominant powerful locus of control.

Several studies show that many patients with ESRD do not receive optimum preparation for hemodialysis prior to commencement of this treatment. This lack of preparation made noncompliance a major problem that has significant impacts on patients’
adaptation (Kinchen, et al., 2002; Mapes, et al., 2004; Owen, 2003). Hill-Briggs, Gary, Hill, Bone, and Brancati (2002) identified socioeconomic and familial barriers as risk factors for non-compliance with hemodialysis for African Americans with Type 2 diabetes. While White, Richter, Koeckeritz, Lee and Munch (2002) learned that family dynamics, communication patterns, and stressors imposed by the illness were significant factors shaping complying and adjusting to hemodialysis. These authors also discovered that cultural perspective could be a major determinant to adapting and living with hemodialysis.

Mode of Assessment

In a review of over 20 published studies since 1990, Rebollo and Ortega (2002) found great differences in the applied conceptual model of Health Related Quality of Life (HRQOL), in the assessment instruments used, in the methods of data collection recording, and in the results and conclusions. They found that different instruments were used to measure the HRQOL and the questionnaire results did not offer any explanation of what was being measured, i.e., “Is it health related quality of life or quality of life in general terms, or physical well-being or psychological well-being?” (p. 196).

When looking at the mode of administration of HRQOL instruments, Unruh et al. (2003) found that dialysis studies that restricted HRQOL measurements to patients who were able to complete pencil-paper surveys without assistance do not accurately represent the health of the overall hemodialysis population. Their results showed that exclusive reliance on self-administrated questionnaires would result in under-representation of the aged, minority groups and the very sick, and these are the patients who may benefit most from intervention. Their study consisted of 5% Hispanics and the majority had diabetes or hypertension as the cause for ESRD. Wu et al. (2003) used the self-reported HRQOL to assess changes in overall outcome of health care and health status based on the modality - hemodialysis or peritoneal – used by patients. They looked for improvement in quality of life without assessing it before the patients began their treatment. This study did not include a racial or ethnic category for Hispanics even though eligible patients had to speak either English or Spanish to participate.
Mapes et al. (2004) used several HRQOL instruments to look for an association between “physical, mental and social well being” and mortality and hospitalization and patients with ESRD. This study did include a significant number of Hispanic participants. They found that the summary scores on the physical, mental, and kidney disease components of the HRQOL instruments were significantly associated with mortality risk, regardless of ethnic group. Hispanics showed a higher association between the physical components and mortality risk.

Using the 36 Short Form Health Survey that looked at vitality, physical functioning and physical role limitations, Cleary and Drennan (2005) concluded that end-stage renal disease and its ensuing treatment negatively affect quality of life. With the same Medical Outcome 36 Short Form Health Survey, Morsch, Goncalves, and Barros (2006) found in their study of patients on hemodialysis that patients treated for over one year and with less schooling had better results about general health perception. Patients diagnosed with diabetes perceived their physical functioning more negatively compared with those with other etiologies of ESRD.

Despite these studies and others, controversy exists regarding the measurement of QOL in patients with renal disease. Very few have explored the quality of life as defined by the World Health Organization. Even fewer of these studies have focused on or included Mexican Americans. Therefore, using these instruments to ascertain quality of life among Mexican Americans may be premature. A quality of life instrument that measures psychosocial status, support, spiritual domains, occupational performance, as well as satisfaction/dissatisfaction with all aspects of life among Mexican Americans, would be beneficial in the treatment of this population.

Quality of Life

ESRD and dialysis have an impact on the individual’s quality of life, physical and mental health, functional status, independence, general well-being, personal relationships, social functioning, and occupational performance. It not only interrupts one’s life but it also demands adjustment, adaptations, and new reservoirs of coping strategies. At the same time it is accompanied by losses, feelings of powerlessness, and stigma (Hailey & Moss, 2000;
Krespi, et al., 2003). To move beyond describing dimensions of health and begin drawing conclusions about the impact of ESRD treatment on quality of life, Kutner (2004) expounded as a result of her preliminary study of quality of life and daily hemodialysis, “A patient who begins dialysis may have a significant improvement in symptoms but may dislike the increased exposure to treatment or the extra work involved in receiving treatment, making it difficult to draw conclusions about that patient’s resulting quality of life on daily hemodialysis” (p. 94). Even though hemodialysis has been reported to increase quality of life in ESRD, patients report that they remain substantially burdened by limited physical functioning and by dialysis-related symptoms (Morsch, Goncalves, and Barros, 2006).

One of the few studies that have explored hemodialysis patients’ beliefs, attitudes and quality of life was conduct by Krespi, Bone, Ahmad, Worthington, and Salmon (2004) in the United Kingdom. Qualitative analysis of interviews with 16 hemodialysis patients identified beliefs about ESRD and its treatment. These beliefs were converted into a questionnaire, which was completed by 156 similar patients. They found that many patients regarded dialysis and dietary control as externally imposed challenges that dominated their lives. Most believed that hemodialysis weakened the body and dominated their lives. On the other hand they believed that hemodialysis had extensive physical effects such as better sleep, improved appearance and something that kept them alive. They perceived few immediate positive effects about the diet and fluid restrictions but regarded them as externally imposed constraints.

Kimmel et al. (2003) felt that patients’ perceptions may be more important than objective clinical assessments in determining quality of life for patients with ESRD. Using a quality of life questionnaire that included the Satisfaction with Life Scale and McGill QOL Scale to interview 165 white and African American hemodialysis patients, they found pain along with psychosocial and spiritual factors as the most important determinants of quality of life among patients with ESRD. In a study by Al-Arabi (2006), quality of life was often discussed in the context of having abilities and energies to go places, perform tasks, have social relationships with family and friends, having a pleasing diet, and not being sick. A
change occurred in their appraisal when they realized that surviving a chronic disease was worth the efforts required to make choices and changes.

Studies have identified depression and depressive affect and patients’ perceptions regarding quality of life (QOL) as key factors in adaptation, long-term sequelae, survival, and mortality in patients with ESRD. Drayer et al. (2006) found that depression was common and associated with decreased health-related quality of life and increased mortality in hemodialysis patients. Martin and Thompson (2000) looked at quality of life, locus of control, depression and anxiety among ESRD patients. They found that depression was a significant predictor of quality of life, which is likely to be related to compliance. Social support and marital relationships can be a source of strength and consolation, at the same time isolation and marital discord might worsen life for patients with CKD (Kimmel et al., 2003). Sleep quality, sexual functioning, and cognitive functioning are QOL dimensions that may be impacted by hemodialysis but about which there is limited information (Kutner, 2004).

Dealing with the transition from diagnosis to treatment and management of a chronic illness can be difficulty. However, viewing ESRD as a life-restricting illness at first, making the conscious choices to stay alive and feel good will follow in time as the individual become convinced that quality of life is within their own reach and under their own control says Al-Arabi (2006).

**Occupational Deprivation**

A growing body of literature is showing that lifestyle and occupational choices inspire and shape both physical and psychological well-being. Engagement in occupations has been shown to not only influence happiness but also life satisfaction and quality of life (Christiansen, et al., 1999; Christiansen & Townsend, 2004). “People thrive when their personalities and needs are matched with environments or situations that enable them to remain engaged, interested, and challenged” (Christiansen & Townsend, 2004, p. 23). So, what happens when people are unable to do the things they want and need to do for extended periods of time in a manner of their choosing? What consequences does this have for people individually, in families, and even communities?
Occupations are vital to a person’s identity and competence, and they influence how one spends time and makes decisions. “Occupation is everything that people do to occupy themselves including looking after themselves, enjoying life, and contributing to the social and economic fabric of their communities” (Law, Polatajko, Baptiste, & Townsend, 1997, p. 32). Occupations are those human actions that are goal directed and necessary to perform and participate in to achieve a goal. An activity that is purposeful and meaningful to the individual contributes positively to that individual’s perception of his or her own quality of life. Occupation comprises all the ways in which we occupy ourselves individually and as societies. “Occupation is the process of being occupied, being engaged in a doing experience” (Velde & Fidler, 2002, p. 9). Occupational performance is the ability to perceive, desire, recall, plan, and carry out roles, routines, tasks, and subtasks for the purpose of self-maintenance, productivity, leisure and rest in response to demands of the internal and/or external environment (Chapparo & Ranka, 1997).

Not all people are afforded equal opportunities to participate in occupations of choice or in occupations having individual or cultural meaning (Wilcock, 1998). People who are deprived of occupational opportunities beyond their immediate control, such as being born with or acquiring a chronic illness or disability, may suffer from occupational deprivation or disruption (Christiansen & Townsend, 2004). Occupational deprivation occurs when someone or something external to the individual is creating conditions that lead to permanent disruption of occupations of meaning or cultural significance such as ESRD and hemodialysis (Whiteford, 2004).

Bejerholm and Eklund (2004) study results painted a picture of stagnation and purposelessness throughout their participants’ occupational patterns and time use. They found that most occupations which the persons with schizophrenia engaged in were not triggered by a facilitating environment but from within the person by basic, immediate life needs or wanting to escape reality. They performed most activities alone in their home environment. They did not interact with the environment and many of the activities were accompanied with a feeling of emptiness and neutral reflection about the occupational outcome. Pearson, Rivano-Fisher, and Eklund (2004) found that occupational performance
was indicative of change in a pain management program. Increases in changes in general activity level, general health and vitality, and decreased pain severity were associated with positive changes on perceived occupational performance and performance satisfaction. Lindstedt, Soderlund, Stalenheim, and Sjoden (2005) found that life history and demographic variables were considered important influences for occupational performance and life satisfaction among mentally disordered offenders.

The central question to occupational involvement is whether various types of disabilities or medical conditions are barriers or predictors to participation in occupations themselves or whether human, contextual and physical environments are the real impediments to occupational performance. What are the occupational deprivations experienced by individuals with ESRD living on hemodialysis that will prevent them from participating in occupations necessary for their spiritual, mental, physical, or economic well-being? Improved awareness of the importance of occupations in daily lives will lead to more widespread appreciation of the effects of occupational disruption and deprivation when they occur.

**Acculturation**

Dressler (1993) posited that culturally-based knowledge, attitudes and beliefs cause people to make behavioral choices that result in the observed health patterns. Individuals choose or reject behaviors based on their cultural beliefs and such choices are a prime factor affecting their health. Cultural influence on health is often operationalized as the level of acculturation, which is measured using acculturation scales designed to quantify the extent to which individuals embrace mainstream versus ethnic culture (Hunt, Schneider, & Comer, 2004). All definitions of acculturation refer to a process of cultural change resulting from contact between two cultures.

Acculturation measures are common in U.S. studies of Hispanics and have been used to examine a variety of health concerns for this group.

Socioeconomic variables are often used as proxies for the degree of acculturation experienced by people - presuming that individuals are born in another country. Acculturation is always measured by proxy variables, primarily language (Hunt, Schneider,
Language proficiency, however, does not convey the entire spectrum of acculturation as a complex construct, but has been proved to be a reliable measure of health status. Chiriboga (2004) suggests that multiple methods to measuring acculturation should be created. These methods must go beyond language fluency. “The functional significance of level of acculturation must be considered in the context of the social environment. This type of measure may further our understanding of the socioenvironmental dynamics faced by these individuals” (p. 289). In addition to language, other elements of acculturation experience should include place of birth, cultural expressions and feelings, attitudes, emotional behaviors and beliefs, and ethnic loyalty (Ploeg & Perrin, 2004).

The Acculturation Rating Scale for Mexican Americans-II (ARSMA) is a good example of a type of multidimensional scale that includes concepts of integration, separation, assimilation, and marginalization (Cuellar, Arnold, & Maldonado, 1995). Language indicators with multidimensional scales have been shown to be powerful predictors of health status among Hispanics. There is no perfect measure but an individual’s degree of acculturation is dependent on other characteristics as well: home, work and social interactions, exposure to the cultures in the United States, and proficiency with the English language before immigration. Other aspects of the individual that are associated with acculturation include socioeconomic status, discrimination, occupational experiences, and neighborhood environments (Cabassa, 2003; Cuellar, et al., 1995; Marin & Marin, 1991; Ploeg & Perrin, 2004).

Despite the conceptual and factual errors associated with the acculturation constructs such as lack of a clear definition and insufficient conceptualization (Hunt, Schneider, & Comer, 2004), acculturation has been associated with many aspects of health behavior. High levels of acculturation have been shown to be associated with greater use of mental health services among female Chinese immigrants (Tabora & Flaskerud, 1997), increased alcohol intake and smoking prevalence among Mexican American women (Otero-Sabogal, Sabogal, Pérez-Stable, & Hiatt, 1995), and increased cervical and breast cancer screening for Filipino and Korean immigrants (Maxwell, Bastani, & Warda, 1998). It has also been shown to
influence knowledge and attitudes that shape and influence health behaviors (Marin & Marin, 1991; Hubbell, Chavez, Mishra, & Valdez, 1996; Maxwell, Bastani, & Warda, 1998).

These studies show that acculturation is an important factor in observable health behaviors. It does affect the individual in terms of language, content, context, and psychological factors related to health beliefs and behaviors. Measures of acculturation and proxies, such as language use, place of birth, and generation and time in the United States, must be taken into account in any target population research as well as in designing effective and culturally appropriate health interventions.

Summary

The Mexican American population is at a high risk of developing ESRD and an increasing number will end up living on hemodialysis. Probing the human and nonhuman environment will make it possible to identify how occupations or the conduct of everyday life indicate a means for providing structure, identity, and meaning in people’s lives. This proposed study would add to the body of research a framework for viewing the interrelationships of occupation, environment, risk factors, compliance, culture, and acculturation for defining a lifestyle in harmony with personal and societal needs and expectations. By exploring the contextual configuration of daily living activities, we will be able to discover the occupational deprivations and disruptions created by ESRD or hemodialysis and its consequent limitations on activity, social participation, and quality of life. This proposed study will provide a clear narrative regarding the reality of life for Mexican Americans with ESRD living on hemodialysis.
CHAPTER II: METHOD

Purpose of the Research

The purpose of the study is: 1) to identify the needs, perceptions, and issues related to the occupational performance of Mexican Americans with end-stage-renal disease (ESRD) living on renal replacement therapy, 2) to compare the points of view between the individual with ESRD, the family members, and healthcare, and 3) to describe the day-to-day occupational performance of Mexican Americans with ESRD living on renal replacement therapy and family members. In order to accomplish those objectives, the researcher used a qualitative cross-sectional research design, with the Health Belief Model and Lifestyle Performance Model as theoretical structures, to explore the most prominent needs, perceptions and issues as well as occupational disruptions facing individuals with ESRD living on dialysis, their families and healthcare providers.

Qualitative research is the systematic, empirical strategy for answering questions about people in a particular context (Locke, et al., 2000). Qualitative ethnographic methods are often used to describe what is going on, what people do and to report what they experience. Qualitative studies provide a way to document those events that impede or enhance the participants’ efforts. They focus on “what makes the people tick – how they behave, how they define their world, what is important to them, why they say and do what they do, and what structural or contextual features influence their thoughts, behaviors, and relationships” (LeCompte & Schensul, 1999, p.85).

A qualitative design method was appropriate for this study because it allowed for gathering information, assessing and gaining an understanding of the role of culture and context in influencing the occupational performances associated with Mexican Americans with ESRD living on dialysis in the Rio Grande Valley. The narratives represent the participants’ accounts and not the investigator’s account. This approach is not about collecting normative data or comparing individuals but to provide a way to identify how quality of life is changed as a result of a disability or medical condition.
Theoretical Framework

The Health Belief Model is an appropriate theoretical framework for exploring this population. It is a “value-expectancy” model developed to explain individual’s health actions under conditions of uncertainty. It postulates that health-related actions depend upon the perceptions of the individual in four areas: a) the belief that one is vulnerable (susceptible) to the sequelae of the illness or conditions (perceived threat), b) the belief that the illness or condition is serious enough to be a threat, c) the belief that compliance with medical recommendations would be beneficial in reducing the perceived threat, and d) the belief that perceived barriers must be overcome in order to comply with medical recommendations. Having reminders to act (cues to action) are also important constructs in this model that allow patients to exert some control over their lives (Janz, et al., 2002).

Perceived collective efficacy is the definition that a group or organization can solve its problems and improve through concerted effort. It influences what people choose to do as a group, how much effort they put into it and their staying power when the group fails to produce results (Bandura, 1986).

The Lifestyle Performance Model hypothesizes that health is supported and maintained when individuals are able to engage in occupations and activities that allow desired or needed participation in community life. This model makes it possible “to identify the relationship of activity [occupation] patterns to the pursuit of a person’s unique needs to achieve a personal identity, to understand the activities [occupations] within the context of sociocultural norm, and to take into account aspects of freedom and control within a personal lifestyle” (Velde & Fidler, 2002, p. 13). This model is concerned with identifying and describing a contextual configuration of daily activities that will potentially optimize individual wellness and quality of life. The key construct of the model is occupational lifestyle. Occupational lifestyle is composed of four domains: self-care/self-maintenance, intrinsic gratification, reciprocal interpersonal relatedness, and social contribution. Activities in the four domains can be supported and/or constrained by the environment. When daily living activity configuration is in harmony, then a perception of quality of life follows (Velde & Fidler, 2002).
The constructs of the Health Belief Model and Lifestyle Performance Model guided the design and methods used for collecting the narratives from individuals with ESRD living on dialysis, their family members and the healthcare providers who serve them. They were used to direct the semi-structure observations and interviews questions. The constructs are used to explain the role of occupations in both shaping and reflecting the quality of life within an environmental context.

Constructs Definition

Table 1: Constructs Operational Definition

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Operational Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Susceptibility</td>
<td>Uncertainty of &amp; dependency on dialysis: medical complications, physiological deterioration, death, associated side effects, risk of infection</td>
</tr>
<tr>
<td>Perceived Severity</td>
<td>Death from kidney failure; living on hemodialysis</td>
</tr>
<tr>
<td>Perceived Threat</td>
<td>Combination of perceived susceptibility &amp; severity; Risk of family members &amp; children developing ESRD</td>
</tr>
<tr>
<td>Perceived Benefits</td>
<td>Physical well-being; extended, prolonged life</td>
</tr>
<tr>
<td>Perceived Barriers</td>
<td>Dialysis regimen: 3 x wk dialysis sessions for 3-4 hrs; dietary &amp; fluid restrictions, and medications regimen; constant doctor’s appointments</td>
</tr>
<tr>
<td>Cue to Action</td>
<td>Interdialysis weight gain; Interaction with healthcare providers</td>
</tr>
<tr>
<td>Collective Efficacy</td>
<td>Collective effort of the family unit</td>
</tr>
<tr>
<td>Self-Care &amp; Self-Maintenance</td>
<td>Activities that are routinely carried out as one’s chosen patterns of personal hygiene, health care, grooming &amp; dressing &amp; those activities concerned with feeding self, money management, clothing self, household management, living in the community, and travel</td>
</tr>
<tr>
<td>Societal Contribution</td>
<td>Activities that contribute to the welfare and need fulfillment of others</td>
</tr>
<tr>
<td>Intrinsic Gratification</td>
<td>Activities devoted to personal pleasure and enjoyment</td>
</tr>
<tr>
<td>Reciprocal Interpersonal Relatedness</td>
<td>Activities that enrich one’s relationships with others, activities shared with loved ones, family, friends, colleagues, group memberships</td>
</tr>
</tbody>
</table>
Sample Design

The goal of qualitative inquiry is to achieve richness rather than representativeness (LeCompte & Schensul, 1999). In keeping with this aim, a purposive non-probability sample design was used in the present study. The sampling criteria were: a) Mexican Americans living in Cameron County with a diagnosis of ESRD with more than 6 months living with renal replacement therapy, b) family members including spouse, sibling(s), child (children) or blood relatives who may or may not be the primary caregiver, and c) full-time, paid healthcare providers with a minimum of 2 years direct contact with dialysis patients. The rational for including more than the primary caregiver was that anyone who regularly interacts with an individual with ESRD may be affected and insight into the full impact of dialysis on the total family could be ascertained. It also increased the number of individuals available for the family member interviews. The limitation of years working with dialysis patients was based on the frequent turnover of dialysis staff personnel and it only minimally reduced the number of healthcare providers available for the study. The criterion of time on dialysis was based on the assumptions that a six-month period is sufficient to allow stabilization of the individual’s physiological functioning and adequate experience of the requirements of the treatment regimen i.e., medication, dietary restriction, fluid intake restriction, permanent physical alteration. Individuals with ESRD on peritoneal were included in this study if they had also experienced hemodialysis.

The population of interest for this study consisted of the 787 individuals with ESRD living in Cameron County (ESRD Networks, 2008). Initially, the population was the 273 hemodialysis patients from two in-center facilities in Brownsville, TX of which 95% - 97% are Mexican Americans. However, in the course of obtaining access to the patients, one center choice not to grant the researcher onsite access to its patient. Therefore, the hemodialysis population in Harlingen, TX was approached in order to reach an adequate sample size. The healthcare providers came from the three in-center facilities in Brownsville.
Subject Recruitment

Several strategies – snowballing, networking, and advertising - were used to identify and recruit participants for this study. Snowballing is the investigator talking with one patient and that person talks with other patients, receiving permission to forward their contact information and the investigator contacting them by way of the phone. Some ESRD participants and families members were identified and recruited through flyers placed at the Ukoli Care Clinic and Brownsville Kidney Center (currently known as DSI). Some subjects were asked to participate based upon recommendations from the staff. Subjects from Harlingen were identified through snowballing. Others were recruited from personal contact by the research and translator.

Six months into the study only 4 individuals from Brownsville had agreed to participant in the study. One of the nursing staff from DSI was enlisted to assist with recruiting subjects. The researcher and translator were available on site 2-3 days per week to solicit participants and answer questions. To provide detail information about the study and confirm participation, telephone calls were made to all participants for the semistructured observations and interviews. Each participant was telephoned at least one day prior to the interview or observation for the purpose of describing the purpose, content, structure and location of the interview session.

ESRD participants and their families were also identified through the Cameron County Hispanic Cohort Study. This randomized population study through the Hispanic Health Research Center of the Lower Rio Grande Valley has over 1400 participants and focuses on the socioeconomic impact of diabetes, its complications and related diseases. Six individuals who indicated that they or a family member have /had received kidney dialysis were contacted by the Cohort project coordinators to seek permission to share their contact information with the PI for this study. Three consented to having their contact information shared. The researcher and/or translator were in touch with these individuals to provide information about the occupational performance study and answer questions. However, none agreed to participant in this study.
The healthcare providers were recruited by the PI for this study via snowball strategies from the three in-center facilities in Brownsville. Using current contacts within the facilities, the PI verbally recruited the healthcare providers to participate in the study who then asked for the identity of other potential healthcare providers.

Methodological research has shown that modest monetary incentives improves and increases the response rates without biasing the study results (Aday & Cornelius, 2006). Incentives have been shown to be an effective method in recruiting participants from underserved or hidden population (Schensul, et al., 1999). All participants were given a monetary token for their time and participation in this study. Each participant interviewed received a $20 gift card and each family unit was given a $25 gift card for the one day semi-structure observation.

The resulting sample consisted of 15 individuals with ESRD (3 on peritoneal & 12 on hemodialysis), 15 family members (1 loved one on peritoneal), and 6 healthcare providers. Three individuals with ESRD living on dialysis and their family participated in the semistructured video taped observation [documentary] regarding their daily life.

Table 2: Summary of Sample Selection

<table>
<thead>
<tr>
<th></th>
<th>Brownsville</th>
<th>Harlingen</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual with ESRD</td>
<td>10</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>Family Members</td>
<td>12</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Health Providers</td>
<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>8</td>
<td>36</td>
</tr>
</tbody>
</table>

Data Collection

Data collection for this study was performed at three levels: a) demographic data was obtained (Appendix A-1& 2), b) acculturation level through the Acculturation Rating Scale for Mexican Americans-II [ARSMA] (Appendix A-4 & 5), and c) subjective data regarding participants’ occupational performance and perceptions were collected via in-depth interviews and videotaping (Appendix A-6-9). Selected demographic was solicited from the
healthcare providers (Appendix A-2). Consents to participate were obtained prior to the observations and interviews. Potential participants were assured that no names would be used in the course of data collection. Tracking numbers were assigned sequentially in the order in which participants were interviewed. A master list cross referencing participants’ names and identification numbers was maintained in a locked file. Finally, participants were informed that they would be given a $20 gift card and the family units $25 for their time and participation in the study.

Guided by the constructs of the study’s theoretical frameworks the interview questions were pilot tested with one of the facility manager, a patient and family member. Based on the results of the pilot test, an effort was made to simplify the wording of the interview questions. The language of the instrument appeared to be meaningful to the respondents. However, an effort was made to use more concrete language whenever possible.

Procedure and Instruments

Individualized interviews were the data collection method. Initially focus groups were planned however, the use of focus groups as a method of data collection for this study population proved to be problematic. Everything revolves around dialysis and the medical condition of the individual with ESRD for both family members and individuals with ESRD. Many potential participants were reluctant to commit to attending a focus group because of the uncertainty of their medical condition after the dialysis treatment. Their condition can vary after each session and range from “being in pain, being tired and weak, to feeling uncomfortable.” On their non-dialysis day, many reported other doctors’ appointments as well as not feeling well as reasons for not wanting to attend a focus group. Others feared participating because they spoke only Spanish; they felt it would not make a difference or they distrusted outsiders.

Transportation to the focus group location was also given as a problem for the potential subjects. Many of the individuals with ESRD depended upon family members for transportation. With family members working during the day, being transported to a neutral
focus group site was impossible. Many of the family members were also not available to meet for a focus group because of other family obligations and the uncertainty of the medical condition of the individual with ESRD. Therefore, on June, 2008 the IRB of the University of Texas at Houston-School of Public approved a change in the data collection method to individual interviews. This allowed for flexibility within the participants lives.

*Individual & Family Member Interviews*

Initial contacts were made individually through a telephone call or in-person at the dialysis center during the participants’ regularly scheduled treatment time. Some patients were approached by one of the facility nurses who informed them about the study and gained permission to share their contact information with the investigator or she provided them with the investigator’s contact information. Other patients and family members were directly contacted by the investigator or translator at the dialysis center. The patients in Harlingen were identified via snowballing. The investigator talked with one patient and that person talked with other patients, received permission to forward their contact information and the investigator contacted them by way of the phone.

All but nine of the interviews were conducted in the participants’ homes. Two took place at a restaurant; one at the participant’s work site; four at the focus group location; and two at the in-center dialysis facility. In accordance with the language preference of the participants (English or Spanish), the interviews were conducted in the preferred language of the participant and audiotaped. One focus group was conducted with 3 family members in Spanish. Interviews with three individuals with ESRD and three family members were also conducted in Spanish. All other interviews were done in English. The interviews varied in their length lasting from 45 minutes to 1 1/2 hour. A monitor was present during several of the interviews to record the responds, impressions, nonverbal behaviors (i.e., facial cues or eye contact) and other fieldnote observations.

Prior to the interviews the investigator or translator explained the purpose of the study, what would be required of the participant, and how much time the interview would take. The date and location of the interview was agreed upon. At the scheduled interview, the participant received and signed a consent form in their preferred language (Appendix C).
They were asked to complete the background questionnaire and acculturation scale. Assistance was provided with completion of the forms if needed.

Semistructured Observations

Semistructured observations focus on observable behaviors that occur regularly. It requires the observer to identify and record in detail the behaviors believed to be important. Naturalistic observation results are important to the process of developing and assessing intervention programs. Observations of individuals in real-life contexts can be used for program design through examples of real-life problem situations and current repertoire of skills and resources, for program implementation by identifying need for staff training, program modification, and program evaluation to assess the use of target strategies and behavior changes (e.g. pre-, post) (Schensul, Schensul, & LeCompte, 1999). Occupational deprivation can occur when situations and conditions that exist outside people, deprive them of occupational opportunities beyond their immediate control. Persons with disabilities are often exposed to deprivation experiences imposed by the human and nonhuman environment (Whiteford, 2004).

The intent of the semi-documentary was to identify the occupational performance, deprivations and disruptions created by ESRD and dialysis. By exploring the daily living activities of Mexican Americans with ESRD and their family members, the researcher hoped to describe the occupational limitations, social participation and quality of life for this population. The subjects for the observations were contacted by telephone and provided with information about the study, answered questions and confirmed their participation in the study. The date and place of the videotaping was confirmed along with which family members would be included. The activities and/or occupations that would be taped were discussed and agreed upon.

A video documentary of three individuals with ESRD living on dialysis (2 hemodialysis and 1 peritoneal) and their family members were recorded. The original plan was to follow and video tape these individuals for about eight hours, morning to night, as they went through their daily routines for two days (one day in which they receive dialysis and one day in which they do not receive dialysis). The videotaping was modified at the
request of the patients and to accommodate the schedule of the photographer. The two individuals on hemodialysis requested to be taped on their non-dialysis day only because of the uncertainty of their medical condition on their dialysis days. Therefore each individual was videotaped and photographed for about four to five hours. Exceptions were made for those activities or occupations (i.e., worksite) that involve family members and non-family members who do not consent to being videotaped.

These semistructured observations were conducted in English. The theoretical frameworks of the study guided the taped occupations and activities as well as the discussions. A skilled photographer was hired to photograph the subject and family members as well as compile the documentary video. The researcher serviced as the videographer for the observations. On the scheduled day the researcher and photographer arrived at the location at the agreed upon time. The consent form was reviewed and signed by all participants. Each subject completed the background information and acculturation scale. The procedure and activities to be videotaped and photographed were reviewed. The researcher asked questions of the subjects and family members related to living with ESRD and dialysis throughout the taping.

Each subject and his family members were videotaped and photographed as they reenacted their daily routine. In addition to the video recordings and photos, which captured the range of variations in occupations and behavioral responses, fieldnotes were taken to supplement the tapes. The written notes recorded activities outside of the camera’s range, informal interactions and impressions, the physical features of the environment, and context of the activities.

Healthcare Provider’s Interview

In-depth, open-ended, audio taped interviews were carried out with 6 health care providers – four nurses, social worker, physician- who worked at one of the three in-center hemodialysis facility in Brownsville. The purpose of these interviews was to explore all facets, perceptions and concerns related to living on dialysis from a provider’s perspective. These interviews investigated such topics as issues surrounding compliance, the medical
process of dialysis and impact of the Mexican American culture. Personal impact of working with dialysis patients was also explored.

After contacting and receiving verbal confirmation of the healthcare provider willingness to take part in the study, the date, time and location of the interview will be agreed upon. Three of the interviews were conducted at their place of employment; one was performed at the participant’s home; one was conducted over the phone at the participant’s office; and one took place at a local restaurant. At the beginning of each interview, the aims of the research were explained. The healthcare provider completed the consent form and selected background information questionnaire. For the telephone interview, consent and background information were given verbally. All the interviews were conducted in English and guided by the construct of the study’s theoretical frameworks.

**Interviewer & Monitors**

The translator/interviewer for the individuals with ESRD living on dialysis and family members was recruited from those individuals who had completed the School of Public Health-Brownsville focus group training program. The translator/interviewer conducted the focus group interview, three individuals with ESRD interviews, and family member’s observation interview in Spanish.

Three monitors for the interviews were recruited from among the master’s level students of The University of Texas-Pan American Occupational Therapy Program. Two monitors were present for the focus group that was conducted in Spanish. One monitor was present for three healthcare provider interviews which were conducted in English. The project researcher conducted all the in-depth interviews with the healthcare providers.

The translator/interviewer and monitors were proficient in Spanish and English (bilingual). These individuals spent several hours with the project researcher learning about the purpose of the study, the study population and their roles. The interviewer/translator and project researcher also met to ensure that terms and concepts to be used in the project were in line for with the local language prior to any data collection.
Table 3: Data Collection Matrix

<table>
<thead>
<tr>
<th>Concepts / Dimensions</th>
<th>Healthcare Provider</th>
<th>Family Member</th>
<th>Individual with ESRD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Susceptibility</td>
<td>C</td>
<td>A, B</td>
<td>A, B</td>
</tr>
<tr>
<td>Perceived Severity</td>
<td>C</td>
<td>A, B</td>
<td>A, B</td>
</tr>
<tr>
<td>Perceived Barriers</td>
<td>C</td>
<td>A, B</td>
<td>A, B</td>
</tr>
<tr>
<td>Perceived Benefits</td>
<td>C</td>
<td>A, B</td>
<td>A, B</td>
</tr>
<tr>
<td>Cue to Action</td>
<td>C</td>
<td>A, B</td>
<td>A, B</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>A, B</td>
<td>A, B</td>
<td></td>
</tr>
<tr>
<td>Self-Care/Self-Maintenance</td>
<td>A, B</td>
<td>A, B</td>
<td></td>
</tr>
<tr>
<td>Societal Contribution</td>
<td>A, B</td>
<td>A, B</td>
<td></td>
</tr>
<tr>
<td>Intrinsic Gratification</td>
<td>A, B</td>
<td>A, B</td>
<td></td>
</tr>
<tr>
<td>Reciprocal Interpersonal Relatedness</td>
<td>A, B</td>
<td>A, B</td>
<td></td>
</tr>
<tr>
<td>Concerns &amp; Issues</td>
<td>C</td>
<td>A, B</td>
<td>A, B</td>
</tr>
</tbody>
</table>

A = Observation  B = Interview with Individuals with ESRD or Family Members  
C = Interview

Background Information

Basic background / demographic (gender, age, income, education, marital status, and years on dialysis) information was solicited on the study subjects via pencil and paper in English or Spanish (Appendix A-1 & 2). Selected demographic information was solicited from the healthcare providers (Appendix A-3). To determine whether cultural beliefs and behaviors impact perceptions and day-to-day life of Mexican Americans with ESRD living on hemodialysis and their families, acculturation level was assessed through the Acculturation Rating Scale for Mexican Americans-II [ARSMA] (Cuellar & Maldonado, 1995). The ARSMA-II is the revised version of the ARSMA. It is an instrument that assesses the acculturation process through an orthogonal, multidimensional approach by measuring cultural orientation toward the Mexican culture and the Anglo culture independently. It includes items which assess (a) language use and preference, (b) ethnic identity and classification, (c) cultural heritage and ethnic behaviors, and (d) ethnic interaction. The two subscales, Anglo Orientation Subscale (AOS) and Mexican Orientation Subscale (MOS) were developed from items of the original ARSMA scale. The two scales have good internal reliabilities with Cronbach’s Alpha of .86 and .88 respectively. The
ARSMA-II has a high Pearson correlation coefficient ($r = .89$) with the original scale. The construct validity was demonstrated using a sample of 379 individuals representing 5 generations (Appendix A-3).

**Data Analysis**

Qualitative content analysis is the strategy of choice for qualitative descriptive studies. In qualitative studies, raw data are coded, categorized and summarized (Locke, Spirduso, & Silverman, 2000). These methods allow for discovery of patterns and themes in the data and linking them with other patterns and themes. Using the techniques of grounded theory (Charmaz, 2006), the data was analyzed within the context of the research questions. Staged in a series of steps the data was (a) coded line-by-line, (b) recorded insights and reflections, (c) sorted through the data for themes and patterns, (d) looked for commonalities and differences in the data, and (e) examined the findings to answer the research specific aims. The investigator followed this process of qualitative analysis.

**Data Preparation**

Prior to analysis, copies were made of all the study materials – videotapes, audiotapes, transcriptions, fieldnotes, questionnaires, interviews, documents and written artifacts. All materials were categorized not only by chronological date but also by the type of individuals (i.e. individuals with ESRD, family member, and healthcare provider) who provided the information. The materials were logged and labeled with an item number, date transcribed, and transcriber’s name. Originals and copies were stored separately in a locked safe place to ensure against theft, loss, fire, and absent-mindedness.

The interviews with individual with ESRD living on hemodialysis, family members, and healthcare provider were audio taped. Verbatim written transcriptions were created from all audiotapes. Each written transcription was reviewed and compared with the verbatim transcriptions and audiotape to ensure accuracy and completeness by the investigator and an outside transcriber. Corrections and editing were made as needed. Interviews conducted in Spanish were transcribed in Spanish then translated into English. The English translated transcriptions were reviewed and compared with the Spanish audiotape to ensure accuracy of
translation by an outside individual. The semistructured observations were videotaped. The interview component of the videotapes was transcribed and reviewed against the videotapes.

In the field, inscriptions (mental notes) and fieldnotes were made throughout the semistructured observations and interviews by the monitor and/or investigator. A notebook in which I recorded my reactions and impressions was kept. Reactions and issues related to the method as well as research aims, perceptions and feelings on my part as the researcher were recorded.

Data Analysis

The information gathered from the interviews will provide an opportunity to understand and create meaning regarding the occupations and lifestyle of Mexican Americans with ESRD living on hemodialysis. Once the transcriptions were completed, the files were saved and imported into ATLAS.ti 5.2 statistical software for qualitative analysis. Using the technique of line-by-line coding of grounded theory, an open coding process was utilized to identify implicit and explicit statements and concerns. This process allows you to actions in each segment of data rather than applying preexisting categories to the data. This type of coding gives you insights into what kind of data to collect or pursue next as well as areas in which you are lacking data (Charmaz, 2006).

