

California State University, San Bernardino

CSUSB ScholarWorks

Theses Digitization Project

John M. Pfau Library

2006

Cultural beliefs and attitudes among Latinos with end stage renal disease

Guillermina Robles-Burgos

Ada Ocasio-Pa e

Follow this and additional works at: <https://scholarworks.lib.csusb.edu/etd-project>



Part of the [Clinical and Medical Social Work Commons](#), and the [Race and Ethnicity Commons](#)

Recommended Citation

Robles-Burgos, Guillermina and Ocasio-Pa e, Ada, "Cultural beliefs and attitudes among Latinos with end stage renal disease" (2006). *Theses Digitization Project*. 3452.

<https://scholarworks.lib.csusb.edu/etd-project/3452>

This Project is brought to you for free and open access by the John M. Pfau Library at CSUSB ScholarWorks. It has been accepted for inclusion in Theses Digitization Project by an authorized administrator of CSUSB ScholarWorks. For more information, please contact scholarworks@csusb.edu.

CULTURAL BELIEFS AND ATTITUDES 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
Guillermina Robles-Burgos
Ada Ocasio-Paré
June 2006

CULTURAL BELIEFS AND ATTITUDES AMONG LATINOS
WITH END STAGE RENAL DISEASE


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


by
Guillermina Robles-Burgos
Ada Ocasio-Paré
June 2006

Approved by:


Rosemary McCaslin, Faculty Supervisor
Social Work

5/18/06
Date


Pat Smith, Clinical Manager,
Gambro Dialysis Center


Dr. Rosemary McCaslin,
M.S.W. Research Coordinator

ABSTRACT

This study examined cultural beliefs and attitudes among Latinos with end stage renal disease in comparison with their compliance with their dialysis treatment. The sample was selected from 46 Latino of patients of varying age at Gambro Dialysis Center in San Bernardino. The study was a quantitative design utilizing correlations to measure the associations among cultural factors and compliance. This study examines the common attitudes and beliefs of this population and how these perceptions impacted compliance with their dialysis treatment three principle areas were addressed in the study: alternative medicine, culture, and support system.

ACKNOWLEDGMENTS

I wish to thank the patients at Gambro, San Bernardino for their support in this project. I shall always remain impressed by their generosity and courage throughout their management of their illness. I also wish to acknowledge my life-partner Judy and our three children Kassie, Nicholas, and Tyler who have remained patient and supportive throughout these three years in attaining my degree. I could not have done it without you. I love you all very much.

Finally, I wish to dedicate this thesis to my father, Santo Ocasio who was my mentor and lived his life as an informal social worker, always willing to help those in need.

I would like to thank my husband, Julio for his endless love and support throughout my graduate career. Thank you for providing me with love, encouragement, advice, comfort, and for always believing in me. I would not have been able to do this without you. I would also like to thank my children, Alex, Samantha and JJ for being patient with mami when she couldn't be there for you. I love you with all my heart. I would also like to thank my mami, Guillermina Contreras Robles who instilled in me the desire to obtain an education. This thesis is dedicated to

my father Javier Robles (1943-1987). Last but not least,
to "La Familia" for the laughs, tears and support, and to
my thesis partner Ada Ocasio for her love and support.

TABLE OF CONTENTS

ABSTRACT	iii
ACKNOWLEDGMENTS	iv
LIST OF TABLES	viii
CHAPTER ONE: INTRODUCTION	
Problem Statement	1
Purpose of the Study	3
Significance of the Project for Social Work	7
CHAPTER TWO: LITERATURE REVIEW	
Introduction	9
How the Kidneys Functions	9
Latinos and Culture	12
Latinos and Support Systems	14
Latinos and Alternative Medicine	14
Theories Guiding Conceptualization	19
Summary	20
CHAPTER THREE: METHODS	
Introduction	22
Study Design	22
Sampling	23
Data Collection and Instruments	24
Procedures	28
Protection of Human Subjects	30
Data Analysis	31
Summary	31

CHAPTER FOUR: RESULTS

Introduction	32
Demographics	32
Summary	41

CHAPTER FIVE: DISCUSSION

Introduction	43
Discussion	44
Limitations	47
Recommendations for Social Work Practice, Policy, and Research	48
Conclusions	50

APPENDIX A: LETTERS OF INFORMED CONSENT	52
---	----

APPENDIX B: SURVEY	55
--------------------------	----

APPENDIX C: DEBRIEFING STATEMENT	60
--	----

REFERENCES	63
------------------	----

ASSIGNED RESPONSIBILITIES PAGE	66
--------------------------------------	----

LIST OF TABLES

Table 1. Crosstabulation for Marital Status	33
Table 2. Crosstabulation for Gender	34
Table 3. Internal Locus of Control	36
Table 4. God Locus of Control	37
Table 5. Cultural Definition	38
Table 6. Support System	39
Table 7. Correlation Matrix	40

CHAPTER ONE

INTRODUCTION

This study focused on the importance of cultural beliefs and attitudes among the Latino population and how this influenced their decisions regarding dialysis treatment when diagnosed with End Stage Renal Disease.

Problem Statement

The Latino population is one of the fastest growing groups in the United States today (U.S. Census Bureau, 2000). Approximately 35.3 million persons in the United States identify themselves as Latinos. There are factors that have arisen with this increase such as health care concerns. In comparison to other groups the incidence of kidney disease among Latinos is being recognized as an increasing health concern in the United States. According to research, there is a greater concern because of the racial disparities in the prevalence, morbidity and mortality rates for kidney disease (Nicholas, Agodoa, & Norris, 2004). Concurrently, the incidence of end stage renal disease is unequally distributed across persons of varying racial and ethnic backgrounds and represents examples of the disparities in health care outcomes in the United States (Nicholas, Agodoa, & Norris, 2004). Factors

that contribute to this increase in the Latino population are the prevalence of other diseases that lead to end stage renal disease such as diabetes mellitus, both types I and II.

According to recent studies, diabetes rates among Latinos are two to five times higher in comparison to non-Hispanics (Benabe & Rios, 2004). Latinos represent the largest minority group in the United States and there are many factors that affect their treatment or health care concerns. Some factors that have been discussed as barriers are language, cultural and religious beliefs and attitudes.

This study assessed some of the beliefs and attitudes that Latinos had in regards to their treatment for end stage renal disease. Furthermore, this study was interested in the views of Latinos on traditional treatment as well as the use of other forms of treatment such as "el curandero" or alternative herbal treatments. El curandero is considered to be a Mexican folk healer who has the "don" (gift) for healing. Their intervention is through natural or supernatural means of treatment (Applewhite, 1995).

One major problem that was addressed in this study was that Latinos are a group that is not receiving

adequate medical care. This can be attributed to many factors such as being uninsured or being monolingual. According to research findings, 33% of Latinos are estimated to be uninsured (Warda, 2000). The influence of medical insurance on access is complicated because lack of insurance is correlated with low-income. Furthermore, many Latinos work for companies that do not offer to subsidize their insurance or they tend to work in low paying jobs (Warda, 2000).

Another factor that hinders their access to healthcare is the fact that many Latinos are monolingual. This tends to be a barrier because there are few Spanish speaking health care providers in most areas. This produces a sense of powerlessness and lack of ability to gain knowledge that would assist Latinos in making informed choices regarding their health (Warda, 2000).

Finally, much of the literature has attributed the under use of the healthcare system to barriers imposed by the healthcare system itself, mainly the high costs of services (Warda, 2000).

Purpose of the Study

The purpose of this study was to provide a quantitative analysis of beliefs and attitudes among

Latinos who are diagnosed with end stage renal disease. This study explored the common attitudes and beliefs of this population, which may be both beneficial and harmful in their medical care. How these perceptions impacted compliance with their dialysis treatments was considered. Three principle areas were addressed in the study, which were found to influence attitudes and beliefs: alternative medicine, culture and support systems.

These three principle areas were selected due to the various findings in the literature review. For example, in the Latino population alternative forms of medicine have historically played an important role in meeting their critical health care needs (Applewhite, 1995).

