Health literacy and treatment adherence among Latinos with end stage renal disease

Marielena Michel

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HEALTH LITERACY AND TREATMENT ADHERENCE AMONG
LATINOS WITH END STAGE RENAL DISEASE

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

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

by
Marielena Michel
June 2008
HEALTH LITERACY AND TREATMENT ADHERENCE AMONG LATINOS WITH END STAGE RENAL DISEASE

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Approved by:

Rachel Estrada, M.S.W., L.C.S.W.,
Faculty Supervisor, Social Work

Marciano B. Ocon, RN, BSN,
R.A.I. Glendora Dialysis Center

Dr. Janet C. Chang
M.S.W. Research Coordinator
ABSTRACT

The purpose of this study was to examine health literacy and treatment adherence among Latinos with End Stage Renal Disease. Health literacy has been overlooked as one of the factors that affect's one's ability to comply with the physician's prescribed medical treatment. Health literacy is defined as one's ability to read, understand and act on health information. Patients with low health literacy are at risk for the worse health outcomes. The relationship between health literacy and health outcomes is greatly impacted. Latinos are the largest minority group in the United States. At the same time the Latino patients with End Stage Renal Disease are faced with complex barriers including issues of language, low health literacy, and cultural beliefs.
ACKNOWLEDGMENTS

I am deeply grateful to my family, especially my husband Juan for his belief in me and putting up with the roller coaster of emotions. Thanks to my children Eliza and Alejandro for being tolerant throughout these two years I realize how difficult it was not having mom around. I Love you!

Thanks to the supportive staff at Glendora dialysis that believed in me, listened to my frustrations and always had encouraging words like, "you can do it" or "just think it's almost over". Very special thanks to the center director, Marciano Ocon, without whom this project would not be possible.

I would like to acknowledge my field supervisor, Felipe Amaya for his dedication and commitment. Thanks to you and Pat Smith, administrator at R.A.I. Rialto for allowing me to complete my research project.

Finally, I would like to thank my project advisor, Rachel Estrada, for your guidance and knowledge.
DEDICATION

To honor the memory of my mother, who encouraged me before she left this world to join my father and brother to continue my education. Thanks for believing in me and guiding me along this difficult journey. I miss you mom.
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CHAPTER ONE

INTRODUCTION

Problem Statement

Kidney disease is the ninth leading cause of death in the United States (United States Renal Data System, 2004). According to the National Kidney Foundation (NKF), it is estimated that more than 20 million Americans or 1 in 9 adults have kidney disease and another 20 million are at risk and unaware of it. People with kidney failure are expected to reach 650,000 by the year 2010. Diabetes and hypertension represent 65 to 75 percent of the leading causes of kidney disease.

Recent studies have shown that the prevalence of type 2 diabetes is higher among Latinos, specifically Mexican-Americans, than non-Hispanic Whites (CDC • Prevalence of Diabetes among Hispanics in Six U.S. Geographic Locations, 2005). In the United States Latinos represent the largest minority population and fastest growing in the country (Campos, 2007).

End Stage Renal Disease (ESRD) is a chronic illness that results in kidney failure. This chronic condition requires life long treatment. Hemodialysis (HD) is the
preferred form of treatment modality for individuals with ESRD, which account for 65 percent of the ESRD population. HD is a medical treatment in which a patient is connected to a dialysis machine, which removes extra fluid, waste, and salt from the blood. The blood is returned to the patient’s body through tubing connected to the patient via catheter or access. This process takes approximately an average of four hours in length and typically is performed three times per week (Gehlert & Browne, 2006).

The demand for the patients to be compliant with their dialysis treatment along with accepting a new lifestyle change can place enormous stress in their ability to accept their chronic condition. Noncompliant patients routinely experience a greater risk of infections, hospitalization, diet related issues such as over fluid and cardiovascular failure. Studies show that patients who often miss or shorten their dialysis treatments increase their risk of mortality (Yagi, 2006).

Studies have shown that eighty-nine percent of ESRD patients experience lifestyle changes from the disease that affects their quality of life and health outcomes. Nephrology social workers can assist the patient in
adjusting to the demands of the disease and in coping with the psychosocial issues (Gehlert & Browne, 2006).

To assist with these issues, in 1972, Congress established the ESRD program, to fund dialysis treatment for those with ESRD regardless of age or disability status. As a result, medicare mandates that a master’s level social worker be a member of the interdisciplinary team. The intervention of the nephrology social worker is aimed at "improving the patient’s ability to adjust to and cope with chronic illness and the health-care system’s ability to meet the needs of the patient" (Gehlert & Browne, 2006, p. 481).

Because ESRD is considered a public health issue, in 2005, medicare spent $21.3 billion compared to $17 billion in 2002 toward the ESRD program. In the same year providing dialysis treatments to a patient costs on average $68,585 (USRDS, 2007).

Through political advocacy Congress is being urged to restructure the Medicare ESRD program.

Currently, The Kidney Care Quality and Education Act of 2007 (S.691; H.R.1193) has been introduced to Congress. This bill focuses on pre-dialysis education for
kidney patients before they qualify for the ESRD program (NKF, 2007).

In 2001, a team of nephrology social workers created the wellness program for ESRD patients. This is an outcomes-driven practice model. This model seeks to improve health outcomes by empowering ESRD patients to have more control over their disease management. Patients who comply with their medications, fluid, diet restriction and treatment regimen not only experience a better quality of life but prevent hospitalization, where an abundance of the ESRD money is spent (Johnstone, 2005).

One issue that is receiving national attention is health literacy, and several states are taking an initiative or even passing legislation to address health literacy. Health literacy is defined as one’s ability to read, understand and act on health information. Patients with low health literacy are at risk for the worse health outcomes. The individuals most at risk are seniors, low-income and the chronically ill. (Murphy-Knoll, 2007).
Purpose of the Study

The purpose of this study was to examine health literacy and treatment adherence among Latinos with ESRD. Four principle areas were the focus of this study: culture, language, health literacy, and family. The literature reviewed suggests that these four principle areas are interrelated for ESRD Latino patients.

Culture is defined as “the configuration of shared attitudes, values, goals, spiritual beliefs, social expectations, arts, technology, and behaviors that characterize a broader society in which people live” (Zastrow & Kirst-Ashman, 2007, p. 20). It is believed that the individual is influenced by the “dominant culture” or the “culture of origin” (Amaya, 2001, p.11).

Language is the expression of human communication through knowledge, beliefs, and behaviors that can be expressed, explained, and shared (NIDCD, 2007).

Health literacy is the ability to read, understand and use healthcare information to make informed healthcare decisions and follow the recommended treatment regimen (Campos, 2007).

Family plays an important role and perhaps is the strongest cultural value. Familism is defined as giving
priority to family needs rather than individual needs (Wells, 2006).

