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Determinants of Adherence to Living on Dialysis for Mexican Americans

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Abstract

This study explores perceptions that affect adherence behaviors among Mexican Americans living with dialysis. In-depth narrative interviews were conducted with 15 Mexican Americans with end-stage renal disease (ESRD) living on dialysis, 15 family members, and 6 health care personnel who provided care to them. Four themes emerged: (a) positive influences to adherence, (b) obstacles to adherence, (c) daily activity losses, and (d) fears about living with dialysis. From the findings, the perceptions given for non-adherence with the dialysis regimen ranged from denial of the condition, lack of pre-education, to cultural factors. Those given for adherence included prolonged life, family, and hope of getting a transplant. Health care providers were the reminder to adhere. Several cultural factors influenced their adherence perceptions. Strategies to enhance adherence behaviors should focus on knowledge about dialysis, use of the collective efficacy of the family, and the inclusion of cultural values.

Keywords

cultural values, Health Belief Model, compliance, illness perceptions

Introduction

It is estimated that more than 20 million adults have moderate or severe chronic kidney disease (U.S. Renal Data System [USRDS], 2013). Inadequately controlled diabetes and hypertension increase the risk of progression to kidney failure, which requires dialysis or a kidney transplant (Centers for Disease Control and Prevention, 2014). End-stage renal disease (ESRD) is disproportionately frequent in racial and ethnic groups. It is 4 times more likely in African Americans, 1.8 times in American Indians/Alaska Natives, and 1.6 times in Asian Americans. By ethnicity, Hispanics have 1.5 times the risk of developing ESRD than non-Hispanics (ESRD Network, 2013; USRDS, 2013). In Texas, the incidence and prevalence rates of ESRD are above the national average. The most notable increases have been among Hispanics (Kidney Health Care Program, 2013). In 2012, of the 40,445 persons with ESRD who received dialysis, 17,352 were Hispanics. Diabetes followed by hypertension is the most common cause and predictor of kidney failure among Mexican Americans (ESRD Network, 2013).

ESRD is a progressive, debilitating, and chronic illness. Most studies have placed attention on the medical or clinical dimensions of ESRD with the gauge of success for intervention on reduction of patient mortality (Daugirdas, 2011). Individuals receiving dialysis spend 3 to 5 hr per session 3 times each week attached to a dialysis machine (Flythe, Curhan, & Brunelli, 2012). Failure to comply with the dialysis regimen can lead to bone demineralization, congestive

heart failure, and death (O'Flaherty et al., 2013; Sud, Tangri, Pintilie, Levey, & Naimark, 2014). Although dialytic therapy is life-saving, it does not restore normal health and well-being to patients. Few studies have paid attention to non-medical factors such as self-maintenance, societal contribution, interpersonal relationships, social support, and occupational performance (McAdams-Demarco et al., 2012; Turkmen et al., 2012). Kara, Caglar, and Kilic (2007) found that non-adherence with the diet and fluid restrictions was more common among younger, married dialysis patients, and those with lower levels of perceived social support. They concluded that patients' perceptions may be more important than objective clinical assessments in determining compliance. Quality of life and dialysis studies have focused on physical functioning, locus of control, depression, and anxiety among ESRD patients (Zhang et al., 2014; Weisbord et al., 2014).

Relatively little work has been directed at the adaptations these individuals and their families must make to live with ESRD and dialysis (DePasquale et al., 2013; Molzahn et al., 2012). Fewer studies have focused on or included Mexican

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Americans. And whether cultural values and acculturation level influence adherence is ill-defined and poorly understood (Kim, Evangelista, Phillips, Pavlish, & Kopple, 2012). Various values within the Mexican American culture (i.e., familism, machismo, and fatalism) and level of acculturation have been characterized in the literature as factors that influence health behaviors (Ghaddar, Brown, Pagan, & Diaz, 2010; Min & Barrio, 2009).

Perceptions of illness develop from exposure to a variety of social and cultural information (Petrie & Weinman, 2012). The Health Belief Model (HBM) postulates that health-related actions and compliance depend on the perceptions of the individual in four areas: (a) perceived susceptibility, (b) perceived severity, (c) perceived benefits, and (d) perceived barriers to the consequences of the illness or condition. Having cues to act as well as the confidence (self-efficacy) to act allow the individuals to exert control over their lives. The HBM has been found to be helpful in explaining individual's health action under condition of uncertainty. Research has shown that its key variables are associated with adherence behaviors (Simons-Morton, McLeroy, & Wendel, 2012).

Thus, guided by the constructs of the HBM, this qualitative study was conducted to explore the values and perceptions of Mexican Americans with ESRD, their families, and the health care providers who serve them as they relate to adhering behaviors when living with dialysis.