The qualitative analysis process began after five of the healthcare provider interviews were completed and analysis continued simultaneously with data collection and transcriptions. Codes were created and added with each interview. Memos were created to capture ideas, reflections, and patterns during the coding of the interviews. Next, networks were created to organize the codes into clusters around the domains of the Lifestyle Performance Model, the constructs of the Health Belief Models, and the aims of the research. ATLAS.ti 5.2 was used to create and maintain the list of codes, quotes, memos, and networks.

To address aims # 1 and #2, the data was coded regarding the subjects’ perceptions, issues and concerns related to living on dialysis. The codes were compared between the family members, healthcare providers, and individuals with ESRD for item saturation and/or
triangulation (Appendix B). To address the study aim #3, the data was coded regarding the
daily routine and activities of daily living for the individuals with ESRD and family
members. From this an occupational performance profile, based on the constructs of the
Lifestyle Performance Model, outlining the areas of occupational deprivations and
disruptions, as it currently exists for this population (Figure 1). The investigator and
photographer viewed and composed the videotapes and photographs into a visual document
of the impact of living with dialysis. The researcher will maintain the audio-visual material
(video tape, audio tape, photographs, and other resulting records) for use in scientific
publications or teaching purposes or lectures. The tapes will be erased or destroyed after five
years.

Using STATA 8.2 statistical software, the demographic characteristics of each study
group – individuals with ESRD, family members, and healthcare providers - were
summarized (Table 4-6). The Acculturation Rating Scale for Mexican Americans–II was
administered and scored according to the instrument in a bilingual format in both language
versions-English and Spanish (Appendix A-4 & 5). The ARSMA-II is a 30 items self-rating
scale composed of a 13 items Anglo Orientation Subscale (AOS) and a 17 items Mexican
Orientation Subscale (MOS). The sum of the AOS scale is divided by 13 to obtain a mean
score for that subscale. The sum of the MOS scale is divided by 17 to obtain a mean
subscale score. The MOS mean is subtracted from the AOS mean to obtain a linear
acculturation score that represented the individual’s score along a continuum from very
Mexican oriented to very Anglo oriented. Individuals scoring greater than ½ standard
deviations below the mean on both the AOS and MOS scales are classified as highly
integrated biculturals. Those individuals scoring between -1.5 standard deviations below the
mean to -.5 standard deviations below the mean on both the MOS and AOS are defined as
low integrated biculturals (Cuellar & Maldonado, 1995).
Table 4: Summary of Data Collected

<table>
<thead>
<tr>
<th>Data Type</th>
<th>Number Collected</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background Information</td>
<td>36</td>
<td>Descriptive Statistics using STATA 8.2</td>
</tr>
<tr>
<td>In-depth Interviews</td>
<td>36</td>
<td>Thematic Coding using ATLAS.ti 5.2</td>
</tr>
<tr>
<td>Acculturation Scale</td>
<td>30</td>
<td>ARSMA-II Analysis</td>
</tr>
</tbody>
</table>

Reliability and Validity

Qualitative inquires are not exempt from concerns about validity and reliability. In qualitative research, the researcher lacks the kind of control over the conditions of the research that is seen with clinical, experimental, or cross-sectional survey. Field conditions are not exact and can not be replicated (Schensul, Schensul & LeCompte, 1999). The consistency of the answers to the same questions may vary as a function of personal factors, variations in the ways interviewers actually phrase the questions at different time periods, and real changes that can take place between these periods (Aday & Cornelius, 2006). “If theory, methods, analytic procedures, and results are clearly described in local context, the potential for reliability and generalizability is enhanced” (Schensul, Schensul, & LeCompte, 1999, p. 290).

To enhance the reliability of the study data, the semistructured observations was videotaped and all interviews was audio taped. Photos and fieldnotes were taken to supplement the videotapes. A monitor was in the room during the focus group with the family members and 3 healthcare provider interviews to record fieldnotes. All material were accurately dated and transcribed as much as possible. All English transcribed materials were reviewed against the audiotapes by the investigator and an outsider individual. Interviews conducted in Spanish was transcribed in Spanish then translated into English. An outside individual reviewed the English transcriptions with the Spanish audiotape to ensure accuracy of translation.

To enhance the validity of the study and reduce interviewer bias, the interview questions were achieved by acquiring input and review from the facility manager of one in-
center dialysis facilities in Brownsville. The interview questions were piloted with an individual with ESRD living on dialysis and a family member of an individual living on hemodialysis. Each interview was conducted in the preferred language of the participant. To reduce the variations in results stemming from “interviewer difference,” the same interviewer/translator conducted all the interviews in Spanish. Peer debriefing occurred between the interviewer/translator and investigator regularly regarding the process and cultural translations of terms and concepts as well as to discuss feelings and thoughts about the study.

Protection of Human Subjects

It was of utmost concern to protect the participants from any negative consequences that might arise by participating in this study. Risks to the participants might include but were not limited to physical fatigue with the videotaping or feelings of discomfort with some questions. To minimize the discomforts the investigator closely observed the participants for any signs of discomfort. If a participant expressed discomfort in answering questions at any point during the interview and/or observation they were free to terminate participation. The University of Texas Health Sciences Center at Houston Committee for the Protection of Human Subjects approved this study.

Limitations of the Study

The population of Mexican-Americans was selected as the focus of this study due to a higher risk of ESRD and dialysis treatment. Race and ethnicity have been associated with differences in health status and practices among this population. Therefore, the major systematic error that was anticipated in this study was with the sample design – non-coverage bias. Non-coverage of certain groups in a study means that estimates for that study as a whole or for those groups in particular may not be accurate because of the groups’ underrepresentation in the study (Aday & Cornelius, 2006). Originally, only those individuals who were currently attending one of two dialysis centers in Brownsville were
eligible for the study. To reduce the lack of randomization as well as increase the pool of participants, the study was open to any Mexican American with ESRD in Cameron County regardless of where they obtained treatment (i.e. in-center or hospital based) or the type of renal replacement therapy (i.e., peritoneal or hemodialysis) they received.

The participants for this study were not randomly selected but asked to volunteer. This opened the study to nonparticipation. Often people who do not participant in a study differ from those who do in regard to many demographic, socioeconomic, cultural, lifestyle, and medical characteristics (Gordis, 2004). A significant number of reasons were given for nonparticipation in the study by individuals with ESRD and family members. They ranged from not medically feeling well to a distrust of anyone outside of the dialysis family. Particularly to this Mexican American population was a fear of losing funding or being deported. To address this limitation, snowballing through colleagues and flyers were used to solicit a wide range of participants. The staff of one center was asked to recommend and assist with the solicitation of participants because of their understanding and awareness of the study population. They were able to ensure participation of a cross-representation of Mexican Americans living on dialysis.

Triangulation was use to address the potential of information bias. In qualitative research the replication of information obtained through different sources provides a cross-check of the findings that ensure an effective representation of the phenomenon being measured (Schensul, Schensul, & LeCompte, 1999). Observations and interviews with individuals with ESRD, family members and healthcare providers were conducted in order to obtain item saturation. The investigator made comparisons between the findings of each group within the study and descriptions revealed in the literature.
CHAPTER III: RESULTS

This section contains the results of a qualitative study of the occupational performance of Mexican-Americans with ESRD living on dialysis, the major concerns and issues facing this population based on the perspective of 15 individual with ESRD, 15 family members and 6 health providers. In-depth interviews were conducted to explore each group’s perception regarding their experience living on dialysis. The purpose of the research was to identify the major concerns and issues facing Mexican-Americans with ESRD living on dialysis, the occupational deprivation created by dialysis, and the cultural impact on complying or not complying with the dialysis regimen. The findings are reported in 4 major sections:

(1) Demographic characteristics of the sample,
(2) Concerns, issues and needs of Mexican-Americans with end-stage-renal disease living on dialysis in the lower Rio Grande Valley from the perspectives of the individual with ESRD, family members and healthcare providers,
(3) Benefit, Barriers and Threats, and
(4) Occupational performance of Mexican-Americans with ESRD living on dialysis and their family members,

Findings are described using descriptive statistics, narrative excerpts and illustrative stories of selected participants. Major findings from the qualitative interviews are reported in the context of the research aims and frameworks guiding the study.

Demographic Characteristics

Individuals with ESRD

As illustrated in Table 5, the characteristics of the 15 individuals with ESRD are distributed well across the categories, indicating a diverse group of participants. The sample was evenly divided between males and females. The median age range was 41-60 years. The educational background was evenly distributed across all categories. The majority of the respondents was unemployed, had a family income of less than $20,000, and was currently
married. The average years reported on renal replacement therapy was three and half years. In terms of acculturation, the majority possessed high characteristics of and identification with the Mexican cultural which corresponded with their status as first or second generation Mexican American.

Among the self-reported precipitating causes of ESRD, the majority (n=8) was type 2 diabetes. Other causes reported were lupus, West Nile virus, Focal Segmental Glomerulosclerosis (FSGS), rare kidney disease, rheumatoid arthritis, and high blood pressure. In-center hemodialysis was the renal replacement treatment modality experienced by 80% of the participants (n=12). Three participants are currently undergoing home peritoneal dialysis. One participant started with hemodialysis but moved to peritoneal and one moved to hemodialysis after four years on peritoneal due to severe peritonitis. The length of time on dialysis for the participants ranged from six to 132 months (11 yrs), with a median of 36 months or three years. Four women had been dialysis patients for one to two years while one had been a dialysis patient for six months, three to four years and ten years or longer. Three of the men had been dialysis patients for one to two years, four had been dialysis patients for three to four years, and one had been a dialysis patient for five years or longer.
Table 5: Demographic Characteristics of Individuals with ESRD

<table>
<thead>
<tr>
<th>Demographic Characteristics of Participants with ESRD</th>
<th>N=15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
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<tr>
<td>Female</td>
<td>7</td>
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<tr>
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<td>4</td>
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<tr>
<td>Divorced</td>
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</tr>
<tr>
<td>Separated</td>
<td>1</td>
</tr>
<tr>
<td>Never Married</td>
<td>3</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>21 yrs – 40 yrs</td>
<td>4</td>
</tr>
<tr>
<td>41 yrs – 60 yrs</td>
<td>6</td>
</tr>
<tr>
<td>61 yrs – 80 yrs</td>
<td>5</td>
</tr>
<tr>
<td>&gt; 80 yrs</td>
<td>0</td>
</tr>
<tr>
<td>Income Level</td>
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</tr>
<tr>
<td>&lt; $20,000</td>
<td>11</td>
</tr>
<tr>
<td>$20,000 - $40,000</td>
<td>2</td>
</tr>
<tr>
<td>$41,000 - $60,000</td>
<td>1</td>
</tr>
<tr>
<td>&gt; $61,000 - $80,000</td>
<td>0</td>
</tr>
<tr>
<td>&gt; $81,000</td>
<td>1</td>
</tr>
<tr>
<td>Education Level</td>
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</tr>
<tr>
<td>&lt; High School (1-8 yrs)</td>
<td>4</td>
</tr>
<tr>
<td>HS graduate (9-12 yrs)</td>
<td>4</td>
</tr>
<tr>
<td>College years (1-4 yrs)</td>
<td>3</td>
</tr>
<tr>
<td>College graduate &amp; Higher</td>
<td>4</td>
</tr>
<tr>
<td>Employed</td>
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<tr>
<td>Yes</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
</tr>
<tr>
<td>Generation Status</td>
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<tr>
<td>First</td>
<td>4</td>
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<td>Second</td>
<td>4</td>
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<td>Third</td>
<td>3</td>
</tr>
<tr>
<td>Fourth</td>
<td>4</td>
</tr>
<tr>
<td>Fifth</td>
<td></td>
</tr>
<tr>
<td>Years on Dialysis</td>
<td></td>
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<tr>
<td>&lt; 1 yr</td>
<td>1</td>
</tr>
<tr>
<td>1 yr – 2 yrs</td>
<td>7</td>
</tr>
<tr>
<td>3 yrs – 4 yrs</td>
<td>5</td>
</tr>
<tr>
<td>&gt; 5 yrs</td>
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<td>Acculturation Level</td>
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<tr>
<td>Level II</td>
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</tr>
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<td>Level III</td>
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</tr>
<tr>
<td>Level IV</td>
<td>0</td>
</tr>
<tr>
<td>Level V</td>
<td>0</td>
</tr>
</tbody>
</table>

Family Member

The total number of family members who participated in the study was 15 (see Table 6). The median age was between 21 to 40 years. The majority were high school graduates. They were evenly divided between those who worked outside the home and those who worked inside the home. Seventy-three percent were married. They majority identified themselves as first or second generation Mexican American with a strong identification with the Mexican culture. The majority of the family members who indicated a preference for the Spanish language were first-generation and those who preferred English were fourth or fifth-generation Mexican American.
Table 6: Demographic Characteristics of Family Members

<table>
<thead>
<tr>
<th>Demographic Characteristics of Family Members</th>
<th>N=15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Income Level</td>
</tr>
<tr>
<td>Male</td>
<td>$&lt; 20,000</td>
</tr>
<tr>
<td>Female</td>
<td>$20,000 - $40,000</td>
</tr>
<tr>
<td>Age</td>
<td>$41,000 - $60,000</td>
</tr>
<tr>
<td>&lt;20 yrs of age</td>
<td>$61,000 - $80,000</td>
</tr>
<tr>
<td>21 yrs. – 40 yrs</td>
<td>&gt; $81,000</td>
</tr>
<tr>
<td>41 yrs – 60 yrs</td>
<td>Generation</td>
</tr>
<tr>
<td>61 yrs – 80 yrs</td>
<td>First</td>
</tr>
<tr>
<td>&gt; 80 yrs</td>
<td>Second</td>
</tr>
<tr>
<td>Education Level</td>
<td>Third</td>
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<tr>
<td>&lt; High School (1-8 yrs)</td>
<td>Fourth</td>
</tr>
<tr>
<td>HS graduate (9-12 yrs)</td>
<td>Fifth</td>
</tr>
<tr>
<td>College years (1-4 yrs)</td>
<td>Acculturation Level</td>
</tr>
<tr>
<td>College graduate &amp; Higher</td>
<td>Level I</td>
</tr>
<tr>
<td>Employed</td>
<td>Level II</td>
</tr>
<tr>
<td>Yes</td>
<td>Level III</td>
</tr>
<tr>
<td>No</td>
<td>Level IV</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Level V</td>
</tr>
<tr>
<td>Now Married</td>
<td>Family Relationship</td>
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<td>Spouse</td>
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<tr>
<td>Divorced</td>
<td>Child/Children</td>
</tr>
<tr>
<td>Separated</td>
<td>Sibling</td>
</tr>
<tr>
<td>Never Married</td>
<td>Other: mother, father, daughter-in-law, grand-daughter</td>
</tr>
</tbody>
</table>

Healthcare Providers

Six healthcare providers that worked with dialysis patients agreed to participate in the study (see Table 7). Professionally, there were a social worker, a physician, and four nurses. All but one had work in dialysis longer than five years. In terms of their roles they included a facility manager, a shift head nurse, and peritoneal coordinator. Their job descriptions were:
My job is to oversee the training, oversee the patient, and assess all the work on a daily basis… We train them basically how to start the treatment, what to do if there is an infection, trouble-shooting, and stuff like that. With the cycler, we show them how to do the cycler, how to put on the lines, how to do all that stuff.

*Peritoneal Dialysis Coordinator, Nurse*

A little bit of everything… I work …. on admission, education. I’m the one that actually made sure that the patient began treatment; made sure their resources were in place; made sure their funding was going to be procured. Also psycho-social counseling, making sure they are adjusting to the treatment, monitoring for depression, adjusting to living with their treatment.

*Social Worker*

I am a physician and I’m responsible for the health management of individuals with end-stage-renal-disease. I do not get involved in issues related to dialysis itself but their general health needs.

*Physician, Nephrologist*

I’m a facilities manager for a dialysis unit. My current work duties include supervising staff, and making sure it meets federal and state requirements, and making sure the patients get the best care we are able to give.

*Nurse, Facilities Manager*
Table 7: Demographic Characteristics of Healthcare Providers

<table>
<thead>
<tr>
<th>Demographic Characteristics of Healthcare Providers</th>
<th>N=6</th>
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<tr>
<td>Female</td>
<td>3</td>
</tr>
<tr>
<td>Age</td>
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</tr>
<tr>
<td>&lt;20 yrs of age</td>
<td>0</td>
</tr>
<tr>
<td>21yrs. – 40 yrs</td>
<td>3</td>
</tr>
<tr>
<td>41 yrs – 60 yrs</td>
<td>3</td>
</tr>
<tr>
<td>61 yrs – 80 yrs</td>
<td>0</td>
</tr>
<tr>
<td>&gt; 80 yrs</td>
<td>0</td>
</tr>
<tr>
<td>Type of Health Provider</td>
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<td>Nurse</td>
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<tr>
<td>Technician</td>
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</tr>
<tr>
<td>Social Worker</td>
<td>1</td>
</tr>
<tr>
<td>Physician</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
</tr>
<tr>
<td>Worked in Dialysis</td>
<td>1</td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>0</td>
</tr>
<tr>
<td>1 yr – 2 yr</td>
<td>0</td>
</tr>
<tr>
<td>3 yr – 4 yr</td>
<td>1</td>
</tr>
<tr>
<td>&gt; 5 yrs</td>
<td>5</td>
</tr>
</tbody>
</table>

Summary of Characteristics of Mexican Americans Living on Dialysis

The demographic characteristics of this study depict a population of Mexican Americans with ESRD primarily due to type 2 diabetes and high blood pressure. Hemodialysis is the preferred renal replacement therapy. The sample is unemployed and has a household income of less than $20,000. This population is highly oriented to the Mexican culture in terms of preference, language use, ethnic identification, and cultural heritage. They have lived with dialysis for at least three years. The spouse is the primary caregiver and does not work outside of the home.

The healthcare providers that work with this group are primarily nurses. They are in charge of educating, training, counseling, and assisting the patients and their family members. They are responsible for the day-to-day medical management of this population.

The following sections will explore the needs, concerns, and perceptions of this group as they relate to living with dialysis. It will also describe the occupations that this population engages in on a daily basis as they adjust to the demands and living with dialysis.
Research Aim #1: Concerns, Issues and Needs

This section describes qualitative findings related to the research question, “What are the most prominent concerns, needs, perceptions and issues related to the occupational performances of Mexican Americans with ESRD living on dialysis in the Lower Rio Grande Valley of Texas from the points of view of the individuals with ESRD who have lived with dialysis for 6 months or more, their families, and the healthcare providers who serve them?” The intent of this research was not only to identify but also to compare the needs, perceptions and issues related to this population from different points of views. Major findings related to this research question are reported in four areas corresponding to those concepts identified in the review of the literature as influencing the adjustment to life on dialysis:

1) What are the identified major concerns and issues facing Mexican –Americans with ESRD living on dialysis and their family members?
2) What are the identified needs of this population?

Findings are reported according to themes that were identified from the qualitative analysis of the in-depth interviews.

Concerns, Issues and Needs of Individual with ESRD

When asked about the major concerns and issues facing people living on dialysis, the individuals with ESRD (n=15) focused on the process of dialysis and the associated treatment recommendations, i.e. diet, medications, fluid restrictions, and other health complications. Five themes emerged: prolonged life, a heightened awareness of death, uncertainty, meaning of one’s life, hopeful for a future, and needs.

I. Prolonged Life

Despite the radical changes, losses, and uncertainty associated with ESRD, the individuals viewed dialysis with a profound sense of gratitude for a prolonged life and a concern for the dialysis process. The sentiment is illustrated in the follow excerpt:
…you know what dialysis does for me [it] makes me like a new man for another day… It’s like a see-saw to me because you do dialysis and you know for that day you’re gonna be down and then the following day you’re gonna go out because you feel great. You feel like nothing’s wrong with you and you have that mentality that nothing’s wrong with me.

Mike, patient on dialysis for 3 years

Nine of the respondents expressed sentiments suggesting that they view dialysis as a small price to pay for the privilege of prolonged life. For example, a patient on dialysis for one year said, “I’m kind of glad [for dialysis] because it [life] can be prolonged. “I feel better now, 100% better…they clean your blood. They take out the toxics.”

Undergoing Needle Stick. The individuals with ESRD in this study were concerned with the dialysis process itself. First, undergoing the constant needle stick evoked a restriction to prolonged life for several of the respondents. One respondent (a dialysis patient for two years) described her reaction to being stuck as, “I’ve learned to deal with it. I mean it’s nothing nice, I wouldn’t wish it on anybody because I mean who likes to get stuck 3 times a week, with big needles.” Another (a dialysis patient for one year) stated, “They use bad needles and sometimes I get big balls [on my arm] and they have to go to the same spot and you just have to stand the pain.” Dena related the reaction of her sister to seeing the needle used for dialysis:

One time I brought home a pack of the needles that they put in us, my sister fainted. She said, “Oh my god, they put those things in your arm? They look like nails.” … well I don’t’ faint when they put them in me. “Do they numb you?” and I said, “No.” “I don’t know how you do it.” I’m like well you gotta do what you gotta do….

Dena, a dialysis patient for 11 years

This fear of needles led some to choose peritoneal as their renal replacement option. Ana stated:
The doctor told me, he knows I’m a terrible coward when it comes to needles, so hemo [dialysis] wasn’t really even on the table for me. No. I couldn’t handle that so we went with the peritoneal which had been working out ok.

*Ana, a dialysis patient for 1 year*

**Frequency & length of dialysis.** The amount of time spent on dialysis was identified as another limit to prolonged life. Typically, a hemodialysis patient is required to attend the center three-times a week for a three hour session. “Studies have shown that the more patients dialyze, the better. They actually live a better quality of life and a longer life,” stated a healthcare provider. However, the participants (n=12) who received in-centered hemodialysis treatments disliked dialyzing for more than three hours each session. The time spent dialyzing ranged from 3 hours 35 minutes to 4 hours 30 minutes. One participant (a dialysis patient for three years) reported, “I started off at 4 hours and now I’ve gone down to three and a half.” Another (a dialysis patient for five years) said, “I started off with 4 hours, 30 minutes, now its 3 hours because my cleanings are very good.”

Just going to the center three times a week created a mental but necessary limitation to prolong life for several of the participants (n=8). One respondent (a dialysis patient for two years) stated, “It’s not difficult [getting to dialysis], it just a hassle. But once you get used to it, it’s just like second nature.”

Well, it’s hard to get there three times a week. It takes a lot out of me. I’m real tired after dialysis. The next day I feel better but then I have to go back to dialysis. I’m getting used to that now.

*Daniel, a dialysis patient for 4 years*

I have never missed a treatment; I go 3 days a week. If I travel I make sure we have things lined up for out of town travel and I just make sure that I do my thing and that’s what keeps me going. I’m one of the longest running ones [patient] because I run for about 4 ½ hours every treatment.

*Hector, a dialysis patient for 3 years*

The participants on peritoneal had a different viewed of dialysis. “Oh, everyday is a dialysis day,” stated Ana, a dialysis patient for one year.
For me this [peritoneal] works much better than the hemo, because hemo you’re there in a chair for I don’t know how many hours, how many times a week. You gotta stop your life and go to the clinic. For peritoneal, I hook up to the machine, I go to bed, I go to sleep, I wake up and it’s over. It’s taken virtually no time out of my day so…I can still do everything else I did before with of course limitations, because I do tire easily...

Ana, a dialysis patient for 1 year

When asked, how did she make the decision to do peritoneal, Linda stated:

I didn’t mind hemo but it was stricter. The diet was stricter. They have more restrictions on the diet…the only problem was that I hated coming here [clinic]. If I wanted to do something, I couldn’t because I was stuck here….It was cold. Sit there for 4 hours with no blanket. It was just that I couldn’t do anything else. I couldn’t go walk around. I had to be stuck to the chair…Peritoneal is more freedom. Do the exchange. Get it over with and do what you need to do. Come back do another one in four hours.

Linda, a dialysis patient for 1 year

Bodily alteration. Just site of the access for dialysis proved to be distressing to some participants. For example Ana, in the context of discussing her progression of renal failure after a catheter was placed in the peritoneal cavity, stated:

I think it’s just the physical thing of having a tube coming out of your body and having to deal with that because it’s just bizarre. After the surgery it was more than a couple of weeks before I could even look at it because it was covered up with a bandage. But my daughter came to take care of me and when she would change the dressing, I would just turn my head away and close my eyes because I don’t want to see it. I don’t wanna know what it looks liked. I don’t want to touch it. I just can’t do that yet. And that was hard, just dealing with the physical alteration in your body, that wasn’t too pleasant.

Ana, a dialysis patient for 1 year
Changes in the physical body not only affected their body image but also the participants’ perceptions of how they were viewed by others. One woman with extensive scarring from use of her fistula, talked about her daughter’s reaction to people staring at her arm:

I know she looks deformed because of her arm,” because that is the first thing they stare at and she gets all up upset, like when we’re at the mall, she says “What the hell are you looking at? That’s my mother, she’s human!” and I’m the one that tells her to calm down because I’m used to it already. But it bothers her a lot.

*Dena, a dialysis patient for 11 years*

In order to hide their scarring and access, many dialysis patients changed their dress style. One respondent explained how he had his access point [fistula] site in an area so he could still wear short sleeves shirts and it would not be seen. But this did not change the potential stigma on the parts of others. For example:

I used to wear short-sleeves and now I wear long-sleeves because I don’t want people to see me with this thing here, this thing inside my arm, because you can see it…. Every time that I go out now, I gotta wear long-sleeve because I don’t want people to see my arm and say oh look at that guy what does he have in his arm, holes or what? ... There’re people that have little golf-balls, on their fistula. A friend said to me “Hey I saw this guy with these little balls on his arm…well it was ugly.”

*Mike, a dialysis patient for 4 years*

The ability to “go on” in the face of a devastating disease and an unrelenting treatment regimen is mediated by the desire to extend life. For those on hemodialysis the amount of time and frequency of the process as well as the use of needles and bodily alterations are necessary obstructions to overcome. Without exception, the participants in this study had a clear sense that without dialysis they could not survive. Overall dialysis did prolong their lives.
II. Heightened Awareness of Death

The second overarching theme in the individuals’ perceptions of life as a dialysis patient was the constant prospect of death. This sensitivity began prior to dialysis as a result of experiencing serious episodes of illness. Ten of the participants recounted experiences in which they were “near death,” “could have died,” or “would die” if they did not start dialysis. Mike, a dialysis patient for four years, describes living on dialysis in these terms: “It’s hard to be between life and death all the time. I’m always between life and death, always in the middle.”

Medical complications. Many participants spoke of the influence of other medical conditions such as diabetes, high blood pressure, heart condition and cancer, on dialysis or the impact of dialysis on those conditions. Roel talked about this interaction:

With the diabetes, I don’t heal as quickly, I can cut easily, I bleed a little easier, and I bruise a little be more… So I need to watch it, not only the sports but even the daily activities such as working on the cars. So I need to make sure that I don’t put myself in places that can do more damage to me in the long run.

Roel, a dialysis patient for 5 years

Dena explained:

I had severe peritonitis, a very bad infection and I was in the hospital for 4 months. And during those 4 months I was getting so many medications and antibiotics that I became immune to them and a lot of steroids. Which was the cause of my hip breakage and stuff and that I can no longer walk….I feel them now, but I just can’t walk without the pain in my hips. So, I’m in a wheelchair now.

Dena, a dialysis patient for 11 years

Participants were also sensitive to the potential for something going wrong during the treatments. Dena told the story of a patient who had difficulty during each treatment session:
Sometimes he gets anxiety attacks and they call her [wife] in and all he wants is for her to sit right there next to him and hold his hand. She takes care of him for 4 hours, talking to him and holding his hand and he’s alright. But if he’s there by himself, he starts yelling and scaring all the rest of the patients. Sometimes we have to deal with a lot of crap there. It’s just like, oh my god, I can’t believe it. Mentally I’m still there, looking at everybody crying and freaking out, and it’s like…

_Dena, a dialysis patient for 11 years_

For the participants on peritoneal, experiencing peritonitis was the biggest fear related to being a dialysis patient. For example, Ana was unable to hide her fear of dying, stating:

I can’t go on like this indefinitely, but what worries me with the peritoneal, is the perinea can wear out and it can stop being effective and that’s a little bit of a concern of mine. Because when I was in the hospital I had shortness of breath and all and he x-rayed me and he said you know you’ve got fluid in your lungs. I’m going well geez. I’m doing the manual bag thing now because I’m recovering from the peritonitis. It’s the second round of that and that’s incredibly painful. I don’t know how many rounds of that I’ll have to go through before I get transplanted.

_An, a dialysis patient for 1 year_

Given their recognition of the need for dialysis in order to survive, a number of participants expressed concern over the potential complications such as infections or clotting which could make their access sites unusable and even require the creation of new sites if and when the original one fails. For without an access point, dialysis cannot be performed and the person will die. Mike recounted his recent experience with a clotted fistula:

The thing [fistula] clotted and they have to unclot it… So I had to go over there [VA hospital in San Antonio] and they operated on me for this graft. When it went out [clotted] they also put a stent or something inside of me…and had to put me on Plevax… And he told me “You’re a diabetic and your veins are getting thin and weak.” … Well that means you gotta go with that thing in your stomach [if it clots again].

_Mike, a dialysis patient for 4 years_

63
Fellow dialysis patients. Another factor that contributes to the participants’ daily anxiety of dialysis is knowledge of the deaths of fellow dialysis patients. Knowledge of death and conditions of fellow patients are a reminder of their mortality for some and a comfort to others. Selma and her daughter reported their sense of doom after visiting the dialysis center for the first time and finding an album of obituaries in the waiting area:

And I don’t know, there’s something about the Mexican people thinking that dialysis is, like people go on dialysis and they die you know… because when we first went to the center… they had a big photo album in the waiting room, and my sister’s looking through it. And my mom said, “What’s that?” And it was all the obituaries of all the people that got sick that died…it had all the people who had gone to the center that died.

Selma, a dialysis patient for 1 year

Dena however, expressed a comfort and closeness with the information about patients’ deaths:

If somebody passes away, oh god, everybody feels it, everybody that’s in that shift, everybody. And every time somebody dies from my shift I cut it out and I have it in a notebook… Whenever I am sick or whenever I feel depressed I just take out the notebook and I read out the obituaries from the patients that I knew because we’re all close, everybody.

Dena, a dialysis patient for 11 years

For some patients dialysis has become so consuming that they wish their life would be over. Several patients (n=4) reported dealing with depression, loss of control and uncertainty of their life at this point. Ana recounted her feelings being told that she must go on dialysis:
There was a night…and I was just so depressed with all this. I remember walking outside after my classes and it was just so still. It had just finished raining and walking through the campus it was so quiet… you could just hear the water, the rain dripping off the leaves and the crickets. I was thinking this world is so beautiful, I don’t want to die and I remember crying like a little kid all the way home.

*Ana, a dialysis patient for 1 year*

The fear of death is a constant for dialysis patients whether from the treatment, other medical complications, or life events. This population live with a heighten awareness of death on a daily basis along with the bodily remainder and stigma that accompany it. Direct and indirect observances of situations involving deaths of fellow patients are a constant reminder of their own mortality and risk of the same fate.

### III. Uncertainty

However, faithfully the participants follow the regimen of dialysis; it does not eliminate the reality of sitting in the chair and dialyzing. As a result of their inability to control the course of the disease and the changes it bring, the participants cannot predict how they will fare during their treatment session. Side effects including cramping, sudden drops in blood pressure, nausea and headaches were frequently reported and the potential for physical discomfort are among the effects associated with dialysis. Dena, a dialysis patient for 11 years, described her first day at the dialysis center:

The first day that I was put on hemodialysis, I cried for 4 hours. They were giving me medication because I was getting anxiety, wanting to pull out the needles, and it was bad. Then they let my daughter stay with me for the first two days, and we talked a lot, she was still very young but I started realizing ok, if I give up now she’s gonna miss me very much because it’s been just me and her for a very long time.

*Dena, a dialysis patient for 11 years*

To endure the treatment and reduce their uncertainty of the session, several participants have established routines. The following examples illustrated how they spend their time while sitting on dialysis:

65
I watch TV and then take a Zanax before I start to get anxiety and shaking. I wanted to leave so the doctor prescribed me the Zanax and that keeps me calm. I watch TV all the 3 ½ hours.

Mike, a dialysis patient for 4 years

For the first hour, from 8-9 am, I watch my Mexican soap opera then I watch the country music videos, 2 hours long, there goes my 3 hours. I'm out of there, quick. At first, nothing would make me pay attention to the TV, I would get anxiety. I just wanted to get out of there. But now I’ve learned to calm down and have my daily routine, nobody mess with me, I turn on the TV and put in my earplugs. I eat my chips or my peanut butter sandwiches; I make small little ones, until I have to get disconnected to go to the bathroom or throw up or whatever. I just eat any little thing that will make me hold on until I get home and eat my lunch or whatever.

Dena, a dialysis patient for 11 years

Since the dialysis environment is an open format with rows of chairs, the experiences of fellow patients are observed by all. In addition to their inability to predict the physical effects of the treatment session, several respondents (n=4) expressed anxiety in watching the experiences of fellow dialysis patients during treatment especially new patients. They worried that the same thing could happen to them. These feelings were expressed by Petra:

Let’s say, the new patients walk in and they’re telling them, “Ok you’re gonna sit here for 4 hours and we’re gonna put the needles in you and you’re gonna have to just sit there and don’t move.” They start crying and kicking. I start thinking of how much more time do I have, 30 minutes? Ok, I can do this. I just start talking to myself and thinking when I get home I’m gonna tell my daughter this and do this… Next thing I know it, my time is up and I get out of there. If I stay there I start panicking because I remember when I used to do that. I psych myself out to just sit there and don’t look over there, look over, just listen to the radio or turn up the TV so I won’t hear them crying and then just wait for my time to be up and I get out of there.

Petra, a dialysis patient for 2 years
Hector expressed his perception about fellow patients who reside in nursing home, rest homes, assisted living or living with family members who worked:

… Some people’s lives revolve around dialysis. You know, they’re shut in and the only time they get out is to go to dialysis. I’ve known a couple, older people on dialysis, that just wish it would be over… sometimes the problems [living with dialysis] get to that point that some people… don’t want any more dialysis.

*Hector, a dialysis patient for 3 years*

The experience of being a dialysis patient generated frustration and perceptions of loss – loss of freedom, loss of time, loss of choice, and loss of participation in valued activities. Because of increased dependency and loss of self-sufficiency at least three respondents spoke of feeling angry and mad with their life on dialysis and the burden they had become to their families. Ruben spoke directly to this level of distress as a dialysis patient:

First I had to accept this [dialysis] and depend on what they [healthcare staff] have… With renal failure if you don’t take care of yourself, you will die. I ain’t talking about within a year I’m talking about weeks… I feel like I’m a burden because nobody [family and friends] are able to do things because I have to dialyze somewhere, somehow.

*Ruben, a dialysis patient for 1 year*

Although dialysis is lifesaving, it clearly does not restore normal health and well-being to patients. Successful dialysis requires effort on the part of the patient. Not only must they show up for scheduled sessions, but must also endure all the uncertainty of the treatment. Distressing symptoms such as cramping, nausea, and physical fatigue as well as watching the experiences of fellow patients are direct factors that can complicate the course of dialysis. These are all symptoms of varying degrees associated with depression and depressive affect and poor perceptions of quality of life. Most of the patients view dialysis as dominating them, so their lives revolve around this activity, and a few are frightened by it.
IV. Meaning of One’s Life

Values, beliefs and spirituality influence a person’s motivation to engage in occupations and give his or her life meaning (AOTA, 2008). Those with children and grandchildren (n=12) cited them as their source of motivation and life meaning. Ruben said, My son. I guess he is my strength to keep going. He’s the one that kept saying, “Daddy it’s okay, daddy it’s okay. He’s always there for me. And that keeps me happy. I do everything for him because when I am down and out he’s always a positive in my life.

Ruben, a dialysis patient of 3 years

Those who are single (n=3) reported the future and lifelong goals as a motivator for action. Linda (a dialysis patient for one year) said, “I did say to myself one day that I want to die of old age. I guess that’s what’s keep me going. Because that what’s I have in my mind.”

There are still a lot of things, still a lot of goals that I want to accomplish and this is just a little setback. I don’t feel sorry for myself. It’s just a consequence of my actions. And now I do what I need to do to straighten that out. But it just slows me down for the goals that I want to accomplish. But it’s not going to stop me from trying. And I still have things that I want to get done. I’m driven by that and have always been.

