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Lived Experiences of Individuals with End-Stage Renal Disease on Peritoneal Dialysis

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Lived Experiences of Individuals with End-Stage Renal Disease on Peritoneal Dialysis

by

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A thesis submitted to the faculty of
Gardner-Webb University Hunt School of Nursing
in partial fulfillment of the requirements for the
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Abstract

End-stage renal disease (ESRD) is a prevalent condition among the elderly population in the United States. ESRD is the most feared stage of chronic kidney disease (CKD), as it is a terminal diagnosis requiring long-term management. Peritoneal dialysis (PD) is the most common method of home-dialysis treatment for individuals with ESRD. The purpose of this research is to gain insight into patient experiences of integrating PD therapy into daily lifestyle for a selected sample of people diagnosed with ESRD and currently on PD therapy. The research questions addressed include: how decisions about ESRD treatment options are made, choosing between PD and hemodialysis (HD) and choosing between ambulatory peritoneal dialysis (APD) versus continuous ambulatory peritoneal dialysis (CAPD); how ESRD treatment choices impact the home environment and daily routines; and how ESRD treatment choices affect quality of life. A total of six participants voluntarily agreed to participate in interviews. Several overarching themes were identified in the transcripts: initiation, transition, convenience, quality of life, and personal well-being. The findings of this study revealed that individuals with a diagnosis of ESRD who require renal replacement therapy (RRT), experience a greater sense of normalcy when able to perform their dialysis therapy at home. These findings will provide firsthand information for future individuals diagnosed with ESRD who are facing treatment options, as well as medical professionals and family members who are involved in these individuals' care.

Keywords: chronic kidney disease; end-stage renal disease; peritoneal dialysis; self-care

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CHAPTER I

Introduction

Chronic kidney disease (CKD) is a term used to describe all stages of impaired renal function and continues to remain a worldwide public health problem. According to Arora (2015), “kidney disease is the ninth leading cause of death in the United States” (para. 1). There is a continued rise in the percentage and prevalence of individuals diagnosed with CKD; and some will experience disease progression resulting in end-stage renal disease (ESRD). ESRD is a terminal diagnosis requiring lifelong renal replacement therapy (RRT) or transplant (Arora, 2015). Thus, in hopes of preserving quality-of-life, peritoneal dialysis (PD) is the most common home-based dialysis therapy utilized for patients with ESRD (Griva et al., 2015).

Candidates for PD ideally require some degree of mobility and vision, an abdominal peritoneum without surgical history, and the ability to learn and perform a meticulous daily PD treatment individually or with caregiver support (Griva et al., 2015). Patients performing or receiving PD at home may choose to use automated PD (APD) or continuous ambulatory PD (CAPD). When using APD, dialysis treatment is performed while the patient is asleep for eight to ten continuous hours by an automated machine. Whereas, with CAPD, patients must manually perform their dialysis treatment by completing four to five dialysate fluid exchanges per day (Griva et al., 2015).

Significance

Griva et al. (2015) states “given the increase in prevalence and need for assisted PD, evaluation of patient-reported outcomes become particularly pertinent in informing patient education and healthcare provision” (p. 379). Therefore, the more patient-

reported data available regarding PD therapy, the more effective patient education will be for future PD candidates. Also, knowledge regarding the lived experiences of patients performing home-based APD and CAPD renal replacement therapies would be beneficial for nephrology nurses preparing to educate and empower patients to make treatment decisions that will best meet their needs (Wright & Wilson, 2015).

“Assisted peritoneal dialysis (PD) involving caregivers allows more patients to get started on home-based dialysis with good clinical outcomes, but evidence on patient-reported and caregiver-reported outcomes is lacking” (Griva et al., 2015, p. 373). Quality of life is of tremendous importance when evaluating patients receiving or performing home PD treatments. Thus, a thorough baseline assessment of the patient’s quality of life prior to beginning PD should be documented, as well as ongoing evaluations once the patient begins PD treatment. The comparison of the two assessments is a good measure of treatment effectiveness (Griva et al., 2015). Although prior research indicates that PD is a practical, safe, and effective renal replacement option, “evidence on patient-reported outcomes is largely lacking” (Griva et al., 2015, p. 374). According to Baillie and Lankshear (2014), “few qualitative studies explore PD specifically” (p. 223).

Purpose

The purpose of this study was to investigate the lived experiences of individuals diagnosed with ESRD and undergoing PD treatment. As medical treatment is aimed at enhancing life experiences and survival in the older adult population who require renal replacement therapy; the utilization and promotion of PD therapy offers improved quality of life (O’Shaughnessy, 2014). Therefore, this study will provide firsthand information about the lived experiences and quality of life of several individuals utilizing home-based PD therapy as their primary RRT.

Theoretical/Conceptual Model

Due to changes in life expectancy, and the increasing prevalence of hypertension, diabetes, and cardiac disease, a higher number of individuals are being diagnosed with CKD (O'Shaughnessy, 2014). Should CKD progress into ESRD, individuals will face decisions regarding kidney transplant or renal replacement therapy. Fortunately, many elderly patients have the advanced coping and critical thinking skills necessary to perform self-care treatments such as PD (O'Shaughnessy, 2014).