Method

Participants

A cross-sectional research design was used. The study included (a) Mexican Americans living in Cameron County, Texas, with a diagnosis of ESRD and living more than 6 months with renal replacement therapy, regardless of the type of renal replacement therapy they received (peritoneal or hemodialysis); (b) family members, including spouse, sibling(s), child (children), or blood relatives who were or were not the primary caregivers; and (c) full-time, paid health care providers with 2 or more years of direct contact with dialysis patients. Several strategies—snowball, networking, and advertising—were used to recruit participants for the study. Local contact persons in three in-center facility and a nephrologist's practice assisted in identifying potential participants. The resulting sample consisted of 15 individuals with ESRD (3 on peritoneal and 12 on hemodialysis), 15 family members, and 6 health care providers. Reasons for non-participation in the study ranged from not feeling well, distrust of anyone outside of the dialysis family, to fear of being deported.

Method

Demographic data were collected via a questionnaire. The Acculturation Rating Scale for Mexican Americans–II

(ARSMA-II, Cuellar, Arnold, & Maldonado, 1995), a 30-item revised scale that measures cultural orientation on two subscales - Mexican Orientation Subscale (MOS–17 items) and Anglo Orinetation Subscale (AOS–13 items) -independently, was used to assess acculturation level of the participants. Lower levels of acculturation have been found in first-generation Mexican Americans and increasing with each generation after. The two subscales have good internal reliabilities (.86 and .88) and high correlation coefficients ($r = .89$). The primary limitation of the scale is its linear measure of acculturation (American Psychological Association, 2014). Horevitz and Organista (2012) found that for people of Mexican descent, the more time in the United States often means the eroding of protecting factors such as close knit and supportive families and traditional cultural values.

Subjective data on participants' perceptions were collected via in-depth interviews. The constructs of the HBM guided the interview questions that were pilot tested with a facility manager, individual with ESRD, and family member. Semi-structured interviews, lasting from 45 to 90 min were completed at the participant's home or dialysis center and in the preferred language of the participant. Interviews in English were conducted by the study investigator. An experienced interviewer who had completed a formal training program conducted interviews in Spanish with the Spanish speakers. Consent to participate was obtained prior to tape recording and documenting non-verbal and contextual observations. The University of Texas Health Sciences Center at Houston, Committee for the Protection of Human Subjects approved this study.

Data Analysis

Using STATA 8.2 statistical software, the demographic characteristics of each group of participants were summarized. The ARSMA-II was scored according to the instrument instructions (Cuellar et al., 1995). Verbatim written transcriptions were created from all audiotapes. Interviews conducted in Spanish were transcribed in Spanish and then translated into English. The English-translated transcriptions were reviewed and compared with the Spanish audiotape to ensure the accuracy of the translation. Transcriptions were imported into ATLAS.ti 5.2 statistical software for qualitative analysis. Data were analyzed within the constructs of the expanded HBM proposed by Rosenstock, Strecher, and Becker (1988). The data were coded line-by-line then sorted through for the operational definition of the HBM constructs. Codes were compared between the family members, health care providers, and individuals with ESRD for item saturation and/or triangulation. Four major themes emerged: positive influences for adherence, obstacles to adherence, daily activity losses, and fears of living with dialysis.

Results

Participant Characteristics

The participants (See Table 1) were Mexican Americans with ESRD ($n = 15$) that was due primarily to diabetes and high blood pressure. Hemodialysis was the most common renal replacement therapy. Most were unemployed (67%), married (40%), or widowed (60%) and had a household income of less than \$20,000 per year (73%). Length of time on dialysis ranged from 6 to 132 months. The family members ($n = 15$) were largely female (93%), married (73%), and had a family income less than \$60,000 (73%). They comprised of spouses, daughters, and other family members. Seventy-three percent were the primary caregiver and did not work outside the home, whereas 53% worked outside the home and served as the primary caregiver. The health care providers ($n = 6$) were nurses (4), a physician, and a social worker with more than 5 years working in dialysis. The participants (83%) were highly oriented to the Mexican culture in terms of preference, language use, ethnic identification, and cultural heritage. Eighty percent were first- and second-generation Mexican Americans.

Themes

Positive influences to adherence. Perceived benefits and self-efficacy, which produced improvement in family interaction, lifestyle, and occupational performance, were indicators of positive influences to adherence. The individuals with ESRD viewed dialysis with a sense of gratitude for a prolonged life. One participant said,

. . . you know what dialysis does for me [it] makes me like a new man for another day . . . It's like a see-saw to me because you do dialysis and you know for that day you're gonna be down and then the following day you're gonna go out because you feel great. You feel like nothing's wrong with you and you have that mentality that nothing's wrong with me.