Roel, a dialysis patient for 5 years

The welfare of their children was of great concerns for several of the participants and impacted their adjustment to dialysis. Dena described the influence and impact that her daughter made to her adjustment to dialysis:
She [daughter] was 2 years old when I started [dialysis]…. For my entire life, she’s been with me in every hospital stay. She knows a lot and I always try and get information from the internet on lupus and have her read it. To me, she hasn’t had a normal childhood because of that. She lives with the fear of me getting sick… I’m pretty sure her life would’ve been different because of all the things that I need and I depend on her…she’s very paranoid that something will happen… And she’s always reassuring me that she can do a lot of things. Like I told you she’s a little adult in a 13-year old body… When I had the catheter in my stomach, I had a hole about that deep under my belly button and she would stick the gauze in there and take it out and clean it out and oh how I cried. She would put on the gloves like a nurse; she would take care of me; bathe me and everything… I was embarrassed to have her do this and she said, “I want to take care of my mother. I’ll give her a bath and I’ll clean her and change the gauze and everything.” Sometimes kids at school make fun of her because I’m in a wheelchair; we’ve had a lot of problems with that and she comes home crying because of that. But then recently she’s found 2 or 3 children at the school whose parents are there with me [at dialysis], but they don’t talk about it. She talks about it at school like its normal and now those children come up to her and asked her how come she isn’t embarrassed that I was in a wheelchair. And her response was, “Well, at least I have my mother with me.” There are a couple of times she cried because of that… ‘I just thank god that my mother is alive and with me and I don’t care what she looks like.” She’s helped me a lot and she’s basically the reason why I keep praying for my life.

*Den, a dialysis patient for 11 years*

Several of the participants (n=5) cited their spirituality and religious faith as a source of providing meaning to their illness and life situation. Ana said:
I believe my faith in God has gotten me through this more than anything. I was raised Catholic, so I mean god has worked in my life all the way through this lupus thing and I know that I’m here for a purpose and when the purpose is over I’ll go. I just hope it’s later rather than sooner.

*Ana, a dialysis patient for 1 year*

Yadira said,

Going to church is a spiritual strength. If it was not for that, I would not be able to endure and to keep going…. I have dedicated myself to God. I take my Bible to dialysis, I read. I pray with my eyes closed for all who are there, for the doctors, for the nurses and that helps me a lot. [Translated from the Spanish]

*Yadira, a dialysis patient for 2 years*

The children and grandchildren are often seen as the reasons to “go on” and meaning for life. Fear of their children and other family members experiencing dialysis was a concern for this population. They were the trigger for action and compliance. Spirituality and religious faith also gives meaning to their illness and life situation.

V. *Hopeful For a Future*

Another overarching theme in the participants’ perceptions of needs, concerns and issues facing Mexican-Americans with ESRD centered on their hope for a future without dialysis and the needs to endure this lifestyle. Organ transplantation was the most prominent need of this group. All but one of the participants feared not getting a kidney transplant because of the lack of available organs. They saw a transplant as the answer to a normal life. In relating their dreams, Ana said:

Five years from now…I’ll have my kidney and won’t have to mess with this dialysis stuff anymore and I’ll be about ready to retire.

*Ana, a dialysis patient for 1 year*
Arturo stated:

Five years from now? Well hopefully I’ll get my transplant by then. You know continue on with my regular life, go back to trucking…when I get my transplant then I’ll take care of myself so I don’t lose that kidney.

*Arturo, a dialysis patient for 3 years*

Ruben voiced:

After getting a kidney transplant your life much better without the difficulties and obstacles you go through living with dialysis such as doctor appointments, medicines, and all that.

*Ruben, a dialysis patient for 3 years*

Linda talked about her ambivalence with wanting an organ transplant:

Sometimes I feel like I don’t want to wait that long to have a kidney. I want a transplant right away. I don’t want to wait more than 2 years for it. And sometimes I just lie there thinking, “Why can’t somebody just die so I can have their kidney?” I know I not suppose to think that way, but.

*Linda, a dialysis patient for 1 year*

Daniel stated that he selected not to be placed on the waiting list for a transplant because of stories told to him by a healthcare provider. He said,

No, I got off because I work with the VA. I put myself on that list there and when I went up there the nurse said “Ok let me be frank with you. If you get your kidney, you’re gonna live 5 years, that’s it.” “… ‘Because if you have a kidney, your diabetes is going to shoot up and your sugar is going to shoot up all over the place and now that kidney is going to shoot it up. I’m not going to lie to you because my dad went through a kidney transplant and he was a diabetic and his thing [sugar] was all over the place. It would be high and low. I saw my dad suffer for 5 years. A friend of mine was on dialysis and he got a transplant and he only lasted about 3 years.” I said, “Wow, maybe this lady is talking sense. Why do you want to do a transplant?” I said, “No. I don’t want to go through that experience.”

*Daniel, a dialysis patient for 4 years*
Transplantation is the treatment of choice for patients with ESRD because of the improved patient survival. Most viewed a transplant as regaining their freedom – freedom of time, freedom of choice, and freedom to participate in valued activities – and their lives. Despite substantial survival and health-related quality of life benefits, most eligible transplant recipients especially Hispanics experience a delayed placement on the transplant waiting list.

VI. Informational and Support Needs

The last theme identified by the Mexican Americans individual with ESRD was “needs.” Education programs and materials to social and support services were acknowledged as being urgently needed to change behaviors and adjustment to living with dialysis.

Knowledge and information. Knowledge about the dialysis process, both the mechanic treatment process and associated treatment recommendations i.e. diet, medication, and fluid restrictions, were reported. Seven of the respondents articulated their opinions about the way information is given to them. Dena stated:

They don’t sit down and teach it to you, they just give you a packet, pass them out, or say sign here, sign there. One thing I do is ask, “What am I signing?” This is to make sure that they know what information they gave you. “Well I’m not signing anything until you’ve given it to me and I’ve read it and then I’ll sign.” They just pass us around like we were little kids. They never sit down and educate you on anything.

Dena, a dialysis patient for 11 years

Having access to more information and the cultural understanding of information were identified by Roel as a source of need. He stated:

… in this region, the culture tends toward wise tales to cure things - other than medicinal remedies. And I guess people need to be educated. It’s hard to educate with the culture and beliefs and what they’ve been told and how they’ve grown-up. I think once they are educate, things will get better - what’s available, what’s to do, and how it can be avoided at an early stage.

Roel, a dialysis patient for 5 years
When asked about their source of information regarding the treatment process and regimen, eight of the individuals volunteered that their relationship with the healthcare providers were very conducive to asking questions and seeking additional information. Overall the nursing staff and physicians were generally perceived as caring and attentive especially the peritoneal nursing staff. Dena recalled how her physician personally showed her what to expect:

Before I was put on dialysis I had never heard of that word, I didn’t even know what it was. When Dr….told me I was gonna be put on dialysis, I was like ok is that some kind of medication of something? But my sister started totally crying, and freaking out. I said “Ok, what does that mean?” And then he took me on a tour to where they did hemodialysis. I saw all those patients with the mirrors; all of them were sick; and I was like I don’t know how I’m going to cope with that.

Dena, a dialysis patient for 11 years

**Support group.** Four of the individuals with ESRD specifically reflected on the lack of support groups and counseling services for them. Dena remembered a time when support groups were available:

We used to have [support groups]; … and a lot of patients would show up, but since he [former staff person] stopped working there, nobody has set up any groups or any meetings or anything… he would always tell us, “Ok this Saturday or this Sunday there’s a group, to talk about your illness.” But this was maybe like 3 years ago.

Dena, a dialysis patient for 11 years

Here they don’t put out something like a therapy group, like those groups where they go to the library… well here they should have a dialysis group… but they don’t in the Brownsville area. I was reading in the community section of the paper and we don’t have anything. So maybe… ought to start a group here and get all the patients on dialysis so we can learn, get together and get the government to help us out… and people can be aware about what’s going on with people on dialysis. Nobody knows…. but I guess the government doesn’t want to spend the money on us.

Mike, a dialysis patient for 4 years
… counseling would really help. It [dialysis] really causes abrupt lifestyle changes. And I needed some kind of counseling. Better attitude [from the staff] need to come out … and we do not need to be treated like a poor little puppy you know.

Lauro, a dialysis patient for 1 year

Social Services. The respondents also identified a need for social service such as food stamps, home care providers, and adaptive equipments in order to deal with the impact on dialysis. Medicare, Medicaid, and the Kidney funds cover the medical cost related to dialysis but the individuals are responsible for other expenses that may incur to living on dialysis or other medical conditions. Most of the participants did not qualify for these additional services. Mike voiced his concern about this:

Well, I feel like I should be receiving food stamps or something but I don’t qualify for that because supposedly I get too much Social Security per month. You know there’re other people who come from other countries and get all this help. I’m from here and I’ve always worked and I don’t qualify.

Mike, a dialysis patient for 4 years

Effective strategies are needed to achieve better patient education. Educational materials and projects specially targeted for the Mexican American population require the involvement of this population in planning and implementation. They should take into account the local culture and needs aimed at changing behaviors, increasing understanding of the treatment process, compliance, and adjusting to living with dialysis. Support groups and counseling might improve their quality of life by reducing negative beliefs about dialysis and influence their adjustment to ESRD and its treatment.

Summary of Concerns, Issues and Needs of Individuals with ESRD

For the present sample of Mexican Americans with ESRD, life as dialysis patients is occupied with the day-to-day reality of the dialysis treatment – frequency of the session, length of time for dialysis, medical complications and bodily alteration for access, and mentally tolerating the dialysis session itself. These individuals live with the constant awareness that dialysis treatments are prolonging their life and that they are constantly at risk.
for complications, deterioration, and death. They perceive their lives as marked by increased dependency and uncertainty. As stated by Mike: “I’m always between life and death, always in the middle.” The actuality of sitting and dialyzing three times per week for three to four hours for the rest of their life is a daunting reality. Yet, this is the life of the subjects in this study. Reliving their first experience with each dialysis session, watching fellow dialysis patients die and suffer, and enduring the uncertainty of the treatment itself is the price they pay for the privilege of a prolonged life.

Fear of their children and other family members experiencing dialysis provides another layer of concern as well as a reason for living. Religious beliefs and engagement gives their life meaning and strength to endure this way of life. Having experienced the toll of dialysis and many of its associated side-effects, the individuals expressed a need for more and regular information about the mechanical side of dialysis as well as its regimen. They want ongoing support groups and counseling to assist them with mentally adjusting and managing their condition. And any assistant that could be made with getting social services would be greatly appreciated.

Concerns, Issues and Needs of Family Members

The needs, concerns and issues expressed by the family members (n=15) were somewhat different from the individuals with ESRD. When asked about the prominent needs, perceptions, and issues facing family members, they identified matters related to living with the demands of the dialysis regimen, taking care of the individual with ESRD and the impact this condition have on the family. The major themes that emerged from their qualitative analysis were: the dialysis process and regimen, accommodating dialysis, fear the death of their loved one, and meaning in one’s life.

I. Dialysis Process and Regimen

Knowledge about the dialysis process and regimen. Prior to their loved one starting dialysis, the family members’ level of knowledge about renal replacement therapy was limited. Most of the family members indicated that they had no idea what dialysis entailed
and had never seen a dialysis machine or the inside of a dialysis center before their loved one became a patient. Due to their prior lack of awareness, the family members held varied perceptions about what dialysis called for or its outcome. Five family members (n=5) indicated that their perceptions and initial reactions were based on information regarding other people they knew who had received dialysis. One family member said:

When my husband and I found out we were devastated. I had a friend from work who went through the process. Since my friend did not survive long [on dialysis], we thought it would happen the same for us. [Translated from the Spanish]

Helen, husband on dialysis

Another family member reported that she had heard about hemodialysis but didn’t know if it was good or bad. So, they asked the doctor. He said:

If you are asking me whether it [hemodialysis] is good or bad, I will not answer that. But if you tell me that you want to live, I will tell you it will help you. [Translated from the Spanish]

Carina, husband on dialysis

Most of the family member did not know what to expect or what it was until they got to the clinic. Pearl was so stressed about her lack of information that she had to be hospitalized. She recalled:

… I was thinking, “What will I do?” I didn’t know anything about dialysis. I had no hint, no idea, what it was going to be like. It was just so different than him being a diabetic. After I went to the dietician, I didn’t see that they really helped me all that much. I couldn’t breathe one night, and I had to be put in the hospital because I thought I was having a heart attack because I was so stressed out about it. I started crying. The kids came over. I told them all of it because I didn’t have any idea of what to do. It was a lot different than anything else that I’ve done. It was very hard. It was very hard when he went on dialysis - hard for him and hard for me, too. I just didn’t know what to do…

Pearl, husband on dialysis
By contrast, Patricia relied on her son, who was a nursing student at the time, to provide information to her and her husband, the dialysis patient:

…when my husband went into dialysis my son was already taking nursing [courses]. And it did help a lot because he talked to him and me. He told him if you don’t go to dialysis this is gonna happen. It’s better for you… you’re not going to be able to take it home but you’re going to go there three days a week. He explained to him and me most of the things that were going to happen… And if I don’t have an answer for him we’ll go to my son.

*Patricia, husband on dialysis*

*Communication.* Communication about the dialysis process, prevention, and care of the individual were voiced as a concern and need of family members. Several family members reported that they were not informed or lacked knowledge about the renal replacement options. Eve stated, “They’ve been telling me that dialysis could be done at home. I want to know some more information. Can she do it herself?” Rosa said, “I don’t know if they told us about the home dialysis or did they? I don’t think so.” She was also concerned about the lack of communication regarding the consequence of not complying with the treatment schedule:

There was a time when she [mother] decided that she wasn’t going anymore [to dialysis]. And she flat out refused and she missed a day’s dialysis because she refused to go. Not really knowing what the consequences were. You know because nobody really told her or us if you don’t go this is gonna happen. They just said you need to go, you know.

*Rosa, mother and grandmother on dialysis*

One family member was distressed about the operation of the dialysis machine and the respond she received from the healthcare provider was not very helpful. She said,

I was worried when the machine signaling turned red. So, I asked the doctor what it meant. He said very coldly, “It’s nothing” and walked away. [*Translated from the Spanish]*

*Carina, husband on dialysis*
Despite this type of response, Pearl provided the following advice. She stated,

\[
\text{If you don’t ask, you don’t get it even if it’s the stupidest question. If you need something, you’d better ask for it. And you’d better be persistent because if you don’t, sometimes you don’t get what you asked for.}
\]

\textit{Pearl, husband on dialysis}

Many of the family members remain in the dark as to what the dialysis treatment involves. Due to prior lack of knowledge, varied perceptions and anxiety about dialysis are held even to the point of emotional trauma when confronted with the reality of their loved one beginning dialysis. Communication between family members and healthcare providers play an essential role in the families’ acceptance, understanding, and compliance with dialysis.

II. \textit{Accommodating Dialysis}

\textit{Changes in family life.} The findings of this study indicate that anyone with direct or frequent contact with an individual with ESRD will change their life to accommodate dialysis on some level. May of the family members reported changes in interaction, roles, communication, diet and eating habits, activities, and lifestyle choices. In planning for care of her mother who has only been on dialysis for 6 months but with multiple hospitalizations, Eve struggled with their financial situation. She said:

\[
\text{My parents, well my dad has insurance but like the last time we were looking into it we didn’t [qualify for] any assistance for her like for providers and all that… So it’s like my dad works, I’m working… Because my mom received Social Security, it would only be for her medicines. So my dad and I, you know we split the bills and everything.}
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\textit{Eve, mother on dialysis}

Seven of the family member talked about the way dialysis created changes in their lifestyle and activities choices. It was not uncommon among this population for multiple family units to live under the same roof in order to care for their loved one. Alicia, a single parent, reflected how her mother starting dialysis changed her life:
I was used to going out and doing whatever I wanted to do and not caring [about her]… I would get the kids and just go. Now it’s like no way. I have to go take my mom and I have to go pick her up [from dialysis]. I now live with my mother. It changes like your whole lifestyle….even to buying a car. I can’t get a truck because it’s too high for my mom. So, I had to get a car in order for me to get her in and out. This is not only because of the dialysis but because of her amputation. But it goes together….It changes your whole lifestyle, your whole perspective on life you know.

_Alicia, mother on dialysis_

Lela became responsible for all family matters especially the management of her husband’s healthcare:

I’ve started taking care of everything. Even his medicine, he didn’t know which medicines he was taking… every time we went to the doctors, they were asking him and he would look at me and say, “Ask her because I don’t know what I’m supposed to take.” He didn’t know anything; he didn’t know anything about his medicines. He just left everything on me and I was taking care of all the payments and everything, everything, everything.

_Lela, widow, husband on peritoneal dialysis_

The family members felt that the most important change to their lives was accommodating the dialysis schedule. A lot of time is spent dropping their loved one off at dialysis and picking them up later. For those family members who worked their work schedule revolve around the dialysis session. Rosa described her life on a typical dialysis days as:
And about 10:30 am, I come over here to get her [mother] ready for dialysis. Take her to dialysis. And once we get into the dialysis room, I set mom up. I set grandma up with her earphones and turn on their TVs. Then I go back to work. Then at 3:00 pm I go back to the center. Mom gets out at 3:00 pm then we wait there ‘til 4 o’clock until my grandmother gets out. Once my grandmother gets out, we call the nursing home to come get her. Once they come get her [grandmother], I get her [mother] something to eat and then bring her home.

*Rosa, mother & grandmother on dialysis*

Non-dialysis days were spent taking her mother to doctor’s appointments. This would be a hardship if her employer were not accommodating.

*Changes in diet and eating habits.* Complying with the diet requirement was the second most frequently reported impact. This entailed changing eating habits, routines, and cooking style. Pearl voiced her frustration with the dialysis diet. She said:

> When you have diabetes, you can have some beans, tomatoes and stuff like that. But when you get on dialysis, you can’t have beans; you can’t have tomatoes, or any cream of chicken, cream of mushroom, or any of that. It’s a whole different ballgame. I couldn’t find any information on it so I just started doing things myself. If we’re going to have spaghetti and he can’t have tomatoes, but he has a little bit. Then he doesn’t have any the next night or the following night. So he doesn’t eat that much of it. That’s how I got by with having so many things he can’t eat. I just fix the things I usually do, and we eat in moderation. That’s what we do.

*Joann, husband on dialysis*

Many talked about reducing their use of salt or cooking with Pam instead of oil. Several also talked about giving up or cutting down on drinking Cokes. Cynthia described here current eating pattern as:
I changed because there are things that he cannot eat, like chips and bananas so, I don’t buy them at all so he won’t see them. I don’t buy cheese so he won’t see the cheese and I don’t eat it either. Things that he cannot eat I really don’t buy. We go and buy the food together or I cook simple things…. I also used to eat a lot of spinach and they told him not to eat spinach anymore… I don’t even eat the beans because they said it’s too high in potassium… I have made a lot of sacrifice…

_Cynthia, husband on dialysis_

*Changes in family interaction.* Sixty-six percent (n=10) of the family talked about the impact of dialysis on their family interaction. Family vacations and traveling are not easy to arrange and carry out. Rosa who mother is on dialysis, said:

We’re planning a family vacation this summer. But we’ve never tried to find an outside place [for her to dialyze]. I’m sure it would be difficult. We don’t want to leave mom by herself. We want her to go with us if we go. What do you do? Even if she wants to go for a week to somewhere close, “What do you do? You can’t skip dialysis.”

_Rosa, mother and grandmother on dialysis_

Taking care of their loved one was also given as a reason for not engaging in volunteer activities or with friends. Lela explained how this limitation occurred:

… We were limited to go out at night somewhere because he needed to be connected to the machine. We very seldom did it - let’s say that if we had a wedding, we had to come back [home] at 10 o’clock…That means that for 12 hours he had to be there- so he had to have breakfast in bed because he was still connected to the machine…so, we were not having that many activities at night...

_Lela, widow, husband on peritoneal dialysis_

Dialysis creates excessive demands on the family and requires extensive role and lifestyle changes. Losses and daily life changes for dialysis families are considerable and the stress can severely strain their coping capacities. It impacts all aspect of their lives from what type of car a daughter will buy because she must transport her mother to dialysis daily to not buying and eating bananas because they are not allowable on the dialysis diet.
Understanding the adaptation and dynamics of family interaction in the face of this condition can help determine interventions or program that support the family’s abilities to deal with the disease, the prognosis, and treatment.

III. Fearing Death of Loved One

The most common reason given for accommodating the dialysis lifestyle changes is the fear of loved one dying. It was more important for the loved one to be alive. Rosa voiced the sentiment of the family members:

I love my mom. I want her to be here. I want her to be alive for my granddaughter and for her other grandchildren and for you know her children. I want her to be, I want her to be around for a long time. So you know because of that I am willing to do whatever I have to do to help her.

*Rosa, mother and grandmother on dialysis*

He wanted me to go in and pre-arrange his funeral but I just can’t get myself to go through that. I’ve been putting it off. It’s been hard but I’ve learned to stay with it. Some days I just go in my yard and feel like screaming my head off.

*Pearl, husband on dialysis*

Several (n=3) of the family members wished that their loved ones had taken care of themselves early on and prevented dialysis. Pearl explained,

When he first found out he’d been a diabetic for a long time, he hadn’t taken care of himself through the years… He worked at night. He’d go to bed and then when he got up, he’d go to the chair and just sit there and sleep. He drank a lot of water and stuff. I kept telling him, “Dad, I think you have diabetes.” “The doctor said I don’t have diabetes,” he said. And he just kept going on like that. And then I said, “I think you need to go to my doctor and see.” So we took him to my doctor and he told him outright, “You have diabetes.” Well, he had it for like 4-5 years or more before we even knew that he had it. Back then, we just didn’t pay that much attention to it. We didn’t take care of it.

*Pearl, husband on dialysis*
You know because had she listened to us twenty years ago to take her medicine. She wouldn’t take care of herself because she felt fine. So twenty years ago had she just taken her medicine.... We fought with her and fought with her and she didn’t want to. We told her, “If you don’t take it [medicine] you’re gonna lose your vision.” And here’s her vision, there goes her vision. We told her, “If you don’t do it you’re gonna go on dialysis.” Well here she is not able to see and on dialysis.

*Rosa, mother & grandmother on dialysis*

Maintaining the cohesiveness of the family unit is a significant stressor for the family in the face of this condition. Keeping their loved ones alive becomes the primary goal. ESRD and the constant need for dialysis emphasize to the family members the gravity of the situation as well as resentment on the part of some family members. Perhaps the long-term impact of having someone on dialysis produces differences in perceived illness demands, family resources, and the “half full versus half empty glass” perspective.

*IV. Meaning of One’s Life*

The family members often referred to God and their faith as the source of their encouragement and motivation to deal with this situation. Many of them indicated [n=6] that they prayed often for “strength to help them through this difficult time:”

I just take it a day at a time and thank God in the morning and thank him at night when I go to sleep… I’ve been in this family for close to seven years and I had never personally had to deal with it [dialysis] until I got married and until we all lived together. So this is an ongoing learning process for me. Every day it’s something new. Every day there’s something to learn. So I just take it day by day.

*Angie, father-in-law on dialysis*

We have faith in God that he will pave the way for a transplant… We have faith in God and we cannot lose that. [Translated from Spanish]

*Dorali, brother on peritoneal dialysis*

Several of the family members felt that this situation has made their faith stronger and dialysis is a part of God’s plan for them and their family:
Every time there's been a little setback it's been very depressing. But God has a plan and that's what we just have to keep, you know there's a reason why… We don't know what it is but for some reason God doesn't want him [father] to have a new kidney right now. God wants him to stay on dialysis and that's okay. But that's probably the hardest thing for us, it is just all the little, small setbacks, well I guess they're pretty big [setbacks].

_Betty, father on dialysis_

Well actually for me, for my family, faith. Because I know that whatever happens He [God] knows what He’s doing. He has her [mother] like that for a reason. I say it’s been for the better because we’re looking more for our Lord. So, its better, it’s for the better you know. Sometimes things happen for a reason. And I believe that this is what had to happen, you know so we could start looking for our Lord more.

_Eve, mother on dialysis_

Religion in combination with love for the individual on dialysis plays a major role in the family members’ motivation to accept and dealing with dialysis and providing meaning to this situation. Religious belief appears to give them a sense of hope and comfort especially as they wait for a transplant. The stoic acceptance of living with dialysis tends to be the norm.

**Summary of Concerns, Issues and Needs of Family Members**

For the family members in this study their day-to-day life revolves around the needs of their loved one with ESRD and the requirements of dialysis. They are willing to change their lives and the lives of their children in order to keep their loved one alive. Fearing the death of their loved was not only their driving force but also their reason for making life changes. However, to accomplish this they need information and knowledge about the dialysis procedure and regimen. Once treatment began, the family members have limited avenue for obtaining information about the regimen. Communication from healthcare providers is not always perceived as supportive and informative. As a group they want particular details regarding the diet, cooking, and grocery shopping; they desire healthcare
providers who will communicate with compassion; and they need social support for adjusting to life with dialysis.

Concerns, Issues and Needs of Healthcare Provider

When the healthcare providers (n=6) were asked to identify the major concerns and issues facing Mexican Americans on dialysis, they tended to focus on issues related to managing the medical aspect of dialysis. The findings designated three major areas: communication, complying with the dialysis regimen, and preventive care.

I. Communication

Language. The Spanish language and limited education have been identified by the healthcare providers as major barriers to communicating with this population. With nine of the interviewees primarily Spanish-speakers and the majority of the others bilingual, brings into question their comprehension of the technical and medical terminology used to in dialysis as well the staff’s ability to translate these terms into Spanish. A nurse with three years of experiences in dialysis said, “We have a high proportion of patients who don’t speak English. They expect you to be able to communicate and give them the information in Spanish.” Another healthcare provider noted:

A lot of them speak Spanish and some of them have a different dialect of Spanish as well…the main things [information] that we can give them, which we try to translate, are all in English.

Nurse, facility manager with >5 years in dialysis

There are some people [staff] who can speak excellent Spanish, but then you have others, like me and some staff in the unit, who don’t speak the language very well. Therefore, it’s difficult for us to be able to explain it [dialysis] to them with any empathy or compassion because we’re thinking in English and speaking in Spanish. It’s very difficult to cross that. It’s very difficult.

Social Worker with 5 years in dialysis
**Education Level.** With 53% of the individuals with ESRD and 60% of the family members’ in this study having a high school education or less, placed their ability to comprehend and understand most health information in jeopardy. The educational limitation was identified by four of the healthcare providers as the biggest issue facing this population not only in terms of health information but also for communication in general. For example:

In the last year, I saw a huge group of patients come in under the age of 50. So I can’t say the majority is illiterate, but we do have a large group that is illiterate. This affects what they understand about their treatment, their medications, their doctor appointments, transportation, and so on.

*Social Worker with 5 years in dialysis*

The population in this area, especially the age of people who are dialyzed here, their education is not of a high regard….how can you educate somebody when a lot of them can’t read? A lot of them don’t understand what you’re trying to tell them. You’re trying to put into basic words about their medicine, but you can only go so far in being basic so people can understand, and some people don’t understand.

*Nurse, facility manager with >5 years in dialysis*

All the healthcare providers felt that this population needs a great deal of education about dialysis. They need education as to what’s going to happen, how to change their eating habits, and how to deal with pressure from family and friends. What would mainly help this population as identified by the healthcare providers included education on the different types of dialysis; programs stating what will happen if they are not compliant with the treatment regimen; and preventive programs especially for those people with type 2 diabetes and hypertension. The Spanish language and low educational level are also crucial barriers to communicating with this population. Both have direct impact on this population comprehension and acceptance of dialysis.

II. **Compliance with Dialysis**

*Pre-service education.* Complying with the all aspect of the dialysis regimen has been identified by the literature as the number one determinant that impact survival and
The healthcare providers in this study concluded that education or lack of education was the key to compliance for Mexican Americans. Pre-service or early education is considered to be crucial for compliance. One nurse stated, “I just wish there was some way we could meet these patients before they become end-stage renal disease. Better education before they need our services, I think is the key.” Other healthcare providers agreed:

The key is to get them educated beforehand so they know what they’re dealing with so when it does happen. They’re not in shock and it doesn’t take them a year to get used to the routine of dialysis.

Physician with >5 years in dialysis

I think pre-education before coming onto dialysis about what dialysis is what you’re expected to be doing while you’re on dialysis so you can keep your health at an optimum, would be beneficial. Things like getting a fistula before coming onto dialysis so you can be prepared. It all gets the mind ready. ‘This is going to happen.’ ‘No, it’s not going to happen.’ Then they arrive and they see a big machine and people standing around them. And they see these needles getting plugged into them, and they go, ‘What’s going on here?’ They don’t really comprehend what’s going on.

Nurse with >5 years in dialysis

Educating about renal replacement options was felt to be a reason to increase compliance among this population. One provider voiced:

…the majority of our patients don’t come pre-ESRD. They come post. Because of that, it’s a little harder. So, we often don’t have time to give options. They don’t have time to get options.

Nurse with >5 years in dialysis
Other healthcare providers discussed alternate dialysis methods:

There are so many options to dialysis. There’s peritoneal, there’s home hemodialysis, there’s nocturnal dialysis. There are all these options out there. I think the biggest problem is that we as the dialysis professional community don’t give our patients these options. We just say, ‘Ok, you’re going to be on this dialysis.’ Because we think this one is better suited without actually looking at the patient and their environment.

*Nurse with 5 years in dialysis*

There’s more than one option. There’s transplant, there’s PD [peritoneal], there’s hemodialysis, and sometimes no treatment is another option especially when you’re 90 years old. Sometimes the patient decides it’s time for them to go and that’s also an option. Sometimes the family members don’t know there are options for that. So education on the treatment options is very important.

*Nurse with > 5 years in dialysis*

Several providers felt that a variety of renal replacement therapy options may prevent denial and refusal to attend dialysis, voiced several providers. This would also allow the patients to make choices and comply with all aspect of the treatment regimen. One provider explained:

I would like to see something specifically for the dialysis patients and the future dialysis patients - something about chronic kidney failure, the different stages - so they know where they are, what their chances are of developing Stage 5 where dialysis is needed. Give them more information beforehand.

*Nurse with >5 years in dialysis*

On the contrast, even with education, one healthcare provider felt that nothing will change because people do not change. She said:
They are not going to change. If you educate them, they may…They’re always going to tell you what you want to hear, and the minute they leave the building, they’ll go back to doing what they want to do… I think one of the biggest things is that our patients, as dialysis patients, are going to do what they want to do…They’re going to live their life the way they want to live their life. That’s not going to change. I think that it doesn’t matter if they’re white, black, Asian, men or women. They’re going to lead their lives however they want to.

Social Worker with 5 years in dialysis

Scope of non-compliance with dialysis. In order to improve compliance one must understand why people do not comply. One of the most common reasons given for non-compliance by this population, according to the providers was denial of the health condition. A provider stated, “One of the things we see all the time is that they’re in denial. They don’t believe the bad things we tell them can happen to them until it affects somebody they know or it affects them.” The social worker felt that the noncompliance went beyond dialysis:

You’d be surprised how many [patients] haven’t been to a doctor and then they end up in the ER and on dialysis. A lot of them don’t even go to the doctor regularly… Some, even though they know they’re at this ESRD stage, still don’t follow their instructions. It’s like, that’s never going to happen to me.

Social Worker with 5 years in dialysis

Other reasons offered for non-compliance by the healthcare providers included, “Nobody can take care of the kids. Nobody was home at the time.” “I went out or they invited me to go out, or my sister came down so we had to go eat.” One nurse stated:

They don’t have the finances to comply with the diet, to get the medications they need and take them routinely, or to take their protein supplements. All of those things cost money and these people don’t have money to spare.

Nurse, with < 5 years in dialysis
Sometimes you can just tell what’s going on at home. They’re trying to pay bills and just trying to get their mind around what’s happened. You know, some bills are being missed and they don’t have the same income. That can affect the way you feel. It can drag you down into depression... I think if you start educating pre-dialysis, give them counseling then you get a lot more compliance. You get people back into the workforce or staying in the workforce and being more productive...

*Nurse, facility manager with >5 years in dialysis*

Transportation was mentioned as a reason for non-compliance. One provider articulated this issue:

> Even though we have transportation available, they have to wait so long to get picked up after their treatment. And they’re picked up two or three hours before their scheduled time so they sit in our lobby for two hours waiting because of the public transportation. There isn’t enough of it so that people have to be inconvenienced unnecessarily for long periods of time. They don’t want to deal with that. A lot of them can’t because they’re in pain, they’re uncomfortable, they’re weak, they’re tired, and they don’t feel good. That’s an issue for our patients who come for treatment. A lot of them don’t have the family support. They live at home with their extended family members but everybody’s working. There’s nobody at home to help them out.

*Nurse with > 5 years in dialysis*

According to healthcare providers, compliance with dialysis starts prior to ESRD and dialysis. Early or pre-dialysis services is key to avoiding denial of the condition as well as allowing the individual to participate in the decision-making process regarding the type of renal replacement therapy he or she desire. Understanding the reasons for noncompliant provides a framework for improving compliance. The reasons given for not complying with the dialysis regimen ranged from denial of the condition, lack of finances to buy appropriate food and medications, to lack of transportation.
III. **Prevention**

The healthcare providers made it very clear that early referral, working with primary care physicians, and prevention of ESRD must be embraced and acted upon. Early referrals by primary physicians to nephrologists have been identified in the literature as a key to reducing ESRD and the need for dialysis. The healthcare providers in this study voiced this as a major tool to curtail the increase of Mexican Americans on dialysis. One nurse said:

Most of the time, a general practitioner won’t refer them [patients] to a specialist until they’re in the early stages of renal disease. They could refer them when they first learned they had a potential for renal failure…Education, early referrals - follow-up; follow up with their primary; and follow up with their specialist.

*Nurse with >5 years in dialysis*

If the primary [physician] goes in and doesn’t know anything about it [ESRD], they’re going to end up on dialysis… it has to do a lot with them [patients] going in for their checkups and getting their physician involved, especially the primary one because he’s the one basically controlling the diabetes. He’s the one controlling the hypertension. If he doesn’t do anything about it, well - guess what. They’ll end up coming to us at the last minute. And that’s what we’re trying to prevent here with the programs and all that stuff. We’re trying to prevent them from coming in like, ‘Oh, guess what, we just ended up in the hospital one day.’ We’re trying to get them before. We’re trying to educate them. We’re trying to tell them there are different options. Maybe they can work something out like take their medicine or take their insulin. That’s the main thing.

*Nurse with 3 years in dialysis*

The healthcare providers discussed the importance of educating Mexican Americans on “how to prevent diabetes and hypertension and how to change their eating habits.” These features are essential to reducing the increasing number people with ESRD and dialysis. If people have diabetes, high blood pressure or declining kidney function, they need to start taking charge of themselves. They need to start controlling them.
Summary of Concerns, Issues and Needs Reported by Healthcare Providers

Healthcare providers have an essential role to play in encouraging, educating and communicating with Mexican Americans with ESRD on dialysis. Early and pre-dialysis education and services on the different types of renal replacement therapy; programs on what will happen if they are not compliant with the treatment regimen; and preventive programs especially for those people with diabetes and hypertension have been identified as needs. The language and educational level of this population are crucial barriers to communicating which the providers must overcome. Both along with lack of finances, transportation, and denial of the condition have direct impact on this population comprehension and acceptance of dialysis.

Summary of Concerns, Issues and Needs of all Participants

For the sample in this study, the identified needs, concerns and issues were different for each group of participants. The individuals with ESRD lived with the constant awareness of the day-to-day dialysis treatment—frequency of the session, length of time for dialysis, medical complications and bodily alteration for access, and mentally tolerating the dialysis session itself— and its impact on their occupational performance - clothing choices, work, social, and leisure activities as well as time loss with family and friends, and the dreams of a future and long live. These individuals live with the constant awareness that dialysis treatments are prolonging their life and that they are constantly at risk for complications, deterioration, and death. Their lives as marked by increased dependency and uncertainty. Having experienced the toll of dialysis and many of its associated side-effects, the individuals expressed a need for more and regular information about the mechanical side of dialysis as well as the regimen its. They want support groups and counseling to assist with mentally adjusting and managing their condition. And any assistant that could be made with getting social services would be greatly appreciated.

The family members concerns revolved around the reality of living with and accommodating for dialysis as well as the needs their loved one. They are willing to change their lives and the lives of their children in order to keep their loved one alive. Fearing the
death of their loved one was not only their driving force but also their reason for making life changes. They have an immediate need for all types of information from what to expect with dialysis to making dialysis fit into their lifestyle. Challenges for the families arose not only from knowing little about dialysis and ESRD but also from food preparation that meet the diet restriction of dialysis. Additionally, traveling and managing with less income were also challenges faced by the families. The families desire healthcare providers who will communicate with compassion and social support to assist with adjusting to life with dialysis.

Healthcare providers believed that lack of education is the biggest issues facing Mexican Americans. Moreover, it is also the answer to increasing compliance, prevention, and managing the medical aspects of the condition. Needs included early and pre-dialysis education and services on the different types of renal replacement therapy. Also needed are programs on what will happen if a patient is not compliant with the treatment regimen. Finally, preventive programs especially for those people with type 2 diabetes and hypertension also should be implemented.

Dialysis is an externally imposed challenge that dominates the lives of Mexican American individuals with ESRD as well as family members and healthcare providers that serve them. The findings in this study contribute to an evidence-base for patient and family-centered care to address their concerns, issues and needs.

