

2021-11

Exploring the Perspectives of Hemodialysis Nurses in Supporting Patient Coping and Resilience: An Interpretive Description Study

Ortiz, Mia Maris

Ortiz, M. M. (2021). Exploring the perspectives of hemodialysis nurses in supporting patient coping and resilience: an interpretive description study (Master's thesis, University of Calgary, Calgary, Canada). Retrieved from <https://prism.ucalgary.ca>.

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Exploring the Perspectives of Hemodialysis Nurses in Supporting Patient Coping and Resilience:

An Interpretive Description Study

by

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A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE

DEGREE OF MASTER OF NURSING

GRADUATE PROGRAM IN NURSING

CALGARY, ALBERTA

NOVEMBER, 2021

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Abstract

Chronic kidney disease (CKD) is on the rise, as is the prevalence of people with end-stage CKD reliant on hemodialysis (HD) treatment. This is concerning as the burden of disease of CKD, especially in conjunction with HD, is substantial. From a literature review, there is a knowledge gap in HD nurses' perspectives in supporting patient coping and resilience. HD nurses spend the most clinical time with HD patients, in an ideal position to support patient coping and resilience. The initial research question was: "What are HD nurses' perspectives on supporting patient coping and resilience when caring for CKD patients receiving chronic HD treatment?" The qualitative methodology of Interpretive Description (ID) was used. Recruitment occurred at a provincial level within Alberta Kidney Care. Semi-structured interviews were conducted with HD nurses (Registered Nurses and Licensed Practical Nurses, $n = 12$) working in HD with ≥ 2 years of HD experience. In tandem with ID, Braun and Clarke (2004)'s method of descriptive thematic analysis was used in data analysis and code generation. During data collection, the research question evolved to: "What negotiations in care do HD nurses experience in striving to support patient coping and resilience for CKD patients on chronic HD treatment?" HD nurses experience four types: *nursing perspectives* \leftrightarrow *patient perspectives*; *medical care* \leftrightarrow *psychological care*; *professional boundaries* \leftrightarrow *therapeutic relationship*; and *organizational considerations* \leftrightarrow *patient-centered care*. Overall, moral distress was prevalent among HD nurses' negotiations in care. Tailored initiatives to alleviate these specific negotiations may help to assuage this moral distress.

Keywords: chronic kidney disease, hemodialysis, nursing, patient coping, patient resilience

Acknowledgments

My first heartfelt thanks must be to my supervisor, Dr. Eloise Carr. Thank you for your guidance and wisdom throughout the years—I am putting it lightly when I say I do not think I could have started, let alone complete, this journey without you. I am forever indebted to you for your steadfast support, friendship, and belief in me.

I would also like to express my profound gratitude to my supervisory committee members, Dr. Shelley Raffin-Bouchal and Richelle Forest. Thank you both for sharing your research and clinical expertise with me and for your unfailing patience, invaluable insights, and gentle encouragement throughout my thesis work. It was a joy to work with both of you.

Lastly, thank you to my loved ones: to my family, for whom I would not be who I am today; to Ricka (Ate) and Vivian, my ballasts of love and laughter; and to Amarveer, you will always be my heart.

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List of Abbreviations

AHS	Alberta Health Services
AKC	Alberta Kidney Care
AKC-N	Alberta Kidney Care-North
AKC-S	Alberta Kidney Care-South
CANNT	College & Association of Nephrology Nurses and Technologists
CARNA	College & Association of Registered Nurses of Alberta
CKD	Chronic Kidney Disease
CLPNA	College of Licensed Practical Nurses of Alberta
CNA	Canadian Nurses Association
HD	Hemodialysis
ID	Interpretive Description
LPN	Licensed Practical Nurse
PD	Peritoneal Dialysis
RN	Registered Nurse

Dedication

For Nicole, who first taught me that the kidneys were the poets of the body.

Chapter 1: Introduction

It is estimated that the current global prevalence of chronic kidney disease (CKD) is 13.4%, affecting at least 1 billion people worldwide (Hill et al., 2016). In Canada, over 4 million Canadians live with CKD, approximately 12% of the Canadian population (Arora et al., 2013). CKD denotes a wide range of etiological causes, the most common in Canada being diabetes, obesity, and cardiovascular disease (The Kidney Foundation of Canada [TKFC], 2019). Although CKD typically affects individuals over 65 years of age, the incidence of CKD in people 45 to 65 years of age has increased by 37% in the last decade (Turner et al., 2016). With the projected rise of diabetes, obesity, and cardiovascular disease in the Canadian population and across age cohorts, it is expected that CKD rates will also rise to reflect these trends (Arora et al., 2013; Turner et al., 2016). Internationally, CKD is also becoming increasingly widespread, rising 19.6% in prevalence in the last 15 years (Coresh, 2017).

Despite various management alternatives, end-stage CKD treatments are solely life-sustaining; even renal transplantation, although often the treatment goal, is regarded as but another form of renal replacement therapy (TKFC, 2019). However, most peoples with end-stage CKD are ineligible for transplant due to advanced age or pre-existing comorbidities and must therefore indefinitely rely other renal replacement therapies. These include therapies such as variations of peritoneal dialysis (PD) and hemodialysis (HD) treatment as well as conservative management (TKFC, 2019, 2020).

In PD, a catheter is inserted into the peritoneum, an abdominal lining within the body which acts as a filter between one's body and dialysate, a sterile fluid which is cycled in and out of the peritoneum by a peritoneal catheter (TKFC, 2020). While inside the body, dialysate helps remove internal wastes; dialysate containing body wastes is then drained from the body by the

peritoneal catheter and replaced with fresh dialysate, and the cleansing cycle repeats. This cleansing cycle is known as PD, removing wastes from the body that normal-functioning kidneys otherwise do effectively. There are two main types of PD: continuous ambulatory PD, where PD patients do dialysate exchanges by hand three to five times a day, and automated PD, which uses a machine to facilitate dialysate exchanges, which are typically done overnight (TKFC, 2020).

In HD, blood is taken from patients via an HD vascular access (a central venous catheter, an arteriovenous fistula, or an arteriovenous graft). This blood is cycled through a HD machine, which has a dialyzer that filters waste from the blood and removes fluid for HD patients who can no longer make urine. Cleansed blood is then returned to the patient and the cycle repeats for the prescribed treatment time. There are typically two types of HD: home HD, where HD patients conduct HD at home four to six times per week for six to eight-hour overnight treatments, and dependent or in-center HD, where HD patients go to a satellite clinic or hospital unit for HD treatment. Most patients on in-center HD treatment are on a conventional HD schedule, where patients go for HD treatment at set intervals during the week; however, some patients are on a nocturnal in-center HD schedule, where patients go for treatment at set overnight intervals during the week (Alberta Health Services [AHS], 2020a; TKFC, 2020).

Outside of renal replacement therapies, end-stage CKD patients can also choose conservative management, which is a treatment plan that focuses on end-stage CKD symptom management exclusive of dialysis treatment and transplantation. Conservative management treatment plans are primarily palliative, uniquely tailored for each patient to optimize quality of life, preserve remaining kidney function, manage symptoms of end-stage CKD that can reduce quality of life, and ultimately prepare end-stage CKD patients for end-of-life care (AHS, 2016).

In Canada, most people with end-stage CKD rely on HD treatment, a number which has increased by 31% over the last ten years (Turner et al., 2016; TKFC, 2019). This is concerning as the burden of disease of CKD, especially in conjunction with HD treatment, is much higher when compared to other similar chronic conditions (Gerasimoula et al., 2015; Luyckx et al., 2018; TKFC, 2019; Yong et al., 2009).

Conventional, in-center HD treatment comprises of four-hour treatments, three times a week, at an HD clinic (TKFC, 2019). This treatment schedule may vary, with many people necessitating longer or more frequent HD sessions for adequate treatment (TKFC, 2019). Common side effects of HD treatment include fatigue, nausea, urticaria, pain, and muscle cramping (Gerasimoula et al., 2015; Li et al., 2018). These side effects are not limited to the duration of an HD session, often becoming chronic issues for people with long-term reliance on HD (Gerasimoula et al., 2015; Li et al., 2018). In addition to this symptom burden, people on HD must also dedicate a considerable time commitment to balancing medical appointments, taking an assortment of medications, and attending time-consuming HD treatment, all while dealing with the side effects of CKD and HD (Gerasimoula et al., 2015). All these factors have a substantial negative impact on the quality of life for people receiving HD treatment, leading to a high incidence of depression, anxiety, and overall poor mental health in this population (Gerasimoula et al., 2015; Li et al., 2018; Yong et al., 2009).

A Personal Story: Arriving at the Topic of Patient Coping and Resilience

I am a Registered Nurse with a practice specialty in nephrology; in the six years of my nursing practice, I have specifically worked in HD care, providing care to people living with end-stage CKD. In my clinical work, I have witnessed both the psychological and physical afflictions of CKD and HD treatment, with present literature confirming the high burden of

disease associated with both. Throughout my practice, even as a student nurse and during my graduate studies, I have been passionate about improving care for this patient population, especially with supporting patients in coping with end-stage CKD and HD. Although I have always had an interest in this topic given my practice area, it now holds a personal investment following my own recent experiences with mental health, coping, and ongoing recovery.

In April 2019, I decided to take a medical leave from my graduate studies. Despite my academic progress and achievements in my research commitments, I was becoming increasingly unhappy and lethargic in my day-to-day life. Since starting the Master of Nursing program in 2017, I had sought to balance clinical work, graduate studies, research commitments, and various extracurricular activities, all without thought to potential deleterious effects on my mental health. I was ultimately diagnosed with depression in March 2019, which in turn led me to take a leave from my commitments for my mental health to recover.

In returning to my graduate studies, I felt compelled to address patient mental health in the context of CKD and HD treatment. Due to my recent experiences with depression and attempting to foster positive coping strategies, I became more aware of the importance of mental health, especially in the context of a chronic condition. Namely, how can healthcare professionals, especially those in nursing, support coping and mental wellbeing for patients? How do people with chronic conditions cope? What are effective coping strategies for patients with chronic conditions, and how can healthcare professionals better support these patients? These were the key questions I wanted to explore in my thesis work.

Patient Coping and Resilience with Chronic Kidney Disease and Hemodialysis

According to the American Psychological Association (APA), “coping” refers to “the use of cognitive and behavioral strategies to manage the demands of a situation when these are

appraised as taxing or exceeding one's resources or to reduce the negative emotions and conflict caused by stress" (APA, 2020a, p. 1). In turn, "resilience" is described as

...the process and outcome of successfully adapting to difficult or challenging life experiences [...] A number of factors contribute to how well people adapt to adversities, predominant among them (a) the ways in which individuals view and engage with the world, (b) the availability and quality of social resources, and (c) specific coping strategies. (APA, 2020b, p. 1)

From these definitions, it would appear that "resilience" is a result of one or more successful coping strategies to overcome stressors. Despite these nuances, much of current literature examining patient coping and coping strategies in CKD also explored patient resilience, making it difficult to conceptually demarcate between the two terms (Abdul-Kader et al., 2009; Gerasimoula et al., 2015; Harwood et al., 2009; Liu et al., 2018; Ma et al., 2013).

At present, there appears to be an extensive body of literature that explores patient coping, resilience, and quality of life in the context of CKD and HD. Patients have been noted to use a variety of approaches in dealing with the symptom burden of CKD and HD treatment. Common coping strategies in this population include increased reliance on social supports (Gee, et al., 2008; Harwood et al., 2009; Logan et al., 2006; Liu et al., 2018; Tong et al., 2009), use of religion (de Guzman et al., 2009; Ma et al., 2013; Soliman & Mawgoud, 2014; Yodchai, et al., 2017), and striving to become more knowledgeable about CKD and effective self-care (Harwood et al., 2009; Keskin & Engin, 2011; Liu et al., 2018; Ma et al., 2013). Many patients have cited that maintaining an overall positive outlook, as well as conserving strong social support systems, was vital in day-to-day coping with CKD and HD treatment (Gee et al., 2008; Harwood et al., 2009; Logan et al., 2006). Similarly, patients on chronic HD treatment have often attributed their

resilience and optimism, in the face of their chronic illness, to their spirituality and religious views (de Guzman et al., 2009; Yodchai et al., 2017). Another key coping strategy that patients appear to employ is maintaining control; across studies, patients have cited that becoming more knowledgeable about their condition and treatment helped them become more assertive with respect to their health (Logan et al., 2006; Yodchai et al., 2017). Overall, many patients did not employ just one coping strategy, often citing a blending of two or more coping strategies, such as the dependence on social supports from one's religious community (Yodchai et al., 2017).

Further still, coping strategies within this patient population have been typified into either active participation or avoidance of CKD (Harwood et al., 2009; Ma et al., 2013; Subramanian et al., 2017). In the former, people with CKD employ coping strategies which deal with acceptance of their condition, learning more about CKD and involving their social supports in their CKD experience, and actively participating in their continued care and respective treatment. Conversely, avoidant coping strategies allude to behaviours such as non-acceptance of the CKD diagnosis, non-compliance with treatment, and refusal to participate in personal day-to-day care. Generally, active participatory coping strategies have been associated with more long-term positive health outcomes (Gee et al., 2008; Harwood et al., 2009; Keskin & Engin, 2009, Liu et al., 2018, Logan et al., 2006; Ma et al., 2013; Soliman & Mawgoud, 2014; Subramanian et al., 2017; Tong et al., 2009; Yodchai et al., 2017; Yong et al., 2009).

A few contemporary studies have also explored predictive factors for active participatory versus avoidant coping strategies. Education level, socioeconomic status, gender, and the existence of health-promotive behaviours and stable social supports preceding CKD diagnosis have all been found to be somewhat predictive of which coping strategies patients will adopt once they are diagnosed (Ma et al., 2013; Subramanian et al., 2017). The trajectory of a patient's

CKD, relative symptom burden, and available treatment alternatives also seem to have some effect on patient coping styles (Abdel-Kader et al., 2009; Gee et al., 2008; Gerasimoula et al., 2015; Harwood et al., 2009; Ma et al., 2013; Subramanian et al., 2017). Although most studies call for further research on these predictive factors, it has been suggested that the most vital part of effective coping with CKD is patient flexibility and adaptability, as the illness trajectory of CKD and symptoms associated with treatment are prone to constant change (Ma et al., 2013; Subramanian et al., 2017).

The Nursing Role in Chronic Kidney Disease and Hemodialysis Care

Clearly, living with a chronic disease such as CKD and HD treatment creates an enormous burden of disease. Understanding the factors that contribute to patient coping strategies in this population enables nurses to better anticipate the needs of people living with CKD and HD treatment and provide more effective support to patients throughout their care and illness trajectory (Canadian Nurses Association [CNA], 2015; College & Association of Registered Nurses of Alberta [CARNA], 2013). Luckily, there appears to be extensive literature to date exploring patient coping, resilience, and general experience of living with CKD and its different forms of treatment.

Nevertheless, there are clear gaps in related literature, such as the coping styles of patients with pediatric-onset CKD (Tjaden et al., 2016). Conversely, perhaps the most glaring research gap involves a lack of healthcare professionals' perspectives and experiences of supporting patient coping and resilience in this patient population. This lack of research on healthcare professionals' perspectives, specifically nurses, is in sharp contrast to the abundant literature surrounding patient perspectives (Subramanian et al., 2017; Urquhart-Secord et al., 2016).

Among all healthcare professionals involved in CKD and HD care, nurses have the most contact with this patient population; nurses have the most direct and consistent contact time with patients through HD treatments and overall access to healthcare services (Dad et al., 2018; Nobahar & Tamadon, 2016; Shahgholian & Yousef, 2018). This puts HD nurses in a unique position. Over time, nurses can build an inimitable rapport with patients that allows nurses to both understand and empathize with patient needs and preferences in care (Dad et al., 2018).

According to CARNA (2019), Registered Nurses (RNs) are to “provide safe, competent, ethical, compassionate, client-centered, and evidence-informed nursing care [...] in response to client needs” (p. 7). CARNA also states that nurses are to “assist individuals, families, groups and communities to achieve their optimal physical, emotional, mental, and spiritual health and wellbeing,” (2013, p. 4) as well as “teach, counsel and advocate to enhance [client] health and wellbeing” (2013, p. 4). This nursing focus on holistic, patient-centered care is echoed as well by the College of Licensed Practical Nurses of Alberta (CLPNA) as well as the Canadian Association of Nephrology Nurses and Technologists (CANNT). As per the CLPNA, Licensed Practical Nurses (LPN) competencies include in-depth assessment and care for both the physical and psychological wellbeing of patients receiving ongoing care (CLPNA, 2020); similarly, CANNT stipulates the importance of nephrology nurses to encourage and facilitate positive coping strategies for patients with CKD throughout their disease trajectory (CANNT, 2014).