Culture is defined as "as system of symbols that are shared, learned and passed on through generations of a social group. Culture mediates between human beings and chaos; it influences what people perceive and guides people's interactions with each other. It is a process rather than a static entity and it changes over time" (Lipson, 1996, p. 3).

Family support is a strong, almost universal value in the Latino community. Familism is defined as the valuing of family considerations over individual or community needs (Juarez, & Ferrell, & Borneman, 1998).

This study examined how these principles impacted Latino adherence to their dialysis maintenance. Since noncompliance with dialysis is of great concern to the nephrologist, the question of whether there is competition between biomedicine and alternative medicine is important. Also examined were the role culture and support system play in compliance with hemodialysis treatments.

To measure these issues a questionnaire was administered to participants. The data were collected during the patient's dialysis treatment and a survey allowed the participants to have privacy during this time. An interview would take longer and is not feasible during the treatment due to the close proximity of the treatment chairs. Furthermore, the participants answered questions pertaining to their healthcare and their disease. The participants might feel uncomfortable answering questions that they might believe will affect or hinder their treatment.

Lab values were reviewed for potassium, phosphorus and fluid intake, which were consistent with the dialysis healthcare system definition of noncompliance. The study considered measurable excess of two or more of the three lab values reviewed to indicate noncompliance.

By examining the link between attitudes and beliefs with compliance with dialysis treatment the knowledge base will broaden. Hopefully this study will assist renal healthcare professions in providing culturally sensitive management of the healthcare needs of this community as well as provide opportunities for future research.

Although the current political climate does not appear sympathetic to the healthcare needs of Latinos, the results of this study will hopefully provide an impetus for social activists and politicians to propose policy changes that will benefit this community over the long term. Hopefully practitioners will also be better able to understand how the three areas addressed in this study affect the perception and understanding that Latino clients have of their illness. Also, it is important that practitioners use client strengths in each of these areas to help the clients cope with and live with kidney failure.

The variations in beliefs and practices that extend across the nation's diverse cultural backgrounds complicate health care delivery. Therefore, recognizing and respecting diverse cultural practices achieves a patient's confidence in the health care provider. The likelihood of patient adherence to treatment

recommendations will also improve (Nicholas, & Agodoa, & Norris, 2004).

Significance of the Project for Social Work

Latinos are the fastest growing minority group in the United States yet there are very few studies that have examined Latinos who are diagnosed with end stage renal disease. Findings from the literature suggested that Latinos are two times more likely to develop kidney failure than non-Latinos. Therefore, the role the medical social worker plays in working with this population is a crucial one. Raising awareness of how attitudes and beliefs contribute to the Latino's view of their dialysis healthcare will strengthen the cultural competency of renal healthcare professionals.

Cultural competency is strongly supported by the NASW Code of Ethics. Two dimensions for social work practice, which this study supports, are the "understanding of how their own cultural heritage and belief system differs from and may influence interaction with clients who have a different cultural background and a commitment to learning about clients' culture" (Kirst-Ashman & Zarstow, 2001).

This study was in alignment with the generalist phase of assessment. According to Kirst-Ashman & Zarstow (2001)

different ethnic groups often live within two cultures, one that is dominant and one, which is of their ethnicity. This may be a problem since the client must operate in dual and incongruent environments. Therefore, the practices of one group may differ from the practices of another (Kirst-Ashman & Zarstow, 2001).

The challenge for the health care provider and dialysis social worker is in making an effective assessment, which recognizes the client system's strengths. Understanding how to work best with this population to facilitate their psychosocial well-being and improve dialysis outcomes is also an essential role of the dialysis social worker (Roots, 2004).

The aim of this study was to provide an understanding of beliefs and attitudes among Latinos with End Stage Renal Disease. The design of this study was to discover and identify trends among Latinos with End Stage Renal Disease with the awareness that the specific results of the study cannot be generalized to the Latino population as a whole. It is hoped that the outcomes of this study will encourage the medical social work profession to participate in research which address health disparities and cultural competency.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This research was on a very specific group of individuals, Latinos on dialysis. In reviewing the literature available for this group it became apparent that not much has changed since a candidate for a Masters in Social Work visited this topic in 1999 (Amaya, 1999). There is a scarcity of literature specific to Latinos diagnosed with End Stage Renal Disease (ESRD) (Medical Compliance for Hispanics E.S.R.D. p. 8) The literature assisted the researchers to become more informed about attitudes and beliefs among the Latino population in decisions regarding their healthcare.

How the Kidneys Functions

The primary job of the kidneys is to remove excess fluid and waste from the bloodstream. When the kidneys function is below 15% of normal, one needs dialysis to filter these toxins from the blood. Removing the harmful wastes and extra salt and fluids help control blood pressure and keep the proper balance of chemicals such as potassium and phosphorus in the body. The dialysis center tests the blood to make sure enough wastes are removed.

The main test used to measure dialysis dose is called Kt/V. Another test used by the center is called urea reduction ratio or URR. For hemodialysis patients, Kt/V should be at least 1.2 and URR should be at least 65 percent.

These tests as well as results on the patients potassium, phosphorus and fluid intake are available in the patient's rounding report conducted monthly. A patient's potassium level is monitored and daily intake of potassium is controlled to help prevent hyperkalemia, a high level of potassium, a common problem for people on dialysis. The mineral phosphorus is also controlled by a renal diet. Phosphorus is not effectively removed by dialysis treatments therefore patients need to reduce their intake of dairy products and other foods high in phosphorus. They are usually prescribed calcium supplements, which bind the phosphorus in food.

During kidney failure, the amount of urine produced drops. The urine output usually stops completely once patients have been on dialysis for more than six months. The dialysis patient must cut back on fluid intake, which is a restriction difficult to follow particularly in the summer months. The recommended daily amount of fluid is based on the amount of urine produced in a 24-hour period

and the amount of weight gained between dialysis treatments. Other considerations are the amount of fluid retention, the level of dietary sodium, and whether the patient has congestive heart failure. If these restrictions and recommendations are not followed the results can be fatal.

Among the adjustments made by dialysis patients is following a rigid treatment schedule. Most patients go to a dialysis clinic three times a week for three to five hours per treatment. For example, there is a Monday, Wednesday, Friday schedule or a Tuesday, Thursday, Saturday schedule. The center may offer morning, afternoon, or evening shifts, depending on availability and capacity at the dialysis center.

The dialysis patient must take responsibility for many factors related to their dialysis care, for example, deciding on which treatment modality, hemodialysis or Continuous Ambulatory Peritoneal Dialysis (CAPD), applying for funds to cover the medical expenses of treatment, and collaborating with the social worker to arrange transportation to and from the dialysis center. The patient must know about taking medication as prescribed and keep the health care staff informed of any problems with taking medicines or lack of funds to get them. The

patient must arrive on time for scheduled dialysis treatments, follow the prescribed diet and fluid restrictions and inform the health care staff about any problems in following the diet. Finally, the patient needs to notify the social worker of any planned traveling in order to assist with transient dialysis arrangements.

Latinos and Culture

Current statistics show that kidney disease in the Latino community is a growing concern. Literature confirms repeatedly that Latinos are twice as likely to develop kidney failure as non-Latinos. The U.S. Census points out that the Latino population grew from 10.3% in 1995 to 12.5% in 2000, making this population the fastest growing of racial and ethnic groups. With this growth is the probability of growth in the category of ESRD (U.S. Census Bureau, 2000). Reviewing facility reports regarding ethnicity of clients supported this probability. In 2000, Latinos at Gambro, San Bernardino were 36.0 % of patients and in 2003 the percentage was 42.5 according to a facility report from 2004.

Due to the nature of this disease and its impact on the Latino population, it is worth considering how this population's attitudes and beliefs affected their

dialysis. Basic concepts regarding illness differ among racial groups. Among the general American population, good health is seen as a universal right. Among some Latinos, illness is viewed as an imbalance of the body due to fate, heredity, bad luck, wrongdoing, or other factors (Da Silva, 1984).