When considering self-care PD treatment, Dorothea Orem's grand nursing theory may be implemented in order to promote positive patient outcomes (O'Shaughnessy, 2014). Orem's general theory of nursing is titled *The Self-Care Deficit Theory of Nursing*, which combines a *theory of self-care* and a *theory of self-care deficits* with the encompassing *theory of nursing systems* (Orem, 2004). The nursing systems theory unites two patient variables, therapeutic self-care demands and self-care agency, then relates them to the nurse variable, nursing agency (Orem, 2004). Dorothea Orem's concept and theory of nursing system identifies the essence of nursing as a helping service (Orem, 2004).

According to Orem's theory, people are self-reliant and responsible for their own care, as well as for others in their family requiring care (Petiprin, 2015). Orem's theory consists of three basic, inter-related concepts which include: self-care, self-care deficit, and nursing agency (O'Shaughnessy, 2014). However, originally "at least eight terms were used as referents for the concepts that in relationships described and explained the theory of self-care" (Orem, 2004, p. 8). Together, all of these concepts and terms may

help to explain and interpret patient experiences; and are beneficial for patients who are potential candidates for utilizing home-based RRT, such as PD.

Based on Orem's theory, *self-care* refers to the practice of activities that an individual initiates and executes on their own in order to preserve their life, health, and well-being. This concept also includes the individual's ability to perform self-care based on their age and developmental level, life experiences, sociocultural status, health, and access to resources (Petiprin, 2015). Second, the concept of *self-care deficit* within this theory specifies when nursing care is needed. The five methods of helping that Orem identified are: acting for and doing for others; guiding others; supporting others; providing an environment to promote personal development to meet future demands; and teaching others (Petiprin, 2015). Lastly, *nursing agencies* or *nursing systems* determine how each of the patient's needs will be met by the nurse, patient, or both. The self-care theory identifies three classifications that may be utilized to meet the self-care requirements of the patient—wholly compensatory system, partly compensatory system, or supportive-educative system (Petiprin, 2015). Figure 1 illustrates a conceptual-theoretical-empirical (CTE) diagram illustrating the relationships between the variables in the proposed study and concepts in Orem's nursing theory.

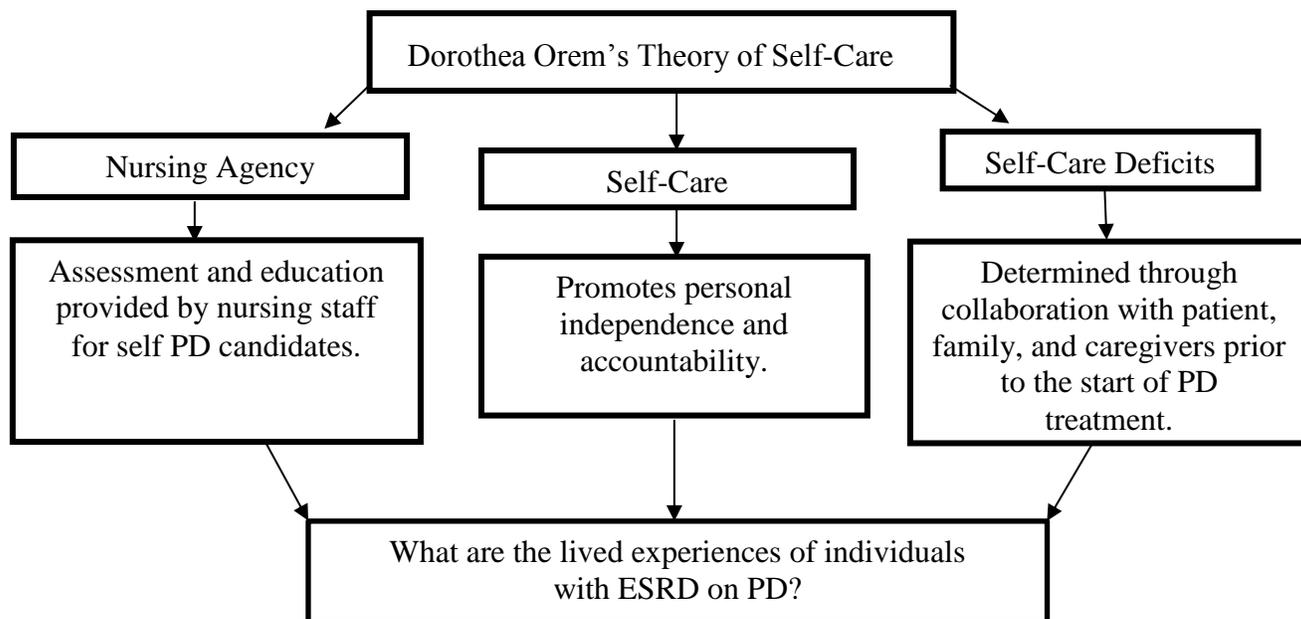


Figure 1. CTE structure outlining the primary research question “what are the lived experiences of patients diagnosed with ESRD on home PD?” using Dorothea Orem’s Self-Care Theory.

