ABSTRACT

Chronic kidney disease (CKD) is a multidimensional global health issue that can affect various individuals worldwide. Although renal transplantation is the preferred form of renal replacement therapy for most individuals with CKD, the lack of kidneys from suitable donors means that most of these individuals will not receive one. Many of these individuals living with CKD manage their kidney failure through peritoneal dialysis (PD) at home and under the guidance and support of nurses working with them in an outpatient clinic. Literature has suggested that healthcare providers perceive primary nursing as the ideal care delivery model for many patients and that the elements of primary nursing are correlated to improved patient outcomes. Although literature supports the use of primary nursing, there is very little known about this model from the perspectives of patients and the experiences of PD patients. The purpose of this study was to explore the nursing care experiences of PD patients managed by a primary nursing care delivery model and further understand the unique healthcare experiences of this population. Using interpretive description as a research methodology, 15 participants were purposefully sampled from an outpatient PD clinic and participated in one-on-one face-to-face interviews. Interviews were digitally audio-recorded and conducted using a semi-structured interview guide. Findings from the study illustrated that PD patients were not experiencing all of the elements associated with primary nursing. A modified form of primary nursing was being experienced by the patients in which they received individualized and comprehensive nursing care. The nursing care of the patients was underpinned by a philosophy of patient-centred care that emphasized relational engagement between patients and nurses. In addition, organizational influences of nursing care such as PD nurse availability and operational hours of the PD clinic contributed to the experiences of patients having to navigate through unforeseen challenges in
their care. This study can inform future research involving the analysis of health outcomes for PD patients, understanding family perspectives, and exploring nursing leaders’ perceptions to further improve the nursing care experiences of PD patients.
LAY SUMMARY

Many individuals living with chronic kidney disease manage their kidney failure through peritoneal dialysis (PD). These individuals are provided care under the guidance and support of nurses. The nurses organize their nursing care of patients under a primary nursing model, however, very little is known about the model and the perspectives of patients within an outpatient PD clinic. The purpose of this study was to explore the nursing care experiences of PD patients managed by a primary nursing model. Using interpretive description as a research methodology, 15 participants were interviewed. Findings from the study highlighted that PD patients were experiencing a modified form of primary nursing and had to navigate through challenges that were influenced by the healthcare organization. Future research involving families and nurse leaders, and a closer look at health outcomes is needed to better understand the experiences of PD patients.
This research project is an original and unpublished study conceptualized by the author, Nathaniel Roxas. This thesis was written by me and revised based on feedback received from my thesis committee (Dr. Vicky Bungay, Dr. Alison Phinney, and Dr. Sally Thorne). I conducted data collection independently. Data analysis was initially completed by me with final themes being refined in collaboration with my thesis supervisor, Dr. Vicky Bungay. Ethical approval to conduct the study was received by the University of British Columbia-Providence Health Care Research Ethics Boards (Certificate # H15-03140). Funding for this study was received by the University of British Columbia School of Nursing’s Helen Shore Nursing Endowment Fund.
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LIST OF ABBREVIATIONS

CAPD         Continuous ambulatory peritoneal dialysis
CCPD         Continuous cyclical peritoneal dialysis
CKD          Chronic kidney disease
PD           Peritoneal dialysis
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For Allyssa—who stayed when she shouldn’t have
CHAPTER ONE: INTRODUCTION

Background on the Issue

As a nurse, I had the opportunity to care for numerous patients diagnosed with chronic kidney disease (CKD) in an outpatient peritoneal dialysis (PD) clinic. Over time I observed how much importance patients placed on their nurse-patient relationships, especially with nurses that they were familiar with. The outpatient PD clinic that I worked in organized the nursing care of patients according to a primary nursing model. Based on what is known about this specific care delivery model, primary nursing supports effective nurse-patient relationships; however, I wondered how well the organization of nursing care was working. I became intrigued and curious about the nursing practices in the PD clinic and how the patients perceived their nursing care. In addition, I noted that the way the PD clinic organized its nursing care was different than the traditional organization of primary nursing as described in current literature. I wondered if the PD patients were truly receiving nursing care from a primary nursing care delivery model and what patients thought about the care they received. In this thesis, I describe the research study I conducted to explore the healthcare experiences of PD patients with their nurses who are managed by a primary nursing care delivery model.

Chronic kidney disease (CKD) is a multidimensional global health issue that is estimated to affect more than 10% of individuals worldwide, with an average of 12 Canadians experiencing some degree of kidney failure daily (Eckardt et al., 2013; Jha et al., 2013; The Lancet, 2013). In British Columbia, there is an estimated 1 in 10 individuals within all ages diagnosed with CKD (BC Provincial Renal Agency, 2012). Chronic kidney disease is associated with various co-morbidities such as diabetes and hypertension, which can increase the risk of experiencing heart attacks and heart failure (Eckardt et al., 2013; Jha et al., 2013; The Lancet, 2013). Individuals
diagnosed with CKD may have a progressive decline in their kidney function, resulting in an inadequate ability to maintain the regulation of normal body processes such as filtering toxins from the body. When this progressive decline occurs, artificial methods to replace the function of an individual’s kidneys are needed, which is known as renal replacement therapy (Wong, Chow, & Chan, 2010). Although most individuals diagnosed with CKD prefer kidney transplantation as their form of renal replacement therapy, the lack of available kidneys from suitable donors means that most people requiring a kidney transplant will not receive one (The Lancet, 2013). The individuals with CKD who do not receive a kidney transplant must rely on other forms of renal replacement therapy, such as PD (Finkelstein, Ezekiel, & Raducu, 2011).

Peritoneal dialysis is a type of renal replacement therapy that patients can independently administer in their homes. Peritoneal dialysis is used as an artificial means to replace kidney function to sustain life (Wong et al., 2010). There are approximately more than 272,000 PD patients worldwide and over 4000 of them are in Canada (Jain, Blake, Cordy, & Garg, 2012; Karopadi, Mason, Rettore, & Ronco, 2013; Li et al., 2017). The BC Provincial Renal Agency (2012) anticipates that this number of PD patients is growing annually.

Peritoneal dialysis is administered daily by the patient after receiving comprehensive education and training from members of the multidisciplinary healthcare team, particularly nurses (Piraino et al., 2011; Rubin et al., 2004). Upon completion of training, PD patients are in regular contact with nurses either in person, over the phone, or through email. The nurses work together with other members of the multidisciplinary team to ensure that patients’ kidney function does not decline any further. Nurses are responsible for conducting thorough physical, psychological, and social assessments with their PD patients (Wong et al., 2010). Nurses follow-up with patients for any signs of complications related to PD, anticipate patients’ health
concerns, and reinforce positive behaviours leading to adherence with PD therapy (Wong et al., 2010).

Nursing care delivery models represent how nursing care is organized and delivered to patients (Marram, Barrett, & Bevis, 1979; Mattila et al., 2014; Shirey, 2008). Different nursing care delivery models have been used to support patients with CKD such as functional, team, and primary nursing. Although functional nursing maximizes the skills of various healthcare providers, its emphasis on achieving efficiency through the division of tasks can lead to the fragmented care of patients (Dobson & Tranter, 2008; Shirey, 2008). Team nursing decreases the fragmentation of care for patients by having one Registered Nurse (team leader) delegate the care of patients to healthcare providers with different levels of education, skill, and licensure (Dobson & Tranter, 2008; Shirey, 2008). Unfortunately, patients may still experience suboptimal quality of care with team nursing due to the time required for communication amongst team members (Shirey, 2008). The top-down hierarchical framework of team nursing means that information cannot be given directly to the team leader without going through the appropriate communication channels. As a result of patients having multiple assigned healthcare providers and fragmented patient care from functional and team nursing, the model of primary nursing care was created (Dobson & Tranter, 2008; Marram et al., 1979; Shirey, 2008).

Primary nursing moves nurses away from a work environment focused on tasks to one that is focused primarily on patients (Shirey, 2008). Primary nursing places emphasis on patients by having a staff nurse act as a primary nurse for select patients (Mattila et al., 2014; Shirey, 2008). Primary nurses are responsible for the overall planning, coordinating, delivering, and monitoring of their select patients 24 hours a day (Shirey, 2008). The core elements of primary nursing include comprehensive, continuous, individualized, and coordinated nursing care
(Marram et al., 1979; Shirey, 2008). In the absence of the primary nurse, patients are cared for by associate primary nurses who follow the care plan created by the primary nurse (Dobson & Tranter, 2008). Any recommended changes to a patient’s care plan by other members of the healthcare team are reviewed by the primary nurse prior to its inclusion and further discussed if clarification is needed.

Over the past two decades multiple researchers have described the use of primary nursing in multiple settings. These researchers have found that the implementation of primary nursing differs between hemodialysis units, emergency departments, operating rooms, psychiatric hospitals, and maternity wards because of unclear role expectations, workload, or healthcare provider preferences (Boumans & Landeweerd, 1999; P. Johansson, Lundström, & Heiwe, 2015; Jost, Bonnell, Chacko, & Parkinson, 2010; Melchior et al., 1996; Wan, Hu, Thobaben, Hou, & Yin, 2011). In addition to these differences, researchers have suggested that patient-centred care is an underpinning philosophy for how patients receive care with their primary nurses. Current literature has illustrated that patient perceptions of patient-centred care are attributed to their experiences of being respected, being involved in the decision-making process, being provided with information, or given care that is adapted to their preferences (Cann & Gardner, 2012; Edvardsson, Fetherstonhaugh, & Nay, 2010; Ferguson, Ward, Card, Sheppard, & McMurtry, 2013; Kvale & Bondevik, 2008; Marshall, Kitson, & Zeitz, 2012; McMurray, Chaboyer, Wallis, Johnson, & Gehrke, 2011; Ploeg et al., 2013; Poochikian-Sarkissian, Sidani, Ferguson-Pare, & Doran, 2010; Radwin, Cabral, & Wilkes, 2009; Rubin et al., 2004). Patients who have experienced patient-centred care report better health status (Bertakis & Azari, 2011), increased adherence rates (Kahn, Schneider, Malin, Adams, & Epstein, 2007; Tucker, Marsiske, Rice,
Nielson, & Herman, 2011), improved weight and blood pressure management (Su, Lu, Chen, & Wang, 2009), and increased satisfaction with overall care (Cann & Gardner, 2012).

**Study Setting**

St. Paul’s Hospital, a healthcare facility within Providence Health Care in Vancouver, British Columbia, Canada, has established a growing network of multidisciplinary services focused on CKD prevention, education, monitoring, and treatment. The PD clinic at St. Paul’s Hospital supports people with CKD who require PD therapy. At the time of this study, the PD clinic was providing care to approximately 150 patients managed by primary nurses under a primary nursing care delivery model. The nurses are responsible for planning, coordinating, delivering, and monitoring any aspect of their assigned patients’ care plans in relation to PD. The nurse’s role includes regular visits to their assigned patients’ homes and in-person follow-up assessments when their patients come to the PD clinic to see the entire multidisciplinary team.

Through my experiences of working in the St. Paul’s Hospital PD clinic, all PD patients have a primary nurse. When patients complete their education and training on how to independently perform their own PD therapy, the nurse that provides them with the education and training usually becomes their primary nurse. Primary nurses are responsible for 25-35 PD patients from the total PD patient population in the PD clinic (i.e. 25-35 PD patients out of the total 150 patients). These nurses work closely with the multidisciplinary team to coordinate the care of their assigned patients (e.g. arrange access to specialty medical services such as ultraviolet light therapy or dietary consultation), while delivering comprehensive nursing care through thorough assessments, clinical interventions, and evaluations with their patients.

Within the primary nursing care delivery model, primary nurses incorporate the needs and values of their patients by focusing on goals that are created in partnership between the
patient and the multidisciplinary team. It was my experience that primary nurses invited the participation of their PD patients in their own care. Primary nurses invited participation by asking their PD patients what they wanted out of the relationships with their healthcare teams and if they had any specific preferences that could be included in their care plan, such as learning in the home rather than learning in the PD clinic. Primary nurses in the PD clinic adapted their care to reflect the goals, needs, and values of their individual patients (Dabney & Tzeng, 2013). Peritoneal dialysis patients have access to their primary nurses through various communication channels such as phone, in person, or email. Peritoneal dialysis patients have the option to contact their primary nurse about new or potential complications with their PD catheter, education on medications, treatment goals, diet, or fluid management. Based on my prior experiences, if primary nurses are not available to assist their assigned patients, care for their assigned patients are typically delegated to another previously determined nurse.

Research Purpose

During my time as a nurse in the PD clinic, I became curious as to what extent patients were receiving care from the primary nursing care delivery model because of what I observed. It was evident through my observations that PD patients were being cared for by the nurses, however, PD patients were regularly cared for by multiple nurses during follow-up appointments or when requesting assistance with their PD therapy. When PD patients required assistance outside of the PD clinic hours, they were required to contact a nurse in the inpatient kidney unit who would provide assistance to PD patients over the phone. The responsibility of the PD patients was temporarily transferred from the primary nurses in the PD clinic to the nurses on the inpatient kidney unit. In addition, multiple PD patients would be rotated between different
primary nurses to prevent nurse burnout from patients who required a large amount of nursing care or if nurses had specific preferences for certain PD patients.

In my experience, I witnessed that there were changes to the primary nursing care delivery model as a result of organizational practices and individual nurse preferences. I noticed that insufficient nurse staffing levels, varying work schedules, nurse burnout, and individual preferences of nurses to care for selected patients were potentially linked to the way primary nursing was being implemented in the PD clinic. These changes made me question the quality and type of nursing care PD patients were receiving in the clinic.

