



Published in final edited form as:

Nephrol Nurs J. 2013 ; 40(2): 113–123.

The Experience and Self-Management of Fatigue in Hemodialysis Patients

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Abstract

Fatigue is a common and debilitating symptom for adult patients with end stage renal disease on hemodialysis and has been associated with decreased survival and quality of life. Patients on hemodialysis must find ways to manage their fatigue and mitigate its effects on their lives. Currently, there is no description of the experience of fatigue for patients on hemodialysis living in the U.S., nor is there any description of the ways in which they manage their fatigue. The purpose of this qualitative descriptive work was to describe the experience and self-management of fatigue. Several themes were identified which included: the nature of fatigue, management of fatigue, consequences of fatigue, and factors associated with fatigue. This information will be valuable to nephrology nurses as they continue to care for and educate patients on hemodialysis.

Keywords

fatigue; hemodialysis; experience of fatigue; self-management of fatigue

Introduction

Chronic kidney disease (CKD) is often unpredictable and patients may not feel ill as the disease progresses to end stage renal disease (ESRD), an illness that affects over 593,000 people in the U.S. (United States Renal Data System [USRDS], 2012), and requires dialysis (hemodialysis or peritoneal dialysis) or kidney transplant. Patients on hemodialysis account for approximately 92% of the overall dialysis population (USRDS, 2012) and endure a high symptom burden as they may experience troubling symptoms such as fatigue, decreased appetite, trouble concentrating, swelling in their feet and hands, muscle cramps, and itching (Almeras & Argiles, 2009; Murtagh, Addington-Hall, & Higginson, 2007; Yong et al.,

Disclaimers: none

2009), all of which cause daily distress and negatively affects their quality of life (Jablonski, 2007; Kimmel, Emont, Newmann, Danko, & Moss, 2003; Weisbord, Fried, Arnold, Fine, & Levenson, 2005).

Fatigue is one of the most common symptoms that patients with chronic illness experience (Kirshbaum, 2012). Fatigue is under-recognized and under-treated by providers (Ahlberg, Ekman, & Gaston-Johansson, 2005), most likely due to its insidious, invisible nature. Patients with ESRD identify fatigue as one of the most troubling symptoms with which they contend (Jablonski, 2007; Ossareh et al., 2005), with a prevalence ranging from 60% to 97% (Bossola, Luciani, & Tazza, 2009; Chang, Hung, Huang, Wu, & Tsai, 2001; Letchmi et al., 2011; Murtagh et al., 2007; Weisbord et al., 2005). Fatigue in patients on hemodialysis has been associated with lower quality of life (Yong et al., 2009; Jhamb, Weisbord, Steel, & Unruh, 2008; Weisbord et al., 2003) and lower survival rates (Jhamb et al., 2009).

The Experience of Fatigue in Patients on Hemodialysis

Patients on hemodialysis are unique due to the frequency, intensity, and chronicity of their dialysis treatments, and the degree of disruption that these treatments cause. Hence, a description of the experience of fatigue is important for the development of interventions to help alleviate fatigue. The only five studies to discuss the experience of fatigue in patients on hemodialysis, three of which were conducted outside of the U.S., focused on how fatigue affected physical and cognitive functioning. Fatigue was negatively correlated with physical functioning (McCann & Boore, 2000; O'Sullivan & McCarthy, 2007) and role limitations (McCann & Boore, 2000) and activity levels ($r=-0.51$, $p<0.0005$) (Brunier & Graydon, 1993) in patients on hemodialysis. Two qualitative studies conducted outside of the U.S. also indicated that fatigue affected physical and mental functioning. Patients attributed physical fatigue to the side effects of hemodialysis and lack of kidney function (Lee, Lin, Chaboyer, Chiang, & Hung, 2007). Physical fatigue seemed to be worse on hemodialysis days (Heiwe, Clyne, & Dahlgren, 2003) and affected participants' abilities to manage their everyday lives (Lee et al., 2007) and carry out daily activities (Heiwe et al., 2003). Participants noted that they also experienced cognitive fatigue that affected their ability to remember and concentrate (Lee et al., 2007; Heiwe et al., 2003).