Another said, "I'm kind of glad [for dialysis] because it [life] can be prolonged. I feel better now, 100% better . . . they clean your blood. They take out the toxics."

The participants described themselves as recipients of physical and emotional support from their family. One participant described her observation at the clinic:

I guess it's harder for men because they're so used to being in charge. Now she [wife] has to take care of him . . . He doesn't have a leg, she has to carry him; she has to feed him . . .

A participant talked about her emotional ties:

[My sisters] are very important, because sometimes I get depressed. Like if there's one day that goes by that they don't call me or they don't come over I get so depressed; I'm used to

having them around me. I mean they're the reason I'm still here . . . We've always been very close, but now it's even closer.

Another expressed his gratefulness for his family:

They accommodate me. Now I live with my parents . . . There are times when I will not take care of myself. They've taken the responsibility to watch over me, making sure that I'm doing what I'm supposed to do . . . taking my medicine, taking my blood pressure, almost to the point of nagging. Without them around I may not be here.

The family members reported that their family had become closer, more communicative, and involved with each other. The closeness extended beyond the immediate family unit to extended family members, friends, and neighbors. The benefits included positive family coping, coherence, and increased family resiliency.

It is hard seeing him all the time unable to do the things he really likes. So, we have come together—children, grandchildren, and great grandchildren—to support him.

Another said,

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

Cultural values. Within the Mexican American culture, the family is the most valued institution. *Familism* is the belief that family at all levels—nuclear, extended, fictive kin—is central to one's life. The needs of the family take precedence over the needs of the individual (Min & Barrio, 2009). The shared effort of the families gave all of the participants the assurance that they could adjust to living with dialysis. They reported that their family, religious beliefs, and children were positive sources for living with dialysis. One participant with ESRD said,

I can handle it. Well more accept it . . . you do have to alter your lifestyle. I mean, going on dialysis, your life is not over. You don't have to hide under a rock and wait for death . . . You're still alive.

The overall sentiment of the family members was expressed as, "We are overcoming it [dialysis] and we will come out ahead." One family member said,

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

The family members perceived themselves as guardians and protectors of their loved ones with ESRD.

Table 1. Demographic Characteristics.

Characteristics of individual with ESRD (n = 15)	
Gender	
Female	7
Male	8
Marital status	
Married	6
Single/divorced/separated/widowed	9
Age	
21-40 years	4
41-60 years	6
≥61 years	5
Educational level	
≤H.S.	8
College and higher	7
Cause of ESRD	
Chronic glomerulonephritis	2
Diabetes	8
Hypertension/other diseases	5
Years on dialysis	
6 months-2 years	8
3-4 years	5
>5 years	2
Dialysis duration (median)	3 years (36 months)
Income	
≤\$20,000	11
\$21,000-\$60,000	3
\$61,000-\$80,000	0
≥\$81,000	1
Employed	
Yes	5
No	10
Generation status	
First-second	8
Third-fourth	7
Fifth-more	0
Acculturation level	
Level I-II	12
Level III-IV	3
Characteristics of family member (n = 15)	
Gender	
Female	14
Male	1
Marital status	
Married	11
Single/divorced/separated/widowed	2
Never married	2
Age	
21-40 years	7
41-60 years	6
≥61 years	2

(continued)

Table 1. (continued)

Characteristics of family member (n = 15)	
Educational level	
≤H.S.	9
College and higher	6
Income	
≤\$20,000	4
\$21,000-\$60,000	7
\$61,000-\$80,000	4
≥\$81,000	0
Employed	
Yes	8
No	7
Generation status	
First-second	12
Third-fourth	1
Fifth-more	2
Acculturation level	
Level I-II	13
Level III-IV	2
Family relationship	
Spouse/sibling	6
Child/grandchild	5
Mother/father/in-laws	4
Characteristics of health care providers (n = 6)	
Gender	
Male	3
Female	3
Worked in dialysis	
≤2 years	0
3-4 years	1
<5 years	5
Type of provider	
Nurse	4
Social worker	1
Physician	1

Note. ESRD = end-stage renal disease; H.S. = high school.

The hope of getting a transplant was another positive influence for adherence. The participants with ESRD and family saw a transplant as the key to returning to a normal life. Most viewed a transplant as regaining their freedom.

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

One respondent would not travel outside of the area for fear of missing the call for a transplant.