In addition, I observed that patient care and patient outcomes may have been negatively influenced in relation to these organizational practices and individual nurse preferences. The lack of available nursing staff working in the PD clinic and varying work schedules left patients interacting with other nurses and not their primary nurse. I noticed when different nurses cared for patients, continuity of care was negatively affected and decreased patient satisfaction and health outcomes which were evident in patient feedback and physiological changes. The different levels of nursing expertise and clinical judgment of nurses led to care plans being interpreted in different ways, which caused confusion for patients, because they did not know which of the nurses’ instructions they should follow. Also, patients experienced conflicting expectations concerning how often or when to contact a nurse for assistance. In addition, I noticed that when patients were not in regular contact with their primary nurse, the nurse-patient relationship between the patient and the other PD nurse was difficult to establish. I have witnessed with some patients that the inability to form relationships with the other PD nurses can influence trust between the patients and the healthcare team, and subsequently adherence to PD therapy. Although every effort is made to keep the same patient with the same primary nurse,
nurse burnout and individual preferences for selected patients was apparent in the PD clinic. Patients were receiving care from different primary nurses and information about patients’ treatment plans were sometimes not accurately communicated. In addition, some patients receiving care under my organization’s primary nursing care delivery model have experienced health complications such as PD related infections, fluid overload, dehydration, and blood pressure issues.

Although I have witnessed PD patients experiencing complications such as non-adherence to PD therapy and negative physiological changes potentially in relation to the current nursing care delivery model, I could not find any published literature substantiating such experiences in a PD clinic that uses primary nursing care. Research that is available often discusses other nursing care delivery models such as nurse-led case management programs in PD clinics (Chow & Wong, 2010) or primary nursing in areas such as hemodialysis clinics, maternity wards, and acute care settings (L. Johansson, 2013; Jost et al., 2010; Melchior et al., 1996; Wan et al., 2011). In these areas outside of PD clinics, research suggests that modified forms of primary nursing are being implemented as a result of nurses not following the care delivery model or a lack of role clarification (Jost et al., 2010; Melchior et al., 1996; Wan et al., 2011).

In order to address the current gap in knowledge about the healthcare experiences of PD patients managed by a primary nursing care delivery model and further understand the unique healthcare experiences of this population, I conducted an interpretive description study. I interviewed 15 adults who self-administered PD therapy. To help guide my research study I used the following research question: How are patients experiencing nursing care within the primary nursing care delivery model in the St. Paul’s Hospital Peritoneal Dialysis Clinic?
Overview of Thesis

In this first chapter, I have provided context to the issue that supports the need to further explore my research problem. I have articulated the experiences of PD patients from my observations as a PD nurse and the importance of further exploring these nursing experiences from their perspectives. In chapter two, I illustrate the current state of literature based on how primary nursing is portrayed by other researchers. I indicate what is known about the primary nursing model and how nurses are implementing this specific model in their practice. In addition, I include information about patient-centred care practices and its associated patient outcomes because researchers have mentioned its linkage as a philosophical underpinning to primary nursing. In chapter three, I purposefully outline the research methods I used to conduct my study. I describe my rationale for using an interpretive description research methodology, criteria for participant sampling and recruitment, process for data collection and analysis, and methods of maintaining credibility. In chapter four, I illustrate the experiences of the PD patients that participated in the study. I include excerpts from participant interviews to highlight how they viewed certain aspects of their nursing care. In chapter five, I conclude my thesis by discussing my findings within the context of current published literature and describe how my study contributes to the field of nursing. In addition, I discuss potential implications of my findings for future research and potential limitations of my study.
CHAPTER TWO: LITERATURE REVIEW

Introduction

In order to develop a comprehensive understanding of the current literature pertaining to the experiences of PD patients of nursing care and how patients experienced nursing care within a primary nursing care delivery model, I systematically conducted a review of the literature—utilizing four different online electronic databases and various search strategies to inform my understanding of the current state of literature in relation to my research question. I have organized my literature review to reflect the current state of literature. In other words, I have organized this literature review based on how primary nursing is portrayed within the literature. The literature review begins with a portrayal of what is currently known about the primary nursing model and how nurses are implementing this specific model in their practice. More specifically, I illustrate the various core elements of primary nursing that are similar to the descriptions of the model by various researchers. In addition, I include information about patient-centred care practices and their associated patient outcomes because researchers have linked patient-centred care as a philosophical underpinning to the primary nursing care delivery model. As there was a lack of available literature specific to the PD patient population, I expanded the scope of my literature review to include settings beyond the PD patient population.

Literature Criteria

Predetermined criteria were used to decide what literature to include in the review. Inclusion and exclusion criteria were determined based on their relevance to the research question. In order to ensure a rigorous review of the literature, the search focused on primary research articles (Polit & Beck, 2012). However, secondary research, opinion articles, discussion articles, and commentaries were briefly reviewed to provide direction for the
literature review and gain a better understanding of the current literature pertaining to the research problem if no primary research articles were available (Polit & Beck, 2012). Although the literature search was expanded to go beyond the PD patient population, individuals in the samples had to be over the age of 18 because my research study involved adult participants. Qualitative and quantitative studies were included as these research study designs were appropriate for gaining information about primary nursing, patient-centred care, and nurse-patient relationships. Generally, only publications within the past 10 years were considered to ensure that only the most recent literature was included, although, literature over 10 years was included if it was highly relevant to my research questions.

**Literature Review Search Strategy**

Four online electronic databases were used to undertake the literature review. These databases were Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, PubMed, and Web of Science. These databases were chosen for their extensive coverage on healthcare related literature (EBSCO, 2017; Thomson Reuters, 2017; U.S. National Library of Medicine, 2017) and potential for having literature related to PD patients, primary nursing, and patient-centred care. Key terms obtained from the research question were used to begin the search through the databases: primary nursing, peritoneal dialysis, healthcare experience, patient, and nurse. Additional key terms such as patient-centred care, renal, renal replacement therapy, outcomes, and chronic illness, were added to the search criteria incrementally until relevant literature to the research topic was found. In order to prevent the exclusion of literature that used a similar term as an alternative to the term patient-centred care, known synonyms of the concept were used. These terms were person-centred and individualized.
care. In addition, the reference lists of key articles were reviewed for any additional relevant sources that would complement the literature review (Polit & Beck, 2012).

The Literature Review

Definition of Primary Nursing

During the early 1970s, a definition of primary nursing was written by Marram, Bevis, and Barrett (1979). Marram et al. (1979) indicated that primary nursing emerged in the late 1960s to address multiple healthcare providers and fragmented care that patients experienced because of functional nursing and team nursing. Originally, primary nursing incorporated core elements and a model of care that supported the unique distribution of nurses to patients in the hospital setting (Marram et al., 1979). Primary nursing was defined as patients being assigned a primary nurse when they were admitted into the hospital (Marram et al., 1979). Core elements of primary nursing included comprehensive nursing care through assessments, interventions, and evaluations (Marram et al., 1979). Primary nurses coordinated interdisciplinary and nursing activities on behalf of their patients and created individualized care plans by including patient preferences or patient specific care needs (Marram et al., 1979). In addition, primary nurses were responsible for their patients 24 hours a day to ensure continuity of care (Marram et al., 1979). In the event a patient’s primary nurse was not available, an associate primary nurse would temporarily be responsible for the patient, but follow the care plan outlined by the primary nurse (Marram et al., 1979). The inclusion of these core elements (continuous care, comprehensiveness, coordination, and individualization) supported the idea that patient-centred care was an underlying philosophy of primary nursing, by which patient-centred care focused on all medical and social aspects of the patient (Marram et al., 1979).
After Marram et al.’s (1979) definition of primary nursing, there was little advancement of the definition within the literature until Shirey’s article in 2008. Shirey (2008) further added to Marram et al.’s (1979) definition of primary nursing, indicating that primary nurses were responsible for their assigned patients from hospital admission to discharge. In addition, primary nurses had accountability for the planning, delivering, and monitoring of their patients’ care. Primary nursing changed how nurses delivered and organized care for their patients by decentralizing decision-making and actively involving patients in their own care (Shirey, 2008). Unfortunately, due to various hospital constraints such as limited financial resources and a lack of available nurses, healthcare organizations were implementing modified forms of primary nursing in various healthcare settings to overcome these constraints (Marram et al., 1979; Shirey, 2008). It remains unclear from the literature if primary nursing is still being implemented as defined by Marram et al. (1979) and Shirey (2008).

**Current Implementation of Primary Nursing**

Over the past two decades multiple researchers have illustrated the implementation of primary nursing (i.e. what nurses do to provide primary nursing) in various settings such as hemodialysis units, emergency departments, operating rooms, psychiatric hospitals, and maternity wards. Although the findings from these research studies provided insight into the impact of primary nursing in relation to nurse burnout, nurse well-being, or patient satisfaction, the findings highlighted the variability of how primary nursing was implemented (Boumans & Landeweerd, 1999; P. Johansson et al., 2015; Jost et al., 2010; Melchior et al., 1996; Wan et al., 2011). The current state of literature describing primary nursing revealed different variations of the care delivery model, which seemed to be defined differently than Marram et al.’s (1979) and Shirey’s (2008) original primary nursing definition.
Studies that highlighted the variability of how primary nursing occurred included the randomized control trial by Wan, Hu, Thobaben, Hou, and Yin (2011), where researchers found that pregnant women were assigned a primary nurse prior to admission to the hospital until discharge for a predetermined amount of time. The experimental group received primary nursing and the control group was provided task centred nursing. The primary nurses were responsible for education and nursing care during delivery and after delivery (Wan et al., 2011). However, the researchers did not indicate if these primary nurses were responsible for their patients 24 hours a day or if associate primary nurses were involved in their patients’ care (Wan et al., 2011). In addition, the quasi-experimental pre-test post-test research study by Melchior et al. (1996) found that primary nursing as outlined by Marram (1979) was being implemented at the discretion of individual primary nurses. These authors found that primary nurses across five different psychiatric hospitals independently chose what attributes of primary nursing they would provide to their patients (e.g. continuity of care, comprehensive care, coordination, and individualization) (Melchior et al., 1996). In Boumans and Landeweerd’s (1999) quasi-experimental non-equivalent control group research study, findings demonstrated that certain units in a hospital were using a modified form of primary nursing. The authors indicated that 3 units (surgical, medicine, and orthopaedic) out of the 5 units included in the study deviated from providing nursing care according to the traditional primary nursing care delivery model (Boumans & Landeweerd, 1999). Registered Nurses were only responsible for their patients 8 hours a day (one work shift), 5 days a week, similar to the findings from Wan et al. (2011). There was no indication from the authors that these patients were cared for by other primary nurses, associate primary nurses, or information as to who was responsible for the patients after the 8 hours had ended (Boumans & Landeweerd, 1999).
In addition, Jost, Bonnell, Chacko, and Parkinson (2010), who discussed their quality improvement initiative to better the nursing care of patients, illustrated the implementation of a modified form of primary nursing. Jost et al. (2010) described a blend of traditional primary nursing and relationship-based care called integrated primary nursing. This integrated primary nursing care delivery model was implemented in selected inpatient and outpatient areas such as the emergency department, operating room, endoscopy unit, oncology unit, and perioperative areas (Jost et al., 2010). In this model, the concept of being highly present or actively engaged with patients was emphasized (Jost et al., 2010). Nurses actively engaged their patients by focusing on key elements of care delivery such as ensuring care was patient and family focused, evidence informed, accountable and autonomous, coordinated, and continuous (Jost et al., 2010). Nurses focused on seeing their patients as human beings within the overall setting of their world and in relationship to them seeking care from the multidisciplinary team (Jost et al., 2010). Although the nurses were not labelled as “primary nurses”, the nurses incorporated core elements of primary nursing such as individualization, continuity of care, and coordination on behalf of their patients (Jost et al., 2010; Marram et al., 1979). Similar to the previous research studies mentioned (Boumans & Landeweerd, 1999; Wan et al., 2011), patients did not have a specific nurse assigned to them to coordinate their care or nurses who were responsible for the patients 24 hours a day. Rather, nurses would only be responsible for their patients during the duration of their shift and implemented select key elements of integrated primary nursing according to patient specific needs.

Additional authors such as Johansson, Lundström, and Heiwe (2015) described how primary nursing was being implemented in Swedish hemodialysis units in their phenomenological research study involving hemodialysis nurses. The intended primary nursing
care delivery model for use in the hemodialysis units included all of the core elements of primary nursing (Marram et al., 1979). Primary nurses cared for and were responsible for the same patients during their 3-5 hour treatment sessions (continuity), coordinated care on behalf of their patients by fostering direct communication between patients and the multidisciplinary team (coordination), involved patients in the creation of their individualized care plan (patient-centred care and individualization), and delivered comprehensive patient care through education, assessments, and interventions (comprehensiveness) (P. Johansson et al., 2015). Despite the findings illustrating the description of primary nursing, primary nurses in the hemodialysis units did not completely implement the entire primary nursing care delivery model as described by Marram et al. (1979). The unclear role descriptions of primary nurses led nurses to rearrange their work schedules so that they only cared for selected patients a few times a year because the patients were labelled as “difficult” or “required more attention” (P. Johansson et al., 2015). In addition, the authors reported that some primary nurses did not include education in their care plans for patients or made decisions on behalf of the multidisciplinary team without consulting them (P. Johansson et al., 2015). The primary nurses in this hemodialysis unit rationalized their actions by indicating that they wanted to control their patients’ individualized care plans or members of the multidisciplinary team had limited availability (P. Johansson et al., 2015).

