

Running header: RENAL DISEASE

Renal Disease, Dialysis, and Sleep Deprivation

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Abstract

Renal disease was the ninth leading cause of death in 2004 taking the lives of 42,480 Americans (CDC, 2004), and 500,000 people are receiving dialysis (Wrobel, 2007). Renal disease is a serious problem in the United States and will continue to get worse as rates for hypertension and diabetes increase. Individuals on dialysis have a difficult time falling asleep, staying asleep, and reaching rapid eye movement while sleeping. The purpose of this honors thesis was to explore and better understand renal disease, dialysis, and sleep deprivation. Audio-taped interviews were done with one man and one woman who were currently undergoing dialysis and had sleep deprivation. Phenomenology was the method selected with a goal of understanding the meaning of a lived experience of renal disease, dialysis, and its impact on sleep disturbances. Volunteers were recruited from the community, informed consent obtained, and meeting time established. Data was analyzed using Giorgi's method. Data analysis revealed the following themes: Keeping Busy, Quieting the Mind, Losing Independence, Restricting Diet, Restricting Fluid and Interrupting Sleep Patterns. Results of this study cannot be generalized; however the findings allow nurses to better understand the lived experience of persons with sleep deprivation in renal failure.

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Dedication

I would like to dedicate this thesis to my loving, patient and supportive family- Justin, Seth, Sarrah and Madison. You have all been my inspiration and constantly reward me. I would also like to thank Britt Ballinger for her optimism, valued friendship and sharp mind. I love you all!

Chapter I

Background

Renal Disease

Renal disease was the ninth leading cause of death in 2004 taking the lives of 42,480 Americans (CDC, 2004), and 500,000 people are receiving dialysis (Wrobel, 2007, p 14). Michigan had the highest rate of renal failure in 2004, and was ranked the second fattest state in the nation (CDC, 2004). At the start of 2004, 3,695 Michigan residents were put on some type of renal treatment- transplant or dialysis. By the end of the year, 614 were given a new kidney and over 11,000 were on dialysis; 40% were diabetic while 30% suffered from hypertension (CDC, 2004). Renal disease is a very serious problem in the United States and will only continue to get worse as rates for hypertension and diabetes increase. There are a significant number of individuals with renal disease that have difficult time falling asleep, staying asleep, and reaching rapid eye movement while sleeping (Wrobel, 2007). Sleep disturbance is prominent in individuals on dialysis (Carpenito-Moyet, 2004). The purpose of this honors thesis was to explore and better understand renal disease, dialysis, and sleep disturbances.

Pathology

Acute renal disease results from the kidney not functioning properly within hours to days, and may be reversible. The kidney is not able to maintain electrolyte and fluid homeostasis resulting in decreased glomerular filtration rate [GFR], and fails to excrete waste products such as uric acid, urea nitrogen, and creatinine (Bonventre, 1996). Acute renal disease affects individuals who are seriously ill such as individuals in the intensive care unit [ICU]. According to Porth, there is a 40-75% mortality rate for these specific individuals. This mortality rate has not changed since the 1960s and is linked to elderly

patients in addition to other life threatening events such as trauma or sepsis (2007).

Chronic renal disease differs from acute renal disease. Chronic is progressive and damage caused to the kidney is irreversible. Chronic renal disease progresses in four stages: diminished renal reserve, renal insufficiency, renal failure, and end-stage renal disease [ESRD]. Signs and symptoms gradually occur and may not be present until the individual has progressed into destruction of nephrons caused by the body's natural ability to compensate for the failing kidney (Porth, 2007).

Risk Factors

There are many factors that can lead to renal disease. Factors that occur with acute renal failure are prerenal, intrarenal, and postrenal. Prerenal failure may be caused by hypovolemia from dehydration or hemorrhage, decreased vascular filling attributed to shock (both anaphylactic and septic), or heart failure. Also prerenal failure may be caused by decreased kidney perfusion related to drugs, diagnostic agents, or vasoactive mediators. Intrinsic or intrarenal failure is caused by acute tubular necrosis, prolonged decrease of oxygen to the kidney, exposures to heavy metals, organic solvents, and nephrotoxic drugs, in addition to acute pyelonephritis or glomerulonephritis. Post renal failure is caused by an obstruction, such as a kidney stone, of the ureter or bladder outlet (Porth, 2007). Chronic renal failure risks are most often associated with conditions causing permanent loss of nephrons, such as hypertension, diabetes, polycystic kidney disease, and glomerulonephritis (Porth, 2007). Understanding these comorbidities are more prevalent in certain ages, states, and cultures is vital in the diagnosing, treating, and prevention of renal disease.