According to a recent article by Roots (2004), these cultural beliefs are not readily accepted among health professionals and conflict with Western medicine. The Latino culture differs also from the mainstream culture in their attitude toward life and death. Latinos who are closer to nature and religion have a tendency to accept death as a natural course of life. When death is a threat, one does not fight it but succumbs to "God's will." Health professionals interpret this "fatalistic attitude" as defeatist, a symbol of "not caring" and not valuing human life, which clashes with the medical model that prescribes always doing something to fight death. It is also interpreted as "ignorance" and "primitivism" rather than a coming to terms with the unknown and therefore with life itself. This attitude of acceptance without struggle can also interfere with the expected compliance toward medical treatment or consent to treat (Guendelman, 1983).

Latinos and Support Systems

In the Latino community, the support system is very unique and important. What makes this structure unique is that the Latino community stresses the importance of the nuclear family as well as the extended family (Amaya, 1999). Family involvement among Latinos is very important. Family is considered to play an important role among Latinos to consult regarding important decisions such as healthcare.

There is a strong sentiment among Latinos regarding family obligation. This refers to the sense of responsibility for providing material and emotional support to members of the immediate and extended family (Warda, 2000). Latinos utilize their support systems as primary caregivers, which serves as a means to deny any outside assistance if there is a problem or illness. The extended family also serves as an effective source for emotional support, which lowers the incidence of caregiver feelings of being overwhelmed (Amaya, 1999).

Latinos and Alternative Medicine

In a study comparing the use of alternative therapies among Mexican Americans and Anglo-Americans, findings showed that both groups used alternative practitioners,

but that Mexican Americans reported using them more than twice as often as did Anglo-Americans. The most prevalent therapies sought by Mexican Americans were prayer, herbal medicine, massage, relaxation, spiritual healing, and chiropractic. The most prevalent therapies sought by Anglo-Americans were prayer, massage, chiropractic, herbal medicine, megavitamin therapy, and spiritual healing. Almost twice as many Mexican American (45%) reported discussing their therapies with their established primary health providers than did Anglos (26.7%) (Keegan, 2000).

Healthcare practitioners are often concerned that the use of alternative treatments by Latinos will compete with conventional medicine. In one study it was found that Latino participants emphasized conventional medical treatment and only used alternative treatments as secondary strategies. It has been hypothesized that as a consequence of the use of curanderos, Latinos tend to delay seeking medical care, often until the condition becomes critical. The data did not support this hypothesis (Higginbotham, Trevino, Ray, 1990).

Curanderos or folk healers are recognized by the Latino community to treat physical, spiritual, and psychosomatic illnesses as well as traditional folk illnesses. Their existence is closely guarded. The

curanderos are kept a secret from outsiders and even to many residents of the community; therefore it is often impossible to estimate the number of curanderos. Latinos reluctance to discuss their use of curanderos may impact the results of studies conducted according to Higginbotham (1990). This reluctance to disclose the use of curanderos may stem from the fear of being ridiculed or reprimanded by biomedical healthcare professionals for using alternative healing practices not usually advocated by conventional health care providers. This may also be due to cultural and language differences between the conventional health care provider and patient (Martin, & Martinez, & Leon, 1985).

Patients who have chronic conditions that cannot be cured may feel that conventional medicine does not know how to treat them, and they may turn to a folk healer (Benabe & Rios, 2004).

Garza (1998) reports that, alternative health care is fast becoming popular in the United States. In 1990, it represented a \$14 billion-a-year business. According to these statistics, it is apparent that there is a market for alternative medicine. According to the National Institute of Health's Office of Alternative Medicine (1998, p. 33) when looking worldwide "only an estimated 10

percent to 30 percent of human health care is delivered by conventional, biomedical oriented practitioners. The remaining 70 percent to 90 percent ranges from self-care according to folk principles."

The literature commonly reports that most Latinos participate in the dominant health care system. Oftentimes, while utilizing conventional health care, the Latino patient continues to use his or her own culturally appropriate health care practice. Besides the use of curanderos, many products used by Latinos for preparing remedies are purchased in stores known as botanicas, which are found throughout the United States. Botanicas sell medicinal herbs, religious amulets, and other products used for healing remedies. The botanicas can serve as a referral to curanderos in the community (Gomez-Beloz & Chavez, 2001).

A study conducted by Hunt (2000) found that conventional medicine and alternative medicine can work together. The study found that Latino patients diagnosed with diabetes type II used both conventional and alternative forms of medicine without conflicting consequences (Hunt, Arar, & Akana, 2000). Aside from following methods of treatments which are culturally influenced, Latinos may choose alternative medicine due to

economics. Costs for conventional health care can prevent those without health care insurance or at a low-income level from visiting a physician (Gomez-Beloz & Chavez, 2001).

According to the literature reviewed, Latinos who use conventional health care services do so interchangeably with alternative medicine, making it an important health care resource for Latinos in the United States. Effective healthcare for the Latino dialysis patient is dependent on social workers and health care practitioners being knowledgeable about and respectful of the diverse population's culture, beliefs and practices. The generalist model for social work promotes the view that when the client has faith in the work of curanderos, the social worker should not discourage their utilization. "Using both clients' cultural resources and those of their community are appropriate helping activities" (Kirst-Ashman & Zarstow, 2001).

Patients' use of alternative treatment should not be labeled as noncompliant. Instead, careful consideration of how individuals actually use and evaluate alternative medicine may be more useful in helping to better understand the effectiveness of traditional herbal medication as compared to modern pharmacological

equivalents. Health care professionals should also know how simultaneous use of alternative and conventional treatments may help or hinder health (Applewhite, 1995).

Theories Guiding Conceptualization

Since this research is in its infancy, more than likely as more data are collected the theories that guide this study may broaden. Currently the strengths-based approach was identified since one major source of strength in Latino communities is the use of natural support systems. An essay by Delgado and Delgado (1982) identified four important components of the Latino natural support system: (1) the extended family, (2) folk healers, (3) religious institutions, and (4) merchants' and social clubs that function totally or partially to help individuals in distress.

Numerous researchers in regards to the Latino patient recommend cultural competence by all healthcare practitioners. Social science literature suggests that overall the health needs of ethnic minority groups are largely unmet and that services to them are flawed and misguided. An article appearing in the 1999 edition of the American Journal of Kidney Disease concluded that discrimination continues in our day even among patients

with health insurance. A delayed referral to nephrologists is more likely in Latino patients with chronic kidney failure than in their Anglo-American counterparts (Kausz, Obrador, & Aronra, 2000).

Another theory that was considered was the ecological systems perspective since recent Latino immigrants often present more challenges not only than the dominant group, but also than other Latino groups in the United States. While many Latinos have formed an emerging middle class, more are educated and many have lost the language, much of the Mexican immigrant population remains poor and monolingual. According to Sisneros, many integrated Latinos have conformed to Western thought, while some rural Mexicans still believe in "old thought," or folk medicine (Sisneros, 2002).

Summary

The literature review pointed out many aspects that are important in how Latinos make decisions about their healthcare, most of which have to do with cultural beliefs, the utilization of alternative medicine and support systems. All of these influenced the choices that Latinos made in the treatment of end stage renal disease. Other factors that were explored were the barriers that

Latinos experienced as a group. The lack of access either by being monolingual or not having insurance was prevalent in the literature. It was the goal of this research to bring awareness and cultural sensitivity to the healthcare providers who service this population.

CHAPTER THREE

METHODS

Introduction

This chapter includes the following sections. The first section describes the study design, which includes the type of research that was utilized. The second section describes the sample, population and agency that were selected for data collection. The third section provides the specific procedures that were utilized to gather the data and the instrument that was utilized. The fourth section described how the researchers protected the confidentiality of the participants. Finally, the data analysis is described.

Study Design

The purpose of this study was to better understand beliefs and attitudes among Latinos and how these affected their treatment for end stage renal disease. Cultural factors such as the use of alternative medicine and support systems were evaluated to explain the choices that a patient made regarding their dialysis treatment. A survey instrument was utilized to gather data, which examined beliefs and attitudes of Latino people who suffer from end stage renal disease. Data were drawn from the

patient's medical file to review the lab values that determined if the patient was compliant with dialysis treatment. The research question in this study was, do beliefs and attitudes among Latinos affect their treatment for end stage renal disease?