Benefits, Efficacy, Barriers, Threats, Cue to Actions, and Advice

This section continues to address the research question, “What are the most prominent concerns, needs, perceptions and issues related to the occupational performances of Mexican Americans with ESRD living on dialysis in the Lower Rio Grande Valley of Texas from the points of view of the individuals with ESRD who have lived with dialysis for 6 months or more, their families, and the healthcare providers who serve them?” It describes the qualitative findings related to the constructs of the Health Belief Model - perceived severity, susceptibility, threats, benefits, barriers and collective efficacy. Results of this analysis revolved around accepting and adjusting to life on dialysis and advice for others.
(1) What are the benefits, barriers, and threats to adjusting and complying with the dialysis regimen?

(2) What advice and recommendations do you give to other individuals, families and society?

For the purpose of this discussion, those perceptions (perceived benefits and self-efficacy) which caused improvements in such areas as family interaction, lifestyle, and functional performance, are indicators of positive influences for adjustment. The perceived barriers are considered obstacles to adjustment. Those perceptions related to the physical outcome of dialysis (perceived susceptibility and severity) and risk to family members (perceived threat) are indicators of fears. Collective efficacy refers to the collective efforts of the family unit to accept and adjust to life with dialysis.

Benefits, Barriers, Threat, Efficacy, and Advice for Individuals with ESRD

I. Perceived Benefits

In this study, the Health Belief Model construct perceived benefits was defined as an increase in physical well-being, extended life and improved quality of life. Eighty percent (n=12) reported that dialysis had had a positive influence on their quality of life especially through their family interaction, prolonged life, and increased well-being. The participants described themselves as recipients of physical as well as emotional support particularly from their family. Physical support was presented in the form of household duties, food preparation, transportation, and financial assistance. In one case, a great granddaughter was being paid to provide home health care to the respondent. While the women were generally more appreciative of the physical support provided by their family member, one female participant felt that this was harder for men to accept based on her observation at the clinic. She stated:
I guess it’s harder for men because they’re so used to being cocky, you know. Now she [wife] has to take care of him and it’s very hard for him because he’s used to be the big man. Now he doesn’t have a leg, she has to carry him; she has to feed him and all of that, so he cries a lot because he feels worthless.

_Anna, a dialysis patient for 1 year_

Emotional support for actions related to compliance and adjustment was also attributed to their family members. For example, Dena talked about the emotional ties she has with her sisters:

[My sisters] are very important, because sometimes I get depressed. Like if there’s one day that goes by that they don’t call me or they don’t come over I get so depressed; I’m used to having them around me. I mean they’re the reason I’m still here… We’ve always been very close, but now it’s even closer. We’ve become very much united, my sisters and I…my sisters and I are always there for each other, no matter what.

_Dena, a dialysis patient for 11 years_

I think that maybe my kids in a way…they don’t take me for granted. They know that with a disease like this one of these days dad may not be around. So, we’re a close-knit family and I guess we just remain close.

_Hector, a dialysis patient for 3 years_

A few were grateful for their family willingness to accommodate and change their lives on their behalf. Roel stated:
They accommodate me. Now I live with my parents. The reason for that is not only for the ESRD but also the diabetes. My history is that I take chances and risks with my personal health. So, there are times when I will not do or take care of myself. Because of that I’ve been asked to be watched over. They’ve taken that responsibility, making sure that I’m doing what I’m supposed to do. My mother makes sure I have my medicine and takes my blood pressure, almost to the point of nagging. But I understand where she’s coming from because of my past history. I’ve gone into insulin shock, been delusional, and my blood pressure was dropping. Without them around I may not be here.

Roel, dialysis patient for 5 years

The participants overall agreed they had received some benefit being on dialysis. They described themselves as recipients of physical as well as emotional support from their family. Physical support was presented in the form of household duties, food preparation, transportation, and financial assistance. Emotional support for actions related to compliance and adjustment was also attributed to their family members. Perhaps the social network of the individuals weakens over time, leaving immediate family members to provide the primary support which they need.

II. Collective Efficacy

The collective effort of the families gave all of the respondents in this study the confidence to handle and adjust to living with dialysis. Accepting the condition and cultural up-bring were identified as factors in their ability to handle this life over a prolonged period of time. Eight (53%) alluded to accepting the condition for what it is as being paramount in the development of confidence:

I can handle it. Well more accept it…I think a lot has to do with accepting it but you do have to. And you do have to alter your lifestyle. It’s not over. I mean, going on dialysis, your life is not over. It keeps going you know…if you give up on life, life will give up on you. You don’t have to hide under a rock and wait for death. It maybe a little bit slower, but you can still do it. You’re still alive.
Ruben, a dialysis patient of 3 years

Knowing what to expect and having information also contributes to the confidence of the unit needed to continue with dialysis. Lauro talked about his family experience with his sister as a source of their confidence:

I’m very confident of how I’ve managed all my situation of dialysis. Since my sister had a kidney transplant, my parents have also taken it in a different way because they have passed through this experience already. So it does help because they know what to expect. And I have taken it in a way that it’s my health.

Lauro, a dialysis patient for 1 year

All the individuals feel they have the confidence to handle this condition. This sense of self-assurance came from a variety of sources – their family, religious belief, and children. The cultural value of the family among Mexican Americans is a positive strength for this population. The welfare both physically and emotionally, of the children creates not only stress for the individuals with ESRD but also provides the reasons and confidence for adapting and adjusting to dialysis. Chronic illnesses create excessive demands on the affected individual who require the family to go on.

Summary of Benefits and Collective Efficacy for Individuals with ESRD

The physical and emotional support given by the family members were appreciated and cherished. The cultural value of the family among Mexican Americans is a positive strength for this population. The family, children, and grandchildren were indicated by the individuals with ESRD as their reasons for complying with and adjusting to the dialysis regimen. The perception of confidence to execute the behaviors to successfully adjust and handle the demands of living with dialysis was shared by the participants. This sense of self-assurance came from a variety of sources – the family, religious belief, and children.

III. Perceived Barriers

For this study the construct of perceived barriers was defined as issues related to compliance with the dialysis process and procedure such as the dietary and fluid restriction, 3
times a week treatment sessions for 3-4 hours, and medication regimen. Some Mexican American cultural behaviors and beliefs were also identified as a barrier to adjusting to dialysis.

**Compliance.** The first major obstacle to living with dialysis that was reported by the respondents was accepting and complying with the dialysis regimen. Depending upon the cause and type of dialysis, other complications and restrictions limited adjustment. One respondent stated:

> With renal failure if you don’t take care, you will die. I ain’t talking about within a year, I’m talking about weeks. The toxins will kill you within a week or two weeks depending on how shut down your kidneys are. I’ve seen a lot of people that drink too much water and they actually drown. They drown because their kidneys can’t process the water out of the body.

*Luis, a dialysis patient for 3 years*

Therefore the diet and fluid restrictions are not only obstacles to adjusting and living on dialysis but also for prolonging life. A number of the participants (n= 7) stated that they just did not like the food on the diet list. For example, a dialysis patient for one year said, “I know they gave me a list of foods that I am supposed to eat but most of them I just don’t like.” Another stated:

>I’ve learned how to watch the food, count the carbs, and know what’s good and what’s not good. I know when to splurge a little bit and when not to. It’s hard because the foods that I like are the ones that I need to stay away from. [*Translated from the Spanish*]

*Ashley, a dialysis patient for 6 years*

Others discussed the conflict between the food allowed for other medical conditions and those for dialysis:
Well, for diet restrictions, it’s amazing when you pick up the list and look and think of all the vegetables that you can’t have or aren’t supposed to have, I’m not saying I can’t have them but you’re not supposed to have them. So many different things when you lose the function of your kidneys, it just changes things. Everybody thinks, ‘Oh wheat bread.’ No I can’t eat wheat bread I have to have white bread. Real dark vegetables I’m not supposed to have. You know broccoli is off the list, spinach is off the list. You know as a kid I hated spinach, now I love it and I can’t have it. You know there are a lot of restrictions and you have to watch what you eat. Before I lost the use of kidneys they wanted me to limit my intake of protein and now they want me to increase my protein. So, I’m always eating chicken. I eat a lot of chicken and fish. I eat a lot of beef. I learned to eat fish, broiled or blackened rather than fried.

_Hector, a dialysis patient for 3 years_

In terms of fluid restrictions, Hector continued:

Liquids are probably the biggest problem I have….I just consume a lot of liquid over the years, a lot of tea and coffee. So I had to limit those and it really gets me in trouble a lot on the weekends. Because if I’m not careful I’ve get that big glass of tea in front of me at a restaurant and the guy keeps refilling it and I keep drinking it and drinking it. By Sunday afternoon I can tell and I’m looking forward to Monday morning when I can go in [to dialysis] and get some of that liquid out of me. So that’s what my biggest problem is - the fluids because I can really overdo it when it comes to that. I mean we’re supposed to drink no more than 36 oz. a day so that’s one trip to the 7-11 and that’s over with. So it’s just real hard, especially for a big guy like me that tries to stay on the go, it’s just real hard to avoid the liquids.

_Hector, a dialysis patient for 3 years_

Cultural food preference however, did create a conflict for some participants because of the restrictions of phosphorus and potassium. These are found in high content in beans and potatoes which are a staple of the Mexican-American diet. Arturo stated:
I don’t follow the diet because I eat whatever my wife makes. She’s from Mexico so all she does is Mexican food… She does try to cook the required foods but I’m just picky. Rice and beans, chicken, tortillas, that’s about it, pure Mexican food. Once in a while pizza, you know when I buy pizza for the kids. I’ll grab a slice or two. But you know when you’re on dialysis you’re not supposed to eat cheese or none of that, but I still do it. And I take my pills with it, for like the phosphorous, because like having high phosphorous for a while will weaken your bones. But with the pills I take it keeps it normal… Yes [it’s hard to comply], because you know everything around us down here has beans and cheese with the high phosphorous. It’s hard to get away from all that.

Arturo, a dialysis patient for 3 years

Ana expressed her thoughts about the diet:

I gave up chocolate, potatoes, which was hard because I mean no more French fries, no more mashed potatoes, baked potatoes…that was tough; corn products, so there goes tortillas, there goes corn chips, there goes just corn, Corn Flakes… beans of any kind, it pretty much just wiped out Mexican food, you know, dried beans, no peas, none of that; and I’ve just have to eat protein, protein, protein, which is tough. I never thought it would be that tough, but I’m supposed to eat more meat than anything. And what about the things that are light like ham and bacon, well no. So what are you supposed to live on, for crying out loud? So I eat eggs. Eggs until I’m about ready to grow feathers. And I can have pork chops and chicken. I discovered protein shakes, protein bars… It’s been tough.

Ana, a dialysis patient for 1 year

Ruben reported that the constant physician appointments are an obstacle to living with dialysis:
There have been obstacles that I’ve encountered since I started dialysis such as going to doctor’s appointments. I mean, usually every two weeks. Not just going to one doctor, I mean with the nephrologist, the neurologist, and the internal medicine doctor. There’s, at a point it becomes frustrating because you say ugh, I have to go to the doctor again. Oh I have to go to the doctor.

*Ruben, a dialysis patient for 1 year*

Compliance with the dialysis diet and fluid restrictions proved to be problematic for many of the respondents. In terms of the diet, just not liking the allowable foods was an issue that contributed to noncompliance. The restriction of the quantity of fluid allowed also lead to noncompliance. The traditional Mexican cuisine itself proves to be a barrier because of its high content of potassium and phosphorus. Lastly, the continuous and multiple medical appointments was a source of frustration.

*Cultural Impact.* The cultural “fatalistic” stigma of being on dialysis was reported by four respondents as an obstacle to adjusting. Selma described the reactions that she received:

I don’t know there’s something about the Mexican people thinking that people go on dialysis and they die. Oh dialysis is a bad. Oh, you’re on dialysis. You go on dialysis and you die… everybody that you tell you’re on dialysis they feel sorry, they feel bad for you as if your life is over.

*Selma, a dialysis patient for 1 year*

The Mexican American cultural beliefs and attitudes have been cited as an obstacle to adjusting and living with dialysis. Hank talked about the affect of culture as an obstruction to adjustment:
… In the Hispanic, Mexican American culture the diet is high in fat; foods are cooked in grease or lard or deep-fried, and lots of flour. The foods are high in calories and high in salt which causes high blood pressure. Not being active or a tendency to be overweight all come from the culture and the diet. The beliefs that herbal cures, old wise-tales of drinking certain things, boiling leaves, I guess other religious beliefs on prayers and things, almost to the point where health beliefs are …. Some of the older Hispanics from Mexico…have a tendency toward voodooism or believing in spells and things like that so nothing will hurt you. Or you hear of studies experimenting with animals that the FDA doesn’t approve of here that they might get away with that over there [Mexico] that they tried. People will tend to hear about them. And when you are looking for anything to help you out, your belief is to give that a try, you know….All we have to offer here is transplants. It’s very difficult to get them to think in a different way when they don’t believe it. Sometimes they say … I know there something about lava being produced from some swarm or there’s something going on in Mexico, where they can give an injection to cure your pancreas, people believe that. And they believe there are herbals and teas that can lower you blood pressure or to start your kidney function again or cure diabetes. There are old wise-tales that been passed down for generations and cultural beliefs that people will tend to try.

_Hank, a dialysis patient for 5 years_

Among some Mexican Americans, cultural remedies and beliefs about health care can prevent adjustment to dialysis. If they cannot be cured through western medicine, they turn to folk healers and unproved approaches. The fatalistic stigma placed on dialysis patients by others does not aid in the acceptance of dialysis.

**Summary of Perceived Barriers for Individuals with ESRD**

The obstacles of adjusting and living with dialysis - diet and fluid restrictions, cultural preference, and cultural beliefs and attitudes – are complex. They may act as a barrier to optimal occupational performance. For this population, traditional Mexican food is a dietary barrier because of its high content of potassium and phosphorus. But noncompliance with
the diet and fluid regimen appears to be caused more by personal food preference than cultural ones. Continuous and multiple medical appointments are also a source of frustration. The perception of the intrusiveness of the illness such as diminished physical strength, persistent fatigue, weakness, medical complications, socializing with family and friends, and cultural beliefs and attitudes suggest that these obstacles are important not only to adjusting to life with dialysis but also complying with the dialysis regimen and occupational performance. Understanding the obstacles to compliance with the dialysis regimen is fundamental to understanding noncompliance. And noncompliance is associated with undesirable and sometimes fatal outcomes.

IV. Perceived Threat

Perceived threat is the combination of perceived susceptibility and perceived severity. It entails the uncertainty of and dependency on dialysis that this population must endure. The insights and opinions of the individuals with ESRD regarding the possibility of dialysis becoming the fate of their children and other family members were also seen as a threat.

Perceived severity. This construct was defined as the risk of death for the individual with ESRD for this study. Several interview questions were analyzed to access the participants’ perceptions of how the experience of being a dialysis patient had influenced and/or changed their view regarding the future. With a heightened awareness and increased sensitivity to the prospect of death, nine respondents reported a change in their prior views about life and death. Life is perceived as more precious now and not something to take for granted:

…When you’re young you make the world spin around you, but once you get sick and then you’re on dialysis you start seeing everything real different, everything has a meaning to you, the trees, the birds, the songs of the birds.

Mike, a dialysis patient for 4 years
The first thing I do when I wake up is thank God for letting me wake up and giving me another day of life. And I just live life to its fullest because you never know. You could be gone from one day to the next…So I just try to enjoy my daughter’s company and my sister’s company as much as I can because life is too short.

*Dena, a dialysis patient for 11 years*

Direct observation of situations involving fellow patients is a constant reminder of their own mortality and risk for the same fate. So, to deal with the severity of the condition, the Mexican Americans with ESRD have become a family, a very close-knit family. These feelings are expressed by Dena:

We’re all like a big family [dialysis patients]. Somebody doesn’t show up or they’re late for the shift, “What happened to this person?” Somebody is calling the house, either the relatives that are waiting outside, or somebody inside. But anytime somebody is missing everybody finds out what happened or why he or she is coming in late. What happened, everybody knows. The relatives are outside [waiting area] calling the hospitals, and if they’re not in the hospital, they come in and say they’re not in the hospital. “It’s, ok he’s just a little tired, he’ll come in later” and everybody relaxes a little bit. There’s always this old lady that comes in from the nursing home and she’s forever hungry. Everybody always shares; they give her tacos or they give her chips or cookies or whatever. But we’re one big family. And if somebody passes away, oh God, everybody feels it, everybody that’s in that shift, everybody.

*Dena, a dialysis patient for 11 years*

**Perceived susceptibility.** For this study, perceived susceptibility referred to the medical complications, physical deterioration, associated side effect, and risk of infection that this population is subjected to daily. Due to changes in physical functioning, a number of participants described changes in their social relationship and identities as friends, parents, wives and partners. Lauro described how his weakness and fatigue and condition precluded his engagement in social activities:
Before I could drink and stay up very late and even stay over at some other friends’
house or some other place but now that I have to do dialysis I have to get home
because I have to do my dialysis.

*Robert, a dialysis patient for 1 year*

Diminished physical strength, persistent fatigue, and other medical complications were
reported as dominant fears. Fatigue and weakness immediately following the dialysis
treatment sessions along with the time-intensive dialysis schedule typically combined to
preclude the participants from maintaining and accepting social roles they previously
fulfilled. Physical limitations are perceived as barriers to the performance of preferred
recreational past-times. Ashley (a dialysis patient for six years) said, “It makes me mad
because I can’t do a lot of things. I liked attending church now I can’t go.” [Translated from
the Spanish] Ruben noted the impediments of dialysis on traveling:

Vacations, you really can’t go anywhere unless there’s a dialysis center close by and
if you can get into it. You go to dialysis but you really don’t go to vacation because
you’ve still got to go to dialyze wherever you’re at. So it’s not a vacation. Actually I
really don’t get out because of it. I feel like I’ll be a burden because nobody would
be able to do things because I would have to be dialyzed somewhere, somehow you
know.

*Ruben, a dialysis patient for 3 years*

Diminished physical functioning contributes to the perception of illness. The
participants talked about the impact of their diminished physical strength, persistent fatigue,
weakness, and other medical complications as obstacles to participant in their chosen
occupational roles and activities. Inability to attend church, travel, and socialize with friends
was only a few occupational roles that are limited by dialysis. The individuals’ perception of
the intrusiveness of the illness on their lives may be related to their perception of their
decreasing physical functional capacity.

*Perceived risk.* For this study the perceived threat was also seen as the risk of
developing ESRD, type 2 diabetes and obesity particularly for their children and other family
members. Many of the participants (n=12) fear that their children and/or family members
may one day suffer their fate if changes are not made in their lives. Linda is very concerned about her mother who is diabetic and does not take of herself:

My mom she is seeing Dr….and he has already told her that her kidneys are failing as well because she has diabetes. She has been diabetic for 28-29 years. Her kidneys are at 1%. She needs to control her sugar if not they [kidney] are going to fail completely. My brother, the one in Houston, is also diabetic.

Linda, a dialysis patient for 1 year

I’m very afraid for my daughter. But as far as I know, I took her to her doctor, the pediatrician, to have a lupus profile test done. She can’t have it done until she’s 15, so I’m waiting for that. But any little pain that she gets here or there …And every time she tells me that something hurts, I take her to the doctor. And sometimes my sisters tell me not to exaggerate it, but I say nobody knows how I feel and it scares me because she everything that I have, she the only thing that I have, she’s my life.

Dena, a dialysis patient for 11 years

Summary of Perceived Threat for Individuals with ESRD

The perceived threat of dialysis to the individuals with ESRD was seen as their death and their children suffering the same fate as themselves. With the heightened awareness and increased sensitivity to death, this population sees each day as something to not take for granted. Fear of their children experiencing this condition gives them cause to worry and encourage lifestyle changes among their family members, children and grandchildren.

Because of the perceived susceptibility of accepting this chronic condition, this population has become a very close and closed-knit group.

V. Advice

With their knowledge and experience living with ESRD and dialysis, the participants are in a unique position to offer advice to others. The following is compilation of their advice.

Their advice to everyone:
The best trick is to not get into the situation in the first place and that’s preventive medicine. It’s just like anything else - any equipment you have like cars, computers, whatever to keep it from breaking down, you got to make sure that you keep it up and do what you need to do to prevent it from breaking down. It’s the same with the body. Take care of it now for later on, it will tell you if you don’t.

Roel, a dialysis patient for 5 years

Their advice to the community:

We don’t have anything…to start a group here and get all the patients on dialysis so maybe we can learn. Get us together and get the government to help us out so we can learn more and people can be aware about what’s going on with people on dialysis. Nobody knows.

Mike, a dialysis patient for 4 years

Their advice to family members with loved ones on dialysis:

…the wives that are waiting outside if their husbands are on dialysis, …the only thing I tell them is just be patient, thank God that they’re still alive and don’t complain in front of them because it makes them feel worse. And I can tell you that because I’m a patient and sometimes I feel bad.

Dena, a dialysis patient for 11 years

Their advice to others living on dialysis:

It’s not over. I mean, go on dialysis, your life is not over. I mean it keeps going you know. I mean make the best of it. You gotta keep going if you give up on life; life will give up on you. You don’t have to hide under a rock and wait for death you know. It maybe a little bit slower, maybe not as much but you can still do it. You’re still alive.

Ruben, a dialysis patient for 2 years

Summary of Advice from Individuals with ESRD

The advice given by this group echoes their fears, concerns and needs. Prevention programs targeted to change people’s behaviors and lifestyle especially those with diabetes
and high blood pressure. Policies and educational programs targeted to resources for providing access to kidney disease prevention and care. And programs targeted to support the person with ESRD and family members adaptation and coping with the pileup of stress that they may experience in dealing with this disease, the prognosis, and the treatment.

Summary of Benefits, Barriers, Efficacy, Threat and Advice of Individuals with ESRD

The individuals with ESRD living on dialysis in this study identified several benefits, barriers, collective efficacy, and threats. First it appears that despite extensive experiences with illness and medical treatment, the individuals with ESRD did perceive dialysis as having a positive impact on their quality of life. They had prolonged life; the families became closer, more communicative, and involved with each other; and the individuals with ESRD were appreciative and grateful for the physical and emotional family support. Secondly, the collective effort of the family is imperative for accepting and adjusting to dialysis. Thirdly, the cultural value placed on the family was associated with developing their confidence to undergo dialysis on a daily basis. Chronic illness creates excessive demands which require the family to go on.

Complying with the dialysis regimen proved to be an everyday barrier to adjusting and accepting dialysis. The typical Mexican diet made it unlikely that these individuals could make the nutritional choices necessary to comply with the dietary restrictions. Additionally, the individuals frequently described the challenges of limiting their intake of cultural foods that often tended to be high in potassium and phosphorus content, and personally preferred these foods. Diminished physical strength, persistent fatigue, weakness and other medical complications along with the time-intensive dialysis schedule combined to preclude the individuals from maintaining and accepting social roles they previously fulfilled. The stigma of dialysis as a death sentence or use of folk medicines to cure kidney failure can impel some Mexican Americans to give up on life.

With a heightened awareness and increased sensitivity to the prospect of death life is perceived as more precious and not something to be taken for granted. The susceptibility of
their children and other family members following the same pattern is unbearable to many of the individuals with ESRD. Therefore, they advise anyone who will listen to take care of themselves, follow medical advice and practice healthy lifestyle habits.

Benefits, Efficacy, Barriers, Threats and Advice for Family Members

I. Perceived Benefits

Five of the family members positively reported that their family had changed for the better. They became more communicative, interactive and supportive. But more importantly their primary focus became the individual with ESRD both physically and emotionally:

It's made us more aware of everything and we definitely come together. We've always been very close but we've definitely just kind of bonded through some of it… We all became even more aware of his condition and what all was going on.

Betty, father on dialysis

It’s hard seeing him all the time unable to do the things he really likes. So, we have come together - children, grand children and great grandchildren – to support him.

Randy, grandfather on dialysis

It has given us a better family relationship with our sisters, brothers, and cousins. They are always on the lookout for us and always taking care of... For us there is nothing more important than family.

Sam, son on peritoneal dialysis

Overall the family members expressed a positive outcome having a loved on dialysis. The perceived benefits of dialysis included positive family coping coherence and increased family resiliency. This closeness extends beyond the immediate family unit but also to the extended family members. The family, including the extended family is the most valued institute in Mexican and Mexican American cultures.
II. Collective Efficacy

When asked about the level and source of confidence to handle this situation, the majority of the family members reported that it came from wanting their loved one to feel better even though they wished their loved one had taken better care of themselves early on. Rosa explained:

She wouldn’t take care of herself because she felt fine. Twenty years ago had she just taken her medicine, we started insulin and she refused her insulin. And we fought with her and fought with her and she didn’t want to, she didn’t want to. And we told her, “If you don’t take it you’re gonna lose your vision.” We told her, “If you don’t do it you’re gonna go on dialysis.” Well here she is not able to see and on dialysis.

*Rosa, mother and grandmother on dialysis*

When they told him that he was a diabetic, I mean he was young. He was about 32-35 somewhere around there. And he was working and he played sports. He was a healthy man. When they told him, “Your blood sugar is going a little bit higher and you should take care of yourself.” He said, “No I feel good. I’m okay I don’t have to do anything.” My parents were not diabetic. My parents didn’t have high blood pressure. I mean his parents were healthy people. His dad died at 107 years old and his mom was 92 years. They never had any problems with their health. So he didn’t think that he was going to be where he is now.

*Patricia, husband on dialysis*

Others stated that their self-assurance came from the pure fact that they love the individual on dialysis. And they wanted their loved one to be around for a long time. Lela said,

What kept me going? Because I loved him. I loved him and I think it was very hard. I also had my bad moments. Don’t get me wrong I also had my breakdowns, and the hardest was when he lost his legs, that was the hardest. But like I said that’s what kept me going, because I loved him, ya I loved him.

*Lela, widow, husband on peritoneal dialysis*

For me? I love my mom. I want her to be here. I want her to be alive for my granddaughter and for her other grandchildren and for you know her children. I want
her to be, I want her to be around for a long time. So you know because of that I am willing to do whatever I have to do to help her.

*Rosa, mother and grandmother on dialysis*

So what keeps me motivated are the kids and to see that she’s [mother] in a way healthier you know. She’s still alive and you know we can still have conversations and whatever like a normal life. And I think that’s what keeps me going you know.

*Alicia, mother on dialysis*

The love for the individual with ESRD on dialysis gives the family member the reasons and strength to face this condition. Even though earlier health behaviors on the part of the individual with ESRD may have prevented the current condition, it was not held against them.

**Summary of Perceived Benefits and Collective Efficacy for Family Members**

The perceived benefits and collective efficacy to accepting and adjusting to living with dialysis were related to the family members love and desire to keep their loved one alive. The cultural characteristics or core values of enduring existential suffering have been identified as strongly rooted in their religious. The stoic acceptance of living with dialysis tends to be the norm. The overall sentiment of the family members is, “We are overcoming it and we will come out ahead.” Religious practices and beliefs were identified as the major source of strength and coping for the family members. This suggests that religious aspect must be given considerations in assisting the families in the development of coping strategies.

**III. Perceived Barriers**

**Communication.** Lack of communication between the family and healthcare providers was indicated as a major obstacle. From the perspective of the family member, the individual with ESRD tend not to ask about things that they want to know. They are afraid to ask for clarification or to tell the healthcare provider that they do not understand. And the healthcare providers tend to give only general answers to their questions. When heath
information is given to the patient, the family members may not get it. One family member commented:

   It would be nice for the healthcare providers to help the patients and family who are experiencing this [dialysis] for the first time to understand the process. They should talk with the family to get to know them better and to listen to their stories because talking about it helps.

Rosa wished:

   If they tell her something she’s very forgetful. If they tell her something she doesn’t remember. I like her to have stuff in writing. Did the doctor want you to stop taking the pill? Well which one? Well I don’t know. Well that’s not good.

   *Rosa, mother and grandmother on dialysis*

Communication between the family and healthcare providers often became strained once dialysis started. Communication between family members and healthcare providers play an essential role in the families’ acceptance, understanding, and compliance with dialysis. Since the family members are usually the caregiver, education, feedback on the treatment sessions, and involvement in the effort to ensure compliance may help Mexican Americans with ESRD to improve their outcome.

   *Dialysis Schedule*. Many acknowledged that scheduling around the dialysis treatment was problematic for them:

   When they get out late [from dialysis] I have to rush to go pick up my daughter from school. Sometimes my kids feel that I don’t spend enough time with them. They are young and don’t know the severity of his [father] illness. *[Translated from the Spanish]*

   *Denée, husband on dialysis*

Pearl described how she spends her time when her husband is on dialysis at 5:00am in the morning.
Well, that’s a little after 5:00 in the morning and Wal Mart is open. I go there and get my groceries. I look around the store. It’s something to be away from the house for a little while. Then I come home and do things in the yard or around the house or whatever I need to. Then I go back and pick him up about 9:30 or 10:00. When we come home, I fix him breakfast again because it’s been quite a while since he’s eaten. Then my granddaughter comes. She feeds him his lunch whenever he wants it. Some days he doesn’t want it ‘cause he doesn’t feel good enough to eat it. We watch TV programs and stuff. Before you know it, another day is gone.

_Pearl, husband on dialysis_

Jessica talked about the impact of the manual every 4 hours peritoneal dialysis schedule that her son followed prior to his change to night time dialysis:

…Before if we were at the mall or at a party we would have to leave to take him home or to pick him up. It would complicate the day because we would have to break our day into parts…it affected our daily routine. [Translated from the Spanish]

_Jessica, son on peritoneal dialysis_

Individuals with ESRD must go to all scheduled treatments and stay the entire time. These 3-4 hours treatment sessions may interfere with family members work schedule or other family commitments. Therefore the family members must also make a commitment to the dialysis schedule.

_Compliance._ The cooking and eating habits of the family were identified as obstacles to complying with the diet regimen and required change on the part of the family:

We don’t use salt anymore. We have changed, you know like, instead of oil we use Pam. And we’ve try to cut down on drinks and Cokes. We try to drink more Gatorade instead of Cokes.

Betty described how complying with the diet changed the types of food brought to their family outings:
… When the family gets together, we make different things… We still make the traditional things that we've always done but we may make something you know for him also or for everybody to share that's more on his diet. He's had trouble with sticking with some of the stuff [diet]. He's cut a few things out but he still partakes of a few food options that he probably shouldn't.

*Betty, father on dialysis*

I guess that we try to eat healthier. We were brought up with tortillas de harina and you know it's like now we can’t eat them or just in moderate. We try to exercise more and do a little here and there. My sister and the kids are making sure that they eat well.

*Alicia, mother on dialysis*

On family reported that their diet and eating habit did not change because their loved one was on dialysis:

We have not made an effort to change our eating habits only because…has to be on dialysis… we do not have bad eating habits, we are not diabetic, so we do not really try to change that aspect…As far as out diet is concern she [wife] prepares food but not fried and not spicy. In our pantry, you will not find chips or junk food. We do try to eat healthy.

*Sam, son on peritoneal dialysis*

Compliance is a function of individual self-control but for individuals with ESRD it is also a compliance of the family as a whole. The family must also adhere to same very strict restrictions on food and fluid intake. Eating habits, grocery shopping, and food preparation become associated with another change in the family interaction.

**Summary of Perceived Barriers for Family Members**

The obstacles to adjusting to life with dialysis identified by the family members are related to the day-to-day task and daily activities. Communicating with healthcare providers, accommodating for the dialysis schedule, and complying with the dietary and fluid restrictions are all things that are need to keep the individuals with ESRD alive. The
obstacles and stress placed on the family must be directly addressed in any efforts plan to increase compliance and adjustment to dialysis.

**IV. Perceived Threat**

_**Perceived susceptibility.**_ Ten of the family members feared for their children, especially those in which diabetes ran in the family:

> It runs in the family. So I am concerned. Diabetes runs in our family. But if we take care of ourselves, hopefully we won’t get to that point. But my mom has diabetes; my dad has diabetes; and my grandmother is on dialysis from diabetes. It doesn’t look good for us.

_Rosa, mother and grandmother on dialysis_

Pearl’s message was echoed by other family members:

> I have one daughter who has diabetes and I tell her all the time, “If you don’t take care of yourself, you’re going to end up just like your dad.” His sisters have diabetes. It’s real prevalent on both sides of the family. My parents had it - my dad did. And I’ve got it. I’m trying to control mine with diet. Our kids are doomed, more or less. If they don’t take care of themselves, they’re going to be in the same position I’m in or whatever as they get older…The message is getting to them because they see their dad and how bad he feels…

_Pearl, husband on dialysis_

Several of the family members gave an account of the lifestyle changes made by their children in response to their loved one illness and experiences. These ranged from stop drinking, exercising more, to having frequent medical check-ups. Others were concerned about the inherited traits of diabetes and its impact on their children. Betty whose father is on dialysis, said, “We know some things are hereditary and so we must make them aware of this and they must do all they can to prevent this from happening to them.”

_**Perceived severity.**_ Several of the family felt that their views about life and death had changed after their loved one was placed on dialysis. Their comments focused on taking care of their health to avoid the possibility of dialysis:
When you have someone with that many health problems, next to you, that close to you, is when you really realize how lucky you are to have your health. You have to do your best to take care of your health.

*Rosa, mother and grandmother on dialysis*

Alicia summed up their perspective:

Because you know we read it on the newspaper, we see it in magazines, about taking care of your health and diabetes. But once you actually live through something like this, your mom having her leg amputated and having to go to dialysis. It’s like either you do it [take care of yourself] or you die.

*Alicia, mother on dialysis*

**Summary of Perceived Threat for Family Members**

The perception of threat was seen in relationship to other family members and children ending on dialysis. Living with this experience has been life changing for the family members. Lifestyle changes such as stop drinking, exercising more or having frequent medical check-ups are being encouraged and promoted. Because of their fears and the social consequences taking care of themselves and other family members is paramount.

**V. Advice**

With their vast amount of experiences living with dialysis, the family members offered the following advice to other families dealing with dialysis:

Just try to be as patient as you can with the person because they’re going through enough and they get all frustrated and fussy but they’re the only ones that know what’s going on with them, you know. So I guess just be patient and have faith. That’s it.

*Eve, mother on dialysis*
Well, my advice to anyone living with someone on dialysis is that you just have to hang in there and do the best you can do. That’s all you can do. Everybody is different... Everybody’s different as far as how it affects you. You’ve just got to deal with whatever it is that comes your way.

*Pearl, husband on dialysis*

…If you trust first of all, you trust the medicine, you gonna get better. Just, be there for every treatment. I mean don’t miss treatments because that’s what my husband always tells them. I mean don’t miss treatments because if you miss treatments, you’ll miss life. I mean you’ll lose life.

*Patricia, husband on dialysis*

To people in general:

I see a lot of people just like my mother. And some of these people are very young. They’re like 30 or 40, very young people. It changes your whole lifestyle, your whole perspective on life. Take advantage of what you have right now. Take advantage of that leg or that arm or whatever. I don’t know it just changes your whole life… Take care of yourself because we tend not to go to the doctor… go to the doctor, check yourself.

*Alicia, mother on dialysis*

Summary of Advice for Family Members

The advice from the family members was similar to the advice given by the individuals with ESRD. Take care of yourself; change your lifestyle; and follow medical advice. For dealing with loved ones on dialysis, their primary advice is to be patient, “Have faith and trust that the treatment will keep your loved one alive.”

Summary of Benefits, Efficacy, Barriers, Threat and Advice for Family Members

The family members in this study identified their “loved ones on dialysis” as the driving force and major influence to them accepting and adjusting to dialysis. Yet, the
family members referred to God and to their faith when recounting their sources of encouragement, confidence, and motivation. Several of the family members described the perceptions of their life situation as the will of God, their burden to carry or a chance to strengthen their faith. They prayed for strength and courage, to give thanks, and for the well-being of their family and loved ones. Challenges to the family members’ ability to adjust and manage the demand of the illness arise from factors related to dialysis itself such as communicating with healthcare providers, dialysis schedule, and compliance with the dialysis regimen. They perceive themselves as guardians and protectors of their loved ones with ESRD and family.

Their experiences with this illness cause them to worry about their children and other family members ending up on dialysis. They are begging them to change their lifestyle, eating habits and routines immediately. This is also the challenge they have issued to the community at large especially for those living with diabetes and high blood pressure. Stop drinking, exercise more and have frequent medical check-ups have become their mantra and recommendations for avoiding a life of dialysis. One family member, Sam who son is on dialysis, communicate the impact of living with someone on dialysis as, “…It is a great responsibility to know that if they don’t get treatment they will die. You get this huge sense of responsibility not only for the patient but also for the family and relatives that live with them. That is when your life changes completely.” [Translated from the Spanish]

Cue to Action, Barriers, and Advice for Healthcare Providers

The interviews of the healthcare providers revealed their role in trigging actions to comply for this population. They can also serve as barriers to compliance. The family, healthcare providers, education, and culture, all exerted both positive and negative impact on the individuals and family members.
I. **Cue to Action**

**Manner of care.** Healthcare providers heavily influence the manner of cared for patient. They are the patients’ constant reminder to comply. In dialysis, patients are treated as a person and not a number. The providers interact with them to give better care:

We see these people three times a week and we do become part of their family. Some of them get even closer. You try and keep that distance but it’s hard when you see the same ones three times a week, every week for years.