Fatigue Management in Patients on Hemodialysis

Similar to patients with other chronic illnesses, patients on hemodialysis must devise self-management techniques to lessen the effects of fatigue. The literature in the area of self-management of fatigue in patients on hemodialysis is extremely limited. What is known comes from the area of general symptom management in patients on hemodialysis.

Patients on hemodialysis have identified fatigue as a symptom that is highly stressful and intrusive (Burns, 2004; Logan, Pelletier-Hibbert, & Hodgins, 2006; Mok & Tam, 2001). While the literature identifies coping mechanisms such as keeping a sense of humor (Burns, 2004; Logan et al., 2006), trusting in God (Burns, 2004; Logan et al., 2006), and telling oneself not to worry and think positively (Mok & Tam, 2001; Logan et al., 2006), these general coping mechanisms do not specifically address fatigue. Thus, existing research findings are not sufficient to inform or further our knowledge about specific self-management strategies that patients on hemodialysis use to deal with fatigue.

While there have been significant improvements in the quality of care for patients on hemodialysis, morbidity and mortality rates remain high and life expectancy is limited. Symptom management is an important part of disease management for patients on dialysis particularly because they have a decreased life expectancy which, in turn, reduces the amount of time they have to adjust to, adapt to, and learn management strategies for the

symptoms they experience. Identifying the techniques patients use to manage their fatigue is also important for improving quality of life for patients on dialysis. There remains a critical lack of knowledge regarding the experience and self-management of fatigue in patients on hemodialysis, a detailed description of which could help establish a knowledge base for the development of approaches to help lessen the effects of fatigue. Further, little information exists on how patients on hemodialysis manage their fatigue, and how successful they are (Curtin & Mapes, 2001). Studying the experience and self-management of fatigue in patients on hemodialysis is critical to the development of techniques that will help ameliorate or even alleviate fatigue for these patients. Therefore, the purpose of this study was to describe the experience and self-management of fatigue in adult patients on hemodialysis.

Methods

Design

A qualitative descriptive study design which included an initial in-depth interview and a second interview to clarify and validate findings from the first interview and to perform member checks was used to explore the experience and self-management of fatigue in patients on hemodialysis.

Setting and Sample

Participants were recruited from a dialysis center in a rural area in the mid-Atlantic U.S. that treats approximately 120 patients weekly. Interviews were conducted in a place that participants identified as the most convenient place for them to be interviewed, most often their homes. At times, it was more convenient for participants to be interviewed before their dialysis session. Interviews at the dialysis center were conducted in a private conference room.

The study sample consisted of 14 adult patients on incenter hemodialysis. Patients were eligible to participate in the interviews if they experienced fatigue; were 21 years of age or older; could read, speak and understand English; had an absence of co-morbidities such as hepatitis, HIV, cancer or multiple sclerosis; and reported that they were not pregnant. The absence of co-morbidities and conditions marked by fatigue was required to ensure that the fatigue patients experienced, and therefore explored by this study, was fatigue related to ESRD. In this study, participants were identified as experiencing fatigue if, when asked how fatigue made them feel, they described a sensation that required rest.

Procedures

After approval from the Institutional Review Board was obtained and prior to participant recruitment, an employee from the dialysis center approached patients, gave a brief description of the study, and asked if they would be willing to speak with the researcher (AH) about participating in the study. If patients gave permission, the researcher then spoke with potential participants about the study and what it would entail. Purposive sampling was used to recruit participants for this study. This form of sampling is used to recruit participants who have knowledge or experience of the phenomenon under study (Bowen, 2008; Tuckett, 2004). Therefore, recruitment of participants was limited to only those who reported experiencing fatigue. Participants were recruited until saturation of data was reached; that is, information gleaned from interviews as the study progressed became repetitive and no new information was added to existing data (Bowen, 2008).

If patients agreed to participate in this study, an appointment was set up for the researcher to come to a location chosen by them, usually their homes, to review the consent form, obtain

their informed consent, collect demographic data and conduct the first interview. Participants were given a copy of the consent form for their review prior to the appointment. They were encouraged to write down any questions or concerns for discussion at the first meeting.

Instruments

Sample interview questions are shown in Table 1.

