

The Experience and Self-Management of Fatigue in Adult Hemodialysis Patients

by

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Dissertation submitted in partial fulfillment of
the requirements for the degree of Doctor of Philosophy in
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ABSTRACT

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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 American hemodialysis patients, 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 as well as how fatigue changes over time from one dialysis session to the next. Several themes were identified which included: the nature of fatigue, management of fatigue, consequences of fatigue, and factors associated with fatigue. Further, hemodialysis patients experience two types of fatigue, post-dialysis fatigue only, fatigue that occurs acutely after the dialysis session and resolves after sleep or rest, and continuous fatigue, a persistent, underlying fatigue that patients experience at all times and worsens after the dialysis session usually requiring a prolonged period of recovery.

Dedication

This work is dedicated to mom and dad who supported me in every way imaginable; to Jim and John who reminded me that it's not always about me; to The Babies, my favorite dogs, Atilla, Chewy, Teddy, Taffy and Chi Chi who walked every step of the way with me, never asking questions, never complaining, and always ready to give me kisses when I needed them the most; and to Wally and Hazel who couldn't be here when I finished my "report".

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1. Dissertation Introduction

Fatigue is one of the most common symptoms that patients with chronic illness experience (Kirshbaum, 2012). It is thought to be under-recognized and under-treated (Ahlberg, 2005), most likely due to its insidious, invisible nature. Patients with end-stage renal disease (ESRD), a common, chronic illness that affects over 525,000 people in the United States (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2009), identify fatigue as one of the most frequent symptoms with which they contend (Jablonski, 2007; Merkus, Jager, Dekker, de Haan, Boeschoten et al., 1999; Parfrey, Vavasour, Henry, Bullock, & Gault, 1988; Weisbord, Fried, Arnold, Fine, Levenson, Peterson et al., 2005), with a prevalence ranging from 60% to 97% (Bossola, Luciani, & Tazza, 2009; Cardenas & Kutner, 1982; Chang, Hung, Huang, Wu, & Tsai, 2001; Letchmi et al., 2011; Murtagh, Addington-Hall, & Higginson, 2007; Parfrey et al., 1988; Weisbord et al., 2005). Patients with ESRD require renal replacement therapy, dialysis (hemodialysis or peritoneal dialysis) or a kidney transplant, for survival. Patients on hemodialysis account for approximately 92% of the overall dialysis population and they may experience fatigue as a symptom of ESRD, or as a result of the hemodialysis treatment itself (Sklar, Riesenber, Silber, Ahmed, & Ali, 1996). Fatigue in patients on hemodialysis has been associated with lower quality of life (Jhamb, Weisbord, Steel, & Unruh, 2008; Weisbord, Carmody, Bruns, Rotondi, Cohen et al., 2003; Yong, Kwok, Wong, Suen, Chen et al., 2009) and with lower survival rates (Jhamb, Argyropoulos, Steel, Plantinga, Wu et al., 2009).

Research about the experience of fatigue in this population, which includes the person's perceptions, evaluations, and responses to fatigue (Dodd, Janson, Facione,

Faucett, Froelicher et al., 2001), is limited. We have little information regarding the patterns of fatigue that exist in patients on hemodialysis. We do not know how patients manage their fatigue or how to most effectively intervene. A detailed description of the fatigue experience in patients on hemodialysis and identification of patterns of fatigue, such as how often it occurs and when it worsens, could help establish a base for the development of approaches to help lessen the effects of fatigue. Treatments such as exercise (Fitts, 1997; Wilson, Malahy, Scialabba, & Woodrow, 2006) and management of anemia with erythropoietin–stimulating agents (Ossareh, Roozbeh, Krishnan, Liakopoulos, Bargman et al., 2003) have been used to treat fatigue in patients on hemodialysis. However, these interventions are not effective for all patients on hemodialysis who have fatigue (Williams, Crane, & Kring, 2007; Williams, Stephens, McKnight, & Dodd, 1991) and may even be dangerous for some (Singh, Szczech, Tang, Barnhart, Sapp et al., 2006).

Like patients with other chronic illnesses, patients with ESRD who are on hemodialysis assume much of the burden for managing their illness and symptoms, such as fatigue (Curtin & Mapes, 2001; Holman & Lorig, 2000; Thomas-Hawkins & Zazworsky, 2005). While there have been significant improvements in the quality of care for patients on hemodialysis (NIDDK, 2011), morbidity and mortality rates remain high and life expectancy is limited (NIDDK, 2011). Symptom management is an important aspect of self–care for patients on hemodialysis because engaging in effective management techniques leads to longer lives (Curtin, Mapes, Petillo, & Oberley, 2002; Schatell, Thompson, & Oberley, 1999). Self-management of fatigue is also important for improving quality of life for patients on dialysis. However, little information exists on

how hemodialysis patients 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 specific aims of this study were to:

1. Describe the experience of fatigue, including the participant's perceptions, evaluations, and responses to fatigue, for patients on hemodialysis.
2. Describe how patients on hemodialysis manage fatigue, including management strategies and perceived effectiveness of the strategies.
3. Describe how fatigue changes over time from one dialysis session to the next.

A qualitative study using a longitudinal descriptive study design addressed the above aims. Patients on hemodialysis were recruited from a nephrology practice in the southeast United States. Semi-structured interviews were conducted to gain an in-depth understanding of the experience and self-management of fatigue. Patients were asked to keep a diary of their fatigue and self-management practices beginning on a dialysis day and ending on the next dialysis day, 48 hours later, and again over a 72-hour period which provided information regarding how fatigue changed over time from one dialysis session to the next.

Findings from this study are presented in chapters two through four followed by a conclusion chapter. In chapter two, I present the state of the science on the factors associated with fatigue in patients on hemodialysis, a paper that is in press in the *Journal of Pain and Symptom Management*. I have obtained permission to reprint this article in my dissertation. In chapter three, the findings from my exploratory qualitative descriptive

study are presented. Four themes emerged from the data I collected and analyzed; these themes describe the experience and self-management of fatigue in hemodialysis patients. Themes found in the data include: the nature of fatigue, management of fatigue, consequences of fatigue and factors associated with fatigue. In chapter four, a comparison of two groups of dialysis patients with fatigue is made. These groups emerged as data were analyzed and include a group of patients who experienced post-dialysis fatigue only and a group who experienced continuous fatigue. Data from those with post-dialysis fatigue only -- those who have fatigue only after their dialysis sessions-- were analyzed separately from the whole group to find themes in the data that were specific to this group. These findings were compared to the findings from participants with continuous fatigue: those who experience a persistent fatigue daily that is exacerbated after their dialysis session. Finally, in chapter five, I elaborate on areas of the dissertation work that were not discussed in the manuscripts including: sampling in qualitative work, age versus illness effects, implications for policy, and preliminary theorizing based on my model of fatigue before and after my study was completed.

Literature Review

As ESRD is increasing in incidence and prevalence, it is important to understand the current knowledge regarding fatigue in this population. The following review of the literature begins with a description of the experience of end-stage renal disease, including disease progression and changes in health and lifestyle. The possible causes of fatigue in patients on dialysis, and the definition and measurement of fatigue as they relate to patients on hemodialysis, are discussed. Current treatments for fatigue are described, including a discussion of their utility in this population. Lastly, the experience of fatigue

and its self-management in patients with chronic illness and patients with end-stage renal disease on dialysis are discussed.

Experience of End Stage Renal Disease

Chronic kidney disease. Chronic kidney disease has an illness trajectory in which there is a progressive deterioration of kidney function that eventually results in end-stage renal disease requiring dialysis or kidney transplant. Chronic kidney disease is often unpredictable and sometimes patients do not feel ill as the disease progresses to ESRD (Iles-Smith, 2005). Patients who experience symptoms of kidney failure often feel tired, have a decreased appetite, trouble concentrating, swelling in their feet and hands, muscle cramps, itching, and either a decrease or increase in urination (Daugirdas, Blake, & Ing, 2001). When chronic kidney disease transitions to end-stage renal disease, the glomerular filtration rate has dropped below 15 mL/min, and the kidneys have ceased to function properly, necessitating the initiation of dialysis. Selection of dialysis modality, hemodialysis or peritoneal dialysis, depends largely upon physician recommendation, patient preference, and the patient's clinical and social status (Mendelsohn, Mullaney, Jung, Blake, & Mehta, 2001; Shahab, Khanna, & Nolph, 2006; Stack, 2002; Thamer, Hwang, Fink, Sadler, Wills et al., 2000). Since hemodialysis patients account for approximately 92% of the dialysis population (NIDDK, 2009), this research will focus on hemodialysis patients. Hemodialysis involves the removal of wastes and excess fluid from the blood through a type of vascular access (Martchev, 2008; Muringai, Noble, McGowan, & Channey, 2008). Blood is pumped through a dialyzer that has a semipermeable membrane that allows the diffusion of solutes and excess fluid from the blood (Martchev, 2008).

Changes in health and lifestyle. Patients on hemodialysis are confronted with changes in their health status and lifestyle (Al-Arabi, 2006). These changes may be considered transitions in the illness trajectory. Several transitions experienced by patients have the potential to affect their personal and social trajectories such as work, travel, and family. Patients must adhere to prescriptive and restrictive dietary guidelines, limiting the amount of fluid, phosphorus, potassium, sodium, and protein in their diets (Daugirdas et al., 2001). Before the initiation of hemodialysis, patients must undergo at least one surgical procedure to establish arterio-venous access for hemodialysis. Further, dialysis patients spend a significant amount of time in dialysis each week, travelling to and from free-standing centers three times per week with each session lasting 3-5 hours (Martchev, 2008; Muringai et al., 2008). They may spend significant amounts of time waiting to be put on the machine, or waiting for their dialysis sites to stop bleeding from the needles used to penetrate the access sites for dialysis (Curtin et al., 2002). They must adhere to strict dialysis schedules including changing plans to meet the dialysis center's schedule (Polaschek, 2003a). Many feel as though they have lost their freedom, as they are literally tied to a machine for 12 hours per week (Al-Arabi, 2006; Polaschek, 2003a, 2003b) and traveling becomes problematic. Some patients must plan their other activities around their dialysis days as they are not able to predict how they will feel on those days (Polaschek, 2003b). Many patients find that they are unable to maintain employment after starting dialysis. The complex dialysis schedule and the time involved in each dialysis session make it difficult, particularly for blue-collar workers, to meet the scheduling demands of their employers, such as shift work and weekend schedules (Antonoff, 1991; Holly & Nespor, 1994; Rasgon, Schwankovsky, James-Rogers, Widrow, Glick et al., 1993).

Additionally, many do not feel well enough to work long hours performing physical labor (Ferrans & Powers, 1985; Hirth et al., 2003; Kutner, Brogan, & Fielding, 1991; Molsted, Aadahl, Schou, & Eidemark, 2003; O'Sullivan & McCarthy, 2007). They experience troubling symptoms such as sleep disturbances, pruritis, muscle cramps, fatigue, restless legs, and bone and joint pain (Weisbord, et al., 2005). There is little, if any, flexibility in dialysis schedules, surgical procedures, and dietary restrictions; these are essential for survival. All of this makes symptom management an essential part of the disease experience for hemodialysis patients.

Causes of Fatigue in Patients on Dialysis

Physical, social and dialysis-related factors have all been identified as possible causes of fatigue in dialysis patients (Jhamb et al., 2008). Malnutrition (Pagels, Heiwe, & Hylander, 2006), anemia (Jhamb et al., 2008), inflammatory changes (Dantzer & Kelley, 2007), sleep disorders (Unruh, Buysse, Dew, Evans, Wu et al., 2006) and depression (Weisbord et al., 2005) are just a few of the sources of fatigue. Post-dialysis fatigue that commonly occurs after a dialysis session and is incapacitating is a particularly debilitating source of fatigue for this population. Often, treatment for fatigue is focused on the suspected cause. However, regardless of the cause(s) of fatigue, the purpose of this study is to fully describe the experience of and changes over time in fatigue for patients on dialysis and to describe how they manage this symptom.

Definition of Fatigue

Fatigue can be viewed as a multi-faceted concept (Srivastava, 1986). Common characteristics of fatigue that may be mutually agreed upon by researchers and clinicians are not presented in the literature; consequently there is no universal definition of fatigue

(Trendall, 2000). A conceptual definition is needed to appropriately measure a concept and develop related interventions. Researchers who study chronically ill patient populations frequently attempt to define fatigue as it applies to their population of study. Most of the literature on fatigue in patients on hemodialysis fails to provide a definition of fatigue. Of those studies that do offer definitions of fatigue, none are specific to patients on hemodialysis. Many authors refer to Ream and Richardson's (1996) definition that states that fatigue is subjective, unpleasant and exists on a continuum that extends from being tired at one end to being exhausted at the other. Further, it is unyielding and affects people's abilities to function normally. Another frequently referenced definition in the literature on fatigue in dialysis patients is Piper's: a subjective feeling of tiredness that varies in duration and intensity and is influenced by circadian rhythms (Piper, Dibble, Dodd, Weiss, Slaughter et al., 1998). Jhamb, Weisbord, Steel, and Unruh (2008) used a definition of fatigue developed by Lee, Hicks, and Nino-Murcia (1991) that states fatigue exists on a continuum, with tiredness and lack of energy at one end and energy and vitality at the other (Lee et al., 1991). These definitions are helpful, but they may not be an accurate definition of fatigue in patients receiving hemodialysis as they were developed through work done with other patient populations. Ream and Richardson (1996) developed their definition through a concept analysis and did not focus on a specific patient population. Piper's definition is based on work done with cancer patients, and the definition adopted by Jhamb et al. (2008) was developed through work done with patients with sleep disorders. It is plausible that fatigue for hemodialysis patients is different from other patient populations due to the dialysis process: a process that is literally and metaphorically draining, and occurs at least three times a week for four to

five hours each session. The development of a disease-specific definition of fatigue in hemodialysis patients is important to appropriately measure the concept and develop related interventions.

Measurement of Fatigue in Patients on Dialysis

The ways in which fatigue has been measured in patients receiving dialysis are problematic. Many of the tools used to measure fatigue simply measure the presence or absence of fatigue, particularly those that were developed by researchers for use in their own studies. Others were developed for use with other patient populations and have not been validated for use in the dialysis population. Those tools that have demonstrated acceptable psychometrics in the dialysis population are either symptom checklists or are measures of quality of life with a short section on fatigue. These tools are useful because they indicate that fatigue exists in this population, but they do little else in describing fatigue. Measuring the presence or absence of fatigue does little to further our knowledge about the phenomenon. The use of instruments that were not validated for use in the hemodialysis population is a problem because we do not know if we are measuring the phenomenon that is fatigue in this population. Further, symptom checklists and quality of life measures do not explicitly focus on fatigue and include other variables that may cloud the measurement of fatigue. These assessment tools may not capture the full experience of fatigue for dialysis patients (Jhamb et al., 2008). Please see Tables 1 through 3 for a list of studies and the instruments used to measure fatigue.

Table 1.
 Fatigue Instruments Used in Research with Hemodialysis Patients

Instrument	Author and year	Scoring	Psychometrics	Domain of Fatigue Covered in Tool
Visual Analogue Scale for Fatigue (18 items)	Kim & Son, 2005 Kutner, Brogan, Fielding & Hall (2000) Kutner & Devins (1998) McCann & Boore (2000) Rocco, Mercieri, & Yavuzer (2006) Tsay (2004) Williams, Crane, and Kring (2007) Yurtkuran, Alp, & Dilek (2007)	0-100	Reliability Multidimensional Assessment Fatigue Scale = .80 Brief Fatigue Inventory = .76 Vitality scale of SF-36 = .71	Fatigue intensity
Profile of Mood States (65 items)	Brunier & Graydon (1993)	0-200	Internal consistency of subscales (0.63-0.96), concurrent validity with Beck Depression Inventory (coefficient not reported)	Overall mood state with subscales in anxiety, depression, anger, fatigue, confusion, lack of vigor

Piper Fatigue Scale (22 items)	Cho & Tsay (2004) Ridley, Hoey & Ballagh-Howes (1999) Tsay (2004) Tsay, Cho & Chen (2004)	0-10	Cronbach's alpha 0.93 for entire scale.	Behavioral/intensity, affective meaning of fatigue, sensory, cognitive/mood
Medical Outcomes Survey Short Form (36 items)	Foley, Curtis & Parfrey (2009) McCann & Boore (2000) Morsch, Goncalves, & Barros (2006) Rocco, Mercieri, & Yavuzer (2006)	0-100	Vitality scale of SF-36 concurrent validity with MFI General fatigue = -.79, physical fatigue = -.50, reduced activity = -.62, mental fatigue = -.49, reduced motivation = -.61 (reported by McCann and Boore only)	Overall quality of life with subscales in general health perception, physical functioning, role limitation due to physical problems/emotional problems, social functioning, pain, energy and fatigue, and mental health
Multidimensional Fatigue Inventory (20 items)	McCann & Boore (2000) O'Sullivan & McCarthy (2007)	4-20 on each subscale with higher score indicating higher fatigue	Internal consistency = 0.89, convergent validity between each subscale and VAS (0.69)	General fatigue, physical fatigue, mental fatigue, reduced activity and motivation

The Pearson Byars Fatigue Feeling Checklist (10 items)	Srivistava (1989)	0-100	Not reported	Fatigue intensity
The Fatigue Symptom Checklist (30 items)	Srivistava (1989)	0-30	Not reported	Fatigue intensity, drowsiness/dullness, difficulty with concentration, projection of physical impairment
The Brief Fatigue Inventory (9 items)	Leinau, Murphy, Bradley & Fried (2009)	0-70	Not reported	Presence of fatigue, interference of fatigue with activity, mood, relations with others and enjoyment of life
The Fatigue Assessment Scale in Mandarin Chinese (18 items)	Liu (2006)	18-90, higher score = higher fatigue	Internal consistency for total FAS = 0.85	Physical problems due to lack of energy, psychosocial responses to fatigue
The Hemodialysis		0-87	Internal	Rates incidence and severity of

Stressor Scale (29 items)	Mok & Tam (2001)		consistency: 0.89, test-retest reliability = 0.71	stressors associated with HD with a physiological and psychological subscale
Kidney Disease Questionnaire (26 items)	Brass, Adler, Sietsema, Hiatt, Orlando, & Amato (2001) Canadian Erythropoietin Study Group (1990) Sklar, Riesenber, Silber, Ahmed, & Ali (1996) Keown, et al. (2010)	7-point Likert scale for each item, no description of scoring	Construct validity with Sickness Impact Profile, no overall coefficient reported. Test-retest reliability: 0.85 (physical and fatigue), 0.96 (relationships with others and frustration) 0.98 (depression)	5 dimensions of kidney disease, physical symptoms, fatigue, depression, relationships with others and frustration
Likert scale	Harris, Chapman, Stewart, Lawrence, & Roger (1991)	1 = severe, 7 = no problem	None reported	Fatigue intensity
Likert scale	Malagoni, Catizone, Mandini, Soffritti,	0 = absent, 5 = severe	None reported	Fatigue intensity

Manfredini, Boari, et al. (2008)

Likert scale

Williams, Sklar, Burright, & Donovan (2004)

0 = none, 5 = overwhelming

None reported

Fatigue intensity

Table 2.
Researchers who Measured the Presence or Absence of Fatigue in Hemodialysis Patients

Author and year	How information obtained
Raju, White, Barnes, Smith, & Kirchner (1982)	Patients questioned by dialysis staff as to whether symptom was present or absent
Sadowski, Allred, & Jabs (1993)	Post dialysis symptom occurrence, not clear if asked by staff or used questionnaire
Singh, Bansal, Thakur, Kohli, Bansal, & Agarwal (2003)	Occurrence of symptom measured at 3 time points, not clear how information was obtained

Table 3.
 Researchers who Created a Fatigue Instrument

Author and year	Instrument details
Jablonski (2007)	Rate 11 most common symptoms experienced by HD patients. Patients rated intensity 1=not severe to 5=severe; frequency 1=not frequent to 5=every day; duration 1=not long to 5= all day, distress 1= none to 5=severe distress. Scored 0-20. Internal consistency = .67, test-retest = .78
Sklar, Newman, Scott, Semenyuk, Schultz, & Fiacco (1999)	Post-dialysis fatigue intensity rated hourly. Range 0-none, 1 = mild (noticed but without effects), 2 = moderate (sluggish), 3= severe (required rest), 4= overwhelming (slept). Maximum fatigue score within a 6-hour period after dialysis session recorded and compared to fatigue rating on a non-dialysis day. No psychometrics reported.
Sklar, Riesenbergm Silber, Ahmed, & Ali (1996)	A patient who complained of feeling fatigue was asked to rate frequency, duration, and intensity on a 1 (none) to 5 (extreme) scale. These three ratings were divided by 3 to give a fatigue index. No psychometrics reported.
Sklar, Beezhold, Newman, Hendrickson, & Dreisbach (1998)	Total number of hours a patient slept or felt fatigued for up to 6 hours after dialysis. Measured only presence or absence of fatigue and the duration. No psychometrics reported.