There is a clear, consistent focus across current nursing practice guidelines and regulatory bodies that allude to the importance of facilitating both patient resilience and coping as a means of quality care provision in ongoing care. In the context of chronic illness, as with CKD patients dependent on HD treatment, it is evident that effective quality nursing care includes promoting

patient mental health, safeguarding of patient quality of life, and moreover supporting patients in effective coping practices.

Hemodialysis Nurses and Care Provision

Optimizing coping and resilience for people with CKD appears to be a central component of their care, as supported by the considerable amount of literature on this topic. To date, there is extensive literature that has explored patient mental health, coping, and resilience in chronic illness (White et al., 2018). After an extensive review of related literature, White et al. (2018) were even able to create the THRIVE Framework, which details internal and external factors that patients use to cope and develop positive coping strategies in living with chronic illness. As per the THRIVE framework, these internal and external factors can be typified into five essential domains: *therapeutic interventions*; *habit and behavioral factors*; *relational-social factors*; *individual differences*; *values and beliefs*; and *emotional factors* (White et al., 2018).

Therapeutic interventions refer to treatments or initiatives enacted by third-party healthcare professionals, such as educational workshops, to help patients living with chronic illness from day to day. *Habit and behavioral factors* involve patient behaviours that promote or negate health and well-being (e.g., alarm-setting for medications, meditating, substance use) and *relational-social factors* concern the ways in which patients approach and maintain social relationships around them. *Individual differences* refer to patient characteristics (e.g., education level, sex, age) while *values and beliefs* more so allude to innate patient perspectives on life and illness experiences (e.g., religion, spirituality). Lastly, *emotional factors* deal with how patients process emotions and express emotional responses to certain situations (e.g., stress-avoidance). Aspects of the THRIVE Framework have also been observed with research on patient coping and resilience in CKD and HD (AlmatURY et al, 2013; Cukor et al., 2006). Overall, patient

perspectives on care provision in the context of CKD and HD have also been largely investigated (Subramanian et al., 2017; Urquhart-Secord et al., 2016). However, this lies in stark contrast to the limited literature that explores nurses' perspectives and experiences of supporting patient coping and resilience in the CKD and HD setting.

Study Rationale and Research Question

There are a substantial number of people with end-stage CKD reliant on HD treatment, a number which is predicted to increase. Across all healthcare professionals in contact with this patient population, HD nurses consistently spend the most amount of time with each individual HD patient. As such, nurses are in an ideal position to support these patients to cope with both the considerable burden of CKD and HD as well as its negative impact on their quality of life. Whilst there is a large body of literature around how patients cope and develop resilience in this context, less is known about how nurses understand these needs and the ways they feel they can support patients to cope and develop resilience.

The purpose of my thesis research study was to explore and gain further understanding of the nuances of HD nurses' experiences in care provision. Using the qualitative methodology of Interpretive Description, I intended to specifically address the research question: "What are HD nurses' perspectives on supporting patient coping and resilience when caring for CKD patients receiving chronic HD treatment?" Developing a better understanding of the nursing perspective on this topic—supporting patient coping and resilience with CKD and HD—can help to potentially identify and highlight similarities and incongruencies with that of the patient perspective.

Chapter 2: Literature Review

Learning more about hemodialysis (HD) nursing perspectives would enhance understanding of the nursing role in this setting and subsequently illuminate opportunities to better support HD nurses in care provision. Due to the unique role of nursing in HD patient care, nursing perspectives in chronic kidney disease (CKD) and HD would be invaluable to supporting and improving care for patients reliant on HD. To inform my thesis research study and its design, I conducted a literature review to answer the query: “What is known about the perspectives of HD nurses in providing nursing care to CKD patients receiving chronic HD treatment?” In this chapter, I will detail my search strategy as well as relay and discuss the literature review findings.

Literature Review Search Strategy

Compared to other types of literature reviews (e.g., systematic reviews, meta-syntheses), integrative literature reviews prioritize comprehensiveness of review of a subject matter over critical appraisal (Whittemore & Knafl, 2005). In doing so, integrative literature reviews ultimately serve to form a thorough understanding of a phenomenon to highlight gaps in knowledge and avenues for future research (de Souza et al., 2010; Torraco, 2005; Whittemore & Knafl, 2005). Following an initial literature search, it was noted that literature pertaining to HD nurses’ perspectives surrounding patient care were quite limited. To optimize comprehensiveness of synthesis, an integrative approach to the review was adopted.

An initial exploratory literature search served to examine the breadth of the topic of interest as well as determine commonly used keywords and subject headings by relevant literature. In conducting the literature review, key search terms were used for HD, nurses, and perspectives (Table 1). Combinations of these search terms were constructed using Boolean

terms (and, or) and used to search the databases of CINAHL, MEDLINE, PsycINFO, and ProQuest Global.

Table 1

Search Terms and Literature Databases

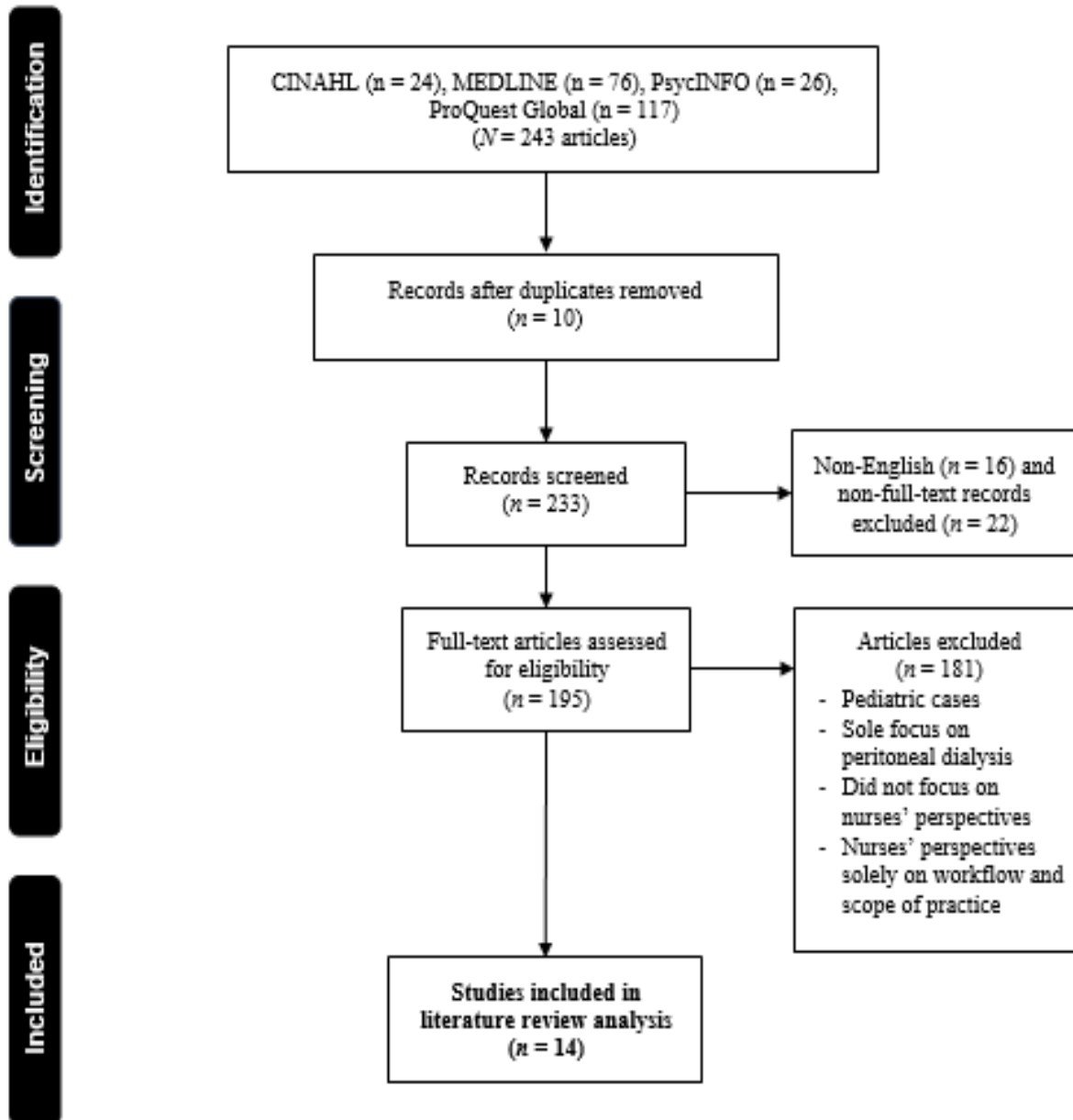
Query Terms	Subject Headings and Databases	Keywords
<i>Hemodialysis</i>	<ul style="list-style-type: none"> • CINAHL: Hemodialysis, Hemodialysis Therapy, Hemodialysis Care • MEDLINE: Renal Dialysis • PsycINFO: Hemodialysis 	Hemodialysis, Haemodialysis
<i>Nurses</i>	<ul style="list-style-type: none"> • CINAHL: Nurses, Nurse Attitudes, Nurse-Patient Relations • MEDLINE: Nursing Staff-Hospital • PsycINFO: Nurses, Nursing 	Nurs*
<i>Perspectives/ Experiences</i>	<ul style="list-style-type: none"> • CINAHL: Job Experiences, Work Experiences, Life Experience • MEDLINE: Stress-Psychological, Perception, Attitude, Attitude to Health, Culture, Emotions • PsycINFO: Perception, Attitude Change, Attitude Formation, Attitudes, Health Attitudes, Health Personnel Attitudes, Emotions 	Perspective*, Experience*, Perception*, Attitude*, Belief*, View*, Feeling*
<i>N/A</i>	<ul style="list-style-type: none"> • ProQuest Search: <i>noft = anywhere except full text</i> • noft(Hemodialysis OR Haemodialysis) AND noft(nurs*) AND noft(Perspective* OR Experienc* OR Perception* OR Attitude* OR Belief* OR View* OR Feeling*) 	

Inclusion parameters included full-text articles in English; original research, literature reviews, opinion articles, and dissertations; and literature focusing on nursing perspectives in relation to adult patient care (≥ 18 years of age) on chronic HD treatment. Literature that exclusively examined pediatric patients (< 18 years of age); other forms of renal replacement therapy (e.g., peritoneal dialysis); aspects of nursing workflow (e.g., nurse-patient ratios); nursing knowledge and competency assessment; and the perspectives of non-nursing healthcare providers were excluded from review. No parameters were set for publication date or nursing designation (e.g., Licensed Practical Nurses [LPNs], Registered Nurses [RNs]) to maximize yield of relevant literature.

The literature search returned a total of 243 articles (CINAHL = 24, MEDLINE = 76, PsycINFO = 26, ProQuest Global = 117); a PRISMA diagram (Moher et al., 2009) was used to track retrieved articles (Figure 1).

Figure 1

Prisma Diagram of Literature Review Articles



Following removal of duplicates ($n = 10$), non-English literature ($n = 16$), and literature with no accessible full text ($n = 22$), 195 articles were obtained. Reviewed literature which did not meet

the inclusion and exclusion criteria were either irrelevant to the topic of interest ($n = 85$), specifically examined aspects of nursing workflow ($n = 18$), or focused solely on patient perspectives on HD care provision or CKD illness experience ($n = 78$). Abstracts of these articles were reviewed for relevance, of which 14 articles met inclusion criteria for final review.

Of the 14 articles included in this literature review, 11 featured original research. Of the remaining articles, two articles were personal reflections or anecdotal accounts (Hughes, 2004; Luehr, 2013) and one article featured case studies (Doss et al., 2011). Reviewed articles that adopted a qualitative study design ($n = 8$) used phenomenology (Bevan, 2007; Deal & Grassley, 2012; Gronlund et al., 2015; Kim et al., 2016), content analysis (Morehouse et al., 2001), critical discourse analysis (Aasen et al., 2012), thematic analysis (Bourbonnais & Tousignant, 2020), and grounded theory (Woodcock, 1999) as methodological approaches to data analysis. Quantitative studies ($n = 3$) used statistical analyses to analyze data results from questionnaires (de Miguel, 2003; Wertz et al., 1977) or a validated tool (Huber & Tucker, 1984). Reviewed articles referenced both satellite and in-hospital HD treatment centers and were published primarily in North America (Bourbonnais & Tousignant, 2020; Deal & Grassley, 2012; Doss et al., 2011; Huber & Tucker, 1984; Hughes, 2004; Luehr, 2013; Morehouse et al., 2001; Woodcock, 1999) and Europe (Aasen et al., 2012; Bevan, 2007; de Miguel, 2003; Gronlund et al., 2015; Wertz et al., 1977), with one study from Asia (Kim et al., 2016).

Perspectives of Hemodialysis Nurses in Care Provision

The objective of this literature review was to explore what is known about the perspectives of HD nurses in providing nursing care to patients reliant on CKD and HD treatment. From the literature, two key themes emerged with respect to nursing perspectives in

CKD and HD patient care: (a) the nurse-patient relationship is central to nursing care provision in this setting and (b) nurses fundamentally considered HD patients from a holistic point of view.

The Nurse-Patient Relationship

A positive nurse-patient relationship has always been deemed essential to quality nursing care (College & Association of Registered Nurses of Alberta [CARNA], 2013, 2019, 2020; Luchsinger et al., 2019; Shigaki et al., 2010). This is especially true in the context of chronic illness, where an in-depth understanding of patients' medical history, clinical and psychosocial needs, support systems, and coping strategies are necessary to optimize patient health trajectories (Luchsinger et al., 2019; Shigaki et al., 2010).

According to Morse (1991), nurse-patient relationships can be typified into one of four forms: a clinical relationship, a therapeutic relationship, a connected relationship, and an over-involved relationship. The clinical relationship is typically formed when the nurse-patient interaction is brief; the nurse provides needed clinical care for the patient over a short time interval and the relationship ends after that encounter (e.g., a routine vaccination). As the nurse-patient relationship becomes more involved and complex, typically with repeated and consistent contact, the relationship becomes therapeutic and even connected; nurses are able to see patients as a "person first and a patient second" (Morse, 1991, p. 458), all while maintaining a professional relationship with the patient. When a nurse begins to lose a professional view on a nurse-patient relationship, the relationship then becomes over-involved (Morse, 1991).

In addition to the above, the nurse-patient relationship is also dynamic; transforming as the nurse and patient builds rapport over time and through repeated contact (Luchsinger et al., 2019; Morse, 1991; Shigaki et al., 2010). Nurse-patient relationships are established from an ongoing negotiation between involved parties until the relationship becomes mutually

satisfactory (Luchsinger et al., 2019; Morse, 1991). Albeit from different approaches, reviewed relevant literature all appeared to focus on the nurse-patient relationship as a central tenet of care provision in the context of HD, aligning with the consensus of related literature.

In a study by Aasen et al. (2012), HD nurses' perspectives on the clinical experiences of older HD patients and their next of kin were explored through semi-structured interviews. Aasen et al. (2012) noted that nurses were cognizant of the power differential between clinical staff and that of patients and their next of kin. In their care provision, HD nurses ultimately endeavoured to give patients and their families back this power over the patient's care direction by promoting self-care and attempting to educate and involve patients and their families in patients' CKD management and HD care. Nurses engaged in this negotiation of power through repeated contact and rapport-building with patients and their families during HD treatments.

Similar findings with Aasen et al. (2012) were reflected in the research conducted by Bevan (2007), Bourbonnais and Tousignant (2020), de Miguel (2003), Deal and Grassley (2012), Kim et al. (2016), Morehouse et al. (2001), and Woodcock (1999). In exploring the care experiences of both nurses and patients in satellite HD units, Bevan (2007) observed that nurses tailored their care provision with respect to knowledge of each patient's preferences and health status, thus exhibiting the use of the nurse-patient relationship to enhance patient care. Comparably, in examining nurses' experiences surrounding the assessment and management of patient pain in tertiary-care outpatient HD units, Bourbonnais and Tousignant (2020) found that nurses in their study heavily relied on individualized patient cues and comorbidities to effectively treat patient pain in the HD setting. The study by Deal and Grassley (2012), which focused on the lived experiences of HD nurses in giving spiritual care, also found HD nurses relating the importance of rapport- and relationship-building with patients in order to provide

effective spiritual care. Across multiple studies, HD nurses advocated for a palliative, quality of life-centered approach to nursing care for patients on chronic HD treatment (Bourbonnais & Tousignant, 2020; Deal & Grassley, 2012; Woodcock, 1999).