Data Collection

At the first appointment, after informed consent was obtained, an individual semi-structured interview was conducted. These interviews are an appropriate data collection method when the researcher knows enough about the phenomenon to devise questions prior to the interview but not enough to anticipate subject's answers (Richards, 2006). Further, because hemodialysis schedules are fairly complicated, requiring patients to attend sessions for 3–4 hours three times weekly, individual interviews, rather than focus groups, were the most pragmatic and appropriate method of data collection for this study. Demographic data were collected at the beginning of the interview. Interviews lasted approximately 45–60 minutes. They were audio-tape recorded and conducted in a quiet, private place. Interviews began with a grand tour question (Brenner, 2006; McCaslin & Scott, 2003): "Tell me about your fatigue." If this question did not elicit expected responses regarding fatigue (i.e., how it affects activities, when it occurs, any patterns associated with it), more specific questions were asked about how long fatigue lasts, how often episodes of fatigue occur, what makes the fatigue worse, how it is related to dialysis, and how it affects sleep patterns. Additionally, questions about how fatigue affected the subjects' abilities to perform and participate in activities such as activities of daily living, dialysis sessions, and social gatherings, were asked.

A second meeting was scheduled with the participant after the first interview was analyzed so that participants could clarify or elaborate on their responses given in the first interview. At this meeting, member checks were conducted; the researcher shared the initial analysis of the first interview with the participant in order for them to validate the findings were accurate (Cho & Trent, 2006; Steinhäuser & Barroso, 2009). Field notes were written immediately after each interview to capture the natural environment of the subject and to use in validation of the interview data.

Data Analysis

All tape-recorded interviews were transcribed verbatim and proof-read for accuracy. Qualitative content analysis, in particular manifest and latent content analysis, was used to analyze all transcribed interviews. Content analysis refers to the interpretation of text data (Hsieh & Shannon, 2005) and is appropriate when the aim of the research is to describe a phenomenon or experience. Each transcript was read to gain a general sense of the data and transcripts were analyzed as soon as possible after an interview as the data from each interview informed future interviews. Questions were added to the interview guide based on data collected from prior interviews. Analyzing line-by-line, key thoughts in the interviews were identified. Text was condensed and codes were developed based on the key thoughts identified in the data. Therefore, the knowledge gained from this type of analysis was grounded in the data (Hsieh & Shannon, 2005) and while text was condensed, the meaning was preserved (Graneheim & Lundman, 2004). Condensed data were aggregated into more abstract categories of content that have commonalities. Themes, or recurring topics in the data, were identified within and across categories on an interpretive level.

Rigor

Rigor was maintained throughout this study with attention to credibility, dependability and confirmability. The researcher spent a lengthy amount of time in the field completing clinical work with patients on hemodialysis, and attending grand rounds and journal clubs with nephrology residents (credibility). Further, member checks were conducted during the second interview to make sure that our analysis of data was accurate and to clarify any questions that arose in analysis (credibility). The researcher kept a study notebook in which analytic memos and decisions regarding themes found in data analysis were recorded (dependability). Another researcher (JB) read and coded 80% of the transcripts from this study in order to ensure that the analysis of data was dependable but also to make sure that analysis lead to neutral findings that were not tainted by the researcher's opinions or values (dependability and confirmability). Findings are presented in detail with thick description of data so that readers may determine if the findings are transferable to their own context or circumstance (Milne & Oberle, 2005; Steinhauser & Barroso, 2009; Tuckett, 2005).

Findings

Demographic characteristics of the study sample are found in Table 2. Four themes emerged from the data that describe the experience of fatigue for adult patients on hemodialysis, and how they attempt to manage their fatigue. Participants described fatigue as having physical and mental components, being difficult to manage, and as having consequences and associated factors. These themes are described in detail below.

Nature of Fatigue

Fatigue was described by most participants as a symptom of ESRD as well as the dialysis process. Two subthemes are included in this description: physical fatigue and mental fatigue.