The words "Latino" and "Hispanic" are used interchangeably to refer to persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish cultures regardless of race (Zastrow & Kirst-Ashman, 2007,).

Studies have shown that these four principles, health literacy, culture, language, and family, have a direct impact on adherence to prescribed treatment among Latinos. Nonadherence with medical recommendations for the dialysis patients is a major problem. Nonadherence with dialysis is a complex problem; the question is how it's being defined. There are three types of compliance that are associated with the dialysis regimen: dietary and fluid restrictions, medication compliance and completion of prescribed dialysis treatments (Hailey & Moss 2006). The literature suggests that dialysis professionals can help improve the health care needs of this population of Latino ESRD patients by first being sensitive to the cultural beliefs of Latino ESRD patients.
A qualitative analysis was used to measure the issues of adherence to treatment regimens among Latinos with ESRD at the dialysis clinic.

Significance of the Project for Social Work

The object of this study was to explore health literacy and treatment adherence among Latinos with ESRD. Exploration in this area will hopefully assist the renal health care community in their responsiveness to the levels of health literacy with Latinos with ESRD.

Latinos are the largest minority group in the United States. In 2005, 59.8% of Latinos were US citizens at birth and 40.2% were immigrants from Mexico (Morris & Baird, 2007). Studies show that there is a high prevalence of low health literacy among Latinos (Campos, 2007). Latinos have been identified as one of the vulnerable groups who lack the ability to comprehend medication instructions; consent forms, diagnosis, or treatment plans (U.S. Department of Health and Human Services, 2003). Compliance with medical recommendations by Latino ESRD patients has complex barriers including socioeconomic issues, language, low health literacy, and cultural beliefs.
As it pertains to the generalist model of social work practice, this study focuses on the assessment phase. It is often the case that Latino patients, due to low literacy skills or speaking little or no English, respond passively as health information is disseminated (Knoll-Murphy, 2007).

End Stage Renal Disease is a serious, involved and lifelong chronic illness. The complications related to dialysis are many and psychosocial stressors can affect the lives of the ESRD patients on a daily basis. The nephrology social workers' goal is to positively influence the quality of life for individuals suffering from end stage renal disease. The challenge is for nephrology social workers to begin looking at the connectedness between one's health literacy and treatment adherence in the ESRD patient populations.
CHAPTER TWO
LITERATURE REVIEW

Introduction
The focus of this review was specifically on Latino patients undergoing hemodialysis. The literature reveals that Latinos are confronted with multiple factors interfering with compliance (adherence) to treatment. The terms adherence and compliance have been used interchangeably in the past. However, adherence is a more appropriate term for the purpose of this study. The term adherence implies that patients are active and involved in their treatment plan in collaboration with their health team (Kugler, Vlaminck, Haverich & Maes, 2005).

Health literacy has been overlooked as a factor that negatively affects adherence to treatment regimens. This chapter will examine health literacy, hemodialysis and adherence to physician's prescribed medical treatment, and how Latino culture influences prescribed treatment.

Health Literacy
The National Institutes of Health (NIH) has defined health literacy as the "degree to which individuals have the capacity to obtain, process and understand basic
health information and services needed to make appropriate health decisions" (2006, p. 11). Literature confirms that poor health literacy needs to be looked at within the context of language and culture (Andrulis, 2007). Similarly, current articles add that education, race/ethnicity, and age are also associated with health literacy in general (Paasche-Orlow 2007). The relationship between health literacy and health outcomes is greatly impacted. There is limited empirical evidence that demonstrates a cause and effect schema (Andrulis, 2007).

Hemodialysis and Adherence

Hemodialysis is the preferred treatment modality for individuals with End Stage Renal Disease. Hemodialysis is a process by which excess fluid, waste, and salt are removed from the blood. Hemodialysis is generally performed three times a week, for the duration of three or more hours per treatment (Ferro, 2005). Dialysis patients are required to follow strict dietary, fluid restriction, and medication regimens. Adherence with the prescribed medical regimen places great demands on the patient (Denhaeynck, Manhaeve, Dobbels, Garzoni, Nolte, &
A result of nonadherence to the dialysis prescription is morbidity and mortality (Kugler et al., 2005).

According to a recent article by Costantini (2006), several studies demonstrated that patients' beliefs, values and concerns needed to be considered when examining the prevalence of nonadherence with the prescribed diet, fluid and treatment regimen. The findings of a multicenter cross-sectional study indicated that further studies are warranted where patients' behaviors are included (Kugler, et al., 2005).

**Latino Culture**

According to the 2000 U.S. Census, Latinos represent 13.3 percent of the U.S. population. In 2002, there were 32.5 million living in U.S. who were born outside of the United States. More than one-third of them were either from Mexico or Central America (Schmidley, 2003).

As noted, most Latino adults were foreign-born which brings rise to the issue of acculturation. The impact of acculturation into Western culture affects Latinos from a social and psychological perspective (Miranda, 2006).
Subsequently, due to the challenges and life changes brought on by acculturation the health of Latino immigrants can either have positive or negative affect (Abraida-Lanza, A., Armbrister, A., Florez, K., & Aguirre, Al., 2006). Acculturation has been defined as, “an ethnic person’s adoption of the dominant culture in which he or she is immersed. There are several degrees of acculturation; a person can maintain his or her own traditional cultural beliefs, values, and customs from their country of origin to a greater or lesser extent” (Zastrow & Kirst-Ashman, 2007, p.142).

In fact, English-language proficiency is one indicator of acculturation that has significantly influenced Latinos and their families (Miranda, Bilot, Peluso, Berman & Van Meek, 2006). Furthermore, Latino’s cultural values can influence the patients’ attitudes, behaviors and emotions. The common cultural values that can influence Latinos’ perceptions on health care are: family (familism), respect (respeto), personal relationships (personalismo), politeness (simpatia) and fatalism (falalismo) (Campos, 2007).

Familism (family) is perhaps the strongest cultural values for Latinos (Wells, 2006). The composite of the
family includes the nuclear as well as the extended family. In fact, included are those individuals that are tied to the family through baptism, first communion, confirmation, or marriage (Root, 2004). The family is involved in the decisions of healthcare (Amaya, 2001). It is not uncommon to have a family spokesperson; usually the spokesperson is the eldest son or daughter. One of the responsibilities of the spokesperson is to secure services for the patient (Wells, 2006).

Respect (respeto) is highly valued from others. It is based on age, gender and authority (Antshel, 2002). Respect is seen as privacy, dignity, and trust. Older Latinos expect respect from those younger than themselves. One example in how the cultural value respecto be seen as a barrier to treatment adherence is for a patient to be hesitate to ask an authority figure like a physician a question because this is seen as disrespectful. Latinos may agree with the physician’s instructions as a sign of respect even when they do not understand (Campos, 2007).