De Miguel (2003), Kim et al. (2016), and Morehouse et al. (2001) echoed these findings in their exploration of HD nurses' lived experiences in care provision. In the study by Kim et al. (2016), which analyzed interviews from nurses of two HD units in South Korea, HD nurses strove to build strong relationships with their patients; HD nurses expressed that maximizing patient comfort, during patients' HD treatments and everyday lives, was a primary goal in HD nursing care. Morehouse et al. (2001) observed that the nurse-patient relationship in the context of HD care was not dissimilar to a psychotherapeutic therapist-patient relationship. HD nurses believed that the nurse-patient relationship in HD required much more self-involvement as compared to other clinical settings (e.g., general medical and surgical units) (Morehouse et al., 2001). With repeated, consistent contact, HD nurses developed deeper interpersonal relationships with patients and provided more mental and spiritual support alongside clinical care in the HD setting (Aasen et al., 2012; de Miguel, 2003; Deal & Grassley, 2012; Kim et al., 2016; Morehouse et al., 2001; Woodcock, 1999). HD nurses believed that a strong nurse-patient relationship and subsequent quality nursing interventions could make a significant, positive impact on patients coping with the burden of CKD and ongoing HD treatment (Woodcock, 1999).

Supplementary to the original research articles discussed are the personal reflections and case studies included in this review. In their reflections of direct nursing care in the HD setting, Doss et al. (2011), Hughes (2004), and Luehr (2013) provide specific examples of how HD nurses cultivate and prioritize positive nurse-patient relationships. This rapport enables HD

nurses to fully engage with patients in pivotal moments of care, such as coping with sudden, long-term detrimental changes to health status and end-of-life conversations surrounding HD treatment cessation (Doss et al., 2011; Hughes, 2004; Luehr, 2013).

Despite the common focus of reviewed literature on cultivating positive nurse-patient relationships in HD settings, it appears that negative nurse-patient relationships can also play a central role in HD nursing care provision (Bevan, 2007; Wertz et al., 1977; Woodcock, 1999). In a quantitative study by Wertz et al. (1977), nurse-patient relationships in a chronic HD setting were analyzed using a personality inventory test. A key finding that emerged from the study was that both HD nurses and patients generally agreed on the characteristics of an “ideal patient”, which included attributes such as submissive, undemanding, consistently pleasant with healthcare staff and other patients, and adherent to medical recommendations (Wertz et al., 1977). HD nurses viewed patients who deviated from this profile as difficult and were at times provided a different, more clinically focused care approach by nurses as compared with non-difficult patients (Bevan, 2007; Hubert & Tucker, 1984; Wertz et al., 1977; Woodcock, 1999). Patients were largely aware of this phenomenon; some patients reported efforts to become that “ideal patient” while others accepted that their personality style and coping strategies did not fit those “ideal patient” characteristics (Hubert & Tucker, 1984; Wertz et al., 1977; Woodcock, 1999). HD nurses appear to adopt a more compliance-centered and medical-focused nurse-patient relationship with difficult patients as this was a more straightforward and facile approach to care provision (Bevan, 2007; Woodcock, 1999). It has been well-documented that an in-depth nurse-patient relationship in the chronic HD setting requires more time and personal resources (e.g., spirituality, empathy) from HD nurses (Deal & Grassley, 2012; Gronlund et al., 2015; Kim et al., 2016; Wertz et al., 1977).

It is worth noting that some of the articles discussed above, notably those by Hubert and Tucker (1984), Wertzel et al. (1977), and Woodcock (1999), are relatively older studies; contemporary HD nurses may differ in their perceptions, beliefs, and approach to care for “ideal” and not so “ideal” patients. Nevertheless, what is clear is that the nurse-patient relationship is a fundamental aspect of HD nursing care, irrelative of whether nurses maintain a positive or negative view of a patient and the subsequent nurse-patient relationship. The complexity and chronicity of the CKD illness trajectory and HD treatment gives rise to difficult care situations, in a clinical and at times ethical sense (Dad et al., 2018; Gronlund et al., 2015; Luchsinger et al., 2019; Shigaki et al., 2010). HD nurses heavily rely on the nurse-patient relationship to navigate these challenging care situations to provide the most effective, quality nursing care that they are able to offer to patients and their families (Gronlund et al., 2015).

Viewing Hemodialysis Patients from A Holistic Perspective

In addition to the importance ascribed to the nurse-patient relationship, HD nurses appear to consistently refer to their holistic view of patients when relating care experiences and perspectives of care provision in HD. This is perhaps most transparent in the personal reflections (Hughes, 2004; Luer, 2013) and anecdotal accounts of HD nursing (Doss et al., 2011) found in literature. An HD nurse, Hughes (2004) describes her interactions with a patient that vacillated between continuing or ceasing HD treatment based on the patients’ quality of life and medical and interpersonal issues. Hughes (2004) recounts the patient’s life history, personality traits, and social support system in addition to the patient’s health-related quality of life. The holistic care detailed by Hughes (2004) is further supported by Luer (2013) in their article. Luer (2013) expounds on the unique way HD nurses view patients, stating that there is much more interpersonal involvement between nurses and patients in the HD setting. Through repeated and

consistent contact, HD nurses become much more aware of patients' lives outside of CKD and HD, transforming the traditionally clinical lens of nursing care to a more holistic form (Aasen et al., 2012; Deal & Grassley, 2012; Doss et al., 2011; Hughes, 2004, Luer, 2013). As per Luer (2013):

The defined professional boundaries between nurse and patients that had been drilled into my head in nursing school suddenly became quite blurred. These [HD patients] knew my husband's name, my children's names, my cat's names and I knew about their families, friends and pets, too. I had patients give me handmade baby afghans and quilts when my daughter was born. I was the patients' nurse first and friend second. (p. 1)

This sentiment expressed by Luer (2013) was also repeatedly reflected in the case studies Doss et al. (2011) reported in their article, wherein HD nurses considered patients' individual coping strategies and psychosocial support in tandem with clinical presentation to tailor care provision. As an example, Doss et al. (2011) recounted a case study where an HD nurse was asked to train a relatively frail patient and their spouse on home HD, as per the request of the patient and the patient's spouse. Initially, the HD nurse refused to train the patient, believing that the patient was too physically frail to start the rigorous home HD training and continue with independent HD. However, the HD nurse decided to interview the patient and the patient's spouse regarding their personal reasons for wanting to try home HD for the short remainder of the patient's life. Ultimately, they agreed to train the patient on home HD; as the HD nurse came to know the patient, they began to understand how important it was to the patient and their spouse to maintain an independent life, together in their home. The HD nurse supported the patient in home HD, including the patient's spouse, in the patient's chosen HD modality until the patient's death a few months later (Doss et al., 2011).

From a more general perspective, research conducted with numerous HD nurses from various HD settings also complement one-on-one nursing experiences detailed by Doss et al. (2011), Hughes (2004), and Luer (2013). HD nurses fundamentally considered HD patients from a holistic point of view, even if this perspective was not largely reflected in nursing practice or everyday care (Aasen et al., 2012; Deal & Grassley, 2012; Gronlund et al., 2015; Kim et al., 2016; Woodcock, 1999). In the study by Deal and Grassley (2012), it was observed that HD nurses felt that providing spiritual care to patients and their families in the HD setting was an important aspect of quality nursing care. Despite this belief, HD nurses largely expressed reluctance in providing or even offering spiritual care; many nurses felt that spirituality was “deeply personal” (Deal & Grassley, 2012, p. 471) and were anxious of overstepping professional as well as patients’ personal boundaries (Deal & Grassley, 2012). Similarly, despite reflections on care provision which demonstrate HD nurses’ ascribed importance to patient mental health in tandem with clinical wellbeing in the HD setting, some HD nurses admit that they at times adopt a primarily clinical approach to patient care (Aasen et al., 2012; Gronlund et al., 2015; Kim et al., 2016; Wertz et al., 1977; Woodcock, 2019). Using a primarily clinical approach appeared to occur when nurses were confronted with ethically difficult care situations (Gronlund et al., 2015); nurses face time constraints in their work or are caring for medically complex patients (Bevan, 2007; de Miguel, 2003; Woodcock, 1999) and when HD nurses were caring for patients perceived to be behaviourally difficult or noncompliant to treatment (Aasen et al., 2012; Kim et al., 2016; Wertz et al., 1977; Woodcock, 1999).

Overall, literature to date has shown that nurses have an innately holistic view of patients and patient care needs in the context of CKD and HD. This holistic view could be a natural result of the repeated, consistent contact of HD nurses with their patients but may also be iteratively

related to the importance HD nurses place on the nurse-patient relationship in care provision. Nevertheless, there are evident, noted barriers to holistic nursing care in the HD setting. HD nurses need further support in removing these barriers so that nurses can provide the holistic care that coincides with their holistic view of patients reliant on CKD and HD treatment.

Implications for Further Research

This literature review sought to answer the following question: “What is known about the perspectives of HD nurses in providing nursing care to CKD patients receiving chronic HD treatment?” In the context of CKD and HD nursing care provision, as stated earlier, two key themes emerged from the literature: (a) the nurse-patient relationship is central to nursing care provision and (b) nurses have an intrinsically holistic view of patients and patients’ needs in this setting.

From the conducted literature search, 14 of 243 articles met the inclusion and exclusion criteria for final review. Of these 14 articles, six were published before 2005 (de Miguel, 2003; Huber & Tucker, 1984; Hughes, 2004; Morehouse et al., 2001; Wertz et al., 1977; Woodcock, 1999) and three articles were personal reflections or case studies (Doss et al., 2011; Hughes, 2004; Luehr, 2013). Most of the articles reviewed were published in the United States (Deal & Grassley, 2012; Doss et al., 2011; Huber & Tucker, 1984; Luehr, 2013; Morehouse et al. 2001).

Clearly, more current, original research is needed surrounding nursing perspectives in HD, specifically in the Canadian healthcare setting. The nursing scope of practice in Canada, especially in the context of chronic illness, has been in recent flux to accommodate changes in workplace environments and public health needs (Canadian Nurses Association [CNA], 2012; MacKinnon et al., 2018). In addition, while CKD and HD care approaches are similar between Canada and United States, there are still key differences between the two countries in terms of

healthcare professionals' roles and scopes of practice as well as care delivery (Mendelssohn & Wish, 2009). Nearly a third of the studies in this literature review collected data in the United States and may not reflect the uniqueness of the Canadian perspective.

Another prominent characteristic of the reviewed literature is the predominantly qualitative approach that the original research articles adopted. Only three of the 11 reviewed original research articles used a quantitative study design to explore HD nurses' perspectives (de Miguel, 2003; Huber & Tucker, 1984; Wertz et al., 1977). Although this methodological decision makes sense given the topic of interest, it is notable that half of the qualitative original research articles employed phenomenology (Bevan, 2007; Deal & Grassley, 2012; Gronlund et al., 2015; Kim et al., 2016). Traditionally, phenomenology is a qualitative methodology that focuses on exploring general lived experiences around a specific phenomenon or phenomena (Creswell & Poth, 2018). Further research employing methodologies that concentrate on practical perspectives surrounding clinical experiences may yield more insight into HD nurses' views in care provision, and thereby afford more opportunities to better understand and improve nursing care in the CKD and HD setting. An example of one such methodology would be Interpretive Description (ID), which specifically arose to better understand phenomena within the context of healthcare and healthcare provision (Thorne, 2016). An approach expressly tailored to explore clinical phenomena, ID may serve as a better methodology to generate unique insights in nursing perspectives specific to the CKD and HD setting.

In summary, more in-depth research was evidently needed in exploring HD nurses' perspectives in care provision, especially in the Canadian healthcare setting, using methodologies tailored to explore clinical phenomena. In their repeated and consistent contact time with patients reliant on HD treatment, HD nurses are in a unique position to assess, treat,

and support CKD and HD patients for the duration of their illness trajectory. I sought to address this gap in literature with my thesis research study, which I detail in the following chapter.

Chapter 3: Methods

For my thesis, my intent was to explore the nursing perspectives of care provision in the context of chronic kidney disease (CKD) and hemodialysis (HD) using Interpretive Description (ID). As detailed in Chapter 2, increasing knowledge around HD nurses' perspectives in care provision can highlight opportunities to better support HD nurses in providing care, help identify barriers to effective care provision in day-to-day practice, and may overall improve the care that patients receive in the CKD and HD setting. ID is particularly valuable as a methodological approach for nursing because it can provide understanding around the complexity of the clinical context.

Research Aim

With my study, my aim was to use the research methodology of Interpretive Description (ID) to conduct an in-depth exploration of nurses' perspectives in caring for CKD patients reliant on HD treatment, irrespective of their transplant eligibility. The study research question was: "What are HD nurses' perspectives on supporting patient coping and resilience when caring for CKD patients receiving chronic HD treatment?" In devising this research question, the parameter of "chronic" HD treatment was chosen to specify CKD patients whose chief renal replacement therapy is HD. As an example, some CKD patients primarily reliant on peritoneal dialysis (PD) develop short-lived issues, such as peritonitis, which necessitates a temporary switch to HD treatment; once these issues resolve, however, these patients return to PD and are thus not considered chronic HD patients.

Research Design

In terms of overall design, I used ID as the overarching methodology to approach recruitment, data collection, and data analysis. Individual semi-structured interviews were used

to collect data, which I then transcribed and analyzed as guided by the ID tradition. These aspects of the study will be further detailed in the following sections. With ethics approval obtained in late September 2020 (Ethics ID #REB20-1031), recruitment and data collection occurred from October to December 2020 (Appendix A). Data analysis occurred concurrent with data collection and thereafter, from October 2020 to May 2021 (Appendix A). The research study cost approximately \$70 to conduct, which I self-funded (Appendix B). Participant recruitment was ceased once data saturation was observed.

Research Methodology

A qualitative approach was ideally suited to address the exploratory nature of the research question of this proposed study (Creswell & Creswell, 2018; Creswell & Poth, 2018; McCusker & Gunaydin, 2015). According to Creswell and Poth (2018), there are five main methodological traditions in qualitative inquiry: narrative research, case studies, grounded theory, phenomenology, and ethnography. In narrative research, the perspectives and experiences of individuals are explored using a focus on storied understandings centering around a phenomenon (Creswell & Creswell, 2018; Creswell & Poth, 2018). Case studies and ethnographic research also explore phenomena, although in the specific context of real-life occurrences. The difference between these traditions is that case studies investigate phenomena from individual perspectives while ethnographic research includes the perspective of the researcher, typically an external albeit naturalized observer, situated within that context (Creswell & Creswell, 2018; Creswell & Poth, 2018). Like the other qualitative approaches, grounded theory and phenomenology also seek to further understand individual experiences of specific phenomena. However, grounded theory focuses on theory generation around process-related phenomena; in contrast, phenomenology strives to comprehend phenomena through an

exploration of individuals' lived experiences of said phenomena (Creswell & Creswell, 2018; Creswell & Poth, 2018). Each qualitative methodology has its own unique set of philosophical underpinnings and subsequent approach to inquiry, data collection, and data analysis.

Due to the observed gaps in literature surrounding HD nurses' perspectives in care provision leading to the research aim of this proposed study, ID was identified as the most suitable qualitative methodology. Albeit like phenomenology in its focus on better understanding of phenomena through lived experiences, ID is different in its methodological approach to data analysis and overall goals of inquiry (Ghorbani & Matourypour, 2020; Thorne, 2016). Despite being influenced by all traditional qualitative research methodologies, ID perhaps borrows the most from grounded theory in epistemology as well as in the treatment and close reliance on data to generate understandings of phenomena (Ghorbani & Matourypour, 2020). However, ID should not be considered as a form or subset of grounded theory; ID does not focus on theory generation of process-related phenomena, but rather focuses on better understanding phenomena of interest through rich description (Ghorbani & Matourypour, 2020). In turn, the interpretive aspect of ID comes from the researcher's personal, and often clinical, perspectives that contribute to forming rich descriptions of the phenomenon of interest (Ghorbani & Matourypour, 2020; Thorne, 2016).