Physical Fatigue—Participants described a lack of physical strength and energy that made them feel lifeless, washed out, weak, and drained. It was an overpowering, bodily feeling. Often participants experienced a sensation of being lightheaded and dizzy in conjunction with extreme fatigue, particularly immediately after dialysis. As one participant, a 69-year old woman on hemodialysis for eight years, who worked part-time cleaning office buildings and was a primary caregiver for her grandson stated: "It feels just like your life has just went out of you." Activities as simple as sitting up in a chair or riding in a car became physically taxing. In a sense, the fatigue dictated what patients could and could not do on a daily basis. The same participant stated when speaking about holding the phone to her ear during a phone conversation she had just had: "Just like holding the phone there, it just feels like all of my strength is just gone out of my arm." Another participant, a 52-year old woman on hemodialysis for one and a half years, who continued to work part-time as a receptionist in a doctor's office and had adult children, stated: "The whole day was shot because I couldn't really do anything...you know it does control what I can and can't do." Participants described a lack of interest and energy for participating in activities because they were so overwhelmingly fatigued. Added one participant, a 74 year old man who lived with his wife and was retired from his job as a manager at the county department of works, on hemodialysis for three years: "Well, I still feel lazy and I don't feel like getting up and do a lot of stuff, it doesn't take long to realize the couch looks better, and the chair looks better than what you doing."

Mental Fatigue—Participants discussed a mental fatigue that affected their ability to remember conversations, names of people they had known for years, and where they were driving in the car. This fatigue specifically accompanied the physical exhaustion that came

after dialysis sessions. Stated one man in his late 50's who was disabled due to ESRD, lived with his father, and was a partial amputee: "I can't think of people's names, people I've known." At times, participants wondered if this fatigue was due to the process of aging but seemed to discount this as they could pinpoint times in the day and on specific days when they were not as mentally sharp as usual and were able to related these times to their dialysis sessions.

Management of fatigue

When asked about what makes the fatigue better, participants frequently responded, "Nothing makes it better." After a moment of thought, they were able to discuss some of the activities they employ to alleviate their fatigue. Overall, none of these management techniques were consistently successful, nor were patients satisfied with the degree of relief the techniques provided. Three subthemes were evident in the data.

Rest after dialysis—All participants indicated that they had to rest immediately after their dialysis session. At times, when they had driven themselves to their sessions, they were so fatigued at the end that they had to call a friend or relative to drive them home from hemodialysis. Others talked about a delayed effect; the fatigue did not become overwhelming until they got home from hemodialysis. Participants stated that they usually slept during their rest time, but that was not always the case and sleep was not always required to feel better. Added a 45-year old attorney, retired due to the need for hemodialysis and to fatigue:

I don't always fall asleep, if I fall asleep it's hard from me to wake up for hours. I can't take a thirty minute or one hour nap, I'm a two, three, four hour nap. The longer I nap, the groggier I wake.

Adjustment or adaption of routine—Participants adjusted the timing and intensity of their activities to accommodate their fatigue. They saved more strenuous activities, like grocery shopping, for times when they had more energy or times when they knew they could shop in increments. Some napped in anticipation of events that would require time and energy. Others lived by a schedule, knowing when they would be able to participate in activities and when they would need to rest. Stated a 52-year old woman who lived with her husband and worked part-time as a receptionist in a doctor's office: "I try and get my laundry done, I've even been cooking supper in the mornings and put it in the refrigerator and just come home and all we have to do is heat it up." Added a 27-year old part-time student who helped care for her nephew in the home: "I have to schedule everything, I've learned that I'm going to have to, it's like money, you have to budget."

Management of comorbidities and related symptoms—Participants found that if they were able to manage their comorbidities such as diabetes and the pain from arthritis and calciphylaxis, a calcium and phosphorus disorder that patients on hemodialysis experience that results in painful sores on the skin, their energy levels were higher. Those who had old fractures from bone and mineral disease or difficult healing wounds from calciphylaxis stated that when their pain was controlled, whether it was with medicine, heating pads, or rest, they felt less fatigued. Stated one participant, a 70-year old woman who worked as a dietary assistant and cook who has been on hemodialysis for 10 years and had calciphylaxis: "The pain is so great from the calciphylaxis that I don't even think about fatigue." When asked if pain makes the fatigue worse, she responded, "Yes, ma'am." Others found that infections and fluctuations in blood sugar sapped their energy levels, making them feel even more worn out. Said one: "I notice that if I'm more careful about following my blood sugars and keeping them on an even keel, it (the fatigue level) is night and day."