CHAPTER II

Literature Review

A literature review was performed using the Cumulative Index to Nursing and Allied Health Literature (CINAHL) through the EBSCOhost online research database. The key terms related to ESRD searched included: *end-stage disease and renal replacement therapy; peritoneal dialysis and patient experiences; and Dorothea Orem's nursing theory*. Limiting searches to yield results published within the past 10 years was important to ensure recent literature would be reviewed; however, later works by Dorothea Orem were utilized as primary theory sources.

Peritoneal Dialysis

“Peritoneal dialysis (PD) is a home-based renal replacement therapy for patients with end-stage kidney disease, offering a degree of autonomy and flexibility of lifestyle” (Ellam & Wilkie, 2015, p. 484). Once a catheter is placed into the patient's peritoneal cavity via a minimally invasive procedure, the patient or their caregiver is taught how to perform dialysis exchanges. A dialysis exchange consists of dialysate being instilled into the peritoneal cavity, either manually or by using a machine (Ellam & Wilkie, 2015). Peritoneal dialysis that is performed manually is referred to as continuous ambulatory peritoneal dialysis (CAPD); whereas peritoneal dialysis that is performed by using a machine is called automated peritoneal dialysis (APD). During either method of peritoneal dialysis, small solutes, such as urea, potassium, and creatinine diffuse from the body's circulation into the dialysate and are removed when the waste drains out (Ellam & Wilkie, 2015). With CAPD, the standard approach is to perform four dialysis exchanges during the 24-hour period using at least two liters of dialysis with each exchange. In

contrast, with APD, the dialysis machine performs repeated exchanges throughout the night while the patient is sleeping, and if necessary, additional daytime exchanges may be required. Excess water is also removed during the exchanges through an osmotic effect of the glucose in the dialysate (Ellam & Wilkie, 2015).

The literature reveals that “PD is particularly valuable as a therapy in the first years following the development of end-stage renal disease while the patient may still have a degree of residual renal function—although it can be performed successfully in anuric patients” (Ellam & Wilkie, 2015, p. 484). Several advantages of peritoneal dialysis include: preserved patient autonomy and independence; flexibility for work and travel; preservation of vascular access sites; decreased risk for transmission of blood-borne viruses; and less stringent dietary restrictions (Ellam & Wilkie, 2015). In contrast, disadvantages of peritoneal dialysis may include: peritonitis and catheter exit site infections; patient or caregiver must be able to perform correct PD technique; and the patient may become fatigued from performing exchanges (Ellam & Wilkie, 2015). Other potential complications stemming from peritoneal dialysis include: ultrafiltration failure; inadequate dialysis; catheter related problems; leakage; hernia development; metabolic problems; and long-term changes to the peritoneal membrane (Ellam & Wilkie, 2015). Thus, PD treatment should be individualized, while maintaining clearance above the minimal level (Ellam & Wilkie, 2015).

Lifestyle Consideration

PD therapy is a very involved treatment modality in which patients and/or their caregivers must be aware of potential complications and warning signs. There are very few treatments for chronic diseases that are as time-consuming and life-altering as

dialysis (Schatell, 2015). Aside from the clinical challenges that dialysis treatment poses, individuals diagnosed with ESRD are also faced with numerous lifestyle alterations including diet and fluid intake limitations; school, work, and travel modifications; sleep and energy level variations; burdens placed on loved ones; inability to control changes in physical appearance, body image, sexuality, and fertility; and lastly, overall prognosis (Schatell, 2015). Based on Schatell's (2015) patient interactions and 18 years of experience, lifestyle is the most important factor considered by individuals with ESRD who are faced with choosing a long-term treatment option. In order to assist individuals in making this decision, the non-profit Medical Education Institute (MEI), developed a decision aid called 'My Life, My Dialysis Choice' (Schatell, 2015). By utilizing the decision aid as a first step in ESRD treatment decision making, and then following up with more specific information about relevant treatment options, the discussion will likely transition from how to do dialysis to why a particular treatment option may be appropriate (Schatell, 2015). Using the 'My life, My Dialysis Choice' decision aid allows patients to select a treatment option that best fits their lifestyle, and also promotes patient-centered care.

Theory of Self-Care and Self-Care Deficit

Dorothea Orem's Theory of Self-Care and Self-Care Deficit can positively impact the outcomes of patients with ESRD. "Offering a patient the opportunity of using peritoneal dialysis independence to perform his or her own treatment and using judgment skills developed throughout a lifetime of experience and knowledge promote accountability for actions with increasing self-esteem" (O'Shaughnessy, 2014, p. 495).

Orem's theories and concepts assume that individuals possess the natural ability to care for themselves, which makes these theories easily adaptable to home RRT.

According to Orem et al. (2003), nursing science consists of "the technologies of human assistance through which help or service is rendered by one person to another" (p. 54). Three general types of assisting technologies recommended by Orem, include wholly compensatory, partly compensatory, and developmental (Orem, Renpenning, & Taylor, 2003). And overall, "all systems of nursing assistance are seen as coming in part from the application of techniques and procedures derived from one or a combination of these assisting technologies toward the accomplishment of nursing goals" (Orem et al., 2003, p. 54). By accepting that a nurse may contribute to "(1) accomplishing the self-care of the patient in a therapeutic manner when a patient limitation must be compensated for and (2) overcoming a patient's present limitations, it is possible to narrow action down to four types" (Orem et al., 2003, p. 61). Thus, the four basic designs for nursing action are: wholly compensatory, partly compensatory (supportive), supportive-educative, and compensatory-educative (Orem et al., 2003).