Summary of Current Implementation of Primary Nursing

The previously mentioned studies highlight important information about the current state of literature about primary nursing. However, it is evident from the literature as illustrated by Boumans and Landeweerd (1999), Johansson et al. (2015), Jost et al. (2010), Melchior et al. (1996), and Wan et al. (2011), that various modified forms of primary nursing have been implemented in different healthcare settings. Although the research studies have illustrated that
patients are being cared for using the primary nursing care delivery model, most of the studies involved patients in settings other than PD clinics, such as psychiatry, maternity, hemodialysis, medical, surgical, and oncology areas (Boumans & Landeweerd, 1999; P. Johansson et al., 2015; Jost et al., 2010; Melchior et al., 1996; Wan et al., 2011).

In addition, most of the studies focused on how primary nursing affected nurses in terms of emotional well-being (Boumans & Landeweerd, 1999; P. Johansson et al., 2015) and burnout (Melchior et al., 1996). Only one study focused on the perspectives of patients in relation to primary nursing (Wan et al., 2011). Gaining patient perspectives facilitates the understanding of PD patients from their point of view, a perspective which has been absent from the literature until now. Also, despite the efforts of Jost et al. (2010) to thoroughly describe the implementation of their integrated primary nursing care delivery model, the authors did not provide any information that indicated their work was a part of a research study; rather the information was a description of their quality improvement initiative which may be considered low on the hierarchy of evidence (Polit & Beck, 2012).

**Nursing Care with PD Patients**

In order to better understand how PD patients were cared for by nurses, I reviewed the electronic databases for literature that discussed the nursing care of PD patients. The only published research study I could find discussing the nursing care of PD patients was by Chow and Wong (2010) who conducted a randomized control trial with a pre-test post-test design. Chow and Wong (2010) examined the effectiveness of a nurse-led case management program in improving the quality of life of PD patients in Hong Kong. The control group consisted of PD patients receiving routine hospital discharge services. In the experimental group, PD patients were assigned a nurse case manager when they were admitted into hospital. Prior to the PD
patients being discharged from the hospital, the nurse case manager reviewed the proposed discharge plan with patients and family members and conducted a comprehensive assessment of the patient’s physical, social, cognitive, and emotional needs (Chow & Wong, 2010). Shared objectives between the patient, family members, and the nurse case manager were developed into the care plan (Chow & Wong, 2010). Weekly phone calls were made by the nurse case manager to the patient for 6 weeks after discharge from the hospital. The phone calls consisted of the nurse case manager checking-in with the patient, reinforcing patient behaviours to achieve PD health objectives, maintaining a nurse-patient relationship, and identifying new and potential complications related to PD (Chow & Wong, 2010). If patients required assistance that logistically could not be provided over the phone, the nurse case managers would use their clinical judgment to provide the patient with the most appropriate solution (e.g. referral to community nurse for home visit or referral to renal physician for advanced assessment) (Chow & Wong, 2010). After the 6 week period, the authors did not indicate how PD patients were further supported by the PD nurses, only that patient satisfaction improved for the PD patients in the experimental group which was measured through a self-reported questionnaire (Chow & Wong, 2010).

Patient-Centred Care Practices

Within the literature concerned with primary nursing, I observed that the concept of patient-centred care occurred. Marram et al. (1979) and Shirey (2008) repeatedly indicate that patient-centred care is an underpinning philosophy within the primary nursing care delivery model. Specifically, patient-centred care has been defined as an approach to care in which patients receive care that is tailored to their specific medical and psychosocial needs, and are involved in care-related decision-making processes. A multi-disciplinary approach is used in
which healthcare providers focus on the whole patient when providing care (Marram et al., 1979; Poochikian-Sarkissian et al., 2010; Shirey, 2008). Because this concept occurs in the primary nursing literature, although outside of the context of PD patient care, I have included patient-centred care literature in this literature review. For clarity, I separated patient-centred care practices into three components that represent the common practices that patients believe to be patient-centred and how they experience them: shared decision-making and providing information to patients, individualized and continuous care, and giving patients respect. In addition, I incorporate information about patient outcomes that are associated with patient-centred care and how patients are benefiting from these patient-centred care practices in an effort to understand the potential relationship between them.

**Shared decision-making and providing information to patients.**

Multiple researchers have supported that patients experience patient-centred care when they are involved in the decision-making process and are provided with information relevant to their care. Several studies have illustrated that shared decision-making is an important aspect of patient-centred care. Authors found that oncology and surgical patients believed they were receiving patient-centred care when their nurses partnered with them to ensure that they had an active role in their care (Kvale & Bondevik, 2008; Marshall et al., 2012). Examples of partnership included nurses asking their patients what they wanted out of their care, involving patients in deciding which treatment options to select, and nurses encouraging patients to share their preferences, values, beliefs, and opinions (Kvale & Bondevik, 2008; Marshall et al., 2012). Patients perceived that the invitation to participate in the decision-making process with their healthcare team reflected their nurse’s willingness to provide patient-centred care and better
achieve their health goals (Ferguson et al., 2013; McMurray et al., 2011; Poochikian-Sarkissian et al., 2010).

In addition, different studies emphasized that providing information to patients is a key practice for patient-centred care. Authors consistently indicated that patients from residential care and medical healthcare settings were routinely informed and made aware of their progress within their individualized care plans (McMurray et al., 2011; Ploeg et al., 2013). Patients believed that they were receiving patient-centred nursing care when their nurses informed them about any changes to their health status or treatment plan, the name of the upcoming shift nurse who would care for them, or any additional information that would be relevant for them to know (e.g. medication changes) (McMurray et al., 2011; Ploeg et al., 2013). Also, McMurray, Chaboyer, Wallis, Johnson, and Gehrke (2011) highlighted that patient-centred care occurred when nurses provided information to patients about their conditions in terms that patients understood.

Furthermore, the implementation of key patient-centred care practices such as shared decision-making and information sharing led to positive patient outcomes as illustrated in the literature. Kahn, Schneider, Malin, Adams, and Epstein (2001) concluded that women with breast cancer who were included in the decision-making process for cancer treatments were more likely to adhere to their medication regimen than women who were not included in the decision-making process. Positive correlations between high patient self-reported health status and including patients in the decision-making process, providing patients the opportunity to ask questions, or sharing information about treatment options were found in the quantitative research study by Bertakis and Azari (2011). Also, statistically significant physiological changes such as improved weight and mean blood pressure results were found when primary nurses encouraged
their patients to be actively involved in their own care, kept patients informed of their progress, and supported the participation of family members (Su et al., 2009).

**Individualized and continuous care.**

Another common patient-centred care practice identified by patients was individualized and continuous care. Various qualitative and quantitative research studies illustrated that patients voiced they were experiencing patient-centred care when their care was individualized by their healthcare providers. Researchers defined individualization as the practice of nurses adapting their nursing care to meet the specific needs of their patients (Edvardsson et al., 2010; Radwin et al., 2009). Nurses adapted their care for residential care patients by making an effort to tailor activities that would suit their preferences, enabling their participation, and personalizing their physical environments with familiar photos (Edvardsson et al., 2010). In addition, patients experienced individualized care when nurses adapted their care to the desired level of patient involvement (Radwin et al., 2009). One descriptive correlational quantitative research study found that patients perceived they were experiencing patient-centred care when their nurses were attending to their needs and providing nursing care according to their preferences (Poochikian-Sarkissian et al., 2010).

In addition, focus groups of dialysis patients led by Rubin et al. (2004) emphasized that continuity of care was an important element within the patient-centred care approach. As described by the patients, continuity of care occurred when members of the patient’s healthcare team readily shared patient information with each other. Examples of information included future care plan changes or treatment options. Patients from the focus group indicated that continuity of care was evident when they did not have to constantly mention the same information to multiple healthcare team members or correct inaccurate information on separate
occasions because team members already had the same information. The research study by
Wolf, Lehman Quinlin, Zullo, and Hoffman (2008a) further outlined the implementation of
continuity of care through the presence of a single nurse that would be responsible for the
patients throughout their surgical experiences. Prior to surgery, patients were provided education
by a nurse who also provided post-operative nursing care for the patient while in hospital (Wolf,
Lehman, Quinlin, Zullo, & Hoffman, 2008a).

Patient outcomes associated with the patient-centred care practices of individualized and
continuous care included improved patient satisfaction and improved patient adherence. Cann
and Gardner (2012) conducted a quantitative pre-test post-test research study with 1115 patients
from an acute surgical unit. These researchers found a clinically significant improvement in
patient satisfaction levels when healthcare providers included patient preferences in care plans
(Cann & Gardner, 2012). Wolf et al. (2008a) who conducted a randomized post-test study on 36
gastric bypass patients as previously mentioned, found that higher ratings of satisfaction with
health care services and quality of services was evident when the same nurse provided care to the
patient pre-and post-surgery in comparison to having different nurses (Wolf et al., 2008a). Also,
self-report questionnaires indicated significantly improved diet regimen adherence rates and
improved medication regimen adherence rates when healthcare providers individualized their
care to meet the cultural needs and preferences of their patients (Tucker et al., 2011).

Giving patients respect.

Additional patient-centred care practices discussed in the literature included healthcare
providers giving their patients respect. The phenomenological research study by Marshall et al.
(2012) illustrated that respect was an essential component to patient-centred care. The
researchers interviewed 10 patients from a surgical unit to explore their experiences and
meanings of patient-centred care. Researchers concluded that when patients believed they were
given respect, they were also experiencing patient-centred care. Common examples of respect
included, nurses taking the time to sit with their patients, asking for permission before doing
anything with them, and asking them how they felt or if they were comfortable (Marshall et al.,
2012).

**Summary of Patient-Centred Care Practices**

Overall, the current literature illustrates that patients are experiencing various patient-
centred care practices. Patients have described their experiences of being involved in the
decision-making process of their treatments, having care that is adapted to their personal
preferences, and being provided with care that is respectful. However, research studies
examining the elements and outcomes associated with patient-centred care have largely occurred
outside of the PD patient population (Bertakis & Azari, 2011; Cann & Gardner, 2012; Kahn et
al., 2007; Poochikian-Sarkissian et al., 2010; Radwin et al., 2009; Tucker et al., 2011; Wolf et
al., 2008a). The majority of research studies discussing patient-centred care outcomes involved
patients diagnosed with cancer, patients in hemodialysis or specialty care units, or patients in
acute care settings, making it difficult to confirm whether these outcomes are also applicable to
PD patients. Although the studies by Rubin et al. (2004) and Su et al. (2009) examined PD
patients, their sample sizes were small (3 and 30 respectively), which limited the ability to
generalize the results outside of the sample population (Polit & Beck, 2012). In addition, most
of the quantitative research studies had multiple questionnaires in which pre-tests and post-tests
were administered to patients. Despite the researchers’ attempts to ensure multiple
measurements to capture participant responses, the risk of testing bias increased as a result of
participants being exposed to the same questionnaire on different occasions which could have
potentially affected their responses and ultimately decreased the rigour of their study (Polit & Beck, 2012).

**Summary of Literature Review**

Recent literature has illustrated that variations of the implementation of the primary nursing care delivery model exist. These variations include discretionary use of the core elements of primary nursing and care by numerous nurses that may not be coordinated by a primary nurse. In addition, various authors have suggested that an underpinning philosophy to primary nursing is patient centred care. Although there is information about primary nursing and the relationship between primary nursing and patient-centred care, the use of the primary nursing care delivery model within the PD patient population in an outpatient clinic setting remains unknown. By exploring the experiences of PD patients with their nurses and how these patients experienced nursing care within a primary nursing care delivery model, my research study attempts to fill the gap in knowledge currently present in the literature. Furthermore, addressing the gap in the literature provides information about how PD patients view certain aspects of their care and the factors that influence their nursing care experiences, which can inform the improvement of patient-centred care practices and enhance the management of PD patients.
CHAPTER THREE: RESEARCH METHODS

Introduction

In chapter two, I demonstrated that little is known about the use of a primary nursing care delivery model with PD patients. Researchers have not analyzed primary nursing care delivery models within the context of providing patient-centred care. Although current research supports the use of primary nursing care delivery models for the benefit of patients, the gap in the literature suggests the need for further investigation and analysis. In order to gain a better understanding of my research topic, I used the following research question to guide my study:

How are patients experiencing nursing care within the primary nursing care delivery model in the St. Paul’s Hospital Peritoneal Dialysis Clinic?

In this chapter, I provide detailed information about the methods I used to conduct my research study. I will do this by describing sampling and recruitment, data collection, data analysis, and how I maintained credibility in the study.

Methodology

I employed interpretive description as the methodological framework to guide my study. Originally developed by Thorne, Kirkham, and MacDonald-Emes (1997), interpretive description assists in the creation of a meaningful and purposeful framework to understand the healthcare experiences of people within the context of an applied health science, such as nursing. Interpretive description is not a series of steps, rather, it is a conceptual approach to qualitative research that provides a logical structure and philosophic rationale derived from the discipline where research is conducted to justify the use of specific techniques and procedures in research (Thorne, Kirkham, & O’Flynn-Magee, 2004; Thorne, 2008). Interpretive description explicitly attends to the subjective and experiential knowledge of the study participants as a fundamental
source of clinical insight (Thorne, 2008). Interpretive description uniquely added value to the process of my qualitative study by providing direction for the interpretation of participant experiences that extends “beyond mere description and into the domain of the ‘so what’ that drives all applied disciplines” (Thorne, 2008, p. 33). Interpretive description guided me in keeping my study focused on the practice goal of improving nursing practice. In answering my research question about determining how patients were experiencing nursing care within the primary nursing care delivery model in the St. Paul’s Hospital PD Clinic, I sought to inform future nursing practice.