As a qualitative approach to inquiry, the objective of ID in exploring phenomena is to derive practical outcomes, especially in the context of clinical phenomena and healthcare delivery. Of the qualitative approaches that were considered for this study, ID was pragmatically adopted for its ability to derive applicable insights from HD nurses' perspectives to inform and moreover improve care delivery for chronic HD patients.

Interpretive Description. Compared to other traditions commonly used in qualitative research, ID is a relatively new methodology, with epistemological and ontological roots in constructivism and naturalism, respectively (Hunt, 2009; Thorne, 2016; Teodoro et al., 2018). Arising from the social sciences and associated research methodologies, ID was initially constructed as a pragmatic means to conduct qualitative research. Developed by Thorne, Kirkham, and MacDonald-Emes (1998), the objective of ID as a methodology was to drive knowledge generation or elucidate necessary areas of practice improvement within the contextual structures of a specific discipline (Hunt, 2009; Thorne, 2016; Teodoro et al., 2018). With this pragmatic approach and focus on context, ID quickly became indispensable to qualitative explorations of phenomena in the healthcare setting and especially with allied health and other healthcare professions (Hunt, 2009; Thorne, 2016; Thorne et al., 1998). Qualitative research in the healthcare field must contend with an extremely complex array of contextual structures, ranging from the biomedical concepts of health and illness; the different roles and interactions of allied health and healthcare professionals; the patients' health and illness experiences; and so on and so forth. In developing ID, Thorne et al. (1998) strove to create a methodology which acknowledged this contextual complexity. ID arose from the need for applied qualitative research "that could generate the kinds of understandings of complex experiential clinical phenomena that would be optimally relevant and useful to the practice of nursing and other professional disciplines concerned with questions 'from the field'" (Thorne, 2016, p. 29-30). Consequently, ID as a methodological approach fits well with the intents and purposes of this study: in striving to better understand nursing care perspectives to enhance patient coping and resilience in CKD and HD, and it was the hope that this study will also offer insight on how to better support both nurses and patients in the CKD and chronic HD setting.

Considerations of Reflexivity and Rigour. In qualitative research, the concept of reflexivity is an important consideration surrounding trustworthy knowledge generation, especially in data analysis (Creswell & Poth, 2018; Thorne, 2016). In qualitative data analysis, I inevitably drew from personal experiences and perspectives to interpret and draw insight from data; reflexivity alludes to (a) an awareness of the researcher, their personal beliefs, experiences, and perspectives surrounding the phenomenon of interest that can influence data collection and analysis, and (b) a systematic approach to document and track this awareness (Creswell & Poth, 2018; Thorne, 2016). Throughout recruitment, data collection, and data analysis processes, I maintained a journal (Appendix C) and notes (Appendix D) about the research process, interview data, and emerging findings for the purposes of reflexivity and rigour (Florczak, 2021; Johnson et al., 2020; Medico & Santiago-Delefosse, 2014; Thorne, 2016). I documented my beliefs, experiences, and perspectives on the collected data and developing analysis, as well as consulted these journal entries throughout the data analysis and knowledge construction process.

While closely related and both used to discern quality of qualitative research, rigour and reflexivity are not the same. The concept of rigour alludes to a qualitative study's *credibility*, *transferability*, *dependability*, and *confirmability*; rigour is an overall gauge regarding confidence in study findings (Johnson et al., 2020). Reflexivity and activities that document reflexivity, such as journaling, falls under the consideration of *credibility* in that researchers must remain transparent throughout the research process in communicating potential biases and personal influences in data analysis (Florczak, 2021; Johnson et al., 2020; Medico & Santiago-Delefosse, 2014). In turn, the concept of study *transferability* alludes to the clear communication of study participant demographics and research timeframe; *dependability* refers to the well-articulated documentation of the study's research methods; and *confirmability* indicates that study analyses

have been corroborated by a trustworthy second- or third-party (e.g., peer review) (Florczak, 2021; Johnson et al., 2020; Medico & Santiago-Delefosse, 2014). However, it is important to note that rigour in ID will moreover stem from “the way the specific analytic decisions are presented and contextualized within the larger picture” (Thorne et al., 2004, p. 7). To align with demonstrating study rigour as per ID methodology, I strived to assess interview data and prepare study findings within the local context of CKD and HD care setting in tandem with other techniques I used to incorporate reflexivity in this study: reflexive journaling, maintaining an audit trail, and engaging in peer-review of my analyses via my supervisory committee.

Study Setting

Participant recruitment for this study occurred at a provincial level, with recruitment taking place from the two renal programs in Alberta, Alberta Kidney Care-North (AKC-N) and Alberta Kidney Care-South (AKC-S) (Alberta Health Services [AHS], 2020a). For further detail regarding the study setting, see Appendix E.

AKC-N has 21 in-center HD sites across urban ($n = 4$) and rural settings ($n = 17$) (AHS, 2020a), employing 99 full-time equivalent nursing staff across its in-center HD sites in Alberta (A. Stalker, personal communication, July 14, 2020). In turn, AKC-S has 13 in-center HD sites, also across urban ($n = 7$) and rural settings ($n = 6$) (AHS, 2020a), employing 261 full-time equivalent nursing staff across in-center HD sites (J. Scarrett, personal communication, June 29, 2020). As of March 2020, there are 2,860 patients on renal replacement therapy across both AKC-N and AKC-S: of these patients; 70.7% ($n = 2021$) receive some form of in-center HD treatment, with most on conventional HD treatment (A. Stalker and J. Scarrett, personal communication, July 9, 2020). AKC-N and AKC-S are structured similarly in terms of urban and rural settings, with only two primary urban centres across the two programs: Edmonton (AKC-

N) and Calgary (AKC-S) (AHS, 2020a). Edmonton and Calgary are comparable urban centres with respect to population size and demographics (Statistics Canada, 2017). As the primary researcher of this study, I am also an HD nurse currently employed at the largest HD facility in Calgary (Foothills Hospital – Unit 27).

Participants and Recruitment

A provincial approach was taken to recruit HD nurse perspectives from urban and rural settings. All professional nursing staff (Licensed Practical Nurses [LPNs], Registered Nurses [RNs]) that have worked in their respective HD site in Alberta for at least two years and are currently working in HD were eligible to participate in the study. These criteria were set to glean perspectives from HD nurses who have had the opportunity to build relationships with chronic HD patients in their HD sites. For this reason, nursing students were not eligible to participate in the study.

Once ethics approval was obtained for this study (Ethics ID #REB20-1031), key stakeholders from AKC-N and AKC-S HD sites (e.g., patient care and HD site managers) were be asked to disseminate the electronic research posters inviting participants to the study. As I am currently employed as an HD nurse in the primary urban HD site in AKC-S (Calgary), I collaborated closely with the unit manager of my current site of employment to identify these key stakeholders from both AKC-N and AKC-S. During the recruitment phase of the study, my unit manager asked key stakeholders to identify nursing staff who meet the eligibility criteria of the study (Appendix F). I provided electronic media advertising the research study to my unit manager, who in turn sent the media to key stakeholders, such as other HD site managers, across AKC-N and AKC-S. Key stakeholders were then asked to send electronic media detailing the study via work email to eligible nursing staff working within their respective HD sites.

Prospective participants were sent a total of two recruitment emails (September and November 2020) advertising the study.

Electronic media included an invitation email (Appendix G) and an electronic poster (Appendix H); media contained the title of the study, the ethics certificate number, the research aim and details of the study, participant eligibility criteria, and my contact information as the primary researcher of the study. The research poster was circulated via email and interested participants then contacted me directly. I then coordinated with prospective participants to schedule a phone or online interview at a time convenient for the participant during non-work hours. I also sent a copy of the study consent form (Appendix I) to the participant for them to peruse and return a signed copy of the form to me prior to the interview.

Data Collection: Semi-Structured Interviews

As with qualitative traditions, data collection in ID typically involves individual interviews, focus groups, and participant observations (Thorne, 2016). In balancing feasibility and the potential to collect in-depth data, semi-structured interviews were chosen as the sole means of data collection for this study. Given the current COVID-19 pandemic and uncertain timelines of public health recommendations such as social distancing (Government of Alberta, 2020), it was decided that one-on-one online or phone interviews would both be safest and most convenient for participants. This mode of data collection was also chosen for feasibility in consideration of factors that would have made intra-provincial travel difficult (e.g., budget constraints for the study and COVID-19 public health restrictions for non-essential travel).

Although participant observations would help provide context to HD nurses' perspectives on care provision, care facilities at the time had limitations of essential personnel physically on premises due to the COVID-19 pandemic (Government of Alberta, 2020). For similar reasons,

focus groups were not selected as a feasible mode of data collection; albeit possible to be arranged through online meeting platforms, focus groups may have proved difficult to arrange due to the nature of nurses' shift and on-call work. Overall, one-on-one online or phone interviews were chosen as they were safest in the current public healthcare climate; more flexible to nurses' schedules; and participants could perhaps feel the most comfortable in a one-on-one setting, potentially contributing more of their perspectives in a private environment.

In terms of data collection for this study, I was the sole interviewer and used a semi-structured interview guide to interview participants (Appendix J). At the start of the interview, I reviewed the consent form with the participant, addressed any participant questions or concerns regarding the study, and obtained consent to proceed with and audio-record the interview. The first part of the interview featured a collection of questions to ascertain the demographic characteristics of study participants while the second portion comprised the main data collection aspect of the study. HD nurses' broad perspectives on care provision in the CKD and HD setting was first explored to ascertain their priorities in care. Throughout my first three interviews, I observed that participants did not specifically mention supporting patient coping and resilience unless otherwise asked. For the following participant interviews, I specifically asked about this topic in relation to my study research question if participants did not independently comment or allude to it in their interviews. I digitally audio-recorded all interviews for transcription and data analysis.

As per the ID tradition, recruitment, data collection, and analysis were ongoing for the duration of the study and occurred concurrently (Thorne, 2016). With respect to sample size estimation, Thorne (2016) states that data saturation should not be a consideration due to its potential of exclusivity and researcher imposition on expected data generation. Instead,

maximum variation within the population of interest should be the overall goal in recruitment size for ID studies (Thorne, 2016). However, for the purposes of feasibility, data saturation in tandem with participant number was considered as an endpoint for recruitment in this study. I felt data saturation occurred with collected data from interviews with Participants 10 and 11; however, I proceeded to interview Participant 12 as I had already confirmed and scheduled an interview time with the participant.

It was anticipated that a minimum of 6 to 8 participants was needed for data saturation; past ID studies have observed data saturation to occur from anywhere between 6 to 30 participants (Teodoro et al., 2018). Overall, the final sample size of this study depended on data that emerged in addition to the number of eligible, volunteering participants and resource constraints (time and personnel) of this study (Thorne, 2016). As I was the only interviewer and transcriptionist for this study, as well as the sole researcher, the sample size goal of this study was estimated to be between 10 to 15 participants. Once data saturation had been reached or the maximum sample size of 15 participants had been met, participants who wished to participate in the study would have been provided an email or phone response detailing the end of recruitment (Appendix K). I did not have to send an end-of-recruitment response to any prospective participants.

Data Analysis: Using Interpretive Description

Knowledge derivation using ID ultimately comes from an inductive approach, where insights and understandings of phenomena emerge from collected data (Hunt, 2009; Teodoro et al., 2018; Thorne, 2016). For each semi-structured interview, I transcribed the interview for ease of coding and thereby analysis. As per the pragmatic approach of ID to data analysis, Thorne (2016) acknowledges that coding is inevitable to organizing data for manageable analysis.

Thorne (2016) suggests adopting the grounded theory approach to employing different types of coding for various purposes in initial organizations of data, such as using *open coding* to conduct a line-by-line analysis. However, Thorne (2016) warns against “fixed-form coding” (p. 161), where coding becomes the sole basis of a study’s final findings. Coding is used iteratively and reflexively in ID, to drive further insight and interpretation of data (Thorne, 2016; Teodoro et al., 2018).

Although aspects of data analysis can be borrowed from other traditions of qualitative inquiry, such as coding style, there is a specific analytic process associated with the ID tradition (Thorne et al., 2004). Firstly, before the analytic process commences, Thorne et al. (2004) advises researchers to first “[find] the knowable” (p. 4). To generate insightful interpretation of study data that effectively extends knowledge and in-depth understanding of the phenomenon of interest, researchers must first be knowledgeable about what is already known of that phenomenon. By being conversant with this baseline body of knowledge, researchers are then able to critique the knowledge frameworks that have been used to explore and understand the phenomenon of interest in past and current literature. This ability to critique knowledge frameworks also falls in line with the beginning of the analytic process, where Thorne et al. (2004) encourages researchers to be critical of early interpretations of study data. As a nurse with over five years of experience in CKD and HD care at the time of the study, I felt that employing ID as my study methodology afforded me the means to optimally utilize my nursing experience and knowledge in my research. Although I gained a substantial amount of knowledge into my research study topic by conducting an integrative literature review (Chapter 2), I felt that my personal experiences in caring for CKD and HD patients in turn allowed me a more in-depth understanding of the literature as well as the experiences in care provision related by participants

in this study. My experiences in HD nursing allowed me to connect and relate meaningfully with study interview data, and thereby understand what potentially new insights could be gained from this topic with respect to literature to date.

At the start of the analytic process, Thorne et al. (2004) posits that “breadth is more useful than precision” in the initial stages of data coding and organization, asserting that the analytic process is iterative, and that data coding and organization should be open to re-visitation as new insights into data emerge over time. Throughout the analytic process as guided by ID, and as data collection continues concurrently, it is recommended that researchers continue to analyze data using a critical and iterative approach to ultimately effect engaged, insightful, and novel interpretations of data (Thorne et al., 2004). At all stages of the analytic process, researchers must be critical of their interpretations, striving to arrive at interpretations that are representatively “constructed truths” (Thorne et al., 2004, p. 6) of the collected data. In addition, researchers must endeavour to arrive at novel interpretations of data, and not interpretations that simply echo known knowledge frameworks associated with the phenomenon of interest. In simultaneously using an iterative approach to data analysis, researchers should also move flexibly in examining the gestalt of collected data to analyzing, comparing, and contrasting specific, smaller components of collected data (Thorne et al., 2004).

To address the notions of reflexivity and rigour, I first consulted my research journal (Appendix C) to note my first general impressions of interviews prior to reviewing each interview transcript in turn and noting my analyses (Appendix D). Although I utilized ID with respect to my overarching approach to critical and iterative data coding and organization (Thorne et al., 2004), it is worth noting that I also employed the coding approach and reflexive coding-journaling technique (Appendix C, D) used in thematic analysis as outlined by Braun and Clarke

(2006) for its procedural clarity. In thematic analysis, there are six phases of code generation and assignment (Braun & Clarke, 2006):

- Phase 1: Preliminary coding. Data is read and re-read for familiarity and to identify initial patterns. Preliminary codes, their description, and their specific sources in data will be journaled.
- Phase 2: Comprehensive coding. Data, and moreover assigned preliminary codes, are collapsed into labels for category-creation; researchers begin to infer how codes address the research question(s). The process of category-creation and inference-making will be journaled.
- Phase 3: Preliminary themes. Categories, or higher-level codes, are grouped into themes. Themes and the meaning of themes are expanded upon in relation to the research question(s). The process of theme creation and code groupings will be journaled.
- Phase 4: Organization of themes. Themes are organized into a logical pattern that is representative of study data and how study data addressed the research question(s). Researcher understandings of the connections between themes, study data, and the research question(s) will be journaled.
- Phase 5: Analyzing themes. Themes are analyzed to generate further understandings of study data. Descriptions of each theme will be journaled.
- Phase 6: Description of results. Researchers detail an in-depth description of the results. The relative importance of each theme with respect to the research question(s), understandings of data, and the decision process surrounding result-reporting will be journaled.

Lastly, in completing the analytic process as per the ID tradition, researchers are tasked to prepare and communicate study findings that are meaningful, relevant, and applicable, either in the day-to-day lives of people experiencing the phenomenon of interest, or in the practice of healthcare professionals working in the clinical realm of the phenomenon of interest (Thorne et al., 2004). In concluding my analyses for this study, I sought to interpret and frame interview data to allow for applicable, relevant recommendations for possible improvement of nursing experiences and care provision in the CKD and HD setting. When I felt comfortable with my study themes and subthemes distilled from interview data, I then engaged my graduate program supervisor and supervisory committee in iterative discussions to review and critique my analysis work and interpretations of data.

