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Shirley A. Wells

The University of Texas Rio Grande Valley, shirley.wells@utrgv.edu

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RESEARCH ARTICLE

Occupational Deprivation or Occupational Adaptation of Mexican Americans on Renal Dialysis

Shirley A. Wells*†

Occupational Therapy Department, The University of Texas–Pan American, Edinburg, Texas, USA

Abstract

The aim of this study was to explore the occupational changes and perceptions experienced by Mexican Americans with end-stage renal disease (ESRD) and their families living with dialysis. In-depth interviews were conducted with 17 Mexican Americans with ESRD and 17 family members. The participants with ESRD described altered or lost activity patterns, capacities and freedoms. With a heightened awareness of death, the family members made altered occupational choices, which were consistent with their cultural values. Changes in the physical body, adhering to the dialysis regimen and environmental restrictions created barriers to occupational participation. These findings suggest that living with dialysis facilitate occupational deprivation among individuals with ESRD and adaption among the family members within cultural alignments. This phenomenon could affect the design of occupational therapy intervention and call for research on the role of occupation therapy services with this population. Copyright © 2015 John Wiley & Sons, Ltd.

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Keywords
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*Correspondence
Shirley A. Wells, DrPH, OTR, FAOTA, Chair & Associate Professor, Occupational Therapy Department, The University of Texas–Pan American, 1201 West University Drive, Edinburg, Texas 78539-2999, USA.
†Email: sammiew@earthlink.net or wellssa@utpa.edu

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Introduction

End-stage renal disease (ESRD) is a chronic and debilitating condition that requires everyday adherence and changes to accept living with dialysis. Globally, the reported incident rates of ESRD have slowed in some countries, while rising or remaining stable in others. The United States continues to rank among the highest in the world because of high rates of diabetes, high blood pressure and obesity among its population with the prevalence of renal disease being approximately 1.924 per million (United States Renal Data System [USRDS], 2013). Kidney failure is also more likely to occur among ethnic and racial groups—4.4 times among African Americans, 1.6 times among American Indians/Alaska Natives and 1.4 times among Asian Americans. By ethnicity, Hispanics have 1.5 times the risk of developing ESRD than non-Hispanics (ESRD Network, 2013).

End-stage renal disease necessitates everyday adherence and adaptations to live with dialysis. Individuals must adhere to prescribed medical, dietary and fluid restrictions. Failure to do so can lead to bone demineralization, congestive heart failure and death (Sud et al., 2014). Individuals receiving dialysis spend 3–5 hours per session three times each week attached to a dialysis machine. Missing one or more dialysis sessions or shortening one session by more than 10 minutes foretells a decrease in survival and an increased risk of death (Flythe et al., 2012). Up to 60% of individuals...
on dialysis may experience episodes of depression (Weisbord et al., 2014). Caregivers, spouses, family and friends bear the increasing financial and human resources burdens to care for the individual with ESRD. Personal satisfaction for the caregivers is seeing an improvement in their loved one’s well-being and knowing their efforts have contributed to that improvement (DePasquale et al., 2013).

**Occupation deprivation and adaptation**

Everyday life is carried out through a myriad of occupations embedded in a variety of contexts – cultural, physical, social, personal, temporal and spiritual realities (Christiansen and Townsend, 2010). When individuals are engaged in occupations that meet their needs and interests, their lives are assumed to be in balance and satisfaction and quality of life are influenced (Matuska and Christiansen, 2009). Health conditions influence what people are able to do and whether or not they can create a satisfactory balance of activities in their lives. People who have acquired a chronic condition may suffer from occupational deprivation or disruption (Whiteford, 2010). Individuals who have ESRD are deprived of occupational choice because of circumstances beyond their immediate control. Their condition often dictates what their activity options are for any given day (Weisbord et al., 2014).