Interventions to Help Alleviate Fatigue in Patients on Dialysis

Fatigue is a troubling and intrusive symptom for many patients receiving dialysis. Numerous interventions have been explored in an attempt to alleviate the effects of fatigue in this population. This section will discuss and evaluate the types of interventions that have been used in this population and their success in lessening fatigue.

Physical Activity. Engaging in physical activity appears to be successful in alleviating fatigue in dialysis patients (Chang, Cheng, Lin, Gau, & Chao, 2010; Gordon, Doyle, & Johanson, 2011; Malagoni, Catizone, Mandini, Soffritti, Manfredini et al., 2008; Ridley, Hoey, & Ballagh-Howes, 1999; Wilson, 2006; Yurtkuran, Alp, & Dilek, 2007). Modified yoga sessions done for 30 minutes, two times a week, for 12 weeks, and range of motion exercises at home resulted in significantly decreased fatigue levels as compared to engaging in range of motion exercises only (Yurtkuran et al., 2007). Participating in exercise during the hemodialysis session that included stretching, light weight lifting and flexibility training (Ridley et al., 1999; Wilson, 2006); leg ergometry exercise (Chang et al., 2010); and a home exercise program such as walking for 10 minutes twice a day on non-dialysis days has also been effective in lessening fatigue (Malagoni et al., 2008). Gordon et al. (2011) found a significant negative relationship between physical activity as reported on the Human Activity Profile ($r = -0.32, p = 0.02$) and recorded with accelerometers ($r = -0.45, p = 0.02$), and fatigue. However, in contrast to these positive results regarding exercise and fatigue, Henson, Gillespie, McCarthy, Finch, Chatterton et al. (2010), in an exercise feasibility study using stationary bicycles found that there was no significant difference between baseline fatigue scores and post-intervention fatigue scores. The small sample sizes and quasi-experimental study designs

(Malagoni et al., 2008; Ridley et al., 1999; Wilson, 2006) limit generalizability of these findings to the larger hemodialysis population. Further, these studies had large ranges in participant ages and differing lengths of time on hemodialysis, which may affect findings as older participants may have a more difficult time with exercise due to arthritis or other physical ailments not related to kidney disease, and duration on hemodialysis may affect overall fatigue levels. This complicates our ability to determine if certain groups respond better to physical activity than others. Each study used a different measure of fatigue such as the Piper Fatigue Scale (Ridley et al., 1999), the Fatigue Severity Scale (Wilson, 2006), the Visual Analogue Scale (Yurtkuran et al., 2007), the Multi-Fatigue Inventory (Henson et al., 2010) and a fatigue index created by Sklar (1996) for use in his studies of post-dialysis fatigue (Gordon et al., 2011); yet none of the studies provided an explanation for their choice of measures and none discussed the reliability and validity of these tools in the dialysis population. Appropriately, all intervention studies excluded patients who had uncontrolled blood pressure problems, recent cardiac events such as myocardial infarction, or those deemed too ill by their care provider to participate, as many dialysis patients have cardiac conditions, pain, and other issues that prevent them from exercising regularly or effectively (Williams, Stephens, McKnight, & Dodd, 1991). Different forms of physical activity may be an effective means for decreasing fatigue in relatively healthy dialysis patients. However, physical limitations, varying patient demographics, and measurement issues pervade this area of study and limit our ability to decide which dialysis patients and what type and duration of activity is needed to have the maximum beneficial effect on fatigue.

Correction of physiological deficiencies. Another method used to help ameliorate fatigue in patients on dialysis is the supplementation of substances that occur naturally in the body but become deficient as the kidneys fail (Barany, Pettersson, & Konarski-Svensson, 1993; Brass, Adler, Sietsema, Hiatt, Orlando et al., 2001; Foley, Curtis, & Parfrey, 2009; Harris, Chapman, Steward, Lawrence, & Roger, 1991). Erythropoietin and L-carnitine are substances made in the kidneys whose production is impaired due to kidney failure.

Erythropoietin. Erythropoietin is a hormone that is produced by the kidneys and stimulates red blood cell production in the body. Dialysis patients have low erythropoietin levels, leading to impaired production of red blood cells in the body, resulting in anemia. These patients may receive recombinant human erythropoietin (EPO) to stimulate red blood cell production and raise the levels of hemoglobin in the body. There is much debate over what constitutes optimal hemoglobin levels for dialysis patients. In a healthy person, the normal hemoglobin level for an adult male is 13.5-18 g/dL and for an adult female is 12-16 g/dL. Targeting these “normal” levels for patients on dialysis with the use of EPO has been shown to be unsafe, resulting in a higher risk of cardiovascular and cerebrovascular events (Singh et al., 2006). These findings led to the current recommendations from the National Kidney Foundation that suggest a hemoglobin level between 11 g/dL and 12 g/dL, not to exceed 13 g/dL, for patients on dialysis (National Kidney Foundation, 2006).

Regardless of the debate, correcting anemia resulting from kidney failure with EPO has been effective in mitigating fatigue in dialysis patients. In a small study, patients who received EPO titrated to reach a stable hemoglobin level were followed over a year

and reported that they experienced a significant reduction in fatigue (Harris et al., 1991). Another small study found that dialysis patients who received EPO to a target hemoglobin of 10g/dL had significantly lower fatigue levels after the target hemoglobin was reached (Barany et al., 1993). The Canadian Erythropoietin Study Group found that patients treated with EPO also had a significant decrease in fatigue from baseline to 2 month follow-up as compared to those who were treated with a placebo ($r^2 = 0.395$, $p=.03$) (Keown, Churchill, Poulin-Costello, Lei, Gantotti et al., 2010). A large longitudinal study found that patients who received EPO at randomization to achieve a normal hemoglobin level (13.0-15.0 g/dL) had significantly better vitality scores as measured by the SF-36 than patients who were randomized to the subnormal range (10.5-11.5 g/dL) and received EPO only after their hemoglobin dropped below 10.5 g/dL (Drueke, Locatelli, Clyne, Eckhardt, Macdougall et al., 2006). A similar longitudinal study found that patients randomized to the normal target group (13.5-14.5 g/dL) had significantly better fatigue scores than those randomized to the low target group (9.5-11.5 g/dL) (Foley et al., 2009). Two of these studies had small sample sizes (28 and 24) and did not discuss power calculations for their study. Therefore we are unable to determine if the participant pool was large enough to provide reliable statistical results. This limits our ability to generalize these findings to the larger population. One of the larger longitudinal studies investigated only patients without pronounced cardiac disease, limiting the generalizability of these findings to other populations with kidney disease (Foley et al., 2009). It seems that achieving higher target hemoglobin levels is more effective in lessening fatigue in dialysis patients, but these higher levels are detrimental to patients' health. These results are in stark contrast to results presented earlier in this

article that suggest that anemia is not related to fatigue as indicated in primarily cross-sectional studies, demonstrating the need for further research into the association between anemia and fatigue, and what are safe, effective doses of EPO for dialysis patients.

L-carnitine. L-Carnitine is a nutrient made by the kidneys and liver that converts fat into energy and is important for muscle function. L-Carnitine supplementation is used to treat erythropoietin resistance, intradialytic hypotension, cramping (Ahmad, 2001; Hedayati, 2006) and muscle weakness and fatiguability that negatively affect patients' quality of life (Eknoyan, Latos, & Lindberg, 2003).

L-Carnitine supplementation may be an effective intervention for reducing fatigue in dialysis patients (Brass et al., 2001) but it is not approved by Medicare for use in treating fatigue only (Ahmad, 2001; Hedayati, 2006). Patients who are hypo-responsive to erythropoietin supplementation or patients who experience dialysis-related hypotension are covered by Medicare for L-Carnitine supplementation, but to continue coverage, there must be improvement of these conditions within three months after starting this treatment. Findings from three studies suggest that L-carnitine supplementation may be useful in lessening fatigue in dialysis patients. Dialysis patients who received intravenous L-Carnitine over a 12 week period had significantly reduced fatigue levels (Brass et al., 2001). Another study found that patients on hemodialysis who were treated with oral L-Carnitine over a 12 week period experienced improvement in muscle weakness and fatigue (Sakurauchi, Matsumoto, Shinzato, Takai, Nakamura et al., 1998). Similarly, oral L-Carnitine supplementation over a three month period in hemodialysis patients significantly improved the vitality score of study participants (Sloan, Kastan, Rice, Sallee, Yuenger et al., 1998). While all of the aforementioned

studies were randomized, controlled trials with large samples, none of the studies investigated fatigue explicitly. Two studies focused on quality of life (Brass et al., 2001; Sloan et al., 1998) and reported fatigue findings as a subset of their quality of life instrument. Sakurauchi et al. (1998) investigated muscular symptoms such as fatigue and weakness, which may not be the same phenomenon studied in the other studies. Further, Sloan et al. (1998) did not discuss the psychometric properties of the instrument used or justify its use with this population. Sakurauchi et al. (1998) relied on self-report of muscular symptoms with no observation to validate these reports. Two studies used oral L-Carnitine (Sakurauchi et al., 1998; Sloan et al., 1998); the other used intravenous L-Carnitine (Brass et al., 2001). Finally, inclusion and exclusion criteria for all of the studies were vague. Being clinically stable and able to exercise were two inclusion criteria found (Brass et al., 2001; Sloan et al., 1998). Brass et al. (2001) were the only authors to mention that they excluded patients who had conditions that would interfere with their ability to perform exercise such as respiratory or cardiac conditions. Indeed, L-Carnitine may be useful in lessening fatigue in dialysis patients, but the lack of evidence regarding its use specifically for fatigue makes it difficult to draw conclusions about its effectiveness. Additional studies are needed that have clear inclusion and exclusion criteria, measure fatigue explicitly, and have some type of observational data that reinforces self-report findings.

Adjustment of Dialysis-Related Variables. When a patient is dialyzed, waste and extra fluid in the blood diffuse across a membrane in the dialysis machine, and are removed from the body. The composition of these membranes was thought to be a source of clinical symptoms experienced by hemodialysis patients. One study investigated the

difference in cytokine release by blood when it came in contact with two different types of membranes (Singh, Bansal, Thakur, Kohli, Bansal et al., 2003). Cytokines are inflammatory markers and higher levels have been associated with fatigue in cancer patients. The study concluded that cytokine release increased with both types of dialyzer membranes, but the occurrence of clinical symptoms, including fatigue, after the dialysis session did not change based on the membrane used (Singh et al., 2003). This randomized prospective crossover study was conducted with 20 hemodialysis patients who had been on dialysis for at least one month. The majority of the sample (18) was men. The authors did not discuss participant recruitment methods other than to mention that patients had to be on dialysis for over one month and patients with certain comorbid conditions were excluded. Lastly, the study was conducted in India where cultural factors such as diet and activity levels may play a role in symptoms that patients experience. This single study indicated that dialyzer membranes may not play a part in symptoms, including fatigue, that are experienced during dialysis; however, this study alone did not provide enough evidence for care providers to draw definitive conclusions regarding the benefits of using different dialyzer membranes in the treatment of symptoms related to dialysis. Additional work is needed to determine if there is a relationship between dialysis membranes and fatigue in dialysis patients.

Another possible contributor to fatigue in dialysis patients is the type of dialysate used in the dialysis process. Dialysate is the fluid that is used in the diffusion process that is dialysis. The dialysate fluid draws extra fluid and waste from the blood through the dialyzer membrane. Normally, dialysate has a high concentration of glucose among other electrolytes (Sharma & Rosner, 2008). Three studies found that changing the composition

of the dialysate fluid seemed to be successful in ameliorating fatigue in patients on hemodialysis. The difference in the frequency and number of clinical symptoms after dialysis when using a glucose-free dialysate versus a low-glucose dialysate was investigated by one set of researchers (Raju, White, Barnes, Smith, & Kirchner, 1982). They found that fatigue after dialysis decreased significantly when glucose was added to the dialysate solution (Raju et al., 1982). A different trial investigated the impact of different glucose levels on fatigue in diabetic and non-diabetic dialysis patients (Raimann, Kruse, Thijssen, Kuntsevich, Diaz-Buxo et al., 2010). They found that fatigue scores in diabetic patients were significantly higher in the group who received higher glucose levels in the dialysate. Further, a lower glucose concentration decreased fatigue in diabetic patients to levels similar to healthy subjects (Raimann et al., 2010). Another group of researchers studied the response of clinical symptoms to the tailoring of sodium levels in the dialysate throughout the hemodialysis session (Sadowski, Allred & Jabs, 1993). Typically, the sodium concentration in the dialysate remains at a constant level throughout the hemodialysis session (Sadowski et al., 1993). Findings from this study indicated that fatigue after dialysis sessions significantly decreased in those whose sodium levels were tailored (Sadowski, et al., 1993). While these studies present seemingly successful ways in which physiology can be manipulated to decrease fatigue in dialysis patients, these are the only studies of their kind. Further, two are over 15 years old. All studies have a small number of participants, and investigated post-dialysis fatigue only. These factors limit our ability to conclude that these methods are a successful way to decrease fatigue in dialysis patients. Manipulating dialysate composition may be

successful in lessening fatigue in hemodialysis patients, but further research is needed to inform the practice of health care providers.

Receiving dialysis more frequently, at night, and cooling the dialysate have all had a positive impact on fatigue, but they have been studied primarily in relationship to post-dialysis fatigue. Daily hemodialysis, occurring five to seven times per week rather than intermittent hemodialysis which occurs 3 times per week, has demonstrated success in decreasing post-dialysis fatigue (Jaber, Lee, Collins, Hull, Kraus et al., 2010; Maduell, Navarro, Torregrosa, Rius, Dicenta et al., 2003; Ting, Kjellstrand, Freitas, Carrie, & Zarghamee, 2003). One study cooled the temperature of the dialysate from the normal 37 degrees Celsius to 35 degrees Celsius. They used a modified questionnaire developed by Sklar et al. (1999) that asks about the duration and intensity of post-dialysis fatigue. Researchers found that cooler dialysate significantly decreased the severity and duration of post-dialysis fatigue ($p < 0.001$) (Azar, 2009). Lastly, Van Eps, Jeffries, Johnson, Campbell, Isbel et al. (2010) found that switching patients to dialysis performed at night significantly decreased fatigue scores, as measured by the Kidney Disease Quality of Life instrument, over six to twelve months ($p = 0.03$). While these findings are important, they do little to expand our knowledge regarding the general fatigue that patients on hemodialysis experience and how more frequent dialysis, lower dialysate temperatures, and nighttime dialysis might affect this. Different instruments were used in the various studies to measure post-dialysis fatigue, all of which measure a different element of the phenomenon. The fatigue index, developed by Sklar (1996, 1999), measured intensity and duration of post-dialysis fatigue (Maduell et al., 2003), and the Kidney Disease Quality of Life instrument contains a subset of questions that measured energy/fatigue

(Ting et al., 2003; Van Eps et al., 2010). The last study used a single question that asked participants how long in minutes it took them to recover from dialysis sessions. Further, three of the four studies had small participant numbers (8, 42, and 50). All of the studies investigating dialysis frequency included participants who were previously receiving dialysis three times weekly and were over 18 years of age but failed to exclude participants with co-morbidities or taking medicines that could affect how they felt immediately after dialysis. Further work is needed to determine what effect, if any, these variables have on overall fatigue that hemodialysis patients experience.

Alternative therapies. In addition to adjusting physiologic and dialysis-related variables in the attempt to decrease fatigue, several alternative therapies have been used successfully to decrease fatigue in patients on hemodialysis (Cho & Tsay, 2004; Su, Wu, lee, Eang, & Liu, 2009; Tsay, 2004; Tsay, Cho, & Chen, 2004). Far infrared rays to stimulate acupoints (Su et al., 2009), accupressure used alone (Tsay, 2004) and in conjunction with massage (Cho & Tsay, 2004), and transcutaneous electrical acupoint stimulation (Tsay et al., 2004) all have been effective in decreasing fatigue in dialysis patients. In a randomized control trial, Tsay (2004) found that acupressure done 3 times a week for 4 weeks significantly decreased fatigue in Taiwanese patients on hemodialysis, and there was a significant difference in mean fatigue levels between the experimental group and the control group (Tsay, 2004). Using the same sample from the aforementioned study, Tsay et al. (2004) studied the effect of acupressure and transcutaneous electrical acupoint stimulation (TEAS) on fatigue. TEAS is an alternative to acupressure and uses low frequency electrical stimulators on acupoints (Tsay et al., 2004). Researchers used four acupoints in the feet and legs. They found that those who

received acupressure or TEAS had lower levels of fatigue than the control group, but there was no difference in fatigue levels between the acupressure and TEAS groups. Similarly, Cho and Tsay (2004) found that acupressure and massage significantly decreased fatigue in a separate sample of patients on hemodialysis in Taiwan. Su et al. (2009) found that far infrared acupoint stimulation was more effective in mitigating fatigue in hemodialysis patients than heat pad therapy. Stanley, Leither, and Sindelir (2011) used a holistic breathing technique that consisted of slow breathing while focusing on moving air in and out of the chest. They measured fatigue and quality of life variables using the Kidney Disease Quality of Life instrument prior to teaching patients the breathing technique but did not re-administer this tool after the intervention, citing the short time frame of the pilot. Rather, they asked participants if the breathing intervention was helpful to them (Stanley et al., 2011). We are unable to speculate about the success of interventions in western countries such as the United States where alternative therapies are less accepted and not covered by medical insurance. While Stanley et al. (2011) conducted their study in the United States, they did not measure fatigue consistently from the baseline measurement to the post-intervention measurement, making it difficult to discern the effects of the intervention on fatigue. Furthermore, three of these studies (Cho & Tsay, 2004; Tsay, 2004; Tsay et al., 2004) use the Piper Fatigue Scale, developed to measure fatigue in cancer patients, to measure fatigue in the hemodialysis population, without addressing the reason for choosing this tool or why it was appropriate to use in this population. None of these studies provided a rationale for the time frame for treatment or dosage of treatment. Moreover, they did not address intervention decay. Alternative therapies pose a viable alternative to physiologic supplementation and

exercise in mitigating fatigue for dialysis patients; however, a regimen and dosage for these treatments should be supported by the literature. These treatments may be difficult to institute in a culture where western medicine is seen as the gold standard. Longitudinal studies that investigate dosage and decay of the intervention would be helpful in advancing the science of alternative therapies.