Ethical Considerations

The four principles of biomedical ethics include respect for individual autonomy; beneficence (do good); non-maleficence (do no harm); and justice (Canadian Nurses Association [CNA], 2017). These four principles were used to inform the decisions around participant recruitment and data collection and storage for this study. The research proposal for this study was also subjected to review from the research ethics board and did not proceed until approval was obtained (Ethics ID #REB20-1031).

In respecting participant autonomy, there were initial concerns surrounding recruitment in Calgary due to ethical considerations of potential participant coercion. Despite currently working at only one HD site at this time, I have worked in a few HD sites within Calgary in the last six years; recruitment in Calgary could possibly result in my interviewing of HD nurses that are professional colleagues or that share mutual professional acquaintances. Ultimately, however, I decided to include Calgary in recruitment due to the recruitment process; although

prospective participants were made aware that I would be the interviewer for this study, information about the study were initially disseminated to participants via email. It was then incumbent on individual HD nurses to contact me should they wish to participate in the study. I would not be involved in the direct recruitment or advertisement of the study, and hence avert possible participant coercion. In reviewing the consent form with participants before commencement of interviews, I also addressed any prior relationship I may have with the participant. I reassured participants of the confidentiality of their participation and that their participation had no bearing on their employment.

Participants also had at least two opportunities to review details of the study via the consent form: participants were sent the consent form upon initial contact with me, and I also reviewed the consent form with the participant at the start of the interview. Interviews were scheduled at a time convenient for participants. At the start of the interview, they were also assured that they would be able to stop the interview at any time or refrain from addressing an interview question if they preferred not to answer. Although there were no foreseeable risks to study participants, participants may have experienced some temporary psychological or emotional stress (e.g., anxiety) upon recollections of nursing care provision for specific patients during the interview process. If participants felt distress from participating in the study and desired further counselling and wellness services, contact information for the AHS Employee and Family Assistance Program was provided in the consent form. As current employees of AHS, all participants in the study had free access to the Employee and Family Assistance Program, which offers a wide array of counselling and wellness services to all AHS staff (AHS, 2020b).

Participants were also given a grace period of two weeks following their interview to redact the interview data; participants were made aware that they could not redact their interview data after this grace period due to the concurrent data collection and analysis aspect of this study. Participants were also informed that they may be re-contacted in the two-week period following their interview if further clarification was needed on interview data. All study participants were amenable to these terms; none requested to withdraw their interview data, and I did not feel the need to re-contact any participant for data clarification post-interview for my analyses.

I had sole access to the consent forms and audio-recordings of the interviews. In preparing the interview transcripts, I assigned a number to each participant, e.g., “Participant 1”. I retained a hard-copy master list of the participants and their respective pseudonyms for later reference. Audio-recordings of the interviews were kept on one audio-recorder; the audio-recorder and the hard-copy master list of participant pseudonyms were kept in a locked storage container at all times at my residence when not in use. No data was stored on ZOOM. As the sole interviewer in this study, I only used my institutional (University of Calgary) online platform account on ZOOM to facilitate interviews with participants; I also set up online interviews so that participants required a password to join online interviews on ZOOM.

Transcripts and electronic consent forms were stored in an encrypted, password-protected file in my personal laptop computer, which also requires an additional password for initial access that only I know. When not in my use or close possession, my laptop was stored at my residence. I alone had access to my email, and thus the communication between myself and participants were confidential. I also reviewed the same consent form with participants before the start of interviews and obtained verbal consent from the participant before starting audio-recording. As

stated in the study consent form, data containing participants' personally identifiable information (audio-recordings and consent forms) will be stored for five years and then destroyed.

In supporting the principles of beneficence, non-maleficence, and justice, consideration was given around the recruitment strategy with respect to engagement and representation of the different HD sites across AKC-N and AKC-S. Following the completion of my thesis, final findings and insights of the study will be shared with key stakeholders and participants of the study as well as be made available to the HD nurses within the province. To track personal assumptions and related contributions to data analysis and interpretations, I have worked closely with my supervisory committee and maintained an audit trail of data analyses (Appendix D). I did not feel or witness that any participant experienced extreme psychological distress or any physical harm while participating in the study. Nevertheless, in reviewing the consent form with participants before each interview, I highlighted to participants that they were free at any time to bypass interview questions or stop the interview process at any time. I also emphasized that the AHS Employee and Family Assistance Program contact information was listed in the consent form should participants require the information. Although no study participants paused their interview or refused to answer an interview question, I cannot conclusively assert that no participants accessed the AHS Employee and Family Assistance Program for counselling and wellness services following or as a result of their interview.

In summary, ID provided a qualitative research methodology that afforded in-depth understanding of the complexities surrounding nursing care provision in the CKD and HD setting. In particular, ID enabled me to utilize my HD nursing knowledge and experiences in interpreting data and in the preparation of findings. It was anticipated that the study findings would be able to provide valuable insights regarding HD nursing care and how patient coping

and resilience can be further supported in the CKD and chronic HD setting. In the following chapter, the findings of this study will be explored in more detail.

Chapter 4: Findings

As a hemodialysis (HD) nurse, I opted to use Interpretive Description (ID) for the purposes of “illuminating relevant insight” (Thorne, 2016, p. 188) on a clinical practice question I am extremely passionate about. As detailed in Chapter 3, ID allows for the exploration of a clinical phenomenon with the objective of yielding both insights and opportunities for improvement germane to direct practice.

In this chapter of my thesis, I will be presenting the findings, as framed by ID and in tandem my personal and experiential understandings of the CKD (chronic kidney disease) and HD clinical setting. Specifically, I will be detailing: (a) my research question and its transformation with respect to collected data; (b) the participants involved in the study and the clinical setting of HD care; (c) the overarching theme; and (d) associated subthemes that emerged from interview data.

The Research Question and its Evolution

My initial research question for the research study was: “What are HD nurses’ perspectives on supporting patient coping and resilience when caring for CKD patients on chronic HD?” However, from my first three interviews with HD nurses, participants did not specifically discuss how patient coping and resilience was supported in nursing care provision, even with probing. Consequently, subsequent participants were explicitly asked how they supported patient coping and resilience in their care provision. Common concepts emerged: (a) HD nurses already largely recognized that patients on HD treatment were likely to have persistent mental health concerns such as anxiety and depression, and (b) HD nurses strived to provide ongoing support in various ways. Such acts of support in nursing care provision included:

- Becoming a supportive companion with patients throughout patients' disease trajectory for the duration of their HD treatment;
- Helping patients find inner strength and personal reasons to continue adhering to their HD treatment schedules (e.g., personal health, more time with loved ones);
- Recognizing the different nuances of acute versus chronic nursing care, and the focus on rapport-building in tandem with medical care in the latter context;
- Ongoing assessment of patients' receptivity to care; and
- Attempting to alleviate the burden and negative connotation of HD treatment by establishing meaningful relationships.

When the topic of supporting patient coping and resilience was explicitly asked about, HD nurses revealed examples of “balancing acts”, or negotiations in care, that they experienced when providing care provision to patients on chronic HD treatment. As this was a consistent observation throughout the participant interviews, I revised my thesis research question to: What negotiations in care do HD nurses experience in striving to support patient coping and resilience for CKD patients on chronic HD treatment? This revision served to acknowledge that, firstly, all participants communicated awareness that HD patients generally experienced a high burden of disease and required support in coping and resilience. Secondly, all participants consistently alluded to negotiations in care that they experienced in striving to offer that specific patient support in care provision.

Study Participants and the Clinical Setting of Chronic Hemodialysis Care

Recorded semi-structured phone and online (ZOOM) interviews were conducted with nursing staff (Registered Nurses [RNs], and Licensed Practical Nurses [LPNs]) who had at least 2 years of renal nursing experience in a chronic HD care setting. Although Participant 2 only had

approximately 1.5 years of HD experience at the time of their interview, an exception was made to include this participant in the study as they had extensive experience and rapport with the same group of HD patients they currently care for in their previous renal nursing.

Table 2

Demographic Information of Study Participants

Participant	Nursing Designation	Gender	Primary HD Site of Work	Age (Years)	HD Experience (Years)	Other Clinical Experiences (Years)
1	RN	F	In-centre	29	2	- Burns/Plastic Surgery, General Surgery (1.5) - Home Care (unknown)
2	RN	F	In-centre	43	>1	- Nephrology (20)
3	RN	F	In-centre	27	2	- Home Care (2)
4	RN	F	In-centre	65	21	- Internal Medicine, Long-Term Care, Cardiac Care, General Surgery (9-10)
5	RN	F	In-centre	54	18-19	- Nephrology, Medical-Surgical, Plastic Surgery (unknown)
6	RN	F	In-centre	28	3	- Labour/Delivery (3) - Palliative care (<1)
7	RN	F	Satellite	53	23	- Surgery, Gynecology, Internal Medicine, Pediatrics, Critical Care (7-8)
8	RN	F	In-centre	37	8	- Medical-Surgical (7)
9	RN	F	In-centre	49	17	- Long-Term Care, Pediatrics, Neonatal Intensive Care (unknown)
10	LPN	F	In-centre	50	8	- Obstetrics/Gynecology (12)
11	LPN	M	Satellite	52	6	- General Surgery (10)
12	RN	F	Satellite	35	12	- No other clinical experiences

I recruited from the two renal programs within Alberta: Alberta Kidney Care-North (AKC-N) and -South (AKC-S) with the intent to interview 10-15 HD nurses who met the eligibility criteria of this study (Chapter 3, p. 40). In this study, all HD nurses interviewed ($N = 12$) were from AKC-S, with a mixture of RNs ($n = 10$; male = 0, female = 10) and LPNs ($n = 2$; male = 1, female = 1) with various years of experiences in HD and other clinical settings (Table 2). Participants ranged in age from 27-65 years of age, possessed 1.5-23 years of HD experience,

and identified primarily as female (91.7%; F: female, M: male). Most HD nurses who participated in the study were RNs (83.3%).

In AKC-S, there are several types of chronic HD services offered based on patient preference, ability, and feasibility: primarily, these services can be delineated to home HD and site-based HD. In home HD, patients are provided an HD machine and their residence outfitted with a water system to facilitate at-home treatment. Home HD patients receive training to self-administer HD and typically dialyze overnight several times a week based on their prescription.

Alternatively, site-based HD refers to HD treatment provided by trained nurses at a care facility. The type of care facility can vary, from “in-centre” HD, which refers to a care facility that is based at a hospital, and “satellite” HD, which is HD offered at community-based clinics. Most patients who receive site-based HD dialyze on a “conventional HD” schedule, meaning that they dialyze 2-4 times a week for 4-6 hours per treatment, with the typical chronic patient HD schedule being 4-hour treatments thrice weekly (e.g., every Monday, Wednesday, and Friday). Conventional HD patients have HD treatment scheduled in the morning, afternoon, or evening. Some in-centre HD sites also offer nocturnal programs for chronic HD patients, where patients are cared for by HD nurses as they dialyze overnight for 8-hour treatments thrice weekly. Most HD nurses who participated in this study work at an in-centre (75%) versus satellite HD care facility (25%).

At HD care facilities, patients are typically situated in adjacent spots, with each spot a designated care area containing an HD machine and a bed or chair for patient use. In AKC-S, the largest HD care facility, which provides in-centre HD, has 30 patient spots. Patients usually spend their HD treatment sleeping or watching TV if there is a bedside or room TV available; many patients also bring their own media devices (e.g., iPads), books, puzzles, and hobby items,

such as knitting or jewelry-making supplies, to occupy their time. Although most chronic HD patients experience uneventful HD treatments, common intradialytic adverse events include hypotension, muscle cramping, nausea, and fatigue. Patients have also reported experiencing these symptoms post-HD treatment, albeit with varying recovery times and severity (Cabrera et al., 2017).

HD nurses in AKC-S work 8- to 12-hour shifts but primarily work the former. Depending on the length and type of shift (day, evening, or night), they can care for up to 6-7 different patients in one shift. As site-based HD patients have different treatment schedules and receive HD treatment every 1-2 days, HD nurses can interact with and care for many different patients, especially if they work near to full-time hours. This unique structure of HD care, paired with the inherently chronic aspect of CKD care and HD treatment, affords HD nurses and patients the time and opportunity to build rapport and become familiar with one another.

Overarching Theme: Hemodialysis Nursing as Ongoing Negotiations in Care

As per the ID tradition, one of the fundamental means to convey ID analyses is “to organize the findings within an overarching conceptual claim, the elements of which become the organizing structure for the pieces required in order to understand the whole” (Thorne, 2016, p. 200). Throughout the interviews, HD nurses repeatedly spoke of “balancing acts” in care provision, or the need to negotiate between related albeit opposing, influencing factors of patient care. Due to its consistent and recurrent emergence across interviews, this concept of “negotiations in care provision” became the overarching theme of the study (Table 3).

To provide some context regarding these “negotiations in care provision”, HD nurses commonly related struggles and conflicts, especially when endeavouring to support patient coping and resilience. Upon further exploration with participants, there seemed to be a general

element of moral distress underlying care provision, in varying degrees. Participants alluded to a struggle to balance seemingly opposing directives, or influences, on how they effected patient care. Moreover, various constraints in clinical practice seemingly gave rise to specific negotiations in care provision found in the HD setting. In the next section, these care constraints that comprise the subthemes will be explored.

Subthemes: Personal, Professional, and Organizational Perspectives

Table 3

Themes and Subthemes from Interview Data

	THEME
<p>RESEARCH QUESTION: What negotiations in care do HD nurses experience in striving to support patient coping and resilience for CKD patients on chronic HD treatment?</p>	<p>HD nursing care is a “balancing act”, entailing ongoing, various negotiations in care.</p> <hr/> <p>SUBTHEMES</p> <ul style="list-style-type: none"> • <i>Nursing Perspectives ↔ Patient Perspectives</i> <ul style="list-style-type: none"> - Perspectives on what is best for the patient • <i>Medical Care ↔ Psychological Care</i> <ul style="list-style-type: none"> - Medical care: optimizing dialysis adequacy, medications, addressing bloodwork, etc. - Psychological care: counselling, emotional support, etc. • <i>Professional Boundaries ↔ Therapeutic Relationship</i> <ul style="list-style-type: none"> - Professional boundaries: nurses’ perspectives on social and emotional boundaries that must be maintained in a professional relationship - Therapeutic relationship: meaningful, restorative rapport that requires more investment with chronicity of care • <i>Organizational Considerations ↔ Patient-Centered Care</i> <ul style="list-style-type: none"> - Organizational considerations: policies, procedures and system-level constraints (e.g., capacity issues) - Patient-centered care: nurses’ perspectives on what constitutes patient-centered care that may not align with organization- or system-level care directives

HD nurses appeared to often be caught in negotiating between perceived conflicting views, beliefs, and practice directions—at a personal, professional, and even organizational level (Table 3). As aforementioned, different practice constraints have led to specific types of negotiations in HD nursing care, which in turn constitute the subthemes of study findings. These practice constraints are imperative to understanding the complexity of the different negotiations

in care, as it is the culmination of these constraints that have precipitated and shaped each type of negotiation in HD nursing care. This section outlines how the individual subthemes, and moreover the overarching theme, were developed: during the interviews, HD nurses relayed constraints in care and how they responded to those constraints, which was to ultimately negotiate between specific aspects of their care in lieu of various constraints they experienced in care provision.