Prevalence

In Michigan, the disease mortality rate was significantly higher in the elderly population over 75 years of age (CDC, 2004). In 2005, age-specific mortality rates were 174 per 100,000 for persons over 75 years of age, compared with 19 per 100,000 for those aged 50-74, and only 1 per 100,000 for those less than 50 years old. During 1989-2005, the age-adjusted kidney disease mortality rate in Michigan was consistently higher among black males and females. In 2005, the age-adjusted death rate among males was approximately 2.0 times higher among blacks than whites per 100,000 populations. Among females, the age-adjusted rate was 2.3 times higher among blacks than whites. (CDC.2004)

Scope of Problem

Quality of life. Among levels of quality of life [QOL] affecting individuals with renal disease, the psychological domain ranked the lowest (Ho-Su, 2005). Individuals who had received a kidney transplant ranked their psychological QOL higher than individuals who were on hemodialysis or peritoneal dialysis. Economical status can play a major role in QOL as well. Those considered economically sound ranked higher in their QOL than individuals in a lower socioeconomic standing. Ho-Su (2005) concluded QOL affects not only how family members make decisions about treatment, but also how the medical team responds to each individual and his or her personal needs in order to enhance QOL.

Impact of renal disease on society. Many renal patients have complex medical problems. The medical field needs to address these problems in relation to ESRD. Knapp and Reams (2004) suggested looking at palliative care versus dialyzing high-risk patients with a small chance of survival. The focus of care should be based on maintaining a

satisfactory QOL, not just a diagnosis alone, “Conservative management may provide an equally good QOL” (Knapp & Reams, 2004, p. 333).

Transplants play a major role in ESRD and society; however, not all individuals have medical insurance to pay for a transplant, nor are they at a facility that receives benefits from Medicare. In order for ESRD facilities to receive Medicare coverage, they must participate in Medicare surveys. Bell and Payne (2005) stated:

The Social Security Act requires facilities or hospitals to be approved to participate in the End Stage Renal Disease (ESRD) Program. Kidney transplant is a part of the ESRD program, so kidney transplant centers must demonstrate they meet the requirements spelled out in the ESRD Conditions for Coverage to achieve and maintain Medicare approval and funding. (p. 56)

One can certainly question the ethical dilemma involving kidney transplants and approval from Medicare based on medical facilities' meeting program requirements.

Ethical decisions. One might also debate the ethics behind determining who receives a kidney. Is it ethical to go to another country and obtain a new kidney because the wait list in the United States can take years? One can also question the ethical dilemma involving ceasing dialysis; where does one accept end of life care and give in to ESRD?

Summary

ESRD affects individuals in every aspect of their lives. Family members, healthcare teams, and society are drastically affected by ESRD as well. Our society will continue to be faced with the impact of ESRD as life expectancy increases and the rate of diabetes and hypertension skyrocket. One of the main focuses of the healthcare team in ESRD is maintaining the highest QOL possible for each and every ESRD patient and his

or her family. Awareness in preventative medicine could save millions of taxpayers' dollars in fighting ESRD. Lastly, providing individuals and their families' information regarding ESRD could make the impact of transitioning into dealing with ESRD a great deal more manageable and ultimately enhance QOL.

Chapter II

Review of Literature

Sleep is a vital component in the human circadian rhythm. It plays a major role in how an individual responds to illness, stress and when sleep deprived, can result in a lowered immune system. Sleep disturbance is prominent in individuals on dialysis (Carpenito-Moyet, 2004). Literature and research related to sleep disturbance, dialysis, interventions, and education will be analyzed throughout this literary review.

Sleep Disturbance

A recent study concluded that individuals who were on dialysis had a harder time falling asleep, staying asleep and reaching rapid eye movement while sleeping. The study linked an increase in core body temperature to sleep deprivation. According to Wrobel (2007), individuals were given dialysis fluid at 35 degrees Celsius versus the normal 37 degrees Celsius. The lower temperature of the fluid did in fact help in obtaining a normal sleep pattern. Other factors affecting sleep disturbances can include the following: impact on performance, recovery from illness, health conditions related to sleep disturbances, and associations between older adults and increased alcohol abuse in hopes of getting a better nights rest.

Impact on performance. Sleep disturbance can cause lack of concentration and depression. Bulbotz, Brown, and Soper (2001) explored the association that sleep disturbance can cause a lack of concentration and depression among college students. Considering some individuals on dialysis fall into this age bracket, one should examine the correlation that “interestingly, even students who sleep 8 hours nightly but shift their sleep-wake cycle by 2 hours experience increased feelings of depression, reduced affability, and difficulty in concentrating” (Bulbotz, Brown and Soper, 2001, p. 131).

Nursing implications should involve education and interventions such as training that involves appropriate sleep behaviors and avoiding other behaviors that can lead to sleep disturbances (alcohol consumption, cramming). These interventions are very important for an adolescent on dialysis who feels he or she is not able to perform to the best of his or her ability.