Personal relationships (personalismo) are characterized as personal, warm relationships. Latinos seek to find in their healthcare providers a sign of
personalismo by a handshake or showing interest in their life. Latinos place a personal relationship on the individual or healthcare provider rather than on the clinic (Antshel, 2002). One way personalismo can serve as a barrier to treatment adherence is when the patient perceives that their healthcare provider does not care about them so therefore, may be unwilling to disclose medical information or nonadherent to follow prescribed medical regimen (Campos, 2007).

Fatalism (fatalismo) is seen as a religious belief in Latinos. Latinos are more likely to believe that the chronic illness was a punishment from God (castigo de Dios) as a result of their own sins or those of their family (Antshel, 2002).

Latinos and Health

In a recent study the mortality rates for Latinos were found to be much lower than the overall United States population (The Provider’s Guide, 2003). It is unclear why Latinos have a low mortality rate but what is clear is that their culture influences this behavior that will eventually influence their health (Hayes-Bautista, 2004). Research studies indicate that to fully comprehend
the unique health issues faced by Latinos one must address the connection between acculturation and health (Miranda et al., 2006). Penn, Kar, Kramer, Skinner, and Zambrana (1995) explain that English-language proficiency and place of birth are indicators of more traditional cultural values. The role of culture will influence Latinos health behaviors and treatment adherence.

Latinos value holistic health care. Reliance on the use of alternative therapies is not uncommon for ESRD Latino patients who turn to curanderos (folk healers) and sobadores (massage therapist or bone healers) or herbalists. It is believed that these folk healers will treat physical, spiritual, and psychosomatic illnesses (Robles-Burgos & Ocasio-Pare, 2006). The practice of folk healers is not readily accepted by Western medicine therefore, Latino patients may not readily disclose this information (Root, 2004).

Several Latinos steer clear of disagreeing with or expressing doubts to their health care provider about the treatment that is being recommended (United States Department of Health and Human Services, 2000).
Theories Guiding Conceptualization

A systems theory offers the social worker a way to conceptualize the relationship between people and their environment (Zastrow & Kirst-Ashman, 2007). Systems theory was developed by biologist Ludwing von Bertalanfly in 1936. He realized that the work of scientists and scholars were parallel in many ways. The development of this theory was to provide the common framework where they could share their findings and at the same time build upon them (Nash, Munford, & O’Donoghue, 2005).

Systems theories and ecological concepts have been combined and referred to as ecosystems theory. The ecosystem places more importance on individuals and individual family systems (Zastrow & Kirst-Ashman, 2007).

Summary

The literature review examined many aspects that are important factors that affect Latinos ability to make an informed decision about their healthcare, most of which have to do with cultural beliefs, values and how health literacy affects them. All of these influenced the choice that Latinos make in the treatment of End Stage Renal Disease. Other factors that will be explored further are
the barriers that Latinos experience as a group such as: socioeconomics, education, access to health insurance and language. It is the goal of this research to bring awareness to the issue of health literacy and cultural sensitivity to the healthcare providers who service this population.
CHAPTER THREE

METHODS

Introduction

This chapter includes six sections. The first section describes the study design, second section is the sampling, third section is the data collection and instruments, fourth section is the procedure used for the study, fifth section covers the protection of human subjects and the final section discusses the data analysis.

Study Design

The purpose of this study was to examine health literacy and treatment adherence among Latinos with ESRD. A qualitative study was conducted by interviewing Latino patients that were undergoing hemodialysis treatments. This qualitative study was aimed at better understanding the cultural values, language, family and health literacy among Latinos and how these affect their adherence to the prescribed treatment regimen.

A face-to-face interview allowed Latino patients to provide insight into their understanding of health literacy and how their cultural beliefs may impact
treatment adherence to dietary, fluid or treatment regimen. External data was drawn from patient’s medical files to review the lab values that determine if the patient was compliant with dialysis treatment.

Sampling

This study utilized a non-random convenience sample consisting of 18 Latino patients who were undergoing In-Center Hemodialysis at Glendora Dialysis Center in Glendora, California and Rialto Dialysis Center in Rialto, California. This researcher was part of the interdisciplinary team and had the full cooperation from the medical director and the clinic administrator to conduct this study.

Data Collection and Instruments

Face-to-face interviews and external data was used to determine a link between health literacy and Latino patients’ adherence to their treatment regimen. A questionnaire was developed by the researcher in the form of an interview guide. The questions were based on the review of the literature. The questions were open-ended and were conducted in English and Spanish. The initial portion of the questionnaire pertained to demographic
information, independent variables which include gender, age, ethnicity, language, education and income level.

The qualitative interview measured how low health literacy among Latino patients was linked to nonadherence regarding dietary, fluid and/or physician prescribed treatment regimen. The interview questions were divided into three sections: demographic information, health literacy and adherence to the physician’s prescribed medical treatment.

A typical question would be for demographic information was: Where were you born? How long have you been living in the United States? An example of a question in the health literacy sections was: what is/are your biggest health problems? Were you able to understand the seriousness of your health problems as explained to you by your doctor/doctors? In the section for treatment compliance questions asked were: Tell me your understanding of what could happen if you drank too much fluid between dialysis treatments? Tell me your understanding of what could happen if you missed a dialysis treatment?
Procedures

The procedure for collecting the data from each individual participant was by arranging a face-to-face meeting that was most convenient for the participant. The participant was approached at the dialysis center and asked if he or she was interested in volunteering to participate in the study. The option was offered to the participant if the interview should take place before, during or after their dialysis treatment. The interview process and data collection took approximately one month.

Protection of Human Subjects

Participation in this study was strictly voluntary and each participant was given a letter of informed consent and a debriefing statement in their primary language. The patient was informed of the purpose of the study along with the protection of their confidentiality.

Data Analysis

In this qualitative research study the researcher was analyzing interview data. Specifically, looking for major themes and patterns in the data. The data was sorted and organized in order to be coded.
Summary

The purpose of this study was to identify the relationship on how health literacy influences adherence to the physician’s prescribed medical treatment among ESRD Latino patients. Data collection for this study was qualitative interview. Recruited for this study were Latino patients undergoing hemodialysis at the Glendora Dialysis Center and Rialto Dialysis Center.
CHAPTER FOUR

RESULTS

Introduction

Chapter four presents research collected from the oral interviews with Latino patients' diagnosed with End Stage Renal Disease undergoing hemodialysis. The first section describes the demographic characteristics of the sample included in the study. The second section describes whether health literacy influenced treatment adherence among Latinos with End Stage Renal Disease. The third section explores cultural influences among Latinos with End Stage Renal Disease. The fourth section summarizes the results of the study.