An evaluative design based on quantitative data was used for this research. This type of research was selected because of the nature of the sample. The data were collected during the patient's dialysis treatment and a survey allowed the participants to have privacy during this time. An interview would have taken longer and was not feasible during the treatment due to the close proximity of the treatment chairs. Furthermore, the participants answered questions pertaining to their healthcare and their disease. The participants might have felt uncomfortable answering questions that they might believe would affect or hinder their treatment.

Sampling

This study utilized a non-random convenience sample consisting of 46 Latinos, of varying ages, although most were over the age of 40. Due to the specific group that was studied the sample selection was implemented via convenience sampling. The researchers selected the sample

population. The intake person at the agency identified those patients with Spanish surnames and assigned them a random number. The researcher then was able to conduct the study by giving the survey to those participants with an assigned number. The researchers did not know the identity of the participants and the numbers were shredded once the participant completed the survey.

Gambro Dialysis Center services a large Latino patient population. The dialysis center services over 180 patients, half of which are Latino. The patients are divided among six shifts in four-hour intervals. The shifts are either on Monday, Wednesday and Friday or Tuesday, Thursday and Saturday. Samples were obtained from each of the six shifts in an effort to include a diverse population and to provide equal opportunity for participation from patients that receive their dialysis treatment at different times of the day. This method for data collection was employed to ensure that the sample was representative.

Data Collection and Instruments

The dependent variable in this project was compliance with the dialysis treatment, the patient's effort to follow their dietary and fluid restrictions. The dependent

variable was measured by obtaining information from the patient's medical records, specifically, the laboratory report that has tracked the past ten month's lab values for potassium, phosphorus and fluid gains. To determine the patient's compliance with treatment the three most current lab values were utilized. Compliance with two of the three lab values for each month determined that a patient was compliant with the treatment regimen. A score of 1 or 2 was assigned to indicate if the patient was compliant with treatment or not. Thus, the level of measurement was nominal.

The Dialysis Outcomes Quality Initiative (DOQI) and the medical director's adherence to protocols that are standardized guided the levels acceptable for potassium, phosphorous and fluid weight gains. Acceptable potassium levels were to be within 3.5 -5.5, phosphorus within 3.5 - 5.5 and interdialytic weight gain (IWG) not to exceed 2.5 kilograms over the individuals determined dry weight for the month that the survey was conducted.

The independent variables were attitudes and beliefs among Latinos who have been diagnosed with end stage renal disease. Attitudes and beliefs were measured via the constructs culture, patient's understanding of treatment, spirituality, and support systems. The research instrument

that was used to conduct this study was a questionnaire developed by the researchers, based on existing literature on Latino's attitudes and beliefs about their healthcare. (See Appendix B.) The survey instrument consisted of 22 closed-ended questions, which measured beliefs and attitudes about treatment of end stage renal disease. The questionnaire also included five demographic variables that asked for marital status, years in treatment, gender and level of education. The levels of measurement for these variables were nominal except for age, which was interval.

The questionnaire was provided in both Spanish and English, and was presented to the participant in their primary language. This was done to ensure that the study was culturally sensitive to the participants by respecting the need to understand the instrument in their own language.

The first concept that was analyzed in this study was culture. The conceptual definition of culture is common forms of practices and beliefs that are used as treatment choices. The second concept was what Latinos understand about their treatment options. The conceptual definition was what the participant knew about their healthcare and if he/she felt that it has hindered or aided their

treatment. The third concept was spirituality. The conceptual definition was the person's beliefs about God and their treatment. Finally, the fourth concept was support systems. This was defined as the importance that friends and family played in their treatment.

The level of measurement for cultural items were ordinal because a Likert scale was utilized to obtain the responses from the participants. Each item was rated on a four point Likert scale, where a value of four indicated that the subject strongly disagreed with the item statement, and one indicated that the subject strongly agreed. There were eight questions regarding the understanding of treatment, five questions in respect to spirituality, four questions that related to culture and four questions about support systems. Added to create a four interval scores that potentially ranged from strongly agree to strongly disagree.

Data from the questionnaire, completed by the patients, and the patient's laboratory values that are drawn monthly, were compared to determine if Latino beliefs and attitudes correlated with compliance and if Latino beliefs and attitudes played a role in compliance with dialysis treatment.

A limitation of this study was that the sample was small and cannot be viewed as representative of the Latino population. The sample was primarily from the San Bernardino area and participants were mostly Mexican or Mexican-American. Therefore, it failed to reflect the diversity of all Latinos from other areas such as Central and South Americas, and the different Latino Islands. Another limitation was that the instrument was limited to closed-ended questions that did not allow the participant to fully disclose their true feelings about their treatment.

Procedures

The procedure for collecting the data from each individual participant was as follows. The researchers met face to face with the participant. The participant was receiving their dialysis treatment at the time of the survey. Guillermina Robles Burgos explained the purpose of the study and determined who was willing to participate and reviewed the Letter of Informed Consent (Appendix A) with the potential participant in the participant's primary language, either Spanish or English. Due to the fact that Ada Ocasio works for this center she did not

take part in the data collection to ensure confidentiality for participants.

Once the participant agreed to participate in the study and signed the informed consent, the researcher reviewed the instrument with the participant. The instructions were read out loud to the participant and he or she was asked to circle the answer, which best applied. At this time the researcher stepped outside the room to protect the confidentiality of the participant and allow for privacy. The participant remained alone in their cubicle to complete the survey. If the participant did not feel comfortable answering the questionnaire during treatment, he or she was requested to step outside the dialysis cubicle to complete the questionnaire. The researcher waited for their dialysis to finish and then gave them the survey to be completed in private. To further ensure the confidentiality of the participant they were given the option of completing the questionnaire in the social worker's office. If the participant needed assistance completing the questionnaire, the researcher was available to assist them. An envelope was provided to the participant in which to place the finished questionnaire.

The questionnaire consisted of 22 closed-ended questions and the approximate length of time it took to complete each questionnaire was 15 to 20 minutes. Data collection took approximately eight hours.

Protection of Human Subjects

Once the participant agreed to participate in the study they were given a letter of informed consent and once they completed the questionnaire they were given a debriefing statement. (See Appendix C.) These forms were provided in their primary language. The informed consent included the purpose and goal of the study. The debriefing statement thanked the participant for their participation in the study and reminded the patient of the purpose of the study. It also provided information on where and when the results of the study would be available.

Participation in this study was voluntary and confidential. The researchers assured that no identifying information about the participant would be recorded. The participant's identity appeared only in numeric form. Results of this research were reported without any details about the participant that might cause any harm. Using a numeric form known as rim numbers assigned to each patient by the agency to identify them only by numeric form

protected the subject's identities. The rim numbers were written on the front page of the survey and used to obtain lab values, from the participant's medical files.

Data Analysis

The hypothesis was that beliefs and attitudes among Latinos diagnosed with end stage renal disease affect their treatment choices. Univariate analyses included measures of central tendency and dispersion, which includes the mean, the mode, the median and the standard deviation. Bivariate analyses included correlations (Pearson's r), and factor analysis to determine how the subscales could best be summarized, using Varimax rotation.

Summary

This chapter presented a discussion that detailed the procedures, study design, sample, data collection and instruments. A sample was selected and data were collected to assess the research question. The independent and dependent variables were identified as well as the levels of measure.

CHAPTER FOUR

RESULTS

Introduction

Bivariate analysis was used to compare the hemodialysis patient's compliance with their dialysis regimen. Measurements of compliance were based on the patient's individual blood laboratory values. A factor analysis was also conducted to assess the different constructs within the independent variables. The dependent variable steering this research, compliance, was compared to the participant's responses to the four concepts of spirituality, feelings related to treatment, culture and family involvement. The findings are presented and reviewed in this chapter.

Demographics

Out of the 176 dialysis patients at Gambro, 46 patients participated in this study. Of the 46 patients that completed the questionnaire the oldest was 89 years old and the youngest was 19 years of age. The average age was fifty-six (s.d. = 16.026) Of the surveys completed, 20 (43.5 %) were from men and 26 (56.5%) from women.

Questions one through five at the end of each questionnaire (See Appendix B) also collected demographic

information regarding marital status, number of years in treatment and level of education.