Time was the most often cited care constraint in study interviews: despite chronicity of care, HD nurses only care for patients for less than 4 hours per treatment, and patient assignments change from shift to shift. This time constraint requires HD nurses to prioritize urgent or “quick task” items (e.g., fluid removal and blood pressure management, medication administration), leaving counselling and psychological support, which requires much more time to understand patients’ needs and tailor effective support accordingly, often becoming ancillary items in HD nursing care. From the interviews a participant stated:

I feel that there is more to explore and we just don’t have time. The dialysis nurses only have time, for mostly task-oriented activities. Although we want to be, ah, patient-oriented, more connected to the patient, there is not much time. They’re basically running out to finish up their tasks. Because now...it was one is two [nurses to patients], now we’re one to three patients. So...we get 4 hours with three patients. So basically you get 1 hour to 1 hour and 15 or 20 minutes for each patient in one dialysis session. In that time period, the nurse goes for one half an hour break, then, you cover the other nurse for half an hour break. So for one hour, you’re just going for break. So for three hours you have three patients to deal with. Then we have huddles, 15 to 30 minutes. So...you have two and a half hours for three patients now. So...we’re, the nurses are kind of forced to finish

up their task. Where is the time to...ventilate with the patients' emotions? You don't have time. You always have to go, "Excuse me but I have to go see my other patients, I'll come back,"...but even though you want to come back, most times you can't. I think we don't have enough time to communicate with the patient, um...and explore more to help with their resiliency. (Participant 7, Lines 312-329)

I think, yeah, it can be overwhelming with the time, like the timing of patients, um...like, their put-on and their take-off, like they'll change the schedule one day and you'll have patients on at 7:00 and 7:15 but because they changed the schedule around then you have two patients to be put-on at 7:00...like, it makes it, and if there's no extra staff to help you put them on and take them off then you have to, like, adjust the timing? Um, which I don't feel good about, um...but you have, you don't have any other choice, like if a patient arrives late, like, you try to give them as much treatment time as possible but then their take-off time is going to conflict with your next patient or it's going to conflict with the time needed to get the machine cleaned for the patient after that, um...I think it can be challenging. (Participant 6, Lines 244-255)

Other constraints participants revealed in the interviews include HD nurses' personal emotional capacity and resilience, perceived skill level, and scope of practice (e.g., limited knowledge drawn from life experiences, counselling skills):

...we nurses know most of it, ah, when it comes to, in terms of...what policy is done, what you have to do in this situation, or in that situation, or how do you put a patient on dialysis or how do you manage this or that...but you know what we don't know? We don't know how they feel about it...do they want to have it done? Do...does it really benefit them, do they feel like they are listened to? Yeah, we might be the experts on, ah,

how to provide their care...but I'm not sure that we're the experts on, um, help them get better in the sense of...accepting their illness and making the most of their, improving their quality of life...because we're just doing, ah, like I said, we, we dictate them on what to do and most of them follow our direction but...um...I feel that sometimes we're just too stuck sometimes on that part of the deal, on telling them what to do without having to listen on what they want or have to tell us. (Participant 12, Lines 305-317)

I think having more...either more psychological training or...psychological support. And it's just general health—sorry, mental health, I should say—in general. Because a lot of what I see in our chronic patients is...a sadness and a, a loneliness, and sometimes you have a desire to just, to just want to talk or interact with them for the 3 or 4 hours that they're stuck there, you know...and, especially if you have another patient that's not doing well, or you have, you know, someone's who's just recently discharged from hospital so you have a ton of paperwork that you have to do...sometimes you can't spend that little bit of extra time that you want with them, and I think that...if we had some more skills in helping patients with their mental health and [...] having those skills, especially with our chronic patients, would be helpful. (Participant 2, 155-169)

HD nurses have also alluded to constraints surrounding professional boundaries (e.g., what comprises a therapeutic “nurse-patient” relationship):

Like, for example, [...] I haven't worked in [chronic hemodialysis care] for a few months the patients will ask me, “Oh, where were you? Were you on vacation,” you know. So, they know us, they know what's going on. But I heard from the, ah, satellite units or the...in the rural places, like, um, you know, Lethbridge, the [HD] nurses who are coming from there, they say...they even see the patients in the, you know, shopping mall

[...] Yeah, they see each other every single day, they almost know everything, you know.

Mm, they even go for funerals, weddings...they'll be seeing them more often. So, it's more than a nurse-patient relationship for them. (Participant 8, Lines 135-149)

Ultimately, these diverse constraints in care have given rise to related albeit distinctly different negotiations in care HD nurses experience in care provision. These negotiations in care specifically include:

- Nursing perspectives ↔ patient perspectives
- Medical care ↔ psychological care
- Professional boundaries ↔ therapeutic relationship
- Organizational considerations ↔ patient-centered care

It is important to note here that these negotiations in care do not involve opposing directives or influences that are strictly mutually exclusive; rather, these negotiations appear to exist on a continuum of care.

Nursing Perspectives ↔ Patient Perspectives

This sub-theme reflects the how HD nurses negotiated care by balancing their perspectives with the patients' perspectives in care provision and treatment goals. At times, HD nurses discussed how their perspectives on what is "best" for the patient may not align with patient perspectives; this can pertain to short-term items, such as fluid removal goals within one HD treatment, or long-term considerations such as general adherence to a patient's HD treatment schedule. The balancing act reflects how nursing recommendations of care may not be adhered to by the patient because of previous medical experiences, or inherent patient values and preferences. This alludes to the notion that HD nurses have seemingly acknowledged, that

although HD nurses are the experts in HD treatment, patients are in turn experts of their body, or alternatively, what will ultimately improve their quality of life:

I think, in a sense, it's a double-edged sword...[laughs] in that like, it can be easy knowing their preferences but it can also be difficult, because...at times, patient's aren't...so flexible, or, yeah, like you try to teach them or educate them, like, "This is why we're doing what we're doing," but in their mind they have their own understanding of what they think is right, and so...regardless of what you say or how you say things, they still want things to be done a certain way even if it may negatively impact their health. (Participant 6, Lines 106-145)

Inevitably, this balancing of nursing and patient perspectives in care provision can result in some distress for HD nurses in care provision, especially with respect to HD nurses' efforts to create a care environment that facilitates patient coping and resilience in this care setting. As stated by Participant 2:

My experiences can be very rewarding but also very frustrating [...] you get patients who are very involved in their care, ah, and then you get patients who are not involved in their care at all, and those can sometimes get a bit on the frustrating side. Um, especially when you, you get into that as well and you get what I think are self-destructive patients who don't show up for dialysis days and, you know, then you become worried about them (Participant 2, Lines 36-66)

Participant 9 also noted that, in balancing nursing and patient perspectives, that nurses must also consider patients' personalities, preferences, and day-to-day receptivity to care:

Hm. I think that...you have to take each person as you meet them. So...you have to get to know, you have to get to know a patient and how they, you know...ah, it's hard to

explain, I don't know. I just think you have to take each person for who they are and...you know, if they're going to be willing to listen, then you teach. And if they're not willing to listen then you chart. You know what I mean? [...] I just mean that some people...you just have to take each person like how you meet them. Like, because some people will be really open, and so that gives you the opportunity to talk to them, right? And some people are really...closed, and they don't want to learn, and they don't want to...like, they're there because they have to be, they certainly don't want to be, and...they don't want to have any more disruption to their lives that has already happened, right? [...] So you have to be able to know where each person's at so you can, you can reach them accordingly. Because they may not be having the best day either, right? Or something may have happened to their family, or...maybe they just don't feel well, or maybe they're going through a rough patch, like in their health, and it's just not doing the best at the moment, so...you just have take each, you just have to assess each person day by day. (Participant 9, Lines 249-295)

In striving to support patients, HD nurses must constantly balance their perspectives with that of each HD patient's unique perspectives and preferences in care provision.

Medical Care ↔ Psychological Care

Closely related to the balancing act that HD nurses manage between their perspectives and patients' perspectives, HD nurses also relate negotiating between medical and psychological care when attending to HD patients' needs. In this instance, *medical care* primarily refers to attending to a patient's physical health, which includes ensuring patient vital signs are stable throughout HD and that the patient's HD treatment prescriptions are safe and adequate for the

patient's current health status and lab results. In turn, *psychological care* is care aimed to support the patient's mental health and wellbeing.

As previously mentioned, negotiations in care provision appear to primarily occur as a result of constraints experienced by HD nurses in the care setting. In particular, the constraints of time and nurses' perceived skill level and scope of practice appear to largely contribute to the balancing act of *medical care* ↔ *psychological care*. Specifically, time seems to be the primary limitation for this negotiation in care provision. Although patients are typically at dialysis for 3 to 4 hours every HD run, HD nurses also spend a lot of this time not in direct patient contact as patients might be sleeping or resting. HD nurses also spend a sizeable amount of time in non-direct patient care and logistical tasks, such as medical rounds, patient research, documentation, as well as break and break relief for colleagues. Compared to medical care, psychological care may require much more of HD nurses' time:

...she said, "Well, my husband died two days ago and I'm making his funeral arrangements." And of course that was heartbreaking for me...but at the same time, you know, I gotta get the patient on, I gotta get the next patient on. And I felt horrible that, you know...I did end up afterwards providing her with some support, but I felt horrible that in that moment, I felt she needed to talk...I mean, I would to, I should have given her a hug for crying out loud, um...but that...the, the dialysis itself was stopping me from providing her—like, getting her on dialysis was preventing me from providing her the support that I wanted. And that really stuck out to me, like...one of those heartbreaking moments when, you know you want to do more but you know just can't. (Participant 2, Lines 214-235)

In a similar incident, HD nurses have also recognized the constraint of their perceived skill level and scope of practice that resulted in having to balance medical and psychological care:

So I find that that's the challenging piece, like, how do you support patients dealing with complex life issues. Um...and you, you don't have any real experience dealing with those issues. That's, that's the challenging piece, and then the, so I guess, the therapeutic communication piece for these types of patients can be extremely complex. Whereas the nursing care itself, like the technical care, that's easy. You can look up bloodwork, titrate medications, or change HD prescriptions but...that is challenging to talk to people dealing with pretty heavy life situations and life decisions. (Participant 1, Lines 123-130)

As related to Participant 1, HD nurses may not feel comfortable or that they are the most appropriate healthcare professional to provider to offer psychological support to patients on a meaningful level. However, HD nurses must often try and attend to these patient issues, in turn due to limited social work personnel available or HD nurses' perceptions of limited to no healthcare providers available that are properly trained in psychological care. Interestingly, HD nurses have also revealed that, due to their age or lifestyle, that they have no similar or limited life experiences to draw from to give advice to patients, and as such felt that they were not the best person overall to help patients cope with certain difficult life circumstances. From

Participant 1:

I feel like the easiest part of care is the routine tasks. Like, it's easy to initiate hemodialysis, it's easy to do the dressing on a central line or those, ah, nursing tasks that are easy. [...] The hard piece is that piece that's unique to [HD], which is that you get to know these patients. So it's, it could be challenging to hear, "Oh, remember my daughter who I told you, blank-blank-blank? Well now there's this awful thing that's happened,"

or “Now there’s this really great thing has happened,” or...somebody might say something to you like, “I want to stop [HD] but I just want to make it until my grand, my granddaughter is born, I just want to meet my granddaughter.” And you’re like, “Oh, my god.” Or they’re like, “I just want to make it to my son’s graduation,” stuff like that. Those are, that is a challenge. And I’m, I’m only 29, I don’t have a ton of life experience to...to be really of a valuable person to talk to about these kinds of things. So I find that that’s the challenging piece, like, how do you support patients dealing with complex life issues. Um...and you, you don’t have any real experience dealing with those issues.

(Participant 1, Lines 109-125)

It was repeatedly expressed throughout the interviews that, when faced with a constraint in care, HD nurses more often opted to prioritize medical care over psychological care, even if they recognized the importance of the latter.

Okay...we see, like, we have a medical background already...in time, we develop this clinical eye where you can see, just when the patient is coming in, if they are okay or not. That is the first thing, assessment that we do. By the time they are coming, you can know what the problem is, if they’re okay or not, and...more so if you do the further assessment. Those are the really easy parts [...] Ah, we’ve been doing this before, so...and continuous monitoring has also been part of our practice before, so...yeah, those are the easy parts of dialysis for us [...] The biggest challenge to me is the attitude of the patient...especially if they are new to dialysis. It can be...I know it’s hard, especially the acceptance part of it, and the...the challenges of going into dialysis for them. And sometimes there’s the denial part, and...we as nurses have to, ah, it’s our part to explain to them what was not explained to them or what is not making clear to them where they

have to go with hemodialysis. Sometimes it can be really time-consuming and emotionally-draining because...you can feel how hard it is go to into dialysis. (Participant 11, Lines 160-189)

In balancing the nuances between medical and psychological care in care provision, HD nurses must inevitably develop a therapeutic relationship with the patient to effectively provide psychological care. As per Participant 4:

Okay, this is where the compassionate and empathic nurse has to come in, um...sometimes I struggle, because, you know what, we nurses are human too, right? Um...we have things that happen in our lives, and we try not to bring in to our work, which I'm usually pretty good at, but at the same time, um...I don't know. My philosophy—as my mom's philosophy was—was that you got to just get on with it, um. You know what, engage with the patient, that's basically what you have to do is, become more compassionate, more empathetic. Especially when they're anxious, and depression can be more difficult to deal with because it's invisible...but you have to think, what can I do to reduce that anxiety. (Participant 4, Lines 399-408)

However, this therapeutic relationship can in turn lead to yet another negotiation in care associated with the chronicity of HD nursing: that between maintaining professional boundaries and maintaining a therapeutic relationship with a patient.

Professional Boundaries ↔ Therapeutic Relationship

In general, this sub-theme deals with HD nurses' ongoing negotiations of how much to share of oneself with patients in order to develop an effective therapeutic relationship. In the context of chronic illness and prolonged treatment, such as HD, building a therapeutic relationship between nurses and patients may involve more personal investment. In this

subtheme, *professional boundaries* denote HD nurses' perspectives on what comprises a professional nurse-patient relationship; this involves nurses' perspectives on specific social and emotional boundaries in place to preserve the professional nature of the relationship.

Alternatively, the *therapeutic relationship* focuses on meaningful, restorative rapport. Participant 3 shares this *professional boundary ↔ therapeutic relationship* balancing act in their interview:

...I've had a few patients like...really want to get to know me—in a polite way—but they ask like really personal questions too. And, um...they're like, "Oh, are you married? Do you have any kids?" And I know it comes from a place of, they're just being genuine and friendly, um, but from my experience, once you kind of open that door you can't really go back. Um, so I try my best to um...maintain a therapeutic relationship, you know, I try to be a little vague, turn it around on them, give them an opportunity to chat...(Participant 3, Lines 78-98)

Throughout the participant interviews, this subtheme is perhaps the most consistent experience discussed. When asked about giving advice to new HD nurses re: patient care provision, many participants encouraged new HD nurses, regardless of if they were new to the nursing profession or simply to HD care, to switch focus from the HD machine and nursing tasks and concentrate more on the provision of holistic care to HD patients. A few participants have shared in interviews that it was important for HD nurses to remember that there is a patient, a human being attached to the HD machine:

Yeah, for a new dialysis nurse I always promote good communication with the patient, I always tell them. You know, it is, a...we have to be a quality care-oriented nurse rather than a task-oriented nurse. If you have some time, with all that, despite all the...most of

the time we are busy, but sometimes if you do get time if you have a stable patient...then spend some time talking to the patient. (Participant 7, Lines 535-540)

Similar to Participant 7, Participant 10 stated:

...the best advice that I could give, ah, new nurses that go into hemodialysis is patience. Be patient with patients. [laughs] Especially for, ah, patients, ah...who are new to dialysis. They are in a state of denial so most of them would be...you know, having behavioural problems so if you'll just be patient with them, you know, over time, they will accept their situation. (Participant 10, Lines 498-503)

The predominant constraints that contribute to HD nurses' negotiations between *professional boundaries* and *therapeutic relationships* include HD nurses' perceptions of professional constraints; their willingness to share personal information and preferences of personal privacy; and HD nurses' own perceived inherent emotional capacities and resilience. Previous negative or distressing experiences associated with developing in-depth patient relationships may reduce nurses' emotional investment. In detailing a past patient relationship, Participant 4 states:

...so one day he just decided that he was going to turn his life around, you know. He started exercising, started eating properly, and, ah, you know, he just, it was just a miracle to see such a huge shift in his thinking and, ah...I was kind of going through an emotional period in my time, he was a good listener, so, we became connected not only through the dialysis but through, ah, what was happening to each of us, which was...and that's where I learned my lesson that you can't do that, you know? [...] I miss him terribly to this day because he's no longer with us [...] Him, I won't forget, just because of that one connection that we had, and maybe because I was the first to put him on [...]