Summary

With the increasing incidence of ESRD, longer life expectancy of dialysis patients, and an inability to meet the need for kidney transplants, symptom management is an important component in enhancing dialysis patients' quality of life (Heiwe, Clyne, & Dahlgren, 2003; Lee, Lin, Chaboyer, Chiang, & Hung, 2007; McCann & Boore, 2000). The lack of a definition of fatigue in the dialysis population is troublesome, and the measurement of fatigue in patients on dialysis is even more problematic.

Interventions exist that help ameliorate fatigue in hemodialysis patients. Physical activity has demonstrated promise in the hemodialysis population as a way to lessen fatigue; however, exercise is not always a viable option for hemodialysis patients, as often they have disabilities or medical conditions that prevent them from exercising. Correction of physiological deficiencies, such as erythropoietin and L-Carnitine, also shows promise in alleviating fatigue in hemodialysis patients. Unfortunately, correcting these deficiencies does not work for all patients. Research regarding adjustment of dialysis-related variables such as dialyzer membranes, glucose and sodium concentrations in dialysate is inconclusive due to the small number of studies addressing this topic. Alternative therapies have also emerged as an effective way to ameliorate fatigue in hemodialysis patients. Again, these studies are limited in number and are conducted

outside of the US. It remains to be determined if they would be as successful in the US where alternative therapies are not as readily accepted.

Since there has been limited success in determining factors that are consistently associated with fatigue, and interventions for fatigue in this population are not effective for all patients on hemodialysis, the next logical step was to examine the experience of fatigue and its self-management in hemodialysis patients. Determining how fatigue affects patients' lives and identifying the steps that they take to manage fatigue has the potential to help other hemodialysis patients experiencing the same symptom. The following section describes the experience and self-management of fatigue in chronic illness followed by a description of the experience and self-management of fatigue in hemodialysis patients.

The Experience of Fatigue in Chronic Illnesses

Patients who begin hemodialysis experience many changes in their lives, one of which may be facing different symptoms related to their illness, such as fatigue. There is little evidence about the experience of fatigue for dialysis patients. Therefore, to gain an understanding of the experience of fatigue, findings from the literature on cancer-related fatigue, HIV-related fatigue, and fatigue in patients with heart failure were reviewed. These findings indicated that while the experience of fatigue in different illnesses may be similar in some aspects, there are also differences in the experience among illnesses. Similarities in fatigue among patients with these illnesses include a lack of energy, weakness, and loss of mobility that can be unpredictable and negatively impacts their ability to participate in daily household tasks, fulfill roles that are important to them, and work (Barroso, 2001; Falk, Granger, Swedberg, & Ekman, 2007; Hagglund, Boman, &

Lundman, 2008; Holley, 2000; Jenkin, Koch, & Kralik, 2006; Magnusson, Moller, Ekman, & Wallgren, 1999; Rose, Pugh, Lears, & Gordon, 1998; Wu & McSweeney, 2007). Differences in the experience of fatigue seem to be related to the underlying illness. Patients with heart failure found they needed to ask for help with physical activities such as lifting objects and walking up stairs (Ekman & Ehrenberg, 2002; Hagglund et al., 2008). For patients with HIV infection, fatigue signified a deterioration in health status and progression toward AIDS (Rose, et al., 1998). Particularly frustrating for patients with HIV-related fatigue was that their immune systems were restored to health, but their physical symptoms persisted (Barroso, 2001). Patients with cancer-related fatigue noted that their fatigue changed over time in relation to their treatment (Magnusson et al., 1999). Health care providers cannot assume that the fatigue experience of one illness is mirrored in another, emphasizing the need for a disease-specific knowledge base about the experience of fatigue. The extent to which the experience of fatigue for patients on hemodialysis is similar to that of those with cancer, HIV and heart failure-related fatigue is unclear.

Fatigue Management in Chronic Illness

Just as important as understanding the experience of fatigue among different illnesses is understanding how those with these illnesses manage their fatigue. Self-management in chronic illness is becoming increasingly important as medical treatment alone is not able to attend to the psychological, behavioral, and physical challenges of chronic disease (Costantini, Beanlands, McCay, Cattran, Hladunewich et al., 2008). Self-management includes the positive attempts that patients make to use resources and be active participants in their health care in order to optimize their health and mitigate

complications, symptoms, and disease burden (Curtin & Mapes, 2001). Involved in this process are the preventative actions, self-treatment, and decisions patients make concerning their health (Richardson, 1992). Fatigue is one of the most common symptoms in chronic illness and affects daily activities (Barroso, 2001; Falk et al., 2007; Hagglund et al., 2008), quality of life (Weisbord, et al., 2003; Yong et al., 2009), and longevity (Jhamb et al., 2009). Therefore, understanding the techniques and strategies patients employ to allay fatigue is essential to improve our ability to educate and support patients in the development and utilization of these techniques.

Evidence suggests that patients with cancer and HIV use several methods to manage fatigue, commonly modifying their activity and rest patterns (Borthwick, Knowles, McNamara, Dea, & Stroner, 2003; Corless, Bunch, Kempainen, Holzemer, Nokes et al., 2002; Lee, Tsai, Lai, & Tsai, 2008; Richardson & Ream, 1997; Siegel, Brown-Bradley, & Lekas, 2004). Patients with cancer-related fatigue tried to stay involved in social activities (Borthwick et al., 2003; Richardson & Ream, 1997) and elicited moral support from family and friends (Lundberg & Rattanasuwan, 2007). Unfortunately, these self-care techniques were largely ineffective for patients with cancer-related fatigue (Borthwick et al., 2003; Richardson & Ream, 1997). Patients with HIV-related fatigue enhanced diets with vitamins and nutritional supplements, used complementary or alternative therapies (Corless et al., 2002; Siegel et al., 2004), and limited social commitments (Corless et al., 2002; Siegel et al., 2004). This research indicates that patients with chronic illness employ several means to manage their fatigue and that strategies of self-care differ among chronic illnesses. It is important to identify the ways in which patients on hemodialysis manage their fatigue in order to intervene in a

manner that is most helpful.

The Experience of Fatigue in Patients on Dialysis

Dialysis patients are unique because of 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 that includes the patient's perceptions, evaluations and responses to the symptom is important for the development of interventions to help alleviate fatigue. The only studies (five) to investigate the experience of fatigue in dialysis patients focused on how fatigue affected physical and cognitive functioning. Further, three of the studies were conducted outside of the United States; thus, there is a need for similar research in the US since cultural and health care system differences may affect the experience of fatigue. There was a negative correlation between fatigue and physical functioning ($r=-0.76$, $p<0.01$ [(McCann & Boore, 2000)]; $r=-0.37$, $p=0.007$ [(O'Sullivan & McCarthy, 2007)] and role limitations ($r=-0.47$, $p<0.01$; [(McCann & Boore, 2000)] in patients on hemodialysis. Brunier and Graydon (1993) found that fatigue was inversely correlated with activity levels ($r=-0.51$, $p<0.0005$) in patients on hemodialysis. These studies are helpful because they illustrate that in general, fatigue negatively affects physical functioning, but they fail to capture the full impact of fatigue. Two qualitative studies conducted outside of the US 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 et al., 2007). Physical fatigue seemed to be worse on hemodialysis days (Heiwe et al., 2003) and affected participants' ability 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 abilities to remember and concentrate (Heiwe et al., 2003; Lee et al., 2007). This study sought to provide a detailed description of the experience of fatigue and the techniques patients used to manage fatigue. Further, the use of a fatigue diary in data collection provided a real-time account of the experience of fatigue and helped describe how fatigue changes over time between dialysis sessions.

Fatigue Management in Dialysis Patients

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. Symptom management is an important part of disease management for patients on dialysis; particularly because they have a decreased life expectancy (NIKKD, 2009), which in turn, reduces the amount of time they have to adjust to, adapt to, and learn management strategies for the symptoms they experience. Much of the literature focused on symptom management when a patient has declined dialysis initiation or on end-of-life care when a patient decides to withdraw from dialysis (Chan, Noble, Lo, Kwan, Lee et al., 2007; Cohen, Germain, Poppel, Woods, & Kjellstrand, 2000; Daines, 2004; DeVelasco & Dinwiddie, 1998; Germain & Cohen, 2007,2008; Germain, Cohen, & Davison, 2007; Holley, 2005, 2007; Kuebler, 2001; Madar, Gilad, Elenhoren, & Schwarz, 2007; Murphy, Murtagh, Carey, & Sheerin, 2009; Murray, Arko, Chen, Gilbertson, & Moss, 2006; Murtagh, Addington-Hall, Donohoe, & Higginson, 2006; Murtagh, Murphy, Shepard, Donohoe, & Edmonds, 2006; Neely & Roxe, 2000; Noble, 2008; Noble & Kelly, 2006; Noble & Rees, 2006; Weisbord et al., 2003; Yong et al.,

2009). Indeed, these are important times for symptom management, but this focus has discounted the significance of symptom management for dialysis earlier in the trajectory of the illness when patients are struggling with the challenges associated with ESRD and dialysis. Patients on hemodialysis have identified fatigue as a symptom that is highly stressful and intrusive (Burns, 2004; Devins, Mandin, Hons, Burgess, Klassen et al., 1990; 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 (Logan et al., 2006; Mok & Tam, 2001), these general coping mechanisms do not specifically address coping with fatigue. Thus, existing research findings are not sufficient to inform or further our knowledge about specific self-management strategies that dialysis patients use to deal with fatigue. There remains a critical lack of knowledge regarding this area of inquiry. Identifying the ways in which dialysis patients manage fatigue will allow us to support patients who manage their fatigue successfully, and to educate and intervene with patients who need assistance in managing their fatigue.

Summary

Fatigue is one of the most common symptoms that patients with chronic illness experience; patients on hemodialysis must find ways to manage their fatigue and mitigate its effects on their lives. To date, there is no description of the experience of fatigue for US patients on hemodialysis. Further, there is a significant lack of information about how patients on hemodialysis manage their fatigue. This dissertation study described fatigue as it was experienced by patients on hemodialysis, identified self-management techniques

used to lessen the effects of fatigue, and described how fatigue changed over time from one dialysis session to the next.

2. Fatigue in Hemodialysis Patients: A Review of Current Knowledge

End-stage renal disease (ESRD) is a common chronic illness that is increasing in incidence and prevalence (National Institute of Diabetes and Digestive and Kidney Disease, 2011). In 2008, more than 570,000 Americans were treated for ESRD and the incidence was 355 per one million (National Institute of Diabetes and Digestive and Kidney Disease, 2011). Furthermore, renal patients on dialysis are living longer, as the all-cause mortality rate among patients on dialysis has decreased over the last five years, and waiting longer for a kidney transplant (National Institute of Diabetes and Digestive and Kidney Disease, 2011). Although kidney function is partially replaced through dialysis, patients with ESRD endure many symptoms of the disease such as fatigue, nausea, vomiting, sleep disturbances, and pruritis (Almeras & Argiles, 2009; Yong, Kwok, Wong, Suen, Chen et al., 2009). Like patients with other chronic illnesses, patients on hemodialysis endure a high symptom burden that causes daily distress and negatively affects their quality of life (Davison & Jhangri, 2010; Jablonski, 2007a; Weisbord, Fried, Arnold, Fine, Levenson et al., 2005). Fatigue is one of the most common symptoms experienced by dialysis patients (Jablonski, 2007; Weisbord et al., 2005) with its prevalence ranging from 60% to 97% (Murtagh, Addington-Hall & Higginson, 2007; Weisbord, et al., 2005) and has been found to be predictive of cardiac events (Koyama, Fukuda, Shoji, Inaba, Tsujimoto et al., 2010) and all-cause mortality (Jhamb, Pike, Ramer, Argyropoulos, Steel et al., 2011). Symptom management of fatigue is an essential part of improving quality of life for patients on hemodialysis. To help patients on hemodialysis manage their fatigue, it is important to understand the relevant science regarding fatigue in this population. The purpose of this review is to provide a

“state of the science” of fatigue in hemodialysis patients by examining the experience of fatigue for patients on hemodialysis and correlates of fatigue. The review concludes with implications for clinical practice and suggestions for future research.

Methods

A search of PubMed, the Cumulative Index to Nursing and Allied Health Literature, PsycINFO, and Sociological Abstracts generated the majority of articles referenced in this review. Databases were searched using the key terms “fatigue,” “dialysis,” and “hemodialysis.” The search was limited to articles in English written after 1980 and focused on articles that discussed the measurement and experience of fatigue as it relates to hemodialysis patients; factors related to fatigue; and interventions aimed at decreasing fatigue in hemodialysis patients. Only articles that had explicit findings related to fatigue were included in this review; hence, articles that included quality-of-life findings with no discernable fatigue findings were not included. To focus on fatigue in hemodialysis patients, articles that discussed fatigue in peritoneal dialysis patients or renal transplant patients or studies that included peritoneal dialysis or transplant patients were excluded from this review. The reference lists of each selected article were searched and any applicable manuscripts found were researched and included if they fit the above criteria.

Results

The Experience of Fatigue

The literature regarding the experience of fatigue in hemodialysis patients indicates that fatigue seems to impact primarily the physical and mental domains. Physical fatigue was described by patients as a constant lack of energy, which seemed worse on dialysis days. Fatigue is negatively correlated with physical functioning

(McCann & Boore, 2000; O'Sullivan & McCarthy, 2007), role limitations (McCann & Boore, 2000), activity levels (Brunier & Graydon, 1993), and mental and physical quality of life (Davison & Jhangri, 2010). It impacts patients' abilities to manage their everyday activities (Kazemi, Nasrabadi, Hasanpour, Hassankhani & Mills, 2011; Lee, Lin, Chaboyer, Chiang & Hung, 2007), which require more time to complete when patients are fatigued and leads them to feel isolated from others and society (Kazemi et al., 2011). Fatigue also negatively affects patients' abilities to remember and concentrate on conversations and what is going on around them (Lee et al., 2007). Some feel too fatigued to communicate with others and have difficulty maintaining close relationships (Kazemi et al., 2011). Clearly, fatigue is frequently debilitating and hinders participation in even simple physical and mental activities for patients on dialysis.

Postdialysis fatigue. Postdialysis fatigue is a frequent complaint of hemodialysis patients and occurs after dialysis sessions (Sklar, Riesenberg, Silber, Ahmed, & Ali, 1996). Patients who experienced fatigue after dialysis required almost five hours of sleep to recover after their session and had more depression, insomnia, and body aches than those who did not experience postdialysis fatigue (Sklar et al., 1996). Furthermore, patients with postdialysis fatigue experienced limitations in their functional independence and participation in social activities on the day of dialysis (Rocco, Mercieri & Yavuzer, 2006). Postdialysis fatigue is not predicted by clinical measures such as nutrition, laboratory results, or the adequacy of dialysis (Sklar et al., 1996). Research suggests that it may be part of a symptom complex that includes nausea, muscle cramps, and headache, which may be the result of the fluid shifts that occur during hemodialysis (Sklar, Newman, Scott, Semenyuk, Schultz et al., 1999). It is possible that postdialysis fatigue is

conceptually similar to the persistent fatigue that patients experience but differs in severity and timing.

Factors That May Contribute to Fatigue

Many researchers have explored factors thought to be related to fatigue in patients on hemodialysis, yet none have been able to pinpoint a cause or identify a combination of factors that could consistently predict fatigue. The following sections review factors thought to be associated with fatigue, including demographic, psychosocial and physiological factors, and sleep (see Table 4 for details).

Demographic factors. Research indicates that, in general, patients who are older, female, and white/Caucasian may have higher levels of fatigue, but at times, the evidence is not clear. Some studies found no relation between fatigue and demographic variables such as age (Kim & Son, 2005; O'Sullivan & McCarthy, 2007), gender (Kim & Son, 2005), and education level (Liu, 2006). However, others found significant relationships between these and other demographic variables and fatigue. Most findings indicate that women report higher levels of fatigue than men (Liu, 2006; Morsch, Goncalves & Barros, 2006; O'Sullivan & McCarthy, 2007). Other studies demonstrate that age is associated with higher fatigue levels among patients on dialysis (Bossola, Luciani & Tazza, 2009; Jhamb et al., 2011; Koyama et al., 2010; Letchmi, Das, Halim, Zakariah, Hassan et al., 2011; Liu, 2006). Liu (2006) found that patients receiving hemodialysis in their early sixties reported significantly higher total fatigue levels ($r = 0.24$, $P < 0.01$) than those in their thirties. In contrast, Letchmi et al.(2011) and Bossola et al. (2009) found that age was negatively correlated with fatigue levels ($\chi^2 = 7.683$, $P = 0.00$) ($r = 0.25$, $P = 0.04$). Other findings indicate that being Caucasian and unemployed may be related to higher

levels of fatigue (Jhamb et al., 2011; Kutner, Brogan, Fielding & Hall, 2000) ($t = 4.32$, $P < 0.01$). Yet O'Sullivan and McCarthy (2007) and Koyama et al. (2010) found no significant differences in fatigue levels between the employed and unemployed ($t=1.221$, $P = 0.22$). It is possible that demographic variables such as these may help identify a group of patients who are more at risk for fatigue than others.

Psychosocial Factors. Psychosocial variables related to fatigue have not been well studied in the hemodialysis population. Depression, anxiety, and social support have been studied with regard to their relationship to fatigue in patients on hemodialysis. Three studies (Bossola et al., 2009; Kim & Son, 2005; Leinau, Murphy, Bradley & Fried, 2009) found that fatigue was significantly correlated with depression in hemodialysis patients. Furthermore, Chen, Tsai, Hsu, Wu, Sun et al.(2010) found that not only depression but also a risk of suicide was correlated with fatigue ($r = 0.68$, $r = 0.37$, $P < 0.001$). Depression was correlated with fatigue severity (Kim & Son, 2005; McCann & Boore, 2000;) and physical and mental fatigue (McCann & Boore, 2000). Liu (2006) and Garcia, Veiga, da Motta, de Moura & Casulari (2010) found that fatigue scores were significantly higher for those hemodialysis patients who were depressed than for those who were not depressed ($t=-7.63$, $P = 0.01$ and $r^2=0.518$, $P < 0.001$, respectively) and that depression was a significant predictor of fatigue in this population ($r^2 = 0.46$, $P < 0.05$). Similarly, Williams, Crane & Kring (2007) found that mood disorder, which included depression and anxiety, significantly predicted fatigue, explaining 28% of the variance ($F = 13.119$ (1,34), $P = 0.001$) in this population. Four other studies found that anxiety was significantly correlated with fatigue (Bossola et al., 2009; Chen et al., 2010; McCann & Boore, 2000; Williams et al., 2007). Conversely, Letchmi et al.(2011) found that there

was no significant relationship between fatigue and anxiety ($\chi^2 = 0.042$, $P = 0.838$). Two studies found that social support is not related to fatigue in hemodialysis patients (Kim & Son, 2005; Williams et al., 2007) but this relationship has not been studied extensively. Seven of these studies were conducted outside the U.S. (Taiwan [2], Korea, Malaysia, Brazil, Italy, and Ireland), where perceptions of depression, anxiety, fatigue, and social support may vary as a result of differences in the social context of other cultures.