Consequences of fatigue

Participants identified the ways in which fatigue negatively affected everyday life and activities. Often these consequences revolved around their abilities or desires to spend time with other people. Three subthemes were found in the data and comprise the consequences of fatigue that patients on hemodialysis experienced.

Socialization is negatively affected—While patients on hemodialysis have sacrificed much of their socialization, they do not see themselves as isolated from others. This may be due to the fact that they leave their homes three times weekly for hemodialysis and while they may not visit socially with the other patients and nurses, they are around others and feel like they could socialize if they desired. At the very least, their socialization has changed in nature from what it used to be due to their fatigue. The participants did not commit to social gatherings or outings because they never knew if they would have enough energy to participate. Said a single mother on hemodialysis for one and a half years: “I don’t see my family...I love to cook and entertain. I’d invite them over more which I can’t do...because I never know when I’m really gonna have the energy to complete a promise.” A 70 year old woman who lived with her adult son and liked to socialize after church in the evenings stated: “Sometimes they want me to go out to dinner with them, I just don’t feel like it...everybody is talking and having a good time and I’m sitting over there yawning.”

Time spent with children is compromised—For those participants who lived with children in their homes or were close with their grandchildren, the amount and quality of time they were able to spend with them was compromised. Participants had to make arrangements for child care on hemodialysis days as they were rendered unable to care for them due to their fatigue. Yet others were themselves cared for by their grandchildren after hemodialysis. These changes left parents and grandparents feeling guilty and insufficient in their role responsibilities. Added a 27-year old part-time student talking about caring for her nephew with autism after school:

We usually chill at the house because that way, I still lay around and still watch him, but you know when it comes to the bathroom and stuff. I struggle because I just want to sit here and do nothing.

A 69-year old grandmother who lived with her single daughter and was a primary caregiver for her grandson: "And he won't go outside while I am here. Cause if he goes outside then I got to go out and sit and watch him."

Participation in activities is difficult—Participants discussed that it was difficult, not only to enjoy activities with others outside of the house, but it was difficult to keep up with activities and chores in the house. Participants had difficulty getting groceries from the car to the house and then put away. They struggled to maintain their yards and keep their cars clean. There was a sense of not being able to accomplish a simple task and so activities were prioritized and only the necessities were accomplished fully. One participant, a 68-year old man, who lived alone with his wife who had cancer, and who liked to work around the house said, “I always washed my cars twice a week, but I just don’t have that energy...I don’t even give it a thought.” Another participant added:

I'd get home and I couldn't get the groceries out of the car. I'd bring in the cold things or the frozen things and in the summer I'd just leave them here in the air conditioning and they'd have to wait a little bit and then I'd put the frozen things away and then I'd put the refrigerated things away and then I'd do the canned goods.

Another participant, a 56-year old woman who worked as a store clerk and lived in a two bedroom, 800 square feet apartment with her husband and multiple pets, stated: "I don't go to the store as much. I send my husband to the store. I'm too tired to go. I used to love to go shopping but I don't have enough energy to do that."

Factors associated with fatigue

Fatigue has been associated with many other symptoms in the hemodialysis population. Depression has been historically associated with fatigue in chronically ill individuals as well as those on hemodialysis. In this study, the frequency of depression was very low and those who stated that they were depressed or had periods of depression denied that the depression made their fatigue worse or vice-versa. "No, I ain't depressed, I just don't have the energy," stated one man, 69 years old, who has been on hemodialysis eight years. In fact, only four out of 14 participants stated that they were depressed or had episodes of depression. All four of these patients could articulate a reason for their depression, such as the loss of a loved one, or a husband's loss of job and subsequent loss of house and car. These participants noted that their depression was well-treated with antidepressant medications. One participant, a 69 year old woman who was upset about her significant other leaving her, said, "...and still if I don't take them (anti-depressants), I will cry at anything."