Demographics

The total number of participants who participated in the interview was 18. A summary of the demographic characteristics is shown in table 1. Eight of whom were male and 10 were female. They ranged in age from 28 to 89 years with a mean age of 33. The ethnic make up was three participants classified themselves as "Mexican-American" (Born and raised in the United States, but of
Table 1. Demographics of Participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Male (n = 8)</th>
<th>Female (n = 10)</th>
<th>Total%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (mean = 58.5)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-45</td>
<td>2</td>
<td>2</td>
<td>22%</td>
</tr>
<tr>
<td>46-65</td>
<td>2</td>
<td>5</td>
<td>38%</td>
</tr>
<tr>
<td>66-75</td>
<td>2</td>
<td>2</td>
<td>22%</td>
</tr>
<tr>
<td>76+</td>
<td>2</td>
<td>1</td>
<td>16%</td>
</tr>
<tr>
<td><strong>Ethnic Background</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mexican-American</td>
<td>2</td>
<td>1</td>
<td>16%</td>
</tr>
<tr>
<td>Mexican</td>
<td>5</td>
<td>8</td>
<td>72%</td>
</tr>
<tr>
<td>Central American</td>
<td>1</td>
<td>1</td>
<td>11%</td>
</tr>
<tr>
<td><strong>Place of Birth</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Native of U.S.</td>
<td>2</td>
<td>1</td>
<td>16%</td>
</tr>
<tr>
<td>Non-Native</td>
<td>6</td>
<td>9</td>
<td>83%</td>
</tr>
<tr>
<td>Mexico</td>
<td>5</td>
<td>8</td>
<td>72%</td>
</tr>
<tr>
<td>Central America</td>
<td>1</td>
<td>1</td>
<td>11%</td>
</tr>
<tr>
<td><strong>Raised</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within U.S.</td>
<td>2</td>
<td>1</td>
<td>16%</td>
</tr>
<tr>
<td>Outside U.S.</td>
<td>6</td>
<td>9</td>
<td>83%</td>
</tr>
<tr>
<td><strong>Number of years in U.S.</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-10</td>
<td>2</td>
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<td>16%</td>
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<td>11-20</td>
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<td>4</td>
<td>27%</td>
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<tr>
<td>21+</td>
<td>5</td>
<td>5</td>
<td>55%</td>
</tr>
<tr>
<td><strong>Dominant Language</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spanish</td>
<td>6</td>
<td>7</td>
<td>72%</td>
</tr>
<tr>
<td>English</td>
<td>1</td>
<td>0</td>
<td>5%</td>
</tr>
<tr>
<td>Bilingual</td>
<td>1</td>
<td>3</td>
<td>22%</td>
</tr>
<tr>
<td><strong>Religious Faith</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catholic (Active/practicing)</td>
<td>7</td>
<td>8</td>
<td>83%</td>
</tr>
<tr>
<td>(Not practicing)</td>
<td>5</td>
<td>5</td>
<td>55%</td>
</tr>
<tr>
<td>Christian (Active/practicing)</td>
<td>1</td>
<td>1</td>
<td>11%</td>
</tr>
<tr>
<td>(Not practicing)</td>
<td>0</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Variable</td>
<td>Male (n = 8)</td>
<td>Female (n = 10)</td>
<td>Total%</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>--------------</td>
<td>-----------------</td>
<td>--------</td>
</tr>
<tr>
<td>Most Important Family Members</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>2</td>
<td>3</td>
<td>27%</td>
</tr>
<tr>
<td>Children</td>
<td>3</td>
<td>6</td>
<td>50%</td>
</tr>
<tr>
<td>Parents</td>
<td>1</td>
<td>0</td>
<td>5%</td>
</tr>
<tr>
<td>Siblings</td>
<td>1</td>
<td>0</td>
<td>5%</td>
</tr>
<tr>
<td>Partner</td>
<td>0</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Other family</td>
<td>1</td>
<td>0</td>
<td>5%</td>
</tr>
<tr>
<td>Educational Experience</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Schooling</td>
<td>2</td>
<td>1</td>
<td>16%</td>
</tr>
<tr>
<td>Elementary</td>
<td>2</td>
<td>4</td>
<td>33%</td>
</tr>
<tr>
<td>Junior High</td>
<td>1</td>
<td>2</td>
<td>16%</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>3</td>
<td>1</td>
<td>22%</td>
</tr>
<tr>
<td>Some College</td>
<td>0</td>
<td>2</td>
<td>11%</td>
</tr>
<tr>
<td>Source of Income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government Assistance</td>
<td>3</td>
<td>7</td>
<td>55%</td>
</tr>
<tr>
<td>Retirement</td>
<td>2</td>
<td>1</td>
<td>16%</td>
</tr>
<tr>
<td>Family Support</td>
<td>1</td>
<td>2</td>
<td>16%</td>
</tr>
<tr>
<td>Employed</td>
<td>2</td>
<td>0</td>
<td>11%</td>
</tr>
</tbody>
</table>

Mexican descent or heritage), thirteen participants classified themselves as "Mexican" (Born and raised in Mexico), and two participants classified themselves as "Central American" (One was born and raised in El Salvador and another born in Guatemala). Of the 15 participants born and raised outside of the United States, the range of years living in the United States was 4 to 54, with a mean of 23.8 years.

Thirteen or 72% of the participants reported that Spanish was their dominant language (monolingual
Spanish). While four others reported being bilingual in both Spanish and English. Only one participant reported to be English speaking only. Fifteen or 83% of participants described their religious faith as Catholic, with 55% of the 15 describing their faith with active participation by attending weekly services, daily prayer, praying the rosary and/or reading the bible. A total of 16% of participants described their faith as Christian, with 11% of the participants describing their faith by attending weekly services.

Regarding the importance of family members among the sample group, 50% of participants reported that their adult children were the most important members of their family. There were 33% of participants reported that their spouses/partner were most important and only 5% of participants reported their parents. Another 5% of participants reported their siblings and other family as most important was 5%.

Educational experience ranged from “no schooling” to “some college”. Four or 22% of the participants reported graduating from high school, while two or 11% reported some college. A total of 16% of participants had no
schooling, while 33% of participants reported attending elementary school and 16% attended junior high school.

Information regarding income ranged from receiving government assistance to family providing financial support. There were 55% of participants reported receiving social security benefits and 7% of these participants also received financial assistance from family. A total of 16% of participants reported receiving no income on their own and were completely financially supported by family. There were 11% of participants who were employed.