Physiological Factors. Physiological variables have been investigated in relation to fatigue in patients on dialysis. It is difficult to determine which specific facet of human physiology is most culpable in the occurrence of fatigue. Indeed, it may be a combination of physiological factors that contribute to fatigue in hemodialysis patients. Interdialytic weight gain, weight gain that occurs between dialysis sessions as a result of fluid accumulation, has been significantly correlated with fatigue in dialysis patients. One study, conducted with 104 Korean patients, found a weak but significant correlation between fatigue and interdialytic weight gain ($r = 0.21$, $P < 0.05$) (Kim & Son, 2005). This association indicates that weight gain may be one of the many contributors to fatigue in hemodialysis patients. Serum chemistry and hematology measures also have been investigated with regard to fatigue in dialysis patients and, for the most part, do not seem to significantly contribute to fatigue in this population. In a study of 38 African American women on hemodialysis, Williams et al.(2007) found that fatigue was weakly correlated with anemia ($r = 0.374$, $P = 0.012$). Furthermore, two Italian studies found that interleukin-6 levels (3.08 ± 1.5 , 10.9 ± 11.9 , $P < 0.0001$; $r = -0.65$, $P < 0.0001$) (Bossola et al., 2009; Bossola, Luciani, Giungi & Tazza, 2010) and C-reactive protein levels (4.1 ± 4.4 , 9.2 ± 6.3 , $P = 0.001$) were significantly related to fatigue (Bossola et

al., 2010). Conversely, in cross-sectional analyses, most studies found that anemia (Kim & Son, 2005; Koyama et al., 2010; Leinau et al., 2009; Letchmi et al., 2011; McCann & Boore, 2000; Morsch et al., 2006); albumin levels (Koyama et al., 2010; Liu, 2006; McCann & Boore, 2000; Morsch et al., 2006; Williams et al., 2007); blood urea nitrogen and creatinine levels (Kim & Son, 2005; McCann & Boore, 2000); and calcium, phosphorus (McCann & Boore, 2000), potassium, and magnesium levels (Leinau et al., 2009) were not related to fatigue in patients receiving hemodialysis. However, Bossola et al.(2009) found that fatigue increased with lower creatinine levels ($r=-0.33$, $P = 0.01$) and decreased significantly with higher albumin levels ($r = 0.29$, $P = 0.02$). The majority of these studies failed to exclude patients with comorbid conditions that may cause or exacerbate fatigue such as cancer or heart failure. All studies included subjects of varying ages and patients who had been on hemodialysis for varying lengths of time. One study made no mention of the time frame patients were on hemodialysis as an inclusion/exclusion criterion (McCann & Boore, 2000). Others included patients who were on hemodialysis for at least three months (Kim & Son, 2005; Leinau, 2009; Morsch et al., 2006), more than six months (Letchmi et al., 2011; Liu, 2006), one year (Bossola et al., 2009; Williams et al., 2007), or had been on hemodialysis for a maximum of four years (Kim & Son, 2005). This particular criterion is important as researchers have presented conflicting evidence regarding the impact of duration of hemodialysis on fatigue (Brunier & Graydon, 1993; Letchmi et al., 2011). Furthermore, the honeymoon period (Reichsman & Levy, 1972) that patients experience for about three months after they start hemodialysis may factor into fatigue levels. Dialysis adequacy, how well the dialyzer does the work of the kidneys, has been suspected as the source of various uremic

symptoms including fatigue in patients on hemodialysis. Three studies investigated Kt/V, a measurement of dialysis adequacy, in relation to fatigue. Findings from these studies indicated that Kt/V was not associated with fatigue in hemodialysis patients (Leinau, 2009; Liu, 2006; Morsch et al., 2006). One study included patients 18 years and older (Morsch et al., 2006), drawing upon a much younger population than the other two studies, which may affect fatigue levels. Furthermore, only two studies addressed comorbid conditions that are associated with fatigue as exclusion criteria (Liu, 2006; Morsch et al., 2006), and of these, only two conditions were identified. Lastly, all these studies were cross-sectional, studying variables at one time point.

Sleep. Poor sleep quality may be the result of a combination of physiological and psychological factors and presents a problem for many patients on dialysis. However, the extent to which poor sleep is related to fatigue in this population is unclear (Murtagh et al., 2007). McCann and Boore (2000) noted that less than half of their sample (44%) felt that they had enough sleep to feel rested ($n = 39$). Furthermore, they found that overall trouble with sleep was significantly correlated with general ($r = 0.476, P < 0.01$) and mental fatigue ($r = 0.468, P < 0.01$). Sleep-related breathing disorders also have been associated with fatigue in dialysis patients (Sanner, Tepel, Esser, Klewer, Hoehmann-Riese et al., 2002). Sanner et al. (2002) found that the severity of the sleep-related breathing disorder was significantly negatively correlated with the vitality scale of the SF-36- Health Survey, indicating that as the severity of the disorder increased, vitality in these patients decreased ($r = -0.39, P < 0.05$). Both of the aforementioned studies had small sample sizes ($n = 39$ and $n = 33$, respectively) and were cross-sectional in design. Intuitively, poor sleep is a likely cause of fatigue in the dialysis population; however,

there remains a lack of research regarding fatigue and poor sleep quality in dialysis patients.

Discussion

Fatigue is a significant problem for ESRD patients on hemodialysis (Jablonski, 2007; Weisbord et al., 2005). With the increasing incidence of ESRD, longer life expectancy of dialysis patients, and an inability to meet the need for kidney transplants, symptom management is an important component in enhancing dialysis patients' quality of life (Lee et al., 2007; McCann & Boore, 2000). Studies that address the experience of fatigue illustrate that, in general, fatigue negatively affects physical and mental functioning, but the studies lack detailed descriptions of other domains that fatigue may impact. The ways in which fatigue may influence social functioning, family relationships, and the ability to obtain and maintain employment, among other areas, have not been adequately explored. Additionally, these studies do not consider how postdialysis fatigue factors into the overall experience of fatigue. Furthermore, more than half of these studies were conducted outside the U.S., and cultural, sociological, and health care system differences may have an impact on the consequences of fatigue that are not transferrable to another setting. Hence, these findings may not completely address the unique experience of fatigue for hemodialysis patients in the U.S. There has been little progress in identifying demographic, psychosocial, or physiological factors that are consistently related to fatigue in hemodialysis patients. Studies that address these correlates are helpful in that they begin to identify groups of hemodialysis patients who may be at increased risk for fatigue. For instance, demographic factors such as female gender, older age, and Caucasian race have emerged as possible correlates of fatigue in hemodialysis

patients. However, this evidence is not strong as methodologically the expansive age ranges and large variance in inclusion and exclusion criteria are problematic and do not allow us to conclusively identify groups at risk. Research regarding the relationship of fatigue and psychosocial variables is not extensive. These studies are helpful because they establish a basis for further investigation into psychosocial variables that may be associated with fatigue and may play an important role in predicting hemodialysis patients at risk for fatigue. The small number of studies (nine) prohibits us from drawing conclusions regarding the associations among these variables and fatigue. At first glance, depression and anxiety are likely correlates of fatigue in hemodialysis patients, but research is limited to very few studies, many of which were conducted outside the U.S., where culture may play a role in the findings. In general, we can conclude that individual physiological factors are not related to fatigue in dialysis patients; however, most studies are cross-sectional and were not designed to study variations in these factors over time. Moreover, many studies do not address or exclude comorbid conditions that may be related to fatigue in this population. The small number of studies (12) and differing participant criteria regarding duration of hemodialysis limit our ability to draw conclusions about the relationship of these physiological variables and fatigue. Furthermore, several studies were conducted outside the U.S., where dietary customs may have an effect on serum chemistry levels. Although it seems that these variables are not related to fatigue in the hemodialysis population, there has been no replication of these studies using consistent inclusion and exclusion criteria or longitudinal designs that would better determine the relationship of physiological variables with fatigue. Sleep, logically, may be a significant contributor to fatigue in patients on hemodialysis.

However, there is a lack of research regarding the relationship between the two. Results from two, small, cross-sectional studies indicate that the quality of sleep may play an important role in fatigue in this population.

Implications for Future Work

The findings mentioned previously indicate that there is room for improvement in our understanding of the experience and correlates of fatigue in hemodialysis patients. A thorough understanding of the experience of fatigue in this population has the potential to direct health care practitioners and researchers to areas amenable for intervention. Qualitative work in this area of inquiry would be of benefit and has great potential to shed light on the domains of life that are affected by fatigue for hemodialysis patients and how patients choose to manage their fatigue. Furthermore, it is important to clarify if and how postdialysis fatigue differs from the persistent fatigue that hemodialysis patients experience. Indeed, insight into these phenomena may play a significant part in developing interventions to help alleviate fatigue for patients on hemodialysis. Several areas emerge from these results as promising topics for additional research. The identification of factors associated with fatigue may help practitioners identify hemodialysis patient populations that are at greater risk for fatigue. Demographic variables may prove to be important identifying factors in fatigue risk; these studies demonstrate the need for further research on fatigue as it relates to these variables, particularly age, race, and employment status. The varied inclusion and exclusion criteria in these studies make it difficult to generalize findings to the larger hemodialysis population. Additional research done in the U.S. that uses longitudinal designs and explicit inclusion and exclusion criteria and addresses comorbid conditions is needed to

further our understanding of the relationship between these factors and fatigue. The relationships between fatigue and inflammatory markers, interdialytic weight gain, sleep, and depression have been largely understudied in a rigorous manner. Insight into these areas may provide further explanation of the pathology and contributing factors to fatigue in this population. Baseline and routine screening of hemodialysis patients for issues known to contribute to fatigue in other populations, such as depression and sleep disorders, may help provide an increased awareness of fatigue for health care practitioners. Ideally, this would lead to further evaluation and treatment of these problems, which may not only mitigate the problems themselves but also may have a positive impact on fatigue levels for hemodialysis patients.

Conclusion

Fatigue is a particularly frequent and troubling symptom for patients on hemodialysis, yet our understanding of the experience of fatigue and its correlates in this population is limited. Because fatigue has such a detrimental effect on quality of life and has been associated with increased risk for mortality in hemodialysis patients, it is important to delve deeper into this phenomenon. Further work could illuminate areas appropriate for intervention and identify specific groups of hemodialysis patients who are at increased risk for fatigue; this would allow health care practitioners to intervene sooner and work to prevent the effects of this debilitating symptom.

Table 4.
Factors associated with fatigue in dialysis patients

Author (year)	Factor(s) Studied	Age Range	Inclusion/Exclusion Criteria	Study Design	n	Results
Kim & Son (2005)	Age, gender, education level, depression, social support, interdialytic weight gain, anemia, BUN, creatinine	30-60	<ul style="list-style-type: none"> - HD for 3 months-4 years - HD 2-3 times/week - No complications or disabilities - Complete questionnaires without assistance - 30-60 years of age 	cross sectional, correlational	104	Age, gender, education level, social support, anemia, BUN, and creatinine not associated with fatigue. Depression and interdialytic weight gain positively associated with fatigue
Kutner, Brogan, Fielding, & Hall (2000)	Gender and race	60 years or older	None described other than age requirement	Cross sectional	308	Women have higher fatigue levels than men and Caucasians take longer to recover from dialysis sessions than African Americans

Leinau, Murphy, Bradley & Fried (2009)	Depression, anemia, potassium, magnesium, Kt/V	41-85	<ul style="list-style-type: none"> - English speaking - 45 years or older - on HD 3 months or longer - no exclusion criteria described 	Observational cohort study	109	<p>Depression positively associated with fatigue. Anemia, potassium, magnesium, and Kt/V not associated with fatigue.</p>
Liu (2006)	Education level, gender, age, employment status, depression, anemia, albumin, Kt/V	20-65	<ul style="list-style-type: none"> - Dx with ESRD - regular HD treatments for at least 6 months - between 20-65 years of age - married - conscious, alert, oriented - without comorbidities associated with fatigue or increasing fatigue - able to communicate verbally 	Cross sectional correlational	119	<p>Education level, anemia, albumin, and Kt/V not associated with fatigue. Older people, women, depressed and unemployed have higher levels of fatigue.</p>

McCann & Boore (2000)	Depression, anxiety, anemia, albumin, BUN, creatinine, calcium, phosphorus, sleep quality	18-65	<ul style="list-style-type: none"> - aged 18-65 years - 2-3 HD sessions/week - able to read and write - permission from nephrology consultant - no comorbidities associated with fatigue 	Descriptive correlational	39	Depression, anxiety, and poor sleep quality correlated with fatigue. Anemia, albumin, BUN, creatinine, calcium, phosphorus, levels not associated with fatigue.
Morsch, Goncalves & Barros (2005)	Gender, anemia, albumin, Kt/V	18 years and older	<ul style="list-style-type: none"> - 18 years and older - male and female - ESRD - HD for over 3 months - no known neoplastic disease - no rejection of kidney transplant in last 6 months - no change in method of dialysis in last 3 months - inability to 	Descriptive cohort	40	Women reported higher fatigue levels than men. Anemia, albumin levels and Kt/V not associated with fatigue.

O'Sullivan & McCarthy (2007)	Physical functioning, age, gender, employment status	23-80	<p style="text-align: center;">provide information</p> <ul style="list-style-type: none"> - 18 years of older - ESRD - HD for at least 3 months - no comorbidities such as cancer, COPD, CHF, RA, SLE, depression or wheelchair dependent 	Exploratory correlational	46	Fatigue inversely related to physical functioning, women report higher fatigue levels than men. No correlation between age and employment and fatigue.
Williams, Crane & Kring (2007)	Depression, anxiety, social support, anemia, and albumin	27-65	<ul style="list-style-type: none"> - self-identified African American - speak English - ESRD - HD for at least 1 year - age 21-65 	Descriptive correlational	36	Depression and anxiety associated with fatigue. Social support and albumin levels no associated with fatigue. Anemia weakly correlated with fatigue.

Chen, Tsai, Hsu et al. (2010)	Depression, suicide risk, anxiety	18 years and older	- none discussed other than 18 years and older, HD patient and informed consent	Cross-sectional correlational	200	Depression, anxiety, and risk for suicide correlated with fatigue.
Bossola, Luciani, Giungi & Tazza (2010)	Anorexia, depression, C-reactive protein, Interleukin 6	18-80	- 3 times/week in center HD - HD for at least 6 months - no previous renal transplant - no hepatitis or active malignancy, active systemic infections, chronic inflammatory bowel disease, central venous catheter infections	Cross-sectional	76	Anorexic patients had higher frequency of fatigue, fatigued patients had higher frequency of anorexia. Interleukin 6 levels and CRP, significantly higher in fatigued patients
Bossola, Luciani & Tazza (2009)	Anxiety, depression, multiple comorbidities, insomnia, cognitive	Not discussed	- HD for at least 12 months - excluded due to: sepsis, catheter related infection, HIV, inflammatory	Cross sectional correlational	62	Fatigue in HD patients is common and correlated with age, number and severity of

function, C-reactive protein, IL-6, age, BMI, urea, creatinine, albumin, PTH, Kt/V, phosphorus, hgb, calcium, fibrinogen, ferritin, 25 hydroxyvitamin D

bowel disease, autoimmune disorders, hepatitis, liver failure, hyperparathyroidism, previous renal transplant

comorbidities, depression, anxiety, albumin, creatinine IL-6

52

Sanner, Tepel, Esser et al. (2002)

Quality of life, sleep-related breathing disorder

22-82

- older than 18 years
- ESRD
- HD for at least 3 months.
- Excluded if: uncontrolled HTN, malfunction of dialysis access, stroke, seizures, symptomatic ischemic heart disease, CHF, severe associated disease, anemia unrelated to

Cross sectional

33

Severity of sleep disorder negatively correlated with vitality

Letchmi, Das, Halim et al (2011)	Fatigue, depression, length of time on dialysis, anemia, anxiety, age	Not discussed	<ul style="list-style-type: none"> - aged 18 or older - HD for at least 6 months - write and understand English and local language - volunteered to be in study 	ESRD, use of sedatives or muscle relaxers	Cross sectional	103	No relationship between fatigue and anemia and anxiety. A significant relationship between fatigue and duration of time on HD, and age group
Jhamb, Pike, Ramer et al. (2011)	Quality of life, mortality, cardiac hospitalizations, multiple covariates	Not discussed	- Not discussed		Longitudinal	1798	At baseline patients with higher levels of fatigue more likely to be older, non-African American, unemployed & diabetic, more severe comorbidities, lower albumin

Jhamb, Pike, Ramer et al. (2011)	Quality of life, mortality, cardiac hospitalizations, multiple covariates	Not discussed	Not discussed	Longitudinal	1798	levels. No difference in creatinine, BMI, smoking status, duration on HD, anemia. Patients with lowest vitality scores had higher risk of death from any cause. Older adults had higher severity of comorbidities, used sleep medications had been on HD longer, more likely to have worsening fatigue over time.
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3. The Experience and Self-Management of Fatigue in Adult Hemodialysis Patients

Introduction

Chronic kidney disease, is often unpredictable and sometimes patients do not feel ill as the disease progresses to end-stage renal disease (ESRD), a chronic illness that affects over 525,000 people in the United States (National Institutes of Diabetes and Digestive and Kidney Disorders [NIDDK], 2009), and requires dialysis (hemodialysis or peritoneal dialysis) or kidney transplant (Iles-Smith, 2005). Patients on hemodialysis account for approximately 92% of the overall dialysis population 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; Merkus et al., 1999; Murtagh, Addington-Hall, & Higginson, 2007; Yong et al., 2009), all of which cause daily distress and negatively affects their quality of life (Jablonski, 2007; Kimmel, Emont, Newmann, Danko, & Moss, 2003; Weisbord et al., 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; Merkus, Jager, Dekker, De Haan, Boeschoted, et al. 1999; Ossareh, Roozbeh, Krishnan, Liakopoulos, Bargman, et al., 2003; Parfrey, Vavasour, Henry, Bullock, & Gualt, 1998; Weisbord, Fried, Arnold, Fin,e & Levenson, 2005), with a prevalence ranging from 60% to 97% (Bossola, Luciani, & Tazza, 2009; Cardenas & Kutner, 1982; Chang, Hung, Huang, Wu, & Tsai, 2001;

Letchmi et al., 2011; Murtagh, Addington-Hall, & Higginson, 2007; Parfrey et al., 1988, 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 most recently, with lower survival rates (Jhamb et al., 2009).