Adaptation theories postulate that adaptation is triggered by change in the individual’s experience, the demands of the environment, the roles that individuals occupy in society and the close relationships of people and their purpose (Schilling et al., 2011). Individuals who use conscious awareness, self-reflection and choice to create human and environmental integration experience the process of adaptation. Christiansen and Townsend (2010) defined occupational adaptation as the “adjustments and changes in the methods, tools, locations, and other forces that determine participation in occupations by individuals, groups, and communities” (p. 420). The concept of adaptation means moving towards a fit between the individual and the demands of the environment.

**Cultural values**

Acculturation is a process in which members of one cultural group adopt the beliefs and behaviours of another group. Studies have shown that acculturative changes have influenced health-related outcomes and behaviours (Ramos-Sánchez and Atkinson, 2009; Ghaddar et al., 2010). Horevitz and Organista (2012) found that for people of Mexican descent, the more time in the U.S. often means the eroding of protective factors such as close knit and supportive families and traditional cultural values.

Various values within the Mexican American culture have been found to influence observable health behaviours. Familismo is the belief that family at all levels – nuclear, extended and fictive kin – are central to one’s life. It is a multigenerational value of shared expectations, emotional bonds, traditions, rules and obligations (Kao and An, 2012). Machismo, a strong sense of masculine pride, has been characterized by a set of traditional attitudes, behaviours and gender role with negative and positive aspects (Fernandeza et al., 2009). The belief in a greater power, religiosity, has been linked to prayer and healing. Closely related to this is fatalismo, which has been described as external locus of control. This belief has limited one’s responsibility for adherence to a health care regimen because God would be controlling the outcomes (Kim et al., 2012; Barber, 2014).

**Purpose**

With the prevalence of this condition, understanding the occupational changes experienced by Mexican Americans with ESRD was imperative. There has been a scarcity of studies in the literature on occupations undertaken with people with ESRD and the role of occupational therapy with this population. Therefore, this study examined the occupational configuration of individuals with ESRD and family members from the perspective of Mexican Americans. The specific study questions were as follows: (1) How have Mexican Americans with ESRD and their family members perceived living with dialysis? (2) What is the relationship between cultural values and living with ESRD and dialysis? (3) How has ESRD changed the occupational participation and performance?

**Methods**

**Subjects**

A phenomenological approach was chosen to understand the occupational changes and the role of culture and contexts that influenced the lived experience of dialysis on clients with ESRD. Several strategies – snowballing, networking and flyers – were used to recruit participants.
Local contact persons in three in-centre facilities and a nephrologist’s practice identified adult patients and their families who met the study inclusion criteria: (1) diagnosis of ESRD for 6 months or more living with dialysis; (2) a family member who may or may not be the primary caregiver; and (3) a resident of Cameron County, Texas. Potential participants were contacted by the researcher team who arranged the interview and obtained full consent. The final sample consisted of 17 Mexican Americans with ESRD and 17 family members. Many potential participants were reluctant to take part in the study because of the uncertainty of their medical condition, conflicting doctors’ appointments or not feeling well. The University of Texas Health Sciences Center at Houston Institutional Review Board (IRB) approved the study.

Methods

Data were collected through semi-structured interviews, lasting from 45 to 90 minutes. Interviews in English were conducted by the study investigator. An experienced interviewer who had completed a formal training program at University of Texas Health Sciences Center at Houston School of Public Health conducted interviews in Spanish with the Spanish-speakers. Interviews were conducted at the participant’s home or dialysis centre and in the preferred language of the participant. All interviews were tape-recorded, and field notes of non-verbal and contextual observations were documented.

Sociodemographic data were collected via a questionnaire. The Acculturation Rating Scale for Mexican Americans–II (Cuellar et al., 1995), a 30-item revised scale, was used to determine the participants’ acculturation and generational level. It measured the extent to which individuals embraced the Mexican and Anglo culture independently. The validation sample consisted of 379 undergraduates including Mexicans, Mexican Americans and non-Hispanic Whites. An example of two questions would be “I like to identify myself as…” and “My thinking is done in the English/Spanish language” with a rating scale of 1–5 with 1 being not at all and 5 being extremely often or almost always. The two subscales have good internal reliability (0.86 and 0.88) and a Pearson correlation coefficient ($r = 0.89$) with the original scale.