Recovery from illness. Lee, Low, and Twinn (2007) performed a qualitative study on elderly inpatient males and found a significant relationship between sleep disturbance and hospitalization. The researchers concluded, "The findings demonstrated that all informants experienced dynamic changes in their sleeping patterns during hospitalization, resulting in sleep disruption and deprivation. The public nature of the ward environment and perceived sense of helplessness significantly interfered with sleep" (p. 336).

Interventions that were given for nursing implications consisted of nurses' needing to respond to patients' psychological status during the early days of hospitalization. This could be done by spending time talking and conducting comprehensive assessments of health and psychosocial status of older people, as part of a sleep need assessment on admission (Lee et al., 2007). By encouraging nurses to be advocates for individuals, nurses can help ensure a better hospital stay and aide in a faster recovery. When the patient's body gets the proper amount of sleep necessary, it is easier to maintain a healthy circadian rhythm.

A study regarding sleep disturbance and the ICU was conducted to identify functional outcomes, nutrition, and psychological issues such as anxiety and sleep disturbances (Strahan, McCormick, Uprichard, Nixon, & Lavery, 2003). The researchers further explained that "[s]ixty-seven percent of patients experienced trouble getting to sleep" (2003, p. 52). Evidence- based nursing implications pertaining to this study

involve decreasing anxiety based on the individual's own state of health and that particular diagnosis (Fain, 2004).

Similarly, a study following the sleep pattern of individuals recovering from coronary artery bypass surgery (CABG) found, "The most common health conditions which may have been potential causes of sleep disturbances were, in descending order, pain, nausea/vomiting, and coughing" (Edell-Gustafson, Aren, Hamrin, & Hetta, 1994, p. 332). Other studies have found a correlation between health conditions such as anxiety and depression with sleep disturbances.

Health conditions. Anxiety, depression and tinnitus can lead to sleep disturbances. A study conducted on tinnitus by Di Pietro et al. (2007) found that there is a correlation between anxiety, depression, and tinnitus. Nursing implications include taking a problem solving approach in handling and acknowledging the correlation between tinnitus and psychopathological disorders by reducing anxiety and treating depression, thus allowing individuals an opportunity to enhance their sleep pattern.

Individuals receiving home parenteral nutrition (HPN) were also linked to sleep disturbances as reported by Persoon et al. (2005). These researchers identified that severe fatigue with sleeping disorders affected over 50% of individuals on HPN. Nursing implications suggested therapies such as anti-depressants, cognitive training, and psychosocial support (Persoon et al., 2005). Education might help individuals benefit from therapies like cognitive training or anti-depressants rather than trying to self-medicate themselves with alcohol.

Alcohol and sleep disturbances. Boyle and Davis (2006) discovered a link between sleep disturbance and elderly alcohol/substance abuse. The researchers claimed, "Often, the presence of chronic medical disorders and sleep disturbances may place the

elderly at risk to self-medicate with alcohol to control pain or to induce sleep” (Boyle and Davis, 2006, p. 96). Often, people might not even realize they are abusing alcohol, especially when they have a nightcap to encourage a good night’s rest. One way nurses can intervene and gain a better understanding of how much alcohol is being consumed is through the CAGE questionnaire. This questionnaire involved four questions: Cutting down, Annoyance by criticism, Guilty feeling, and Eye-openers. Understanding one’s chronic medical disorder can play an important role in his or her everyday living.

Coping with Renal Disease

The effects from renal disease can be very taxing not only on the individual, but also on family and friends. Any individual coping with ESRD will have to adjust to major changes in life. Physical activities, spirituality, and music therapy may play a role in enhancing coping and decreasing anxiety.

Cognitive and physical activities. According to Darbyshire, Henning, and Oster (2006), individuals suffering from renal disease varied in their coping mechanisms based on the type of treatment they received. Transplant recipients use cognitive and physical activities to cope with their disease compared to individuals receiving dialysis. One theory conjectures that transplantation corrects bone marrow deficiencies and anemia in ESRD, therefore increasing the client’s mobility and energy (Darbyshire et al., 2006). Age and length of time receiving dialysis played a role on the impact of renal disease on the clients and their families. Darbyshire and researchers (2006) linked older patients with a broader scope of coping mechanisms than younger adolescents, which in turn determines how family members will cope. Darbyshire et al. (2006) tracked 32 adult survivors from a dialysis program and assessed measures of adaptation including personal and social life, education, marital status, and psychiatric problems:

The results indicate that adults treated for ESRD as children and adolescents find it more difficult to form a lasting relationship with the opposite sex, experience a restricted social life and are more likely to live with their parents. In a study of medical and social outcome in 118 adolescents with ESRD, Roscoe et al. (1991) found that adolescents with ESRD who were successfully transplanted achieved a better quality of life compared with those receiving dialysis. (p. 755)

Education. When educating individuals in ESRD that are on dialysis and experiencing sleep deprivation, the nurse should consider individual coping skills and patterns. Family, social, and spiritual support systems must also be evaluated. Medical interventions need to be addressed as well as individual expectations and goals. The role of the nurse is to evaluate these concerns and to be an advocate in finding the best evidence- based practice for these individuals.