Findings on marital status indicated that 17 (38.6%) were not married and 27 (61.4 %) were married. Of the married participants 14 (31.8%) were compliant and 3 (6.8%) were not. Of the not married participants, 17 (38.6%) were compliant and 10 (22.7%) were not.

Table 1. Crosstabulation for Marital Status

Status		Compliance		Total
		Yes	No	
Married	Count	.14	3	17
	Expected	12.0	5.0	17.0
Not Married	Count	17	10	27
	Expected	19.0	8.0	27.0
Total	Count	31	13	44
	Expected	31.0	13.0	44.0

Participants who were married were significantly more likely to be compliant than those participants who were not married ($\chi^2 = 1.884$, $df = 1$, $p = 0.17$).

Of the 19 men that participated in this survey 17 (38.6%) were compliant and 2 (4.5%) were not. Of the 25 women that took part in this survey 14 (31.8%) were compliant and 11 (25.0%) were not compliant. Males were significantly more compliant with treatment than females ($\chi^2 = 5.811$, $df = 1$, $p = 0.016$).

Table 2. Crosstabulation for Gender

Gender		Compliance		Total
		Yes	No	
Male	Count	17	2	19
	Expected	13.4	5.6	19.0
Female	count	14	11	25
	Expected	13.4	7.4	25.0
Total	count	31	13	44
	Expected	31.0	13.0	44.0

Questions 1-22 of the questionnaire consisted of a Likert type scale with eight questions related to the patients feeling of having control over their dialysis treatment. Five questions related specifically to spirituality. Five questions related to culture and four questions related to the patient's perceptions regarding family and friendship involvement and treatment. The 22 questions relating to all categories were measured on a four point Likert scale (Strongly Agree, Agree, Disagree and Strongly Disagree). Because initial alpha scores with the four scales were low (.504, .324, .459 and .715), the twenty-two items of the beliefs and attitudes questionnaire were assessed to identify subscales empirically using factor analysis. Inspection of the rotated correlation matrix revealed the presence of many coefficients of .3 and above. To aid in the interpretation

of the components, a Varimax rotation was performed. New subscales were defined by principle component scores higher than .7.

The new subscales are internal locus of control, trust of health care, God locus of control positive, God locus of control punishment, cultural health definition I, cultural health II, and support system. Alpha scores for the new seven subscales were, respectively (.826, .822, .746, .395, .625, .478, and .713); these were significantly higher than the original alpha scores.

Table 5 provides the results from the Rotated Component Matrix for items on feeling of control over treatment. A two component solution explained a total of 62.7 % of the variance with component one contributing 39.8% and component two contributing 22.9%. There were eight items in this category. This analysis produced a new subscale named, internal locus of control. In reviewing component one ($\alpha = .826$) it appears that if respondents strongly agreed that they were well informed about their treatment related to dialysis, they also felt they had control over their health and it did not matter if the physician spoke Spanish in obtaining the best health the best health care. Respondents felt that they trusted the doctor's judgment related to their medical care.

Component two ($\alpha = .822$) was consistent with previous research related to beliefs and attitudes of people with end stage renal disease. Results from component two (trust in health care) indicated that if respondents felt that not speaking English did not prevent them from obtaining premium health care, they also strongly agreed that using an interpreter interfered with their treatment.

Table 3. Internal Locus of Control

	Component	
	1	2
Well informed about treatment	.792	-.224
Being Latino is a barrier to treatment	.039	.870
Dialysis will prolong my life	.115	-.073
There is a language barrier to my treatment	-.212	.835
Using an interpreter interferes with my health	-.220	.833
I have control over my healthcare	.889	.080
An English only MD doesn't interfere w/health	.773	-.226
I trust my MD decisions	.764	-.022

Questions 9 through 13 asked respondents about their beliefs and attitudes regarding spirituality, there were five items in this category. A two-component solution explained a total of 59.2% of the variance with component one contributing to 32.5% and component two contributing to 26.7%. The new subscale for this category was the God locus of control and punishment. Component one ($\alpha = .746$) indicated that if respondents strongly agreed that God or

a higher power had control over their health, they also strongly agreed that they had a strong religious and spiritual beliefs. In contrast component two ($\alpha = .395$) revealed that if respondents strongly agreed that they had a fear of dying, they also felt that their illness was a punishment from God.

Table 4. God Locus of Control

	Component	
	1	2
God has control over my healthcare	.890	.089
I have strong religious beliefs	.882	-.092
I have a strong fear of dying	-.167	.805
I feel I wont go to heaven	.043	-.004
I feel my illness is a punishment from God	.162	.819

Questions 14 through 18 asked respondents about their beliefs and attitudes related to culture and alternative forms of treatment. A two component solutions explained a total of 59.8% of the variance with component one contributing to 34.0% and component two contributing to 25.9%. Subscale one, cultural health definition I, ($\alpha = .625$) indicated that if respondents strongly agreed that their culture played an important part in their healthcare decisions, they also strongly agreed that alternative forms of treatment were important. In contrast the second cultural health subscale ($\alpha = .478$) indicated

that if that utilizing herbs would improved their health, they also agreed that "El Curandero" was the same as a medical doctor. The results from this data produced a new subscale, cultural definition.

Table 5. Cultural Definition

	Component	
	1	2
Culture is important part in my treatment	.831	-1.62
Alternative forms of treatment are important	.803	.034
Using herbs enhances my health	-.046	.816
Healthcare is not equal to non-English pts	.590	.194
El Curandero is equal to an doctor	.102	.757

Questions 19 through 22 asked respondents about their beliefs and attitudes related to family and friends involvement in their treatment. There was only one component extracted in this matrix; if respondents felt that their family and friends were an important part of their treatment outcome, they also felt that they needed their friends and family during their treatment ($\alpha = .713$). This produced a new subscale, support system.

Table 6. Support System

	Component
	1
Family is important to my healthcare decisions	.671
Family is important to my healthcare results	.706
My friends are important to my health	.744
I need friends and family during my treatment	.863

Pearson's correlations were used to assess the associations among the seven subscales. Internal locus of control significantly correlated with trust of health care, God locus of control positive, cultural health definition I and support system. Trust of health care significantly correlated with internal locus of control, God locus of control positive, God locus of control punishment, cultural health definition and support system. God locus of control positive significantly correlated with internal locus of control, trust of healthcare, cultural health definition I and support system. God locus of control negative significantly correlated with trust of health care and cultural health definition I. Cultural health definition I significantly correlated with internal locus of control, trust of control, God locus of control positive, and God locus of control negative. Trust of health care significantly correlated with support system. Support system significantly correlated with internal

locus of control, trust of health care, God locus of control positive and cultural health definition I.

Table 7. Correlation Matrix

	Internal locus of control	Trust of healthcare	God locus of control plus	God Locus Punishment	Cult. Defin I	Cult. Defin.	Support system
Internal locus of control							
Pearson Correlation	1	-.267	.340	-.048	.252	.063	-.258
Sig. (2-tailed)		.092	.029	.770	.117	.696	.099
Trust of healthcare							
Pearson Correlation	-.267	1	.285	.206	.509	.018	.373
Sig. (2-tailed)	.092		.075	.209	.001	.914	.016
God locus control plus							
Pearson Correlation	.340	.285	1	.010	.365	-.079	.209
Sig. (2-tailed)	.029	.075		.947	.019	.622	.173
God locus control neg							
Pearson Correlation	-.048	.206	.010	1	.341	.073	.026
Sig. (2-tailed)	.770	.209	.947		.031	.653	.867
Cultural health define I							
Pearson Correlation	.252	.509	.365	.341	1	-.035	.061
Sig. (2-tailed)	.117	.001	.019	.031		.832	.701
Cultural health define							
Pearson Correlation	.063	.018	-.079	.073	-.035	1	.343
Sig. (2-tailed)	.696	.914	.622	.653	.832		.026
Support system							
Pearson Correlation	-.258	.373	.209	.026	.061	.343	1
Sig. (2-tailed)	.099	.016	.173	.867	.701	.026	