Data analysis

Verbatim transcriptions were created from all audiotapes. The six interviews conducted in Spanish were transcribed in Spanish then translated into English by an experienced bilingual interviewer. Reverse translation by another individual was used to ensure accuracy of the Spanish translation prior to coding. ATLAS.ti 6.2 statistical software was used for the thematic coding and analysis. Each transcript was coded independently using line-by-line coding and memos. Codes were organized into themes and continued until data triangulation had been reached. The overarching themes that emerged were loss of freedom, heightened awareness of death and obstacles to occupational performance. Cultural values and beliefs were identified directly from the participants’ narratives. The Acculturation Rating Scale for Mexican Americans–II was administered and scored according to the instrument.

Results

Overview

The demographic characteristics and acculturation levels of the participants are presented in Table I. The participants with ESRD primarily received in-centre hemodialysis. The length of time on dialysis ranged from 6 to 132 months. The family members were primarily female and evenly divided between those who worked outside of the home and those who did not. The participants were extremely oriented to the Mexican culture in terms of preference, language use and ethnic identification.

Loss of freedom: individuals with end-stage renal disease

The participants with ESRD reported significant loss and uncertainty associated with ESRD and dialysis. Loss was described in the domains of career and work choices, engagement in pleasurable activities, interactions with family and friend and travel. Dialysis directly impacted their work schedule, career choice and income. One participant said, “I work 20 hours a week. On a good week, I can put in 30 hours”. The loss of income interfered with the participants’ ability to be self-sufficient and independent. Another stated, “Well, the major thing that it [dialysis] changed for me is my job. As a trucker, I used to make $1,000 a week and now it’s like $1,000 every month and half”.

Dialysis eliminated spontaneous decisions to do something for fun and compelled the participants to...
plan pleasurable activities. A decrease in the frequency of these activities was reported.

I can’t go swimming. I can’t even take a bubble bath… that was hard to give up too. Of course that was always my refuge, a nice hot tub, but I can’t be submerged in water, so no more of that. I can’t even go down and have a swim at the beach so no more of that…

Social activities with friends were feared because they did not want to explain to others about their dialysis. Many participants avoided social activities and interaction with friends all together.

I mean alcohol is out. We will go on trips, conferences and in-services. Usually the first night we get there, let’s go find a bar. I’m like, “Thanks but no thanks.” And they’re saying, “Aren’t you gonna come?” And I’m like no, because …you have to explain why you’re only drinking iced tea.

Travelling was another freedom lost. Many did not want to make the arrangements necessary for temporary dialysis in another facility. Fear of missing an opportunity to obtain a kidney transplant was also a reason given for not travelling.

Traveling, oh my God, that’s just not getting on a plane anymore, I mean you have to plan in advance so the dialysis company can deliver your stuff to the place you’re going… Life is complicated now.

Heightened awareness of death: family members

The routines of the family members were determined by the needs of their loved one and fear of their death. The family members’ responsibilities involved handling and managing the loved one’s finances and household as well as ensuring their adherence with dietary restrictions. A participant stated, “The most important thing I have to do every day is taking care of him, making sure he has his food and something to drink, and making sure he’s taken all his medications”.

The family members talked about making career changes and physically relocating to care for their loved one. One participant changed her life to care for her father.

I was living in Corpus [Christi, Texas] and going to school… I moved down here a couple of years ago when he went on dialysis. Shorty afterward I told him that I would help out with the business, since he would be out of work you know for three days each week.

They also reported minimal to no free time for themselves.
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 [for me].

For some families, the relationship and communication between family members and loved one became stronger with dialysis. One said, “I’ve noticed the communication between me and my sister has improved a lot. We are communicating more. We do communicate for my mom”.