Health Literacy

Questions 8-10 and 12-14 on the questionnaire addressed the participants understanding of their health. A summary of the participants understanding of their health problems is shown in Tables 2-5. Each participant was asked to identify their biggest health problem. Ten participants reported that End Stage Renal Disease was the biggest health problem, while 3 reported that hypertension was their biggest health problem. A 74-year-old female stated:
Table 2. Biggest Health Problems

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESRD</td>
<td>3</td>
<td>7</td>
<td>55%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>2</td>
<td>16%</td>
</tr>
<tr>
<td>HTN</td>
<td>2</td>
<td>1</td>
<td>16%</td>
</tr>
<tr>
<td>Cancer</td>
<td>1</td>
<td>0</td>
<td>5%</td>
</tr>
<tr>
<td>Headache/back pain</td>
<td>1</td>
<td>0</td>
<td>5%</td>
</tr>
</tbody>
</table>

Table 3. How Long with these Health Problems

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than a year</td>
<td>0</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>1-5 years</td>
<td>5</td>
<td>4</td>
<td>50%</td>
</tr>
<tr>
<td>6-10 years</td>
<td>2</td>
<td>1</td>
<td>16%</td>
</tr>
<tr>
<td>11+</td>
<td>1</td>
<td>4</td>
<td>27%</td>
</tr>
</tbody>
</table>
Table 4. Who Informed Participants of their Health Problems

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Doctor</td>
<td>4</td>
<td>4</td>
<td>44%</td>
</tr>
<tr>
<td>Emergency Room</td>
<td>2</td>
<td>5</td>
<td>38%</td>
</tr>
<tr>
<td>Nephrologists</td>
<td>2</td>
<td>1</td>
<td>16%</td>
</tr>
</tbody>
</table>

Table 5. Understanding Seriousness of Health Problems

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding</td>
<td>2</td>
<td>7</td>
<td>50%</td>
</tr>
<tr>
<td>Lack of Understanding</td>
<td>1</td>
<td>3</td>
<td>22%</td>
</tr>
<tr>
<td>Vague Understanding</td>
<td>5</td>
<td>0</td>
<td>27%</td>
</tr>
</tbody>
</table>

"The kidney. I don’t know at what level is my kidney working, it doesn’t hurt now but at the beginning it hurt and as a result the back of my neck and left shoulder hurt."

Diabetes was reported as a serious health concern among 16% of participants, while one participant reported
prostate cancer to be his biggest health concern. There was only 5% of participants who identified back pain and headaches as serious health concerns.

Many participants reported diagnosis of chronic illness over many years. There were 22% of female participants who reported receiving diagnoses with their health problems for 11 years or more. The range of years for the 18 participants on hemodialysis was between 10 months and 12 years.

Participants were asked what they believed was the cause of their kidney failure, responses ranged from unknown to diabetes and hypertension. A total of 33% of participants reported:

- "I think I neglected my kidneys by drinking a lot of soda"

- "Stopped automatically by themselves, I'm someone with not vices, I was surprised they stopped and to discover the kidneys never developed and grew as big as it would for a child"
- "I think my life was to work and I guess the diabetes did it at least that’s what the doctor said, the diabetes paralyzed them"
- "My kidneys only hurt once, to date nothing hurts. I say because I didn’t drink water, but they said it is due to diabetes"
- "Drinking beer and not drinking enough water or eating"
- Because I didn’t drink enough water. I only drank soda"

There were 16% of participants who linked hypertension to the cause of kidney failure:
- "Hypertension"
- "Supposedly, the doctor said that it was hypertension"
- "I think it was hypertension"
- "Hypertension, due to a urinary infections that was not attended to that ran through my blood causing the kidney failure"

As participants were asked the cause of their kidney failure 22% reported:
- "I don’t know"
"I don't know, I did not believe it"

"I don't know, It was not explained"

Participants were asked if they understood the seriousness of their health problems as explained by their doctor / doctors. A 70-year-old male participant on hemodialysis for 5 years stated: "I didn’t understand it until now I am beginning to understand". A 60-year-old female participant on hemodialysis for 3 years stated:

"I understood that when kidneys don’t function you don’t urinate, but I did and felt no pain on my kidneys. I ended up in the emergency department with a catheter and still didn’t think it serious."

A 51-year-old female participant on hemodialysis for 12 years stated:

"Not exactly because I thought with dialysis I would die quicker and then later it was explained I could live longer if I follow the regimen."

A 41 year old female participant on hemodialysis for 12 years stated: "No, because it was hard. I had never heard the word dialysis until that day."

Participants were asked why they think they need dialysis. Responses ranged from not knowing to cleaning
A 28-year-old female participant on hemodialysis for 3 years stated: "To clean the blood because kidneys are unable to get rid of toxins in the body."

A 74-year-old female on hemodialysis for 15 years stated: Shrugs. "I don’t know, to clean, what the blood? I am not thirsty, I drink what I need." An 89-year-old female on hemodialysis for 10 months stated: "I don’t know". Four male participants stated the reason for dialysis was in order to live, they did not want to die.

Cultural Influences

Questions 2 through 5, 11 and 15 on the questionnaire addressed the cultural influences on the participant’s perception of End Stage Renal Disease. The majority of participants had family involvement in their life either by daily contact or having a family member accompany them to doctor appointments. Adult children seemed to be the most important members of the participants’ family when assessing support.

For many of the participants, emotional support from the family was identified by giving words of encouragement to asking how they were feeling: "My mother
gives me good words of encouragement” (male). One male participant stated: “They are always behind me all day, how do I feel, what do I feel”. One female participant stated: “They give me courage and motivation to keep on going”.

Participants were asked if anyone accompanies them to their medical appointments and a total of 83% reported that either a family member, spouse or partner accompanied them to offer emotional support.

Question 11 on the questionnaire addressed any practices, rituals or attitudes from the participants’ culture that were helpful or not to their health problems. There were 50% of participants reported that they utilized herbs to improve their health with no success, while 16% of participants stated that they trust in God. One male participant stated: “I ate cactus because I was told it was good for the kidneys, I don’t know but I think it prolonged by kidney function”. A female participant stated: “I bought three bottles of this herbal remedy that I drank with water, I was told I would get well, but it didn’t work. I guess it was too late”.
The 16% of participants stated that their trust in God helped them in coping with the diagnosis. One female participant stated: “My belief in God. I don’t believe in herbal remedies”. Another female participant stated: “God helped me. You know something, the day I went for my access placement I was so afraid I could feel my heart was pumping hard, so I told myself that I needed to relax and suddenly I saw heaven in a light blue color and I know it was my faith in God that helped me relax”.

Latinos and Health

There was a total of 83% of participants that were foreign-born and 38% of those participants reported not understanding the doctors’ explanation to initiate dialysis. There was 16% of participants that were born in the United States and 11% did not understand the doctors’ explanation to initiate dialysis, while only 5% of the participants understood. A total of 11% of participants were foreign born, Spanish speaking only stated: “I didn’t know about dialysis”, “The doctor scared me and sent me to dialysis with no explanation”.