Interpretive description was the most appropriate research methodology for my study for a few reasons. An underlying assumption that underpins interpretive description is the idea that individuals can share similar and diverse experiences which are subjective and complex (Thorne, 2008). This assumption was useful because my study was concerned with understanding multiple experiences of patients, in which perceptions of nursing care could be different from one participant to another. Interpretive description offered the potential to examine current knowledge about primary nursing and patient-centred care, while deconstructing the patient’s journey to “generate new insights that shape new inquiries as well as application of ‘evidence’ to practice” (Thorne, 2008, p. 35). Since interpretive description guides the researcher to think about how to identify themes and patterns within the subjective perceptions of participants and to generate information to inform clinical understanding (Thorne et al., 2004; Thorne, 2008), findings from my study contributed to the generation of new knowledge that could influence the improvement of nursing practice strategies for better PD patient care. In addition, the objectives of improving the management of PD patients and making sense of what needed to be explored within the PD patient population reflected the driving sources of research for interpretive
description; an actual practice goal and an understanding of what was and was not known from all empirical sources (Thorne, 2008).

Methods

Gaining Entry into Study Setting

To recruit patients being cared for at the St. Paul’s Hospital PD Clinic, I negotiated entry into the PD clinic. Upon supervisory committee and ethics approval from the UBC Behavioural Research Ethics and Providence Health Care Research Ethics Boards, I contacted the Patient Care Manager responsible for the PD clinic at St. Paul’s Hospital via email. We met in person to discuss my proposed research study, including the study goals, key objectives, and outcomes. Upon Patient Care Manager departmental approval, I met with the Clinical Nurse Leader and PD clinic nursing staff to discuss my research study and obtain their support for recruitment (discussed later in this chapter).

Study Participants

I developed specific inclusion criteria for individuals to participate in the study. Participants had to be (a) 19 years of age and older, (b) able to speak and read English, (c) able to independently administer their PD therapy, (d) have St. Paul’s Hospital as their primary PD clinic, and (e) be a PD patient for at least six months. I indicated a minimum of six months as a PD patient because in my experience, this length of time provided a sufficient amount of opportunities for PD patients to interact with their primary nurses during PD training, follow-up clinic visits, or unscheduled home visits because of complications associated with PD. The feasibility for completing the study led me to consider additional criteria such as language of the participants and the location of the healthcare facility where participants were cared for. Participants were excluded from the study if they were (a) unable to speak or read English, (b)
did not administer their own PD therapy, or (c) had been a PD patient for less than 6 months. Although PD patients who did not self-administer their PD therapy encountered their primary nurses, nursing support was primarily given to individuals who administered the PD treatment (i.e. family members or support workers) in those cases. The scope of the study was to explore the experiences of patients who independently self-administered their PD treatments and not those whose PD treatments were administered by families or support workers.

**Sampling and Recruitment**

Purposeful sampling was used to recruit participants for this study. Purposeful sampling resulted in strategically selecting information-rich cases that illuminated my inquiry of the research problem (Patton, 2015). Qualitative research, particularly interpretive description research, emphasizes that selecting participants should be more than ensuring findings are transferable to a similar population; rather, it is about selecting participants whose personal experiences can help to answer the research question (Polit & Beck, 2012; Thorne, 2008). By using purposeful sampling, specifically the criterion-based case selection approach (Patton, 2015), I was able to recruit participants who had personal experiences of administering their own PD therapy and could potentially assist in informing the future practice of nurses. Participants were selected based on the previously mentioned inclusion criteria.

Potential participants were recruited through a recruitment flyer and assistance from the PD clinic nurses. Recruitment flyers (Appendix A) included information about my study objectives, time commitment, eligibility, and members of my research study team. Recruitment flyers were posted in the patient care areas of the PD clinic and distributed by the PD clinic nurses to all PD patients. Interested participants contacted me directly through the contact methods indicated on the recruitment flyers. In addition, PD clinic nurses approached potential
participants and asked if I could connect with them about participating in the research study. All potential participants were reassured that their agreement was purely voluntary, did not influence the care they would receive as a PD patient, and were not pressured to participate in the research study. Upon confirming with potential participants that they met the inclusion criteria, I coordinated a time and location for the interview.

**Data Collection**

To ensure that the unique experiences of participants were accurately documented, I used specific processes informed by interpretive description to collect data. I conducted face-to-face one-on-one interviews with participants. Interviews have been widely used as a primary source for qualitative data collection. Interviews have the potential to facilitate understanding of participants’ subjective perceptions through the interpretation of their experiences (Polit & Beck, 2012; Thorne, 2008). Therefore, the use of interviews seemed rational given my research goal of exploring the experiences of individuals who have first-hand knowledge of self-administering their PD therapy. I used a semi-structured interview framework to allow for flexibility in the interview by which I varied the order and wording of the questions from my interview guide (Doody & Noonan, 2013). Examples of interview questions included, “How did you come to be using PD?”, “Tell me what you did over the past week on PD”, and “What are your experiences as a PD patient with your nurses?” (see Appendix B). This flexibility provided me with the opportunity to focus on my topic, while allowing room to explore new information that emerged during the interview which I did not originally account for (Doody & Noonan, 2013). Open-ended questions (questions that could not be answered with a yes or no response) were used throughout the interview so that the interpretive description values of empathizing and understanding subjective participant experiences could be upheld and participants could be
encouraged to tell their stories (Polit & Beck, 2012; Thorne, 2008). Interviews were conducted in locations that the participants preferred, such as their homes or in a hospital meeting room. Interviews were between 45 to 75 minutes in length. All interviews were digitally audio recorded, except for one interview in which the participant did not want to be recorded and I took hand written notes instead. All audio recordings were sent to an experienced transcriptionist for transcribing and I checked them for accuracy against the original audio recordings prior to data analysis.

In order to determine if there was consistency of ideas and themes from the interview data, concurrent data collection and data analysis occurred (Thorne, 2008). As there is a lack of agreement in qualitative research as to what is considered a small study, sample sizes can vary (Polit & Beck, 2012). In interpretive description, there is no absolute number of participants that would comprise a sufficient sample size (Thorne, 2008). Therefore, when completing data collection and data analysis simultaneously I ensured that I did not stop data collection until substantial similar experiences within multiple variations were apparent in the data. Specific to my research study, consistent ideas and themes were apparent after 15 interviews, at which time I stopped data collection.

**Data Analysis**

Various strategies informed by interpretive description were used to complete data analysis with the support of my thesis supervisor and thesis committee. After each transcript was checked for accuracy, I uploaded it into the qualitative data management program NVivo 11™. Since the goal of my data analysis was to make sense of the data inductively by building a coherent interpretation of the participants’ subjective experiences, I spent time being immersed in the data (Thorne et al., 2004; Thorne, 2008). I read each transcript initially without taking any
notes to gain an overall sense of what the participants were experiencing. I allowed myself to reflect on the initial pieces of data that attracted my attention so that I could look beyond the immediate impressions of superficial themes that may have been evident (Thorne, 2008). After completing my initial reading of each transcript, I reread the data, and took notes in the margins of the printed transcripts.

I began to develop potential themes by paying attention to the different elements of primary nursing that participants were experiencing such as comprehensive care, continuous care, individualized care, coordinated care, and patient-centred care (Marram et al., 1979; Shirey, 2008). I attempted to analyze the data and group similar experiences of participants within the key elements of primary nursing (Marram et al., 1979). When analyzing for comprehensive care, I looked for data that represented nurses providing thorough assessments, detailed education and training to participants, and appropriate nursing interventions (Marram et al., 1979). I analyzed the data for continuous care by focusing on participant experiences that included patient information being transferred between one healthcare team to another (Marram et al., 1979; Rubin et al., 2004). When analyzing for individualized care, I looked for data that supported nurses incorporating the preferences of the participants into the care plan (Marram et al., 1979). I analyzed the data for coordinated care by noting participant experiences that included nurses who organized care on behalf of their patients (Marram et al., 1979).

As I engaged in the iterative process of going back and forth between data analysis and data collection, I began to further explore and expand on any developing conceptualizations that arose from the data (Thorne, 2008). During the latter half of my participant interviews, I noticed that participants were describing experiences with the nurses that did not appear to adhere to several core elements of the primary nursing care delivery model such as participants being cared
for by multiple PD nurses. When I realized this, I refocused my data analysis to focus on what nursing care actually looked like from the participants’ perspectives. I was attentive to participant experiences during PD training, interactions between participants and nurses, and examples of when participants needed help from their nurses. I repeatedly challenged my original thinking and expanded on associations by asking questions (Thorne et al., 2004; Thorne, 2008) such as “Why was that participant experiencing that specific event? How did participants perceive their nurses to be during that interaction? How was patient-centred care reflected in nursing practice?”. I developed the final themes by sorting data into like groups of ideas, took pairs of whole texts from the same and different participants, analyzed them for similarities and differences, and identified any reoccurring concepts across the participants (Ryan & Bernard, 2003). The final themes reflected which elements of the primary nursing care delivery model participants experienced and did not experience.

Furthermore, I used additional strategies throughout the data analysis process to minimize potential hazards related to being immersed in the data. In order to minimize premature closure (stopping at first major insight), “bloodless findings” (Thorne, 2008, p. 147) (superficial survey of phenomenon), and premature coding, I highlighted areas in the data that I wanted to remember, kept quotable quotes in a separate node in NVivo 11™, and labelled initial codes with a generic category (e.g. category A) (Thorne, 2008). Using these strategies minimized the risk of making premature claims that might have dominated the analytical process. Also, I ensured that any findings that I identified early in the data analysis stage were later confirmed with additional data (Thorne, 2008). I regularly discussed my preliminary findings with my thesis supervisor and further refined the final themes of my study after receiving feedback. Also, I kept my
research question in mind throughout the entire data analysis process in order to generate the final themes of how PD patients experienced their nursing care.

**Credibility Indicators**

When conducting my research study, it was important for me as the researcher to make explicit attempts at enhancing the credibility of the study due to the subjectivity of participants, data collection, and data analysis. I used criteria for enhancing trustworthiness (believability) by Lincoln and Guba (1985) which builds on the credibility elements of interpretive description. The criteria included credibility, confirmability, and transferability (Lincoln & Guba, 1985).

**Credibility**

Credibility refers to confidence in the accuracy of data and interpretations of them (Lincoln & Guba, 1985; Polit & Beck, 2012). In order to establish credibility, I used methods of recruitment, data collection, and data analysis that aligned with the underlying assumptions of interpretive description (e.g. immersion in the data through concurrent data analysis and data collection) (Thorne et al., 2004; Thorne, 2008). I demonstrated credibility in my research by keeping my research question in mind throughout the research process so that findings were viewed from a practice mandate lens, in which ideas were not understood as purely theoretical, but rather, considered as if they could have been applied in nursing practice (Thorne, 2008). In addition, I deliberately explored emerging topics from one interview to the next by asking new interview questions to confirm and elaborate on previous participant experiences.

**Confirmability**

Confirmability refers to the degree of objectivity in which study findings are representative of the participants’ experiences and not from the subjective interpretations of the researcher (Lincoln & Guba, 1985; Polit & Beck, 2012). In order to ensure confirmability, I
actively engaged in reflexivity. Reflexivity is the process of reflecting critically on one self, acknowledging that the researcher is a part of the setting, context, and social construct of the phenomenon, and analyzing and making note of personal values that could affect data collection and data analysis (Polit & Beck, 2012). In a personal journal, I explicitly acknowledged my role of researcher as instrument in which I drove the interpretation of findings by determining what constituted data, what was relevant, and how final themes were portrayed (Thorne, 2008). I documented my personal values, beliefs, thoughts, assumptions, and emotions that may have biased the data and self-reflected on how my prior experiences as a PD nurse potentially affected the entire research process (Darawsheh, 2014; Thorne, 2008). By engaging in reflexivity, I had a better self-awareness of myself as a researcher in relation to my research study and moved one step closer to enhancing the trustworthiness of my findings (Polit & Beck, 2012).

In addition to engaging in reflexivity, I used probing questions and integrated participant experiences using thick descriptions to ensure confirmability. During my participant interviews, I deliberately used probing questions to ensure that the participants’ meanings were understood correctly; an important technique indicated by Lincoln and Guba (1985) to enhance credibility of the study. I integrated verbatim quotes from participants when discussing the findings from the study to provide thick (rich) descriptions of participant experiences and accurately represent what they said and how they felt (Polit & Beck, 2012; Thorne, 2008).

**Contextual Awareness**

Although Lincoln and Guba (1985) referred to transferability as the extent to which findings could be transferred to or have applicability in other settings or groups, my use of interpretive description guided me to focus on contextual awareness as described by Thorne (2008) instead of transferability to increase the credibility of my study. Contextual awareness
was important in my study because it allowed me to situate the experiences of the participants within their historical and social context. Providing detailed demographic characteristics of the study participants and any contextual information that may have influenced the data in the findings section of my report supported a better understanding of participant perceptions (Thorne, 2008). In addition, the opportunity for me to include any relevant contextual information with the verbatim quotes of the participants further supported the notion of probable truth, where the experiences of the participants were considered to be true from their perspectives (Thorne, 2008).