Obstacles to adherence. Perceived barriers were considered as obstacles to adhere to the dialysis regimen. The obstacles reported ranged from diet and fluid restrictions, bodily alterations, the dialysis procedures, and cultural values. For the participants with ESRD, the dialysis diet and fluid restrictions proved to be problematic for most of the participants. "It's hard because the foods that I like are the ones that I need to stay away from." One participant described the food choice as,

Well, for the diet restriction, when you pick up the list and look and think of all the vegetables that you can't have or aren't supposed to have . . . No I can't eat wheat bread I have to have white bread. Broccoli is off the list, spinach is off the list. Before I lost the use of my kidneys that wanted me to limit my intake of protein and now they want me to increase my protein. So, I eat a lot of chicken, fish and beef. I learned to eat fish, broiled or blackened rather than fired.

In terms of the fluid restrictions, a participant stated,

Liquids are probable the biggest problem I have . . . I just consume a lot of tea and coffee. So I have to limit those and it really gets me in trouble a lot on the weekends. I get that big glass of tea in front of me at a restaurant and the guy keeps refilling it and I keep drinking it and drinking. By Sunday afternoon I can tell and I'm looking forward to Monday morning when I can go in [to dialysis] and get some of the liquid out of me.

Because of the high content of potassium and phosphorus, traditional Mexican foods are a hurdle to dietary adherence.

Rice and beans, chicken, tortillas, that about it, pure Mexican food . . . when you're on dialysis you're not supposed to eat cheese or none of that, but I still do it. Yes, [it hard to comply] because you know everything around us down here has beans and cheese with the high phosphorous. It's hard to get away from all of that.

Non-adherence by the participants with the diet was described as more of a personal choice than cultural preference. A participant said, "I know they gave me a list of foods that I am supposed to eat but most of them I just don't like." Another said,

I don't follow the diet because I eat whatever my wife makes. She's from Mexico so all she does is Mexican food . . . She does try to cook the required foods but I'm just picky.

The bodily alternation necessary for dialysis was also recounted as a limitation for the individuals with ESRD. One participant described her experience after a catheter was placed in the peritoneal cavity. She stated,

I think it's just the physical thing of having a tube coming out of your body and having to deal with that because it's just bizarre

. . . my daughter came to take care of me and when she would change the dressing, I would just turn my head away and close my eyes because I don't want to see it. I didn't wanna to know what it looked like. I didn't want to touch it. I just can't do that yet.

Another talked about hiding the scarring and access point.

Every time that I go out now, I gotta wear long-sleeves because I don't want people to see my arm and say oh look at that guy what does he have in his arm, holes, little golf balls, or what?

The time spent dialyzing created mental stress. One said, "Well, it's hard to get there three times a week. It takes a lot out of me. I'm real tired after dialysis. The next day I feel better but then I have to go back to dialysis." Whereas a participant on peritoneal had a different view of dialysis.

Oh, every day is a dialysis day . . . hemo you're there in a chair for I don't know how many hours, how many times a week. You gotta stop your life and go to the clinic. For peritoneal, I hook up to the machine, I go to bed, I go to sleep, I wake up and it's over. It's taken virtually no time out of my day so . . . I can still do everything else I did before with of course limitations, because I do tire easily . . .

For family members, communicating with health care providers, adjusting to the dialysis schedule, and adhering to the dietary and fluid restrictions were necessary obstacles to keep the individuals with ESRD alive. Communication between the family and health care providers was strained once dialysis started. One family member commented,

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

Information given to the individual with ESRD during the dialysis session was a concern.

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

The dialysis schedule was also problematic for the family. The treatment sessions interfered with their work schedules or other family commitments. One family member describes how she spends her time when her husband is on dialysis at 5:00 am in the morning.

Well, that's a little after 5:00 in the morning and Wal Mart is open. I go there and get my groceries and look around the store . . . then I come home and do things around the house or yard or whatever I need to do. Then I go back and pick him up about 9:30 or 10:00. When we come home, I fix him breakfast again.

Then my granddaughter comes. She feeds him lunch whenever he wants it . . . We watch TV programs and stuff. Before you know it, another day is gone.

Those family members who worked recounted how their work schedule revolved around the dialysis session.

About 10:30 am, I leave work and come over to get her [mother] ready for dialysis. Take her to dialysis. Once we get into the dialysis room, I set mom up . . . with her earphones and turn on the TV. Then I go back to work. Then at 3:00 pm I go back to the center. After 4:00 pm, I get her [mother] something to eat and then bring her home.

The family must also adhere to the restrictions on food and fluid. Eating habits, grocery shopping, and food preparation were identified as a complication for the family. One talked about the changes in her family eating habits to ensure adherence.

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

Another said,

I changed because there are things that he cannot eat, like chips and bananas so, I don't buy them at all so he won't see them. I don't buy cheese so he won't see the cheese and I don't eat it either. Things that he cannot eat I really don't buy . . . I used to eat a lot of spinach and they told him not to eat spinach anymore . . . I don't even eat the beans . . . I have made a lot of sacrifice . . .