*Nurse with >5 years in dialysis*

The healthcare professional is the most important person in their life at that moment. If you have a nurse who is compassionate and caring, the compliance is better. The social worker said:

We know their families; we know what they do; we know what they eat; we know about the party they went to on Saturday, about their grandchild or their great-grandchild that was just born. This makes a complete difference on what we are there to do because we become part of their family.

*Social Worker with >5 years in dialysis*

Several of the providers voiced the difficulties in maintaining their professionalism with this population:

A manager once told me, “Don’t pour everything of yourself into a patient and not keep any for yourself. I’ve seen a lot of nurses who come in and give everything of themselves and they’ve got nothing when they go home.” You don’t have to give them all your passion. All you have to do is give information, give the care, do the physical aspects and the mental aspects of it. But emotionally, you have to keep yourself detached, a lot. I know it’s hard but you have to have that detachment because (1) you give better care and are more objective and (2) you won’t get totally tired and burn yourself out. I think that’s why this is happening anywhere in the world today. We burn out too much with the work plus what we’re trying to do for the patients.

*Nurse, dialysis facility manager, with > 5 years in dialysis*
… Because they’re coming in so many days and so many hours in a week, and they begin to forget that we’re not their friends. And they want to be treated like friends so their feelings get hurt very easily, they feel slighted if they feel like you pay more attention to someone because maybe that person’s family will bring you cake or cookies. We really try to discourage accepting gifts of any kind from the patients. Some of them understand and some of them get offended by that. So, yes, there’s a lot of struggling to maintain that professional boundary.

*Nurse with > 5 years in dialysis*

Because of the extensive amount of time the healthcare providers spend with this population, their relationship sometimes goes beyond the professional rim. They are seen as members of the family and personal friends. This high level of involvement can be a struggle and can contribute to the high level of staff turnover seen in this practice area.

*Education.* Pre-service education was identified by all the providers as the most positive influential service that can be provided to increase the patients’ compliance but also confidence. Getting to this population before they get to end-stage-renal-disease will allow them to feel better and in more control. One nurse felt that with education they could offer the patient a variety of options instead of throwing them into hemodialysis at the last minute. And this would decrease denial and refusal to come altogether. One provider stated:

I think giving options to them before they get there [dialysis] so they know what to do and they can make choices before they get there. Hopefully, we’ll get more patients doing home dialysis so they’re not tied down going somewhere every other day to be taken care of.

*Nurse with > 5 years in dialysis*
Sometimes even when you educate the patient - like there’s this particular patient and she was afraid to ask for the treatment option program. We gave her the education, you know, telling her she had option A, and there’s option B and option C. And she was a nurse. I don’t know if it’s the fear of becoming a valve patient or what. But she said no, she was going to hold on. By the time she decided, she ended up in the hospital short of breath with tubes all over the place. When that happens, you have no choice because it’s an emergency and they’re going to do what’s the important thing for you - not what you want. You can have what you want when you’re up and walking, but when you’re in the hospital, they do whatever’s necessary for you. They do the fastest way to get the fluid out of you.

*Nurse with 2 years in dialysis*

Early and pre-education has been identified in the literature as a barrier and influence to compliance with the dialysis regimen (Owens, 2003). Getting to this population before they get to end-stage-renal-disease and discussing options and information on renal replacement therapy will allow the individuals and family members in more control and part of the decision-making process.

**Summary of Cue to Action for Healthcare Providers**

According to the health care providers the role of the provider and early education are most influential in adjusting and accepting live with dialysis for the Mexican American population. This population tends to favor attention from professional sources. Yet, the intimate and intensive interaction between provider and individual with ESRD and family members pushes the line of professional boundary and burn-out for the providers. With early and ongoing education the goal of a clinician, patient and family member partnership in the care process can be achieved.

**II. Perceived Barriers**

*Cultural Impact.* Several providers expounded on cultural views toward death and how it can negatively impact compliance. One nurse explained, “When asked why they are
not taking their prescriptions, they’ll say, ‘Well, I’m going to die anyway.’” They don’t think that they should try to better their quality of life for whatever amount of time they have left.

A lot of people take the fatalistic view, “If I’m gonna die, I’m gonna die.” They kind of feel helpless to make any changes. They feel like anything they do is not going to make a difference. What I see also is that they don’t want to take responsibility for making any changes. They want somebody else to take on the responsibility for changing their diet, for watching what they eat – “I just eat what they give me.” They’re not choosing. They have choices. That’s their decision. They want the help but they want somebody else to be responsible for giving it to them.

_Nurse with > 5 years in dialysis_

Another nurse stated:

They fear death but yet they’re not preventing it. You become creative in your explanations. You know, “Would you go home and cut a pill in half and just eat half a pill?” They say, “Of course not. The doctor told me I had to take those pills every day.” “Well, then why are you doing that with dialysis? Dialysis is a pill that the doctor has given you.” Then they’ll think about it. They get angry. You have to be creative with explanations because, if you’re not, they’re not going to do it [follow medical advice].

_Nurse with >5 years in dialysis_

Some see dialysis as the end, a death sentence… Like, “Michael mother’s told me what it was like therefore I’m not going to start it [dialysis].” “You know my neighbor or the person at the daycare told me about it.” “I know this man, and he was on it [dialysis] and he looked bad and then he died.” “So, this is going to kill me.”

_Social Worker with > 5 years in dialysis_

Religious beliefs and folk medicine can also impact compliance according to some providers:
Here, they’re Catholics so they might have a belief in a cure by praying. Especially at the border, you know, “My brother told me that instead of using this medicine, I should use that tea grandma used to use so I could get better.” So there’s a lot of ignorance in how they feel in general.

*Nurse with > 5 years in dialysis*

The traditional Mexican diet is a major obstacle to compliance. The social worker explained: The way they eat as a culture is not healthy. That’s the biggest culture-related change they have to make [for dialysis]. But the majority of them don’t make the change. Any dietician you interview in this area is going to tell you the same thing. And they don’t take their pills. When they’re told, “You’re going to have to take a pill as big as a horse, four of them, with every single meal, including snacks.” They’re not going to do it. They don’t understand what the concepts of phosphates or potassium and all those things. I barely understand them. That’s the majority of our patients.

*Social Worker with >5 years in dialysis*

One nurse:

Well, down here are mostly Hispanics and their eating habits are terrible. Even though they’re getting enough calories, they still go and eat extra calories. Or …they’ll go after foods with high amounts of potassium or minerals or phosphorus.

*Nurse with 2 years in dialysis*

According to the social worker, since we live in a high poverty area the type of food consumption has to be considered as an explanation for non-compliance. The majority of the people are buying food they can afford. The staples for this population are cheaper items like corn, flour, eggs and beans. The question becomes, “Is it good for them?” Yes, but not every day. They need to eat in moderation.

Lastly, machismo was also identified as a cultural barrier to adjusting to dialysis.

One nurse stated:
Culture has got a lot to do with it. I think the Mexican-Americans and their machismo of the man has a lot to do with it. The men think if all of a sudden they’re not the main provider, they’re not the man of the house. They watch others do all the things they used to do and that can play a huge part in it… Their machismo is “I have to be the man. I have to be in control.” That’s the biggest thing I see in the Mexican-American culture with their compliance.

*Nurse, facility manager, with >5 years in dialysis*

Summary of Perceived Barriers for Healthcare Providers

A variety of cultural characteristics and attributes were identified by the healthcare providers as obstacles to adjusting to dialysis. One cultural attribute was the concept of fatalism. It implies that one should submit to those things beyond their control or fate. Machismo is another cultural attribute identified which relates to the role of the male within the family unit that dialysis definitely impacts. Turning to folk medicine and healers as sources for a cure was also mention. The traditional Mexican American diet is an obstacle for reasons mention in earlier sections. The healthcare providers truly see perceived the Mexican American cultural attributes as an obstacle to this population living with dialysis.

**III. Advice**
The healthcare providers offered the following advice to Mexican-Americans to avoid becoming dialysis patients:

Diet - Stop eating those tacos and tortillas! And exercise. Diet and exercise.

*Nurse with 2 years in dialysis*

Education, Education, Education. People need health information specifically about dialysis, something about chronic kidney failure, the different stages - so they know where they are, what their chances are of developing Stage 5 where dialysis is needed.

*Nurse with >5 years in dialysis*
Get an annual checkup, identify health problems early, get immunizations, and follow medical regiments and medications. People need to make lifestyle changes.

*Physician with > 5 years in dialysis*

For those family members and individuals facing dialysis:

It depends on their age. If you have an elderly patient who’s had quite a bit of suffering and whose body is fatigued, the first thing I’m going to tell them is, “Think about this.” You really need to think about it. You’re going to follow a strict diet for the rest of your life. You’re going to take a lot of different types of pills so that we can keep your levels intact. You’re going to beef up on the biggest meals you’ve ever seen in two places three times a week. Think about it because this is going to be your life. With younger ones, there’s no choice. It’s not a death sentence. They can live. We can get them on a transplant list, and pray for the best… they can go into rehab counseling, go get an education, and go do something with their lives in the meantime while they’re waiting.

*Social Worker with > 5 years in dialysis*

Summary of Advice of Healthcare Providers

Their advice is very similar to those of the individuals with ESRD and family members. People need to change their lifestyle and behaviors. Prevention, exercise, and diet are imperative to avoid living on dialysis. They healthcare providers did offer an additional advice to family members and individuals who are immediately facing dialysis. Age of the individual must be considered because of the stress and demands of the treatment.

Summary of Cue to Action, Barriers and Advice of Healthcare Providers

The healthcare providers in this study perceived themselves as both a positive and negative influence to accepting and adjusting dialysis for this population. They are viewed as friends and family members to their patients because of the long-term interaction. On the other hand they are the enforcers of the medical regimen and compliance. This dichotomy is a challenge for healthcare providers that work with this population. Maintaining professional
boundary is hard because they perceive the dialysis population as a community - a community that is important to them, personally and emotionally draining, and that has changed their personal life.

Summary of Benefits, Efficacy, Cue to Action, Barriers, Threats and Advice for all Groups

In general, the individuals with ESRD, family members, and healthcare providers’ perceptions of the illness experience reflected three overarching themes: influences and obstacles, compliance and non-compliance, and needs and fears. For the individuals with ESRD, the collective effort of their family and children to accept and adjust to dialysis was seen as both a benefit and source of confidence (self-efficacy). While culture attributes and the actual dialysis regimen created barriers for them. For the family members, their loved ones with ESRD being alive are the driving force (benefit) for their willingness to change and accommodate for dialysis. Lack of information about dialysis and inadequate communication with healthcare providers generate frustrations (barriers) for them. And for the healthcare providers, they are the cue to actions for complying and adapting to life with dialysis.

Cultural beliefs, folk medicine and personal behaviors can hamper compliance. The challenge to managing the demands of this illness and experience arise from factors such as providing prevention, education, and lifestyle changes. These challenges not only influence how dialysis is perceived and the meaning given to it but also affect the level of resources available to adhere to the treatment recommendations. Reducing the number of people who may one day undergo this experience is center to the advice given to individuals, families and society. Prevention and behavior changes are the key. Knowledge specific to kidney failure, the dialysis process and lifestyle changes must be shared and addressed to the public.
Research Aim #2: Comparison of Concerns, Issues and Needs

This section synthesizes the findings described in the preceding section in order to address the second research aim of the study, *To compare the points of views between individuals with ESRD who have lived with dialysis for 6 months or more, their families, and the healthcare providers who serve them regarding the most prominent needs, perceptions and issues related to the occupational performance of Mexican Americans with ESRD living on dialysis.* The qualitative data from this study were analyzed for shared concerns, issues and needs within as well as among each group (see Table 8).

Macro Level of Concerns, Issues and Needs

On a macro level, each group expressed a concern about and need for education, communication, and social support. Limited prior knowledge about renal replacement options, the mechanics of the treatment process, and the physiological aspects of renal failure and dialysis were reported across all three groups. Individuals with ESRD indicated their need for knowledge about the dialysis both the mechanical process and treatment regimen. They understand that dialysis is a cleansing process but they lack a clear and deep understanding of how it cleans the blood and its relationship to the treatment regimen that they must follow. The family members also expressed their concerns about being in the dark regarding the dialysis process and its regimen. Lack of knowledge among this group has created varied perceptions and anxiety and even emotional trauma when confronted with the reality of their loved one being on dialysis. Even though the healthcare providers concluded that education was vital to compliance, they identified a lack of knowledge as a key determinant to noncompliance and adjustment to dialysis for the Mexican Americans population. They felt the educational level of their patients, the preference for the Spanish language, and their inability to provide early or pre-dialysis education were contributing factors to this issue.

Communication between and among the patients, family members and healthcare providers is imperative for this population. An absent of supportive and informative communication between the groups impact their overall acceptance and adjustment to living
with dialysis. The reasons given for noncompliance with the dialysis regimen ranged from denial of the condition, lack of finances to buy appropriate food and medications, to cultural behaviors and beliefs. All of these issues - communication and social support - impact compliance with the dialysis regimen as well as create occupational deprivation for both the individual with ESRD and family members.

Micro Level of Concerns, Issues and Needs

On a micro level, each group of respondents identified concerns, issues and needs specifically to them and their relationship to the other groups. Concerns involving loss of freedom, loss of time, and loss of valued activities as a result of the treatment regimen were identified by the individuals and family members that directly impact their perception of quality of life. Identity loss with respect to body image and perceived stigma of dialysis is likely to sway quality of life and occupational performance. Dealing with the bodily alteration and waiting for organ transplantation were specific stressors to the individuals with ESRD. The family members concerns were directly related to changes that the family members must make in order to increase compliance on the part of the individual with ESRD and to prevent occupational deprivation not only for the individual but also the family as a whole. They were responsible for the day-to-day management of life dealing with such issues as health, money, and household management. For the healthcare providers ensuring compliance with dialysis was the focus. Prevention, early referral and education, and treatment options are essential to reducing the increasing the number of Mexican Americans with ESRD and ending on dialysis.

Summary of Comparison of Concerns, Issues and Needs

The data suggest that the biggest concerns and needs that appear to influence acceptance, compliance and occupational performance in this sample of Mexican Americans living with dialysis are: knowledge, social support, communication, and personal relationships. The relationship between the individual with ESRD and family member is a major determinant for this population to take action necessary to prolong life while living on
dialysis. Therefore it is important for us to develop an understanding of the dynamics of these families and their communication patterns from a cultural perspective because the immediate family provides the primary support, cue to action, and self-efficacy for acceptance and adjusting to living with dialysis.

Table 8: Major Concerns, Issues & Needs

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<thead>
<tr>
<th>Major Concerns and Issues</th>
<th>Individual</th>
<th>Family Member</th>
<th>Healthcare Provider</th>
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<tbody>
<tr>
<td>Prevention / Early referral</td>
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<td>Treatment options</td>
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Research Aim #3: Occupational Performance Profile

This section describes the qualitative findings related to the research question, “To describe the day-to-day impact of living on hemodialysis from the point of view of the individual with ESRD who have lived with hemodialysis for 6 months or more and his or her family members.” In-depth interviews were analyzed to examine the individuals with ESRD and family members’ occupational perspective within the four domains of the Lifestyle Performance Model. The research sub-question, “What are the occupational deprivations experienced by individuals with ESRD living on hemodialysis that will prevent them from participating in occupations necessary for their spiritual, mental, physical, or economic well-being?” is also examined. The investigator did not want to bias the participants by providing a definition of “activities of daily living” or “occupational performance.” Instead the data emerged from the participants. The major reported areas are:

1. Definition of activities of daily living
2. Daily routine on dialysis and non-dialysis days
3. Occupational Profile
4. Occupational deprivation

Occupational Performance for Individuals with ESRD

I. Lifestyle Performance

Occupational functioning entails the interaction of the individual with the objects, situations, and surroundings of his or her home, family, and community (Radomski & Trombly, 2008). To understand the personal way of living for Mexican American with ESRD living with dialysis, the analysis centered on their definition of “activities of daily living” and description of their daily routine on both dialysis and non-dialysis days.

Meaning of activities of daily living. To understand a person’s quality of life from an occupational perspective, the perceptions and meanings applied to “activities of daily living” or “occupational performance” is vital. When asked for their definition, five of the
participants related “activities of daily living” to work tasks. For example, one respondent with 3 years on dialysis said, “Now that I’m on dialysis, it just means working and going back home.” Another respondent with one year of peritoneal dialysis stated, “I guess, I would say daily activity means being at work most all the day from 7:00 am to 2:30 pm in the afternoon.”

Five of the participants gave a more inclusive definition of the term. A dialysis patient with five years of dialysis said, “Activities of daily living for me would be grooming, dressing and bathing. It’s what I do every day.” Another dialysis patient with four years of dialysis stated, “It’s going out with my wife, her taking me to lunch.” A dialysis patient with three years of dialysis affirmed, “Daily activities are something that I do daily not necessarily going to work. It could be things like hobbies or taking medications.” An additional dialysis patient with three years on dialysis said, “Daily occupation is eight hours a day work, getting home, getting dressed and going to play softball.”

To demonstrate how perceptions and meanings can change, dialysis was identified as an activity of daily living, by several participants. When asked about the most important and least important activities they responded:

What’s most important is trying to be as compliant on my dialysis, taking my medications and doing my treatments, because without that, there’s not going to be any daily activities. So that would probably be the most important. The next would be that I’m doing all I can to be as healthy as I can now.

Roel, a dialysis patient for 5 years

The most important one I think is the dialysis and the other is work. And the least important is probably my extra-curricular activities, like fishing or going to the park.

Arturo, a dialysis patient for 3 years

The definition of activities of daily living for respondents entailed those tasks and activities that were relevant to the daily life. Some of them only saw work as their occupational task while others were more inclusive including such things as dressing, bathing, grooming, and leisure activities. Over time dialysis were perceived as just another daily task that must be attended to.
Daily Routine. As the participants described their day-to-day routine, everything revolved around the renal replacement therapy – hemodialysis or peritoneal. It became clear that the renal replacement therapy impacted all routines regardless if it was a dialysis or non-dialysis day. For those who receive hemodialysis, a typical dialysis day completely centered on the treatment session. It was described as:

My usual routine each day is: I’ll get up sometime between 7 and 8, and it doesn’t take me a long time to get out of the house. Usually I like to come to town and have breakfast. My wife is still working so she’s up and out of the house. I’ll just come to town go to one of the coffee shops and I’ll have a cup of coffee, watch my liquids, and have a couple of eggs and some toast, kind of get my day started that way. Then I’ll come by the office maybe for an hour on Monday, Wednesday, and Friday, which are my dialysis days. I’ll just come in and open mail, that’s about all I can get done on those days and then I’ll go to my dialysis. I’m there for 4 ½ hours, of course it’s about 5 or a little more once I get all set up, to get hooked up and unhooked, and out of there. By then I’m ready to go home. I'm not real tired but I realize I don’t need to push myself so I’ll go home for the evening.

Hector, a dialysis patient for 3 years

Dena’s day entailed:

I make breakfast for my daughter, get her ready for school. On the days I have dialysis, I go drop her off at school, go for dialysis. I am there for 3 hours, get out, come home for 1 hour and rest a little bit. Then I go pick her up from school and after school is when she has her after-school activities like kickball, softball, and everything. Since the park is just right here across the street, we are over there until almost 9 o’clock at night.

Dena, a dialysis patient for 11 years
Roel recounted his daily routine as:

Monday, Wednesday and Friday, I have my dialysis days. So when I get up I’m there all day. I go in at 10:30 and I get out around 4 or 4:30 - 4 o’clock. So, I’m usually up about 8:30-9:00. I’ll occasionally turn on the computer. I have an interest in the stock market. I take a look at the stock indexes and see how it’s going. About 9:00-9:30 I have breakfast, get dress and by 10:00 I’m on dialysis. I’m there all day. I get out usually about 4 o’clock, I usually go grab something to eat; I do a little exercise maybe some walking. I’ll go to the mall or golf course there are people there. Then I go home about 8 o’clock eat dinner then I watch some television or get on the computer again.

Roel, a dialysis patient for 5 years

Non-dialysis day routines varied between those who worked and those who did not. For those who worked, the non-dialysis days were focused on work related tasks:

Tuesday and Thursday are my work days, I’m usually in the office by about 9, and I’m either on the phone or making trips up and down the road, calling on customers. …. But usually on Tuesday and Thursday I’m having lunch with somebody on business and sometimes I’ll work to a little bit after 5. I’m pretty active as far as Tuesdays and Thursdays and then of course Wednesday comes back again and it’s back in that routine… Saturday it’s just usually sort of a family day and Sunday is a church day.

Hector, a dialysis patient for 3 years

On a non-dialysis day, I wake up, go wash up, use the restroom, get ready for work, eat breakfast, and take off. And then when I’m working I just deliver loads all day. Eat lunch. Keep delivering loads until I can’t, and just go back home.

Arturo, a dialysis patient for 3 years

For those who did not work, their non-dialysis days centered on attending to general self-care and self-maintenance activities. For example: “Tuesdays and Thursdays, I do my cleaning chores or anything else that needs to be done.” Dena described her non-dialysis day:
Well, I just go drop her [child] off at school, come home, go back to sleep for an hour, two hours, do a little of light cleaning, with the provider if she’s here with me, and then we go out, usually to the mall, just to distract myself. Go have lunch at the mall and then come home, cook something for my daughter and then go pick her up and then the same after-school sports.

_Dena, a dialysis patient for 11 years_

The 3 participants on peritoneal dialysis endure dialysis on a daily basis. Ana, a dialysis patient less than 1 year, stated:

Every day is a dialysis day. I’m on it all night, so in the morning the first thing I have to do is get off of it. Then I have to take the empty bags, put them away, that normally takes 10-15 minutes to get all that squared away. And then I get in the shower. I always have to be careful after that to clean and take care of my exit site, where the tube comes out. I always gotta clean and I gotta remember to do that every day. So, just the physical aspects of dialysis take up a part of my routine now. I eat breakfast, get in the car, go to work and then have fun there all day. At the end of the day, I come home, fix my dinner, watch some TV and then go upstairs. But before I hop into bed, I have to set up the machine and get the bags out, plug in the machine, wait for it to warm up, and do the antiseptic washing. Then I plug it [catheter] into the machine and get into bed. It’s not like I’m tired and going upstairs to go to bed; I got at least a half a hour messing with the machine and waiting on it before I can go to sleep.

_An, a dialysis patient with < 1 year_
Linda, a dialysis patient for 1 year, described her daily routine as:

Well, I wake-up at 3:50 am. I turn the [dialysis] dissolution rate to warm up…It warms up for about an hour. During that time I just lie there or take a shower or just wait for it to warm up. Then I put it [dialysis] on about 5:00 am in the morning. I eat something or just take a quick nap, then leave for work around 6:30 am. And that’s my morning routine, now. I work for 8 hours straight. They do give me 1 hour for lunch, just to come home and to do another exchange. I am suppose to do the exchange at 10:00 am but since I have lunch at quarter to 11:00. So, I go home do the exchange, put in the other one, then eat something and then go back to work. I get home at 3:30 pm. I wait until 4 o’clock to do the other exchange. I wait until 8:00 pm for the fourth bag. You are suppose to do four bags per day. On my days off from work, I start at 8:00 am… I wake up at 7:00 am, turn it on; put it [dialysis exchange] in at 8:00 am, 12:00 noon, 4:00 pm, and then at 8:00 pm.

Lauro, a dialysis patient for 1 year, described his day as:

I got a cycler which is better because I just do it [dialyze] every night. I just take my pills before I go to sleep and then the cycler does everything. It does 5 cycles per night. In the morning by the time I wake up, it’s complete already. In the morning I usually wake up late, I clean my area and I take out the bag, which is all trash. Then I get my pills ready. I take my pills and then eat something. After I’ve had breakfast, the rest of the day I usually just watch TV. After I get bored watching TV I use the computer. After that I go out get some sun. And after that I sometimes get some sleep or just wait until my sister gets home.

The daily routine for this population was dependent upon whether it was a dialysis or non-dialysis day. On dialysis days everything centered on going to the in-center facility for treatment sessions. And non-dialysis days all other life tasks were attended too. For the individuals on peritoneal, everyday is a dialysis day.
Summary of Lifestyle Performance for Individuals with ESRD

Overall the individuals with ESRD found meaning and some level of satisfaction with their daily life tasks. Activities of daily living included dressing, bathing, grooming, working, and leisure activities. These were tasks that they willingly engaged in, gave meaning too, and support by their environment. Over time the dialysis treatment sessions were viewed as just another task that they had to engage in. They distinguished between dialysis and non-dialysis days. Dialysis days revolved the treatment session – get up, get dress, go to dialysis, eat, go home, and go to bed. Non-dialysis days encompassed working, visiting family and friends, or completing basic household tasks. Those on peritoneal, even though it gave them more freedom, faced dialysis on a daily basis.

II. Occupational Profile

Results of the exploration of the domains of the Lifestyle Performance Model provided an understanding of the personal meaning of the individual’s daily activity engagement and lifestyle. It indicates those tasks and activities that are routinely carried out as one chosen patterns. The findings of the analysis revolved around two overarching themes – adapting and changing behaviors.

Changing and adapting were perceived in all of the domains of the Lifestyle Performance Model – self-care and self-maintenance, societal contribution, intrinsic gratification and reciprocal interpersonal relatedness. For individuals with ESRD the necessitate of adapting and changing stemmed from the rigid treatment schedule, diet and fluid restrictions, medical regimen, and loss of time with family and friends.

Self-care and self-maintenance. In the area of personal hygiene, self-care, grooming and dressing, 86% (n=13) reported no changes in their abilities to perform these basic tasks. Only two respondents, one on hemodialysis and one on peritoneal, described how they had to adopt new methods to accomplish these task:

There are times when I need help getting dressed and my wife helps me out. I have a chair, a shower chair that I sit in when I bathe. That makes it a lot easier.

Carlos, a dialysis patient for 3 years
I get in the shower and I always have to be careful to clean and take care of my exit site, where the tube comes out, so I always gotta clean and I gotta remember to do that every day. I need fresh towels every day.

*Ana, a dialysis patient for <1 year*

In the area of managing their living area, fear of damaging their dialysis site or fistula and tiring easily were the driving force behind changes and adaptations:

I can do practically everything I could do before, except for really heavy lifting I have to watch out for my stomach. But I sweep, mop, vacuum, take out the garbage, carry in the groceries, carry out the laundry. It takes me a little longer because I tire easily, but really I haven’t found anything really that I could not do before.

*Ana, a dialysis patient for < 1 year*

A gender difference was noted when asked about household responsibilities. The males (n=8) of the study described their household responsibilities outside of the house such as the lawn or car work. For example, a dialysis patient with one year on dialysis said, “My wife does the meal preparations. I cut the grass.” Another dialysis patient with five years on dialysis stated, “Household tasks, I limit myself to yard work.” One more dialysis patient with four years on dialysis said, “….I cleans up the truck.” The female participants described their household responsibilities as inside the house such as cleaning, doing laundry and cooking. A dialysis patient with five years on dialysis described, “Basically I do cleaning, sweeping, mopping and washing dishes.” One dialysis patient explained, “I guess wiping and dusting and my provider moves the furniture around.” A dialysis patient with one year on peritoneal stated, “I just cleaning, washing dishes and putting away stuff.”

The most prominent areas of change and adaptation were money management and travel. Several of the participants (n=7) talked about the hardship of living on the limited funds from Social Security or disability and its impact on their overall finances. If you work, there is a constant fear of losing those benefits:
You can get the disability check but you really can’t make as much as you want without getting into trouble. I can’t really work as much because I can only make so much per month. You really have to be very careful of how you work and how you are paid. In other words, I’m kind of stuck between a rock and a hard place because if I were to get off my disability, I wouldn’t make enough because I only work twice a week. But with disability of $800 dollars per month you really don’t make that much to live comfortably. So I’m kind of stuck between a rock and a hard place. If I were to go to work, I would have to work Saturdays and Sundays just to make up my 40 hours a week. And that really doesn’t work either.

*RD, a dialysis patient for 2 years*

When receiving social security benefits you can’t earn that much because they’ll cancel them. I have to handle the family finances because they [Social Security] think that what they give you, you’re supposed to make do with that. I’d like to see them try it.

*Arturo, a dialysis patient for 3 years*

Wanting to be self-sufficient, Linda selected to go back to work full time but always mindful of the limits in her earning potential:

I went back to work in June. I was working part-time - 20 hours per week. Supposedly Social Security does not want you to work more than part-time. Working part-time was killing me. I couldn’t make the payments of the car, the rent, and the lights all on one check. I had to manage all that. So, I had to go back to full-time and risk it. Now, I’m still full-time. I’m still getting paid. At least I’m managing but I’m stressed out. Another thing, if I what to do overtime, I have to be careful because of Social Security. Getting the Medicare and Medicaid, I don’t want to risk those being taken away from me. I keep telling my Mom, I can’t do anything. I can’t go do overtime. There’s a lot of overtime at work right now. I can’t do it because I need to be careful. And she says, “Why don’t you just get yourself a kidney and you can do whatever you want. Work all you want.”

*Linda, a dialysis patient for 1 year*
The loss of or change in income was of concern particularly when it was perceived as interfering with the person’s ability to be independent as evident in the following examples:

I try to keep at least one month’s salary in the bank, because I know I’m gonna need it because they only give us 10 sick days in a year. I run through them before Christmas… that happened about a year ago when I had a flair-up and I missed enough days that I lost the entire paycheck… So I called payroll and said, “Aren’t you supposed to take it out half and half.” They said, “Well we decided to take it out all at once.” I said, ‘Well what are people supposed to live on.” So 2 days after that I have a little heart thing in the room and the kids…… I carried this big pile of test booklets and stuff and it seemed like it weighed a freaking ton and I’m worrying you know how I’m gonna make it to my room. But I get them all settled down and I start passing out the booklets and all of a sudden, the walls start to tilt and I’m going, oh my god. I stepped back a minute and then the kid in front of me he goes, “Ma’am are you ok?” All I can think of is I’m feeling extraordinarily bad. He jumped up and he got my rolling chair and he got it behind me so I didn’t fall on the floor. I had pain in my chest and all their eyes are like this and they’re like do you need the nurse and they’re all push the button, push the button. It was a little blockage but I think it was just stress over my paycheck. I was back at work the next day and then the most wonderful thing happened. I was bringing in my folders in the morning and there was an envelope there with all these anonymous little notes with money, with money. It was about $1800. It was from everybody… and that was the minimum amount of [money] that I needed between what I had in savings and everything. God knows that was my budget, so that’s exactly what I got.

Ana, a dialysis patient for < 1 year

Traveling was the other area of major change and adaptation. Even though there was a general awareness that it is possible to receive dialysis treatment on a temporary basis in other facilities, many of the participants did not consider this as a viable option for traveling or visiting families and friends. Either they did not want to go through the perceived hassle
of making arrangements or they were fearful of missing the call for a kidney transplant. One participant stated:

That’s been cut out too. Now being able to just leave and take off and travel can’t be done anymore. I have to make reservations or make sure that I can get my dialysis done. So if I’m going to leave town, I’ve got to plan it a week or a month in advance so I know where I’m going to go, where I’m going to stay, where I need to be and what time. It really does restrict me because I’ve always been one to pick up and go. My nature is to just take off and now I can’t do that. I need to sit back and say “what are the consequences if I do that.” In the last five years, I’ve only taken 2 out of 10 trips because of having to plan in advance. So, if I go to Vegas, I need to call in advance and find out where I can go and what I can do, get a hotel that can accommodate me, get transportation everywhere, etc. It takes all the fun out of it.

Roel, a dialysis patient for 4 years

Another participant said:

I want to [travel] but dialysis has stopped me. I have to be on call. You need to have a phone on you all the time because they can call about a transplant. I don’t travel because I don’t want to miss the call for a transplant. So right now I can’t do anything.

Linda, a dialysis patient for 1 year

Ana, who is on peritoneal, compared traveling with her dialysis machine and supplies to that of traveling with a small child:

And traveling, oh my god, that’s just not like get on a plane anymore, I mean you have to plan in advance so the dialysis company can deliver your stuff to the place you’re going. And then you gotta take your machine with you. Life is complicated now. It’s like having a little kid again, where there’s something else you have to take care of. It’s demanding of your time and you can’t ignore it.

Ana, a dialysis patient for < 1 year

Changes and adaptation were seen in the area of self-care and self maintenance. The main changes were noted in household duties, money management and travel. In regard to
household tasks care had to be taken not to damage the access point for dialysis. Living on the limited funds from Social Security or disability proved to be devastating to their overall finances. If you work, there is a constant fear of losing those benefits. The loss of or change in income was of concerns particularly when it was perceived as interfering with the person’s ability to be self-sufficient and independent. Traveling was another area of change and adaptation due to dialysis. Even though there was a general awareness that it was possible to receive dialysis treatment on a temporary basis in other facilities, many of the respondents did not want to go through the hassle of making arrangements. One participant refused to travel for a fear of missing the call for a kidney transplant.

**Societal Contribution.** This domain comprises of those activities and tasks that contribute to the welfare and need fulfillment of others. It encompasses those activities that contribute to a sense of self as a productive member of one’s society. Five of the participants indentified with their role as a wage earner even those who worked part-timed. One dialysis patient with three years on dialysis said, “I work like 20 hours a week sometimes it’s 20, 25 hours. On a good week, I’ll put in 30 hours.” Their careers and jobs included a teacher, estimator for an electric company, truck driver, insurance person, and customer service representative. When asked about the impact of dialysis on their career choice, one participant stated:

> When I graduated from high school I went to college and I didn’t like it. So I just quit and started working for the school district and every day I would come out with a headache from the kids screaming. That’s when I decided to go into trucking and from there on I liked it. Well the major thing that it [dialysis] changed for me is my job. I really liked my job a lot, being out of the road, seeing all the different states; that is the part I liked a lot, besides the paycheck. I used to make $1000 a week and now it’s like $1000 every month and a half. At first I really liked my [current] job but then you start doing it and you like it, but then you see a truck driver driving by and you think, “Man that could be me.”

*Arturo, a dialysis patient for 3 years*
In terms of non-wage-earning activities that contribute to the well-being and needs fulfillment of others, many of participants (n=10) expressed no engagement in volunteering activities within their community or church. The reason most often given was being tired after dialysis:

When I get home from work, I do the exchange and go straight to bed. I’m a little bit tired because I wake up at 4:00am. And on my days off, just leave me alone.

_Linda, a dialysis patient for 1 year_

I was always doing something for my writing group, but once I got sick, it was just physically too demanding and I had to let it go.

_Anna, a dialysis patient for < 1year_

Some reported that they did not engage in any type of volunteer activities prior to being dialysis. Volunteering did allow at least two participants to use their formal training and skills:

I volunteer with some organizations so when I was helping them I used my background in marketing to help them with fund raising ideas and promotion tasks and ways to raise money. Some of my previous jobs, I held position of promotion manager. I’ve done a lot of special events type promotions mostly for the newspaper. Which events are coming out, which are beneficial to the organizations?

_Hector, a dialysis patient for 5 years_

Ruben, a dialysis patient for one year, expressed the participants’ sentiment about volunteering, “I should [volunteer] but I don’t.”

The respondents in this study identified with their role as a wage earner even if they worked part-time. Their views and sense of being a productive member of one’s society were impacted because of the financial limitation placed on them as a dialysis patient. Career choices and work schedules all required some level of adaptation and change because of dialysis. In terms of non-wage-earning activities such as volunteering, many of the respondents reported no change because they did not engage in those activities prior to dialysis. Those who valued volunteering did so not only to help others but also to maintain
their formal skills and educational training since dialysis has impeded their ability to work full-time.

**Intrinsic Gratification.** This domain focuses on those activities that are devoted to personal pleasure and enjoyment. The participants all reported engagement in some types of pleasurable activities. These activities ranged from gambling, fishing, going to the park, dancing, walking the mall to sleeping. Ninety-three percent (n=14) of the participants described themselves as no longer able to part-take in their fun activities in the same manner. A decrease in the frequency of these activities was the most common change reported.

Arturo, a dialysis patient for 3 years, stated, “I used to go fishing a lot maybe 2-3 times a week. Now I only go once every 1 or 2 months.” Ana talked about her sense of loss:

I can’t go swimming. I can’t even take a bubble bath that was hard to give up too. Of course that was always my refuge, a nice hot tub, but I can’t be submerged in water so no more of that. I can’t even go down and have a swim at the beach so no more of that... In fact that’s the last thing I wanted to do the night before my surgery. The last thing I wanted to do the night before my surgery was to go down to the island. I wanted to go swimming. Of course that was always my refuge but I can’t be submerged in water so no more of that. I can’t even go down and have a swim at the beach so no more of that.