**Ethical Considerations**

In an effort to treat all participants with respect, demonstrate a concern for their welfare, and ensure fairness, a number of ethical considerations were addressed in the research study. These ethical considerations included informed consent, confidentiality, data storage, financial incentives, and the maintenance of respectful relationships. I conducted the research study according to the policies, protocols, and guidelines outlined in the Tri Council Policy Statement: Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014), University of British Columbia Behavioural Research Ethics Board (UBC BREB), and University of British Columbia Providence Health Care Research Ethics Board (UBC PHC REB). My research study only commenced after ethics approval from the UBC and PHC ethics boards, and departmental approval from the Patient Care Manager responsible for the St. Paul’s Hospital PD Clinic.
Informed Consent

Written informed consent was obtained from all participants by reviewing written information that detailed the research study goals, type of information being collected, procedure to collect information, nature of commitment, financial sponsorship, participant selection, potential risks and benefits, financial incentives, confidentiality pledge (assurance to participants that their privacy will be protected), and contact information of the research team (Appendix C) (Polit & Beck, 2012). I reviewed the consent form in person with all participants prior to conducting the interviews and clarified any information as needed. Due to the nature of qualitative research and the inability to fully predetermine what would happen in any research encounter, I constantly negotiated informed consent throughout the interview process (Thorne, 2008). Participants were asked to talk about their experiences of engaging with nurses in the context of their PD clinic. Although the interview questions were not intended to be invasive or too personal, some participants may have felt uncomfortable or emotional. To manage any possible harm, I informed all participants about free counselling services and gave them a take-home brochure prior to the start of their interviews. If participants shared sensitive or secret information leading to obvious emotional distress, I paused the interview, stopped the digital audio recording, and asked them if they wanted to continue with the interview (Thorne, 2008). There were two separate incidences where I had to pause the interviews because the participants were crying due to frustration, loneliness, and family support. I clarified with all participants that their health care and relationships with their healthcare providers would not be negatively impacted by the information they shared or if they chose to voluntarily withdraw from the study at any time. None of the participants in the study expressed to me that they were concerned
about their health care or relationships with their healthcare providers because of participating in the study. None of the participants withdrew from the study during or after their interviews.

**Confidentiality**

The issues surrounding confidentiality in the absence of anonymity were considered throughout the entire research study. Although anonymity (inability to link participants to data) could not be guaranteed because I conducted the data collection and data analysis which inherently led me to recognize participants from their interview transcripts (Polit & Beck, 2012), confidentiality of participant information was assured. Participants were informed that any identifying information (e.g. names) would be removed from any recorded data, computer files, or written documents (Polit & Beck, 2012). Participants were assigned a unique numeric identifier in which a number was placed on all documents containing their data. Participants were assured that comments identifying details of their circumstances, situations that would connect them to their healthcare providers, or any names of their healthcare providers would be removed from the transcripts. In situations where the PD nurses asked for verbal consent from the participants for me to contact them, participant confidentiality remained because the nurses were never informed of who I accepted into the research study and who actually participated.

**Data Storage**

All data collected from participants were secured according to the UBC BREB guidelines. Any hard copies of research data relevant to the study (e.g. transcripts and interview notes) were stored in a locked filing cabinet in the office of my thesis supervisor. Any electronic copies of research data relevant to the study (e.g. transcripts and interview audio) were kept on my local and external hard drives and my thesis supervisor’s local hard drive. All hard drives were encrypted and password protected. All research data, hard copy and electronic, will be
destroyed after a period of 5 years using methods such as shredding paper documents or permanently deleting electronic files.

**Financial Incentives**

Ethical issues surrounding the provision of financial incentives to participants were considered. All participants were provided with an incentive of $25 in the form of a coffee or grocery gift card as an appreciation of their time and effort in sharing their experiences. In order to reduce any perceived power differentials as a result of providing participants with a financial incentive in exchange for a description of experiences, participants were provided with the incentive at the start of their interviews (Canadian Institutes of Health Research et al., 2014; University of British Columbia, n.d.). I shared with the participants that they did not need to return their gift cards if they chose to voluntarily withdraw from the research study during or after data collection. The practice of allowing participants to keep their honorarium aligned with the guidelines set out by the UBC BREB and Tri-Council Policy Statement, where it is considered unacceptable to have honorariums depend on completion of the interview (Canadian Institutes of Health Research et al., 2014; University of British Columbia, n.d.).

**Maintaining Respectful Research Relationships**

In order for me to ethically conduct my research study, I needed to carry out my research in ways that maintained respectful relationships between me and the participants. I needed to establish rapport with the participants by ensuring I exemplified honesty, transparency, and overall concern for conducting humane research (Cohen & Crabtree, 2008). My prior experiences as a nurse caring for individuals with CKD, particularly those who required PD, had given me the opportunity to hear the unique experiences of some PD patients. When engaging with the study participants, I informed them of my prior role as a PD nurse and clarified my role
as a graduate student completing my thesis. I indicated to participants that I wanted to learn from their experiences, rather than simply speak for them through my research findings and interpretations (Cannella & Lincoln, 2011). I wanted to understand and provide a meaningful account of their perspectives and realities (Cohen & Crabtree, 2008). In addition, I conducted the interviews in locations that the participants preferred, such as their homes or in a hospital conference room. I encouraged the participants to ask me questions about the research study for clarification and committed to sharing a report of the findings with any participant who was interested. To ensure that interested participants would receive a report of the findings, I collected their email addresses or mailing addresses for any participants that preferred a hardcopy of the report.

**Summary**

Overall, I used various methods informed by interpretive description to conduct my research study. I kept my research question in mind when recruiting my sample, collecting participant data, and completing data analysis. In addition, I incorporated multiple strategies to enhance the trustworthiness of the study and ultimately improve its credibility.
CHAPTER FOUR: RESEARCH FINDINGS

Introduction

In this chapter, I outline the findings of my research study guided by my research question. I chronicle the experiences of the study participants by sharing the major themes that were generated from participant data. I illustrate the nursing care experiences of PD patients with their nurses in the PD clinic and how they were specifically experiencing and not experiencing primary nursing. The major themes are supported with verbatim quotes to highlight the unique interactions participants had with their nurses and the type of nursing care they received in the St. Paul’s Hospital PD Clinic. In addition, I incorporate participant specific information such as demographic information throughout this chapter to provide context for their experiences.

The Participants

Fifteen participants from the outpatient PD clinic located at St. Paul’s Hospital participated in the study. There were eight participants who self-identified as male and seven participants who self-identified as female. Over half of the participants in the study were over the age of 60 which is indicative of older adults undergoing PD therapy for their CKD (Jha et al., 2013). The mean age of participants was 59.1 years with a range of 27 to 82 years. The age range of the participants reflected the typical patient population that the PD clinic served according to my prior experiences working in the St. Paul’s Hospital PD Clinic. All participants met the remaining predetermined inclusion criteria.

A common trajectory for all patients diagnosed with CKD was to enroll in the pre-dialysis clinic. In the pre-dialysis clinic, patients’ CKD progression was monitored by multiple nurses, physicians, pharmacists, and dieticians on an outpatient basis. For the participants that
participated in my study, most of them were enrolled in the pre-dialysis clinic prior to starting their PD therapy.

All participants required PD as a life sustaining therapy for their CKD. The mean length of time self-administering PD therapy (calculated from the start of PD to the interview date) was 33.4 months with a range of 7-53 months. All participants reported having received education and training about PD by the nurses working in the PD clinic. According to the participants, education and training was typically conducted in person by the PD nurses on a one-to-one basis. Participants were taught about the theory of PD, techniques for PD self-administration, problem-solving related to PD associated complications, and responsibilities of being a PD patient in the PD clinic. Education and training continued for two weeks (4 days/week and 5-7 hours/day) and occurred either in the PD clinic, participants’ homes, or a combination of both. Across the sample of 15 participants there was variability in marital status, employment status, and ethnicity, and all but two had CCPD as their primary PD modality (see Table 1). Although I was not anticipating that marital status, employment status, and ethnicities would influence the nursing care of the participants in this study, I collected this information to document the diverse backgrounds of these individuals living with CKD to provide a snapshot of the contexts in which people lived and/or experienced CKD (Rubin et al., 1997; Wuerth, Finkelstein, Kliger, & Finkelstein, 2000). In addition, I wanted to provide context to better understand the experiences of these participants as a PD patient self-administering PD therapy. Two of the participants had experienced hemodialysis prior to switching over to PD.
Table 1

*Sample Characteristics of Study Participants*

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<thead>
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<th>Characteristic</th>
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<tr>
<td>Age, in years</td>
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<tr>
<td>Length of time on PD, in months</td>
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Findings

Three themes were generated from the data. The three themes represent participants’ perspectives about the nursing care experiences they received as a PD patient and how these experiences were reflective or not reflective of the core elements in primary nursing (Marram et al., 1979). I chronicle the experiences of the participants by describing how the PD nurses were implementing primary nursing in the PD clinic from the perspectives of the participants based on the definition of primary nursing (Marram et al., 1979; Shirey, 2008). Each theme progressively builds on the previous theme in which I situate the journey of the participants during their time as a PD patient. I begin with PD education and training and culminate with participant experiences during the kidney transplant process. Based on the three themes inductively generated from the data, participants consistently did not experience all the core elements of primary nursing; rather, they were experiencing variations of the primary nursing care delivery model.

The first theme was *individualized care*. Individualized patient care was reflected through participants’ perceptions of their PD nurses’ abilities to tailor the plan of care to meet their physical and psychosocial needs. Individualized care was often received by the participants during the start of their PD journey (i.e. during PD education and training) and follow-up clinic visits. The second theme was *comprehensive nursing care*. Comprehensive nursing care was reflected through participants receiving thorough assessments, education, and interventions by the PD nurses to promote their health during post-PD education and training, follow-up phone calls, or follow-up PD clinic visits. The third theme was *organizational influences of primary nursing* in which participants described multiple experiences of not consistently receiving primary nursing care because of the organization of the PD clinic. In addition, the theme of
organizational influences of primary nursing highlighted how the participants overcame the challenges to receiving proper PD nursing care.

**Individualized Care**

Participants consistently mentioned their experiences of primary nursing through the various interactions they had with their PD nurses or through events that were related to their PD care. A consistent experience was how the participants received individualized care. The participants discussed at length their experiences of individualized care and the importance of this for their overall health and well-being. Individualized care included nurses’ actions and approaches that communicated to the patient that they understood their individual needs.

Individualized care involved participants receiving care from nurses who adapted their approach to meet the specific needs of each of their patients (Edvardsson et al., 2010; Radwin et al., 2009).

Individualized care was first noted during the participants’ initial PD education and training where they learned how to administer their own PD therapy safely. Throughout the PD education and training experience, a number of these participants expressed various emotions about their hesitation to learn PD. Most participants felt unprepared or were overwhelmed with the idea that they now had to do PD independently as indicated in the following quotes:

*P3: I just think the whole reality of it was setting in, about what I needed to do and it just looked so complicated with all those tubes and where to put it.*

*P14: Before you get into it, of course, it’s intimidating because it’s a bit of a scary prospect. You’re sort of responsible for looking after yourself and I am by no means any kind of a medical expert and you are always thinking, well, what if something goes wrong? What do I do? Will I know what to do? So, a lot of apprehension going in...*

Participants experienced personalized nursing care (a core element of primary nursing) that decreased anxiety. Participants indicated that they had PD nurses who incorporated patient specific preferences and changed the plan of care to meet their specific learning needs and styles.
For example, participants mentioned that their nurses used various training aids (e.g. step-by-step picture book or video demonstrations) or reinforced specific steps through a hands-on learning approach as noted in the following excerpt:

P14: By learning and actually doing. You know, the training was hands on and I find that I learn things a lot easier when I actually do it rather than trying to read it out of a book and by doing it and practicing it. It [PD training] became a lot easier. Besides, there were a lot of training aids. There was a particularly useful binder, like a flip binder that if you forgot something or got stuck you could always refer to it...I became kind of fairly confident fairly quickly.

The PD nurses further individualized their care by attending to their patients’ needs about where the training occurred. Participants commonly had PD nurses who provided PD education and training in their homes if they were not able to come to the PD clinic, particularly if other health issues prevented them from travelling. As one participant noted,

P12: What happened is that at that time I had just moved and I fell and I hurt my leg, so I had crutches, and the nurse there at PD, [the nurse] came out here and started me on it.

Relational engagement was a significant aspect of individualized care for the participants. The participants stated that they had PD nurses who personalized their nursing care by making attempts to get to know them and relate to them personally. Generally, most of the participants indicated that they thought their nurses were “good”, “nice”, “not too pushy”, “friendly”, “knowledgeable”, “helpful”, and “caring”. The descriptors that the participants used were reflective of what they thought about their nurses; however, it was when their nurses took the time to focus on them or get to know them that really mattered. A retired 54-year-old female participant who had been on PD for 4 years mentioned that the initial greeting by her nurse was important for the clinic visit.