In regards to PD education, the patient and nurse develop a trusting relationship, where the nurse identifies educational gaps and sets objectives for the patient to meet in order to maintain a sense of control over their dialysis therapy (O'Shaughnessy, 2014). As the nursing agency works with the patient to make appropriate treatment decisions, Orem's nursing action designs are implemented to support patient's limitations. Through cultivating the natural ability for an individual to engage in self-care with nursing support during the learning process, patients will achieve better outcomes (O'Shaughnessy, 2014).

Contraindications to PD

Home-based PD therapy allows patients to be involved in their care, and promotes self-awareness. However, while PD is a reasonable option for most patients diagnosed with ESRD; in some cases, contraindications may be determined during the assessment process (Tregaskis, Sinclair, & Lee, 2015). Contraindications may be described as being relative or absolute. “Absolute contraindications will rule out PD as a modality choice and their early identification is a vital component of pre-modality assessment” (Tregaskis et al., 2015, p. 113). The identification of relative contraindications does not necessarily rule out PD. Instead, further assessment is required.

According to Tregaskis et al. (2015), relative contraindications to PD include: large abdominal hernia, including inguinal hernia; high body mass index; chronic respiratory disease; chronic bowel disease; severe malnutrition; recurrent diverticulitis; prior major abdominal surgery; severe peripheral neuropathy; poorly controlled epilepsy or seizures; and physical barriers such as poor dexterity and strength, poor vision, immobility, or frailty. In contrast, absolute contraindications to PD include: major previous abdominal surgeries; abdominal stoma; irreparable abdominal hernia; major psychiatric illness; poor social circumstances, such as homelessness or unsuitable home environment; inability to maintain personal hygiene, self-care, or a sterile environment; significant cognitive impairments; and poor compliance or insight (Tregaskis et al., 2015). Therefore, in preparing individuals for dialysis therapy, they should be completely informed of their options and adequately assessed to determine which modalities may best suit them.

Uncertainty in PD

Patients who are unclear about their options for dialysis therapy, or who are unprepared for what the therapy entails, often experience a feeling of uncertainty. Madar and Bar-Tal (2009) designed a correlational study to examine relationships between various factors that may influence the level of uncertainty faced by patients undergoing PD therapy. Uncertainty was measured using Mishel's Uncertainty in Illness Scale (MUIS), comprised of 26 statements examining vagueness; lack of clarity; unpredictability; inconsistency; multiple meanings and lack of information with respect to diagnosis and treatment; relationship with health care providers; and prognosis (Madar & Bar-Tal, 2009). The sample, 71 PD patients (44 males and 27 females) receiving treatment in the PD units of four Israeli hospitals, responded to the study questionnaire; and data was collected from February 2004 to June 2004 (Madar & Bar-Tal, 2009). Findings revealed that uncertainty plays an important role in the stress process for patients. Specifically, in this study, "the main findings were that uncertainty is associated mainly with patients' self-rated severity of illness, their level of education and their perceptions of their physicians and nurses as credible authorities" (Madar & Bar-Tal, 2009, p. 1667). The researchers suggested that healthcare providers offer PD information to their patients to reduce uncertainty, improve subjective beliefs regarding health, and help them to preserve hope when faced with a terminal diagnosis (Madar & Bar-Tal, 2009). In regards to peritoneal dialysis, "patients with more education, more social support and more trust in their physicians and nurses will experience less uncertainty" (Madar & Bar-Tal, 2009, p. 1665).

Lived Experiences of Using PD

In addition to the Israeli study findings, the concept of uncertainty was uncovered again in a qualitative, ethnographic study of patients and families experiencing PD at home in the United Kingdom (Baillie & Lankshear, 2014). Between January and October 2011, data was collected through semi-structured interviews and observations of PD processes in the home for 20 to 90 minutes each. Although the study participants did not know each other, the results yielded four overlapping themes: initiation, constraint, uncertainty, and freedom (Baillie & Lankshear, 2014).

According to the authors, patients and their families using PD at home share a culture of daily work involved with PD therapy. Self-management of ESRD for patients performing home dialysis therapy includes recording blood pressure and body weight; titrating medications; restricting diet and fluid intake; establishing a dialysis exchange regimen; and adopting aseptic dialysis techniques. Although home PD requires tedious self-management responsibilities and poses challenges to everyday life, participants were motivated to continue to use PD treatment at home (Baillie & Lankshear, 2014).