Cultural values

Cultural values challenged how living with ESRD and dialysis was perceived. The participants with ESRD cited cultural food and machismo as obstacles to their occupational engagement. Traditional Mexican foods tend to be high in sodium, potassium and phosphorus, which are restricted in the renal diet (National Kidney Foundation, 2014). Non-adherence by the participants with the diet was reported as more of a personal choice than cultural preference.

I don’t follow the diet because I eat whatever my wife makes. She does try to cook the required foods but I’m picky. Rice and beans, chicken, tortillas, that’s about it, pure Mexican food.

The male participants acknowledged the positive idea of machismo as someone who is caring, responsible, decisive, strong of character and the protector of the family (Fernandez et al., 2009) was a challenge to maintain. Because they were no longer the primary wage earner, the power granted in the traditional patriarchal structure was turned over to the wife or son.

Family members cited familismo and religiosity as facilitators of their occupational adaptations. They made their own occupational adaptations and altered their choices in order to care for their loved one on dialysis.

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

The participants with ESRD reported that knowledge of death and conditions of fellow patients were a constant reminder of their own mortality and risk of the same fate.

There’s something about the Mexican people thinking that like people go on dialysis and they die… because when we first went to the center… they had a big photo album in the waiting room…And it was all the obituaries of all the people that got sick that died…it had all the people who had gone to the center that died.

Several of the family members voiced their inability to control the illness. This was consistent with the “fatalistic” acceptance of God’s will and belief that control is outside and not within the individual.

Obstacles to occupational performance

Three prominent factors emerged as obstacles to engagement in occupations: body alteration, physiological effects of ESRD and the dialysis schedule. The input of a fistula and scarring from undergoing dialysis prompted changes in lifestyle. Some of the participants reported wearing only long-sleeved shirts.

I gotta wear long-sleeve because I don’t want people to see my arm and say oh look at that guy what does he have on his arm, holes or what? … A friend said to me “Hey I saw this guy with these little balls on his arm… it was ugly”.

One described the reactions he receives when others see his dialysis site.

When they see my fistula they go, “What’s that?” And I say that’s where I do dialysis and my other arm is all small compared to this one with all the scar marks …when I go through a drive-thru or hand them the money, they stare at it but I just try not to think about it.
Undergoing in-centre hemodialysis for 3–4 hours, three times per week prevented them from doing what they wanted to do, when they wanted to do it, how they wanted to do it and when they needed to do it. The participants experienced diminished physical capabilities because of weakness, fatigue and dizziness after the dialysis session. One participant said, “I feel light-headed and dizzy after dialysis. But as long as I take an hour nap afterward, I can get [up] and go”.

For the family members, lack of information or pre-education about dialysis was identified as another obstacle. Most indicated that their perceptions about dialysis were based on what they had heard from other people. One participant stated, “I had a friend who had a friend on dialysis…they told me how hard it was”. They did not know what to expect or what was performed until they got to the centre. One family member was so stressed out about her lack of information that she had to be hospitalized. “I was thinking. “What will I do?” I didn’t know anything about dialysis. I had no hint, no idea, what it was going to be like. It was just so different than him being a diabetic.

Mexican American families tended to rely on their extended family network for health information (Ghaddar et al., 2010). One family member said, “I rely on my son, who is taking nursing courses at this time, to provide us with information”.

Discussion

This study was conducted to describe the occupational changes and perceptions of Mexican American and their family members living with ESRD and dialysis. Based on the findings, the individuals with ESRD viewed living with dialysis as facilitating occupational deprivation. They described altered activity patterns, disrupted time use, decrease capacities and loss of self-identity and freedom. Ongoing fatigue, multiple medical appointments and the dialysis schedule restricted culture and meaningful occupations (Chau et al., 2003; Nussbaum and Garcia, 2009). Mariotti and Rocha de Carvalho (2011) found in their comparison study of 60 hemodialysis patients improvement in pain and emotional and mental health among the group that received the occupational therapy (OT) program. They concluded that to improve quality of life, OT may be included in the therapeutic approach with dialysis patients.