He's in my memory forever, he just gave me things for me that were very nice that are a reminder of who, what he did for me as well, and...that's why you don't get attached to your patient, yeah. (Participant 4, 241-343)

HD nurses are keenly cognizant that HD treatment is not curative. If HD patients are not eligible for transplant, HD nurses are aware that they will eventually witness HD patients experience a decline of health or withdrawal from HD:

...it's hard to accept that all of these people, that we are taking care of, are sick people. And it's a, it always comes as a shock when somebody passes, right? [...] So...it took me a long time to accept the fact that these are not healthy people, people...our patients are not, they're very sick people, they're stable for a certain amount of time and they're having their ups and downs...but you never know what's happening or when something is going to happen. I think that's the hardest part for me...because I get attached, I get to know them, um...and, I, I believe it, it takes a heavier toll on us after we know them, after we establish this professional and therapeutic relationship with them and then, for whichever reason, they're passing away or becoming...to me, anyways, that's the hardest part. (Participant 12, Lines 126-172)

Due to the disease trajectory of CKD, the nature of HD treatment, and associated nursing care, it is evident that *professional boundaries* ↔ *therapeutic relationship* pose a significant balancing act for HD nurses in supporting patient coping and resilience. In particular, there is a clear, consistent element of moral distress with this negotiation in care.

Organizational Considerations ↔ Patient-Centered Care

In this balancing act, *organizational considerations* are any policies, procedures, system-level factors, and care directives that may not align with HD nurses' perceived aspects of *patient-*

centered care. In striving to support patient coping and resilience with their chronic illness and HD treatment, HD nurses at times felt that system-level care directives do not always provide the best care environment. A frequent example that participants mentioned involved patients with documented behaviour issues on HD treatment; patients who have had a pattern of verbal abuse and violence towards staff in past care instances. As per facility protocol, staff are instructed to notify security immediately when episodes of verbal abuse and violence occur as the facility has a zero-tolerance policy on such patient behaviours. However, as stated by Participant 8, patients may benefit more from having the root causes of their frustrations addressed versus simply focusing on attenuating negative patient behaviours:

Sometimes, we...have to understand what's going on with them the most, you know, rather than just saying, "Oh, you know, this is crossing the boundary," you know, sometimes, we have to understand them, what's going on with them...so, you know, let's just give some time for them. Um...rather than just saying, "Oh, no, this behaviour is not accepted," you know, or...sometimes, I see that in our unit, people call security for no reason, you know [...] sometimes just give them some time to settle, you know...we can say, "I can see that at this time you're distressed," you know...but that's all a short solution you know, it's...not, we're not dealing with the problem, actually. Um...and I don't know if the, even the doctors are not trained to do that, give psychological support, right? (Participant 8, Lines 155-168)

In a similar example, there are instances where HD patients can be non-adherent to their HD treatment schedule. Due to physiological concerns surrounding intermittent HD treatment, HD treatment must follow a regular schedule; at the same time, capacity issues at HD sites primarily require patient adherence to a provided, regimented schedule. Care constraints associated with

bed space, schedule time, staffing, or general resources can prevent the accommodation of last-minute patient HD schedule changes and drop-in HD treatment services. This has at times led to patients missing HD treatments or having to reduce their treatment duration, which can ultimately lead to inadequate HD, transplant ineligibility, and poor patient health outcomes. HD nurses both acknowledge and understand, however, that HD patients have to live and manage a life outside of their chronic illness and treatment:

...people always label those patients as “non-compliant”, “Oh, he never comes, he only comes for 2 hours,” but we forget to realize the reason behind his coming late, which is really very sad. [...] And whenever we say stuff like, “Oh, [Patient SM], you’re always so late, you’re not getting good dialysis,” he said, “Oh, I had work, I was working in [City], I’m just coming back,” you know, he’ll say, “I have to send my kids to university, I need money, I’m saving money for my children,” and then I felt...he forgot to live his life, he focused on, more on his family’s life, cutting down his treatment time and at the end...he should get a kidney, I was thinking, a new kidney, and then he will live longer and meet his goals. But, it didn’t happen...he had to quit, stop dialysis...at one point he was so frustrated with his life, obviously missing the dialysis treatment jeopardized his health. (Participant 7, 61-95)

... like at [Dialysis Site], we used to have a guy...and he was homeless, and he was spending a lot of time in shelters or out on the streets. And he will come hungry and shaking. And our guideline was not to give cookies, because he was not diabetic. But, if you think about it, if a starving patient comes in, does he care about dialysis or does he care about that one juice and few cookies that he gets? I always gave him juice and cookies if he asked for it. [...] I don’t know whether it was right or not, but guidelines are

guidelines. Like, it was only for diabetics, and for other patients at that time, we had a little bit limited supply. But I used that supply and I gave it to him. [...] So you kind of have to prioritize what the patient's needs are. So from a renal perspective, maybe giving cookies is not a good thing...but we have to look at what is the best, or what is the most needed necessity for this patient. We have to look from the patient's side. (Participant 5, Lines 354-400)

Overall, the balancing acts that HD nurses face in day-to-day care provision are extremely complex and interrelated. In care provision, HD nurses have relayed that they must negotiate their own perspectives with that of patients' perspectives, patients' medical and psychological care, and must also navigate the nurse-patient therapeutic relationship alongside organizational considerations. HD nurses are required to manage these complex negotiations in striving to support patient coping and resilience in this care setting.

In summary, "A good piece of research will make sense of something that clinicians ought to understand," (Thorne et al., 2004, p. 4). As an HD nurse, I strived to accomplish this in my analysis of collected interview data in this study. The findings detailed in this chapter illuminate specific negotiations in care that HD nurse experience and clarify particular care constraints in practice that contribute to the difficulties of these negotiations. In the following chapter, these concepts will be further explored with respect to current relevant literature and evidence-based practice in HD nursing. In particular, the negotiations in HD nursing care provision will be explored as to how the care in this clinical setting may be improved.

Chapter 5: Discussion

As presented in the previous chapter, the final research question of this study evolved to: “What negotiations in care do hemodialysis (HD) nurses experience in striving to support patient coping and resilience for chronic kidney disease (CKD) patients on chronic HD treatment?” Throughout the study interviews, HD nurses repeatedly spoke about negotiations in care provision, especially in striving to support patient coping and resilience in the chronic HD care setting. These negotiations in care were necessitated by diverse constraints experienced by HD nurses in the care setting, ranging from time constraints in practice to HD nurses’ perceptions of professional boundaries in nurse-patient relationships. Underlying these negotiations in HD nursing care was a persistent element of moral distress, albeit in varying degrees and explicitness.

As such, the concept of “negotiations in care provision” became the overarching theme of this study, with four subthemes of negotiations identified. These specific subthemes of negotiations in care include HD nurses’ negotiations relating to *nursing perspectives ↔ patient perspectives*; *medical care ↔ psychological care*; *professional boundaries ↔ therapeutic relationship*; and *organizational considerations ↔ patient-centered care*. In this chapter, these negotiations in care will be further discussed, specifically with regards to: (a) how these study findings relate to current literature; (b) the relation of negotiations of care to moral distress; (c) subsequent recommendations for education, practice, and research; and (d) study limitations.

Situating Study Findings within Current Literature

From the preceding literature review surrounding HD nurses’ perspectives in care provision (Chapter 2), it was found that HD nurses considered the nurse-patient relationship as central to HD care provision (Aasen et al., 2012; Kim et al., 2016) and largely cared for HD

patients using a holistic perspective (Doss et al., 2011; Hughes, 2004; Luer, 2013). With respect to HD nurses' negotiations in care provision, the findings from this study generally aligned with these findings from literature to date.

Throughout the interviews in this study, HD nurses confirmed that patients reliant on chronic HD treatment were observed to face a tremendous burden of disease, from their comorbidities and CKD to HD treatment. Corresponding with this high burden of disease was HD nurses' acknowledgment that HD patients were especially susceptible to—or were already experiencing—high rates of mental health concerns such as anxiety and depression. It is estimated that anywhere from 18.5 to 36.5% of people with CKD (Stages 1 to 5) have depression and depressive conditions (e.g., anxiety); people with end-stage CKD (Stage 5) on some form of dialysis treatment were estimated to have the highest prevalence rates of depression and depressive conditions at 36.8 to 42.0% (Palmer et al., 2013). In care provision throughout treatments, HD nurses strived to address these ever-evolving patient mental health concerns, in addition to attending to patients' shifting physical medical needs, to the best of their perceived ability and scope of practice. These findings resounded with the study conducted by Kim et al. (2016), where authors noted that HD nurses continuously reflected upon and empathized with HD patients' quality of life throughout continued care. This motivated HD nurses to consistently endeavour to establish strong, supportive relationships with patients and their families (Kim et al., 2016).

Findings from this study also further echo HD nurses' care experiences as examined by Doss et al. (2011), Hughes (2004), and Morehouse et al. (2001). In conjunction with the findings by Kim et al. (2016), these studies noted that the therapeutic nurse-patient relationship was a dynamic entity; as HD patients' psychosocial and physiological care needs changed over time,

HD nurses also strived to note these changes and adapt care provision and support accordingly. In comparing the HD nursing care experiences of participants in this study to that of literature to date, it is imperative to note the unique contemporary care environment that study participants have found themselves in with respect to the COVID-19 pandemic. The pandemic began prior to the commencement of the study and is ongoing at present; study participants are undoubtedly experiencing the reverberations and added stressors of the pandemic in both their personal and professional lives. As HD nurses, study participants must also support the CKD and HD patients in their care during the COVID-19 pandemic, and as such navigate the potential added mental stressors of the pandemic to patient health and mental wellbeing (Lee et al., 2020).

In tandem with aligning with current literature, the findings from this study can in turn be observed in past studies examining HD nursing care provision. Specifically, the different negotiations in care found in this study can be observed in other studies' exploration of HD nurses' care experiences. In the following sub-sections, each negotiation in care will be further discussed with respect to literature to date on this topic.

Nursing Perspectives ↔ Patient Perspectives

This negotiation of care pertains to the balance between nursing versus patient perspectives on what would best benefit patients' health and wellbeing. From the study interviews, this negotiation affects various aspects of nursing care—such as setting fluid removal goals for one HD treatment to long-term symptom management—and is well-documented in the literature (Aasen et al., 2012; Gronlund et al., 2015; Huber & Tucker, 1984; Hughes, 2004; Luehr, 2013; Woodcock, 1999). From past literature, HD nurses have reported being at odds at times with patients, especially in terms of patients adhering to HD treatment schedules and care recommendations such as dietary and fluid restrictions (Aasen et al., 2012; Huber & Tucker,

1984; Kim et al., 2016; Luehr, 2013; Woodcock, 1999). Although HD patients have been noted to have a good grasp of what was expected of them by nursing staff, HD nurses in past studies have acknowledged that nurses' and patients' perspectives on what "quality of life" entails can be markedly different and, as such, required compromise in day-to-day care (Aasen et al., 2012; Gronlund et al., 2015; Kim et al., 2016; Luehr, 2013; Wertz et al., 1977; Woodcock, 1999). To provide an example from the study, Participant 7 related their experience with a patient where the patient ranked their quality of life in terms of maximizing their time spent with loved ones, causing them to either miss HD treatments even if it resulted in symptoms of under-dialysis such as shortness of breath from hypervolemia. However, HD nurses—such as Participant 7—often view patient comfort as a primary component of quality of life, and hence may strive to negotiate with the patient about attending treatment versus spending time with loved ones. This negotiation can be observed as HD nurses discussing the shortening of HD treatment time with patients versus missing treatments altogether, or as in the case with Participant 7, striving to accommodate the patient's personal schedule as best as possible to allow for HD when they were able. As with HD care, the need to strike a balance between nursing and patient perspectives of quality care is even more important with consistent, repeated contact between nurses and patients in the chronic care setting (Doss et al., 2011; Hughes, 2004).

Professional Boundaries ↔ Therapeutic Relationship

As touched upon previously, the chronicity of care in CKD and HD lends itself to unique care settings and situations. HD nurses interviewed for this study were quite aware that meaningful rapport was important to facilitate a therapeutic nurse-patient relationship, especially as the HD care setting involved repeated contact with the same patients. However, HD nurses also conveyed concerns about being mindful of professional boundaries while repeatedly

connecting with patients. While some HD nurses maintained a deliberate emotional distance due to past distressing emotional experiences (e.g., becoming very attached to a patient that will soon pass away), HD nurses were primarily concerned about maintaining preconceived understandings of what constitutes an appropriate nurse-patient relationship. This negotiation of *professional boundaries ↔ therapeutic relationship* is not isolated to this study; HD nurses in past studies have alluded to this struggle in care provision (de Miguel, 2003; Hughes, 2004; Kim et al., 2016). From literature, HD nurses have reported forming strong attachments to long-term HD patients in their care, at times causing HD nurses distress that persisted beyond their work time if a patient's condition deteriorated (de Miguel, 2003) or leading to HD nurses in turn forming strong relationships with their patients' families and caregivers (Hughes, 2004; Kim et al., 2016). With these admissions, HD nurses acknowledged that it was at times difficult to determine and moreover maintain professional boundaries in the chronic HD care setting (de Miguel, 2003; Hughes, 2004; Kim et al., 2016). There is a clear aspect of moral distress that HD nurses appear to experience in navigating their care for CKD patients reliant on HD treatment.

Medical Care ↔ Psychological Care

The negotiation of *medical care ↔ psychological care* is perhaps the most pervasive; relating to the biomedical versus biopsychosocial models of care, respectively, this negotiation of care exists in many healthcare settings (Cabaniss et al., 2015; Wade & Halligan, 2017). The biomedical model of illness, and moreover approach to care, focuses on strictly attending to a person's physical ailments and needs. In contrast, the biopsychosocial model alludes to addressing a person's physical and mental health and wellbeing, in addition to potentially influencing factors (e.g., socioeconomic determinants of health). The strive to direct healthcare

towards a more holistic, less biomedical-centered approach has been a long-standing focus for patient-centered care (Cabaniss et al., 2015; Wade & Halligan, 2017).

Throughout the interviews conducted for this study, HD nurses acknowledged the importance of attending to patients' mental wellbeing but cited several reasons for why they at times focused solely on patients' physical health. For the most part, the reasons pertained to lack of time as well as a perceived inability to provide adequate comfort or address patients' psychological needs. Addressing patients' physical health (e.g., medication administration, bloodwork result assessment) typically took less time than attending to their psychological needs, which often require HD nurses to engage in in-depth discourse with patients to properly explore patient concerns. When faced with time constraints in practice, HD nurses reported prioritizing patients' physical health needs, which were also often more acute or high-risk, over patients' psychological needs. HD nurses in the study also reported that they sometimes did not feel properly trained or suited to provide counsel to patients; in these situations, HD nurses admitted to putting a deliberate focus on attending to patients' physical health needs. These study findings are analogous to what has already been detailed in literature, in HD care provision (Kim et al., 2016; Woodcock, 1999) as well as in general patient care settings (Cabaniss et al., 2015; Wade & Halligan, 2017).

Albeit less pronounced than the negotiation of *professional boundaries* ↔ *therapeutic relationship*, the negotiation of *medical care* ↔ *psychological care* appears to have a persistent element of moral distress associated with it. Despite HD nurses' evident acknowledgement of the importance of holistic nursing care to patients, especially in the context of chronic disease with CKD and HD treatment, there were many situations where HD nurses opted to provide a medical focus in care even though they recognized that this may have not been what the patient wanted.

This dichotomy between knowing ethically-correct care but feeling unable to pursue it creates moral distress (Deschenes et al., 2020).

Organizational Considerations ↔ Patient-Centered Care

It is important to reiterate that the “patient-centered care” aspect of this negotiation refers to HD nurses’ perspectives and ideals of patient-centered care, unencumbered by practice constraints such as lack of time and perceived ineptitude in attending to patients’ mental health and psychological wellbeing. This negotiation refers to how HD nurses must at times navigate between their ideals of what “patient-centered care” constitutes and organization- and systems-level considerations that conflict with those ideals.

Negotiations in HD nursing practice cannot necessarily be typified into one type of negotiation; at times, they can fit into different categories simultaneously. The negotiation of *organizational considerations ↔ patient-centered care* can often be traced to other different types of care negotiations as many practice constraints, such as a lack of time, are determined at a systems-level (e.g., nurse-patient care ratios). As an example, Woodcock (1999) found that HD nurses were keenly aware of CKD patients’ burden of disease and the importance of nursing care in impacting patient coping and resilience. However, nurses interviewed for the study also acknowledged the “production line” (p. 29) aspect of care in busy HD sites and its negative impact on effectively supporting patients (Woodcock, 1999). In these findings by Woodcock (1999), it is possible to view the specific negotiations in care of *medical care ↔ psychological care* as well as *organizational considerations ↔ patient-centered care*. As an aside, it is important to reassert that both organizations and systems can be patient-centered if designed in partnership and consultation with patients.