Quality of Life

The everyday challenges associated with home PD were also examined in another study conducted by Griva et al. (2015). This study aimed at comparing assisted PD versus self-care PD on quality of life and psychosocial outcomes for patients and caregivers. Participants were recruited for three years from a peritoneal dialysis center at a hospital in Singapore (Griva et al., 2015). A total of 231 PD patients and 111 family members and caregivers were recruited during routine clinic appointments. Patients completed a variety of questionnaires, including socio-demographical information,

medical information using The Charlson Comorbidity Index, dependency status, disease-specific quality of life level using the Kidney Disease Quality of Life Short Form, global quality of life using the abbreviated version of the World Health Organization's quality of life instrument, and level of emotional distress using the Hospital Anxiety and Depression scale (Griva et al., 2015). Questionnaires completed by caregivers addressed socio-demographical information; caregiving activities using the Lay Care-Giving for Adults Receiving Dialysis tool; and perceived level of burden measured by the Zarit Burden Interview (Griva et al., 2015). The major case-mix adjusted comparisons revealed comparable quality of life in all dimensions except physical. PD patients and their caregivers reported comparable emotional quality of life, symptoms of distress and caregiver burden (Griva et al., 2015).

Summary

PD is a valuable therapy with advantages and disadvantages, requiring individualized decision-making between patients, families, and caregivers (Ellam & Wilkie, 2015; Tregaskis et al., 2015). Dialysis is time-consuming and life-altering, and requires numerous life-style changes (Schatell, 2015). Orem's Self-Care Theory can support the patient's natural ability to engage in self-care with nursing support during the learning process (O'Shaughnessy, 2014). Quality of life has been found to be affected by uncertainty in Israel (Madar & Bar-Tal, 2009), everyday challenges in the U.K. (Baillie & Lankshear, 2014), and symptoms of distress and caregiver burden in Singapore (Griva et al., 2015). Previously conducted research regarding the lived experiences of individuals diagnosed with ESRD and undergoing PD treatment in the United States is lacking. In fact, no nursing research was found on quality of life issues in patients

undergoing PD in the United States. Therefore, this study will explore the impact of treatment choices on the home environment, daily routines, and techniques at home for PD patients in the United States, specifically North Carolina, guided by Orem's Self-Care Theory. The purpose of this study is to gain insight into the lived experiences of people undergoing PD.

CHAPTER III

Methodology

Purpose

The purpose of this research is to gain insight into patient experiences of integrating PD therapy into daily lifestyle for a selected sample of people diagnosed with ESRD and currently on PD therapy.

Research Questions

1. How are decisions about ESRD treatment options made?
 - a. Choosing PD versus HD
 - b. Choosing APD versus CAPD
2. How do ESRD treatment choices impact the home environment and daily routines?
3. How do ESRD treatment choices affect quality of life?

Study Design

A phenomenological approach, a descriptive qualitative research method, was used for this study. Phenomenological research allows the opportunity for further examination of the meaning, description, and understanding of human experiences (Dinkel, 2005). Phenomenology provides answers to concerns and explanations of lived experiences from the people themselves (Dinkel, 2005). Thus, “results from phenomenological inquiry has the potential to expand understanding about the lived experiences of people and allow nurses to tailor their care to meet the needs of diverse populations” (Dinkel, 2005, p. 7).

Setting and Sample

Patients utilizing home-based PD therapy were recruited during their follow up visits with their nephrologist at an outpatient dialysis center in North Carolina. Purposive sampling was utilized to select six study participants. Identified PD patients were given a flyer explaining the study and asked by the researcher to consider participation. All participants were over 18 years of age, had a diagnosis of ESRD, and were currently using home-based PD as RRT, and not receiving concurrent HD treatment. Volunteers agreeing to participate were interviewed after their appointment with the nephrologist in a quiet, private space. Those who wished to spend a little more time considering participation in the study were asked to contact the researcher by using the information on the flyer. Once contacted, the researcher met the participant for the interview at a time and place convenient to both.

Data Collection

Participants met with the researcher in a private setting to complete the interview. The study was explained. The volunteer had an opportunity to ask questions. The researcher obtained an informed consent signed by the participant. Demographic data including the participant's age, length of time since ESRD diagnosis, current PD therapy used, and how long home-based PD has been used was asked at the beginning of each interview. Once initial demographic data was obtained, the researcher asked the participant three semi-structured research questions. Questions were open-ended and participants were encouraged to elaborate on their feelings and experiences (Doody & Noonan, 2013). Providing open-ended questions during the interviews created the opportunity for new concepts to emerge, and more insights to be revealed. Brief field

notes were taken during each interview and expanded upon immediately after.

Interviews were audio taped and transcribed within one week.

Protection of Human Subjects

Approval for the study was obtained through the University's Institutional Review Board (IRB), and support for the study was also obtained by the Facility Administrator at the outpatient dialysis clinic. No IRB was required for the outpatient facility. There were no foreseeable risks to participants and no compensation was received.

Participation was completely voluntary and the participant could stop the interview at any time they felt uncomfortable. Participants were informed that study results may benefit themselves, future ESRD patients, and healthcare providers caring for patients on home-based PD therapy.

Audiotapes and transcriptions were kept confidential in a locked drawer in a locked office. Analysis of data was stored in a password protected computer. Only the researcher and faculty advisor reviewed the raw data. Following study completion, all raw data was collected and stored for three years at the university.