Music therapy. The application of music therapy can act as a catalyst when promoting an enhanced QOL. The following studies show some of the successes of music therapy related to dialysis and sleep. Kim, Lee, and Sok (2006) found a correlation between QOL and music therapy in individuals undergoing dialysis that suffered from anxiety and depression. The study suggested that music therapy may be applied as a method of nursing intervention. Music therapy contributed to the improvement of QOL by reducing anxiety and depression of individuals undergoing hemodialysis.

Similarly, Chung (2004) found the effects of music therapy and hemodialysis not only decreased stress, anxiety, and depression, but also improved immune function and vital signs. Results showed an increased number of B lymphocytes and a significant decrease in diastolic blood pressure (Chung, 2004). Music therapy can also improve quality of sleep. Sixty people between 60 and 83 years of age were included in a sleep

study involving music therapy. Lai and Good (2005) found a correlation between sleep quality in older adults and music therapy. After three weeks of listening to a 45 minute sedative music tape, these individuals reported an improved quality of sleep. In addition, a case study performed by Scheve (2003) found:

Mrs. S. was in dialysis on the Renal Unit when MT [music therapist] arrived. Mrs. S. had requested specifically some of her favorite songs and she sang every word along with MT. She also liked keeping the beat by tapping her hand on her chest. In the Renal Unit, curtains instead of walls separate patients, so everyone in the Unit could hear the music, and several patients and staff sang along. Towards the end of the session, other patients started requesting songs as well, and the patient agreed to sing those songs to the Unit. Some patients commented how nice it was to have something [like music] structure their dialysis time other than TV. The nursing staff was very receptive and commented how the patients usually keep to themselves but on that day they were all interacting. It was probably the most social interaction Mrs. S. had in a long time. (¶ 6)

Understanding how something as simple as a sing along can enhance ones' QOL during dialysis is a vital component for nurses. Nurses should also consider education when wanting to enhance QOL for individuals on dialysis, particularly those who also experience sleep deprivation.

Dialysis

When an individual is in ESRD, he or she either needs a transplant or dialysis to perform the kidney's function (Vale et al., 2003). During ESRD, the blood-borne metabolites of protein breakdown and water cannot be excreted. An artificial kidney machine (haemodialysis) allows these substances to be removed when blood is passed

over a semipermeable membrane (McLeod et al., 2001). Dialysis can either involve regular visits to a hospital or satellite unit for haemodialysis or home dialysis. Home dialysis or continuous ambulatory peritoneal dialysis [CAPD] does not require a machine. Rather, it involves a permanent tube inserted in the abdomen and allows a fluid called dialysate to be emptied and replaced daily (Vale et al., 2003). Vale and researchers wanted to compare the effects of haemodialysis and CAPD. The review found only one trial comparing the effects of CAPD and haemodialysis and found no significant change in the effects of hospital or home dialysis (Vale, et al., 2003). Historically, Hanly and Pierratos, (2001), found a correlation between nocturnal hemodialysis (receiving dialysis at night) and correcting sleep apnea.

Locatelli, Del Vecchio, and Manzoni (1998) believed that in spite of technical advances in medical care and dialysis delivery, mortality and morbidity remain high in ESRD individuals. A number of factors seem to contribute; however, cardiovascular diseases [CVD] were the leading cause of death in relation to ESRD (Locatelli et al., 1998). The National Kidney Foundation (2005) recommended an assessment for CVD be done at the start of dialysis, as well as screening for both traditional and nontraditional cardiovascular risk factors. Locatelli and researchers (1998) agreed that dialysis adequacy improves blood pressure control which is a strong predictor of survival. The National Institute of Clinical Excellence [NICE] (2006) recommended that all suitable patients should be offered the choice between haemodialysis or CAPD. Family and social support, as well as proper medical care, can enhance QOL and therefore increase compliance to dialysis, diet, and drugs.