Poor sleep quality has also been associated with fatigue in chronically ill populations and this held true in this study. Patients had trouble falling asleep, staying asleep, staying awake in the daytime, and sleeping while on hemodialysis. One patient added: "The time I started dialysis I was up almost every night, I would maybe fall asleep for an hour and then I would wake up and I couldn't go back to sleep." Another woman, 56 years old who lived with her husband and who crocheted as a hobby, stated:

I wake up every morning around one or one-thirty, I look at the clock, go back to sleep, well then I wake up at two-thirty, I wake up again and look at the clock at its quarter till three, maybe I'll just stay up and I usually get up at four.

These patients get up early to go to the hemodialysis unit, fall asleep while on hemodialysis, and sleep to recover after hemodialysis, all of which turn into a vicious cycle of poor sleep.

Discussion

Fatigue is an often debilitating symptom in those with ESRD on hemodialysis. As common and extreme as the symptom is in this population, little evidence is available that describes what the experience of fatigue is like for patients on hemodialysis or how they mitigate its effects. This exploratory study sought to elicit a description of fatigue for patients on hemodialysis in the US and to identify ways patients have been able to manage fatigue. It further expands understanding of fatigue in patients on hemodialysis by offering a detailed description of the consequences and factors associated with fatigue that is not found in existing literature.

Findings from the current study support the findings of other research in this area in that participants reported both physical and mental fatigue, fatigue that is worse after hemodialysis, role limitations, and an inability to carry out daily activities (Brunier & Graydon, 1993; Heiwe et al., 2003; Lee et al., 2007; McCann & Boore, 2000; O'Sullivan & McCarthy, 2007). Patients on hemodialysis reported a physical fatigue that made them feel exhausted (Heiwe et al., 2003), lacking physical energy (Lee et al., 2007), and having a decrease in strength and ability (Kazemi, Nasrabadi, Hasanpour, Hassankhani, & Mills, 2011). Similar to these findings, participants in the current study reported feeling "washed out" and "drained" physically. Further, they reported mental fatigue that they experienced in the form of difficulty remembering names and participating in conversations. This seemed to

happen only in the hours following their hemodialysis session. Other researchers found that patients on hemodialysis experience mental fatigue; but contrary to the current study's findings, Lee et al. (2007) found that participants in Taiwan felt that difficulty with their cognitive abilities to remember and keep their attention focused began after they started hemodialysis and continued to gradually decline. Heiwe et al. (2003) reported that participants in Sweden identified mental fatigue as consistently present, affecting their abilities to concentrate and participate in activities. While the descriptions of physical fatigue are similar in nature across studies, the descriptions of mental fatigue vary in characteristics and should be investigated further.

Due to the profound symptom burden that patients on hemodialysis bear (Almeras & Argiles, 2009; Hutchinson, 2005; Murtagh et al, 2007; Yong et al., 2009), devising ways to manage symptoms is important in order to improve quality of life. However, the self-management of fatigue in this population has been largely unstudied. Participants in this study reported that they rested or slept after hemodialysis, adjusted or adapted their routines to accommodate their need to rest or sleep, allowing them to take advantage of the times when they felt the best and reserve these times for when they needed to be active and managed comorbidities such as pain and blood glucose levels, to help with their fatigue. These findings are unlike the methods that patients with cancer-related fatigue and HIV-related fatigue use to manage their fatigue. Patients with cancer-related fatigue report staying involved in social activities and depending on close friends and relatives for support (Richardson & Ream, 1997; Borthwick, Knowles, McNamara, & Dea, 2003). In fact, patients on hemodialysis decreased their social interactions with others due to their fatigue. Patients with HIV-related fatigue reported using alternative therapies and supporting their diets with vitamin supplements and healthy food (Corless et al., 2002; Siegel, Brown-Bradley, & Lekas, 2004). Similar to patients on hemodialysis, patients with HIV-related fatigue reported that they limited their social interaction to help manage their fatigue (Corless et al., 2002; Siegel et al., 2004). The findings from this study expand our understanding of self-management techniques patients on hemodialysis use to mitigate fatigue. Further, they demonstrate that techniques for the self-management of fatigue differ across chronic illnesses.