Causes of Fatigue in Patients on Dialysis

There has been little success establishing the cause or causes of fatigue in patients with ESRD on dialysis. Physical, social and dialysis-related factors have all been identified as possible causes of fatigue in dialysis patients (Jhamb et al., 2008). Malnutrition (Pagels, Heiwe, & Hylander, 2006), anemia (Jhamb et al., 2008), inflammatory changes (Dantzer & Kelley, 2007), sleep disorders (Unruh, Buysse, Dew, Evans, Wu, et al., 2006) and depression (Weisbord et al., 2005) are just a few of the sources of fatigue. Post-dialysis fatigue, which commonly occurs after a dialysis session and is incapacitating, is a particularly debilitating source of fatigue for this population. Often, treatment for fatigue is focused on the suspected cause. Treatments such as exercise (Fitts, 1997; Wilson, Malahy, Scialabba, & Woodrow, 2006) and management of anemia with erythropoietin–stimulating agents (Ossareh, Roozbeh, Krishnan, Liakopoulos, Bargman, et al., 2003; Williams, Crane, & Kring, 2007) have been used to treat fatigue in patients on hemodialysis. However, these interventions are not effective for all patients on hemodialysis who have fatigue (Williams, Stephens, McKnight, & Dodd, 1991) and may even be dangerous for some (Singh, Szczech, Tang, Barnhart, Sapp, et al., 2006).

The Experience of Fatigue in Patients on Dialysis

Dialysis patients 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 that includes the patient's perceptions, evaluation and response to the symptom is important for the development of interventions to help alleviate fatigue. The only studies (five) to investigate the experience of fatigue in dialysis patients, three of which were conducted outside of the United States, 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) in patients on hemodialysis. Brunier and Graydon (1993) found that fatigue was inversely correlated with activity levels ($r = -0.51$, $p < 0.0005$) in patients on hemodialysis. These studies are helpful because they illustrate that in general, fatigue negatively affects physical functioning, but they fail to capture the full impact of fatigue. Two qualitative studies conducted outside of the US 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' ability 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 Dialysis Patients

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. Much of the literature focuses on symptom management when a patient has declined dialysis initiation or on end-of-life care when a patient decides to withdraw from dialysis (Burns, 2004; Chan, Noble, Lo, Kwan, Lee, et al., 2007; Cohen, Germain, Poppel, Woods, & Kjellstrand, 2000; Daines, 2004; DeVelasco & Dinwiddie, 1998; Germain & Cohen, 2007; Germain & Cohen, 2008; Germain, Cohen, & Davison, 2007; Holley, 2005; Holley, 2007; Kuebler, 2001; Madar, Gilad, Elenhore, & Schwartz, 2007; Mok & Tam, 2001; Murphy, Murtagh, Carey, & Sheerin, 2009; Murray, Arko, Chen, Gilbertson, & Moss, 2006; Murtagh, Addington-Hall, Donohoe, & Higginson, 2006; Murtagh, Murphy, Shepherd, Donohoe, & Edmonds, 2006; Neely & Roxe, 2000; Noble, 2008; Noble & Kelley, 2006; Noble & Rees, 2006; Weisbord, et al., 2003; Yong et al., 2009). Indeed, these are important times for symptom management, but this focus has discounted the significance of symptom management for dialysis earlier in the trajectory of the illness when patients are struggling to face the challenges associated with ESRD and dialysis.

Patients on hemodialysis have identified fatigue as a symptom that is highly stressful and intrusive (Mok & Tam, 2001; Burns, 2004; Devins, Mandin, Hons, Burgess, Klassen, et al., 1990; Logan, Pelletier-Hibbert, & Hodgins, 2006). 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 dialysis patients use to deal with fatigue.

While there have been significant improvements in the quality of care for patients on hemodialysis (NIDDK, 2011), morbidity and mortality rates remain high and life expectancy is limited (NIDDK, 2011). Symptom management is an important part of disease management for patients on dialysis; particularly because they have a decreased life expectancy (NIDDK, 2009), 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 hemodialysis patients; 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 hemodialysis patients 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 hemodialysis.

Methods

Design

A longitudinal 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 hemodialysis patients.

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 hemodialysis patients. 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 (pregnancy) 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 very brief description of the study, and asked if they would be willing to speak with the first author (AH) about participating in the study. If patients gave permission, the first author (AH) 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, as these are the patients who would provide the best information about the phenomenon (Polkinghorne, 2005). 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; Byrne, 2001). In recruiting participants, the first author attempted to sample based on demographic variables such as age, ethnicity and gender, so that the resulting pool of participants was representative of the demographic characteristics of the dialysis population in the geographic area. The local population of dialysis patients was comprised of approximately 50% men and 50% women, 10-20% African American, 70-80% Caucasian, 10% Hispanic and 5-10% of patients were older than 50 years of age. The first author selected new patients for inclusion based on the demographic characteristics of previously recruited participants. An example of recruitment based on these demographics follows. At one point during the study, the sample consisted of six women, five of whom were Caucasian, one was African American and two were under 50 years of age, and one Caucasian man over 50 years of age. The first author proceeded with recruitment with the intent to recruit several more men, one to two more African Americans and one to two more participants under 50 years of age. It was not possible to recruit any Hispanic patients as they all required a translator for communication. Of 22 patients who were approached for participation in this study, 17 met inclusion criteria. Of those who met inclusion criteria, two declined to participate and one was not interviewed as information saturation was reached. Those

who did not meet inclusion criteria did not experience fatigue.

If patients agreed to participate in this study, an appointment was set up for the first author 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. The following questionnaire was used during the first interview conducted with participants.

Table 5.

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?

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, therefore 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 affects the subjects' abilities to perform and participate in activities such as activities of daily living, dialysis sessions, and social gatherings were asked. The order in which these

questions were asked depended on how subjects initially responded to the grand tour question.

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 second meeting, member checks were conducted; the first author 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. First, using manifest content analysis, the visible and obvious components of the text were identified. Then, using latent content analysis, the underlying meaning of the text was interpreted. 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 in several ways. The first author spent a lengthy amount of time in the field completing clinical work with dialysis patients, 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 first author also kept a study notebook in which analytic memos and decisions regarding themes found in data analysis were recorded (dependability). The second author 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 5.

Table 6.

Demographic Characteristics (n=14)

	Demographic Measure	Number of Participants
Gender	Male	7
	Female	7
Race	Caucasian	12
	African American	2
Age range	<50	2
	50-59	3
	60-69	4
	70-79	3
	80-89	2
Number of years on dialysis	<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

Four themes emerged from the data that describe the experience of fatigue for adult hemodialysis patients, 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 end-stage renal disease as well as the dialysis process. Two subthemes are included in this description: physical and mental characteristics of 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 dialysis 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 dialysis 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 dialysis 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 session, they were so fatigued at the end that they had to call a friend or relative to drive them home from dialysis. Others talked about a delayed effect; the fatigue did not become overwhelming until they got home from dialysis. 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 dialysis and 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 dialysis patients 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 dialysis 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 ability or desire to spend time with other people. Three subthemes were found in the data and comprise the consequences of fatigue that hemodialysis patients experienced.

Socialization is negatively affected. While dialysis patients 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 dialysis 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 dialysis 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 dialysis days as they were rendered unable to care for them due to their fatigue. Yet others were themselves cared for by their grandchildren after dialysis. 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 yard and keep their cars clean. There was a sense of not being able to accomplish a simple task and so in turn, activities were prioritized and only the necessities were accomplished fully. One man, a 68-year old participant who lived alone with his wife, a cancer patient, 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 dialysis population. Depression has been historically associated with fatigue in chronically ill individuals as

well as those on dialysis. 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 dialysis 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 on the dialysis machine. 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 dialysis, fall asleep while in dialysis, and sleep to recover after dialysis, all of which turns into a vicious cycle of poor sleep.

Discussion

Fatigue is an often debilitating symptom in those with end-stage renal disease 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 hemodialysis patients in the US and to identify ways patients have been able to manage fatigue.

Patients described four elements that comprised their experience of fatigue: the nature of fatigue, the management of fatigue, the consequences of fatigue, and factors associated with fatigue. They described self-management techniques that they used to mitigate fatigue, the most frequent being rest and sleep; however, participants were not completely satisfied with these techniques due to the inconsistency in efficacy of the techniques.

Few studies have described the experience of fatigue for patients on hemodialysis. 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 dialysis, role limitations, and an inability to carry out daily activities (Brunier & Graydon, 1993; Heiwe, Clyne, and Dahlgren, 2003; Lee, Lin, Chaboyer, Chiang, & Hung, 2007; McCann & Boore, 2000; O'Sullivan & McCarthy, 2007). Similar to the findings of Lee et al. (2007) and Heiwe et al. (2003), participants in the current study also reported difficulty remembering and concentrating due to the effects of fatigue. This study, the first to explore the experience of fatigue for patients in the United States on hemodialysis, further expands understanding of fatigue in hemodialysis patients by offering a detailed

description of the consequences and factors associated with fatigue that is not found in existing literature.

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 dialysis session. Other researchers found that hemodialysis patients 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 ability to concentrate and participate in activities. While the descriptions of physical fatigue are similar in nature among the research, the descriptions of mental fatigue vary in characteristics and should be investigated further.

Patients on hemodialysis bear a profound symptom burden that includes pruritis, nausea, pain, and fatigue, among others (Almeras & Argiles, 2009; Hutchinson, 2005; Murtagh et al, 2007; Yong et al., 2009). Therefore, devising ways to manage these symptoms is important to hemodialysis patients in order to improve their quality of life. However, the self-management of fatigue in this population has been largely unstudied. This study is the first to describe the means that hemodialysis patients employ to manage

their fatigue. All participants in this study reported that they rested or slept after dialysis which had varying levels of efficacy for patients. Some patients were able to get up after resting and continue on with their day, while others did not feel a considerable amount of relief from fatigue after resting. Participants found that adjusting or adapting their routines to accommodate their need to rest or sleep allowed them to take advantage of the times when they felt the best and reserve these times for when they needed to be active. The management of comorbidities such as pain and blood glucose levels was also helpful in managing 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, diabetic patients had to make sure that they stayed awake after dialysis 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. Some of the simplest, minimally energy consuming activities were difficult for patients on hemodialysis, which 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 hemodialysis patients in Iran (Kazemi et al., 2011; Lee et al., 2007) 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 dialysis catheter location (Kazemi, 2011).

In the current study, participants noted that the quantity and quality of time they were able to spend with children, whether they were children living in the home or outside the home, 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, Luciani, & Tazza, 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 dialysis absorbed most of their lives and took time away from their daily activities. However, the authors do not adequately 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 dialysis treatments as the reason for depression and no one felt that their depression was related to their fatigue. This is an area that deserves to be investigated further, as depression and fatigue are frequently identified as co-existing, with no accurate way to discern which is the initial problem; therefore, many times fatigue is confused with and treated as depression.

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 dialysis, sleeping poorly at night, and sleeping

during the dialysis treatment is a cycle that patients endure during their time as dialysis patients, 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.

Limitations

There are several limitations to this study that could affect transferability of this work (Milne & Oberle, 2005; Tuckett, 2005). First, the operational definition of fatigue, used to confirm that patients understood what fatigue was and whether or not they experienced the phenomenon, could have limited the findings of this study. Patients were eligible to participate in this work if they described fatigue as a sensation that required rest. It is possible with this conceptualization of fatigue that the full experience of fatigue was not captured. 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 hemodialysis patients have been conducted in a rural area. This study offers a window into the experience of fatigue for those who live in rural communities in the south. 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 first author 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.

Despite these limitations, 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.

Implications for Practice

Findings from this study identify several areas where nurses could be of support for hemodialysis patients with fatigue. Dialysis 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 dialysis nurses that includes expanding their assessment and teaching to include factors such as symptom assessment and management. This, in addition to assessing dialysis-related factors such as patient weight gain, blood pressure, and assessment of dialysis access site, will promote holistic care of patients. Including education regarding symptom assessment and management will give dialysis nurses the tools needed to positively affect dialysis patients' quality of life.

Findings from this study provide information that nurses can use in patient education regarding fatigue and its effects on daily life. 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. Nurses also play an important role in the control of comorbidities. Educating dialysis patients

about controlling comorbidities such as pain and blood glucose fluctuations may give them the means to help increase their energy levels on their own. Dialysis nurses have the best opportunity to educate these patients while they are on the dialysis machine.

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 dialysis 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 dialysis patients.

Depression is another area that warrants 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 one question method of depression assessment.

Sleep is another area that warrants further investigation. In this study, participants

had sporadic and varied 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. Further longitudinal work that seeks to identify the trajectory of sleep problems over the course of chronic kidney disease and end-stage renal disease could help pinpoint times when these problems are most likely to occur and when it is most appropriate to intervene.

4. A Comparison of Temporal Patterns of Fatigue in Hemodialysis Patients

Introduction

There has been little work in the area of identifying temporal patterns of fatigue in hemodialysis patients. Post-dialysis fatigue is identified in the literature but is not adequately defined; what we do know is that it is a frequent complaint of hemodialysis patients, it occurs after dialysis sessions, and those that experience it require more sleep immediately after dialysis (Sklar, Riesenber, Silber, Ahmed, & Ali, 1996). Patients who experienced post-dialysis fatigue required almost 5 hours of sleep to recover after their sessions and had more depression, insomnia, and body aches than those who did not experience post-dialysis fatigue (Sklar et al., 1996). Further, patients with post-dialysis fatigue experienced limitations in their functional independence and participation in social activities on the day of dialysis (Rocco, Mercieri, & Yavuzer, 2006). Post-dialysis fatigue is debilitating on dialysis days for those who experience it, but elucidating a definition of post-dialysis fatigue is complicated by the fact that there has been no further work done to specify the characteristics of the phenomenon. Limited research indicates that there is no identifiable cause of post-dialysis fatigue, but the lack of work in this area makes it difficult to draw conclusions.

The causes of post-dialysis fatigue remain a mystery. Post-dialysis fatigue is not predicted by clinical measures such as nutritional status, lab results, or the adequacy of dialysis (Sklar et al., 1996). Research suggests that it may be part of a symptom complex or syndrome that includes symptoms of nausea, muscle cramps, and headache that may be due to the fluid shifts that occur during hemodialysis (Sklar et al., 1999). Furthermore, post-dialysis fatigue seems to be ameliorated by rest and sleep (Sklar et al., 1996). While

this information is important, it is the only research of its kind and without additional research it cannot be taken as proof that post-dialysis fatigue is part of a symptom complex or that it is not correlated with clinical measures. Further work in this area is warranted to help remedy these gaps in knowledge.

Two dialysis-related variables have been studied in relation to post-dialysis fatigue; however, these studies are few in number. Singh et al. (2003) studied post-dialysis fatigue in relation to dialysis membrane composition and cytokine production. They found that cytokine levels increased significantly with both types of dialyzer membranes but that levels of post-dialysis fatigue did not vary between dialyzer membranes (Singh et al., 2003). Azar (2009) studied the effect of cooling the dialysate temperature on levels of post-dialysis fatigue and found that levels and length of time post-dialysis fatigue lasted improved significantly when the dialysate was cooled (Azar, 2009). These studies point to areas that are in need of further research.

Post-dialysis fatigue has also been studied in relation to muscle function and exercise, but again, these studies are limited, and conceptually, the definition of post-dialysis fatigue is not well-delineated in this research. Delgado and Johansen (2011) studied barriers to exercise in hemodialysis patients. They found that the most commonly reported barrier to exercise was fatigue, but it was not associated with decreased activity levels (Delgado & Johansen, 2011). In their abstract the authors note that "post-dialysis fatigue was not associated with differences in activity level in multivariate analysis" (Delgado & Johansen, 2011, p. 1152). Yet, in the body of the manuscript, post-dialysis fatigue is not mentioned again; the authors refer to fatigue. It seems that the terms fatigue and post-dialysis fatigue was used interchangeably.

Lockhart et al. (2010) studied the effect of several mobility measures and post-dialysis fatigue on the incidence of falls in elderly hemodialysis patients and found that post-dialysis fatigue increased susceptibility to falls when elderly patients returned home from dialysis. It is not clear what these authors used as their operational definition of post-dialysis fatigue as they report measures of strength, posturo-locomotion tests, dynamic stability and get-up and go times. It is possible that they used strength as a proxy for post-dialysis fatigue or a combination of all of the measures as an overall measure for post-dialysis fatigue. The lack of a clear conceptualization of fatigue in this work makes it difficult to make assumptions about the effect of post-dialysis fatigue on these variables and points to the need for a clear definition of post-dialysis fatigue.

Post-dialysis fatigue may be conceptually similar to the persistent fatigue that hemodialysis patients experience, but differs in severity and timing. It is important to clarify if and how post-dialysis fatigue differs from the persistent fatigue that hemodialysis patients experience in order to intervene effectively. Further, there may indeed be predictors that may be responsible for the phenomenon that could be amenable to intervention. Whether the phenomenon of post-dialysis fatigue progresses to a persistent state is not known and if so, at what point, to whom this occurs, and what factors may be associated with this change. Insight into these phenomena will expand our knowledge base, identify areas for further research, and identify ways to tailor interventions for fatigue as experienced by hemodialysis patients. Therefore, the purpose of this article is to describe the temporal patterns of fatigue and explore similarities and differences of fatigue. Here we report findings from the parent study that was designed to elicit a description of the experience and self-management of fatigue in hemodialysis

patients. Findings from the parent study indicate that patients on hemodialysis experience two distinct types of fatigue: post-dialysis fatigue and continuous fatigue. These are described in detail below.

Methods

Design

A longitudinal descriptive study design which included in-depth interviews followed by the completion of a fatigue diary was used to explore the experience and self-management of fatigue in hemodialysis patients.

Setting and sample

Participants were recruited from a local dialysis center in a rural area in the mid-Atlantic region. The dialysis center where participants were recruited serves approximately 120 dialysis patients weekly. Interviews with participants took place wherever participants felt it was most convenient for them to be interviewed, most often their homes. At times, it was more convenient for participants to be interviewed before their dialysis sessions. These interviews were conducted at the dialysis center in a private conference room.

The study sample consisted of 14 adult hemodialysis patients who had been on dialysis longer than three months, in order to avoid the honeymoon period that occurs after the initiation of dialysis (Reichsman & Levy, 1972). Potential subjects needed to experience fatigue; be mentally competent; be 21 years of age or older; and be able to read, speak, and understand English. Those who reported a co-morbid condition not generally experienced in concert with ESRD, such as HIV, cancer, hepatitis, or multiple sclerosis, as well as those who self-reported pregnancy, were excluded from this study to

be as certain as possible that the participants were representative of the hemodialysis population and that they did not have a co-morbid condition that is also marked by fatigue, which may confound the findings.

Purposive sampling was used to recruit participants for this study. In this type of sampling, participants are selected because of the input they can offer regarding a specific phenomenon (Polkinghorne, 2005). Selection of participants was intentionally limited to those who could contribute information regarding the experience of fatigue, hence participants must experience fatigue to be included in this study. To determine if participants understood the concept of fatigue, the first author (AH) asked participants how fatigue made them feel. If they identified a sensation that made them feel worn out and required rest, they were considered appropriate for this study. The first author attempted to select patients based on demographic factors found in the literature such as age, race, and gender. Subsequent participants were recruited based on the demographic characteristics of previously recruited participants. For instance, at the dialysis center, the population was comprised of 50% men and 50% women, 10%-20% African American, 70%-80% Caucasian, and 10% Hispanic. Recruitment was based on the characteristics of the current sample. If there were too many males, the first author focused on recruiting more females. If fewer Caucasians were needed, the first author attempted to recruit African Americans.