Cultural values. A variety of cultural values were attributed to difficulty in adhering to dialysis for this population. The health care providers identified the cultural aspect of *machismo* as it related to the role of the male as “the provider” in the family unit. One nurse said,

The men think if all of a sudden they're not the main provider, they're not the man of the house. They watch others do all the things they used to do . . . “I have to be the man. I have to be in control.” That's the biggest thing I see in the Mexican American culture with their compliance.

Another attribute was cultural views toward death and a fatalistic acceptance of God's will (Fernandez et al., 2009). One participant with ESRD talked about the reactions she received:

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

One nurse explained,

When asked why they are not taking their prescriptions, they'll say, “Well, I am going to die anyway” They don't think that they should try to better their quality of life for whatever amount of time they have life.

Curanderismo (folk healing) was mentioned by one participant with ESRD as a cultural obstruction. He stated,

Some of the older Hispanics from Mexico . . . have a tendency to believe in spells and things like that so nothing will hurt you. They believe there are herbals and teas that can lower your blood pressure or to start your kidney function again or cure diabetes. And when you are looking for anything to help, your belief is to give that a try . . .

Daily activity losses. Perceived susceptibility covered the daily activity losses. As a result of the inability to control the course of dialysis, diminished physical strength, persistent fatigue, weakness, and medical complications created a sense of loss—loss of freedom, loss of time, loss of choice, loss of participation in valued activities, and loss of life. The participants with ESRD talked about cramping, sudden drops in blood pressure, nausea and headaches, and physical discomfort during dialysis. One participant described it as follows:

The first day that I was put on dialysis, I cried for 4 hours. They were giving me medication because [I was] getting nausea, anxious, and wanting to pull out the needles, it was bad. They let my daughter stay with me for the first two days.

A participant on peritoneal dialysis explained how enduring severe peritonitis created a loss for her.

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

Many of the participants described how the physical limitations led to loss of their daily activities. “I'm too weak or too tired to participate in daily activities.” “I used to dance a lot. But I'm too weak for dancing.” “It makes me mad because I can't do a lot of things. I liked attending church now I can't go.” One participant talked about vacations:

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

The physiological effects led to disruption in the individual's ability to work.

Since I've been on dialysis, as far as working, it's hard. The doctor has restricted what I can and can't do. He restricted me because I can't have anything damage my access [fistula]. With the restrictions I really can't do what I used to do or what I want to do because it either raises my blood pressure or it's to physical for my access.

The family members described a loss of free time and career choices. Having a loved one on dialysis forced the family members to change their sources of livelihood. For some, they became the primary wage earner of the family.

I was going to school . . . I moved down here a couple of years ago when he [Dad] went on dialysis. Shortly afterward I told him that I would help out with the business since he would be out of work for three days each week . . . He has a laptop that he takes to dialysis . . . We email back and forth and call each other constantly.

The family members reported minimal to no free time. The demand of their families and the individual on dialysis appeared to leave no time to pursue leisure activities.

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

Fear of Living With Dialysis

Perceived severity and perceived threats revealed fears about living with dialysis and risks to family members. Several participants recounted experiences in which they were “near death,” “could have died,” or “would die” if they did not start dialysis. One participant said, “It's hard to be between life and death all the time. I'm always between life and death, always in the middle.” With heightened awareness and increased sensitivity to the prospect of death, direct observations of fellow patients were a constant reminder of their own mortality and risk of the same fate.

We're all like a big family [dialysis patients]. Somebody doesn't show up or they're late for the shift, “What happened to this person?” And if somebody passes away, oh God, everybody feels it, everybody that's in that shift, everybody.

The possibility of dialysis becoming the fate of their children and other family members was unbearable for most of the individuals with ESRD and family members.

I'm very afraid for my daughter. Any little pain that she gets here or there . . . and every time she tells me that something hurts I take her to the doctor. And sometimes my sisters tell me not to exaggerate it, but I say nobody knows how I feel and it scares me because she everything that I have, she the only thing that I have, she's my life.

One family member with a family history of diabetes stated,

It runs in the family. So I am concerned. Diabetes runs in our family . . . mom has diabetes; my dad has diabetes; and my grandmother is on dialysis from diabetes. It doesn't look good for us.

All the participants encourage lifestyle changes such as stop drinking, exercise more, and have frequent medical check-ups to family members, children and grandchildren, or anyone who would listen.

Health Care Providers

Health care providers give the patients constant reminders to comply (cue to action). Several of the providers verbalized difficulties in maintaining their professionalism with this population.