P13: They call people by their names. It’s ok [name of participant], better than hello or who are you? It seems like they care. You are more at ease. It’s a more enjoyable visit.
Participants mentioned that their nurses made them feel like their CKD was secondary to their personal lives during conversations. The nurses regularly integrated personal questions in the conversation by asking participants how their life outside of PD was going, which provided a holistic approach to the participants’ nursing care (Marram et al., 1979) as illustrated by the following quote:

\[ P6: \text{They talk to you and say hey how you doing? How is life and how are things? How are you doing in your PD and stuff like that? They always ask those things, which is pertinent information.}\]

A 51-year-old single mother who had been on PD for 4 years further supported that the nurses wanted to get to know her more by describing a time when her nurse asked her about her family life.

\[ P3: \text{[The nurses] went a little bit beyond and remembered something about me, what’s going on for me, and checking in. “How’s your son?” Because that’s a huge issue with me.}\]

Participants indicated that a relationship with their nurse was integral to the entire experience of being a PD patient. In addition to the nurses asking about the participants’ family lives and general well-being, trust between the PD nurses and participants began to form as the professional relationship went on. A professional relationship meant that the PD nurses continued to focus on the participants and the PD nurses did not violate any physical, emotional, or mental boundaries of the participants (College of Registered Nurses of British Columbia, 2017). Participants trusted their nurses because of their professional titles and the expertise their nurses had.

\[ P10: \text{Because they’re nurses, they’re nurses. They know better than me.}\]

\[ P9: \text{Well look, I’m just a patient, I’m not an expert. That goes with anything in life. If I was a lawyer or I was giving advice to a lawyer, I wouldn’t give advice to a lawyer. He’s been trained with it, he’s part of the bar, so it’s not much I can say about it. It’s the same thing with the PD nurses. You guys are trained, you passed your exams, everything...}\]
As participants continued to interact with and trust their PD nurses, participants also experienced the relational aspect of patient care through the development of personal and clinically intimate relationships (Kirk, 2007). Participants developed close connections with their nurses during typical nurse-patient interactions such as physical assessments or follow-up appointments. The physical proximity that participants had to their nurses may have contributed to the development of a personal relationship as described by a retired 65-year-old male participant on PD for the past 3 years who reflected about his most recent clinic visit.

P15: It’s hard to avoid a personal relationship at the hospital with people who are [laughs] running their hands over your body all day and night. It’s very personal.

According to Kirk (2007), clinical intimacy occurs when one person (the discloser) expresses personally revealing information to another person (the listener). The listener responds supportively or empathetically which then leads the discloser feeling understood, validated, and cared for by the listener (Kirk, 2007). Participants felt comfortable and were appreciative of their nurses because they could share anything about their personal lives to them. For example, one of the participants who regularly spoke about his personal life to his nurse indicated the following:

P15: They seem to have a real concern for the patients which is what you want, I suppose. It can’t all be faceless, anonymous or anything like that. I am sure that at least half the interactions with the patients is not just treating them and taking care of whatever their illness is, but developing a relationship with them.

In addition, reciprocity between the PD nurses and participants was evident in the data. The PD nurses and participants were willing to share personal information beyond what was required in a nurse-patient relationship (Kirk, 2007). Participants described multiple experiences with their nurses in which the participants shared information about their vacation plans or
family dynamics and the PD nurses would talk about their personal hobbies or relationship issues as illustrated by the following examples:

P2: [My nurse] and I, we talk about not only things like the stuff I need to know from her for my treatment, but also I know the fact that her [partner] and her play in a band, rock n’roll band, and I was a musician myself years ago...So it’s not strictly all business.

P15: I mean even their life outside the clinic, people have problems. [My nurse] has a crazy husband.

In an effort to personalize their nursing care by getting to know their patients more, one possible outcome of reciprocity was that participants came to see their PD nurses not only as professionals or PD experts, but rather; they also saw their nurses more casually—as friends. A single 70-year-old male who was on PD for 4 years and a retired 82-year-old widow on PD for 4 years mentioned the following:

P4: Because of my involvement with [my nurse] all this time, we have truly become good friends and I know she will always be there for me.

P11: Well actually if anything I needed, they were always there to give or explain. They were very good with me. I actually have made some very good friends. [My nurse] especially. I miss her...we could talk about anything...we talk about everyday things and what life and our girls are doing and that...

In this manner, the nurse-patient relationship became family-like as perceived by the participants. The participants believed that they were close enough with their nurses because they shared personal information with each other. The participants referred to their nurses as a member of their family, often calling them a sibling. For example, a married 75-year-old male who was on PD for 1 year described his perceptions about the relationship he had with his nurse.

P2: Just the fact that we’ve become a bit of a family. In other words, we’re kind of, we know each other like brother and sister...they’ve created a very comfortable attitude, you know, situation for me.
One participant even referred to his nurse as a parent, *P8: I call her ‘mom’*. In addition, another participant who frequently spoke to his PD nurse about his personal life emphasized that feelings of comfort and being cared for were appreciated and wanted.

*P15: It’s not like there is a power imbalance or anything like that…I don’t know what’s the word—infantile when you are there because you are so—okay put on your jammies and get into bed. I feel like I am three again, right. So, there is that part of it but then that’s kind of comforting too. It’s like being taken care of by your mom again. Yeah, I’ve had great relationships with the nurses there.*

The personal information shared between the participants and the nurses created an environment in which both the participants and the nurses related to each other at an interpersonal level as described by Kirk (2007). The attempts of the PD nurses to get to know the participants fostered a feeling of reciprocity. The participants and PD nurses were able to express personally revealing information about themselves (Kirk, 2007). Participants consistently indicated that they found it comforting to know personal information about their nurses. By relating to their patients through the exchange of personal information, the nurses delivered the core element of individualized care in primary nursing as perceived by the participants (Marram et al., 1979; Wolf et al., 2008b).

**Comprehensive Nursing Care**

In addition to individualized care, participant experiences highlighted that comprehensive nursing care, a core element of primary nursing was an important aspect of their care. Comprehensive nursing care included participants receiving thorough assessments, education, and interventions by their PD nurses to promote their health. Participants mentioned that the nurses in the PD clinic made explicit attempts to provide comprehensive care to them either in person or through phone and email; however, comprehensive nursing care was inconsistent between the participants.
Generally, participants saw their PD nurses in person during follow-up clinic appointments scheduled every two to three months. During these appointments, participants indicated that their nurse would routinely complete physical examinations, ask questions about their fluid status (blood pressure, weight, and swelling), inspect their PD catheter exit site, review specific dialysate prescriptions (type of PD fluid used by patients), complete PD catheter exit site bandage changes, and respond to any questions from the participants. A 44-year-old, father of two children, and on PD for 1 year described his recent follow-up clinic appointment.

P8: So if I had a question, there’s the answer. The cloudiness, they explained to me what that was. The microfibers, they explained to me what that was. They showed me how the tube is in there and how it works. If you're on your one side, little twerks or little, you know, if you are sitting on one side and you turn over, it can drain a little bit more because everything flushes that way.

Some participants described how nurses focused their assessments based on their individualized care plan (i.e. personalized plan that includes treatment and monitoring guidelines). For example, a retired 75-year-old participant on PD for 1 year who had one episode of peripheral swelling described his future clinic visits to always involve his nurse checking his legs for any signs or symptoms of swelling.

P2: Because the first time when I first went to the clinic, there was a bit of swelling there; so that kind of alerted her and she’s been checking me ever since.

Between participants’ regularly scheduled appointments, PD nurses also continued to provide comprehensive nursing care by being available through communication technologies. Most participants contacted their nurses by phone or email about issues involving dialysate solutions, troubleshooting with the dialysis machine, or when participants were having signs and symptoms of a PD catheter exit site infection. Participants thought they were receiving thorough nursing care even though they were connecting with their primary nurses through phone or email. The participants perceived that the PD nurses took the time to help them when they
needed them. One participant who consistently used email to communicate with his nurse and preferred email as his main method of communication stated:

   P1: [My nurse], she was really good. Emails, comprehensive. You talk to her about something and say I’ve really got a problem with this, can you find out? Most of the time she knew right away how to handle it…She was back to me with a full, not a vague thing or just do this. Do this but if this happens then do this. You know, given me, that’s what I want. A full picture. She was really good.

In addition, participants received comprehensive nursing care when they had issues with their PD therapy in relation to fluid balance (i.e. proper amount of water in the body). For example, the 44-year-old father who had been on PD for 1 year experienced fluid overload as a result of not using the correct dialysate solution. He indicated that the PD nurses thoroughly intervened when appropriate. The PD nurses followed-up with him for three days after the incident to ensure that he was not experiencing any further signs and symptoms of excess fluid in his body:

   P8: I went to bed one day and I felt that fluid build up in my chest, so I ended up parking myself on the couch and sitting up sleeping and woke up and I phoned them the next day and told them what had happened. They asked me to come down there right away. They did some tests and all that and they told me what to do. ‘We will increase your 4.25% to all day and try to drain out the fluid and all that’. They called me three days in a row to make sure everything was fine and that sensation was gone.

Organizational Influences of Primary Nursing

The experiences of the participants highlighted that they were receiving individualized care and comprehensive nursing care by different PD nurses. In addition, participant experiences illustrated that the primary nursing core elements of continuous and coordinated nursing care were not being implemented by the PD nurses. The reason why the PD nurses did not provide continuous or coordinated nursing care was not because they intentionally chose not to, but because their nursing practice was inhibited by how the PD clinic organized care for its patients. Various organizational influences affecting primary nursing in the PD clinic such as PD nurse
availability and operational hours of the PD clinic became apparent when participants needed assistance with their PD or during the process for a kidney transplant. The lack of primary nurse availability led participants to encounter multiple nurses throughout their experience as a PD patient, which led to feelings of mistrust and dissatisfaction with their healthcare team. In addition, the challenging PD clinic hours prevented participants from getting help from their primary nurse, often leaving the participants to navigate the healthcare system by themselves and struggle with their self-administration of PD therapy.

**PD nurse availability.**

The participants noted that their care was not usually provided consistently by the same nurse, and many had encounters with multiple nurses throughout the course of their PD care. They described how they learned that the PD clinic regularly implemented nursing shift rotations that prevented the PD nurses from working all five days of the work week. Participants began to realize that their primary nurses did not work on specific days because they were not able to contact them. For example, a 75-year-old retired participant who was on PD for 1 year noted the following observation:

*P2: [This nurse] doesn’t work Fridays and [my nurse] does... Monday, [this nurse] is in and [my nurse is not]. [My nurse only works from] Tuesday to Friday.*

Participants indicated that because of their experiences of not being able to reach their primary nurses in the PD clinic during operational clinic hours, they were unsure of who to go to for help. Participants wanted a single person who they could contact in order to ensure continuity in their care (Marram et al., 1979) as illustrated by a 69-year-old retired participant who was on PD for 3 years.

*P14: I mean it would be nice if you had a sort of a designated go-to person. But I realize that’s not possible with shift work and that and turnover and so all I would ask is that there be good continuity.*
The discontinuity of not being able to connect with a primary nurse impacted the participants’ trust in their care. Participants described experiences where they were hesitant to trust the information they received from someone other than their primary nurse when it came to selecting the correct dialysate solutions. Participants felt uncomfortable and often questioned the accuracy of the information as illustrated by the following participant:

P14: Well, you are wondering if they are telling you the right thing... The previous [primary] nurse was telling you to do one thing and then the second one is telling you to do something that might be conflicting a little bit. So, it does sometimes get a little confusing that way.

In addition, when participants received nursing care from someone other than their primary nurse the discontinuity in their care was further revealed. Participants suggested that the nursing standard of care was different from one nurse to another. For example, a 27-year-old male on PD for 2 years described his experience during a follow-up appointment where his care plan was not being followed as prescribed by a new nurse.

P10: It was in the morning and [my nurse] wasn’t there that day and she was supposed to do the dressing change and whatever. It was some other nurse... and she told me she was from [another hospital], and she normally doesn’t do this type of thing. I was like I don’t know, should I come back tomorrow? She was like ‘oh yeah come back tomorrow’. I was about to leave and then I think the [person who organizes the unit] was like no, no, no, you have to do it. I could tell [the nurse] either didn’t want to do it or wasn’t confident in herself. That day she didn’t take down any of my numbers...she didn’t give me the [containers] either.

Furthermore, the work schedules of the PD nurses affected coordinated nursing care of the participants. Coordinated nursing care occurs when a single nurse (primary nurse) organizes the plan of care for the patient and advocates on behalf of that patient as the central point of contact for other interdisciplinary teams (Marram et al., 1979). The inability of the participants to contact their primary nurses because they were not available highlighted the work schedules of the PD nurses as being a significant organizational influence of primary nursing. Participants
regularly described their frustrations about the process for receiving a kidney transplant and assumed that their primary nurse was not organizing the kidney transplant process as illustrated by the following participant.

P3: I don’t know. I mean the only thing that’s kind of missing is more information about the transplant. I think that whole process is really frustrating…I don’t know if the nurses have any, you know, they don’t really have any role in that. But it doesn’t seem like there is any, like it seems very separate.

Another participant who had CKD for over 12 years, transitioned from hemodialysis to PD, and only had the kidney transplant as his last renal replacement therapy option further emphasized the lack of coordinated nursing care. The absence of his primary nurse in ensuring that all healthcare team members were up to date with information related to his kidney transplant application illustrated the disconnection between the PD clinic and the kidney transplant team.

P14: And the things that I tell them [PD clinic] sometimes come as a surprise. You know, they [say] ‘Oh, really, never knew that’. Well, you know, as far as I am concerned it was documented. It should have been on record.

**Operational hours of the PD clinic.**

Another organizational influence of primary nursing was the operational hours of the PD clinic. According to the participants the PD clinic operated between Monday to Friday 8am to 4pm. For any non-urgent help outside of the PD clinic’s operational hours, participants followed instructions previously given to them by their primary nurses or left a message on the PD clinic’s voicemail system and waited for their primary nurse to contact them back when the clinic reopened. Participants often felt frustrated and upset about how the PD clinic organized their nursing care which is illustrated by the following quotes:

P2: Well I know that I’m supported all the time except for the weekends.

P12: I mean it’s just a recording, so I have to leave a message. If it’s on the weekends, forget about it…nobody is there.
If participants urgently needed help with their PD outside of the PD clinic’s operational hours, they contacted nurses from the inpatient kidney unit; which was open 24 hours a day seven days a week. Similar to the findings related to participants having multiple PD nurses, the participants described a lack of trust and doubt in the inpatient kidney unit nurse’s abilities to provide nursing care because the participants were not familiar with any of the nurses. One participant described her frustrations about contacting the inpatient kidney unit nurses in the following quote:

P10: I always ask, like when I call them, like ‘can I get a nurse that understands PD?’. Most of the times if they don’t know, they actually pass it off to someone else.