Data Analysis

“Gathering and analyzing data are conducted concurrently in descriptive qualitative approaches, thus adding to the depth and quality of data analysis” (Vaismoradi, Turunen, & Bondas, 2013, p. 401). Thematic analysis as adopted from Wolcott's (1994) description, analysis, and interpretation approach will be utilized for the data analysis process of this study. Wolcott suggests that “description, analysis, and interpretation are the three primary ingredients of qualitative research” (Wolcott, 1994, p.

49); and “analytical efforts are necessarily focused on parts or constituent elements and how they interact” (Wolcott, 1994, p. 173).

According to Priest (2002), intense engagement with the data through listening to the recorded interviews, reading and re-reading the written transcriptions, and deeply examining the transcribed data is necessary in order for the researcher to become extremely familiar with the data. The researcher will be responsible for performing the data analysis and determining important themes. This process will be discussed with another qualitative researcher (faculty advisor). One of the first steps in the data analysis process will be for the researcher to transcribe the audio-taped interviews verbatim, and then highlight distinct codes. The goal of coding is to synthesize “the raw data into distinct ideas or conceptual units” in hopes of “cleaning” up the data (De Chesnay, 2014, p. 4). Next, utilizing thematic analysis, the researcher will identify recurrent patterns and similarities among the codes, and develop distinct themes or propositional statements for the groupings (De Chesnay, 2014). The themes identified in this qualitative research study will serve as the study’s results.

CHAPTER IV

Results

As the goal of this study was to gain insight into patients' experiences of integrating PD therapy into daily lifestyle, participants were recruited during their monthly follow-up visits with their nephrologist at an outpatient dialysis center in North Carolina. During the clinical appointment times, patients were introduced to the aim of the study by the nephrologist or dialysis nurse prior to or following their appointment time; and if patients were willing to participate, the researcher was made aware. Prior to obtaining informed consent, the researcher reviewed the study's flyer with each individual and addressed any questions. All participants met criteria: diagnosis of ESRD, currently using home-based PD as their primary RRT, and not receiving concurrent HD treatments.

Interviews

The researcher gathered data during semi-structured, one-on-one interviews with each participant. Only one participant fully agreed to allow the researcher to audiotape the interview. The researcher utilized extensive note-taking during the remaining five interviews, and then elaborated on the notes immediately after. The interviews lasted between 10 and 30 minutes, as some participants were willing to elaborate more than others. All of the interviews were conducted by the same researcher to provide consistency of the interview process, reducing any potential bias. Interviews took place in private exam rooms if conducted prior to their appointment with the nephrologist, or in a private office if conducted after their appointment time. During each interaction, the researcher exhibited an attitude of empathy, respect, and interest, allowing participants

time to process and respond to each question. The researcher was sitting at eye level with each participant, and utilized active listening while the participants were speaking.

Participants were not probed for more information once their response was given.

Sample Characteristics

A total of six PD patients were approached during their nephrology appointment times, and all six voluntarily agreed to participate in the interview ($n=6$). Participants included three males ($n=3$, 50%) and three females ($n=3$, 50%); two African Americans ($n=2$, 33%) and four Caucasians ($n=4$, 67%); and ranged in age from 40 to 85. One participant did not wish to state her exact age. Four ($n=4$, 67%) of the participants began their RRT on HD, then transitioned to PD, while the other two ($n=2$, 33%) were able to initially start on PD. All participants reported the use of CAPD therapy, and perform their dialysis exchanges at night. Table 1 outlines the descriptive statistics of the sample.

Table 1

Descriptive Statistics of the Sample

Participant	Age	Gender	Race
1	85	Male	Caucasian
2	Unknown	Female	African American
3	72	Female	Caucasian
4	72	Female	Caucasian
5	58	Male	Caucasian
6	40	Male	African American

Major Findings

The data analysis technique followed Wolcott's (1994) process of transforming qualitative data. Upon completion of all interviews, the researcher examined, compared, and searched for patterns and similarities throughout the participants' responses that were important to the study's aim. Then, once the interviews and field notes were fully transcribed, the transcriptions were reviewed for keywords and phrases, and broad themes were identified. As the transcriptions were further analyzed, new themes emerged and were appropriately combined with the previously identified themes. The supporting data for each theme was coded by highlighting the information in like colors. Data and themes were discussed with another qualitative researcher to support the rigor of qualitative analysis.

Thematic Analysis

Following the coding of transcriptions and data analysis process, several overarching themes were identified throughout each interview. These themes were initiation, transition, convenience, quality of life, and personal well-being. Each theme will be individually discussed with specific supporting details.