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

The intimate and intensive interactions between the provider and the individual with ESRD and family members pushed professional boundaries and led to burn-out for some providers. The social worker said,

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

The health care providers identified communication and education as determinants of adherence by Mexican Americans. “We have a high proportion of patients who don't speak English. They expect you to be able to communicate and give them the information in Spanish.” A provider noted,

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

The providers voiced concern about this population's understanding of the health information given. One provider said,

The population in this area, especially the age of people who are dialyzed here, their education is not of a high . . . how can you educate somebody when a lot of them can't read? A lot of them

don't understand what you're trying to tell them. You're trying to put into basic words about their medicine, but you can only go so far in being basic so people can understand, and some people don't understand.

Educating about renal replacement options was felt to be a strategy to increase adherence. Pre-dialysis education has been identified in the literature as having a beneficial effect (Thomas, 2007). The physician also felt this was of value. He stated,

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

One provider voiced,

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

In contrast, one health care provider felt that nothing will change even with pre-education:

They are not going to change. If you educate them, they're always going to tell you what you want to hear, and the minute they leave the building, they'll go back to doing what they want to do . . . They're going to live their life the way they want to live their life.

When asked about reasons for non-adherence for this population, the health care providers offered a variety of motives—denial of the condition, lack of finances to comply, and inconvenienced transportation service. One stated, "One of the things we see all the time is that they're in denial. They don't believe the bad things we tell them can happen to them until it affects somebody they know or it affects them."

In terms of funds, one nurse stated, "They don't have the finances to comply with the diet, to get the medications they need . . . All of those things cost money and these people don't have money to spare." Another provider articulated the transportation situation:

Even though we have transportation available, they have to wait so long to get picked up after their treatment. And they're picked up two or three hours before their scheduled time so they sit in our lobby for two hours waiting because of the public transportation . . . people have to be inconvenienced unnecessarily for long periods of time. They don't want to deal with that because they're in pain, they're uncomfortable, they're weak, they're tired, and they don't feel good.

Discussion

This study was conducted to examine the perceptions of Mexican Americans living with dialysis and their influence

on adherence behaviors within the framework of the Health Belief Model (See Figure 1). When looking at illness and treatment perceptions, the finding from this study is similar to one by Jansen et al. (2013) that looked at individuals with ESRD. They found that patients on dialysis believe more strongly that their treatment controls their illness and perceive more consequences of their illness. In this sample, individuals with ESRD understand that dialysis keep them alive, although they dislike the time spent dialyzing, bodily alternations, frequency of the sessions, and medical complications. The conditions and deaths of fellow patients compel them to confront not only the effects of illness-related changes but also their own mortality (Molzahn et al., 2012). Previous studies have indicated that most dialysis patients do not comply with their diet and fluid restrictions (Kara et al., 2007; Kugler, Vlaminc, Haverich, & Maes, 2005). Kim and Evangelista (2010) found that negative illness perceptions were associated with low adherence rates to medication and fluid and diet restriction among patients with ESRD on hemodialysis. Their results suggest that specific adherence behaviors can affect clinical outcomes; however, illness perceptions did not predict any clinical outcomes in patients on hemodialysis. Not liking the allowable foods was the reason given for non-adherence with the diet and fluid restrictions by the participants in this study. Several studies have found lack of preparation and pre-education prior to renal replacement therapy (RRT) to be causes of non-adherence among dialysis patients (Thomas, 2007). DePasquale et al. (2013) found that early educational resources on RRT could help patients and their families select options closely aligned with their values. The family members and health care providers in this study identified a lack of pre-education about dialysis as a barrier. Family members want to know about the dialysis process and regimen and how to adhere to the diet and fluid restrictions. Several indicated that their perceptions about dialysis were based on what they had heard from other people.

The health care providers in this study feel that denial of the health condition and lack of financial resources are major causes of non-adherence among this Mexican American sample. Based on the demographic findings of this study, most of the participants were of low socioeconomic status, unemployed, and low educational level. Tareen et al. (2005) concluded that poverty and low levels of educational attainment were strong predictors for the development and progression of ESRD among African Americans and Mexican Americans. Kim et al. (2012) found in their study of racial/ethnic difference in illness perceptions in minority patients on dialysis that poverty created a negative emotional perception about the illness among Hispanics. Hispanics females did not understand their kidney or symptoms related to ESRD as compared with Hispanic males. Also, those with high emotional distress had low understanding of their medical condition. The health care providers also acknowledge that language is a barrier in their communication with this