Although the inpatient kidney unit nurses presumably had the knowledge to assist the participants with their PD, it was evident from their experiences that information about the participants’ PD therapy or dialysate solutions were not known by the inpatient kidney unit nurses. The following examples illustrate the oversight of primary nurses from the PD clinic not sharing their patients’ care plans with the nurses from the inpatient kidney unit.

P2: I just thought I hope they know what they’re doing...I mean you don’t know the people, you don’t work with them everyday...it’s a one off every time, so you don’t know who the hell you’re talking to.

P5: I can phone the hospital. I can phone the nurses that are in the bed area; where people are lying. So, I can talk to them a little bit but of course it’s difficult...they really don’t know me.

Participants wanted a nurse that knew them so that they could feel comfortable and that their care plans would be followed for continuity of care (Marram et al., 1979).

P5: I only think the problem, they close their door at five o’clock on Friday and they come back on Monday. I think that’s not really good. Somebody should be there over the weekend; somebody who knows you and you feel comfortable with talking to them.

In addition to the participants contacting the inpatient kidney unit, participants were informed to contact the PD supply company as an alternative by their primary nurses outside of the PD
clinic’s operational hours. Although the participants reported that their primary nurses were confident that the PD supply company could offer urgent help to the participants, this was not the case for some of the participants. Calling the PD supply company only increased discontinuities in their nursing care.

P3: I always just felt the whole process frustrating because sometimes [the PD supply company] couldn’t help me and I had to call the [nursing unit]. I’ve got medication in me for sleeping, it’s the middle of the night, you know, I’m anxious about what is going to happen and the other person on the line, this nurse that I was talking to just didn’t seem to get what I was talking about and I was getting kind of impatient.

Navigating through the challenges.

In an effort to overcome inconsistent nurses and challenging operational clinic hours, participants navigated through the organizational influences. Participants were creative in overcoming the challenges with how the PD clinic organized its nursing care and operational hours. Generally, participants described that in order to navigate through the complexity of how the PD nurses structured its support for patients, they consistently did not follow the previously agreed upon process of getting help (e.g. contacting primary nurses or contacting inpatient kidney unit). The participants found feasible alternatives to get help promptly and address the issue of timeliness and responsiveness of the PD nurses during the PD clinic’s operational hours.

Most participants deliberately chose not to contact their primary nurses first because of their prior experiences of not being able to reach them. Participants who wanted help right away and almost instantly generally mentioned that they would call all the PD nurses one by one until they reached any PD nurse directly. While the PD clinic was open, timeliness and responsiveness became important for the participants. Participants wanted an immediate response from a PD nurse. It was common for participants not to leave messages for their
primary nurses as illustrated by one participant who spoke about her thought process when needing help for her PD therapy.

P9: Whoever can answer my phone [call], I start from the top. Whoever answers...If nobody answers, then I put it [phone] down because otherwise they will put it on answering [machine]. Then by the time they come back, I have been already helped by the other nurse.

Some participants even discovered that there was an employee of the PD clinic during operational hours that understood the healthcare system and had multiple connections to each of the multidisciplinary team members in the PD clinic. Participants utilized the position of this specific employee by directing any requests for PD related help to this person (bypassing the nurses), confidently knowing that a nurse would get the request and must respond to the participant. The participants used this employee as a broker during operational hours of the PD clinic.

P1: I said to [her] ‘send it to whoever cares and whoever can answer the question’...[she’s] the one that is there at the desk, [she’s] fielding the calls, [she’s] talking, and [she] can forward [it] to anybody [she] wants. So she [is] the point of contact. It was logical. I don’t know why the clinic didn’t figure it out...But other [nurses], if I phone, well it’s hard to get through to somebody...

In addition, some participants illustrated that because they were worried about the trustworthiness of the information they received from nurses who they did not normally interact with, they ultimately bypassed them for help. Participants often bypassed nurses who they did not know or who were new to the PD clinic. Participants wanted nurses who could provide their nursing care safely without hesitation as described by the following participant:

P1: So if I find a nurse is uncomfortable with what they’re telling me and I feel they’re not confident or whatever, and it doesn’t make too much sense, I will bypass them. I won’t ask them next time. I’ll go to somebody else.

Furthermore, the inability of participants to connect directly with their primary nurses outside of operational clinic hours led participants to come up with their own solutions for PD
therapy. Participants opted not to connect with the inpatient kidney unit nurses because they did not know them or did not trust the advice from the nurses. Participants were aware that their solutions were not conducive to safe PD, but had no other option especially when they did not have the required PD supplies. One of the participants described an experience when he knowingly set up his dialysis machine incorrectly simply because he had insufficient PD supplies and could not get in contact with his primary nurse and the PD supply company was unable to help him.

P6: I used one of the twin bags and I wasn’t supposed to do that apparently, but I did it anyways and it worked fine…Of course after hours [the PD supply company] wouldn’t be able to help me either.

Summary

Overall, participant experiences highlighted that they received individualized care and comprehensive nursing care but consistently encountered different nurses and challenging clinic hours. The presence of multiple nurses and strict operational clinic hours inhibited the participants from receiving continuous and coordinated nursing care from their PD nurses. Therefore, participants formed feelings of mistrust and dissatisfaction with their healthcare team. Consequently, the participants navigated through the organizational influences of primary nursing in order to continue their life sustaining PD therapy.
CHAPTER FIVE: DISCUSSION

Patients who self-administer their PD therapy are often educated and trained by nurses who specialize in PD. A multidisciplinary team comprising of physicians, dieticians, and social workers monitors PD patients’ CKD progression and provide psychosocial support in addition to the nursing care these patients receive. Currently, literature supports primary nursing as the ideal model of care to support patients living with chronic illnesses, particularly in outpatient settings (P. Johansson et al., 2015; Jost et al., 2010). However, very little is known about the experiences of patients who self-administer their PD therapy within an outpatient setting. Understanding the experiences of this population will facilitate the potential improvement in their care, specifically around the overall nursing practice for PD patients.

In this chapter, I discuss the contributions of my research study within two main areas: the experiences of PD patients and primary nursing in an outpatient clinic context. I outline opportunities for future research and include potential implications for improving nursing practice. In addition, I conclude with a brief overview of limitations associated with my research study.

Summary of Key Findings

In this current study, I interviewed participants from the St. Paul’s Hospital PD Clinic in order to understand their nursing care experiences as a PD patient. Through my thorough analysis of data, I found that participants consistently experienced two core elements of primary nursing from multiple nurses, individualized care and comprehensive nursing care. These core elements are underpinned by the philosophy of patient-centred care (Figure 1), where the goal of nursing care is to focus on the physical, mental, and emotional needs of the patient throughout the nurse-patient interaction and ultimately, the entire nurse-patient relationship.
Figure 1. Relationship Between Primary Nursing and Patient-Centred Care

![Figure 1. Schematic diagram of research study findings depicting the inter-relatedness between the patient, patient-centred care philosophy, and primary nursing core elements.](image)

The combined experiences of the participants help to emphasize that nurse-patient relationships between PD patients and PD nurses form during the interactions that involve individualization of care. The PD nurses leveraged the meaning of patients as experts (Institute for Patient and Family Centered Care, 2016) where the participants were the best individuals to know what would and would not work for them in terms of their learning, ability to travel, or physical limitations. The nurses’ willingness to adapt PD education and training formed the foundation for the participants to trust their nurses, an essential element in the nurse-patient relationship (Moscato et al., 2007).

In addition, findings from the study further support that primary nursing facilitates trust in the nurse-patient relationship because a bond is created between the patient and the primary nurse. The experience of patients being assigned a primary nurse fills a gap that literature notes is unique to the context of primary nursing in an outpatient setting. Primary nurses are the main point of contact for patients. If patients have questions or need assistance, they contact their primary nurse. The act of patients contacting their primary nurses is reflective of the unique
relationship that patients have with their primary nurses. Therefore, primary nursing becomes a relationship that symbolizes a “life-line” for the patients, where only primary nurses can provide help to the patient because they know unique nuances about the patient and their care.

The complexity of the nurse-patient relationship is highlighted as the relationship between patients and nurses progresses. Based on the experiences of the participants in the study, nurses were perceived to be competent and knowledgeable (i.e. experts) not only because they were able to tell the patients what type of dialysate solution to use but also because the nurses remembered personal things about the patients. Patients want to be humanized. Patients want nurses who know them at the personal level. Nurses who can incorporate personal information about their patients while providing assistance for their medical needs are imperative to the nurse-patient relationship (Bertakis & Azari, 2011; Cann & Gardner, 2012; Kahn et al., 2007; Su et al., 2009; Tucker et al., 2011; Wolf et al., 2008a). Patients want nurses who listen to them, include them in the decision-making process, and most importantly, attend to their feelings (Moscato et al., 2007).

Furthermore, findings from the current study acknowledge the complexity and ambiguity of implementing professional boundaries within the nurse-patient relationship. The College of Registered Nurses of British Columbia (2017) describes professional boundaries as the behaviours that represent what is and is not considered professional. Any behaviour potentially considered as not professional would be outside the professional boundaries of a nurse-patient relationship, such as entering into a friendship or romantic relationship with patients (College of Registered Nurses of British Columbia, 2017). The PD nurses’ attempts to get to know their patients and create trust led the nurses to share personal information about themselves to their patients. A similar situation was found in the literature where nurses provided their personal
mobile numbers to their patients in case of an emergency in an outpatient clinic (Ehrlich, Kendall, & Muenchberger, 2012). The personal disclosure of outside work activities and family dynamics of the PD nurses to their patients may be considered outside the professional boundaries of a nurse-patient relationship because the information may not be considered a pre-requisite for providing care to patients. Despite this potential perception of the PD nurses’ personal disclosure, the sharing of personal details was not discussed by the participants as being unprofessional. Instead, participants saw the sharing of personal details as fostering a respectful, meaningful, and trusting relationship—all of which have been reported as essential to a positive nurse-patient relationship. Although it is uncertain as to what the intentions were of the PD nurses when they shared their personal information with their patients, it appears that they might have been relating on a very social level, building trust, and communicating a holistic approach to engaging with their patients. These findings illustrate that further research exploring patients’ and nurses’ perspectives and experiences about professional boundaries is warranted to assist in improving our understanding of the relationships and professional boundaries between nurses and patients.

In addition to the findings that fill the gap in literature about nurse-patient relationships in outpatient PD clinic settings, findings from the study illustrate challenges in the implementation of a fully integrated primary nursing care delivery model. Current literature indicates that various forms of the primary nursing model exist in different healthcare settings. However, there is limited information about the reasons for the multiple variations of primary nursing (Marram et al., 1979; Mattila et al., 2014; Shirey, 2008; Wong et al., 2010). The St. Paul’s Hospital Outpatient PD Clinic organized nursing work in a manner that impacted the traditional
implementation of primary nursing. In particular, the primary nursing model at that time lacked the 24-hour specific PD nursing coverage and nursing care from the *same* primary nurse.

Multiple factors may have contributed to the healthcare organization’s decision to implement a modified primary nursing care delivery model. The logistics of nursing availability and operational hours of the PD clinic may have contributed to the participants not receiving care from their assigned primary nurses. Potential logistics include the healthcare organization’s duty to permit nurses’ vacations, incorporating different nursing work schedule rotations, not replacing nurses when they call in sick, or limiting the number of nurses in the PD clinic at any one-time due to operational needs and financial budgets. Another factor could be the healthcare organization’s commitment to prevent burnout of their healthcare staff, specifically nurses. Nurses may have been rotated across different patients as a primary nurse to balance the nursing workload required from different patients.

Because of the aforementioned logistics, patients made explicit attempts to overcome the organizational challenges they encountered with the implementation of the primary nursing model. The attempts of the patients are reflective of their desire to connect with a nurse that knows and understands them at the personal level. Various authors have addressed the idea of clinical intimacy and emotional proximity as a situation in which individuals prefer to mutually share information with other individuals (Groysberg & Slind, 2012; Kirk, 2007). The inability of patients to connect with a nurse that understands them can lead to mistrust and the perception that other nurses are not competent or knowledgeable. Gaining knowledge of how patients navigate through the organizational influences can assist nurses in creating a better care plan for their patients that focuses on what patients find important. In addition, healthcare organizations
can use the same knowledge to revise the organization of their nursing care to better promote patient-centred care practices within the primary nursing model.

**Research Recommendations and Implications**

This research study highlights several future research opportunities that have the potential to improve the nursing care and experiences of patients who self-administer their own PD therapy. Future research opportunities may include the relationship between the health outcomes of PD patients when using a specific primary nursing care delivery model or patient satisfaction of PD patients in settings outside of an outpatient PD clinic. In addition, it is vital to initiate qualitative research looking at how nursing care is provided from the perspective of nurses and nurse leaders. Gaining the perspectives of nurses and nurse leaders will facilitate a better understanding of how nursing care is delivered to PD patients. In addition, findings from my study can help to build the foundation for future research analyzing the process of how nurses apply their professional and practice standards within the nurse-patient relationship.

Furthermore, findings from my research study and the Institute of Patient and Family Centred Care (2016) support research involving family perspectives. Understanding family perspectives in conjunction with patient perspectives is essential because patients are understood within the context of their families, which is vital to patient-centred nursing care.