Procedures

After Institutional Review Board approval was obtained, an employee from the dialysis center approached dialysis patients, gave a very brief description of our work, and asked if they would be interested in speaking with the first author about our work. If

they were willing, the first author (AH) then spoke with potential participants about the study and what it would entail. If patients agreed, she screened them for inclusion/exclusion criteria, and those who met the criteria made an appointment for this researcher to come to the place most convenient for them 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 our appointment. They were encouraged to write down any questions or concerns so that they could be discussed at the first meeting.

Instruments. Participants were asked to fill out a fatigue diary at two points, a 48-hour diary during the week, and a 72-hour diary over the weekend. The content of these diaries was identical except that the 72-hour diary contained an additional day to record in. There were four entry points for each 24-hour period contained in the diary: morning, afternoon, evening, and night. In the morning entry point only, participants were asked to circle their sleep quality from the night before as poor, fair, good or excellent. They were asked to record what time they went to bed the night before and what time they got up on the current day. They were also asked to note if they were awake at any point during the night and if so, for how long. All diary entry points had a visual analogue scale where participants were asked to mark their level of fatigue at that time with zero indicating no fatigue and ten indicating extreme fatigue; to list any activities they were able to participate in and any they had to change due to their fatigue; to note anything they did to manage their fatigue at that point and if it made their fatigue better; if they were feeling well, what were they able to do that they were not usually able to do when they were fatigued; and what they thought caused their fatigue or lack of

fatigue. The afternoon, evening, and night entry points also asked that participants compare their fatigue to the previous entry and note any changes in fatigue level and why they thought their fatigue had changed. Please see Figure 1 for a sample diary page.

Morning

Please mark an "X" on the line where it best describes your fatigue

Activities this morning (please list)

0
no fatigue

5
moderate

10
extreme

fatigue

fatigue

How well did you sleep last night? Please circle one: **Poor Fair Good Excellent**

What time did you go to bed last night? _____ What time did you get out of bed this morning? _____

Were you awake for any amount of time during the night? **Yes No** If yes, how long were you awake? _____

Were you able to participate in activities this morning? **Yes No** Please describe any activities you had to change due to your fatigue.

Did you do anything to manage your fatigue (for example, nap, shorten your activities, sit and rest)? Please note what you did to make your fatigue better. Did it make your fatigue better?

If you were feeling well, what were you able to do this morning that you can't do when you are fatigued?

What do you think caused your fatigue OR lack of fatigue this morning?

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Figure 1. Sample fatigue diary page.

Data collection. At the first appointment, after informed consent was obtained, an individual semi-structured interview was conducted by the first author. 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 were the most pragmatic method of data collection for this study. Demographic data was collected at the beginning of the interview. Interviews lasted approximately 45 minutes to one hour. They were audio-tape recorded and conducted in a quiet, private place. The interview started with a grand tour question (Brenner, 2006; McCaslin & Scott, 2003), "Tell me about your fatigue." Further into the interview, specific questions about how long fatigue lasted, how often episodes of fatigue occurred, how it was related to dialysis, and how it affected sleep patterns and activity levels were asked. Please see Table 6 for sample interview questions. Field notes were written immediately after each interview by the first author to capture the natural environment of the subject and to use in validation of the interview data.

Table 7.

Sample Interview Questions

Tell me about your fatigue (Grand tour question)

When does your fatigue occur?

Is your fatigue related to dialysis?

How do you sleep?

Do you think your sleep is related to your fatigue levels?

Describe a typical dialysis day sleep/activity patterns.

When is it more difficult to participate in activities?

Does your fatigue get better? when?

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

When the interview was completed, participants were given two fatigue diaries. Symptom diaries are useful because they provide convergent evidence and the unique viewpoint of the participant (Broom & Tovey, 2008; Furness & Garrud, 2010). They have been used successfully in dialysis patients in previous studies (Yngman-Uhlin & Edell-Gustafsson, 2006). Instructions on how to complete these diaries were reviewed and any questions answered. Participants were asked to fill out the fatigue diary at two different times during the month. One diary was to begin on the morning of a dialysis day and end 48 hours later. This could be completed at any time during the week. The other diary was to begin on a dialysis day, either Friday or Saturday depending on their dialysis rotation, and was kept for 72 hours over a weekend, when the patient had an additional day in their cycle where they traditionally do not receive dialysis. Diaries could be completed in the order that was most convenient, i.e., 48 -hour diary first or 72-hour diary first. This allowed us to capture the phenomenon of fatigue as it changed from one dialysis session to the next. It also allowed us to compare fatigue levels when there was an additional day without dialysis (72-hour) over the weekend with the usual 48-hour dialysis rotation to determine if there was a difference in the dialysis cycles with regard to fatigue. In the diary participants were asked to respond to questions about their fatigue and its management. Participants were asked to record in their diary in the morning,

afternoon, evening, and night. Diaries were mailed back to the first author in a self-addressed, stamped envelope.

A second meeting was scheduled with the participants after the first interview and the diaries were analyzed so that participants could clarify or elaborate on their responses from either the first interview or the diary. At this second meeting, member checks were conducted. This occurs when the researcher returns to the respondent with initial analyses to ensure that these analyses are accurate. Respondents either validate and/or clarify the initial analyses (Cho & Trent, 2006; Milne & Oberle, 2005; Steinhauser & Barroso, 2009). Participants confirmed during the second interview that our analyses of the first interviews and diaries were on target. Any inconsistencies between data from the diary and data from the first interview were clarified at this time. For instance, at times it was difficult to interpret participants' hand writing or a participant circled a level of fatigue that was inconsistent with the activities they had participated in that day. After some discussion, it was determined that the participant was tired and had misread the question. These checks allowed us to make sure that we were presenting an accurate picture of participants' fatigue as they experienced it.

Data analysis

All tape-recorded interviews were transcribed verbatim and proof-read for accuracy. The first author performed all data analysis. Rigor was ensured in several ways in this study. Credibility was maintained by the first author who spent a prolonged amount of time in the field developing knowledge about nephrology and dialysis through clinical courses, grand rounds and journal clubs. Further, she performed member checks after the interviews and fatigue diaries were analyzed in order to ensure that the

participants' views were presented correctly (Milne & Oberle, 2005; Steihauser & Barroso, 2009; Tuckett, 2005). Dependability and confirmability were enhanced by the creation of an audit trail that included analytic memos and decisions regarding the processing of data. Additionally, the second author reviewed codes and coded approximately 80% of the transcripts. This also helped make sure that the findings are true to the participants and are not based on the first author's biases (Milne & Oberle, 2005; Steihauser & Barroso, 2009; Tuckett, 2005). Transferability was promoted by presenting data with thick description so that readers could determine if findings from this study were applicable to their own context (Milne & Oberle, 2005; Steihauser & Barroso, 2009; Tuckett, 2005).

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. The data becomes the source of codes and categories developed. Therefore, the knowledge gained from this type of analysis is grounded in the data (Hsieh & Shannon, 2005). 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. This iterative process ensured that data relevant to the participants and not to the researcher were collected. Analyzing line-by-line, key thoughts in the interviews were identified. First, using manifest content analysis, the visible and obvious components of the text were identified. Then, using latent content analysis, the underlying meaning of the text was

interpreted. Text was condensed and codes were developed based on the key recurring thoughts identified in the data (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 (Graneheim & Lundman, 2004).

Diaries were analyzed first as a separate source of data, and patterns within the data in the diaries were identified. The diaries were then analyzed in conjunction with the initial interview and any data that was new or clarified from the second interview, looking for patterns in the data across these data sources and among all of these sources across subjects (Ong & Jinks, 2006). An example of how typical a 48-hour diary was analyzed follows. When a 48-hour diary was received from a subject, the first author reviewed it to gain a sense of patterns that exist in fatigue occurrence, severity, and what was done to manage fatigue daily. Usually, participants rated their fatigue on a dialysis day, prior to dialysis, as minor to moderate in severity. After dialysis the fatigue was severe with self-management consisting of sleeping or resting. The next day, participants often noted that their fatigue was better, less severe, and they had to do little to manage it. Next, the first author compared diary data to that of the first interview to determine if the diary data supported data from the interview. It was expected that participants would state during their interview that their fatigue was the worst after dialysis requiring them to rest. If there were inconsistencies between the interview data and diary data, these were addressed in the second interview with the subject. New or clarified data was then analyzed in conjunction with the diary. The patterns of fatigue established in the data over 48 hours was then compared among participants to determine if there was an overall

pattern in the diary data (Broom & Tovey, 2008; Ong & Jinks, 2006).

It became apparent upon the analysis of interviews and diaries that there were two groups of participants, one group who experienced post-dialysis fatigue only and a group that had continuous fatigue. Data and themes between these groups were compared to provide an in-depth description of each type of fatigue.

Findings

This section will begin with a description of the two types of fatigue patients experience. Following this, a comparison of the two fatigue experiences will be presented. Demographic characteristics of the sample are presented in Table 7.

Table 8.

Demographic Characteristics (n=14)

Demographic Measure		Number of Participants		
		Post Dialysis Fatigue (n=5) ¹	Continuous with Spike (n=3) ²	Continuous with Plateau (n=6) ³
Gender	Male	3	1	2
	Female	2	2	4
Race	Caucasian	5	3	4
	African American	0	0	2
Age range	<50	0	1	1

¹ Post dialysis fatigue only is an acute fatigue that occurs after the dialysis session and requires sleep or rest

² A persistent fatigue that worsens after the dialysis session and requires sleep or rest to return to baseline fatigue level a few hours after dialysis

³ A persistent fatigue that worsens after dialysis session and requires sleep or rest but requires a prolonged recovery period that lasts until later in the day or until the next day.

	50-59	2	1	0
	60-69	0	0	4
	70-79	1	1	1
	80-89	2	0	0
Number of years on dialysis	<1 year	0	0	0
	1-3 years	4	2	2
	4-6	1	1	0
	7-9	0	0	2
	10-12	0	0	2
Socioeconomic status	Receive disability	2	2	5
	Average monthly income	\$1972	\$907	\$1446
	Range of monthly income	\$886-\$3772	\$556-\$1500	\$700-\$3670
Education	College graduates	1	0	1
	High school graduates	3	3	3
	Did not complete high school	1	0	2
Family	Children in the home	0	1	2
	Patient is primary caregiver for other	1	1	2

Dialysis Patients with Continuous Fatigue

A larger group of patients (n=9) described a persistent fatigue that is their normal, baseline energy/fatigue level. They had a dramatic increase in their fatigue level directly after dialysis from which they recovered slowly, over several hours, with recovery often extending into the evening or the next day. Fatigue for participants with continuous fatigue was never-ending and just as they started to feel better they had to go back to dialysis. Stated one participant, "I just start to get over that real tiredness, but then you turn around and start all over." Within this group, there were two sub-groups of patients. The first sub-group of patients had a spike in their baseline fatigue that occurred directly after dialysis. These patients required sleep and/or rest after their dialysis session and after resting for several hours, they returned to their baseline level of fatigue. "That's what I mean, I have to sit down for 2 hours, I go to sleep, then I wake up and I'm not going to say normal, but I'm better," stated a 68-year old man on dialysis for eight years who is retired and lived with his wife, a cancer patient, in their home. Said another participant, a 74 year old man on dialysis for three years, who lived independently with his wife after retiring as the manager of the department of public works:"...I get so tired especially right after dialysis, I usually sleep till, if I lay down at 12:30, I sleep till about 3 o'clock." When asked if he felt better when he woke up, he replied, "Yeah."

Figure 2 depicts a graph of data from fatigue diaries that participants completed as part of the study. This graph demonstrates how from one dialysis day to the next, fatigue spikes after dialysis and recovery occurs several hours after the dialysis session, returning participants to their baseline fatigue level. All 3 participants who described this pattern are depicted in this graph.

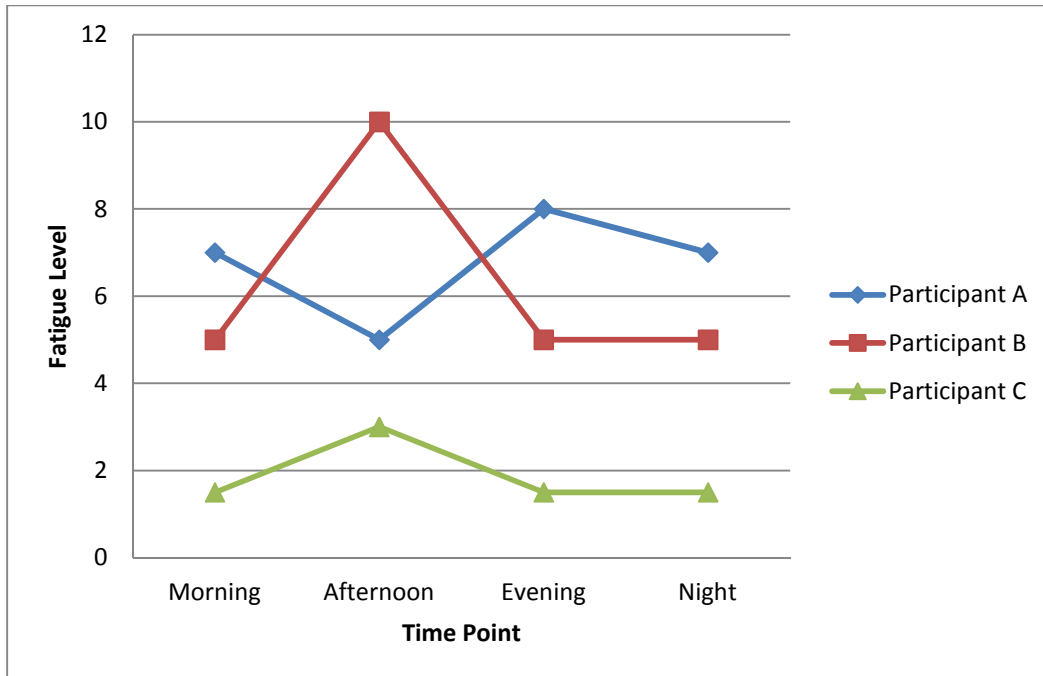


Figure 2. Continuous fatigue with a spike after dialysis. This figure illustrates how participants have a continuous level of fatigue that spikes after dialysis and returns back to their baseline several hours after their dialysis session. Participant A had dialysis in the afternoon with a spike in fatigue in the evening. Participants B and C had dialysis in the morning with a spike in fatigue in the afternoon.

The second sub-group also experienced an acute, extreme fatigue after dialysis, but this fatigue plateaued after dialysis and took most, if not all, of the rest of the day to return to baseline. Often these patients would come home from dialysis, go to bed, rest or sleep for several hours, then get up for a short amount of time and return to bed in the early evening, only to return to their baseline fatigue the next morning. The following quote demonstrates the difference between the two groups. One participant, who was 70 years old and who used to work as a dietary assistant and cook, lived with her adult daughter and had been on dialysis for ten years. She stated that she naps when she comes home from dialysis. When asked if she felt better, she said, "For a little while...and then I have to go back, once I go to bed, have a good night's rest then I can get up the next day and do whatever." Another participant, a 56-year old woman who previously worked as a

store clerk and lived with her husband and multiple pets in a small apartment said: Sometimes it (fatigue) continues on into the evening...I had taken my nap, I went out front to sit down (to watch a parade)...I just couldn't even stay out there, I went to bed and I stayed in bed till the next morning. I missed the parade and everything.

Figure 3 demonstrates how those in the second sub-group (n=6) with continuous fatigue have a prolonged recovery often lasting into the evening or next day.

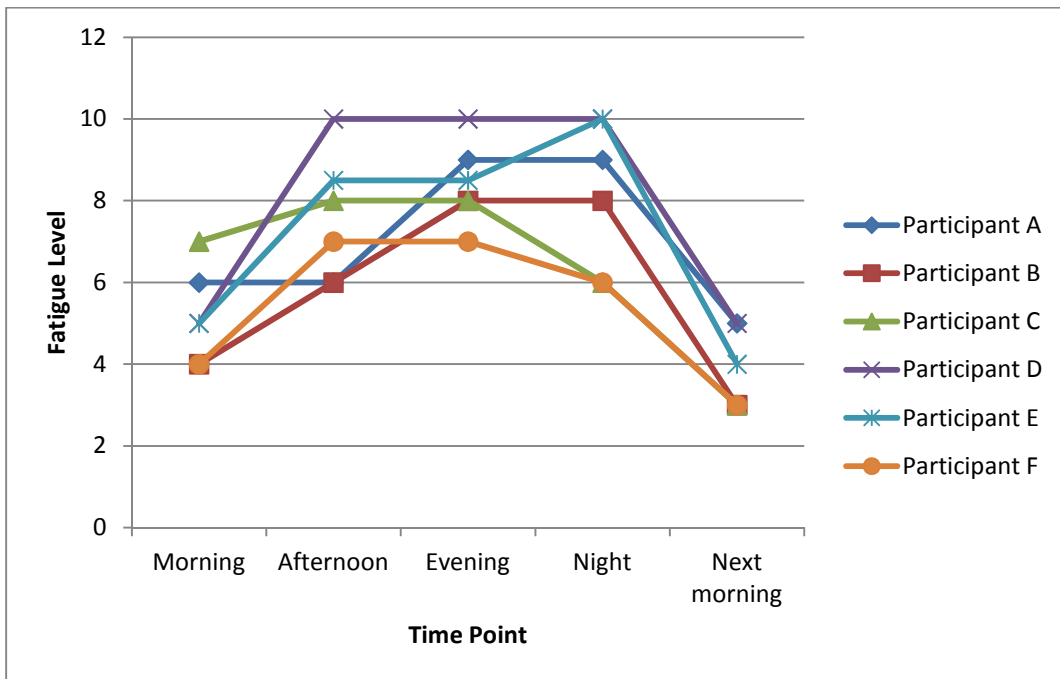


Figure 3. Continuous fatigue with a plateau after dialysis. Figure 2 illustrates that those with continuous fatigue have a prolonged recovery that lasts until the next day. For participants A and B, dialysis was completed in the afternoon. For participants C, D, and E, dialysis was in the morning.

Participants with continuous fatigue attempted to manage their fatigue, but the efficacy of these management techniques was inconsistent. Participants always found it necessary to lie down and rest immediately after their dialysis sessions. Stated one man:

I don't know, I get so tired especially right after dialysis, seems like as soon as they unhook you could lay there and go to sleep, but then starting in the car you

start getting sleepy and by the time I get home I lay down and go to sleep.

Participants with continuous fatigue learned to adjust their routines and activities to accommodate their level of fatigue, often scheduling any necessary activities on non-dialysis days. Stated one participant, a 45 year old single parent and attorney, retired due to ESRD and dialysis: "I consider my dialysis days days where I get nothing done except for dialysis. They're write-off days." Another participant, a 27-year old woman trying to earn a college degree stated:

My school schedule, I made it for Tuesday and Thursday and next semester I will have a Wednesday class, but it's in the evenings that way I'll have time to get home and rest myself and then go to school.