Interventions

Prevention. Risk factors for renal disease such as hypertension, diabetes, and obesity can be prevented. According to Nahas and Bello (2008), the worldwide rise in the number of patients with chronic kidney disease and ESRD is threatening to reach epidemic proportions over the next decade. They also recommend a concerted approach to CKD being implemented in more developed countries as well as less developed countries in order to avoid a major catastrophe (Nahas and Bello, 2005). Also, Levey et al. (2007) recognized the importance of prevention by stating the following:

The message is that kidney disease is common, harmful, and treatable. In this article, we focus on chronic kidney disease (CKD) as a global public health problem and the urgent need for all countries to have a public health policy for CKD. Until recently, decision makers in public health and biomedical science had viewed CKD as uncommon, without consequences, and untreatable until the stage of kidney failure. The care of patients with CKD had been marginalized, relegated to the subspecialty of nephrology, with payment primarily directed at dialysis and transplantation, which are too costly for the vast majority of people who live outside the developed world. At the same time, costs for other chronic diseases have been mounting. In developed countries, hypertension, diabetes, and cardiovascular disease (CVD) consume a large fraction of resources for health care. The epidemic of obesity will magnify these costs, in the young as well as in the elderly. In developing countries, the burden of these noncommunicable diseases is rising even though communicable diseases are not yet under control. We now recognize that CKD is especially common in people with other chronic diseases and multiplies the risk for adverse outcomes and costs. The public health mandate now is clear. No country can afford to overlook the burden of CKD; prevention, early detection, and intervention are the only cost-effective strategies. (p.401)

Lifestyle changes. Diabetic renal disease (diabetic nephropathy) is one of the leading causes of ESRD. Once the process has started, it cannot be reversed by glycemic control; however, progression might be slowed by control of blood pressure and protein restriction. Robertson, Waugh, and Robertson (2000) found a reduction in protein intake slightly slows progression to renal failure. In conjunction, Harris, Thomas, Johnson, Nicholls, and Gillin (2006) stated, "A protein-controlled diet consisting of 0.75

to 1.0 g/kg/day is recommended for adults with chronic renal disease [CKD]" (¶ 1).

Individuals on dialysis have to change their diet and control how much fluid is consumed in order to avoid fluid overload. Some researchers such as Tomson (2001) argued that it is not the amount of fluid consumed but the amount of sodium that will affect one's extracellular fluid which can put one at risk for CVD. Medications can have a significant impact on slowing the progression of ESRD.

Pharmacologic interventions. Strippoli, Bonifati, Craig, Navaneethan, and Craig (2006) reported roughly 1/3 of all diabetic kidney disease [DKD] will progress to ESRD. Many individuals may die from associated CVD before the DKD progresses to ESRD (Strippoli et al., 2006). These researchers reported that antihypertensive drugs such as angiotensin converting enzyme inhibitors [ACE] and angiotensin II receptor antagonists [AIIRA] were effective against mortality associated with DKD and ESRD (Strippoli et al., 2006).

Summary

There is a void of research related to renal failure, dialysis and sleep deprivation. The literature addressed sleep deprivation in hospitalized individuals, in the elderly, in cardiac diseases and students. The purpose of this study is to gain knowledge and understanding of the lived experience of renal failure, dialysis and sleep deprivation.

Chapter III

Methodology

Design

Phenomenology was the method selected with a goal of understanding the meaning of a lived experience of renal disease, dialysis, and its impact on sleep disturbances. As a philosophy, phenomenology views the world of everyday life. “Phenomenology is a qualitative research method that explores and describes everyday experiences as it appears to human consciousness in order to generate and enhance the understandings of what it means to be human” (Russell, 2004, p. 220). As a research method, phenomenology also studies the world of everyday life; therefore, “The approach includes a descriptive, retrospective, in-depth analysis of a conscious lived experience” with the purpose to “describe intrinsic traits or essences of the lived experience” (Russell, 2004, p. 221).

The concept of phenomenology dates back to the 18th century and was introduced by Immanuel Kant. Kant clearly defined phenomenon as “the appearance of reality in the consciousness” (Russell, 2004, p. 221). There were many other contributors to this theory including Edmund Husserl, the “father of phenomenology,” who wanted to “discover the essential structures and relationships of the lived experience and consciousness, uncluttered by scientific or cultural presuppositions” (Russell, 2004, p. 222).

Participants

Participants included two individuals one man and one woman diagnosed with renal disease who receiving dialysis and report that they have sleep disturbances. Volunteers were from a Dialysis Unit from a rural Montana hospital. Researcher had

prior contact with the group allowing her to publicly request the need for volunteers and establish a meeting time for review and signing of consent forms.