**Ana, a dialysis patient for < 1 year**

Ashley voiced the change in her past-time;

My plants, to work on them, but I can’t plow [in the garden] anymore. But the ones that I have in pots, I can add dirt, water, and work on them. [*Translated from the Spanish*]

**Ashley, a dialysis patient for 6 years**
Lauro explained how his fun activities changed:

Activities that I do for fun are play soccer, besides sports, um go out with friends to movie or dinner, bowling, and mall. On the weekend, I go to a club or so. Some of these activities have changed a lot. For example, going out with friends, before I could drink and stay up very late and even stay over at some other friends’ house or some other place but now that I have to do dialysis I have to get home cuz I have to do my dialysis.

*Lauro, a peritoneal dialysis patient for 1 year*

Ruben stated that dialysis has not prevented him from participating on a local softball team:

Once I finish dialysis I have them tape my arm up pretty good because I’ve got to come back to play softball because I play on Mondays, Tuesdays, Wednesday, and Thursday…Come back have a little bit of dinner with my son and get ready to go play ball with him.

*Ruben, a dialysis patient for 1 year*

Some of the respondents discussed balancing planned activities with spontaneous decisions. Roel talked about his loss of spontaneous decisions:

That’s been cut out too. Now being able to just leave and take off and travel can’t be done anymore. Now I have to make reservations or make sure that I can get my dialysis done. So if I’m going to leave town, I’ve got to plan it a week or a month in advance so I know where I’m going to go, where I’m going to stay, where I need to be and what time. It really does restrict me because I’ve always been one to pick up and go.

*Roel, a dialysis patient for 4 years*

Satisfaction in this domain requires a clear understanding of your own wants and needs regarding fun and enjoyment. The respondents in this study expressed the pleasure that they received from the activity. However, dialysis had required them to make adaptations and changes either to the manner or frequency in which they engaged in their pleasurable activities. Because of dialysis spontaneous decision to do something for fun has been eliminated. Everything has to plan therefore making it hard to balance planned activities
with spontaneous ones. Few of the respondents indicated their participation in cooperative, cultural, or indoor activities as a source of intrinsic gratifying.

Reciprocal Interpersonal Relatedness. This domain covers those activities that enrich one’s relationship with others. These are activities that are shared with loved one, family, friends, and colleagues. Interacting with family and friends was important to all of the participants:

Grandkids, we’ve got 3 children and 6 grandchildren and they all live here locally, so we get to go to soccer games and basketball games and football games, so we try to take it all in. My life really revolves around family and church. We’ve always been really involved with family, whether we’ve been close to them or not. Now we’re fortunate to be close to them. But usually during the week sometime I’m with one of my kids, or talking to one of my kids, or doing something with my grandkids. We help out the kids wherever we can with the grandkids and we love to do that. We built our home and one of the bedrooms is the grandkids room and it’s built around the grandkids with bunk beds and a DVD so they can watch their movies, and toys and it’s at the other end of the house from our bedroom, so we were smart in that regard.

Hector, a dialysis patient for 3 years

Several of the participants talked about the impact of prior family relationships and physical proximity on their interaction. Mike, a dialysis patient for four years, described how his family relationships were affected by dialysis:

I’ve only got a sister and she lives here in Brownsville but she doesn’t go out either too much.. Then my brother is over there in Houston, another sister is in Corpus, and the other brother is in California. The only thing I can do is call them up and that’s how we keep in touch.

Mike, a dialysis patient for 4 years
On the other hand, Arturo reflected on the closeness he experiences with his family:

I see my mom, often. If I don’t see her I’ll call her and my dad too. I’ll usually see them on the weekends and during the week too, probably for 30 minutes or an hour. I just stop by and say hi.

*Arturo, a dialysis patient for 3 years*

The importance of this domain to dialysis patients was expressed by Linda:

My older sister is the one who takes me everywhere she goes. Sometimes we go to Corpus, San Antonio, just to go have dinner or whatever. She takes me to the zoo with her, to the mall, everywhere, anywhere she goes. ……. [time with my family members] is very important, because sometimes I get depressed. Like if there’s one day that goes by that they don’t call me or come over, I get so depressed. I’m used to having them around me. I mean they’re the reason I’m still here.

*Linda, a dialysis patient for 1 year*

Loss of friends and fear of socializing emerged as a point of dissatisfaction and change for several of the respondents. This was seen as an unexpected outcome of dialysis:

I go to my friends’ houses. Like last night we went, they had a little cookout there for Father’s Day. I got there at about 8 at night left around 11, so I was there for 3 hours. But I still visit my friends, you know, only up to when I get tired and then I go home.

*Arturo, a dialysis patient for 3 years*

Because of the effect and regimen of dialysis, Lauro lost several friends. He said:
I think my social life has changed most of all….probably the friends that I used to have. I don’t talk to the friends I used to hang out before and it’s weird. After such a thing [dialysis] happen to you, you know who your friends really are… Before I had these friends that would call me and we go out on weekend. Back then we were all good friends, right. But then after I started dialysis, I wouldn’t actually hear from them. I would just hear from my real close friends who are my really good friends right now. I still keep in touch with other people that I used to go out with and used to talk to at school but it’s not the same. They know you don’t go out that much, that you don’t drink anymore, and that you don’t stay up late. Before I could drink and stay up very late and even stay over at some other friends’ house or some other place but now that I have to do dialysis I have to get home. I have to do my dialysis.

Lauro, a peritoneal dialysis patient for 1 year

Ana talked about how dialysis changed her social life.

Well, I mean alcohol is out, not that I was a big drinker anyway, but my friends, we will go on trips, conferences and in-services. Usually the first night we get there, let’s go find a bar. I’m like, ‘Thanks but, no thanks.’ And they’re saying, “Aren’t you gonna come?” And I’m like no, because… you have to explain why you’re only drinking iced tea. But essentially I do things with my husband, we’re separated and we’ll go out to dinner and stuff like that or I go visit my friend, Emily, she’s my best friend.

Ana, a dialysis patient for 1 year

Activities to develop and sustain relationship with others especially family members were very important to the respondents. Not only does the strength of the bond have an impact on the quality of the relationship and satisfaction but also prior family relationships and physical proximity can enhance satisfaction within this domain. Dialysis appears to have the most impact on the relationship with friends and the social activities that go along with these interactions. The change in diet and fluid requirements, treatment schedule, and physiological effect of dialysis caused some respondent to avoid social interaction all
together. Not wanting to explain why they were not able to interact led to a decline of satisfaction within this domain.

Table 9: Areas of Significant Occupational Changes and/or Adaptation

<table>
<thead>
<tr>
<th>Areas</th>
<th>Individual</th>
<th>Family Member</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-care &amp; Self Maintenance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Managing household task</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Preparing meals</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Money Management</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Health Management</td>
<td></td>
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</tr>
<tr>
<td>Traveling</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Social Contribution</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Career or job</td>
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<td>✓</td>
</tr>
<tr>
<td>Volunteer activities</td>
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<td>✓</td>
</tr>
<tr>
<td>Working inside home</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Working outside home</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Intrinsic Gratification</td>
<td></td>
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</tr>
<tr>
<td>Active participant</td>
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</tr>
<tr>
<td>Competitive activities</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Cooperative activities</td>
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<tr>
<td>Outdoor activity</td>
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<tr>
<td>Reciprocal Interpersonal Relatedness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interacting with family</td>
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<td>✓</td>
</tr>
<tr>
<td>Interacting with friends</td>
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<tr>
<td>Social events</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Group activities &amp; affiliations</td>
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<td>✓</td>
</tr>
</tbody>
</table>

Summary of Occupational Profile for Individuals with ESRD

The activities in each domains and the environment in which that take place are dictated by the needs of dialysis. The dialysis regimen, dietary restrictions, and physiological effects force the individuals with ESRD to change and adapt their interaction with family and friend, career and work choices, engagement in pleasurable activities, and self-care and self-maintenance. Fear of damaging the access point, losing income and missing an opportunity to get a kidney were concerns in determining satisfaction with their level of participation. Not wanting to always explain to others why you are not participating in activities caused some to eliminate social interaction all together. Dialysis compelled the respondents to plan
even their pleasurable activities. An activity which is purposeful and meaningful to the
individual contributes positively to that person’s perception of his or her own quality of life.
Family activities and interaction as well as the quality of the relationship—not quantity of
relationships—clearly enhanced their satisfaction with their life on dialysis.

III. Occupational Deprivation

People, who are deprived of occupational opportunities beyond their immediate
control such as ESRD and living on dialysis, may suffer from occupational deprivation or
disruption. The individuals with ESRD in the present study perceived themselves as living
very restrictive and deprived lives. A number of factors previously described contributed to
this perception. However, three prominent factors about living with dialysis emerged from
the data as preventing full participation by individuals with ESRD living in occupations that
have meaning or cultural significance are: bodily alteration, physiological effects of ESRD,
and the dialysis schedule.

Bodily alteration. Occupational deprivation can arise from individual characteristics.
Changes in the physical body constitute a barrier to occupation because “someone or
something external is doing the depriving” (Whiteford, 2000, p. 201). In the present study,
the respondents’ ability to engage in occupational was restricted by the body alteration
needed to receive renal replacement therapy:
It’s just the physical thing of having a tube coming out of your body and having to deal with that because it’s just bizarre. After the surgery it was more than a couple of weeks before I could even look at it because it was covered up with a bandage. But my daughter came to take care of me and when she would change the dressing, I would just turn my head away and close my eyes. I don’t want to see it. I don’t want to know what it looked liked. I don’t want to touch it. I just can’t do that yet. And ya, that was hard, just dealing with the physical alteration in your body, that wasn’t too pleasant… I had to kind of adapt my clothing because I’ve got the tube right at my waist and so I had to find clothes that didn’t irritate it or didn’t pinch and pull my tube. The biggest thing is the discomfort with the tubing snagging my clothing.

*Ana, a dialysis patient for 1 year*

When they [people] see my fistula they go, “What’s that? “ And I say that’s where I do dialysis and my other arm is all small compared to this one with all the scar marks and that’s hard. ……I’ve never had negative comments. The only thing is ….when I go through a drive-thru or something and to hand them the money, they stare at it but I just try not to think about it.

*Arturo, a dialysis patient for 3 years*

I used to wear short-sleeves and now I wear long-sleeves because I don’t want people to see me with this thing [fistula] here, this thing inside my arm because you can see it… Every time I go out now I wear long-sleeve because I don’t want people to see my arm.

*Mike, a dialysis patient for 4 years*

The bodily alteration of renal replacement therapy creates limitation and deprivation in the occupational domains of self-care and pleasurable activities. The respondents have to endure a change in their dressing style and self-image with dialysis. The social exclusion and questions created by the stigma of dialysis may contribute to the experience of occupational deprivation.

*Physiological effects.* The physiological effects of ESRD and dialysis treatment lead to disruption and deprivation in an individual’s ability to work or even engage in routine
activities of daily living. The many medical complications, weakness and fatigue associated with ESRD and dialysis are generally considered the source of this occupational deprivation:

Since I’ve been on dialysis, as far as working, it hard. The doctor has restricted what I can and can’t do. He [doctor] restricted me because I can’t have anything damage my access [fistula]. The other thing is to relief the pressure to keep my blood pressure under control. I’ve been in middle and upper management positions as well as lower position. With the restrictions I really can’t do what I used to do or what I want to do because it either raises my blood pressure or it’s to physical for my access. So, I can’t do any damage to my body in the meantime while I wait for a transplant.

Hector, a dialysis patient for 5 years

I just hate having to ask the operating manager, my supervisor, can I get a day off for doctor’s appointment and things like that. And I really don’t like bothering him. If I end up in the hospital because of an infection or stomach problem, I have to call him. “I need to take an LOA, I’m in the hospital, this just happen right now.”

Linda, a dialysis patient for 1 year

Several participants resounded the phrase “I’m too weak or too tire” to participant in daily activities. One dialysis patient with four years on dialysis said, “I used to dance a lot. But I’m too weak for dancing.” Another dialysis patient with 11 years on dialysis said, “I feel light-headed and dizzy after dialysis. But as long as I take an hour nap afterward, I can get and go.”

The physiological and medical complications associated with each dialysis sessions generate barriers to occupational performance and deprivation. The psychological, mental, and emotional challenges of dialysis alienate these individuals from opportunities to be involved in everyday daily activities.

Dialysis schedule. The fixed four hours three times-a-week dialysis schedule or the every four hours peritoneal exchange created limitations in the participants’ sense of freedom to come and go. As Linda stated:
The only problem [with hemodialysis] was that I hated coming here because if I wanted to do something, I couldn’t because I was stuck here. Sitting there for 4 hours with no blanket…it was just that I couldn’t do anything else. I couldn’t go walking around. I had to be stuck to the chair. Peritoneal offered more freedom. “Do the exchange. Get it over with and do what you need to do. Come back do another one in four hours.” [Are you scheduling your activities around the exchanges?] Basically yes. It’s tiring sometimes. I don’t feel like doing it but I’m supposed to. Sometimes it pisses me off because I have to do it. I want to do it the way that I want to do it at my scheduled time because sometimes thing comes up.

*Linda, a dialysis patient for 1 year*

The physical environment and schedule of dialysis inhibit occupational engagement for people living with dialysis. It prevents them from doing what they want to do, when they want to do them, how they want to do them, and when they need to do them. The physical environment of the in-centered hemodialysis facilities and sitting there for 3-4 hours constrains opportunities for occupational involvement for prolonged periods of time. The shortcoming of the environment fosters dependence and occupational deprivation.

**Summary of Occupational Deprivation for Individuals with ESRD**

Deprivation from occupations of meaning or cultural significance is made worse by dialysis. Diminished functional ability, time restriction, and an alter body combine to deprive individuals with ESRD living on dialysis the opportunities to fully participate in their preferred occupations such as travel, work, spending time with family, household tasks, and leisure activities such as shopping, yard work, going to the movies and dancing. The condition of the environment, social attitudes, and the individual’s physical, psychology, emotional and cognitive limitations are restraints to occupational performance and engagement in individuals with ESRD living on dialysis.
Occupational Performance of Family Members

In the interest of understanding the impact of dialysis on the day-to-day occupational performance of family members, two distinct point of views emerged from the data: those who worked outside the home and those who worked within the home. Even though there were some similarities between the groups, their perceptions were colored by their responsibilities.

I. Lifestyle Performance

Definition of activities of daily living. As the family members talked about their definition of “activities of daily living,” other than the typical items, 80% (n=12) included taking care of the individual with ESRD as a part of their definition. One family member stated:

Daily occupation, well, is taking care of my husband and of his needs for his dialysis because we were doing peritoneal dialysis at home. That’s a lot of work - taking care of having the supplies, preparing the machine, and all of that. Other than that well there are always the homemaker activities which involves house cleaning, laundry, vacuuming, then groceries, taking care of getting all the medical supplies for my husband, and all of that.

Lela, widow, husband on peritoneal dialysis

Another declared:

Well most of my occupation is my husband. I mean, taking him to the doctor, taking him to dialysis on the day that he needs to go and taking care of him. I mean cooking for him and doing a little bit of work around the house. [Translated from the Spanish]

Helen, husband on dialysis

Those family members who worked (n=8) and had their own family, defined “activities of daily living” as a combination of attending to needs of not only their own family but also of the individual with ESRD. Alicia, whose mother is on dialysis, said:
Well most of the time either I’m taking care of my mother or the kids. It’s like in my mother’s case she goes to dialysis three times a week. So that really takes up a lot of my week, like dropping her off and going and picking her up. Even though there’s transportation available she doesn’t like it. She’s afraid. So you know at least we’re trying to make her feel better, you know, not too scare her.

_Alicia, mother on dialysis_

All the family members conveyed the inclusion of attending to the loved one with dialysis as part of or center of their definition of daily activities.

_Daily Routine._ Those family members who do not work (n=7) described their daily routine in relationship to the dialysis schedule of the individual with ESRD. Patricia described her day as:

Well, I get up in the morning. He gets up. I prepare him breakfast and coffee. I check his blood sugar before he eats breakfast and I give him his medicine. And I usually dress him up…I check his feet and sugars. Then after he has breakfast, I give him his insulin. He takes insulin and another pill for taking care of his blood sugar. On a regular day about 10:00 am he goes out for a little walk… So that’s two hours that I have in between, so that’s when I do a little bit of housework or something for myself. And then he comes for dinner [lunch]. And then in the afternoon he has his dialysis. _On dialysis days_ he comes home, he eats then I get him ready and I get ready. Take him to dialysis. And I’ll stay there all afternoon with him. I mean three hours and a half. He doesn’t like to stay by himself, he’s always been kind of nervous. So I’ll stay there in the clinic four hours… I hold him until he stops bleeding. We come home and I have to make supper for him. After that I give him his medicines that he takes in the afternoon. I check his blood pressure and sugar. And after that any little things that he needs. So most of the time, my time is his time. And on a regular _[non-dialysis]_ day the morning is the same. In the afternoon sometimes we go over to Matamorases to see his sister. Sometimes we go with my son and see him play for a little while for an hour or so. Sometimes I do that by myself because he [husband] doesn’t feel like going or he’s tired, so he stays here and watch
TV. I do every morning the same routine and all day long. So I hardly have enough time to go shopping or things like that. I enjoy life because he’s still with us.

*Patricia, husband on dialysis*

Even her daughter-in-law said, “I help her get stuff for him. But usually all day, every day is centered on keeping him [father-in-law] well.”

For those who worked, a typical day is exemplified by the following accounts:

My morning routine is, once I wake up I have my husband and my daughter she’s 6. So we get her bathed, get her dressed, we get dressed, I take her to school, and I go to work. About 10:30 am I come over here and get her [mother] ready for dialysis. Take her to dialysis. We go to dialysis about 11:00 am. My grandma as well goes to dialysis at the same time as she does. My grandma’s in a nursing home so we see her there. And once we get into the dialysis room, I set mom up. Then I go back to work. At 3:00 pm I go back. Mom gets out at 3:00 pm. We wait there ‘til 4 o’clock when my grandmother gets out. Once my grandmother gets out, we call the nursing home to come get her. So once they come get her [grandmother], I get her [mother] something to eat and then bring her home.

*Rosa, mother and grandmother on dialysis*

Alicia described her routine for both dialysis and non-dialysis days:

Very hectic, I come to work. I work fulltime from 8 to 12 [noon] and 1 to 5. From 12 [noon] to 1:00 pm, I go drop her [mother at dialysis] off. That’s where I go during my lunch break. She dialyzes for about 4 hours. So I go pick her up right after work. And then, well since my mom one of her legs got amputated due to diabetes or bad circulation, when we get home I cook for her. I change her and then whatever she needs. Then after that I coach kickball so I go to the park. So I don’t get back ‘til like 9:00 pm. So I’m not at home at all. I’m either at work or with my mother or at the park. On *non-dialysis days*, I get up, I come to work, and I get home. It’s a little bit easier because, you know, I don’t have the pressure of having to go and bring her back [to dialysis] and stuff like that. So I actually can go to a restaurant and sit down and eat during my lunch break. And
then in the afternoon, well you know, I can sit down talk to her a little and with the kids, do homework and then go to the park. It’s always to the park.

*Alicia, mother on dialysis*

One working family voiced how the entire family accommodated their loved one with ESRD:

I come home at noon every day simply to have lunch with him and a friend comes over for lunch as well….We all take turns picking him up. If he needs something that he wants or needs he calls us. We try to make it all very easy so that he does not feel like he is altering our daily routine. He does not like to feel like he is in our way. He tells us that we don’t have to stay with him and that he will call if he needs something. That makes us feel a lot better. At least we know that he is all right. If I call him to see if he needs something he asks why you called. I told you I would call if I needed something, I am all right mom. He makes us feel better. *[Translated from the Spanish]*

*Jessica, son on dialysis*

**Summary of Lifestyle Performance for Family Members**

The family members’ daily routines are adapted and changes to accommodate the need of their loved on dialysis whether they worked or not. They worry about their own health, compliance with the dialysis regimen and overall emotional and psychological adjustment. Even if their own lives are impacted they do it because their loved ones are still alive.

**II. Occupational Profile**

The participants in this study again related their occupational activities to those of the individual with ESRD living on dialysis.

*Self-care and self-maintenance.* The family members felt responsible for everything, especially in the areas of household, money management, food, and health management:
The most important thing I have to do every day is taking care of him [individual with ESRD], making sure he has his food and something to drink, and making sure he’s taken all his medications. Then I’ll feed the dogs and feed me. Clean the house, clean the yard. That’s all.

Pearl, husband on dialysis

All the family members reported that the family’s financial management had fallen to them. For example, one family member whose husband was on peritoneal dialysis reported, “I started taking care of everything. He just left everything on me and I take care of all the payments.” Another, whose mother was on dialysis stated, “I do her finances for one thing, because she can’t see. I pay her bills.” Only one respondent reported no changes in their financial management. She had managed their money prior to dialysis. She stated, “I have always handled the money. Before he got sick, he would get paid and give his paycheck to me.”

In terms of food preparation, this area created the most changes for the family members. They were responsible for ensuring that the individual not only eats but eats correctly:

For his dialysis treatment, I try to give him the right meals, balanced meals. Of course when you’re on dialysis your kidneys don’t work, therefore you need a special diet. On peritoneal dialysis it’s not as limited, it’s more flexible, but anyway, you try to have some control of the sodium and the potassium.

Lela, widow, husband on peritoneal dialysis
When you have diabetes, you can have some beans, tomatoes and stuff like that. But when you get on dialysis, you can’t have beans; you can’t have tomatoes, or any cream of chicken, cream of mushroom, or any of that. It’s a whole different ballgame. I couldn’t find any information on it so I just started doing things myself. If we’re going to have spaghetti and he can’t have tomatoes, but he has a little bit. Then he doesn’t have any the next night or the following night. So he doesn’t eat that much of it. That’s how I got by with having so many things he can’t eat. I just fix the things I usually do, and we eat in moderation. That’s what we do.

_Pearl, husband on dialysis_

The family members are totally responsible for the self-care and self-maintenance of not only their own family but also their loved one with ESRD. They ensure their compliance with the diet restrictions, handle their finances, and manage their household.

_Societal Contribution._ Four family members talked about the changes and adjustments made to their job and career choices because of dialysis. One respondent described how she was forced to leave her job to care for her father who had ESRD. Her extended family agreed to assist with their living expenses. Several family members described the impacted to their livelihood:

_I was living in Corpus and going to school... I moved down here a couple of years ago when he went on dialysis. Shortly afterward I told him that I would help out with the business since he would be out of work you know for three days each week. On Monday, Wednesday, and Friday I don't have a business partner. He has a laptop that he takes to dialysis…. We email back and forth and call each other constantly. We still work, you know, even though he's there. I try to give him his break but sometimes I need him. I take stuff to him over there and we just keep on._

_Betty, father on dialysis_

I used to sew a lot; I made dolls. I made all kinds of things. I had a booth in a place downtown and I sold my stuff. But for the last two and a half years I haven’t done it because I don’t have the time to sit and cut it all out and make it, and so on.

_Pearl, husband on dialysis_
Sarah would like to engage in volunteer activities but the demands of her loved one do not make that possible:

No, I don’t. Between coming over here [grandfather’s home], raising my daughter, home schooling my daughter and taking care of my home – no, I don’t. But I have been thinking that later on when I have more time, I might. This [dialysis] has really impacted my life. It’s made me realize and think, “What can I do to help families like this?” Maybe even later on if I go back to school, becoming a nurse and working with dialysis patients. I think I would have more empathy for them and it wouldn’t be just a job.

Sarah, grandfather on dialysis

Having a loved one on dialysis forced the family members to change their livelihood. For some, they are now the primary wage earner of the family. They made these changes and adaptations with little expectation of reciprocity except the continued life of their loved one.

**Intrinsic Gratification.** A lack of personal pleasure pursuit was evident among those family members who did not work outside of the home. Fifty-three percent (n=8) of the family members cited that the dialysis schedule and the needs of the individual with ESRD as the reason for no free time;

There’s no time anymore. Three days of hemodialysis take all of our time and tires us out. The other days we have doctor’s appointments. Saturday and Sunday- you think this would be my day but then you get visitors and things around the house [chores]. So, there really is no time.

Cynthia, husband on dialysis

Of the few (n=4) who reported having free time, it was spent working in the yard, going to the park with the kids, taking a walk, and going to church. Running errands and shopping as well as spending time with the family were also given as use of free times:
My free time, where do I begin? Errands, shopping you know, going out with my husband which usually means eating. And doing stuff with the girls, going either to a kickball game or the zoo or just taking them walking somewhere. There’s a little trail up front and we’ll take them there also. That’s pretty much our free time. That’s if we have any free time. Usually there’s always something to do.

_Angie, father-in-law on dialysis_

The family members reported minimal to no free time. The demand of their families and the individual on dialysis appeared to leave no time to pursue leisure activities. Those with children did attend and participate in their sports and leisure activities. Activities described as intrinsically gratifying are often the first to be eliminated when there is a lack of time or money. Personal intrinsically gratifying or leisure activities are often difficult to identify when there is a strong cultural influence of service to others (Velde & Fidler, 2002).

**Reciprocal Interpersonal Relatedness.** All the family members (n=15) welcomed and desired an increase in family interaction, but dialysis decreased it. For example, one respondent said, “After dialysis, he doesn’t want to do much. So, we all gather as a family at his nursing home.” Another explained:

With mother it’s kind of hard because she sometimes doesn’t feel well when she has dialysis. After the dialysis most of the time actually she doesn’t feel well, you know. It’s the nausea and vomiting. And it’s been the same thing because of the blood pressure. So she really doesn’t go out a lot. We do try to take her out maybe to the mall, to eat or to a restaurant. Her brothers and sisters do come to see her every once in a while because they know she can’t get out.

_Alicia, mother on dialysis_
Figure A: Interconnectedness of the Lifestyle Performance Domains & Areas of Dissatisfaction

Others described the changes in their family interaction as:

- **Self-care & Self-Maintenance** (Area of dissatisfaction for FM)
- **Societal Contribution** (Area of dissatisfaction for Indiv)
- **Intrinsic Gratification** (Area of dissatisfaction for FM)
- **Reciprocal Interpersonal Relatedness** (Area of Dissatisfaction for individ & FM)

*FM: Family Members  
Indiv: Individuals with ESRD*
Prior to dialysis, we went to visit our kids, to our son’s house. And we went to visit friends and stuff like that. We went to visit other people. Now we just don’t do anything like that. We’ve got some great-grandkids in Kingsville but we never get up there. The last time we went, he felt so bad all the time that we were there. Our daughter lives down in Arroyo and we very seldom get down there because it’s a little far and he doesn’t feel good all the time we’re there. He just didn’t enjoy himself because he felt so bad. To me, it’s just better to stay at home. It’s too hard on him to have to go and do things. It’s better to stay at home and I can be here with him. We go out to eat and go back home. That’s all.

*Pearl, husband on dialysis*

Before when my mom was at home, we would, get together and we would have cookouts. ‘Cause my mom can’t really walk we would try to be at home with her for family reunions. And now that she’s in the hospital, that she’s sick, it’s like everybody’s doing their own little thing. We go visit her but we don’t get together anymore at home like we used to.

*Eve, mother on dialysis*

For others having a loved one on dialysis increased their family interaction and communication:

We just hang out. We go where they live on the water….we just get together for the weekends at whoever’s house and especially holidays. Friends and family usually come over for barbecues. I spend more time with my family than I do with friends.

*Betty, father on dialysis*

We know that she lives by herself. We try to keep her busy. We go out to eat, watch [footballs] games, and go to birthday parties… Sometime she goes and sometimes she doesn’t.

*Rosa, mother and grandmother on dialysis*
We’ve become much closer than what we were. I’ve noticed the communication especially between me and my sister has improved a lot. We are communicating more, all of us. We do communicate for my mom.

*Alicia, mother on dialysis*

The relationship between the family members and individuals with ESRD became stronger with dialysis. The family members were disappointed when the loved one on dialysis was unable to participate in family outings and activities because of the side effects of dialysis. On the other hand some noticed and enjoyed an increase in communication and interaction with their loved ones as well as other family members.

**Summary of Occupational Profile for Family Members**

When considering quality of life from an activity perspective, it is natural to have a balance or equal distribution of activities in each domain. Yet, the family members of Mexican Americans with ESRD living with dialysis tend to lack in the area of intrinsic gratification. They have little or no free time to pursue those activities which bring them pleasure and enjoyment. Their career and work tasks are modified and changed to accommodate the requirements of dialysis. And they experience an increased role in self-maintenance tasks such as household, money, and health management. Most report an increase in activities and satisfaction within the domain of reciprocal interpersonal relatedness. They are engaging in more family interactions and communications. The family members however, have achieved a sense of harmony among the domains. Domains are interconnected, the activities of each domain influence the activities of other domains and together they achieve the objective of keeping the loved one with ESRD alive and well.

**III. Occupational Deprivation**

The findings from this qualitative analysis indicated that the family members also suffer occupational deprivation and disruption.

*Fearing death of loved one.* Even though the respondents did not see their lives as being restrictive, fearing the possibility of death of their loved ones or wanting them to feel
better (n= 9) created conditions that led to occupational deprivation. For example, Carina said,

I like to travel. Now I say, thank god, I traveled a lot in my past. Now, my time is my father’s time. When he is with God than my life will change. [Translated from the Spanish]

Carina, father on dialysis

I’m scared that if I go off and leave him, he could get up and fall on the floor or have a stroke, and I wouldn’t know it. So I’m here 24 hours a day. I go out in the yard for a few minutes and then come in and check on him to be sure he’s Ok. Other than that, I just don’t go anywhere or do anything because I’m afraid to. I can get someone to come in for awhile and check on him. But other than that, I just don’t go anywhere or do anything unless someone can stay here and sit with him while I’m gone. My life has changed quite a bit since he’s been on dialysis.

Pearl, husband on dialysis

For me, I love my mom. I want her to be here. I want her to be alive for my granddaughter and for her other grandchildren and for her children. I want her to be around for a long time. So you know because of that I am willing to do whatever I have to do to help her.

Rosa, mother and grandmother on dialysis

The fear of losing a loved one is the catalyst for changing and enduring a decreased in occupational participation. This results in a condition in the environment in which the family members, for reasons beyond their control, are unable to participate and engage in occupations necessary for spiritual, mental, physical, or economic well-being. The family members experience occupational imbalance and a form of occupational deprivation that results when a single occupation dominates one’s life. Taking care of their loved one with ESRD is seen as their primary occupation. Wanting them to feel better, live longer, and interact with the family are reasons enough for them place their life on hold.
Dialysis process. The dialysis schedule, the physiological effects and complications of dialysis produce situations of occupational disruption. Lela described her experience with her husband on peritoneal dialysis:

It was very, very hard. He was on a 12-hour schedule everyday with the machine, a cycler. I was getting his machine ready, starting at 6:00-6:30pm. Preparing the bags, starting the machine, and then connecting him to…. the cycler. He was basically connected to the machine for the rest of the night. Before he lost his legs, he was up moving around with a long line connected to the machine or getting up to the bathroom, but mostly he was laying in bed watching TV and then just going to sleep. But when he lost his legs he was just in bed…. In a matter of 1 year he lost both of his legs unfortunately. The reason actually of his passing is that he got a bacteria and he got peritonitis and passed away of peritonitis. That’s why he passed away. Sometimes you have to be a caretaker, it was very hard. But I would do it a thousand times again if I would still have him here. I would do it again and again and again. It’s still so hard. Sorry (crying).

Lela, widow, husband on dialysis

Angie reported,

We have to plan around his treatments so, even like the kickball tournaments, the out of town kickball tournaments. He’s in the mindset that he will come out [of dialysis] feeling not necessarily well. So he would say if we leave we should leave on a Saturday morning after I’ve recuperated from the Friday treatment.

Angie, father-in-law on dialysis

Sarah describes her reaction to the outcome of dialysis on her grandfather.

Well, it’s hard…. It’s just hard seeing him so …. (Crying) I didn’t expect this… It’s just hard to see him all the time not being able to do the things he really likes. It’s tough. I always ask him how he feels every day, but I know when he doesn’t feel good. Now he’s more guarded and private. He enjoyed the outdoors, raising rabbits and stuff, and it’s tough seeing him this way.

Sarah, grandfather on dialysis

165
Seeing and experiencing the effect of dialysis on their loved ones provides a reason for accepting occupational limitations. The family members’ experience of occupational deprivation is directly related to the experience of their loved ones.

Summary of Occupational Deprivation for Family Members

The dialysis process and fear of death of their loved one create occupational deprivation for the family members in all of the lifestyle domains. These are events beyond their control. This results in situations and conditions that block the family members for participating and engaging in the necessary occupations for their spiritual, mental, physical, or economic well-being. Their primary occupation has become taking care of their loved one with ESRD. They willingly place their lives on hold if it means their loved ones with ESRD are feeling better, living longer, and interacting with the family.

Summary of Occupational Performance for Individuals with ESRD & Family Members

An activity that is purposeful and meaningful to the individual contributes positively to that individual’s perception of his or her own quality of life (Velde & Fidler, 2002). Therefore the purpose of gathering information on daily activities that influence quality of life among individuals with ESRD and their family members will allow us to understand the significance of the engagement and performance of the daily activities. From this study, the Mexican American with ESRD perceives “activities of daily living” as being able to work and comply with dialysis whereas the family members see “activities of daily living” as caring for the individual with ESRD. The day-to-day routine for both the individuals with ESRD and family members revolve around the renal replacement therapy – hemodialysis or peritoneal. Each day, all aspects of the individuals’ and family members’ life are coordinated and arranged according to the dialysis schedule and its physiological effects and complications. There were little differences between dialysis and non-dialysis days. The needs of the individuals with ESRD are always the center focus.

Of the fours domains of the lifestyle performance model, dissatisfaction was seen in the area of reciprocal interpersonal relatedness for both groups, individuals with ESRD and
family members. They reflected on and mourned the loss of those activities shared with family and friends. They perceived that the physical loss of family and friends started prior to or when dialysis begin. The physiological effects and complications of dialysis facilitated the emotional loss. The experiences of life on dialysis were professed as a loss of participation in social and recreational activities, loss of time available to spend with loved ones or on valued activities and loss of social-identities. Societal contribution was another area of dissatisfaction for individuals with ESRD. This was not only due to the changes of their physical strength, stamina and ability to work but also the limitations placed on them by society and the Federal government. The loss of financial assistance would hurt them as well as their families.

The family members perceived dissatisfaction also in the areas of intrinsic gratification and self-care and self-maintenance. They expressed a loss of free and personal time, self identities, and spontaneity along with increasing responsibilities for household and money management, food preparation, and health management. Yet, they felt that the sacrifice to their personal life was worthwhile because their loved ones were alive.

End-stage-renal disease and living on dialysis do cause occupational deprivation and disruption for both the individuals and family members. The rigid dialysis schedule and regimen, physiological effects and complications of dialysis, the body alterations to receive dialysis, and fearing the possibilities of death are major impediments to full participation in all occupational performance and performance satisfaction for this population. Most of the activities of the subjects in this study were indicative not only of the interaction with their environment but also cultural, economic constraints, and social isolation. Increased socio-environmental challenges negatively influences the level of resources (emotional, mental and material) available for performing tasks associated with activities of daily living. And these negatively impact their perception of quality of life.
CHAPTER IV: DISCUSSION AND IMPLICATIONS

The purpose of the present study was to explore the occupational performance of Mexican Americans with ESRD living on dialysis from the perspectives of the individual with ESRD, family members and healthcare providers. The findings from this qualitative study revealed the (a) prominent concerns, issues, and needs facing Mexican Americans with ESRD living on dialysis, (b) benefits, efficacy, barriers, threat, and cue to actions for adjusting to dialysis and (c) day-to-day occupational activities and deprivations brought on by dialysis. Further, the study revealed the value and role of the family in accepting and adjusting to life on dialysis. Such data does not currently exist and will greatly add more of the human experience. This study provides data that have not been available previously. This section will provide a summary and discussion of the findings as they relate to the literature and conceptual models guiding the study. The final section will present a discussion of the implications to public health, occupational therapy and dialysis healthcare providers as well as additional research.

Summary of the Study Findings

The number of Mexican Americans living on dialysis is steadily increasing (KHC, 2008; USRDS, 2005). Evidence indicates that Hispanics have a threefold risk of developing ESRD due to diabetes and high blood pressure (HHS, 2002; KHC, 2008). The demographic characteristics of this study described a population of Mexican Americans with ESRD (n=15) primarily due to type 2 diabetes and high blood pressure than other ethnic groups. Hemodialysis was their renal replacement therapy with the hope and plan of getting an organ transplant. The majority of the individuals with ESRD were unemployed and married with a household income of less than $20,000 per year. The length of time on dialysis for the participants ranged from six to 132 months (11 yrs), with a median of 36 months or three years. The family members (n=15) were largely spouses who did not work outside of the home or daughters who worked and both served as the primary caregiver. With respect to acculturation, this population was highly oriented to the Mexican culture in terms of preference, language use, ethnic identification, and cultural heritage. The healthcare

168
providers (n=6) that worked with this group were mostly nurses. They were responsible for educating, training, counseling, and assisting the patients and their family members as well as the day-to-day medical management of this population.