Dialysis Patients with Post-Dialysis Fatigue Only

Five participants experienced post-dialysis fatigue only. All of those in the post-dialysis fatigue only group stated that they came home from dialysis and needed to rest or sleep for several hours before they felt well enough to get up and carry on with any activity. They reported sleeping two to three hours after dialysis in order to recover from fatigue. These patients were able to push through the fatigue after dialysis if necessary, although this was not their preference. They found that if they pushed through the fatigue, by the end of the day, they were completely worn out and usually retired early for the evening. Further, they did not feel fatigued on days that they did not have dialysis. In general, this group has been on dialysis for less than 5 years and each reported only one comorbidity when asked about other health problems. Stated one participant with post-dialysis fatigue only, a 59-year old man, who lived with his wife and received disability from his job as a dock worker, and who continued to work part-time: "...on the days I go

to dialysis I'll come home and I'll sleep for two hours and then I get up...as long as I can lay down for a couple of hours, I don't have no fatigue..." Stated another participant, an 87-year old retired professor who lived with his wife in an assisted living community, speaking about when he got home from dialysis: "I always sit down and usually like to have a cup of tea or something. It (the fatigue) just comes over you. I am usually doing ok by supper time." Added another participant, a woman who was 52-years-old with grown children who lived with her husband and continued to work part time in a doctor's office, speaking about how she felt worn out immediately after dialysis:

...after I get off dialysis, I'm just so weak I don't want to drive until I'm ready to...there's been several occasions that he's (husband) had to come and pick me up because I couldn't drive and later on that evening we'd come back and get my car.

Figure 4 demonstrates how patients with post-dialysis fatigue only (n=5) change from the day of a dialysis session to the next.

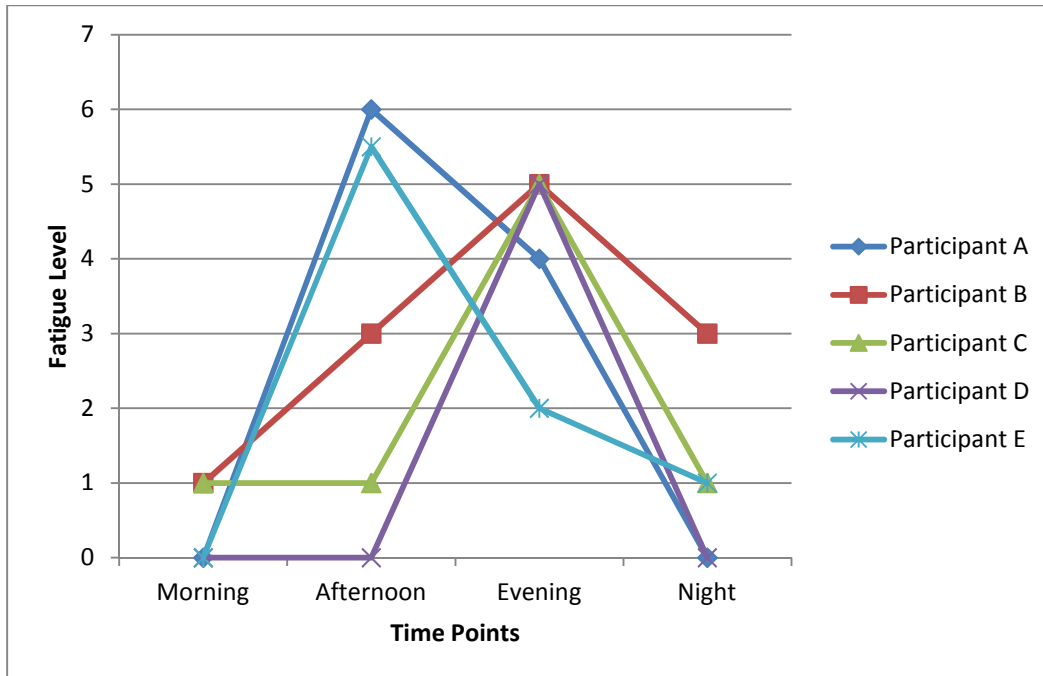


Figure 4. Fatigue levels over 18 hours in patients with post-dialysis fatigue only (n=5). This figure illustrates that patients with post-dialysis fatigue only have very low levels of fatigue that become acutely worse after dialysis and they recover from this by nighttime. Participants A and E completed dialysis in the late morning. Participants B, C, and D completed dialysis in the mid to late afternoon.

Participants with post-dialysis fatigue only described an acute fatigue that occurred after their dialysis sessions only and was relieved by several hours of sleep or rest. While they experienced consequences of fatigue, these occurred only on dialysis days and were not as severe in nature as the consequences for those with continuous fatigue. They discussed the fact that they lost time to their dialysis sessions and dialysis-related procedures. One 58 year old man who received disability from his job as a dock worker who continued to work part-time at home doing clerical work said:

I find that it aggravates me to have to go to dialysis because it kills 4 hours of my time that I can't do anything...I'm stuck over there with needles in my arm...you got another 2 hours you have to rest so there's 6 hours. So there's half a day gone.

They also noted that their fatigue could be insidious at times, causing them to sleep unexpectedly and wake wondering what had happened and how much time had passed. One participant, an 87 year old retired professor who lived in an upscale assisted living facility with his wife, talked about dozing off during his dialysis session, commented:

It just sort of comes over you. Sitting here and I don't even know when it is going to happen...I usually take something to read, but sometimes I am sitting there people watching and I fall off to sleep. They come to check on something and they wake me up...I did not even know I had fallen asleep. You just sort of feel like you lost time, you missed out.

Further, they did not have the same difficulty participating in activities as those with continuous fatigue experienced. Patients with post-dialysis fatigue only had trouble with activities on dialysis days. They scheduled work and exercise on non-dialysis days and the fact that they reported doing either of these activities at all is different from those with continuous fatigue. Stated one participant who continued to work part-time, "I go to work, I get up at 5 o'clock in the morning, I go to work and I work from 8 until 5 or 5:30 those two days (non-dialysis days). I come home, I cook supper, I clean up the kitchen, I have no problem." Participants with post-dialysis fatigue have trouble sleeping similar to those with continuous fatigue; however, those with post-dialysis fatigue only spoke about taking sleep medications to help them sleep, which had varying levels of efficacy for participants. One participant who started an exercise program and worked part-time time at home doing clerical work said:

I mean, I take pills to go to sleep, I take pills to wake up and that's the truth of it. I have muscle relaxers...that I take to relax my muscles at night so I can sleep. A lot

of times I take a sleeping pill and a lot of time I take that muscle relaxer and they will relax me enough to where I can sleep all night long but at the same time, I get up to go to the bathroom at 3 o'clock and at 4:30 I'm awake because the alarm goes off.

Participants with post-dialysis fatigue only also saw themselves as healthier and more fortunate than those with continuous fatigue. They had observed on their own that there seemed to be people who suffered more from fatigue than they did and who were more limited in what they could do because of their fatigue. A 52 year old woman who worked part-time added: "I'm okay, just like a normal day, I don't have any problems. People tell me they don't think there's anything wrong with me," One participant when talking about napping after dialysis stated, "Yes, just a little nap. Some of them say they have to go to bed as soon as they get home."

Discussion

Limited information on how fatigue changes over time for hemodialysis patients from one dialysis session to the next exists. It has been noted that hemodialysis patients often experience a lasting fatigue that does not relent (Sklar et al., 1996), yet the relationship, if any, between this lasting fatigue and post-dialysis fatigue remains unknown. Foundational work on post-dialysis fatigue was done by Sklar et al. (1996) and essentially explained the phenomenon of post-dialysis fatigue. The current study is unique because it further expands our knowledge about post-dialysis fatigue and continuous fatigue by describing the patterns that fatigue follows over time from one dialysis session to the next. One group of patients in this study experienced post-dialysis fatigue only, an acute fatigue that occurred after their hemodialysis session and required

several hours of sleep or rest to recover. After resting, they transitioned back to their normal energy level and were able to participate in daily activities. The other group of patients in this study experienced continuous fatigue, a persistent fatigue that was always present and that worsened considerably after their dialysis session. All patients who experienced continuous fatigue required sleep or rest for several hours after their dialysis session. After resting or sleeping for several hours, some of these participants returned to their baseline level of fatigue, while others had a prolonged recovery that lasted late into the evening or into the next day. We are the first investigators to identify the two types of fatigue in the context of changing from one dialysis session to the next. Sklar et al. (1996) studied patients with and without post-dialysis fatigue in their work and noted that they did not address the common complaint of persistent fatigue in the study. They do not report any findings regarding persistent fatigue, which leaves questions regarding how many of their participants had underlying continuous fatigue and how this is related to post-dialysis fatigue. Findings from the current study are significant because they are the first to describe the three patterns of fatigue that hemodialysis patients experience. While the findings do not clarify the relationship between post-dialysis fatigue and continuous fatigue, they offer a basis for future research. Further work focused on tracking patients with post-dialysis fatigue only over time would help establish whether or not this type of fatigue is stable or if it transitions to continuous fatigue.

Past research in this area of inquiry identified post-dialysis fatigue as an often debilitating and incapacitating symptom requiring several hours of sleep or rest to recover (Sklar et al., 1996). Similar to the findings of Sklar et al. (1996), this study found that dialysis patients had a considerable increase in their fatigue after their dialysis sessions.

However, contrary to their findings, participants in this study did not require 5 hours of sleep to recover. Most participants in this study reported needing 2 to 3 hours of sleep after dialysis. Sklar et al. (1996) also reported that patients with post-dialysis fatigue experienced depression and insomnia more frequently than those without post-dialysis fatigue. While this study did not compare patients with and without fatigue, few participants in this study reported depression; however, the majority reported troubles with sleep quantity and quality similar to Sklar et al. (1996).

Similar to Rocco, Mercieri, and Yavuzer (2006), our research found that patients who experienced post-dialysis fatigue only describe functional limitations and decreased socialization on dialysis days only. They pointed out that they saved their activities for non-dialysis days when they feel good. Our work extends these findings by comparing those with post-dialysis fatigue only to those with continuous fatigue, a condition where patients have a persistent, underlying level of fatigue at all times that is acutely exacerbated after their dialysis sessions and requires varying amounts of time and sleep and rest for recovery. Those with post-dialysis fatigue only do not experience the severity of limitations in their socialization and activities that those with continuous fatigue experience. In fact, those with post-dialysis fatigue only are able to work and exercise on their non-dialysis days.

Often when people are faced with a life-threatening illness, they develop ways to cope with the diagnosis and subsequent treatments and outcomes. One way people do this, called downward comparison, is to compare themselves with patients that they perceive as more ill or in worse condition than themselves in order to decrease the threat that they feel and to make themselves feel better about the situation (Taylor, Buunk &

Aspinwall, 1990). This is a common coping mechanism for patients with life-threatening chronic illnesses such as cancer (Van der Zee, Buunk, Sanderman, Botke & van den Bergh, 2000) and cardiac disease (Helgeson & Taylor, 2006). Similarly, in our research, patients on hemodialysis with post-dialysis fatigue only compared themselves to other dialysis patients who seem to be in worse condition than they are. It remains to be seen what effect this downward comparison has on patients' adjustment to symptoms or to overall outcomes.

Limitations

There are limitations to our work. First, the study was conducted at a rural dialysis clinic in a mid-Atlantic state in the South. This work may not have captured the struggles of post-dialysis fatigue for those that live in an urban setting. However, as is the case, our work provides a view of rural dialysis patients in the US that has not been presented in the literature. Another limitation is the way in which fatigue was operationally defined for inclusion in this study. By including patients who described a sensation of needing rest that other aspects of fatigue were possibly missed. The only participants who were excluded were those who reported that they did not experience fatigue and therefore would not have provided information regarding the phenomenon. Fatigue itself may have played a role in limiting our work, though this was not found to be the case in this study. Participants were informed before the interview that if they felt too tired to continue at any time, the interview could be stopped. Further, the first author closely watched for signs of fatigue during the interview. At no time during our data collection were interviews stopped and rescheduled due to fatigue.

Implications for Research

Our research identified two group of patients, those who experience post-dialysis fatigue only and those who have continuous fatigue. The identification of different patterns of fatigue has helped elucidate differences in the experience of fatigue which need further research. Sleep is troubling for patients with both types of fatigue; while patients with post-dialysis fatigue only take sleep aids, these seem to be only partially effective. Further work in this area would be of benefit to patients as we strive to develop interventions that can be tailored to the specific type of fatigue the patient experiences. Another area that has potential for research and intervention is exercise in dialysis patients. Patients with post-dialysis fatigue only found this an important part of health maintenance and they felt well enough to participate in these activities. Not only do they maintain an exercise program, they are able to initiate a program of exercise, which requires even more energy. Furthermore, there remains a gap in knowledge regarding the causes and associated factors of post-dialysis fatigue. Additional research in this area would be helpful in identifying areas for intervention. Moreover, we do not know if or how post-dialysis fatigue changes over time. It is possible that this fatigue progresses over time to continuous fatigue. A deeper understanding of this would help identify points in the transition to continuous fatigue when patients are more in need of assistance and would allow us to educate dialysis patients on what to expect in the fatigue trajectory.

Implications for Practice

Findings from this research also have implications for understanding the experience of fatigue in hemodialysis patients. The identification of two types of fatigue is important for our development of interventions. Education of dialysis patients is an

important area for intervention. Sleep issues are prevalent with both types of fatigue and assisting patients to understand their sleep cycles, teaching them how to keep a sleep diary and helping with its analysis, and helping to keep patients awake while they are receiving their dialysis treatment are all areas in which nursing can play an instrumental role. Patients with post-dialysis fatigue only are able to exercise and do other activities on their non-dialysis days such as work part-time. Encouraging patients to maintain or implement an exercise program and coaching them through the process is an important part of health-maintenance and prevention. Helping patients to identify ways they can stay active and maintain employment is important for this group of patients. While depression did not seem to play a large part in the lives of participants, frequent assessment for depression is important. Living with a chronic illness that can cause acute changes in health and living with fatigue put patients at risk for developing depression. Treatments for depression are available that have had a positive impact on dialysis patients' lives.

Chapter 5

The design and findings of the dissertation study have several implications for scholarship. First, qualitative work allows for preliminary theorizing about the phenomenon under study which has the potential to lead to future research. Additionally, the nature of the topic, fatigue in dialysis patients, has implications for healthcare policy as the dialysis program is funded by the US government. Not included in portions of this dissertation intended for publication are areas of interest and scholarship that will be discussed here. These topics include: sampling in qualitative research, age versus illness effects, policy implications, and preliminary theorizing that extends previous work.

Sampling in Qualitative Research

The goal of qualitative research is to present knowledge regarding a phenomenon in a way that increases understanding through detailed, meaningful, contextual description so that information can be transferred to other situations (Byrne, 2001). The interest of work done in the qualitative paradigm is in the experience of a phenomenon (Cooper, Endacott, & Chapman, 2009), not in the distribution of it throughout the population (Polkinghorne, 2005). As such, the methods used to sample seek to include participants who have experienced the topic under study. This purposeful sampling, in essence, samples for information about a phenomenon from people who are chosen to participate in the study because they can make considerable contributions to the understanding of that phenomenon (Polkinghorne, 2005; Sandelowski, 1995). As the purpose of this kind of research is not to generalize to a larger population or to test theories, the number of participants needed is usually smaller. However, the information provided must be detailed enough to enrich understanding of the topic (Polkinghorne,

2005; Sandelowski, 1995; Tuckett, 2004). The following is a description of how participants were sampled for inclusion in this study.

Because sampling in qualitative work is focused on richness and depth, participants are often recruited based on study aims. Subsequent selection criteria may change throughout the course of the study, as participants are sampled sequentially based on information obtained from the previous participant (Tuckett, 2004). Therefore, sampling of participants in my work was motivated by the depth and detail of information gleaned from previous participants. Initially, I developed inclusion and exclusion criteria that were based on the aims of the research as well as practicality; these included being on dialysis 3 months or longer; being mentally competent; being able to read and understand English; age 21 years or older; an absence of comorbidities such as cancer, HIV, hepatitis, and multiple sclerosis; and absence of pregnancy. These were developed primarily to ensure that the fatigue I was studying was fatigue related to ESRD and dialysis, and was not fatigue that was related to another condition marked by fatigue. The last inclusion criterion was that participants must experience fatigue; however, I did not determine this until further into the recruitment process for reasons explained below.

The dialysis center required that a staff member approach patients so that patients could give permission for me to speak with them about my research. The staff person was aware of all of the exclusion criteria mentioned above, so that if patients gave permission, I would be speaking with patients who fit my criteria. I did not ask her to speak with patients who she knew experienced fatigue because I did not want to bias selection of participants. I left that determination until the time when I approached the patients and told them about my research. After I explained the topic of my research, I

asked patients if they experienced fatigue. If they answered yes, I asked them to describe it for me to ensure that they understood the concept and did not have it confused with another such as nausea. If patients described a sensation that required them to rest or sleep, they were deemed eligible to participate in my study. Several times when I approached patients and asked them if they experienced fatigue, they would answer that they had fatigue only after dialysis and described the sensation of needing rest. I made a conscious decision to include these patients because I sought to explain the experience of fatigue and the inclusion of these patients added depth to the understanding of the phenomenon. Of 22 patients I approached, 17 fit criteria for participation. The five who did not fit criteria did not experience fatigue. Of the 17 eligible patients, 14 were included in this study. Two participants declined to participate and the third was not interviewed because data saturation was reached. In an effort to recruit a sample of participants that was representative of the dialysis center, and therefore to increase the transferability of the findings, I kept track of demographic variables that were mentioned in the literature that may be associated with fatigue. I was successful at recruiting a gender and racial mix of participants that was representative of the dialysis center. However, I was unable to obtain variation based on age or ethnicity, as the dialysis center serves a very small population of people under age 50, most of the patients who met criteria were over age 50 and those of other cultures, primarily Hispanic and Russian, were unable to speak English.

Sampling in qualitative work is not based on the number of participants recruited but on the quality of information gained from the research. In order to determine if I had accumulated enough information to describe the experience of fatigue for patients on

dialysis, I analyzed data concurrently with participant recruitment. I used the constant comparison method and moved back and forth between data I had already analyzed and data I was in the process of analyzing to determine if the current data added anything new to the previously analyzed data (Tuckett, 2004). When I reached the point that I was not amassing any new information that would help contribute to the understanding of the experience of fatigue, I stopped recruiting participants. I kept a table of themes that arose from the data and which participant had contributed the information. In this way, I was able to visualize the spread of responses and when themes were saturated.

To provide an in-depth understanding of a phenomenon, one must recruit participants purposefully, meaning that selected participants must have knowledge of and experience with the phenomenon. Participants should be recruited until no new information is gleaned. There is no formula that guides qualitative researchers to data saturation; however, when no new information is added and no new themes are found in the data, data gathering is complete. This is a rigorous process that requires the researcher to concurrently analyze data and recruit participants so that they may make determinations regarding the sufficiency of the depth of data in order to provide contextual understanding of the phenomenon (Byrne, 2001; Bowen, 2008; Polkinghorne, 2005; Tuckett, 2004).