Data Collection

This was a qualitative research study using phenomenology to describe lived experiences. Data involved in-depth audio-taped interviews from two individuals with renal disease who were currently on dialysis and spoke English. Data collected was not analyzed with names or connected to any identifiable data. Records were kept confidential in a locked file and identifiable information was not included in this study. Audiocassette tapes were kept in a locked cabinet and destroyed after data analysis was completed. Participants were identified with a pseudonym. The researcher was able to focus on the participant's sleep disturbances in relation to dialysis and the holistic model of mind, body, spirit and environment. As stated by Russell, "Nursing practice is guided by a holistic model that reflects the interrelationship of body, mind, spirit and environment" (2004, p. 220). Research was conducted via interview questions and lasted approximately one hour. Individuals were recruited through a private dialysis facility. This was a voluntary study and confidentiality was maintained and informed consent obtained.

Data Analysis

Data was analyzed using Giorgi's method. This method required two individuals and their description of living with renal disease, dialysis, and its effects on sleep disturbances. The data was generated via audio-taped interviews. Russell (2004) summarized the steps of Giorgi's analysis:

- 1) Read the entire disclosure to discover the lived experience straight through to obtain a sense of the whole.

- 2) Reread the disclosure to discover the essences of the lived experience under study. Look for each time a transition in meaning occurs. Identify abstract these meaning units or themes.
- 3). Examine meaning units for redundancies, clarification, or elaboration. Relate meaning units to each other and to a sense of the whole.
- 4) Reflect on the meaning units, and extrapolate the essence of the experience for each participant. Transform each meaning unit into the language of science when relevant.
- 5) Formulate a consistent description of the meaning structures of the lived experience for all participants. (Russell, 2004, p. 230)

Rigor

In order to maintain rigor, the researcher followed the steps of Giorgi's methodology, and met with faculty director for data analysis. To ensure the integrity of this study the findings were supported by quotes from participants.

Limitations

There were limitations to the research conducted. This was a small pilot study for this researcher's undergraduate honors thesis. The number of participants was smaller than anticipated, therefore limiting the saturation of data this researcher was hoping to obtain.

Chapter IV

Results

Renal disease is becoming so prevalent, that it may become an epidemic within the next decade (Nahas & Bello, 2008). The participant's interviewed had serious complaints of sleep disturbances. Using the phenomenologic method and Giorgi's analysis, the following themes emerged: Keeping busy, quieting the mind, losing independence, restricting diet, restricting fluids, and interrupting sleep patterns.

Keeping Busy

Participants on dialysis tried to maintain an active lifestyle on days they were not dialyzing. Some of the hobbies included but are not limited to: reading, fishing, cross-stitching, spending time with family, friends, watching TV, going out in town, shopping, going out for dinner (Eagle Manor & friends' houses, or restaurants), documenting family genealogy, cooking, and babysitting grandson.

Duane stated that he now does a lot with his friends, "I've got a friend with a boat on Canyon Ferry and I go [fishing] with him a lot." Also, he explained a typical day:

Well, I get up by seven o'clock and then I eat breakfast. Then I read...sometimes I'll take a trip to Wal-Mart or whatever, and then when I get back I'll eat lunch and then supper. It just depends if I have any special plans, you know, or company or whatever.

Diane keeps herself as busy as possible on days that she does not dialyze:

Tuesdays are doctor appointments if I need to go, and lots of errands. Thursday I have my grandson who is 22 months and just absolutely gives me so much joy. I often have him on Tuesdays too if I don't have things going on, but...so that day is totally devoted to him. I do nothing else. I'm his playmate, and we just have fun. I just want to spend so much time with him because I don't know how much time I have, you know, so I just really allow myself that time with him.

Quieting the Mind

Staying too busy might actually counteract sleep patterns with these participants. Naps during the day might affect evening sleep patterns. Staying busy might be a means of coping with their renal disease and can help improve ones quality of life, however; it might be counterintuitive toward sleep. Duane stated, "Sometimes I'll nap during the daytime, you know. Honestly I've got less chance of trouble sleeping during the daytime than I do at night for some reason." He also added, "I do read a lot. I try to read as much as I can, and then...keep my mind occupied. And then I'm watching television. I don't know if that helps you sleep or not, but I do read a lot." According to Diane,

No, there's no sleeping, and I...even on the four days without dialysis I can't sleep. I try to go in and take a nap, thinking I can change my life so I can take a nap every day, be up late and get three or four hours a night. I can deal with that if that's what it will take. I'll lay in there, you know I can't...and if my mind is busy, busy, busy with lots of stuff, if I'm writing something...I'm writing another talk right now...if I'm writing, sometimes when I lay down, the thoughts come to me. I get up, type them up really quickly and go back to bed so that I can let go of them. If I don't, then they just stay there and rumble around. But that doesn't guarantee I'll go to sleep.

Losing Independence

A huge impact on losing independence was repeated in both participants.