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Of a total of 72% of Spanish speaking only participants only 54% were explained about their kidney failure and need for dialysis in Spanish, 23% in English, 15% with an interpreter and 1 participant reported that the doctor and social worker (spoke Spanish) were present. A foreign born, Spanish speaking participant who had an interpreter stated: “I had no choice but undergo dialysis; truthfully, I had no idea what dialysis was”. A participant who received the explanation in Spanish stated: “Did not understand the explanation, didn’t know what dialysis meant, we did what the doctor recommended, no other alternative available just had to do it, my family decided”.

Among the four Bilingual participants one Foreign born understood the explanation for kidney failure and need for dialysis and one did not understand. One female participant stated: “I did not know what dialysis was, no understanding why my kidneys failed”. Of two native born participants, one understood, while the other did not.

The only English Speaking participant did not understand what kidney failure was or the need for dialysis.
There was 55% of participants initiated dialysis through the emergency room where they were informed of their kidney failure. A total of 16% of participants had been informed by their doctor that their kidneys were failing and 5% were being monitored by the nephrologists and among them three still had dialysis initiated at the emergency room. One participant initiated peritoneal dialysis and two other participants had vascular access placed and initiated dialysis at a hemodialysis clinic.

Summary

The results of this study were described in this chapter. There were three principle areas from the data results of this study which were: Health Literacy, Cultural Influences and Latinos and Health. The data was then analyzed to distinguish trends, patterns, themes, connections, and deviations. General themes found among the data were summarized, specific themes were exemplify with direct quotes.
CHAPTER FIVE

DISCUSSION

Introduction

This research study provided a qualitative analysis presented in the form of sixteen questions during personal interview with eighteen Latino patients undergoing hemodialysis treatments. Themes emerged related to participants' perceptions about dialysis (diagnosis and etiology), and adherence (treatment, diet, medication). Education, non-English speaking and born outside of the United States were the factors found to contribute to low health literacy.

Diabetes mellitus continues to be the leading cause of kidney failure among Latinos. In addition, Latinos continue to be the largest minority population in the United States. Yet, when this researcher asked a participant with a diagnosis of diabetes mellitus for the past 15 years: What caused your kidney failure? Her response was, “My kidneys only hurt once and to this date nothing hurts. I say because I didn’t drink enough water, but they say it was due to diabetes”. This is a real concern for the health professional working with Latino
dialysis patients to address the health literacy as well as cultural values.

Discussion

It was evident in this research study that education, language and nationality contributed to low health literacy found among these participants. Eleven (61%) participants had few years of schooling to none, Spanish was their dominate language and they were born outside of the United States. Among participants five were being monitored by a physician to treat their hypertension or diabetes. One participant had a diagnosis of diabetes mellitus for 20 years while another for 15 years and yet another 25 years. The other two participants had a history of hypertension. One for 24 years while the other 3 years. Although, these five participants were being monitored by a physician they all initiated their dialysis at the emergency room. All five participants had never heard of dialysis or understood the explanation for their kidney failure.

Studies show that many adults are ashamed to acknowledge their understanding of basic health information (Scott, 2003). Participants who have been
undergoing hemodialysis for longer than five years seemed not to understand either the purpose for taking phosphorus binders, fluid restriction and/or dialysis prescription.

For example, a participant who had been on hemodialysis for 15 years stated, " Skipping one dialysis treatment as I understand it is bad for you, my heart or lungs will stop working, right?" Another participant on hemodialysis for five years responded that he didn’t know what could happen if he skipped his medication. He just knew that he had to take it. Another participant on hemodialysis for 7 years responded, "I really don’t know, something would happen but, I never skip treatments. I still don’t know why I have to take so many binders, I just know I’m suppose to take it”.

Despite the fact that several Latino patients indicated that they did not comprehend their diagnosis of End Stage Renal Disease and/or the treatment regimes related to End Stage Renal Disease they initiated dialysis at the emergency room and adhere to the physician’s prescribed medical treatment. As stated in the literature, Latinos steer clear of disagreeing with or expressing doubts to their health care provider about
the treatment that is being recommended (United States Department of Health and Human Services, 2000). Whether this is a result of cultural values or lack of health literacy is unclear.

Cultural influences (religion, family, language and acculturation) played a role in the patients’ perception on health literacy. Participants either identified their belief in God to help them deal with their diagnosis and/or attributed to the family emotional support. Several family members accompanied the participants to their medical appointments. This research explored the participants’ families understanding of their dialysis treatment. Mostly all participants’ responded that the family understood their dialysis treatment and demonstrated it by providing words of encouragement and/or reminded them to follow doctors’ prescribed medical treatment. Two participants reported their daughters knew more about End Stage Renal Disease because of access to internet for research.

Limitations

The following limitations applied to this study. The first limitation of this study was the small sample size
(N = 18). The limited amount of participants impacts the validity of this study. In addition, the study presented the opinions of only Latinos from two hemodialysis clinics. This research project's instrument, developed by the researcher for the purpose of this study, does not claim to be as a reliable or comprehensive instrument. Another limitation to this study was confidentiality. It was the patients' decision to be interviewed during their hemodialysis treatment and clearly this could have affected the information they were willing to disclose.

Recommendations for Social Work Practice, Policy and Research

This study was inspired by the fact that ESRD patients experience significant psychosocial issues that can take a toll on them. Latino patients, specifically those born outside of the United States with limited English and fewer years of schooling are at a higher risk of low health literacy. Studies demonstrate that patient's health literacy skills are typically not evident during an initial assessment.

The need for a comprehensive assessment that is culturally competent that includes acculturation, spirituality, literacy and language should be considered.
In addition, social workers should be mindful in the specific ways a person’s cultural background influences their perception of their illness (Gehlert & Browne, 2006).

As part of the interdisciplinary team nephrology social workers are in a position to intervene with the team by prompting physicians, dieticians and nurses to check patients’ understanding of ESRD treatment regimen. This simple task can possibly improve health outcomes for patients.

Health literacy is receiving national attention due to the implications for patient safety, medical errors and overall quality of health. Consequently, low health literacy cost states a significant amount of money.

Many policy-makers have passed legislation or initiatives to address low health literacy. Seniors, low-income people and the chronically ill have been identified as the highest risk. These same individuals qualify for most programs such as Medicaid and Medicare.

Coalitions, government sponsored public campaigns and workshops have been taking place to address the issues of health literacy in America. The Healthy States Initiative brings together state legislators to share
information and find solutions. One solution is to improve health communication between the patient and health providers. Another is for state programs to evaluate written materials to ensure that they are appropriate grade level, written in the language that targets its audience, illustrations should be relevant and are culturally sensitive (The Healthy States Initiative, 2006).