Additional research opportunities exist at the nursing secretariat and hospital senior leadership levels. The British Columbia Ministry of Health documented a positive relationship between decreasing healthcare costs and the implementation of patient-centred care practices (2015). In order to better understand how nursing policy and organizational practices affect nursing care of PD patients, it would be helpful to conduct both qualitative and quantitative research studies of nursing secretariats and hospital executives who make decisions affecting
such care. Gaining the perspectives of these individuals could facilitate the initiation of quality improvement initiatives in areas of patient care management, nursing practice, organizational practice, and implementation of patient-centred nursing care delivery models.

**Study Limitations**

There are some limitations within my research study. The findings were limited to the experiences shared by the participants who participated in the study. There was potential that I may have missed out on the experiences of participants who elected not to participate or those who were lost to care because the only participants that were in my research study were those who maintained contact with the PD clinic. As my inclusion criteria included those who spoke English, my research study could have been further strengthened if I included participants who did not speak English. The experiences of participants who did not speak English could have added more insight into my findings and add an additional layer of analysis where communication was a vital element in the nurse-patient relationship. In addition, participants who received a kidney transplant and were previous PD patients were not included in my research study. Their insights and experiences could have been different than the participants who participated because these patients were no longer being cared for by the PD nurses.

**Conclusion**

Available literature has chronicled the experiences of patients with their nurses; however, most of these studies have not included patients who administer their own PD therapy. As a result, there has been very little known in the literature about the nursing care experiences of PD patients. More specifically, there has been a gap in literature about PD patients who are cared for under a primary nursing care delivery model. In this study, I have addressed this gap by interviewing 15 participants who self-administered their own PD therapy.
Data illustrated that PD patients were receiving a modified form of primary nursing. The participants received individualized nursing care evident through PD education and training that was tailored to meet their individual needs, and comprehensive nursing care evident through the patients receiving thorough assessments and interventions from their PD nurses. However, the organization of nursing care within the PD clinic inhibited the participants from receiving all the core elements of primary nursing. The lack of 24-hour PD nursing coverage (secondary to PD clinic operational hours) and PD nurse availability led the participants to experience discontinuity in their nursing care and a lack of coordinated care between different healthcare teams. Participants had to regularly navigate through these unforeseen organizational challenges that affected the administration of safe PD therapy.

In addition, data illustrated that the participants experienced a relational aspect of nursing care in which the modified primary nursing care they received was underpinned by a philosophy of patient-centred care. Participants built clinically intimate relationships with their PD nurses, which fostered trust for an effective nurse-patient relationship and symbolized a life-line for the participants. However, the nurse-patient relationship described by the participants also highlighted the ambiguity of professional boundaries between patients and nurses. Participants saw their PD nurses as more than professionals; rather, they also saw them as friends.

Although there were limitations to my research study, my findings have the potential to improve the nursing practice of PD patients. Findings from future research involving the analysis of health outcomes, family perspectives, and nursing leadership perspectives can be used to inform potential solutions to better the nursing care experiences of PD patients. Overall, my findings have filled a gap in literature about primary nursing within the context of the PD
patient population—a population that emphasizes the unique attributes of the nurse-patient relationship.
REFERENCES


APPENDICES
Appendix A: Recruitment Flyer

Exploring the Healthcare Experiences of Peritoneal Dialysis Patients with their Nurses

Are you interested in sharing your experiences as a Peritoneal Dialysis patient?
Principal Investigator: Dr. Vicky Bungay
Co-Investigators: Nathaniel Roxas, Dr. Sally Thorne & Dr. Alison Phinney

You may be eligible to participate in a research study

What is Involved?
- One interview in the spring of 2016 (lasting 1-1.5 hours)
- A potential follow-up interview in the spring of 2016 (lasting 30 minutes-1 hour)
- $25 in the form of a gift card as an appreciation of your participation, per interview
- Questions will be about your experiences as a peritoneal dialysis patient in the St. Paul’s Hospital PD clinic and the interactions with your nurses

Study Objectives:
- To better understand the experiences of peritoneal dialysis patients of their nursing care
- To share what we learn from peritoneal dialysis patients so that we can better meet the needs of patients who self-administer their own peritoneal dialysis therapy

Who is Eligible?
- Adults, 30-75 years of age, who independently administer their own peritoneal dialysis therapy, and have been a PD patient at the St. Paul’s Hospital PD Clinic for at least 6 months

If you are interested in taking part in this study or for more information, please contact Nathaniel Roxas at xxx-xxx-xxxx or xxx.xxxxx@alumni.ubc.ca, or Dr. Vicky Bungay at xxx-xxx-xxxx
Appendix B: Interview Guide

A. Introduction:
Thank you for participating in this study and sharing your experiences, memories, and thoughts with me. To get us started I thought it would be helpful to start by getting to know one another.

1. Tell me about yourself. An example, where do you work? How long have you worked? When did you retire?
2. Please describe for me a little bit about your health. For example, when were you diagnosed with chronic kidney disease?
   Probe: What was it like to be diagnosed with chronic kidney disease? What did your healthcare providers say when you were diagnosed?
3. How long have you been a PD patient for? How did you come to be using PD?
   Probe: Tell me what happened after you were diagnosed with chronic kidney disease. How did you find out about PD? Who spoke to you about PD?

B. PD Patient Experiences
In the next few questions I would really appreciate hearing more about your experiences at the St. Paul’s Hospital Peritoneal Dialysis Clinic, specifically your interactions with the nurses.

1. When did you start being a patient in the St. Paul’s Hospital PD clinic?
2. As you know, I am interested in learning about your experiences within the PD clinic. What kinds of things happened in the first few visits?
3. Walk me through a typical week at home on PD. If you can, tell me what you did over the past week on PD.
   Probe: How did you decide to do that? What made you do that? Who did you contact?
4. Please describe for me, if you can, how you and the nurses work together in relation to your PD?
   Probe: How often do you connect with/visit the nurses in the clinic? What sort of things do you and your nurse do together?
5. What are your experiences as a PD patient with your nurses?
   Probe: Tell me about your most recent interaction with your nurse in the PD clinic, tell me what you and your nurse talked about, tell me about a time when you spoke to one of the PD nurses
6. Please describe for me what your perspectives are about your relationships and interactions with the nurses. For example, can you describe a time when you had to contact the nurses for help?
   
   **Probe:** How would you describe your relationships with the PD nurses?

7. When have you had to contact your nurse for help? What did you need help with? How has your nurse helped you? What happened when you contact them—please describe this for me.

8. If you had the opportunity, what advice would you give to nurses taking care of PD patients?

C. Specific Questions

   a. I have done \( x \) other interviews so far and most of the participants talked about kidney transplant and I still don’t understand how it relates to PD patients, can we talk about this? Please describe for me in your experience how transplant relates to your PD treatment.

   b. Some of the participants spoke about their experiences over the weekend or when the PD clinic was closed, what does the weekend look like to you or what does it look like when the PD clinic is closed?

D. Closing Questions

   1. Thank you for sharing your experiences with me. Is there anything else that you want to add that we did not discuss in relation to your interactions with the nurses in the PD clinic?
Appendix C: Consent Form

Consent Form

Exploring the Healthcare Experiences of Peritoneal Dialysis Patients with their Nurses

I. STUDY TEAM - Who is conducting the study?

Principal Investigator:
Dr. Victoria Bungay, University of British Columbia, School of Nursing
Ph: xxx-xxx-xxxx, email: xxx.xxxxx@ubc.ca

Co-Investigators:
Nathaniel Roxas, University of British Columbia, School of Nursing
Ph: xxx-xxx-xxxx, email: xxx.xxxxx@alumni.ubc.ca

Dr. Sally Thorne, University of British Columbia, School of Nursing
Ph: xxx-xxx-xxxx, email: xxx.xxxxx@nursing.ubc.ca

Dr. Alison Phinney, University of British Columbia, School of Nursing
Ph: xxx-xxx-xxxx, email: xxx.xxxxx@nursing.ubc.ca

II. SPONSOR - Who is funding this study?

None

III. INVITATION AND STUDY PURPOSE - Why are we doing this study?

Nathaniel Roxas, as part of the requirement for completion of the degree of Master of Science in Nursing is conducting a study with Dr. Victoria Bungay, Dr. Sally Thorne, and Dr. Alison Phinney, to better understand the healthcare experiences of peritoneal dialysis patients and the nurse-patient relationships from patients’ perspectives in the St. Paul’s Hospital Peritoneal Dialysis Clinic. We want to learn more about the interactions you have with your nurse(s) and your views on certain aspects of nursing care in hopes of informing future nursing care of peritoneal dialysis patients.

You are being invited to take part in this research study because you are a person between the ages of 30-75, who independently administers their own peritoneal dialysis therapy, and have been a patient at the St. Paul’s Hospital Peritoneal Dialysis Clinic for at least 6 months.
IV. STUDY PROCEDURES - *How is the study done?*

If you decide to take part in this research study, you will be involved in one interview lasting approximately 60-90 minutes. You will be asked some questions by Nathaniel Roxas in regards to your health care experiences as a peritoneal dialysis patient, with a focus on the interactions you have with your nurse(s) (e.g. What are your experiences as a PD patient with your nurses? When have you had to contact your nurse for help? How has your nurse helped you?). Your interview will be conducted in a location that you feel comfortable in, but still allows you to share your experiences without be interrupted. If needed, you may be invited for a follow-up interview at a later time lasting approximately 30-60 minutes in order to further understand and explore the experiences you shared in your initial interview. During your follow-up interview, you may be asked questions such as “You mentioned [x] in your prior interview, how has that affected your health? What could have been done better in relation to what you mentioned about your experiences with your nurses?”

The audio from your interview will be digitally recorded, transcribed to accurately record your views and opinions, and interpreted at a later date. An experienced transcriptionist employed by a professional transcription services company will transcribe the audio from your interview (i.e. the conversation between you and Nathaniel Roxas). The transcriptionist will not transcribe personal information such as your name or other individuals’ names if present in the audio recording. If you would prefer the interview not to be recorded, written notes alone will be taken.

V. STUDY RESULTS

The results of this study will be reported in a graduate thesis completed by Nathaniel Roxas. The main study findings may be published in academic journal articles and presented at research conferences. In presenting the findings, all identifying information will be removed and your responses will be aggregated with other participants to ensure that you cannot be identified by anyone who has knowledge of your health care at the Peritoneal Dialysis Clinic in St. Paul’s Hospital.

If you would like to receive a copy of the final report, you can let us know by contacting the researchers on this form, or by leaving your email address at the end of this form.

There are no plans to use any of the data (e.g. audio recordings, interview transcripts, and study findings) in the future for any other purpose other than this research study.

VI. POTENTIAL RISKS OF THE STUDY – *Is there any way being in this study could be bad for you?*

We do not think there is anything in this study that could harm you or be bad for you. As the interview will provide you with an opportunity to discuss your health care experiences, you will be asked questions that may seem sensitive or personal and may make you feel uncomfortable or emotional. Please let one of the researchers know if you have any concerns. In addition, you will receive information about free counselling services in the form of a take-home brochure prior to the start of the interview.
You can leave the interview at any time, and you do not have to answer a question if you do not want to. You can also withdraw your participation in the research study at any time without giving a reason and without any negative impact on your care as a patient or access to further services from the St. Paul’s Hospital Peritoneal Dialysis Clinic.

VII. POTENTIAL BENEFITS OF THE STUDY – What are the benefits of participating?

There are no explicit benefits to you by taking part in this study. However, the interview will provide you with the opportunity to share your unique experiences in a non-judgmental setting. The nursing care of peritoneal dialysis patients in the future may benefit from what we learn in this study.

VIII. CONFIDENTIALITY – How will your privacy be maintained?

All documents will be identified only by a unique code number and hard copies will be kept in a locked filing cabinet in the Principal Investigator’s office. Any information that may identify you or others (e.g. name) will be removed from any recorded data, computer files, or written documents. Any electronic copies of documents will be kept on the local hard drives of each researcher in the study team, password protected, and not uploaded into shared storage drives. Only the members of the research team (Dr. Vicky Bungay, Nathaniel Roxas, Dr. Sally Thorne, and Dr. Alison Phinney) will have access to the study data such as audio recordings and interview transcripts. Your name will not be included or in any way associated with data collected in the study. You will not be identified individually in any way in any written reports or academic presentations of this research.

All documents, hard copy and electronic, will be destroyed after a period of 5 years. For example, shredding of paper documents or permanently deleting electronic files.

IX. PAYMENT

As an appreciation of your involvement in the study, you will receive an incentive of $25 in the form of a coffee gift card or grocery store gift card. If you participate in a follow-up interview, you will also receive an additional incentive of $25 in the form of a coffee gift card or grocery store gift card.

X. CONTACT FOR INFORMATION ABOUT THE STUDY – Who can you contact if you have questions about the study?

If you have any questions or concerns about what we are asking of you, please contact Nathaniel Roxas at xxx-xxx-xxxx or xxx.xxxxx@alumni.ubc.ca or Dr. Victoria Bungay at xxx-xxx-xxxx or xxx.xxxxx@ubc.ca
XI. Who do I contact if I have any questions or concerns about my rights as a participant?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, you may contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free at 1-877-822-8598.

XII. PARTICIPANT CONSENT AND SIGNATURE

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your care as a patient or access to further services from the St. Paul’s Hospital Peritoneal Dialysis Clinic.

- Your signature below indicates that you have received a signed and dated copy of this consent form for your own records
- Your signature indicates that you consent to participate in the study

____________________________________________________________________
Participant Signature

__________________________
Printed Name of the Participant signing above

☐ Yes, I would like to receive a final report of this project. Please email me at:

___________________________________