Participants lost some of their independence when on dialysis, however; social qualities were enhanced as a result because participants had to rely on others, when in the past the participant may have just been alone. Duane struggled with his loss of independence:

I'm here in Helena. Yeah, I had to be closer to my dialysis, you know. I can't drive, you know. So I just take that HATS bus over here, you know, yeah, it's pretty tough when you can't drive. You lose a lot of your independence; it's hard to make plans. That's the main thing, you know. I only have two days a week where I can make plans to do anything, you know. It takes a whole day to do this thing [dialysis], so, I guess that's the main thing. I can't make any plans on the day I'm doing dialysis, you know, it takes the whole day, it's hard to make plans, those days are shot.

Diane also expressed concern over losing her independence:

I've often said I go like a wild woman on non-dialysis days, and I really do. I make the most of them. But, I do know that I can't really do much more than a couple of hours in town of stops and starts, in and out of stores. I just get so tired. I can push myself. Once I get in the store I do better than I think I'm going to, but then I pay for it when I get home and I'm just too tired. So I'm pretty conscious and pretty good at parceling out my energy. It's very frustrating. And I get so tired that I can't sleep." She continued on, "Saturday night we usually go to church, mass at five. We often go out to dinner or to a friend's house for dinner. I'm a great cook, but I can't stand and cook for a long period of time anymore, so I can do quick things like goulash, but it's really hard for me to do the big five course dinner I used to do. My friends don't even expect that any more because they enjoyed them a lot when I could, so we often go to dinner with them, or we go to their house.

Diane has been on dialysis for a few years and has been invited to share her positive outlook with others. One of her philosophies consists of empowerment:

Well, you know, I just have to...I want to cram everything in I can, and I think I said during [my lecture] ...no stinking thinking...I just will not allow myself to go there and feel bad. Oh, I'm not going to be here much longer. I could have done that for ten years, and look what's happened, so, it's working. I'm just going to keep doing it.

Restricting Diet

My participants both had a common theme in needing to restrict their diets. They have to limit their daily potassium, calcium, and phosphorous. According to Duane,

Yeah, I have to make sure I watch my potassium level. I can't eat potatoes and I have to be careful about drinking milk and anything that's high in potassium, you know. And then they got me...and then calcium, I've got to keep my calcium level down, I use a special supplement for that. And then I take Tums also to help me get my calcium.

Diane expressed her limitations with diet:

I eat a lot of fruit because it helps with dry mouth. I have to be cautious about it because there is a lot of potassium in some fruit, and I've been in trouble with potassium, as I mentioned, but I eat a lot of apples. Last night I had some applesauce, which is really the best food in the world for dialysis because it's...if my mouth is dry or I feel really thirsty, a little custard dish of applesauce will take that away, and I can take me pills with it, so I don't waste any fluid. I'm taking a lot of pills, and right now I'm taking about 19 pills a day.

Restricting Fluid

The participants must also restrict their fluid intake. Diane discussed how she first struggled with her fluid restrictions:

The other piece about being here and dealing with the fluid is I tried to deal with it the way they told me to do it; get a liter bottle of fluid and just when it's gone, it's gone. It just didn't work. And, part of it was I hadn't grieved, I hadn't accepted it too, but, or the nurse stood at the machine and said, 'Too much. You're heart is saying too much,' and she'd carry on about it. You know, I'm not a child. Please don't treat me that way. Or, another nurse would get mad at me. 'Well, if you want to die, go right ahead, keep doing this to yourself.' Those extrinsic motivators did not work for me. They made me feel guilty and they made me want more. And so I had to come to terms with what the intrinsic motivators would be and what the skilled...what the strategies were that would help me. You know, part of it was the fluid in the fridge and making some rules, some boundaries by myself as to what I could do. Two swallows of beer, my limit, you know. But, I'm still having a little bit of it, and holding up within me that intrinsic motivation and then realizing how much better I felt, how much more energy I had when I left. There were times when I would go home and I just kind of ache, besides my heart, you know, and cramps in my legs, and so, the benefits came to me in my own method of understanding and curbing.

Duane stated, "Well, yeah, they don't want me to drink fluids, you know, but then you don't want to die thirsty either, so I just don't drink any more fluid than I have to, you know."

Interrupting Sleep Patterns

The main complaint of my participants was an interruption in their sleep habits since starting on dialysis. They expressed concern in both quality and quantity of sleep disturbance. Diane stated,

I often wonder how connected the feeling of fatigue is. Is it all my pulmonary hypertension from the dialysis or is it connected to...how much of it is impacted by the amount of sleep I get. I never needed a ton of sleep, but I usually got seven hours, I think, until the time I started birthing babies and going to school. So I don't...I wish I knew the impact. Not that I can do anything about it, but it must have an impact on the fatigue factor. Sometimes I'm so very tired, it's like an effort to put one foot in front of the other. I'm sure that's related to my heart. And

Momma always said, you know, if you just lay down and lay really still, you rest your heart. Okay, so I do that. That's hard. It's very hard to do.