With a heightened perception of death for their loved ones, the family members viewed their occupational adaptions as being necessary and consistent with their cultural values. The family members altered their occupational choices with many combining caregiving and employment responsibilities (Min and Barrio, 2009). The effect of familismo was consistent with previous research about families and the dialysis regimen (Morton et al., 2012; DePasquale et al., 2013). The positive attributes of machismo being turned over to the wife or son was in keeping with the study of Fernandeza et al. (2009) of Hispanics men and women living on the Texas–Mexico border. The view of dialysis as a death sentence was supported by the findings of Kim and Evangelista (2010) that negative illness perceptions have been associated with increased morbidity and mortality and decreased quality of life among hemodialysis patients. Jansen et al. (2013) found that patients on dialysis believed that their treatment controlled their illness and lives. This study implies that cultural values may affect occupational choices, barriers and health-related behaviours of Mexican Americans (Gorman et al., 2010).

Several studies have found that disease adherence and acceptance could be enhanced by increasing the knowledge about the disease and treatment pre-dialysis (Thomas, 2007). This was in line with the barrier – lack of knowledge – identified by the participants in this study. Educational resources and more time with health care providers may help patients and their families select options closely aligned with their personal and cultural values and improve their sense of control, psychological adjustment and communication (DePasquale et al., 2013).

Relevance to clinical practice

This study has highlighted some of the occupational challenges when living with ESRD and dialysis. Chronic illness has a broad impact on the occupational performance and productivity of individuals and family members (Christiansen and Townsend, 2010). With the rapidly increasing number of people on dialysis (USRDS, 2013), OT intervention should focus on prevention and reduction of deprivation and promotion of adaption. Practitioners can engage clients in
occupation-based activities for self-expression and leisure, advice on energy conservation to maximize their physical functioning and recommendations on home modification to reduce hazard (Mariotti and Rocha de Carvalho, 2011). A program of aerobic training and strength building during dialysis or a daily home-based program can be carried out safely with proper supervision and patient education (Rossi et al., 2014). Customized seating aids and adaptive equipment may reduce the impact of immobility for long sessions (Farragher and Jassal, 2012). Targeting Activities of Daily Living (ADL) for intervention is important. McAdams-Darco et al. (2012) found measuring an individual’s ability to perform ADLs pre-dialysis and post-dialysis may be a tool for identifying individuals undergoing dialysis who are at high risk of dying.

Funding for dialysis services has limited the offering of physical and occupational therapy services to clients. Dialysis administrators and nephrologists have a role in highlighting the benefits of these programs, as part of routine care, in order to encourage referrals and funding (Bennett et al., 2010).

This study contributed to the evidence that family-centred care for dialysis patients can alert providers to cultural values that are likely to compromise or facilitate adherence to the dialysis regimen. Practitioners may need to facilitate cultural patterns that fare successfully within families (Gorman et al., 2010). Reducing stress and improving the emotional and psychological well-being of caregivers who are caring for a family member with high levels of impairment should be a focus of intervention (Rote et al., 2014). Occupational therapists may help the family members before and after to understand the procedures and requirements of dialysis (Chau et al., 2003).

**Limitations and recommendations for further research**

Although qualitative research cannot be generalized, there is a growing reality of individuals and families living with the confines of ESRD and dialysis who experience occupational deprivation and adaptation. Future research should explore the link between occupational deprivation and adaptation in individuals with ESRD and their family members.

Moreover, efficacy studies would be essential to establish the role of occupational therapy services for this condition and population.

**Conclusion**

The participants in this study described the comorbidities that increased mortality and functional limitations, the loss of self-identity and freedoms and emphasized how dialysis necessitated environmental modifications or changes in routines. The results suggested that the experience of renal dialysis impedes previous levels of occupational participation and social interaction. From the findings, it appears that living with dialysis facilitated occupational deprivation among the individuals with ESRD and occupational adaptation among the family members within a cultural configuration.

**Conflict of interest**

The authors declare no conflict of interest.

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