Conclusions

As the Latino population in the United States continue to grow unfortunately, so will Latino patients continue to be diagnosed with End Stage Renal Disease. Social workers have a responsibility to conduct a culturally comprehensive assessment that includes health literacy.

There is a wealth of research out there looking at the Latino patients and compliance to dialysis regimen. In this small study it was important to distinguish compliance from adherence because adherence implies active participation and involvement in the treatment plan. Latino patients truly want to be part of their treatment plan but, perhaps unknown to the renal team
they are too ashamed to admit that they simply don't understand.
APPENDIX A

INTERVIEW GUIDE (ENGLISH VERSION)
INTERVIEW GUIDE

Thank you for agreeing to help me with my research. I am going to ask you some questions regarding how you see your health problems and understand them. These questions will mostly deal with how you understand your health problems and if there are influenced by your culture beliefs, family, and language. Most of the questions I will ask you will address at least one of these areas, so feel free to talk about only those areas you feel comfortable with. You can choose to refuse to answer specific questions, and / or you can end this interview at any time. Is that clear?

Demographic Information

First, I would like to start by asking you some questions about yourself and your background.

1. How old are you?

2. What is your sex?  Male  Female

3. What is your ethnic background?
   a. Where were you born?
   b. Where were you raised?
   c. How long have you been living in the United States?

4. What is your first language?
   a. Do you speak more than one language?
   b. If so, which other languages do you speak?
   c. Describe your ability and comfort level in speaking these languages.

5. What religious faith are you?
   a. What are some of the rituals and routines you usually do to practice your faith?
   b. How often do you practice them?

6. Who are / were the most important members of your family?
   a. describe the level of involvement? Do they accompany you to medical appointments?
   b. Are they a source of emotional support?

7. Briefly, describe your education level?

8. Briefly, describe your income level? Is there anyone who financially support you?
Health Literacy

Now I would like to get an idea of your understanding regarding your health.

9. What is / are your biggest health problems?
   a. How long have you had these health problems?
   b. Who informed you of the seriousness of these health problems?
   c. Did you understand the explanation?
   d. In what language were these health problems explained?
   e. Was someone else with you when you were informed of these problems?

10. What caused your kidney failure?
    a. Do you have an explanation why it failed when it did?

11. Were you able to understand the seriousness of your health problems as explained to you by your doctor / doctors? If not, where do you think there was a misunderstanding?

12. Were there any practices, rituals, or attitudes from your culture that were helpful to you? Were there any that weren’t helpful?

Treatment Adherence

13. What is your understanding of what could happen if you missed a dialysis treatment?

14. What is your understanding of what could happen if you drank too much fluid between dialysis treatments?

15. What is your understanding of what could happen if you skipped your prescribed medication?

16. Do you feel your family understands your dialysis treatment? How?
APPENDIX B

INTERVIEW GUIDE (SPANISH VERSION)
Gracias por ayudarme con mi investigación. Yo le hare algunas preguntas tocante a como ve y entiende los problemas de su salud. Estas preguntas están basadas principalmente sobre el entendimiento de sus problemas de salud y si hay influencias por sus creencias culturales, familiares y de lenguaje. La mayoría de las preguntas que le hare se dirigen por lo menos en alguna de estas áreas, y tome libertad de hablar solamente de esas áreas que ud se sienta confortable. Ud puede rechazar de contestar cualquier pregunta y también puede poner final a esta entrevista a cualquier tiempo. Esta esto claro?

Información Demográfica

Primero, quiero empezar por preguntarle algo sobre ud y sus antecedentes.

1. Cual es su edad?

2. Que es su genero?  Masculino  Hembra

3. Cual es su origen étnico?
   a. Donde nació ud?
   b. Donde se crió ud?
   c. Cuantos anos tiene viviendo en los Estados Unidos?

4. Cual es su idioma principal?
   a. Habla ud mas de un idioma? Si o No
   b. Describa su habilidad y comodidad de hablar estos idiomas.

5. Cual es su creencia religiosa? Cuales son algunos de sus ritos y rutinas que practica ud para mostrar su fe?
   a. Con que frecuencia los practica?

6. Quienes son / eran las personas mas importantes de su familia?
   a. Describa el nivel que están envueltos con ud?
   b. Le acompanan a sus citas medicas? No Si
   c. Le dan apoyo emocional? No Si Como sabe?

7. Brevemente, describa su nivel de educació?

8. Brevemente, describe su nivel de ingreso? Alguna persona lo apoya economicamente?
CAPACIDAD Y ENTENDIMIENTO DE SALUD

Ahora quiero pedirle información sobre su entendimiento de su salud.

9. Cuales son sus enfermedades mas serias?
   a. Por cuanto tiempo tiene con estas enfermedades?
   b. Quien le informo de la seriedad de estas enfermedades?
   c. Entiende la explicación? No o Si
   d. En que idioma le explicaron estos problemas de salud?
   e. Estaba alguna otra persona con usted cuando le explicaron estos problemas?

10. Cual fue la causa de la falla de su riñón?
    a. Tiene alguna explicación porque, como y cuando fallo el riñón?
    b. Porque cree que ud necesita diálisis?

11. Pudo ud entender que tan serio eran sus problemas de salud en la manera que lo explico a su doctor? Si no le fue así, donde cree que hubo un mal entendimiento?

12. Tenia algunas retinas, ritos, o actitudes de su cultura que le ayudaron? Tenia algunas que no le ayudaron?

ADHERENCIA AL TRATAMIENTO

13. Dígame cual es su entendimiento de lo que puede suceder si falla un tratamiento de diálisis.

14. Dígame cual es su entendimiento de lo que puede suceder si toma demasiados líquidos entre los tratamiento de diálisis.

15. Dígame cual es su entendimiento de lo que puede suceder si deja de tomar su régimen de medicinas.

16. Siente que su familia entiende su tratamiento de diálisis? Como lo sabe?
APPENDIX C

INFORMED CONSENT (ENGLISH VERSION)
**Informed Consent Letter**

Dear Participant:

My name is Marielena Michel and I am a Master’s of Social Work candidate at California State University, San Bernardino. I am conducting a study to examine the effects of health literacy and treatment adherence among Latinos with End Stage Renal Disease, and you are invited to participate in my study. It is hoped that the results of this study will assist social workers and health care professionals help Latinos diagnosed with End Stage Renal Disease by approaching their care from a culturally sensitive perspective. The Department of Social Work subcommittee of the CSUSB Institutional Review Board has approved this study.