Initiation

The majority of the study's participants were informed that they would require long-term RRT at the same time they were diagnosed with ESRD. However, four of the participants required the immediate initiation of dialysis treatment, and began hemodialysis therapy with a temporary catheter until a permanent access could be obtained. Participants, who had no other option but to begin hemodialysis immediately, shared their frustrations of having to travel to a dialysis clinic multiple times a week, and

sit in a treatment chair for several hours at a time. They eventually had the option to switch from hemodialysis to PD. As for the other participants, they were able to begin their RRT on PD. When asked about how decisions regarding ESRD treatment options were made, one participant replied: *“I attended a class when I was first diagnosed to learn about both [hemodialysis and PD], and decided on PD.”* And another participant responded by stating: *“I wanted to do PD because I don’t like having to be at a certain place at a certain time.”*

Transition

Ultimately, all of the participants who initially started their RRT on hemodialysis later transitioned to PD. Once the decision was made to transition from hemodialysis to PD, the participants and some of their caregivers underwent extensive training in order to learn how to properly perform PD therapy at home. Participants described how PD therapy impacted their home environments and daily routines when responding to research question two:

- *Participant 1: “Well, once we got on a routine it was no problem—my wife just loads the fluids on it at night before I go to bed.”*
- *Participant 5: “Oh, it’s definitely a lifestyle change! Dialysis changed sleeping arrangements....diet, social life.”*
- *Participant 6: “For the first year, I came here [dialysis center] for dialysis...I can’t remember what that was called [hemodialysis] ...but then I started doing my treatments at home.”*

Convenience

Although performing PD at home requires a considerable amount of preparation and an unwavering commitment to performing daily treatments, participants felt this was a much more convenient treatment option. Participants in the study stated that having the ability to perform dialysis treatments at home eliminates the frequent travels to and from a dialysis center. Participants have created individualized PD schedules that work for their lifestyle and allow them to maintain a sense of normalcy. In fact, one participant even has a second CAPD set-up at her vacation home so that she and her husband can still enjoy their time away from home. Supporting data regarding convenience includes:

- *Participant 1: “This way [PD] is more convenient...it took a lot of time driving back and forth here [dialysis facility] three days a week.”*
- *Participant 3: “I usually hook up to the machine at about 8pm, but I don’t necessarily go to sleep then...I might watch TV or read for a while. I usually sleep about seven hours. My husband works with me and sets the machine up beside the bed on a table with my clipboard...we even have a set-up at our beach house.”*
- *Participant 4: “I usually set up around 5pm, then hook myself up between 9pm and 10pm...I keep all my supplies in my room so it stays clean. I even have extension cords from Fresenius that are 20 feet long so I can reach the front door while I’m connected.”*

Quality of Life

Participants expressed a general sense of an enhanced quality of life while experiencing PD. After transitioning from hemodialysis at the outpatient clinic to PD at

home, participants described various positive benefits that resulted. The third research question addressed the participants' quality of life based on their ESRD treatment choice.

Below are several participants' responses:

- *Participant 3: "I really don't mind it [PD]—just hook up night and then unhook in the morning and go about the day."*
- *Participant 4: "It's not too bad because I can still do what I want during the day and not have to worry about dialysis appointments."*
- *Participant 5: "It's like I describe to people, it's like my energy level is battery charged...I'm good in the mornings and feel like I could do anything and then by the afternoons I can tell my battery charge is dying."*

Personal Well-being

Throughout the interview process, several participants revealed their emotional responses and methods of coping in regards to their ESRD diagnosis and the necessity for lifelong RRT. Two of the participants described dialysis as being unavoidable due to their diagnosis; however, their attitudes were completely opposite when speaking. One participant exhibited obvious frustrations related to her diagnosis and RRT, while the other revealed that he would soon be receiving a kidney transplant.

- *Participant 3: "Ugh, there's just, just too much to tell...it has affected me emotionally and mentally...my children don't like to see their mom like this...I have animosity compared to others...and I mean I have no choice but to do this to live. This has been very emotional for me, I'm still trying to cope because I really wanted a transplant, but I'm not a candidate because of my age...but others have it worse."*

- *Participant 5: “I don’t like dialysis, but with this disease, it’s what you do to stay alive and keep on going...so, I try to keep a positive attitude...we just found out my daughter is a perfect match to donate a kidney to me and actually surgery is already scheduled.”*

Summary

The overall results of this study revealed that individuals with a diagnosis of ESRD who require RRT, experience a greater sense of normalcy when able to perform their dialysis therapy at home. All participants truly felt that home-based PD therapy was the most convenient RRT option for their lifestyle, and provided them with the most independence in their disease management. It is important to note that all participants possessed the dexterity to perform PD treatments. Also, most all participants chose PD therapy so that they did not have to travel to and from the dialysis clinic multiple times per week; and could better integrate their treatment modality into their daily routines by performing CAPD exchanges at night while they sleep. Although a few participants voiced that they had no option but to be on dialysis to stay alive, they too agreed that PD was the most optimal RRT. When transitioning from outpatient dialysis treatment to home-based PD therapy, participants noted there were some aspects of their home lives that were rearranged; however, they quickly adjusted.

CHAPTER V

Discussion

Individuals who are diagnosed with ESRD, also face the initiation of lifelong RRT, whether that be through outpatient dialysis treatment at a facility, or by the use of home-based dialysis therapy. When opting to utilize home-based PD, individuals must remain compliant with a strict treatment regimen, as well as closely monitor their daily weight, blood pressure, and diet. All of the participants in this study perform home-based CAPD, which allows them to sleep at night during their treatment. The participants are connected to the PD machine for approximately 7 to 10 hours each night, and are then able to carry on as normal throughout the day.