Compliant respondents had higher internal locus of control scores ($x = 7.14$) than non-compliant respondents ($x = 9.83$) ($t = -.2.789$, $df = 38$, $p = .008$). Compliant

respondents had higher trust of health care scores (x = 6.67) than non-compliant respondents (x = 7.17) (t = $-.453$, df = 37, p = .653). (t = $.162$, df = 41, p = .05). Compliant respondents had higher God locus of control positive (x = 2.77) than non-compliant respondents (x = 3.42) (t = -1.423 , df = 40, p = .162). Compliant respondents had higher God locus of control punishment scores (x = 6.33) than non-compliant respondents (x = 6.58) (t = -4.51 , df = 39, p = .523). Compliant respondents had higher cultural health definition I scores (x = 4.34) than non-compliant respondents (x = 4.75) (t = $.645$, df = 38, p = .479). Compliant respondents had higher trust of health care scores (x = 2.83) than non-compliant respondents (x = 3.09), (t = $-.715$, df = 38, p = .479). Compliant respondents had higher support system scores (x = 5.47) than non-compliant respondents (x = 5.08), (t = $.557$, df = 41, p = .581)

Summary

As presented in this study it was indicated that there was no significant relationship between respondent's beliefs and attitudes and compliance with their dialysis treatment. It further demonstrated that age, gender, marital status and level of education had no influencing

relationship to compliance. There were some correlations between respondent's internal locus of control and God locus of control positive. There was also a correlation noted between respondent's trust of health care and their support system. Finally, internal locus of control and cultural definitions were approaching statistical significance.

In reviewing the means of compliant respondents versus non-compliant respondents in all seven subscales there were more respondents who were compliant with treatment than non-compliant.

CHAPTER FIVE

DISCUSSION

Introduction

This research provided a quantitative analysis which examined the beliefs and attitudes of Latino patients and compliance with their dialysis treatment. The factors reviewed in this study, included support systems, and culture and alternative medicine.

The growth rate of kidney disease has doubled every ten years. There is a concern about racial disparity in the prevalence, morbidity, and mortality of kidney disease and in the provision of optimal care to prevent or slow the progression of this disease. Latinos, who are among the fastest growing racial group in the United States, are twice as likely to develop kidney failure as non-Latinos whites, largely due to the increased prevalence of diabetes mellitus in the Latino population. Latino patients however, are less likely than the general U.S. population to be screened for risk factors for kidney disease or receive optimal treatment after diagnosis. (Benabe & Rios, 2004). Due to this growing concern it is important that those who work with Latino dialysis patient expand their cultural competency knowledge base and help

create an environment that is more effective in meeting the specific healthcare needs of the Latino community dealing with End Stage Renal Disease. The significance of expanding cultural competency in working with the Latino dialysis patient, regarding their compliance with their treatment, is to have a positive outcome regarding their healthcare and potential benefits for an improved quality of life.

Discussion

Participants in this study who were married demonstrated significantly better compliance than those who were single. And participants who felt that their family and friends were an important part of their treatment outcomes also felt they needed their friends and family during their treatment. This finding supports literature regarding family support, which states that family plays an integral role in the patient's well being, adjustment, and management of kidney disease (Root, 2004). Additional support is the finding in this study that respondents felt that their family and friends were an important part of their treatment outcome.

Level of education of participants in this study did not affect the outcome of compliance. This finding concurs

with studies, which did not find that education had a significant relationship with compliance with dialysis. Other studies did find however, that those patients who were offered pre-dialysis education demonstrated better compliance with their treatments than those who were not provided with pre-dialysis education. This study revealed that females appeared to be more compliant than males. Similar to this finding other studies conducted regarding compliance and gender revealed that men were more likely to gain interdialytic weight (IDWG) than women.

Overall those participants who felt well informed about their treatment also felt it did not matter whether their physician spoke Spanish. These participants also reported that they felt they maintained control over their health and trusted the doctor's judgment related to their medical care. In the clinic where this research was conducted, Spanish speaking patients have access to numerous health professionals who are bilingual, which may account for why the participants felt well informed about their treatment. These results agree with literature, which reports that Latinos who are monolingual feel a sense of powerlessness and lack of ability to make informed choices regarding their health (Warda, 2000).

Participants who believed that they had a strong religious and spiritual belief also believed that God or a higher power had control over their health. This finding supports the literature, which states, that for the Latino culture, death is a natural course of life. When death is a threat, one does not fight it but succumbs to "God's will." (Roots, 2004). Those respondents who had a strong fear of dying also felt that their illness was a punishment from God. These result supports literature stating that among Latinos illness is viewed as an imbalance of the body due to wrongdoing (Da Silva, 1984). Findings in this study support recent studies done on those diagnosed with either cancer or HIV. These studies concluded that an individual's spiritual resources often play an important part in their adjustment process when facing a life-threatening disease (Kang, 2006). Those with a positive reliance on tended to hear good health outcomes while those who saw their illness as God's punishment had poor outcomes.

In consensus with findings in the literature review, respondents strongly agreed that their culture played an important part in their healthcare decisions and also strongly agreed that alternative forms of treatment were important. Those participants, who agreed that utilizing

herbs would improve their health, also agreed that "El Curandero" was the same as a medical doctor. This finding supports the literature reviewed which states that Latinos who use conventional health care services do so interchangeably with alternative medicine (Kirst-Ashman & Zarstow, 2001).

A finding not anticipated is that respondents felt being non-English speaking did not prevent them from obtaining premium health care. These respondents also strongly agreed that using an interpreter interfered with their treatment. Since most literature supports contrasting views it may be worth exploring this finding further. Possibly providing an open ended question regarding this finding could broaden understanding for researchers. In either case further examination of this finding could be found valuable to the social workers.

Limitations

The limitations of this project are related to the various means of measuring compliance. Although the Dialysis Outcomes Quality Initiative (DOQI) has standards of practice for measuring compliance, there remain differing measurements to determine compliance. Other studies have measured compliance with dialysis as missed

dialysis treatments and/or refusing to dialyze, for the full prescribed treatment time. Inconsistency may be found when comparing this study to other research since the methods used for measuring compliancy may vary.

This study measured compliance by the patient's adherence with the recommended levels of potassium, phosphorus and interdialytic weight gains. For this study, those patients who met the criteria in two of the three indicators mentioned were found to be compliant. Another limitation to consider in this research is that the sample of participants was relatively small and future research should consider a larger sample. Also consideration in providing participants an opportunity to elaborate on their answers may broaden findings for this research.

Recommendations for Social Work Practice, Policy, and Research

This study was inspired by the lack of literature available that focuses specifically on social work with the Latino dialysis population. The literature review conducted for this study suggests that the overall health needs of ethnic minority groups are largely unmet and that services provided to them are flawed and misguided. The need for further research in this area is evident and would benefit Latino patients as well those who work in

the dialysis community and serve a diverse patient population.

Many policymakers at the local, state, and federal levels may have an understanding that the Latino population is one of the fastest growing groups in the United States. However policymakers must also understand how this growth also correlates with the growth of Latinos who are diagnosed of End Stage Renal Disease. With today's headlines targeting immigration laws it is uncertain what the plight will be for undocumented immigrant Latino's who are receiving dialysis care in the United States.

Public policy must begin to consider the specific needs of Latino dialysis patients, which are distinct from the needs of other dialysis patients, in order to avoid a social and public health crisis of significant proportions. It is understood that policy changes in this realm may be difficult because of the prevalence of managed care.

However, it should be considered that the cost effectiveness of medical care for Latino dialysis patients could be significantly improved if the managed care industry were willing to adopt some significant policy changes in this area. Managed care organizations should adopt a system of greater flexibility for patients,

especially Spanish-speaking patients, to choose primary physicians and specialists who can communicate in the patient's dominant language. The current system is structured to make this very difficult. For example, patients may be unable to choose a Spanish-speaking specialist in that same medical group. Patients who are enrolled in Medicare and/or Medi-cal already have this flexibility in choosing their primary physician.

Conclusions

Working with Latino dialysis patients presents the nephrology social worker with a variety of challenges and opportunities. As demonstrated in the literature review and validated in this study, Latino culture is very much a family oriented one. This presents an inherent strength in working with this group and is an opportunity that should be seized by the nephrology social worker.