If you voluntarily participate in this study, you will be asked to complete a face-to-face interview with myself, the researcher. This interview will take about 45 minutes to 1 hour of your time. I will ask questions about your illness, family supports, cultural practices and your understanding about your dialysis treatment as well as other factors important to the study. During the interview, I will either take notes, record your answers on a tape recorder, or both. Your participation is strictly voluntary, and you can choose to end your participation at any time before or during the interview. You can choose not to answer specific questions that I ask you, and you can choose not to have the interview recorded on tape. Also, if you decline to participate in this study, your receipt of medical services will not be affected in any way.

As a participant in this study, your confidentiality will be protected. Your full name will never be used on any document, notes, or tape recordings used in this study. Your full name will never be revealed in the final published report, or in any subsequent report based on this study. I will never speak your full name during any recorded interview. The Letter of Consent will be kept in a locked file cabinet for three years and then destroyed. All other collected data directly relating to your participation (documents, notes, or tape recordings) will be kept in a locked file cabinet for the duration of the study, and will be destroyed once the study is completed. The results of this study will be shared with Renal Advantage Inc. (RAI) the sponsor of this research, and no participant will be identified by name.

To complete this study we will need your permission to access your medical records to review the lab values for treatment outcomes.

If you have any questions or concerns regarding any aspect of this study, please feel free to contact my research project advisor, Ms. Rachel Estrada, LCSW at (909) 537-5501. If you agree to participate in the study at this time, please check below. Thank you very much for your participation.

_____ Agree to participate and I am over the age of 18 years old.

_____ Access to medical records.

_____ Permission to audiotape.
APPENDIX D

INFORMED CONSENT (SPANISH VERSION)
INFORMACION DE CONSENTIMIENTO

Estimado Participante:

Mi nombre es Marielena Michel y soy una candidata para el título de Masterado de Trabajador Social en la Universidad Estatal de California en San Bernardino. Estoy investigando un estudio sobre los efectos del analfabetismo en la salud y adhesión con el tratamiento de diálisis en los pacientes Latinos que están diagnosticados con Falla Crónica del Renal y ud esta invitado a participar en este estudio. Se espera que los resultados de esta investigación ayuden a los trabajadores sociales y profesionales en el cuidado medico para poder ayudar a los Latinos diagnosticados con Falla Crónica Renal con un acercamiento del cuidado con una perspectiva de forma cultural y sensitiva. El Departamento de Trabajadores Sociales subcomité de revisión ha otorgado permiso para este estudio.

Si ud voluntariamente participa en este estudio, ud participara en una entrevista conmigo, (el investigador). Esta entrevista tomara entre 45 minutos y 60 minutos de su tiempo, y yo le haré preguntas sobre sus adaptaciones de vivir con sus enfermedades, sus apoyos de familia, sus ritos culturales, y sus entendimientos de su tratamiento del diálisis y otros factores importantes para el estudio. Durante la entrevista, tomare apuntes y / o grabare con maquina sus respuestas. Su participación es estrictamente voluntaria, y ud puede terminar su participación en cualquier momento antes o durante la entrevista. Ud no esta obligado a contestar ninguna pregunta especifica, y puede pedir que la entrevista no este grabada por maquina. También, si ud decide no participar en este estudio, sus servicios médicos no estarán afectados en ninguna forma.

Como participante en este estudio, su confidencialidad será protegida. Su nombre completo nunca será usado en ningún documento, apuntes, o audio grabación usado en esta investigación. Su nombre completo nunca será revelado en el reporte final, ni en ningún reporte basado en este estudio. Nunca diré su nombre completo durante cualquier entrevista grabada por maquina. Esta Información de Consentimiento estará guardada en un archivo asegurado por tres años y después será destruido. Toda la información directamente relacionada con su participación (documentos, apuntes, y audio grabaciones) estará guardada en un lugar de archivo asegurado por la duración de la investigación, y será destruido cuando el estudio se finalice. Los resultados agregados de este estudio serán compartidos con Renal Advantage Inc. (RAI) Glendora Dialysis Center y ningún participante será identificado por nombre.

Para concluir esta investigación necesitaremos su permiso para tener acceso a su expediente medico para poder repasar y valorar los resultados del laboratorio y tratamiento.

Si ud tiene cualquier pregunta sobre algún aspecto de este estudio, favor de llamar a mi consejera de investigaciones de este proyecto, Srita. Rachel Estrada, LCSW a (909) 537-5501. Si ud acuerda participar en este estudio, favor de marcar abajo. Gracias por su participación.

_____ Estoy de acuerdo en participar y mayor de 18 anos.

_____ Acceso a expediente medico.

_____ Permiso para audio grabar.
APPENDIX E

DEBRIEFING STATEMENT (ENGLISH VERSION)
Debriefing Statement

Thank you for your willingness to participate in this study and not to discuss the contents of the interview with other participants. The study you have just completed was conducted by Marielena Michel, a graduate candidate in the Masters of Social Work program at California State University, San Bernardino.

The study you have completed was designed to examine the effects of health literacy and treatment adherence among Latinos with End Stage Renal Disease. The study is an attempt to measure how health literacy among Latino patients is linked to treatment adherence.

It is unlikely that participating in this study will result in any significant distress. However, if you feel you are experiencing any discomfort or stress due to your participation, please contact Ms. Rachel Estrada, LCSW my research project advisor at (909) 537-5501.

Results of this study will be available at Glendora Dialysis Center and at the library on the campus of California State University, San Bernardino in the summer of 2008. If you have questions or concerns about this study, please contact Ms. Rachel Estrada, LCSW my research project advisor at (909) 537-5501. Your participation in this study is greatly appreciated.
APPENDIX F

DEBRIEFING STATEMENT (SPANISH VERSION)

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Declaración de Interrogatorio

Gracias por su consentimiento en tomar parte en este estudio realizado por Marielena Michel, estudiante para el título de Masterado de Trabajador Social en la Universidad Estatal de California, San Bernardino. La entrevista que usted acaba de participar se diseñó para medir los efectos del analfabetismo en la salud y adhesión con tratamientos de diálisis en los pacientes Latinos que están diagnosticados con Falla Crónica Renal. El estudio es una tentativa de medir a qué nivel el analfabetismo en la salud de los pacientes Latinos está enlazado con adhesión de tratamientos.

Quizás sea improbable que su participación en este estudio le cause alguna angustia significante. Pero en caso si usted siente malestar o estrés debido a su participación, por favor de comunicarse con Srta. Rachel Estrada, LCSW consejera de investigaciones de este proyecto a (909) 537-5501.

Los resultados de este estudio estarán disponibles en Glendora Diálisis Center y la librería en el campus de la Universidad Estatal de California, San Bernardino durante el verano de 2008. Si usted tiene cualquier pregunta o procuración por favor comunicarse con la consejera de investigaciones de este proyecto, Srta. Rachel Estrada, LCSW a (909) 537-5501. Se agradece y se aprecia su participación en este estudio.
REFERENCES