Patients on hemodialysis often identified facets of their life that were negatively affected by fatigue. The current study validates the findings of Heiwe et al. (2003) who found that participants in Sweden had difficulty completing daily activities as simple as eating. Lee et al. (2007) reported similar findings with their participants in Taiwan. Participants spoke of difficulty walking up stairs, doing household chores, and even reading. Similarly, the current study found that participants had profound difficulties in carrying out the simplest of daily activities. For instance, patients with diabetes had to make sure that they stayed awake after hemodialysis long enough to eat something before they went to bed to keep their blood glucose from dropping. Holding the phone to their head for a conversation became taxing. This demonstrates the extent to which these patients are fatigued and the considerable effect this has on their lives.

Another consequence of fatigue for patients on hemodialysis in the current study was the inability to socialize with others due to their fatigue. They did not spend as much time with their family or friends as they would have liked. Participants in the current study were able to identify that their social interactions had decreased, but they did not see themselves as isolated. Decreased socialization occurred among patients on hemodialysis in Iran and these patients felt as though they were isolated from others (Kazemi et al., 2011; Lee et al., 2007). Moreover, this isolation was self-imposed due to decreased motivation (Lee et al., 2007), fear of being treated like an outsider (Lee et al., 2007), and body image changes related to the hemodialysis access location (Kazemi et al., 2011).

In the current study, participants noted that the quantity and quality of time they were able to spend with children was negatively impacted. Parents and caregivers of children noted that they limited the activities of the children because they, the caregivers, were too tired to engage with or supervise the child. This finding is unique to the current study and may highlight some of the cultural differences among participants and is an area that warrants further investigation.

Depression and sleep disorders are often associated with fatigue in chronic illness. Depression and fatigue have been correlated in the hemodialysis population in several quantitative studies (Bossola et al., 2009; Kim & Son, 2005; Leinau, Murphy, Bradley, & Fried, 2009; McCann & Boore, 2000). In qualitative work conducted by Lee et al. (2007), participants reported that they were depressed because hemodialysis absorbed most of their lives and took time away from their daily activities. However, the authors do not fully explain how depression was related to fatigue in their study other than to say that participants were experiencing a fatigue that was related to their emotional reactions. In the current study, the majority of participants reported that they were not depressed. Those who reported that they experienced depression could identify the reason for their depression. No one mentioned the chronicity of hemodialysis treatments as the reason for depression and no one felt that their depression was related to their fatigue.

Sleep disorders are often identified as contributing to fatigue in patients on hemodialysis. The current study supports findings by Lee et al. (2007) who found that participants reported trouble going to sleep and staying asleep for a prolonged amount of time. Possibly, sleeping to recover after hemodialysis, sleeping poorly at night, and sleeping during the hemodialysis treatment is a cycle that patients on hemodialysis endure, and is one that likely disrupts the circadian rhythm of sleep. However, research in this area is limited and the effects of sleep disorders on fatigue are not well known.

Summary and Implications for Nursing

The findings from this study contribute important knowledge about the phenomenon of fatigue in patients on hemodialysis. The use of qualitative descriptive methods aided in obtaining a detailed description of fatigue and how participants managed their fatigue. The findings from this work highlight the fact that participants were limited in what they could do to successfully manage their fatigue, and in fact, most were never totally relieved of their fatigue.

There are several limitations to this study that could affect transferability of this work (Milne & Oberle, 2005; Tuckett, 2005). This study was conducted in the rural southeast; therefore, geographically, findings may differ from those findings obtained in other parts of the country. However, this study is unique for the aforementioned reason. To our knowledge, no studies in the US that have focused on the experience of fatigue in patients on hemodialysis have been conducted in a rural area. Further, the phenomenon of fatigue itself had the potential to limit the findings of this study. Yet, this was not the case in our work. While all participants were told that the interview could be rescheduled or stopped at any time if they were tired, no participant felt the need to do this. The researcher observed participants throughout the interview to observe for signs of tiring during the interview. If they had exhibited signs of being tired, the researcher would have suggested that the interview be rescheduled. Lastly, most participants in this study were of retirement age or older; therefore, this work does not demonstrate the challenges that those of working age may face.