Nephrology social work practice should be aimed not only at the individual patient but at the family as well, providing assessment, resources, and interventions that incorporate the entire family into service provision. This is an area with huge opportunities for further study and research.

Nephrology social workers should be encouraged to enhance the knowledge base of this population by evaluating and writing about their practice with this population.

APPENDIX A
LETTERS OF INFORMED CONSENT

Informed Consent Letter

Dear participant:

Our names are Guille Robles Burgos and Ada Ocasio; we are Master's of Social Work students at California State University, San Bernardino. We are conducting a study of beliefs and attitudes among Latinos with end stage renal disease, and you are invited to participate in our study. Although you are not expected to directly benefit from this study, it is hoped that the results of this study will help social workers and health care professionals help Latinos with end stage renal disease by approaching their care from a culturally sensitive perspective. The Department of Social work and the committee of the CSUSB Institutional Review Board have approved this study.

If you decide to participate in this study, you will be asked to complete a questionnaire during your dialysis treatment. The questionnaire will take about 15 to 20 minutes. The questions on the survey pertain to cultural practices, social support systems, spirituality and your understanding about your treatment choices. Your participation is strictly voluntary, and you can choose not to answer specific questions that are on the questionnaire. 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, As a participant in this study, your confidentiality will be protected. Your name will never be used on any document or notes used in this study. Your name will never be revealed in the final published report, or in any subsequent report based on this study. The Consent will be kept in a locked file cabinet for three years and then destroyed. All data collected will be kept in a locked file cabinet for the duration of the study, and will be destroyed once the study is completed and published. The results of this study will be shared with Gambro in a group format, but 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 review of treatment compliancy.

If you have any questions or concerns regarding any aspect of this study, please feel free to our faculty advisor, Dr. Rosemary McCaslin at (909) 880-5507. If you agree to participate in the study at this time, please mark and date below. Thank you very much for your participation.

My mark below indicates that I have been informed about the nature of the study and that I am participating voluntarily. I am at least 18 years of age.

I give the researchers permission to access my medical records.

Informacion de Consentimiento

Estimado Participante:

Nuestros nombre son Guille Robles Burgos y Ada Ocasio, somos estudiantes para el titulo de Masterado de Trabajo Social en la Universidad Estatal de California en San Bernardino. Estamos performando un estudio sobre las altitudes and creyencias de Latinos con fallo permanente de rinon y ud esta invitado a participar en este estudio. Aunque no hay beneficios directos para ud, se espera que los resultados de este estudio ayuden a los trabajadores sociales y profesionales de cuidado medico en trabajar por una perspectiva cultural con Latinos con la enfermedad de fallo permanente de rinon. El departamento de Trajadores Social y el comite de revision han ortogado permiso para este estudio.

Si ud decide a participar en este estudio, ud participara contestando con preguntas en un formulario. Este formulario tomara entre 15 a 20 minutos de su tiempo, y las preguntas son sobre sus apoyos de familia, creencias religiosas, sus ritos culturales, y otros factores importantes para el estudio. Su participacion es estrictamente voluntario, y ud puede terminar su participacion en cualquier momento antes o durante el formulario. Ud. No esta obligado a contestar ninguna pregunta especifica. Tambien, si ud decide no participar en este estudio, sus servicios medicos no estaran afectados en ninguna forma.

Como participante en este estudio, su confidencialidad sera protegida. Su nombre completo nunca sera usado en ningun documento o apuntes usdao en este estudio. Su nombre completo nunca estara revelado en el reporte final, ni en ningun reporte basado en este estudio. Esta Informacion de Consentimiento firmado estara guardada en un archivador asegurado por tres anos y despues sera destruida. Toda la informacion directamente relacionada con sus participacion esta guardada en un archivador asegurado por la duracion de la investigacion, y sera destruida cuando el estudio esta terminado y publicado. Los resultados de este estudio estara compartido con Gambro, y ningun participante estara identficado por nombre.

Le pedimos su autorizacion para revisar sus archivos para completar este estudio. Necesitatmos comparar los resultados de laboratorio y su tratamiento de diaylsis.

Si ud tiene cualquier pregunta sobre algun aspecto de este estudio, favor de llamarle a la directora del tesis, la Dra. Rosemary McCaslin at (909)880-5184. Si ud acuerda participar en este estudio, favor de marcar abajo. Gracias por su participacion.

Les dio permiso a los estudiantes que vean mis archivos medicos.

APPENDIX B

SURVEY

Thank you for helping us with our research. Each item below is a statement, with which you agree or disagree. Below each statement there is a scale that ranges from strongly agree (1) to strongly disagree (4). For each item please circle the number that represents the extent to which you agree or disagree with the statement.

Beliefs and attitudes about End Stage Renal Disease

	Strongly agree	Agree	Disagree	Strongly Disagree
1. I feel that I am well informed about my dialysis treatment	1	2	3	4
2. I believe that being Latino/Latina causes a barrier in obtaining premium healthcare.	1	2	3	4
3. I believe that dialysis prolongs my life	1	2	3	4
4. I believe that not speaking English prevents me from obtaining premium health care	1	2	3	4
5. I feel that using an interpreter interferes with my treatment.	1	2	3	4
6. I feel that I have control over my health care	1	2	3	4
7. I feel that even if my doctor doesn't speak Spanish he is providing me with the best healthcare	1	2	3	4
8. I trust my doctor's judgment about my medical care.	1	2	3	4
9. I believe that God or a higher power has control over my health.	1	2	3	4
10. I have strong religious and spiritual believes.	1	2	3	4
11. I have fear of dying.	1	2	3	4
12. I feel that I might not get into heaven.	1	2	3	4

	Strongly agree	Agree	Disagree	Strongly Disagree
13. I feel that my illness is a punishment from God.	1	2	3	4
14. I feel that my culture plays an important part in my health care decisions.	1	2	3	4
15. I feel that alternative forms of treatment are important.	1	2	3	4
16. I feel that taking herbs will improve my health	1	2	3	4
17. I feel that the quality of my healthcare is not equal to those who speak English.	1	2	3	4
18. I feel that El curandero is the same as a medical doctor.	1	2	3	4
19. I feel that having my family involved in my treatment is helpful to the decisions I have to make	1	2	3	4
20. I feel that my family is important to my treatment outcome.	1	2	3	4
21. I feel that my friends are important to my treatment	1	2	3	4
22. I feel that I need my friends and family during my treatment.	1	2	3	4

1. How old are you? _____
2. What is your sex?
1. Male 2. Female
3. What is your marital status?
1. Single 2. Married 3. Widowed 4. Divorce/Separated
4. What is your highest level of education? _
5. How long have you been receiving dialysis? _

Gracias para ayudarnos con nuestra investigación. Cada artículo debajo es una declaración, con que usted concuerda o no concuerda. Debajo de cada declaración hay una escala que recorre si usted concuerda o no concuerda (1) concuerde totalmente (4) no concuerda totalmente. Para cada artículo por favor escoja el número que representa el punto hasta que usted concuerda o disiente de la declaración.