Those participants who were unable to utilize PD as their first RRT had no other option but to follow the doctor's recommendation and begin acute hemodialysis therapy to survive. These participants learned about PD therapy as they progressed through their hemodialysis treatments, and were eventually able to transition to home-based PD. All participants described many positive aspects to utilizing home-based PD therapy. The ability to manage a chronic disease that requires lifelong therapy at home, increases an individual's sense of autonomy, allows them to maintain a quality of life that is as close to normal as possible, and eliminates traveling to an outpatient dialysis clinic. As expected, participants wish to continue home-based PD therapy as long as possible, so that the need to utilize outpatient dialysis treatment remains at bay. The themes identified throughout the study's interviews include: initiation, transition, convenience, quality of life, and personal well-being. Although the meaning of each theme is different,

the descriptions behind each meaning convey many positive aspects regarding home-based PD therapy being the most ideal RRT.

Implication of Findings Related to Literature

The study's findings closely paralleled findings of previously conducted research studies. In comparison to the themes identified by Baillie and Lankshear (2014), *initiation* was also a theme identified in this study. Several participants in each study were required to begin on hemodialysis acutely until they were able to transition to PD. Thus, the initiation process differs from those individuals who were able to start on PD therapy from the beginning. *Freedom* was another theme identified in Baillie and Lankshear's (2014) study that closely resembles this study's theme of *convenience*. For instance, participants who are able to successfully incorporate their PD regimen into their daily lifestyle, experience a sense of freedom, which also parallels with PD therapy being a convenient treatment option.

According to Schatell (2015), lifestyle should be placed at the forefront of the decision making process for individuals needing to choose a RRT for ESRD. Placing lifestyle at the forefront of treatment decision making, "may help to route around fear and to support greater use of patient-centered, lifestyle-friendly dialysis options such as home therapies" (Schatell, 2015, p. 149). With Schatell's (2015) work in mind, participants in this study agree that home-based PD is the most convenient form of RRT, and they are able to maintain a greater quality of life. Thus, when deciding to transition from in-center dialysis therapy to home PD therapy, individuals must recognize the substantial responsibility of managing their self-care.

As individuals prepare for beginning home-based PD therapy, they should receive extensive training for how to properly perform PD treatments, manage their disease process, identify potential complications, and program the PD machine settings. Madar and Bar-Tal's (2009) study revealed that "to reduce stress in patients having PD, their uncertainty needs to be reduced" (p. 1668). A few of the participants in this study stated they attended classes regarding PD therapy while considering to transition from outpatient hemodialysis to home-based PD; and then another class to learn how to perform PD therapy and operate the machine. Participants who participated in these classes were also the ones who have positively integrated PD therapy into their daily lives. As evident, the education provided in these classes is beneficial for individuals beginning PD therapy.

Application to Theoretical/Conceptual Framework

According to Orem (2004), "nursing's proper object or focus is individuals in society affected by human or environmental conditions associated with their states of health or their requirements for health care that result in inability to provide continuously for themselves the amount and quality of self-care they require" (p. 6). Thus, Orem's theory focuses on the concept and theory of self-care, where individuals demonstrate deliberate involvement in their self-care (Orem, 2004). Based on the study's findings, all of the participants are deliberately engaged in their self-care through performing PD therapy in their home environments, eliminating a sense of dependency on health professionals to perform their dialysis treatments. According to the participants, PD therapy has increased their sense of independence, quality of life, and helps them to maintain a sense of normalcy with a heavily managed diagnosis.

Limitations

A limitation of this study may be that all six participants were recruited from a single outpatient dialysis center in North Carolina. Secondly, all six participants utilize CAPD as their primary RRT; thus, participants' responses may be biased towards CAPD therapy practices versus APD practices.

Implications for Nursing

It is important for nurses, specifically renal and dialysis nurses, to have distinguished competency of PD skills in addition to a clear understanding of the lived experiences of individuals performing PD therapy at home. Understanding the differences between CAPD and APD is important when educating patients about treatment decisions. Also, nurses should be able to speak to how ESRD treatment choices impact the patients' home environment and daily routines, as well as the potential effects on their quality of life. Nurses must also take into consideration individual differences in skill level, social support, and issues such as uncertainty, stress, and caregiver burden when discussing PD therapy with patients and their families. These considerations may negatively affect patient outcomes if not appropriately addressed.

Recommendations for Future Research

As this was a cross-sectional study design; the findings ~~only~~ reveal a snapshot of six individuals' perspectives at one point in time. Perhaps a longitudinal study that follows the treatment journey of six ESRD patients from initial diagnosis, through the treatment decision process, and their experiences on dialysis treatment would yield more beneficial knowledge for patients and their caregivers. Also, recruiting participants from

other geographic areas and dialysis facilities could yield a wider variety of personal experiences.

Conclusion

Determining which renal replacement therapy best fits an individual's needs with ESRD can be extremely complex. As previously discussed, specific criteria must be met in order to qualify for home-based PD therapy. Those patients who are deemed eligible for home PD must demonstrate the ability to successfully perform their treatment, or have a caregiver that is able to do so. Despite the meticulous process and unfailing commitment to performing home-based PD, patients in this study experienced a greater sense of normalcy by performing their dialysis therapy at home. Participants created individualized PD schedules that were convenient for their lifestyle and expressed a general sense of an enhanced quality of life.

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