Concerns, Issues, and Needs

The qualitative portion of the study provides evidence of the complex and intimate connection between the individual with ESRD, family, and healthcare providers. They share the same concerns, issues and needs for early and continuous education about renal replacement options and the dialysis process and regimen, for quality and informative communication, and for social support to deal with the reality of dialysis. These are all intricately tied to accepting, adapting, and complying with life on dialysis. Loss of freedom, time, identity, and valued activities as a result of the treatment regimen were identified by the individuals and family members as factors that directly impacted their perception of quality of life. The family members were also distressed with the day-to-day management of life, dealing with such issues as health, money, and household management.

*Individuals with ESRD.* As a whole, the individuals with ESRD were found to believe that dialysis dominated their lives as well as something that kept them alive. Even though they had significant improvements in symptoms after starting dialysis, they disliked the increased exposure to needle sticks, time spent dialyzing, bodily alternations needed to receive the treatment, frequency of the sessions, medical complications, and mental anguish from enduring the dialysis session itself. The constant fear of death remains a substantial burden to individuals with ESRD. Comparing their altered bodies with their past ones forced the individuals to view the illness as real. The condition and death of fellow patients compelled them to confront not only the effect of illness-related changes in their daily lives but also their own mortality.

Successful dialysis on the part of the individual with ESRD requires compliance with the dialysis regimens. Not only must the individual attend and/or complete all dialysis sessions for the full time, but also they must adhere to dietary restrictions and medication regimens (Hailey & Moss, 2000; Kimmel, et al., 1998; Kutner, 2001). In this exploratory
study, simply not liking the allowable food on the list was more of the reason for noncompliance with the diet restriction rather than the reliance on a traditional Mexican cuisine. Fluid restriction and multiple medical appointments were considered a frustration but not a reason for noncompliance. In contrast, the healthcare providers felt that denial of the health condition as well as a lack of financial resources were the cause of noncompliance among this Mexican American population.

The illness experiences of Mexican Americans with ESRD in this study are consistent with documented experiences of other racial and ethnic groups (Drayer, et al., 2006; Krespi, et al., 2004; Kutner, 2004; Manns, et al., 2003). However, to increase their compliance they pointed out a need for more information about the mechanics of dialysis. They would like more assistance with mentally adjusting and managing their condition. Increasing the level of social support and social services available to them were also voiced as something that would boost their compliance with the dialysis regimen.

**Family Members.** The family members living with a Mexican American with ESRD in the present study were forced to adapt to a different way of living. They are threatened with many potential losses and lifestyle changes including decreased financial income, and ability to fulfill their long-range goals, increased dietary restrictions, changing family roles and responsibilities, and fear of death of their loved one. Family life becomes centered on the individual with ESRD. The literature concludes that family support and involvement are major predictors or barriers to compliance with the dialysis regimen on the part of the individual with ESRD (Boyer, Chlouverakis, & Kaloyanides, 1990; Christensen, et al., 1992; Hills-Briggs, et al., 2002; White, et al., 2002). Yet, the concerns and issues associated with ESRD as faced by the family are not widely described or understood.

The family members in this study indicated a desire for a family-centered approach to care and adjustment to living with dialysis. Family-centered care requires healthcare professionals to consider whether the family as a unit has enough information to make a decision, whether the family is properly motivated, and whether the treatment decisions by the family are in accord with what the client would elect (Hyun, 2003). A family-centered approach requires a communication process that considers multiple receivers of the message
The findings of this study indicated that communication with healthcare providers was often an obstacle for the family members. Communication with providers was not always perceived as supportive or informative especially after dialysis had started.

Cultural values and influences can provide insights into the responses of patients and families to being on and living with dialysis. Among Hispanics illness may be viewed as an imbalance of the body due to fate, heredity, bad luck, wrongdoing, a matter of chance or God’s will (Benabe & Rios, 2004; Leung, 1993; White, et al., 2002). In this exploratory study, these cultural views of the cause of dialysis were implied by the family members in relation to the role that religion plays in their lives. Religion in combination with love for the individual with ESRD served as a reason to accept and live with dialysis. The stoic acceptance of living with dialysis tended to be the norm.

The importance of the family was another cultural value that was demonstrated by the findings of this study. The family, including the extended family, is the most valued institution in the Mexican American culture (Andrews & Boyle, 1999; Benabe & Rios, 2004; White, et al., 2002). Mexican American caregivers have been found to have higher familismo than their Anglo counterparts (White, et al., 2002). The family unit in this study played an important role in assuring the compliance of the individual with ESRD with the dialysis regimen especially if the pre-dialysis family interaction was positive. The families willingly changed and adapted their everyday life to accommodate dialysis despite the stress and strain that it placed on them personally or as a family unit. Therefore it is important to understand the role between the family and individuals with ESRD and the cultural values that guide their interaction.

Healthcare Providers. Insufficient communication between patients, family members and providers is a major barrier identified in this study. Educational level, language, and pre-dialysis information were all expressed by the healthcare providers as contributors to unsatisfactory communication with Mexican Americans living on dialysis. Several studies have found educational level and lack of preparation prior to commencement of treatment were barriers and characteristic of noncompliance among dialysis patients (Baines & Jindal, 2000; Kinchen, et al., 2002; Maples, et al., 2004; Owen, 2003). With 53% of the individuals
with ESRD and 60% of the family members in this study with high school or less education, their understanding of health information and communication with healthcare providers were limited. The healthcare providers in this study also concluded that early referral and predialysis education were crucial to compliance for Mexican Americans.

Because of the different dialects of Spanish and staff not fluent in Spanish, the healthcare providers in this study acknowledged that language is a barrier in their communication with this Mexican American population which can impact their compliance, adjustment, and acceptance of life on dialysis. The literature states that patients are often unwilling or unable to communicate to their healthcare providers if they do not understand or speak English well. They are unable to explain their symptoms or understand their diagnoses (Fiscella, et al., 2002; Schur & Albers, 1996).

Health Belief Model

The Health Belief Model proved to be a useful tool for explaining the individual’s health actions under conditions of uncertainty. Mexican Americans with ESRD and their families are living with the uncertainty of dialysis and imminent death everyday.

Perceived benefits. This construct was defined as an increase in physical well-being, extended and prolonged life. All of the respondents, individuals with ESRD and family members, agreed that dialysis is a lifesaving therapy but it does not restore normal health and well-being. Without exception, they had a clear sense that without dialysis they could not survive. Knowledge of death and conditions of fellow patients are a reminder of their mortality and the benefit of dialysis. This population sees each day as something not to take for granted. Another benefit identified by the individuals with ESRD was the physical and emotional support they received from and given by the family members. For the family members, their loved ones with ESRD being alive were their driving force (benefit) to change and accommodate dialysis into their lives. The families became closer, more communicative, and involved with each other. The cultural value of family among Mexican Americans is a positive strength for this population.
Perceived collective efficacy. This construct addresses the strength of the family unit to solve their problems and improve their lives. This sense of collective effort came from a combined source – the family, children and extended family. The overall sentiment of the family members was expressed as, “We are overcoming it [dialysis] and we will come out ahead.” The love for the individual with ESRD on dialysis gave the family members reasons and strength to face this condition. Since these families do not live in isolation, the strength of the family unit provides the collective efficacy needed to accept, adapt, and comply with living on dialysis.

Perceived barriers. This construct was defined as the dialysis regimen - three times per week - treatment sessions for 3-4 hours, dietary and fluid restriction, and medications regimen. Cultural attributes and the actual dialysis regimen created barriers for individuals with ESRD. The barriers - diet and fluid restrictions, cultural preference, bodily alteration, limited physical functioning and the dialysis procedure – are complex. Because of the high content of potassium and phosphorus, traditional Mexican food is a dietary barrier. Yet, noncompliance with the diet and fluid regimen appears to be caused more by personal food preference than culture. Continuous and multiple medical appointments are also a source of frustration. For the family members communicating with healthcare providers, adjusting to the dialysis schedule, and complying with the dietary and fluid restrictions are all things that are need to keep the individuals with ESRD alive. Therefore these aspects of dialysis become barriers for them. The 3-4 hours treatment sessions three times per week may interfere with family members’ work schedules or other family commitments. Therefore they must also make a commitment to the dialysis schedule. Eating habits, grocery shopping, and food preparation are another change in the family interaction. Lack of information about dialysis and inadequate communication with healthcare providers generated frustrations (barriers).

Perceived susceptibility. In this study perceived susceptibility was defined as the complications of and dependency on dialysis for life. Diminished physical strength, persistent fatigue, and other medical complications were reported as dominant fears. Fatigue and weakness immediately following the dialysis treatment sessions along with the time-
intensive dialysis schedule typically combined to preclude the participants from maintaining and accepting social roles they previously fulfilled. Inability to attend church, travel, and socialize with friends was only a few occupational roles that are limited by dialysis.

**Perceived severity.** This construct was operationalized as the dying from ESRD. Ten of the participants recounted experiences in which they were “near death,” “could have died,” or “would die” if they did not start dialysis. The respondents stated that direct observance of situations involving fellow patients were a constant reminder of their own mortality and risk for the same fate. The outcome of non-compliance with the treatment regimen, diet and fluid restrictions, and medications is death. The possibility of death whether from the treatment, other medical complications, or life events is an everyday reality and fear for individuals with ESRD and family members.

**Perceived threats.** This construct is a combination of perceived susceptibility and perceived severity along with the fear of family members and children experiencing the same fate. The fear of the children following the same pattern was unbearable to many of the individuals with ESRD and family members. Therefore, they are encouraging lifestyle changes to other family members, children and grandchildren or anyone who will listen. Lifestyle changes such as stop drinking, exercising more or having frequent medical check-ups were advised. Others feared the possibility that their children would inherit traits of diabetes which is the leading cause of ESRD among Mexican Americans.

**Cue to actions.** In this study, this construct refers to the triggers to compliance with the dialysis regimen. The healthcare providers are one cue to action for this population. They are the patients’ constant reminder to comply. They reported that dialysis patients are treated as a person and not a number. The providers interact with them to give better care. Several of the providers voiced the difficulties in maintaining their professionalism with this population. The intimate and intensive interaction between provider and individual with ESRD and family members pushes the line of professional boundary and burn-out for the providers. The hope of getting a transplant is another trigger for compliance. All but one of the participants feared not getting a kidney transplant because of the lack of available organs.
They saw a transplant as the answer to a normal life. One respondent would not travel outside of the area for fear of missing the call for a transplant.

The Health Belief Model identified a major psychosocial determinant to adapting, adjusting and accepting life with dialysis for Mexican Americans with ESRD- the collective efficacy of the family unit. The collective effort of the individuals and family has received no attention in the literature. The family unit offers strength, confidence, motivation, encouragement and physical support to tolerate the experience of living with this illness. The stress associated with living with dialysis can be minimized by the family dynamics and communication. The effect of having a parent or family member on dialysis has also not received much attention in the literature, although systems theory would expect that children and other family members would be affected. The family plays an important and central role in traditional Mexican American culture. Therefore it is important for us to develop an understanding of the dynamics of these families and their communication patterns.

Lifestyle Performance Model

The Lifestyle Performance Model hypothesizes that health is supported and maintained when individuals are able to engage in occupations and activities that allow desired or needed participation in community life. The key construct of the model is lifestyle. Lifestyle is composed of four domains: self-care/self-maintenance, intrinsic gratification, reciprocal interpersonal relatedness, and social contribution. In the current study indicators of lifestyle included their definition of “activities of daily living,” description of their daily routine, constructs of the Lifestyle Performance Model and occupational deprivation and disruption.

Activities of daily living. As a whole, the sample of individuals with ESRD and family members engaged in activities that contributed positively to their perception of quality of life as well as mourned the loss of the activities that constrained dialysis. The individuals with ESRD however found meaning and some level of satisfaction with their daily life tasks. Activities of daily living included dressing, bathing, grooming, working, and leisure activities. They willingly engaged in tasks that gave meaning to their lives. These activities
were also supported by their environment. Over time the dialysis treatment sessions were
viewed as just another task of their everyday life. They distinguished between dialysis and
non-dialysis days. Dialysis days revolved around the treatment session – get up, get dress, go
to dialysis, eat, go home, and go to bed. Non-dialysis days encompassed working, visiting
family and friends, or completing basic household tasks. Those on peritoneal, even though it
gave them more freedom, faced dialysis on a daily basis.

*Lifestyle Performance domains.* In terms of the domains of the Lifestyle Performance
Model, the dialysis regimen, dietary restrictions, and physiological effects have forced the
Mexican American with ESRD to change and adapt. In the area of *self-care and self
maintenance* the respondents noted changes were in household duties, money management
and travel. Care had to be taken not to damage the access point for dialysis while performing
household tasks. Living on the limited funds from Social Security or disability devastated
their overall finances. Those that worked constantly feared the loss of their benefits. Even
though there was a general awareness that it was possible to receive dialysis treatment on a
temporary basis in other facilities, many of the respondents did not want to go through the
hassle of making arrangements to travel or take a vacation.

In the area of *societal contribution* the respondents with ESRD identified with their
role as a wage earner even if they worked part-time. Career choices and work schedules
were modified to accommodate the dialysis schedule and effects. In terms of non-wage-
earning activities such as volunteering, many of the respondents reported no change because
they did not engage in those activities prior to dialysis. Those who valued volunteering did
so not only to help others but also to maintain their formal skills and educational training
since dialysis has impeded their ability to work full-time.

In the area of *intrinsic gratification,* dialysis required the respondents to even plan or
eliminate their pleasurable activities. Most had to the change either the manner or frequency
in which they engaged in their pleasurable activities such as going from fishing 2-3 times a
week to 1-2 times a month. Because of dialysis spontaneous decisions to do something for
fun have been eliminated. Everything has to be planned around the dialysis schedule and
regimen. Few of the respondents indicated that they participate in cooperative, cultural, or
indoor activities. The diet and fluid restriction, treatment schedule, and physiological effect of dialysis caused some respondents to avoid interacting with family and friends. Not wanting to explain to others why they are not participating in activities caused some to eliminate social interactions all together (reciprocal interpersonal relatedness). The activities within the domains of societal contribution and reciprocal interpersonal relatedness provided the most dissatisfaction for individuals with ESRD.

The family members of Mexican Americans with ESRD living with dialysis tended to have little or no free time to pursue those activities which bring them pleasure and enjoyment (intrinsic gratification). Their work tasks were modified to accommodate the dialysis schedule (societal contribution). They experienced an increased role in household tasks, money management and health management (self-care and self-maintenance). Most reported an increase in family interactions and activities (reciprocal interpersonal relatedness). Even though the family members have an imbalance among the domains, with self-care and self-maintenance and intrinsic gratification providing the most dissatisfaction, they have achieved a sense of harmony.

**Occupational deprivation.** Deprivation from occupations of meaningful or cultural significance is made worse by dialysis. The individuals with ESRD in the present study perceived themselves as living very restrictive and deprived lives. Diminished functional ability, time restriction, and an altered body combine to deprive the opportunities to fully participate in their preferred occupations such as travel, work, spending time with family, household tasks, and leisure activities such as shopping, yard work, going to the movies and dancing. The physical environment of the in-centered hemodialysis facilities and sitting there for 3-4 hours inhibits opportunities for occupational involvement for prolonged periods of time. It prevents them from doing what they want to do, when they want to do them, how they want to do them, and when they need to do them.

The findings from this study indicated that the family members also suffer occupational deprivation and disruption. For the family members the dialysis process and fear of death of their loved one created the deprivation. Taking care of the loved one with ESRD is their primary occupation. This resulted in a condition in which the family members,
for reasons beyond their control, are unable to participate and engage in occupations necessary for spiritual, mental, physical, or economic well-being. Wanting their loved one to feel better, live longer, and interact with the family are reasons enough for them to place their life on hold.

Dialysis, an external process, has proved to inhibit participation and engagement in occupations necessary for spiritual, mental, physical, or economic well-being for Mexican Americans with ESRD living with dialysis and their family members. From an activity perspective, this population is experiencing an imbalance of the occupations in which they undertake. According to the Lifestyle Performance Model, the activities within the domains of societal contribution and reciprocal interpersonal relatedness provided the most dissatisfaction for individuals with ESRD and the family members were most dissatisfied with activities within the domains of self-care and self-maintenance and intrinsic gratification.

Summary

There is little to no information in the literature that describes the life of Mexican Americans with ESRD and their families living with dialysis. The participants in this qualitative study revealed a wide-range of concerns, issues, and needs. Even though the individuals with ESRD had improvements in symptoms after starting dialysis, they disliked the increased exposure to needle sticks, time spent dialyzing, the body alternations needed to receive the treatment, frequency of the treatment sessions, medical complications, side effects of dialysis, and mental anguish of the dialysis session itself. The constant fear of death is a substantial burden to the individuals with ESRD and their families. Concerns involving loss of freedom, time, identity, and valued activities as a result of the treatment regimen directly impacted the individuals with ESRD perception of quality of life.

Because of the dialysis regimen, the family members dealt with lifestyle changes including reduced financial income, reconstructed dietary habits and food, changed family roles and responsibilities, and diminished ability to fulfill long-range life goals. Family life became centered on the individual with ESRD. The healthcare providers felt that the low
educational level of the individuals with ESRD and family members, different Spanish
dialects between staff and patients, and lack of pre-dialysis information were key
contributors to acceptance, adaptation and compliance with dialysis for the Mexican
Americans population.

The major determinant to adapting and accepting life with dialysis for this population
was the collective efficacy of the family and individual with ESRD. The commitment and
efforts of the family including extended family had a positive impact on their perceptions,
engagement, and quality of life. The role of the healthcare providers as the cue to actions,
prior to and once on dialysis, was imperative as well as the hope of getting an organ
transplant.

From an activity perspective, end-stage-renal-disease and dialysis definitely created
occupational deprivation and disruption for the individuals and family members as well as an
imbalance of occupational participation. The activities within the domains of societal
contribution and reciprocal interpersonal relatedness provided the most dissatisfaction for
individuals with ESRD and the family members were also dissatisfied with the activities
within the domains of self-care and self-maintenance and intrinsic gratification. Dialysis is
an external condition beyond the control of Mexican Americans with ESRD living with
dialysis and their family members that inhibit their participation and engagement in
occupations necessary for spiritual, mental, physical, or economic well-being. It explicitly
impacted the day-to-day occupational performance of Mexican Americans living with this
illness.

Implications and Recommendations

This study has implications for public health, occupational therapy, and the healthcare
providers in the dialysis treatment system. The findings highlight the concerns, issues and
needs of Mexican Americans with ESRD living on dialysis and their family members.
ESRD and the dialysis - hemodialysis and peritoneal - regimen involves not only
physiological but also social, mental, spiritual, economic and occupational challenges. With
the Mexican American population at high risk of developing ESRD, ending up on dialysis,
and living longer with this condition, addressing the human and nonhuman environment will make it possible for this population to engage in everyday occupations that have personal and cultural significance and meaning.

To effectively serve as an agent of change, occupational therapists and public health practitioners along with the dialysis healthcare providers should join forces to develop and implement interventions within the realm of the community to reduce the incidence rates of the disease, the morbidity of the disability, and death through prevention activities and to reduce the impact of occupational deprivation and disruption through early detection and treatment (Fazio, 2008). Using the public health pyramid as an ecological model which stem from system theory each professional has not only a distinguished role but also integrated roles in addressing the needs of Mexican Americans living with dialysis (Issel, 2004).

**Individual level.** At the individual level, the healthcare providers have the critical task of helping the individual with ESRD and family members to understand the dialysis procedures and requirements prior to and after the start of dialysis. It is imperative that they create an environment where the individual with ESRD and family members feel they can ask questions and receive information. Taking the time to listen to and including family members is prominent. Using a family-centered approach engages the familial unit in the decision-making process. Involving the family member(s) in the planning of intervention will be vital in creating intervention methods that will actually produce an increase in knowledge, compliance, and behavior changes. This will produce a mutual partnership between the individuals, family members, and healthcare providers.

Changes in one family member affect all other family members (Kyler, 2005). There must be mutual participation which aims to help the patient and family determine and choose the best health-related values that can be realized in the clinical situation (Emanuel & Emanuel, 1992). Formal support groups for the individuals with ESRD and family members on a regular basis should be provided to this population. There is an increasing trend to involve patients and family members directly in treatment planning which in turn may lead to increased compliance with dialysis (Baines & Jindal, 2000). The findings in this study contributes to evidence that family-centered care for dialysis patient can alert healthcare
providers to common issues and beliefs that are likely to compromise adjustment, adherence, or the therapeutic relationship (Krespi, et al., 2004).

Occupational therapists, at this level, should address the occupational deprivation and disruption created by this condition once an individual is on dialysis. Emphasis must be placed not only on the physical but also the social, economic, environmental, cultural, and familial relationships. Engagement in tasks that the individual perceives as stressful or meaningless may result in occupational alienation, disharmony and/or imbalance. Achieving balance and harmony are dependent upon the individual’s perceptions of continuity even though the type of participation changes. When existing activities are inadequate because the Mexican American with ESRD and family members are no longer able to experience satisfaction, new activities must be suggested using a family-centered approach. Furthermore, any intervention that facilitate opportunities for engagement in culturally and meaningful occupations may reduce the occupational deprivation experienced by both the individual with ESRD and their families.

Community level. At the community level, all professionals should work together with the public health practitioners taking the lead for developing interventions focusing on behavioral changes such as increasing exercise, getting medical check-ups and screening, and reducing weight. Educational programs and materials that specifically target Mexican Americans are needed to raise awareness of the relationship between diabetes, high blood pressure, and kidney diseases. Involving local individuals with ESRD and family members as role models, behavioral journalism, mass media (television, radio, newspapers and magazines, including Spanish-speaking outlets), and outreach groups can be used to promote healthy lifestyles among this population. Interventions to change behaviors should be tailored to the experiences, beliefs, attitudes, and circumstances of the Mexican American society. Educational materials should also be linguistically, educationally, and culturally appropriate for this population. The findings from this study clearly demonstrate that the materials must include the collective efficacy and cultural value of the family as a tool to change behaviors.
**Infrastructure level.** At the infrastructure level, all the professionals are uniquely qualified to advocate for solutions to the concerns, needs, and issues facing Mexican Americans with ESRD and their families living with dialysis. The findings of this study can play a role in shaping and influencing the political environment related to kidney disease and dialysis. One way is through the inclusion of the outcomes in the education and training of healthcare professionals. Mexican Americans with ESRD and the families living with dialysis are often not recipients of occupational therapy services; however the outcomes of this study show that occupational barriers are associated with this population and illness. Another way is by speaking out collectively through the media or through professional organizations about the societal barrier that dialysis creates for this particular ethnic group. Lastly, by advocating for laws, regulations and policies that address the human and non human resources that will be needed to care for this increasing population, appropriate planning for the care of this vulnerable population can be considered and implemented.

**Future Research**

Despite the increasing number of Mexican Americans with ESRD and their long term survival on dialysis, there is a major gap in the knowledge base regarding the concerns, issues, needs, and occupational performance of this population. Although the result of this exploratory study provides a small glimpse of this population, it highlighted a number of areas that need further research. One such area is the collective efficacy of the individuals with ESRD and their families used to accept, adapt, endure and comply with living with dialysis. The strength of the family unit reflects its sense of overcoming adversity and the resiliency of the Mexican family. Since the family is the most valued institution in the Mexican American culture, it is important that we develop an understanding of its dynamics, communication patterns, nature of their needs, and compliance from a cultural perspective.

Another area that requires further research is the interaction or congruence of the domains of the Lifestyle Performance Model that creates balance and harmony of the occupations that shape and reflect the quality of life for individuals within an environment context. The individuals with ESRD and family members in this study demonstrated an
imbalance of the activities of the domains with dissatisfaction in the areas of societal contribution, intrinsic gratification, and reciprocal interpersonal relatedness at this point in time. But it is unclear if this imbalance continues over the life of the dialysis condition or whether harmony is ever achieved. Research is needed to explore the link between the activities of satisfaction and dissatisfaction and their relationship to quality of life as well as occupational deprivation and disruption.

Additional research is also needed to exam the predictive quality and use of the Health Belief Model to determine compliance with and acceptance of the dialysis regimen. More focused studies are required to validate the construct measurements specifically to individuals already on dialysis. Clarification of the constructs can help to substantiate a conceptual framework to explain the relationships between culture and compliance with treatment. Qualitative studies are needed to capture this population’s perceptions of the intrusiveness of the illness. More studies are needed to assess the effectiveness of the Health Belief Model for investigating the actions of the family members.

Finally, this study must be replicated with larger populations to establish the generalization of the outcome. The small sample prevents generalizing the results of this study to the full population of Mexican Americans with ESRD living on dialysis and their family members in the Rio Grande Valley. It would also be helpful to know if other Mexican Americans with ESRD with different demographics (e.g. geographic location, acculturation level) face similar issues and concerns. It would be important to know if other Hispanics and ethnic groups express comparable barriers, benefits, threats, collective efficacy and occupational performance. This information would influence the manner in which services and education are presented to various subgroups.
CONCLUSION

Acquiring and living with the chronic illness of ESRD is a growing reality for many Mexican Americans which challenge their engagement in meaningful and cultural occupations. Although the illness experience of Mexican Americans with ESRD are similar to those documented in the literature, the findings of this study indicate that the collective efficacy of the individuals and their families is key to accepting, adapting, enduring and complying with dialysis. The strength of the family unit reflects its sense of overcoming adversity and the resiliency of the Mexican American family. Because of the cultural value of interdependence and collective effort, a family-centered approach to intervention may prove to be beneficence to compliance and reducing occupational deprivation.

The toll of dialysis and its many side effects have Mexican Americans with ESRD needing and wanting more information about the mechanics of dialysis, assistance with the mental anguish of enduring the treatment and managing their condition, and social support and services to comply with the dialysis regimen which can be under their control. The family members are threatened with many potential losses and lifestyle changes including decreased financial income, and ability to fulfill their long-range goals, increased dietary restrictions, changing family roles and responsibilities, and fear of death of their loved one. Yet, they willingly alter and change their way of living to accommodate dialysis.

Healthcare providers have an essential role in encouraging, educating, and communicating with Mexican Americans with ESRD and their family members about prevention, renal replacement options, and compliance with dialysis. They are the cue to actions along with the hope of getting an organ transplant. Interventions should aim to change behavior by tailoring them to the knowledge level, primary language, experiences, attitudes, and circumstances of the Mexican American population. A mutual partnership between healthcare providers, individual with ESRD and family members is also needed.

The Lifestyle Performance Model and Health Belief Model provide a starting framework for discovering and understanding the perception of illness intrusiveness and balance of occupational activities for Mexican Americans living with dialysis. Dialysis, an externally imposed challenge, prevents this population from engaging in occupational
choices that influence happiness and life satisfaction (Christiansen, et al., 1999; Christiansen & Townsend, 2004; . Satisfactory occupational functioning occurs only within enabling environments and contexts particular to the individual. Yet, the contextual configuration of dialysis is depriving Mexican Americans with ESRD and their families of important occupational opportunities beyond their immediate control. The findings from the present study support the concept of occupational deprivation that “not all people are afforded equal opportunities to participate in occupations of choice or in occupations having individual, familial, or cultural meaning” (Whiteford, 2010, p.305,) thereby demonstrating that the combination of the ESRD condition and dialysis is a barrier to occupational performance.

Based on the data collected in this study by considering the total experience of Mexican Americans undergoing dialysis and the interrelationship of the family, culture and daily occupations, can lead to effective interventions. They can be designed to address the needs of this population as well as reduce the increasing number of individuals and families facing a life with dialysis. This may in turn contribute to enhanced well-being, increased survival and occupational opportunities for these individuals and their families.
Appendix A: Background Information and Interview Questions
### BACKGROUND INFORMATION

**Direction:** Check all that apply

- [ ] Individual with ESRD
- [ ] Family members (specify _______________________

<table>
<thead>
<tr>
<th>(a) Are you:</th>
<th>(b) What is your marital status?</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____ Male</td>
<td>_____ Married</td>
</tr>
<tr>
<td>_____ Female</td>
<td>_____ Widowed</td>
</tr>
<tr>
<td>_____</td>
<td>_____ Divorced</td>
</tr>
<tr>
<td>_____</td>
<td>_____ Separated</td>
</tr>
<tr>
<td>_____</td>
<td>_____ Never married</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(c) What is your age now?</th>
<th>(d) What is your total household income?</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____ &lt;20 yrs of age</td>
<td>_____ under $20,000</td>
</tr>
<tr>
<td>_____ 21 yrs – 40 yrs</td>
<td>_____ $20,000 - $40,000</td>
</tr>
<tr>
<td>_____ 41 yrs – 60 yrs</td>
<td>_____ $41,000 - $60,000</td>
</tr>
<tr>
<td>_____ 61 yrs – 80 yrs</td>
<td>_____ $61,000 - $80,000</td>
</tr>
<tr>
<td>_____ &gt;80 yrs</td>
<td>_____ $81,000 and over</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(e) What is the highest number of years of school competed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____ 1– 6</td>
</tr>
<tr>
<td>_____ 7-8</td>
</tr>
<tr>
<td>_____ 9-12</td>
</tr>
<tr>
<td>_____ 1-2 years of college</td>
</tr>
<tr>
<td>_____ 3-4 years of college</td>
</tr>
<tr>
<td>_____ College graduate and higher</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(f) How long have you received dialysis?</th>
<th>(g) Are you employed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____ &lt; 1 year</td>
<td>_____ Yes</td>
</tr>
<tr>
<td>_____ 1 yr – 2 yrs</td>
<td>_____ No</td>
</tr>
<tr>
<td>_____ 3 yrs – 4 yrs</td>
<td></td>
</tr>
<tr>
<td>_____ &gt; 5yrs</td>
<td></td>
</tr>
</tbody>
</table>
INFORMACIÓN DE FONDO

Dirección: Compruebe todo el que aplíquese

_____ Individuo con ESRD
_____ Miembros de la familia (especifique el) _______________________

(a) Es usted:
_____ Varón
_____ Hembra

(b) ¿Cuál es su estado civil?
_____ Ahora casado
_____ Widowed
_____ Divorciado
_____ Separado
_____ Nunca casado

(c) ¿Cuál ahora es su edad?
_____ <20 años de la edad
_____ 21 años – 40 años
_____ 41 años – 60 años
_____ 61 años – 80 años
_____ >80 años

(d) ¿Cuál es su renta de casa total?
_____ debajo de $20,000
_____ $20,000 - $40,000
_____ $41,000 - $60,000
_____ $61,000 -$80,000
_____ $81,000 y excedente

(e) ¿Cuál es el número más alto de años de la escuela compitió?
_____ 1 – 6
_____ 7 – 8
_____ 9 – 12
_____ 1 -2 años de la universidad
_____ 3 – 4 años de la universidad
_____ Graduado de la universidad y más arriba

(f) ¿Cuanto tiempo usted ha recibido diálisis?
_____ <1 año
_____ 1 años – 2 años
_____ 3 años – 4 años
_____ > 5 años

¿(G) le emplean?
_____ Sí
_____ No
BACKGROUND INFORMATION

Direction: Check all that apply

____ Nurse
____ Physician
____ Social Worker

____ Technician

_____ Other (specify)_________________

(a) Are you: (b) What is your age now?
_____ Male _____ <20 yrs of age
_____ Female _____ 21 yrs – 40 yrs
 _____ 41 yrs – 60 yrs
 _____ 61 yrs – 80 yrs
 _____ >80 yrs

(c) What is the highest number of years of school competed?
_____ 1-6
_____ 7-8
_____ 9-12
_____ 1-2 years of college
_____ 3-4 years of college
_____ College graduate and higher

(f) How long have you worked in a dialysis facility?
_____ < 1 year
_____ 1 yr – 2 yrs
_____ 3 yrs – 4 yrs
_____ > 5yrs
Appendix A-4

Acculturation Rating Scale for Mexican Americans-II

Which generation best applies to you?
____ 1st generation = You were born in Mexico or other country.
____ 2nd generation = You were born in the USA; either parent born in Mexico or other country.
____ 3rd generation = You were born in the USA, both parents born in USA and all grandparents born in Mexico or other country.
____ 4th generation = You and your parents born in USA and at least one grandparent born in Mexico or other country.
____ 5th generation = You and your parents born in the USA and all grandparents born in the USA.

SCALE I
[Circle a number between 1-5 next to each item that best applies]
1= Not at all 4= Much or very often
2= Very little or not very often 5= Extremely often or almost always
3=Moderately

1. I speak Spanish
2. I speak English
3. I enjoy speaking Spanish
4. I associate with Anglos
5. I associate with Mexicans and/or Mexican Americans
6. I enjoy listening to Spanish language music
7. I enjoy listening to English language music
8. I enjoy Spanish language TV
9. I enjoy English language TV
10. I enjoy English language movies
11. I enjoy Spanish language movies
12. I enjoy reading (e.g., books in Spanish)
13. I enjoy reading (e.g., books in English)
14. I write (e.g., letters in Spanish)
15. I write (e.g., letters in English)
16. My thinking is done in the English language
17. My thinking is done in the Spanish language
18. My contact with Mexico has been
19. My contact with the USA has been
20. My father identifies or identified himself as “Mexicano”
21. My mother identifies or identified herself as “Mexicana”
22. My friends, while I was growing up were of Mexican origin
23. My friends, while I was growing up were of Anglo origin
24. My family cooks Mexican foods
25. My friends now are of Anglo origin
26. My friends now are of Mexican origin
27. I like to identify myself as an Anglo American
28. I like to identify myself as a Mexican American  1 2 3 4 5
29. I like to identify myself as Mexican 1 2 3 4 5
30. I like to identify myself as American 1 2 3 4 5

ADMINISTRATION AND SCORING

The Anglo Orientation Subscale (AOS) is composed of 13 items (Items 2, 4, 7, 9, 10, 13, 15, 16, 19, 23, 25, 27, & 30) and the Mexican Orientation Subscale (MOS) is composed of 17 items (Items 1, 3, 5, 6, 8, 11, 12, 14, 17, 18, 20, 21, 22, 24, 26, 28, & 29). The sum of the AOS scale is divided by 13 to obtain a mean score for that subscale. The sum of the MOS scale is divided by 17 to obtain a mean score for that subscale. The MOS mean is subtracted from the AOS mean to obtain the acculturation level.

Cutting Scores for Determining Acculturation Level

<table>
<thead>
<tr>
<th>ACCULTURATION LEVELS</th>
<th>DESCRIPTION</th>
<th>ARSMA-II ACCULTURATION RAW SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level I</td>
<td>Very Mexican oriented</td>
<td>&lt; 1.17</td>
</tr>
<tr>
<td>Level II</td>
<td>Mexican oriented to approximately balanced</td>
<td>≥ 1.17 to &lt; 2.43 balanced bicultural</td>
</tr>
<tr>
<td>Level III</td>
<td>Slightly Anglo oriented bicultural</td>
<td>≥ 2.43 to &lt; 3.69</td>
</tr>
<tr>
<td>Level IV</td>
<td>Strongly Anglo oriented</td>
<td>≥ 3.69 to &lt; 4.95</td>
</tr>
<tr>
<td>Level V</td>
<td>Very assimilated; Angliciz</td>
<td>&gt; 4.95</td>
</tr>
</tbody>
</table>

Acculturation Raw Score = AOS (mean) – MOS (mean)

(Ceuellar, I, Arnold, B, & Maldonado, R, 1995)
Appendix A-5

Version en Español

**Acculturation Rating Scale for Mexican Americans II**

Indíque con un círculo el número de la generación que considere adecuada para usted. De solamente una respuesta.

1. **1st generación** = Usted nació en México u otro país [no en los Estados Unidos (USA)].
2. **2nd generación** = Usted nació en los Estados Unidos Americanos (USA), sus padres también nacieron en México o en otro país.
3. **3rd generación** = Usted nació en los Estados Unidos Americanos (USA), sus padres también nacieron en los Estados Unidos (USA) y sus abuelos nacieron en México o en otro país.
4. **4th generación** = Usted nació en los Estados Unidos Americanos (USA), sus padres nacieron en los Estados Unidos Americanos (USA) y por lo menos unos de sus abuelos nació en México o en algún otro país.
5. **5th generación** = Usted y sus padres y todos sus abuelos nacieron en los Estados Unidos (USA).

---

**SCALE I**

[Marque con un círculo el número entre 1 y 5 a la respuesta que sea más adecuada para usted.]