La Creencias y las actitudes acerca la Enfermedad Renal

	Concuerda totalmente	Concuerda	No Concerda	No Concuerda Totalmente
1. Yo me siento que estoy informado/a bien acerca de mi tratamiento del diálisis	1	2	3	4
2. Creo que siendo Latina/o causan una barrera a obtener asistancia con el tratamiento de mi salud.	1	2	3	4
3. Creo que el diálisis prolonga mi vida.	1	2	3	4
4. Creo que no hablar Ingles me de obtener asistencia para mi salud.	1	2	3	4
5. Yo siento que usando a un interprete interviene con mi tratamiento.	1	2	3	4
6. Yo siento que tengo el control sobre mi tratamiento medico.	1	2	3	4
7. Yo siento que aunque mi doctor no habla Espanol el me propoerciona con la major asistencia medica.	1	2	3	4
8. Confio con las decisiones del doctor sobre mi salud y tratamiento.	1	2	3	4
9. Creo que Dios o un poder mas alto tienen el control sobre mi salud.	1	2	3	4
10. Tengo creencias religiosas y espirituales fuertes.	1	2	3	4
11. Tengo temor de morir	1	2	3	4
12. Yo siento que quizas no entre al cielo.	1	2	3	4

	Concuerda totalmente	Concuerda	No Concuerda	No Concuerda Totalmente
13. Yo siento que mi enfermedad es un castigo de Dios.	1	2	3	4
14. Yo siento que mi cultura juega una parte importante en mis decisiones de salud medica.	1	2	3	4
15. Yo siento que formas alternativas de tratamiento son importantes.	1	2	3	4
16. Yo siento que tomando hierbas son importantes para mejorar mi salud.	1	2	3	4
17. Yo siento que la calidad de tratamiento medica no es igual a los que hablan Ingles.	1	2	3	4
18. Yo siento que usando un curandero es igual que un doctor.	1	2	3	4
19. Yo siento que teniendo mi familia implicada en mi tratamiento es util a las decisiones que tengo que hacer.	1	2	3	4
20. Yo siento que mi familia es importante para el resultado de mi tratamiento	1	2	3	4
21. Yo siento que mis amigos son importantes para mi salud.	1	2	3	4
22. Creo que necesito a mis amigos y familia durante mi tratamiento medico.	1	2	3	4

1. Cual es su edad? _____
2. Que es su genero
1. Masculino 2. Hembra
3. Que es su estado civil?
1. Soltero 2. Casado/a 3. Enviudado/a 4. Divorciado/a
4. Que es su nivel mas alto de educacion? _____
5. Cuanto tiempo tiene recibiendo el tratamiento del dialysis? _____

APPENDIX C
DEBRIEFING STATEMENT

Debriefing Letter

Thank you for your willingness to participate in this study conducted by Guillermina Robles Burgos and Ada Ocasio, graduate students in the Masters of Social Work program at California State University, San Bernardino.

The questionnaire that you have just completed was designed to measure whether attitudes and beliefs affect compliance with dialysis treatments. The study is an attempt to promote the health, well being and compliance of patients who are currently receiving dialysis treatment and for those patients who will need treatment in the future.

Results of this study will be available at the Pfau Library, California State University, San Bernardino campus in the summer of 2006. If you have any questions or concerns please contact Professor Rosemary McCalsin, Ph.D. faculty, Social Work Department, at (909) 880-5507.

CARTA de INTERROGATORIO

Gracias por su consentimiento para tomar parte en este estudio realizado por Guillermina Robles Burgos y Ada Ocasión, estudiantes para el título de Masterado de Trabajo Social en la Universidad Estatal de California, San Bernardino. El cuestionario que usted acaba de completar se diseñó para medir si las actitudes y las creencias afectan la conformidad con tratamientos de diálisis. El estudio es una tentativa de promover la salud, es bien y la conformidad de pacientes que reciben actualmente el tratamiento del diálisis y para esos pacientes que necesitarán el tratamiento en el futuro. Los resultados de este estudio estarán disponibles en la Biblioteca de Pfau, Universidad Pública de California, San Bernardino, el campus en el verano de 2006. Si usted tiene cualquiera pregunta o concierne por favor Profesor de contacto Rosemary McCalsin, Ph.D. La facultad, el Departamento de la asistencia social, en (909) 880-5507.

REFERENCES

- Amaya, F. (2001). *The perceptions of chronic illness among elderly Latino people*. Master's thesis, California State University, Long Beach.
- Applewhite, S. L. (1995). Curanderismo: Demystifying the health beliefs and practices of elderly Mexican Americans. *Health & Social Work, 20*(4), 247-254.
- Benabe, J. E., & Rios, E. V. (2004). Kidney disease in the Hispanic population: facing the growing challenge. *Journal of the National Medical Association, 96*(6), 789-797.
- Cruz, L. (1999). *Medical compliance for Hispanics End Stage Renal Disease*. Master's thesis, California State University, San Bernardino.
- Da Silva, G. C. (1984). Awareness of Hispanic cultural issues in the healthcare setting. *Child Health Care, 13*, 4-10.
- Delgado, M., & Delgado, H. (1982). Natural support systems: source of strength in Hispanic communities. *Social Work, 27*, 83-89.
- Garza, M.J. (1998). Healing Spirits. *Hispanic, 11*(6), 30-35.
- Gomez-Beloz, A., & Chavez, N. (2001). The Botanica as culturally appropriate healthcare option for Latinos. *The Journal of Alternative and Complementary medicine, 7*(5), 537-546.
- Guendelman, S. (1983). Developing responsiveness tot he health needs of Hispanic children and families. *Social Work Health Care, 8*, 1-15.
- Higginbotham, J. C. V., Trevino, F. M., & Ray, L. R. (1990). Utilization of curanderos by Mexican Americans: Prevelance and predictors findings from HHANES 1982-84. *American Journal of Public Health, 80*, 32-35.

- Hunt, L. M., Arar, N. H., & Akana, L.L. (2000). Herbs, prayer, and insulin, use of medical and alternative treatments, by a group of Mexican American diabetes patients. *Journal of Family Practice*, 49(3), 216-223.
- Juarez, G., Ferrell, B., & Bornemena, T. (1998). Perceptions of quality of life in Hispanic patients with cancer. *Cancer Practice*, 6(6), 318-324.
- Kang, C. K. (2006, April 29). *Exploring the connection of Spirit, Body*. Retrieved April 28, 2006 from <http://ktla.trb.com/news/local/la-me-beliefs29apr29,0,4323069.story?coll=ktla-newslocal-1>
- Kausz, A., Obrador, G., & Arona, P. (2000). Late initiation of dialysis among women and ethnic minorities in the United States. *American Society Nephrol*, 11, 2351-2357.
- Keegan, L. (2000). A comparison of the use of alternative therapies among Mexican Americans and Anglo-Americans in the Texas Rio Grande Valley, *Journal of Holistic Nursing*, 18(3), 280-295.
- Lipson, J. G. (1996). Culturally competent nursing care. In J. G. Lipson, S. L. Dibble, & P. A. Minarik (Eds). *Culture & nursing care* (pp. 1-6.) San Francisco: UCSF Nursing Press.
- Martin, H. W., Martinez, C., & Leon, R. L. (1985). Folk illnesses reported to physicians in the lower Rio Grande Valley: A binational comparison. *Ethnology*, 24, 22-236.
- Nicholas, S., Agodoa, L., & Norris, K. (2004). Ethnic disparities in the prevalence and treatment of kidney disease. *Nephrology News & Issues*, 29-36.
- Roots, L. (2004). Literature review and implications for Social Work practice with Hispanic dialysis patients, *Advances in Renal Replacement Therapy*, 11.
- Sisneros, J.A. (2002). Social work practice with Mexican immigrants-steps to understanding. *Social Work Today*, 14.

Southern California Renal Disease Council, Inc. (2004).
2004 Dialysis Facility Report, Los Angeles, CA ESRD
Network 18.

U.S. Census Bureau. (2000). *Profiles of General
Demographic Characteristics: National Summary*.
Atlanta, GA: U.S. Department of Commerce.

Warda, M.R. (2000). Mexica American's perceptions of
culturally competent care. *Western Journal of Nursing
Research*, 22(2), 203-224.

Zarstow, C., & Kirst-Ashman, K.K. (2001). *Understanding
Human Behavior and the Social Environment*. Belmont,
Ca: Wadsworth/Thomson Learning.

ASSIGNED RESPONSIBILITIES PAGE

This was a two-person project where authors collaborated throughout. However, for each phase of the project, certain authors took primary responsibility. These responsibilities were assigned in the manner listed below.

1. Data Collection:

Assigned Leader: Guille Robles Burgos

Assisted By: Ada Ocasio

2. Data Entry and Analysis:

Team Effort: Guille Robles Burgos & Ada Ocasio

3. Writing Report and Presentation of Findings:

a. Introduction and Literature

Team Effort: Guille Robles Burgos & Ada Ocasio

b. Methods

Team Effort: Guille Robles Burgos & Ada Ocasio

c. Results

Assigned Leader: Guille Robles Burgos

Assisted By: Ada Ocasio

d. Discussion

Assigned Leader: Ada Ocasio

Assisted By: Guille Robles Burgos