Implications for Practice

Findings from this study identify several areas in which nephrology nurses could be of support for patients on hemodialysis with fatigue. Nephrology nurses are in an ideal position to assess and intervene with patients on hemodialysis. However, in order for this to occur, there must be added emphasis in education for nephrology nurses that includes expanding their assessment and teaching to include factors such as symptom assessment and management. This, in addition to assessing hemodialysis-related factors such as patient weight gain, blood pressure, and assessment of hemodialysis access site, will promote holistic care of patients. Including education regarding symptom assessment and management will give nephrology nurses the tools needed to positively affect patients on hemodialysis' quality of life. Nephrology nurses can also play a key role in patient and family education regarding fatigue that is related to their illness and the management of comorbidities. The education of patients and families about fatigue prior to them being unexpectedly faced with a life-limiting symptom could help them prepare for and identify future needs. Information from this study can help nurses aid patients in identifying what their future needs may be. Educating patients on hemodialysis about controlling comorbidities such as pain and blood glucose fluctuations may give them the means to help increase their energy levels on their own. Nephrology nurses have the best opportunity to educate these patients while they are on hemodialysis. Sleep is an area in which nurses can make a critical impact on patients. Educating and supporting patients with sleep disorders may help break the cycle of fatigue for some patients. Teaching patients about good sleep hygiene and how to keep a sleep diary may help some with sleep disturbance. Nurses can also play a part by helping to keep patients active and awake while they are receiving their hemodialysis treatments.

Implications for Research

This study highlights several areas for further inquiry. This study recruited participants who were mainly of retirement age who lived in a rural area; future work that focuses on younger adults and those that live in a more urban setting could expand our knowledge of the experience and self-management of fatigue by adding a broader context to the data. This knowledge has the potential to identify areas that are amenable to intervention for patients on hemodialysis.

Depression and sleep are other areas that warrant additional study. In our work, depression was not prevalent among participants. However, the presence of depression relied upon self-report, using a single question assessment method which could have skewed findings. While this method has been shown to be a sensitive measure of depression (Reme & Erikson, 2010; Watkins et al., 2007), it would be interesting in future studies to use a formal depression assessment tool and compare its findings with findings from the single question method of depression assessment. Additionally, participants had sporadic sleep cycles which logically would result in increased fatigue. Minimally, asking participants to keep a sleep diary could illuminate and clarify the specific components of sleep that contribute to fatigue. Longitudinal work that seeks to identify the trajectory of sleep problems over the course of CKD and ESRD could help pinpoint times when these problems are most likely to occur and when it is most appropriate to intervene.

Acknowledgments

The authors would like to thank Diane Holditch-Davis PhD, RN, FAAN for her continued input and support in the writing of this manuscript.

Funding: This work was supported by a grant from the American Nephrology Nurses' Association and by grant number F31NR012342-01A1 from the National Institute for Nursing Research and the National Institutes of Health.

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Table 1**Interview Questionnaire**

Tell me about your fatigue (Grand tour question)

Further questions asked based on response to the above question. Sample questions include:

When is your fatigue at its worst? When is it the least troubling?

Have you noticed a pattern to your fatigue?

Have you found that your fatigue is related to dialysis? How so?

Does anything make your fatigue worse/better?

How long does your fatigue last?

What does your fatigue affect?

Is the fatigue you feel now, different from the fatigue you felt before you began dialysis?

What do you do to manage your fatigue?

How is your sleep?

Does fatigue affect your relationships?

To screen for depression, the following questions were asked:

During the past month, have you often been bothered by feeling down, depressed, or hopeless?

During the past month, have you been bothered by little interest or pleasure in doing things?

Table 2

Demographic Characteristics (n=14)

	Demographic Measure	Number of Participants
Gender	Male	7
	Female	7
Race	Caucasian	12
	African American	2
Age range	Less than 50	2
	50–59	3
	60–69	4
	70–79	3
	80–89	2
Number of years on hemodialysis	Less than 1 year	1
	1–3 years	7
	4–6	2
	7–9	2
	10–12	2
Socioeconomic status	Receive disability	8
	Average monthly income	\$1442
	Range of monthly income	\$582-\$3772
Education	College graduates	2
	High school graduates	9
	Did not complete high school	3
Family	Children in the home	3
	Patient is primary caregiver for another	4