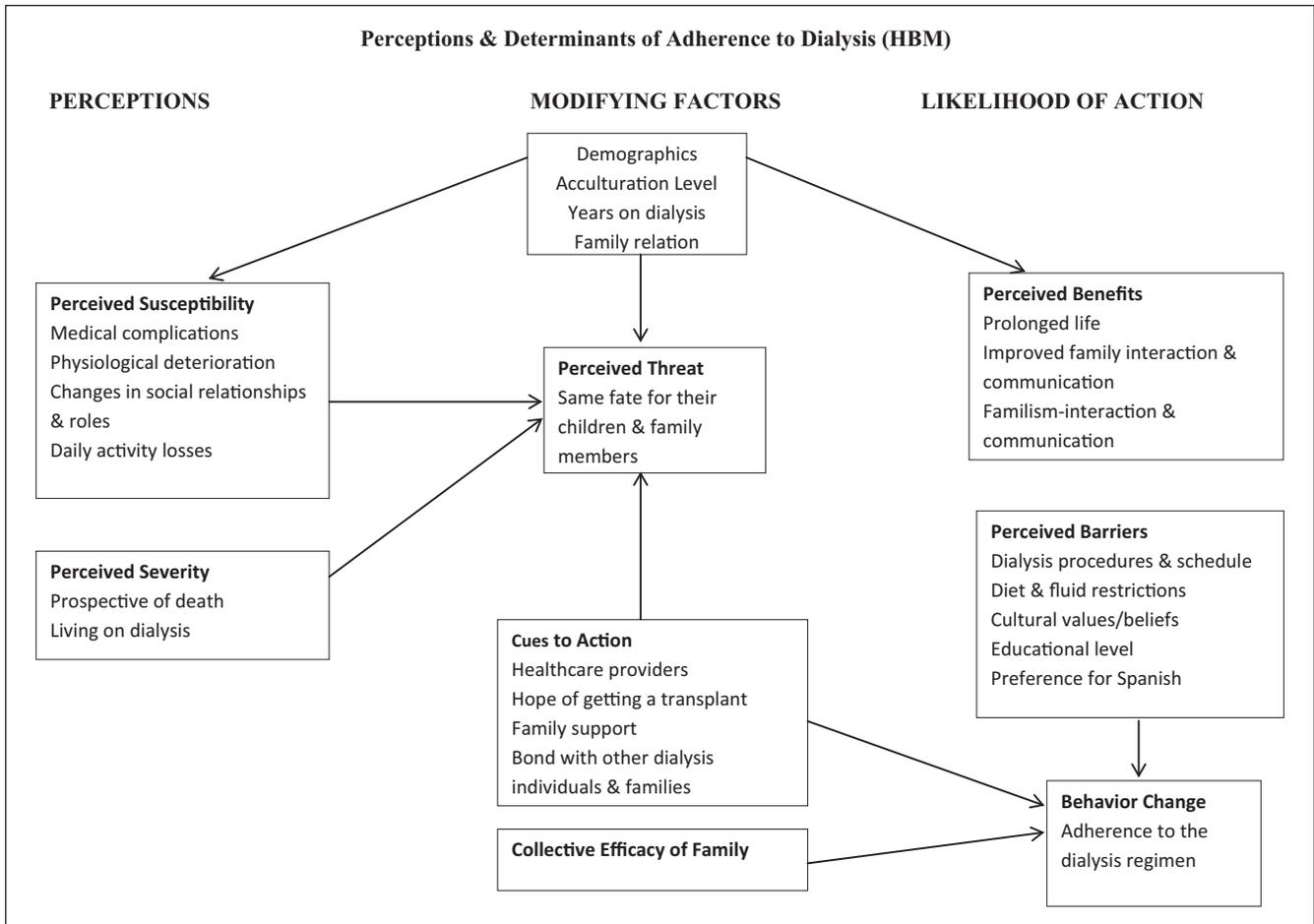


Figure 1. Health belief model.

group because of their own lack of fluency in Spanish. Patients are often unwilling or unable to communicate to their health care providers if they do not understand or speak English well and are unable to explain their symptoms or understand their diagnoses (Fiscella, Franks, & Doescher, 2002). Andr s-Hyman, Ortiz, A nez, Paris, and Davidson (2006) recognize when treating native Spanish speaking patients, certain sentiments are difficult to adequately convey in another language, many words and concepts do not exist or share the same meaning, and information distortion may occur because of differences in dialect.