Age versus Illness Effects

A limitation of this study is the possibility that the experience of fatigue is confounded by the effects of age. Age effects refers to how physical changes in the body occur over time (Zink, Regan, Jacobson, & Pabst, 2003). Many conditions, such as fatigue, are considered "normal" parts of aging (Aapro, Cella, Zagari, 2002). Since my

study sample had primarily participants over 50 years of age, it follows that many of them may experience fatigue as part of the aging process, which is now complicated by ESRD and dialysis. In fact, one participant noted when asked if her fatigue worsened since she started dialysis, "Yes, and too, I'm getting older." It is likely there is no way to disentangle the effects of age and illness except to ask participants to think about their prior experiences with fatigue. Recruiting a group of younger adult patients and comparing their fatigue with those found in this study may also help.

Policy

Fatigue in hemodialysis patients has significant implications for policy. Currently, under the Social Security Act, all patients diagnosed with ESRD are eligible for disability benefits including insurance and income (Tappe, Turkelson, Doggett, & Coates, 2001). The law defines someone with a disability as anyone who is unable to earn an income due to their inability to perform duties that would result in income. The caveat, however, is that this person must be unable to perform such activities due to a physical or mental impairment that would result in death or that has lasted or can last for no less than 12 consecutive months (Tappe et al., 2001). Patients with ESRD are automatically eligible for these benefits because their disease will last for longer than 12 months and because it would result in death without treatment, not specifically because they have fatigue. Therefore, patients with ESRD who do not experience fatigue and who do not experience any other symptoms that interfere with their quality of life are eligible for disability benefits when they may not necessarily need them.

Total Medicare enrollment was roughly 47.5 million in 2010 (National Committee to Preserve Social Security and Medicare, 2011). Of this, 570,000 were

patients with ESRD (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2011). Enrollment of patients with ESRD in Medicare has increased from 66,000 in 1980 to 438,000 in 2010, an increase of 557% (U.S. Department of Health and Human Services, 2011). Approximately 45% of patients with ESRD on Medicare are over 65 years of age (U.S. Department of Health and Human Services, 2011). Medicare spending in 2009 rose 3.1% to 29 billion dollars; however, this number does not reflect Part D spending. In 2009, the ESRD program accounted for 5.9% of Medicare spending, again which does not reflect Part D spending (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2011). In total, 5.9% of the Medicare budget is allocated for 570,000 patients with ESRD, a population that represents 1.2% of the total Medicare population.

The disability criteria for patients with ESRD were developed by physicians in the 1970's (Tappe et al., 2001). Initially, it was thought that once people start dialysis, they would be able to return to work as they would have partially restored kidney function. However, this was not the case and resulted in the above arrangements for patients with ESRD (Kutner, Brogan, & Fielding, 1991; Rasgon et al., 1997). Three reasons for patients' inability to return to work have been identified in the literature. First, educational status and previously being employed in a white collar job play a large role in patients' ability to maintain employment (Blake, Codd, Cassidy, & O'Meara, 2000; Holley & Nespor, 1994; Kutner, Brogan, & Fielding, 1991; Muehrer et al., 2011). Participating in hemodialysis three times a week for 4 hours each session is difficult for those with jobs that require shift work. Those with higher educational levels are more likely to obtain employment that is not based on shift work and that is more apt to have

flexibility in scheduling to accommodate dialysis schedules. Mode of dialysis may also have an impact on patients' ability to work. Patients who are able to dialyze via peritoneal dialysis have more flexibility in their dialysis schedule and therefore could work at different times of the day, including shift work (Hirth et al., 2003; Muehrer et al., 2011). It is likely that fatigue plays a large role in dialysis patients' inability to maintain employment (Hirth et al., 2003; Molsted, Aadahl, Schou, & Eidemark, 2003; O'Sullivan & McCarthy, 2007) as fatigue and physical functioning have been negatively correlated (O'Sullivan & McCarthy, 2007) and poor physical function predicts unemployment in dialysis patients (Blake, Codd, Cassidy, & O'Meara, 2000). If we could devise ways to help ameliorate fatigue, such as treating patients with erythropoietin earlier in the course of chronic kidney disease (Muehrer et al., 2011) decreasing fatigue levels may help return some dialysis patients to the work force. Using peritoneal dialysis (PD) more frequently as the first mode of dialysis may also help return patients to work (Hirth et al., 2003; Muehrer et al., 2011); however, because PD is not reimbursed at as high a rate as hemodialysis, there are fewer nurses and physicians with PD experience, and patients are referred too late in the disease trajectory for specialty care which limits choice of dialysis mode, this option is decreasing in prevalence (Hirth et al., 2003).

Model Expansion and Preliminary Theorizing

In previous work, I proposed a conceptual model of fatigue in hemodialysis patients based on information available in the literature. Conceptual models are useful because they allow us to visualize relationships between and among elements in the model (Brant, Beck, & Miaskowski, 2009). My research focused on the experience and self-management of fatigue, and how fatigue changes over time from one dialysis session

to the next. This work has allowed me to expand the conceptual model and begin constructing preliminary theories regarding fatigue in hemodialysis patients. Figure 5 depicts the conceptual model prior to my research and includes probable contributing factors to fatigue, clinical management of fatigue, and the consequences of fatigue. Question marks indicate areas without enough evidence in the literature to draw conclusions about their impact on fatigue or how fatigue impacts outcomes in these areas.

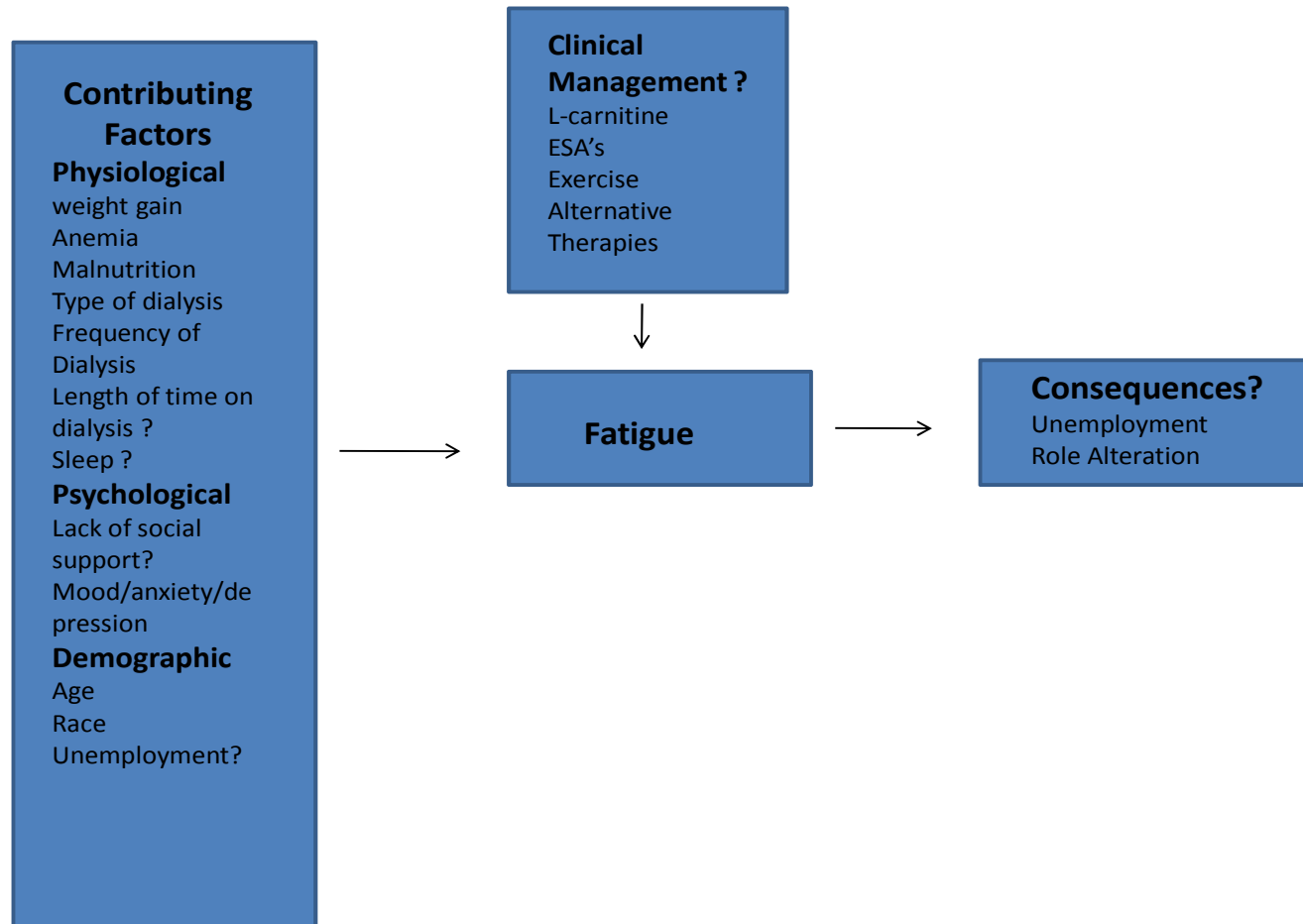


Figure 5. Conceptual model of fatigue in dialysis patients prior to dissertation study.

My dissertation work has expanded this model to include two types of fatigue, post-dialysis only and continuous fatigue; self-management techniques for each type of fatigue; and the experience of each type of fatigue. Please see Figure 6; the red areas are additions.

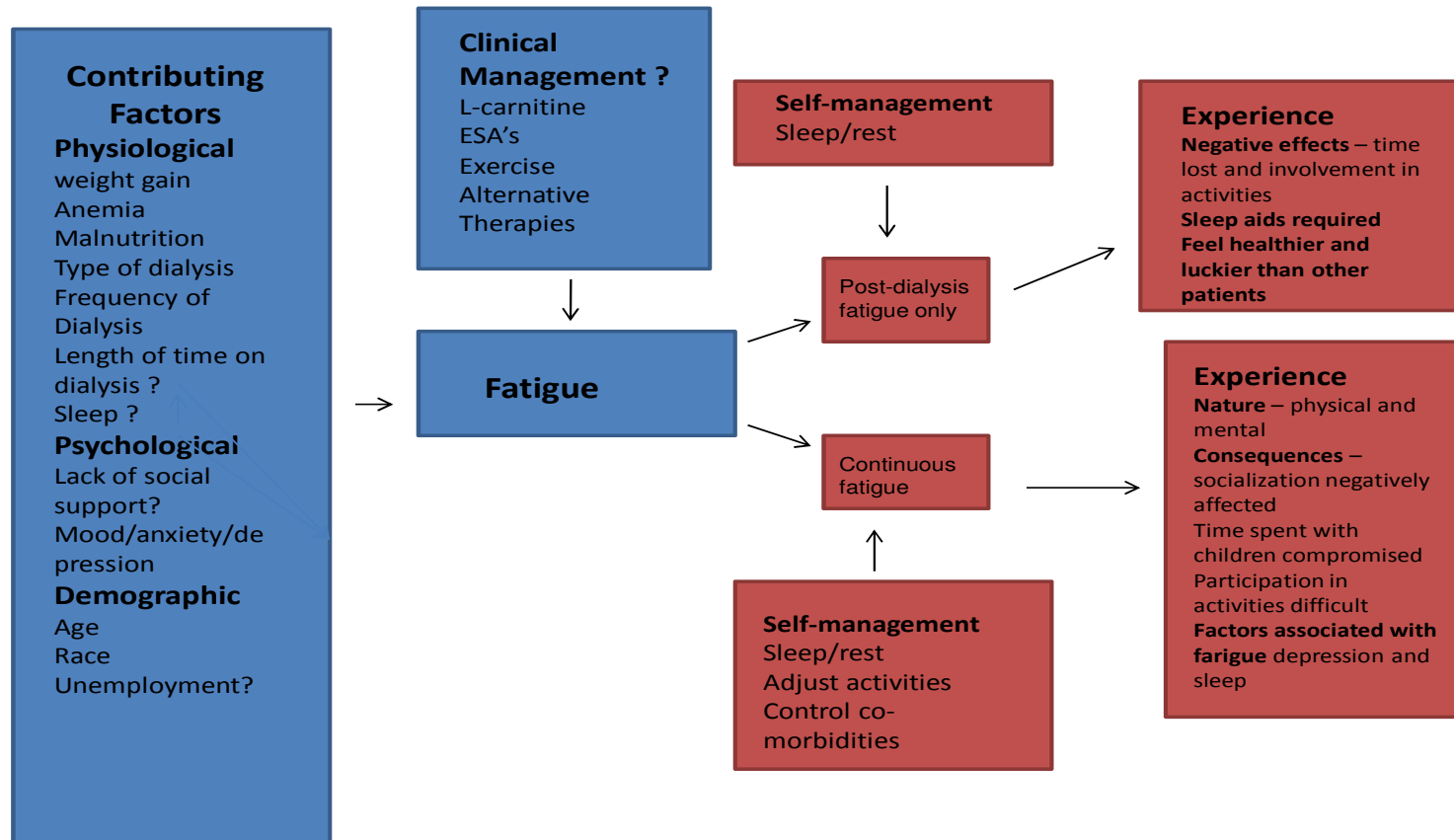


Figure 6. Conceptual model of fatigue in dialysis patients after dissertation work.

Based on descriptions from participants, all had fatigue directly after their dialysis session. For some, this was the only fatigue they experienced (post-dialysis fatigue only), for others this was an exacerbation of their continuous fatigue. The fact that all participants experienced an extreme fatigue that caused them to rest after dialysis sessions points to a physiologic cause of fatigue in this population. There has been little progress identifying the specific cause or group of causes of fatigue; however, this information allows us to focus future research on probable physiologic origins of fatigue.

My research suggests that there are two types of fatigue that patients experience, post-dialysis fatigue only and continuous fatigue. Further work in this area would help confirm and clarify the existence of these two groups. All patients in my study who had fatigue experienced fatigue immediately after their dialysis session; this suggests that dialysis patients who state they experience fatigue always experience fatigue after their dialysis sessions, irrespective of whether or not they have continuous fatigue. This leads us to question if and how the two types of fatigue are related. Patients with post-dialysis fatigue had, in general, been on dialysis for an average of three years. As time progresses, it would be reasonable to think that this fatigue would transition to continuous fatigue as the factors of age, illness and time on dialysis combine to impact the patient.

Longitudinal work in this area would help establish if and where in the illness trajectory this occurs. Additionally, fatigue has been associated with lower quality of life (Yong et al., 2009; Jhamb, Weisbord, Steel, &Unruh, 2008; Weisbord et al., 2003) and increased mortality (Jhamb et al., 2009) in this population. I would suspect that those with continuous fatigue would be more likely to report a lower quality of life and would have higher mortality rates than those with post-dialysis fatigue only. Further work in this area

would help confirm which group of patients, post-dialysis fatigue only or continuous fatigue, is in greater need of assistance and intervention.

In the model, sleep is both a contributing factor and a result of fatigue in the hemodialysis population. It is logical that sleep would be a pivotal factor in fatigue. Determining whether there are physiologic and/or psychosocial contributors to problems with sleep may help curb its effect on fatigue. Even if a cause of sleep problems is found, it may not be amenable to intervention, but rather an effect of ESRD or dialysis. My work suggests that patients on dialysis have sporadic sleep cycles which likely impact their fatigue. Sleep disturbances may directly relate to a patient's dialysis schedule. Determining how the dialysis and sleep cycle are related would allow us to begin to intervene to help patients get quality sleep. Comparing the sleep cycles of patients on the morning dialysis schedule and those on the afternoon dialysis schedule to see if sleep disturbances are linked with dialysis treatments would be interesting. Further, having dialysis later in the day would possibly allow patients to go home, go to sleep, sleep through the night and wake up the next morning feeling better because they have gotten continuous sleep, not sporadic sleep. Many patients stated that they slept while receiving dialysis treatment. Ascertaining why patients sleep while on dialysis will enable us to aid patients in developing a more consistent sleep cycle. If patients sleep because they are bored, nurses have great opportunities to intervene with education and activities that will help keep patients awake. If sleeping on dialysis is a function of the dialysis process itself, determining what contributes to this would be helpful as there are factors in the dialysis process that can be adjusted such as dialysate temperature and the amount of

fluid taken during the process. However, these processes may be necessary for the health and well-being of the patient.

Self-management of fatigue was difficult for patients. The most frequently reported method for ameliorating fatigue was to sleep or rest. Participants also mentioned that keeping comorbidities in check, such as blood sugar and pain levels, helped decrease their fatigue levels. Many patients on dialysis are diabetic; therefore, research that determines the effect of blood sugar levels on fatigue would illuminate a possible area for intervention. If keeping blood sugar under tight control enables patients to have less fatigue, patient education on checking blood sugars frequently and insulin dosing and options for delivery may be appropriate. Participants noted that pain control also helped decrease their fatigue levels. The extent to which this is effective on fatigue levels is unknown but is another area for study which could lead to helpful interventions.

My work suggests that depression was not a problem for most patients in my study. The method that I used to determine if patients were depressed was to ask them if they felt down or blue, and if so, if they felt that this had an effect on their fatigue. This single question method of determining depression is a valid and reliable determination of depression (Reme & Erikson, 2010; Watkins et al., 2007). Based on observations and interactions, I felt there were more patients, particularly men, who were depressed than those who reported depression. It is possible that participants reported not being depressed, even if they were, in order to appear favorable and socially acceptable in the researchers eyes (Crowne & Marlowe, 1960). Researchers have speculated that patients are more susceptible to wanting to be socially desirable on the first meeting with the research or medical team when most of these assessments are done as they are making a

first impression on the team (Deshields, Tait, Gfeller, & Chibnall, 1995). It would be interesting to compare responses from the one question assessment of depression with instruments that have been validated in this population such as the Beck Depression Inventory (Beck, Steer, & Brown, 1996) or the Quick Inventory of Depressive Symptomatology Scale Self-Report (Hedayati, Minhajuddin, Toto, Morris, & Rush, 2009) and see what the results of each indicate.

My exploratory work enabled me to expand the conceptual model of fatigue to include different types of fatigue, self-management techniques and fatigue experiences. This work facilitates preliminary theorizing regarding these concepts and points to areas that merit further inquiry. This will allow us to test and refine the model of fatigue in hemodialysis patients.

Overall, the dissertation has served several purposes. I learned how to design and implement a qualitative research study, how to recruit and interview participants, and how to analyze and present findings. Further, I expanded my thinking to propose areas for future research involving fatigue in hemodialysis patients that include sleep, depression, types of fatigue, and policy implications.

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Biography

Ann Horigan was born in Elmira, N.Y. March 9, 1977. She earned her BSN from James Madison University in 1999, her MSN from Duke University in 2005, and her PhD in Nursing from Duke in 2012. She has co-authored several peer reviewed articles including "A process of decision making by caregivers of family members with heart failure" in *Research and Theory for Nursing Practice*, "Dialysis and Fatigue: A Case Study Analysis Implications for Nurses" in *Medsurg Nursing* and "Fatigue in Hemodialysis Patients: A review of current knowledge" in *The Journal of Pain and Symptom Management*. Ann was awarded the American Nephrology Nurses' Association 2010 Research Scholarship and the Ruth L. Kirschstein National Research Service Award for pre-doctoral trainees from the National Institutes of Health.