Duane stated,

Probably, well, it's really...actually since the time I started dialysis. It's just gotten worse, you know, but I never used to have trouble. When I was in college and I was always so darn tired I never did quit sleeping. Then it seems like it has gotten worse since I started having my dialysis. I don't know what the reason for it is. I just stay up as late as I can and then go to bed and try to get some sleep. I can't fall asleep. I just don't feel tired. And I try to exercise and stuff and whenever I can and I walk quite a bit, and nothing seems to help. I usually stay up until about one or two o'clock in the morning. I just have a hard time sleeping. I can't sleep more than about probably three hours a night, so you know it doesn't do me any good to go to bed early. I just...I like country music, so I turn on the country music channel and see if I'll be able to get to sleep. You know, like I said, I might sleep from two to five or something, but that's about it.

Summary

Keeping busy, quieting the mind, losing independence, restricting diet, restricting fluids, and interrupting sleep patterns were the themes of this study. The participant who was a veteran of dialysis seemed to have more effective coping skills. Keeping busy all day and then attempting to quiet the mind seem to be problematic for participants. Despite multiple measures to improve sleeping patterns, participants continued to have sleep deprivation.

Chapter V

Discussion

Non-Pharmacological Treatments

Quieting the mind. Both participants expressed concern of a busy mind that interfered with falling asleep and keeping them awake at night. One of the participants stated an interest in non-pharmacological approaches to addressing sleep disturbance. There has been more research regarding therapies that will encompass the holistic aspect of a clients care. One of these methods is complementary and alternative medicine therapy [CAM]. According to Keirlin (2008), CAM therapies such as cognitive-behavioral therapy, stimulus-control therapy, relaxation, paradoxical intention, and sleep restriction are treatments that providers can consider when treating individuals with sleep disturbances. Another approach one might consider in quieting the mind is acupressure. Yang and Lin (2008) recommended acupressure as a non-pharmacological approach to sleep disturbance because it causes no side effects and relieved the symptoms of sleep disturbance in their subjects. Researchers Sim et al. (2007) found a correlation between sleep apnea [SA] and CKD. Sim and colleagues demonstrated an increased risk of SA in patients with early CKD. Further evidence of a causal relationship should be sought in the hope that the detection and management of SA may improve the course of CKD (Sim et al. 2007). Nephrology nurses should increase their awareness of the use of CAM therapies and also instructing clients on different CAM therapies for relaxation and sleep.

Independence

One can certainly question whether or not independence would be enhanced if dialysis was performed at home via peritoneal dialysis [PD] versus driving to a hemodialysis unit and dialyzing in a chair for three to four hours. Yngman & Edell-

Gustafson (2006) concluded that nurses should be supportive in predictors for quality of sleep and chronic fatigue in PD clients. Bennett, Simmonds & Buttimore (2008) believed that nurses should be more open to innovative therapies in hopes of a healthier outcome and a superior QOL. One major factor in performing PD is support. One must have an interdisciplinary team committed to proper education and home support.

Social Support

Providing social support is a key element in the scope of nursing. MacNeil (2008) recognized the potential of providing this support for individuals on dialysis as performing satellite dialysis service. It is her recommendation that a group of physicians and nurses have regularly scheduled telecommunications and allow individuals the freedom to remain in their own homes for their dialysis treatments. Because one of this researcher's participants had to relocate due to his dialysis, this researcher believes a program such as this in a rural state like Montana could be very beneficial in QOL and support.

Hobbies

Healing spaces. In recent years, medical advances have been focused around nature and an oneness with the earth. Schweitzer, Gilpin & Frampton (2004) agreed that making healing spaces the ambiance of a space can have a positive effect on individuals utilizing these spaces. By aesthetically enhancing ones health environment, health and healing can be promoted, as well as a reduction in both anxiety and stress (Schweitzer, Gilpin & Frampton, 2004).

Nursing Recommendations

It is this researcher's recommendation that the holistic approach of nursing be used when collaborating with individuals with renal disease that are on dialysis and experience sleep disturbances. Nursing implications such as CAM therapies, acupressure and relaxation techniques should be performed and used as a tool when educating individuals that are experiencing sleep disturbance. Healing spaces can optimize a sense of belonging, relaxation and health promotion while being dialyzed. This researcher would also like to emphasize the importance of advocating for prevention in CKD and ESRD.

Future Research

This researcher would like to recommend future research in the non-pharmacological approach to sleep disturbance. In addition, this researcher would encourage further exploration of correlations between sleep disturbance and the dialysis process, such as cooling the temperature on the dialysate. This researcher would also love to see a pharmacological invention and/or techniques allowing one to reach their REM stage of sleep more rapidly.

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