These findings indicate that several cultural factors may influence the adherence of this population. *Familism* engenders a strong sense of family care and obligation, which leads to family taking care of the sick even when it is a burden. The effect of *familism* in the present study is consistent with previous research (Fernandez et al., 2009; Kao, McHugh, & Travis, 2007). Min and Barrio (2009) found that fewer Mexican American elders than non-Latino White elders preferred to rely on formal/professional caregivers, and a greater proportion of Mexican American than non-Latino White

elders preferred to rely on informal caregivers. The participants in this sample described the family, including the extended family, as a source of support and reason for changing and adhering to the dialysis regimen. The views of *machismo*, extolling the male virtues of responsibility to family and community, honor, and humility, are another cultural factor identified. Fernandez et al. (2009) found positive attributes associated with *machismo* such as taking responsibility for family health issues and being a knowledgeable caretaker in their study of human papilloma virus (HPV) infection among Hispanic men and women living on the Texas-Mexican border. Their research documented how the Hispanic men's cultural obligation to be healthy can serve to instigate health care-seeking behavior. Several of the male participants in the current study described their loss of these positive attributes such as the role of primary wage earner being turned over to the wife or son and becoming the recipient of physical and emotional support from the family. The concept of *fatalismo* (pre-determinism or pessimism about the probability of surviving disease) in this study is consistent with studies about *fatalismo* and cancer (Florez et al.

2009). Fernandez et al. (2009) found that Hispanic women imagined that a diagnosis of HPV was equivalent to a diagnosis of cervical cancer, and to them, this meant certain death. Kim et al. (2012) found that Hispanics had negative perceptions about their ability to control their illness. Those who believed their illness was chronic had lower expectations of treatment efficacy, more physical complaints, and perceived higher adverse consequences from their illness. Several participants in this study discussed the equivalent of being on dialysis and certain death. The use of folk healing (*curanderismo*) practices is only mentioned as a possible reason for non-adherence. Various studies have consistently found an integration of cultural strategies with conventional health methods (Padilla, 2007).

The ESRD literature suggests that family support and involvement are major predictors of adherence with the dialysis regimen by individuals with ESRD (Kara et al., 2007; Morton, et al., 2012). The family members in this study played an important role in assuring the adherence of individuals with ESRD. The family unit including close friends and neighbors was an important force who collectively took action to provide psychosocial, physical, and economic support to the person on dialysis. This description of collective efficacy is most similar to Bandura's social cognitive theory (Bandura, Caprara, Barbaranelli, Regalia, & Scabini, 2011) construct of perceived collective efficacy rather than perceived self-efficacy of the HBM (Simons-Morton et al., 2012). The results of a study by Beanlands et al. (2005) highlighted the experiences of caregiving for adults on dialysis. They described abilities and activities related to managing the illness and its treatment, supporting the demands of ESRD and dialysis, motivating self-care efforts, and preserving a sense of self-worth. In addition, they described activities designed to balance the demands of caregiving with other responsibilities. The stress associated with living with dialysis can be minimized by the family dynamics and communication (Kara et al., 2007; Padilla, 2007). The present study suggests that the collective efficacy among the family is a major determinant for living with dialysis and ESRD and contributes to the evidence that family-centered care can alert providers to cultural beliefs that are likely to compromise or facilitate adherence to the dialysis regimen. This is consistent with previous research among Korean American elders, an ethnic group also known for their collectivistic cultural orientation (Min, 2005).

Study Limitations

Findings from this study should be interpreted with the following limitations in mind. First, the experiences of Mexican Americans living along the U.S.–Mexico border may not generalize to experiences of other individuals with ESRD and their families. The small sample size limits generalization of the results. A larger and diverse sample may be needed

to describe perceptions and adherence behaviors to different geographic areas or other racial/ethnic groups. Second, certain perceptions may have been underreported or unreported. Finally, only one family member was asked to participate in the study. The perspectives of the family members chosen may differ from the viewpoints of the non-participants. Therefore, further research is required to verify cultural factors and their relationship to perceptions and adherence to treatment for patients with ESRD and their families.

Conclusion and Clinical Implications

This study offered information on the perceptions of Mexican Americans living with dialysis, their family members, and health care providers who care for them using the HBM. The findings indicate that non-adherence with the dialysis regimen may be due to denial of the condition, concerns involving loss of freedom, loss of time, and loss of valued daily activities, or cultural factors and beliefs. These findings highlight the importance of intervention approaches that focus on prevention and education, use of the collective efficacy of the family, and inclusion of cultural underpinnings. Intervention should consist of the individual's and family's treatment expectations and their level of adherence to traditional values and gender roles. Consideration should be given to socioeconomic concerns and faith as a coping skill. Giving realistic information and providing tools for incorporating the illness and the dialysis treatment into daily life may promote adherence. Educational resources should be tailored to address factors that the patients and families deem important, that meet the level of patients' educational attainment, and that are in their primary language. Care for this population should be coordinated in partnerships between the health care providers, individuals with ESRD, and family members. The current study provides useful information for developing and testing culturally sensitive approaches to improve outcomes in the dialysis population. Research on the relationship between perceptions, cultural factors, and treatment adherence is warranted.

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