<table>
<thead>
<tr>
<th></th>
<th>1=Nada</th>
<th>2=Muy poco o no muy veces</th>
<th>3=Moderately</th>
<th>4=Mucho o muy veces</th>
<th>5=Extrema veces o casi siempre</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Yo hablo Español</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>Yo hablo Inglés</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>Me gustar hablar en Español</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4.</td>
<td>Me asocio con Anglos</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.</td>
<td>Yo me asocio con Mexicanos o con Norte Americanos</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6.</td>
<td>Me gusta la música Mexicana (música en idioma Español)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7.</td>
<td>Me gusta la música de idioma Inglés</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8.</td>
<td>Me gusta ve programas en la televisión que sean en español</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9.</td>
<td>Me gusta ver programas en la televisión que sean en Inglés</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10.</td>
<td>Me gusta ver películas en Inglés</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11.</td>
<td>Me gusta ver películas en Español</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12.</td>
<td>Me gusta leer (e.g., libros en Español)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13.</td>
<td>Me gusta leer (e.g., libros en Inglés)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14.</td>
<td>Escribe (e.g., cartas en Español)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15.</td>
<td>Escribe (e.g., cartas en Inglés)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Mis piensaminetos ocurren en el idioma Ingles</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------</td>
<td>-----------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Mis piensamientos ocurren en el idioma Español</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Mi contacto con México ha sido</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Mi contacto con los Estados Unidos Americanos ha sido</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Mi padre se identifica (o se identificaba) como Mexicana</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Mi madre se identifica (o se identificaba) como</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Mis amigos(as) de mi niñez eran de origen Mexicano</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Mis amigos(as) de mi niñez eran de origen Anglo Americano</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Mi familia cocina comidas mexicanas</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Mi amigos recientes son Anglo Americanos</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Mis amigos recientes son Mexicanos</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>Me gusta identificarme como Anglo Americano</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Me gusta identificarme como Norte Americaño* (México-Americano)</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>Me gusta identificarme como Mexicano</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>Me gusta identificarme como un(a) Americano(a)</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Estadounidenses de origen Mexicano
Semi-Structured Observation with Individual with ESRD and Family Members

**Perceived Susceptibility**

a) Do you feel that your children or other family members will develop ESRD? Diabetes? Why?

**Perceived Severity**

b) How has living on hemodialysis influenced and changed your views and perceptions about life and death?

**Perceived Benefits**

c) Has undergoing dialysis changed you and your family for the better? How?

**Perceived Barriers**

d) What type of obstacles have you encountered while adjusting to living on hemodialysis?

**Cue to Action**

e) Who or what have kept you going throughout your illness and treatment?

**Self-Efficacy**

f) How confident are you in your ability to handle your condition and illness?

**Occupational Performance**

a) Which activities (occupations) most contribute to your quality of life?

**Self-care / Self-Maintenance**

Has dialysis changed this aspect of your daily life? How?

Which household tasks do you perform regularly? Which ones do you enjoy? Dislike? Avoid?

To what extent do you engage in meal planning and preparation? If not, why?

How frequently do you eat out? Eat alone? With others?

Has being on dialysis changed your eating habits and routines?

**Societal Contribution**

How have your condition/illness changed your ability to engage in your career/job?
What percentage of weekly time do you spend in your career or job activities?
What volunteer activities have you or are you presently engaged in?
Are there other activities that you do to help others such as your family, friends, church and community?

**Intrinsic Gratification**
What activities do you simply do for fun and personal pleasure?
How frequently are you involved in these activities?
How satisfied are you with your performance in these activities?

**Reciprocal Interpersonal Relatedness**
What activities do you engage in with friends? How frequently?
What activities do you share with family members (spouse, parents, sibling, children, and other relative)?
What group activities and/or affiliations is a part of your daily life?

**Overall**
After considering all aspects of your daily life activity patterns, which aspects or parts do you consider as being most important to you at this time? Which is of least importance?
What changes would you like to make? How might you begin to bring about such changes?
Appendix A-7

Interview with Individuals with ESRD

1) Tell us your name, how long have you lived with ESRD and hemodialysis, and what was the cause of your renal failure.

2) When I say daily activities (occupations), what does that mean to you? Which daily activities (occupations) most contribute to your quality of life?

3) Describe your daily routine upon arising each morning.
   Probe for personal hygiene, bathing, grooming, or dressing

4) What household tasks do you perform regularly (i.e., cooking, cleaning, yard work, etc)?
   Probe for dialysis and non-dialysis days

5) What kind of activities do you engage in simply for fun and personal pleasure?
   Probe whether alone or with family members, friends, other & frequency of involvement

7) What group activities are apart of your daily life (i.e., church groups, school, political, neighborhood)?
   Probe for volunteer activities or activities that help others

8) What percentage of weekly time do you spend in your career or job activities?
   Probe for money management, financial difficulties

9) Has your experience with ESRD and dialysis changed your daily routines?

10) After considering all aspects of your daily life activity patterns, which aspects or parts do you consider most important to you at this time? Which is of least importance?

11) How do you feel about renal dialysis?

12) What do you think are the major concerns and issues facing people living on hemodialysis today?

13) Is there anything else you would like to talk about?
Interview with Family Members

1) Tell us your name, your relationship to the individual with ESRD living on hemodialysis, and where you get information or learn about ESRD and hemodialysis.

2) When I say daily activities (occupations), what does that mean to you? Which daily activities (occupations) contribute most to your quality of life?

3) What activities do you share as a family group? How important are these to you?

4) Describe your daily routine and activities. What household activities do you engage in?
   The individual with ESRD?
   Probe for dialysis and non-dialysis days

5) How health conscious is your family?
   Probe for past, present, & future

6) Do you have any free time? If not, why? If yes, what activities do you and/or your family engages in during your free time?

7) What activities do you do to manage your money and finances? How are they organized?

8) After considering all aspects of your daily life activity patterns, which aspects or parts do you consider most important to you at this time? Which is of least importance?

9) How do you feel about renal dialysis?

10) How has ESRD and hemodialysis changed your personal and/or family life?

11) What do you think are the major concerns and issues that face a family when a member has ESRD and lives on hemodialysis?

12) Is there anything else you would like to talk about?
Appendix A-9

Interview with Health Care Providers

1) What could healthcare professionals do to make life better for this population?
2) Have you noticed an increase or decrease in the activity level of your patients after they started dialysis?
3) What services does this population need that is not being provided currently?
4) What are the most common reasons given for not complying with the dialysis regimen?
5) What local cultural beliefs and attitudes have you noticed that appear to impact this population? How?
6) How much attention do you pay to your health since you started working with this population?
7) What do you think are the major concerns and issues facing this population?
8) What do you think are the risk factor to developing ESRD? How can they be avoided or changed?
Appendix B: Graphical Networks
Appendix C: IRB Approval and Consents
NOTICE OF APPROVAL TO BEGIN RESEARCH

October 17, 2007

HSC-SPH-07-0393 - Occupational Performance Among Mexican Americans Living on Hemodialysis in the Rio Grande Valley of Texas

PROVISIONS: This approval relates to the research to be conducted under the above referenced title and/or to any associated materials considered at this meeting, e.g. study documents, informed consent, etc.

NOTE: If this is an investigator-initiated medical intervention study, or if the PI holds the IND/IDE applicable to this study, and no one else has registered this trial on the national registry, you are encouraged to register at www.clinicaltrials.gov in order to publish results in one of the key peer-reviewed journals. For further information contact Catey Carter at 713-500-3524.

APPROVED: At a Convened Meeting on 08/17/2007

EXPIRATION DATE: 7/31/2008

CHAIRPERSON: Anne Dougherty, MD

Subject to any provisions noted above, you may now begin this research.

CHANGES: The principal investigator (PI) must receive approval from the CPHS before initiating any changes, including those required by the sponsor, which would affect human subjects, e.g. changes in methods or procedures, numbers or kinds of human subjects, or revisions to the informed consent document or procedures. The addition of co-investigators must also receive approval from the CPHS. ALL PROTOCOL REVISIONS MUST BE SUBMITTED TO THE SPONSOR OF THE RESEARCH.

INFORMED CONSENT: Informed consent must be obtained by the PI or designee(s), using the format and procedures approved by the CPHS. The PI is responsible to instruct the designee in the methods approved by the CPHS for the consent process. The individual obtaining informed consent must also sign the consent document. Please note that only copies of the stamped approved informed consent form can be used when obtaining consent.

UNANTICIPATED RISK OR HARM, OR ADVERSE DRUG REACTIONS: The PI will immediately inform the CPHS of any unanticipated problems involving risks to subjects or others, of any serious harm to subjects, and of any adverse drug reactions.

RECORDS: The PI will maintain adequate records, including signed consent documents if required, in a manner that ensures subject confidentiality.
NOTICE OF CONTINUING REVIEW APPROVAL

HSC-SPH-07-0393 - Occupational Performance Among Mexican Americans Living on Hemodialysis in the Rio Grande Valley of Texas

PI: Shirley Wells

PROVISOS: Unless otherwise noted, this approval relates to the research to be conducted under the above referenced title and/or to any associated materials considered at this meeting, e.g. study documents, informed consents, etc.

NOTE: If this study meets the federal registration requirements and this is an investigator-initiated study, or if the PI is the study sponsor or holds the IND/IDE applicable to this study, and no one else has registered this trial on the national registry, you are required to register this trial on the national registry at www.clinicaltrials.gov in order to publish results in any of the key peer-reviewed journals. For further information contact Gena Monroe at 713-500-7903.

APPROVED: At a convened meeting

MEETING DATE: 06/20/2008

EXPIRATION DATE: 05/31/2009

CHAIRPERSON: Anne Dougherty, MD

Upon review, the CPHS finds that this research is being conducted in accord with its guidelines and with the methods agreed upon by the principal investigator (PI) and approved by the Committee. This approval, subject to any listed provisions and contingent upon compliance with the following stipulations, will expire as noted above:

CHANGES: The PI must receive approval from the CPHS before initiating any changes, including those required by the sponsor, which would affect human subjects, e.g. changes in methods or procedures, numbers or kinds of human subjects, or revisions to the informed consent document or procedures. The addition of co-investigators must also receive approval from the CPHS. ALL PROTOCOL REVISIONS MUST BE SUBMITTED TO THE SPONSOR OF THE RESEARCH.

INFORMED CONSENT: Informed consent must be obtained by the PI or designee(s), using the format and procedures approved by the CPHS. The PI is responsible to instruct the designee in the methods approved by the CPHS for the consent process. The individual obtaining informed consent must also sign the consent document. Attached is the approved and validated informed consent form. You must discard all previous informed consent documents being used and replace them with this stamped validated version. Please note that only copies of the appropriately dated, stamped approved informed consent form can be used when obtaining consent.

UNANTICIPATED RISK OR HARM, OR ADVERSE DRUG REACTIONS: The PI will immediately inform the CPHS of any unanticipated problems involving risks to subjects or others, of any serious harm to subjects, and of any adverse drug reactions.

RECORDS: The PI will maintain adequate records, including signed consent documents if required, in a manner which ensures subject confidentiality.
INFORMED CONSENT FOR PARTICIPATION IN FOCUS GROUPS OR INTERVIEWS
TITLE: OCCUPATIONAL PERFORMANCE AMONG MEXICAN AMERICANS WITH ESRD LIVING ON HEMODIALYSIS IN THE RIO GRANDE VALLEY IN TEXAS

INVITATION TO TAKE PART:
You are invited to take part in a research project called “Occupational Performance Among Mexican Americans with ESRD Living on Hemodialysis in the Rio Grande Valley,” conducted by Shirley A. Wells, MPH, OTR, a graduate student at the UT HSC at Houston, School of Public Health. This study is being conducted as partial fulfillment of a Doctoral degree.

Taking part in this study is voluntary; you may refuse to take part, or choose to stop taking part, at any time. A decision not to take part, or to stop being a part of the research project will not change the services that are available to you. You may refuse to answer any questions asked or written on any forms.

This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston as HSC-SPH-07-0393.

DESCRIPTION OF RESEARCH:
Purpose: The purpose of the study is to identify the most prominent needs, perceptions and issues related to the occupational performance of Mexican Americans with end-stage-renal-disease (ESRD) living on hemodialysis from the points of view of the individual with ESRD who have lived with hemodialysis for 6 months or more, their families and the healthcare providers who serve them.

You are being asked to take part in a focus group (8 to 10 people who will discuss topics and address questions related to living with hemodialysis with the help of a group leader) or individual interview (an one-on-one discussion on topics and questions related to living with hemodialysis). I am interested in finding out what you think and your opinions.

PROCEDURE:
What to expect as a subject:
• During the focus group you will be asked to talk about your needs, perceptions and issues related to you and your family’s ability to perform or engage in occupations and daily activities while living with hemodialysis. The focus groups will be conducted in a neutral location such as hotel meeting room. The researcher will first telephone to confirm your desire to take part in the group and your attendance. At the beginning of the discussion, the focus group leader will explain the structure and rules of the group discussion as well as assuring the confidential of all information obtained. You will receive and sign the consent form in your preferred language (English or Spanish). You will complete a background questionnaire and acculturation scale. The focus group discussion will be conducted in the preferred language of
the participants by the facilitator. After the discussion, the participants will be thanked for their time and participation in the study as well as when they can expect to receive the written results of this part of the study.

- During the individual interview you will be asked to talk about the needs, perceptions and issues related to Mexican Americans receiving and living on hemodialysis. The researcher will first confirm your willingness to take part in the study. The date, time and location of the interview will be scheduled to your convenient. Prior to the interview, you will sign the consent form and complete the background information then questions will be asked. After the discussion, the participant will be thanked for his or her time, and participation in the study as when they can expect to receive the written results of this part of the study.

- The focus group meetings and individual interviews will be taped recorded. These tapes will be written out and will not include any names or identifying information on the transcriptions. The tapes will be kept in a locked cabinet by the Researcher and will be destroyed after 3 years.

- All information you share with us during the group will not be given to anyone else. The names of people are not published. All the information you provide will be completely anonymous and confidential.

**TIME COMMITMENT:**
The focus group meeting will be last about 1 hour to 1½ hour. The individual interview will last about 45 minutes to 1 hour.

**BENEFITS:**
You may receive no direct benefit from being in the focus group or interview; however taking part may help individuals with ESRD living on hemodialysis and their families get better information and care in the future.

**RISKS AND/OR DISCOMFORTS:**
Participants may experience physical fatigue or feelings of discomfort with some questions. If some questions make you feel uncomfortable, you may refuse to answer them.

**ALTERNATIVES:**
The only alternative to being in the study is not to take part in the study.

**STUDY WITHDRAWAL:**
If at anytime during the focus group meeting or interview you feel uncomfortable or you decide not to participate any longer, you may stop being in the focus group or interview and leave the session.

**IN CASE OF INJURY:**
If you suffer any injury as a result of taking part in this research study, please understand that nothing has been arranged to provide free treatment of the injury or any other type of payment. However, all needed facilities, emergency treatment and professional services will be available to you, just as they are to the community in general. You should report any such injury to Shirley Wells at (956) 455-9737, Dr. Belinda Reininger at (956) 554-5161 and to the Committee for the Protection of Human Subjects at (713) 500-3985. You will not give up any of your rights by signing this consent form.
COST, REIMBURSEMENT, AND COMPENSATION:
You will not incur any costs while taking part in the focus group or interview. We will give you a gift card worth $20.00 at the end of the meeting to reimburse you for the time and effort that you volunteered to the study.

CONFIDENTIALITY:
You will not be personally identified in any reports or publications that may result from this study. Any personal information that is tape-recorded during the focus group or interview will not be transcribed and the tapes will be destroyed after 3 years. A special number will be used to identify you in the study and only the investigator will know your name.

QUESTIONS:
If you have any questions about this study, you may contact Shirley A. Wells at (956) 455-9737 or sammiew@earthlink.net. In addition, you may contact Dr. Belinda Reininger, Dissertation Chair, at (956) 554-5161 and the Committee for the Protection of Humans Subjects at (713) 500-3985.

Sign below only if you understand the information given to you about the research and choose to take part. Make sure that any questions have been answered and that you understand the study. If you have any questions or concerns about your rights as a research subject, call the Committee for the Protection of Human Subjects at (713) 500-3985. If you decide to take part in this research study, a copy of this signed consent form will be given to you.

_____________________________________  _____________________________________
Signature of Participant                Signature of Person Obtaining Consent

_____________________________________  _____________________________________
Name of Participant (Print)             Name of Person Obtaining Consent (Print)

___________________________    ______________________________
Date                          Date

CPHS STATEMENT:
This study (HSC-SPH-07-0393) has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston. For any questions about research subject’s rights, or to report a research-related injury, call the CPHS at (713) 500-3985.
CONSENTIMIENTO INFORMADO PARA LA PARTICIPACIÓN EN GRUPOS PRINCIPALES O ENTREVISTAS

TÍTULO: FUNCIONAMIENTO OCUPACIONAL ENTRE LOS MEXICOAMERICANOS CON ESRD QUE SE SUSTIENEN EN HEMODIALISIS EN EL VALLE DEL RIO GRANDE EN TEJAS

INVITACIÓN A PARTICIPAR:
Ud. esta invitado a que participe en un proyecto de investigación llamado “Funcionamiento Ocupacional Entre los Mexicoamericanos con ESRD que se Sustienen en Hemodialisis en el Valle del Rio Grande,” conducido por Shirley A.Wells, MPH, OTR, estudiante de posgrado en el UT HSC en Houston, Escuela de Salud Pública. Este estudio se está conduciendo para cumplimiento parcial de un Grado Doctoral.

La participación en este estudio es voluntaria; Ud. puede rechazar la participacion, o elegir participar, en cualquier momento. Una decisión a no participar, o a parar de ser una parte del proyecto de investigación no cambiara los servicios que estan disponibles para Ud. Ud. puede negarse a contestar cualquier pregunta hecha o escrita en cualquier forma.

Este proyecto de investigación ha sido revisado por el Comité para la Protección de los Sujetos Humanos (CPHS) del Centro de la Ciencia de la Salud de la Universidad de Texas en Houston como HSC-SPH-07-0393.

DESCRIPCIÓN DE LA INVESTIGACIÓN:
Propósito: El propósito del estudio es identificar las necesidades más prominentes, las percepciones y los asuntos relacionadas con el funcionamiento ocupacional de los Mexicoamericanos con la etapa-final-enfermedad-renal(ESRD) sustenidos en hemodialisis desde los puntos de vista del individuo con ESRD que se han sustenido con la hemodialisis por 6 meses o más, sus familias y los proveedores de asistencia sanitaria que los sirven.

Te están pidiendo participar en un grupo principal (8 a 10 personas que discutiran asuntos y tratarán las preguntas relacionadas a la vida con hemodialisis con la ayuda de un líder de grupo) o entrevista individual (una discussion de cara a cara invoca sobre los asuntos y las preguntas relacionados con la vida con hemodialisis). Estoy interesado en descubrir lo que piensas y tus opiniones.

PROCEDIMIENTO:
Què esperar como participante:
- Durante el grupo principal te pediran hablar de tus necesidades, las percepciones y los asuntos relacionadas contigo y tu familia, la habilidad de realizar o entrar en ocupaciones y actividades diarias mientras que se sustienen con hemodialisis. Los grupos principales serán conducidos en una localización neutral tal como una sala de reunion de hotel. El investigador, primero llamará por telefono para confirmar tu deseo de participar en el grupo y tu asistencia. Al principio de la discusion, el líder del grupo principal explicará la estructura y las reglas de
la discusión de grupo así como asegurar la confidencialidad de toda la información obtenida. Recibirás y firmarás la forma de consentimiento en tu lengua preferida (inglés o español). Llenarás un cuestionario de tu historial y una escala de la aculturación. La discusión del grupo principal será conducida en la lengua preferida de los participantes por el facilitador. Después de la discusión, se le agradecerá a los participantes por su tiempo y participación en el estudio, también se les informara cuando recibiran los resultados escritos de esta parte del estudio.

- Durante la entrevista individual te pedirán hablar de las necesidades, las percepciones y los asuntos relacionadas con los Mexicoamericanos que reciben y que viven en hemodialisis. El investigador primero confirmará tu buena voluntad de participar en el estudio. La fecha, la hora y la localización de la entrevista serán programadas a tu conveniencia. Antes de la entrevista, usted firmará la forma del consentimiento y completará el cuestionario historial y se le haran unas preguntas. Después de la discusión, se le agradecerá al participante por su tiempo, y la participación en el estudio al igual se le informara cuando podra recibir los resultados escritos de esta parte del estudio.

- Las reuniones del grupo principal y las entrevistas individuales serán audio-grabadas. Estas cintas serán escritas Y no incluirán ningún nombre o información confidencial en las transcripciones. Las cintas serán mantenidas en un gabinete cerrados por el Investigador y serán destruidas después de 3 años.

- Toda información que usted comparta con nosotros durante el grupo no será compartida con nadie más. Los nombres de personas no son publicados y toda la información que usted proporcione será completamente anónima y confidencial.

COMPROMISO DE TIEMPO:
La reunión del grupo principal durará cerca de 1 hora a 1½ hora. La entrevista individual durará cerca de 45 minutos a 1 hora.

LOS BENEFICIOS:
Ud. Podrá no recibir ninguna ventaja directa de estar en el grupo principal o la entrevista; sin embargo tomando parte puede ayudar a los individuos con ESRD que viven en hemodialisis y a sus familias para conseguir una mejor información y cuidado en el futuro.

RIESGOS Y/O MALESTARES:
Los participantes pueden experimentar fatiga física o sensaciones de molestia con algunas preguntas. Si alguna pregunta lo hace sentirse incómodo, tiene el derecho de negarse a contestarla.

ALTERNATIVAS:
La única alternativa a estar en el estudio es no participar en el estudio.

RETIRO DEL ESTUDIO:
Si en cualquier momento durante la reunión del grupo principal o entrevista Ud. se siente incómodo o
Ud. decide ya no participar más, puedes dejar de participar en el grupo principal o en las entrevistas y salirse de la sesión.

EN CASO DE LESIÓN:
Si sufres cualquier lesión como resultado de participar en este estudio de investigación, entienda por favor que nada ha sido arreglado para proporcionar el tratamiento gratuito de la lesión o cualquier otro tipo de pago. Sin embargo, todas facilidades necesarias, el tratamiento de la emergencia y servicios profesionales estarán a su disposición, así como están para la comunidad en general. Usted debe informar cualquier lesión a Shirley Wells al (956) 455-9737, Dr. Belinda Reininger al (956) 554-5161 y al Comité para la Protección de Sujetos Humanos en (713) 500-3985. Ud. no renunciará cualquiera de sus derechos firmando esta forma de consentimiento.

COSTO, REEMBOLSO, Y COMPENSACION:
Usted no contraerá ningún costo al tomar parte en el grupo principal ni la entrevista. Nosotros le daremos una tarjeta de regalo valorada a $20.00 al final de la reunión para reembolsarle por el tiempo y el esfuerzo que usted se ofreció al estudio.

CONFIDENCIALIDAD:
Usted no será identificado personalmente en ningún informe ni las publicaciones que pueden resultar de este estudio. La información personal que es audio grabada durante el grupo principal o la entrevista no será transcrita y las cintas serán destruidas después de 3 años. Un número especial será utilizado para identificarle en el estudio y sólo el investigador sabrá su nombre.

PREGUNTAS:
Si usted tiene cualquier pregunta acerca de este estudio, usted puede contactar a Shirley A. Wells al (956) 455-9737 o sammiew@earthlink.net. Además, usted puede contactar a la Dr. Belinda Reininger, Silla de Disertación, al (956) 554-5161 y el Comité para la Protección de Sujetos Humanos al (713) 500-3985.

Firme abajo sólo si usted entiende la información dada acerca de la investigación y escoge tomar parte. Cerciórese que cualquier pregunta ha sido contestada y que usted entiende el estudio. Si usted tiene cualquier pregunta o preocupación acerca de sus derechos como un sujeto de investigación, llama el Comité para la Protección de Sujetos Humanos en (713) 500-3985. Si usted decide tomar parte en este estudio de investigación, una copia de esta forma firmada del consentimiento será dada a usted.
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<th>Firma del Participante</th>
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<td>Nombre del Participante</td>
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**DECLARACION de CPHS**
Este estudio (HSC-SPH-07-0393) ha sido revisado por el Comité para la Protección de Sujetos Humanos (CPHS) de la Universidad del Centro de la Ciencia de la Salud de Texas en Houston. Para cualquier pregunta acerca de los derechos del sujeto, o para reportar una lesión relacionada a la investigación, llame el CPHS en (713) 500-3985.
INFORMED CONSENT FOR FAMILY MEMBERS PARTICIPATION IN SEMISTRUCTURED OBSERVATIONS

TITLE: OCCUPATIONAL PERFORMANCE AMONG MEXICAN AMERICANS WITH ESRD LIVING ON HEMODIALYSIS IN THE RIO GRANDE VALLEY IN TEXAS

INVITATION TO TAKE PART:
You are invited to take part in a research project called “Occupational Performance Among Mexican Americans with ESRD Living on Hemodialysis in the Rio Grande Valley,” conducted by Shirley A. Wells, MPH, OTR, a graduate student at the UT HSC at Houston, School of Public Health. This study is being conducted as partial fulfillment of a Doctoral degree.

Taking part in this study is voluntary; you may refuse to take part, or choose to stop taking part, at any time. A decision not to take part, or to stop being a part of the research project will not change the services that are available to you. You may refuse to answer any questions asked or written on any forms.

This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston as HSC-SPH-07-0393.

DESCRIPTION OF RESEARCH:
Purpose: The purpose of this study is to describe the day-to-day impact of living on hemodialysis from the point of view of the individual with end-stage-renal-disease and his or her family members. For this part of the study, the researcher will video record participants as they engage in day-to-day occupations and activities. Everyday individuals with end-stage-renal-disease and their family members are faced with complaining with and adjusting to the hemodialysis regimen as well as the many complications associated with it. Investigating the lived experiences of Mexican Americans receiving hemodialysis and their families will provide insights into their actual participation in daily life. Information obtained from this study may offer measures to reducing occupational deprivation and improving the quality of life for all individuals receiving dialysis treatment as well as their family members.

PROCEDURE:
What to expect as a subject:
- Prior to any video-tapping, the researcher will come to the home to confirm participation of the family members in the study. At this time the dates and places of the video-recording will be discussed along with the activities and occupations that will or will not be video-recorded.
- On the scheduled dates (a dialysis day and a non-dialysis day), the researcher along with a videographer will arrive at the home at 8:00 am and go over the procedure that will be followed and the agreed upon occupations that will be video-taped. The researcher will
continue to follow family until 5:00 pm. Video recording will be stop at any time if requested by a family member.

- The researcher will also ask questions of the family member throughout the tapping related to having a family member living with end-stage-renal-disease. You may refuse to answer any questions at any time.

- After the video-tapping the family will be thanked for their time and participation in the study.

- The research team will review the tapes and photos and identify the daily occupations of the individual with end-stage-renal-disease and his or her family. The researcher will keep the tapes and photos in a locked cabinet. The researcher can use the audio-visual material (video tape, audio tape, photographs, motion pictures, and other resulting records) for scientific publications or teaching purposes or lectures at any time hereafter without your inspection or approval of the final product. The tapes will be erased or destroyed after 5 years.

**TIME COMMITMENT:**
The observations will take 2 days – one day in which you receive dialysis and one day in which you do not receive dialysis – for about 8 hours per day.

**BENEFITS:**
You may receive no direct benefit for taking part of the video observation however taking part may help individuals with end-stage-renal-disease living on hemodialysis and their families get better information and care in the future.

**RISKS AND/OR DISCOMFORTS:**
Participants may experience physical fatigue with the video recording or feelings of discomfort with some questions (i.e. Describe your daily routine and activities? What activities do you share as a family group? What activities do you engage in during your free time? How has hemodialysis changed your personal and/or family life?)

**ALTERNATIVES:**
The only alternative to being in the study is not to take part in the study.

**STUDY WITHDRAWAL:**
If at anytime during the video observation you feel uncomfortable or you decide not to take part any longer, you may stop the videotaping and ask the researcher to leave.

**IN CASE OF INJURY:**
If you suffer any injury as a result of taking part in this research study, please understand that nothing has been arranged to provide free treatment of the injury or any other type of payment. However, all needed facilities, emergency treatment and professional services will be available to you, just as they are to the community in general. You should report any such injury to Shirley Wells at (956) 455-9737, Dr. Belinda Reininger at (956) 554-5161 and to the Committee for the Protection of Human Subjects at (713) 500-3985. You will not give up any of your rights by signing this consent form.
COST, REIMBURSEMENT, AND COMPENSATION:
You will not incur any costs while taking part in the observation. A gift card worth $25.00 will be given to the family unit for each day of video recording to reimburse for the time and effort that you and your family volunteered to this study.

CONFIDENTIALITY:
You will not be personally identified in any reports or publications that may result from this study. Any personal information about you that is gathered during this study will remain confidential to every extent of the law. A special number will be used to identify you in the study and only the investigator will know your name. As part of this research project, your face, body image and voice will be tapped (audio/video) or photographed while you engage in a variety of daily occupations and tasks. If you wish, a pseudonym or fake name (i.e. “Mr. G” or “Ms. S”) will be used throughout the tapping to identify you and only the investigator will know your name.

QUESTIONS:
If you have any questions about this study, you may contact Shirley A. Wells at (956) 455-9737 or sammiew@earthlink.net. In addition, you may contact Dr. Belinda Reininger, Dissertation Chair, at (956) 554-5161 and the Committee for the Protection of Humans Subjects at (713) 500-3985.

Sign below only if you understand the information given to you about the research and choose to take part. Make sure that any questions have been answered and that you understand the study. If you have any questions or concerns about your rights as a research subject, call the Committee for the Protection of Human Subjects at (713) 500-3985. If you decide to take part in this research study, a copy of this signed consent form will be given to you.

_____________________________________  _________________________________
Signature of Participant     Signature of Person Obtaining Consent

_____________________________________  _________________________________
Name of Participant (Print)    Name of Person Obtaining Consent (Print)

_____________________________________  __________________________________
Date       Date

CPHS STATEMENT:
This study (HSC-SPH-07-0393) has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston. For any questions about the research subject’s rights, or to report a research-related injury, call the CPHS at (713) 500-3985.
University of Texas-Health Science Center  
School of Public Health  

INFORMED CONSENT FOR PARTICIPATION IN SEMISTRUCTURED OBSERVATIONS  

TITLE:  OCCUPATIONAL PERFORMANCE AMONG MEXICAN AMERICANS WITH ESRD  
LIVING ON HEMODIALYSIS IN THE RIO GRANDE VALLEY IN TEXAS  

INVITATION TO TAKE PART:  
You are invited to take part in a research project called “Occupational Performance Among Mexican Americans with ESRD Living on Hemodialysis in the Rio Grande Valley,” conducted by Shirley A. Wells, MPH, OTR, a graduate student at the UT HSC at Houston, School of Public Health. This study is being conducted as partial fulfillment of a Doctoral degree.  

Taking part in this study is voluntary; you may refuse to take part, or choose to stop taking part, at any time. A decision not to take part or to stop being a part of the research project will not change the services that are available to you. You may refuse to answer any questions asked or written on any forms.  

This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston as HSC-SPH-07-0393.  

DESCRIPTION OF RESEARCH:  
Purpose:  The purpose of this study is to describe the day-to-day impact of living on hemodialysis from the point of view of the individual with end-stage-renal-disease and his or her family members. For this part of the study, the researcher will video record participants as they engage in day-to-day occupations and activities.  

Everyday individuals with end-stage-renal-disease and their family members are faced with complaining with and adjusting to the hemodialysis regimen as well as the many complications associated with it. Investigating the lived experiences of Mexican Americans receiving hemodialysis and their families will provide insights into their actual participation in daily life. Information obtained from this study may offer measures to reducing occupational deprivation and improving the quality of life for all individuals receiving dialysis treatment.  

PROCEDURE:  
What to expect as a subject:  
• Prior to any video-tapping, the researcher will come to your home to confirm your participation in the study and to complete the background questionnaire and acculturation scale. At this time the dates and places of the video-recording will be discussed along with the activities and occupations that will or will not be video-recorded.  

• On the scheduled dates (a dialysis day and a non-dialysis day), the researcher along with a videographer will arrive at your home at 8:00 am and go over the procedure that will be
followed and the agreed upon occupations that will be video-taped. The researcher will continue to follow you until 5:00 pm. Video recording will be stop at any time if requested by the subject.

• The researcher will also ask questions of the subject throughout the tapping related to living with end-stage-renal-disease. You may refuse to answer any questions at any time.

• After the video-tapping on the last day, the subject will be thanked for his or her time and participation in the study as well as when they can expect to receive the written results of this part of the study.

• The research team will review the tapes and photos and identify the daily occupations of the subject. The researcher will keep the tapes and photos in a locked cabinet. The researcher can use the audio-visual material (video tape, audio tape, photographs, motion pictures, and other resulting records) for scientific publications or teaching purposes or lectures at any time hereafter without your inspection or approval of the final product. The tapes will be erased or destroyed after 5 years.

TIME COMMITMENT:
The observations will take 2 days – one day in which you receive dialysis and one day in which you do not receive dialysis – for about 8 hours per day.

BENEFITS:
You may receive no direct benefit for taking part of the video observation however taking part may help individuals with end-stage-renal-disease living on hemodialysis and their families get better information and care in the future.

RISKS AND/OR DISCOMFORTS:
Participants may experience physical fatigue with the video recording or feelings of discomfort with some questions (i.e. Do you feel that your children or other family members will develop end-stage-renal-disease? Which activities or daily occupations most contribute to your quality of life? What activities do you engage in with family members, friends, or others?)

ALTERNATIVES:
The only alternative to being in the study is not to take part in the study.

STUDY WITHDRAWAL:
If at any time during the video observation you feel uncomfortable or you decide not to take part any longer, you may stop the videotaping and ask the researcher to leave.

IN CASE OF INJURY:
If you suffer any injury as a result of taking part in this research study, please understand that nothing has been arranged to provide free treatment of the injury or any other type of payment. However, all needed facilities, emergency treatment and professional services will be available to you, just as they are to the community in general. You should report any such injury to Shirley Wells at (956) 455-
9737, Dr. Belinda Reininger at (956) 554-5161 and to the Committee for the Protection of Human Subjects at (713) 500-3985. You will not give up any of your rights by signing this consent form.

COST, REIMBURSEMENT, AND COMPENSATION:
You will not incur any costs while taking part in the observation. A gift card worth $25.00 will be given to the family unit for each day of video recording to reimburse for the time and effort that you and your family volunteered to this study.

CONFIDENTIALITY:
You will not be personally identified in any reports or publications that may result from this study. Any personal information about you that is gathered during this study will remain confidential to every extent of the law. A special number will be used to identify you in the study and only the investigator will know your name. As part of this research project, your face, body image and voice will be tapped (audio/video) or photographed while you engage in a variety of daily occupations and tasks. If you wish, a pseudonym or fake name (i.e. “Mr. G” or “Ms. S”) will used throughout the tapping to identify you and only the investigator will know your name.

QUESTIONS:
If you have any questions about this study, you may contact Shirley A. Wells at (956) 455-9737 or sammiew@earthlink.net. In addition, you may contact Dr. Belinda Reininger, Dissertation Chair, at (956) 554-5161 and the Committee for the Protection of Humans Subjects at (713) 500-3985.

Sign below only if you understand the information given to you about the research and choose to take part. Make sure that any questions have been answered and that you understand the study. If you have any questions or concerns about your rights as a research subject, call the Committee for the Protection of Human Subjects at (713) 500-3985. If you decide to take part in this research study, a copy of this signed consent form will be given to you.

_____________________________________  _________________________________
Signature of Participant     Signature of Person Obtaining Consent

_____________________________________  __________________________________
Name of Participant (Print)    Name of Person Obtaining Consent (Print)

_____________________________________  _________________________________
Date       Date

CPHS STATEMENT:
This study (HSC-SPH-07-0393) has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston. For any questions about the research subject’s rights, or to report a research-related injury, call the CPHS at (713) 500-3985.
LITERATURE CITED


Seminars in Dialysis, 15(1), 35-37.


VITA

Shirley A. Wells have been a practicing occupational therapist for almost 30 years. From the Navajo Indian Reservation of Arizona, the border cities of Texas and Mexico, the urban areas of Minnesota, to the rural areas of Texas, she has worked with a variety of ethnic and diverse populations. Her career experiences have included: administer, educator, researcher, director of an OT rehabilitation department, consultant, acute care therapist, and pediatric and school based therapist.

She has presented, nationally and internationally, on a variety of topics related to diversity, multiculturalism and health care. She has authored & co-authored numerous articles, books and chapters such as: The forgotten population: Health Communication with Rural Racial & Ethnic Communities (2008), Culture and Occupation: A Model of Empowerment for Occupational Therapy (2007), An Ethic of Diversity (2005), Mexican American Women: Impact of Culture and Education on Work Patterns (2005), Cultural Competency for Health Care Professionals (2000), and a video, Creating a Multicultural Approach and Environment (1996).

She was awarded the 1997 Breaking Barriers Award from the Greater Washington Society of Association Executives (GWSAE) for her leadership of the AOTA’s Multicultural Affairs Program. She received the 1998 Recognition of Achievement Award for Advocacy in Diversity by the American Occupational Therapy Association (AOTA) and award the status of Fellow of American Occupational Therapy (FAOTA) in 2002 and the Roster of Merit from the Texas Occupational Therapy Association in 2004.

Ms. Wells has a Master of Public Health degree in Maternal & Child Health with a specialty in chronic and handicapping conditions of children from the University of Minnesota, Minneapolis, Bachelor of Science in Occupational Therapy from the University of Texas Medical Branch, Galveston, and Bachelor of Arts in Latin from the University of Texas, Austin. She is presently an Associate Professor and Interim Chair of the Occupational Therapy Department at The University of Texas-Pan American, Edinburg, Texas.