Overall, the findings from this study both support and are reflected by current literature on HD nursing care provision. Findings from this study do not appear to contradict any findings from past studies about HD nurses' experiences in care, but rather confirms and extends upon what has already been found. A unique aspect of these study findings is the more nuanced glimpse they offer regarding barriers and facilitators HD nurses experience in practice, in supporting patient coping and resilience as well as in general HD care provision. These facilitators and barriers will be expounded upon further in the following section of this chapter.

Hemodialysis Nursing Care Provision: Negotiations in Care and Moral Distress

In providing care to patients, HD nurses faced many practice constraints (e.g., time limitations, perception of professional boundaries, and organizational considerations). In general, these constraints appear to serve as inherent barriers to providing effective nursing support of patient coping and resilience. Albeit these constraints are not unique to HD nursing (Kieft et al., 2014; Rainer et al., 2018), alleviating these constraints in the HD care setting may detract from the need for HD nurses to negotiate certain aspects of care provision. It may be as simple as identifying care constraints and working to resolve them, e.g., clarifying role expectations for HD nurses and providing targeted education around professional boundaries. However, most care constraints involved in HD nurses' negotiations in care are complex and in turn require a multi-faceted approach to resolve. Present-day HD nurses are also part of the contemporary health delivery system and are expected to navigate care negotiations in tandem with supporting patient mental health and wellbeing in holistic care provision (Canadian Association of Nephrology Nurses and Technologists [CANNT], 2014; College & Association of Registered Nurses of Alberta [CARNA], 2019; College of Licensed Practical Nurses of Alberta [CLPNA], 2020).

Ultimately, having the ability to successfully negotiate care provision may help facilitate HD nurses' capacity to provide more balanced care, which is needed to address the high burden of disease and subsequent mental wellbeing of CKD patients on chronic HD (Gerasimoula et al., 2015; Li et al., 2018; Yong et al., 2009). Developing HD nurses' skills in negotiating care may also reduce the persistent aspect of moral distress apparent in HD nursing care provision.

As per Morley (2018), the concept of "moral distress" can be simplified to "the experience of a moral event, the experience of 'psychological distress', and a direct causal relation between [the two]" (p. 19). Despite being a normal response in experiencing a morally challenging situation, there are serious negative ramifications to prolonged and repeated experiences of moral distress, especially in the healthcare setting (Morley, 2018; Morley et al., 2019; Whitehead et al., 2014). For nurses, persistent moral distress in the workplace can lead to reduced job satisfaction, burnout, sub-optimal patient care, and even be a cause altogether to prompt nurses to leave the profession (Ducharlet et al., 2020; Karakachian & Colbert, 2019; Wyld, 2017). With respect to nephrology, the concept of moral distress for healthcare providers practicing in this specialty has been increasingly explored in literature the past few years (Ducharlet et al., 2020; Wyld, 2017).

From literature to date, moral distress in CKD care has been found to primarily precipitate from end-of-life care and care constraints, such as healthcare professionals' perceived ineptitude in providing quality palliative care (Ducharlet et al., 2020; Wyld, 2017). With respect to the findings from this study, however, I would argue that HD nurses experience moral distress not in response to care constraints, but rather in navigating negotiations in care provision that have in turn precipitated from care constraints. To provide an example: in a study by Gronlund et al. (2015) examining HD care provision in the palliative setting, HD nurses related ethical

dilemmas in providing treatment to patients for whom it presented little to no benefit to quality of life, relating back to the *nursing perspectives ↔ patient perspectives* negotiation in care. In their study, Gronlund et al. (2015) found that enacting more open and “deliberative dialogue” (p. 714) among the healthcare professional team—which include patients and patient families—can help set clearer goals for effective treatment, thus addressing the *nursing perspectives ↔ patient perspectives* negotiation in care. Overall, this dialogue helped to resolve moral distress among team members and improve satisfaction with provided care (Gronlund et al., 2015).

In short, HD nurses face an immense challenge in having to negotiate so many aspects of their care, which in turn may have a deleterious impact on the care that HD patients receive. Implementing directed initiatives to diminish the need for these negotiations, and moreover the practice constraints that gave rise to them, can provide HD nurses with more freedom to practice and better support the complex patient care needs in this setting (Bevan, 2007).

Recommendations for Future Initiatives

In this section, I will discuss recommendations for future initiatives that are reflective of study findings and aim to alleviate HD nurses’ negotiations in care provision. In particular, I will explore recommendations for future education, practice, and research initiatives.

Recommendations for Education and Practice

The findings from this study identify several areas for improvement relating to nursing education and practice in the HD clinical setting. Firstly, in endeavouring to support patient coping and resilience in HD, it is evident that HD nurses themselves experience emotional and mental encumbrances in care provision. This finding is not limited to this study and has been repeatedly noted in literature for some time (de Miguel, 2003; Deal & Grassley, 2012; Gronlund et al., 2015; Wertzel et al., 1977; Woodcock, 1999). From this study, HD nurses appear to

struggle most with balancing perceived professional boundaries in building meaningful, therapeutic relationships with patients. Even though many participants were aware that professional boundaries needed to be in place, it was unclear to participants whether these boundaries could be adapted based on the unique context of chronic HD care. Increased education and support for HD nurses on this topic, perhaps from local professional licensing bodies (e.g., CARNA, CLPNA), might alleviate some distress for HD nurses in navigating professional boundaries. Ongoing education from licensing bodies on relational ethics and therapeutic nurse-patient relationships, for example, across various care settings and offered to nurses, may be of help in addressing this potential care dilemma in other unique clinical areas (e.g., end-of-life care) (Canadian Nurses Association [CNA], 2017; CARNA, 2010). At present, there is also no formal syllabus for HD nurses undertaking further study. In this situation, it may be beneficial to compile a list of recommended educational topics for HD nurses to focus on and pursue in their personal continuing education and practice development. One such educational topic could be that of potential strategies to navigate moral distress in care provision, such as providing compassion- versus sympathy-based care as the former is associated with less moral distress (Orellana-Rios et al., 2018; Sinclair et al., 2016). Finally, targeted counselling or support initiatives for HD nurses, such as peer support groups and senior-new HD nurse mentorship pairs, could also be beneficial in providing ongoing emotional and mental support for HD nurses in care provision.

Secondly, numerous HD nurses in the study relayed that they did not feel prepared to counsel and provide ongoing psychological support to HD patients. Study participants were aware that many chronic HD patients experienced issues with anxiety and depression but did not feel that they were ultimately the best healthcare professional to help patients with those issues.

While HD nurses felt that they could speak to patients about their needs from a holistic perspective and refer appropriately as needed (e.g., referral to Social Work about unemployment aid), they did not have the time or expertise to attend to patients' mental well-being in-depth. It is also common for chronic HD patients to exhibit violent and aggressive behaviour (Feely et al., 2014; Janosevic et al., 2019), which HD nurses in the study largely recognize stems from unaddressed frustrations and mental health needs. Most HD nurses felt that the healthcare team at their respective work sites needed trained counsellors or psychologists to effectively address the complex mental health needs of HD patients. A renal psychologist service in some HD care systems, for example, has been observed to both help address patient mental health needs as well as provide counselling training and support for HD nursing staff (Combes et al., 2019). Alternatively, employers could also offer interprofessional counselling training for all members of the healthcare team (nursing, medicine, allied health) involved in HD care. This would increase HD nurses' skills and comfort in engaging in this type of discourse with patients; help distribute the responsibility of attending to patient psychological health among the healthcare team; and moreover improve the overall skill of the healthcare team in working together to support patient mental wellbeing.

Thirdly, there are opportunities for systems-level initiatives that may improve support to HD nurses in care provision. Throughout study interviews, HD nurses consistently related dissatisfaction around organizational care directives that at times conflicted with patient-centered care. Primarily, sources of dissatisfaction pertained to care directives around patient behaviour as well as time constraints of HD care provision and the rigidity of patient HD schedules. Some study participants highlighted systems-level care directives that they felt were not necessarily patient-centered in certain contexts; examples include providing food typically reserved for

diabetic patient emergencies to a homeless patient and staff deciding not to immediately call security for an aggressive display of patient behaviour despite organizational directives that encouraged otherwise. In the latter example, the participant was familiar with the patient and knew that giving the patient space to calm down and think would be more helpful to the situation versus calling for security and potentially escalating the situation. A thorough debrief of these types of situations, as well as reinforced open lines of communication between nursing staff and management, may help to alleviate comparable practice dilemmas that HD nurses may face in practice (Asikainen et al., 2020; Dafny & Muller, 2021). In addressing the time constraints associated with patient HD schedules, spacing out HD schedules to augment nursing time with patients, with consideration of multiple factors (e.g., patient preferences, available spots, and unit operations), may require the use of further innovation and technology. Possible examples include making patients responsible for their booking times, versus Nurse Clinicians managing patient HD schedules, or using specialized computer programs to optimize scheduling capacity (Fleming et al., 2019; Liu et al., 2019).

Recommendations for Research

Alongside recommendations for nursing practice and education initiatives, more research is ultimately needed to better understand the care experiences of HD nurses. As reflected by HD nurses' interviews and from literature to date, HD nurses experience high levels of moral distress in navigating care provision in the HD setting. It was noted in this study that HD nurses negotiate aspects of their care in order to provide patients the best possible care to their ability, culminating in situations of personal dilemma. From previous studies, HD nurses have also related moral dilemmas surrounding other areas of care, such as negotiating power imbalances between healthcare providers and patient and patient families (Aasen et al., 2012; Kim et al.,

2016); providing HD treatment to patients who may not desire it or were receiving more harm than benefit from treatment (de Miguel, 2003; Gronlund et al., 2015; Woodcock, 1999); and dealing with patient loss after a strong relationship has been established over time (Hughes, 2004; Kim et al., 2016). More in-depth research into this phenomenon, the notion of moral distress in HD care provision, may serve to better understand this topic and illuminate strategies to improve support for HD nurses and other members of the healthcare team. Although there is a sizeable body of literature on moral distress in the healthcare setting, more exploratory research is needed to better understand the nuances of moral distress among HD nurses specifically.

Study Limitations

To start, it is imperative to mention here that I am an HD nurse. As aforementioned in the Methods chapter (Chapter 3), my experiences in HD nursing care afforded me a unique knowledge base to understand and connect with the interview data as per the ID tradition (Thorne, 2016). Conversely, there is a risk that my role as an HD nurse—and the accompanying perspectives, beliefs, and experiences I have cultivated in that role—may have inadvertently influenced my data interpretations. To minimize this risk, Thorne (2016) stresses the importance of reflexive practices, such as journaling, to track potential personal biases and trace analyses. Even though I did journal throughout the study for the purposes of reflexivity (Appendix C), there remains a possibility that my HD nursing care experiences may have affected my analyses.

The other limitations noted in this study predominantly related to recruitment and sample representation. At the outset of the study, the aim for recruitment was at a provincial level, to interview HD nurses from across the province of Alberta under the Alberta Kidney Care (AKC) program. AKC is divided into two programs based on geographical region: the North (AKC-N) and South (AKC-S). Though recruitment was conducted for both AKC-N and AKC-S, all

participants in this study were from AKC-S. A likely reason for this may be my current employment in AKC-S and subsequent pre-existing relationships that I had with participants, all of whom I have either previously worked with before in HD care or know through mutual colleagues. Despite strategies to prevent participant coercion in recruitment (Chapter 3), HD nurses who knew me outside of the study may have been more willing to participate upon learning I was conducting the study—perhaps out of eagerness to support a fellow HD nurse. This pre-existing relationship between myself and participants may have also affected interview data collection, as study participants with whom I have worked with in the past may have been more open to share their experiences given our past rapport. However, it is difficult to conclusively discern how a pre-existing relationship influenced interview data as there is no comparable interview data with participants unknown to me before the study. In addition, it is difficult to determine participant response rates with respect to recruitment. Although there is data on the number of Registered Nurse (RN) and Licensed Practical Nurse (LPN) full-time equivalent staff in the provincial renal programs (Chapter 3, Appendix E), I do not have access to data regarding the total number of prospective eligible participants that were made aware of the study.

Another limitation related to sample representation was that interviewed HD nurses in this study were largely RNs, despite all recruitment material specifically identifying that both RNs and LPNs were eligible to participate in the study (Chapter 3). Of all HD nurses that participated ($N = 12$), only two participants were LPNs. It is unclear as to why this incongruity occurred; due to the study's initial eligibility criteria, however, LPNs were eligible to participate and interested LPNs were thus interviewed for the study. Nevertheless, further research is needed

to discern the LPN perspective around HD nursing care provision, especially as AKC has comparable staffing levels of both RNs and LPNs.

Lastly, there were study limitations that stemmed from pandemic precautions incorporated into the study (Chapter 3). From the start of recruitment to the time of the last interview conducted for the study (October-December 2020), Alberta was under public health restrictions considering the COVID-19 pandemic. These restrictions curbed travel and in-person contact, in turn posing limitations to recruitment and data collection. Recruitment solely occurred via email distribution of an electronic poster and all interviews were done online (via ZOOM) or via phone. In non-pandemic circumstances, I would have liked to visit various HD sites, in AKC-N and AKC-S, to raise awareness of the study and promote participation in the recruitment phase of the study. Similarly, I would have much preferred to conduct interviews in-person. Most study participants preferred to be interviewed via phone without a video option, which may have affected my ability to interview effectively and in turn collect study data. In conducting and analyzing research interviews, I feel that I am a more effective interviewer in-person as I can gauge and analyze participants' body language and facial expressions in addition to their dialogue. However, participants may have also shared more in phone interviews for the study as they are afforded more privacy and perhaps felt more comfortable than they would have in an in-person interview.

A Reflection on Next Steps

In summary, it was found in this study that HD nurses, in striving to support patient coping and resilience in the HD clinical setting, engage in various types of negotiations of care in their practice, especially in striving to support patient coping and resilience in the HD clinical setting. Overall, findings from this study are reflected in the literature to date on HD nursing

care. There is an underlying current of moral distress threaded through many of the subthemes that HD nurses seem to experience in care provision, and the negotiations of care that they experience contribute to that moral distress. Although identifying and better understanding these negotiations of care have illuminated opportunities to better support HD nurses and improve their experiences in care provision, more research is ultimately needed to enhance comprehension of and further alleviate moral distress in the HD care setting. With respect to findings from this study, however, my present goal is to engage in knowledge translation activities. In the following chapter of my thesis, I will detail my plans for knowledge translation.

Chapter 6: Conclusion

“When you get, give. When you learn, teach.”

- Maya Angelou (1990, p. 33)

For my thesis research study, I wanted to better understand hemodialysis (HD) nurses’ experiences in supporting patient coping and mental wellbeing in the chronic kidney disease (CKD) and HD care setting. Throughout my interviews with HD nurses, however, it became evident that HD nurses faced a multitude of barriers to optimal care provision. Although HD nurses largely recognized the high burden of disease for patients associated with CKD and HD treatment—and its deleterious effects on patient mental health—their endeavours to support patients ultimately led to various negotiations in care. These negotiations resulted in a host of difficulties for HD nurses in effective care provision, ranging from uncertain boundaries in therapeutic nurse-patient relationships to long-lasting moral distress.

Since my first day in graduate school to writing the concluding chapter of my thesis, I feel as if a lifetime has passed in the span of four years. When I began graduate school, I was a floor nurse in CKD and HD care; since then, I have become a clinical nurse educator in HD. As an educator, one of my primary roles is to train and orientate nursing staff to the world of HD and HD nursing care. This shift in my professional role has afforded me both a new lens in understanding HD nursing care as well as a renewed desire to better support HD nurses in care provision. In this chapter, I will discuss my plans for knowledge translation (KT).

Knowledge Translation

According to the Canadian Institutes of Health Research (CIHR), KT is concerned with “raising knowledge users’ awareness of research findings and facilitating the use of those findings” (CIHR, 2012, p. ii). There are two main types of KT initiatives: *end-of-grant KT* and

integrated KT. End-of-grant KT focuses on knowledge dissemination (e.g., presentation of findings to key stakeholders), diffusion (e.g., peer-reviewed publication), and application (e.g., use of study findings in tool development). In contrast, integrated KT refers to research initiatives which directly involve knowledge users as partners in the research process, with the intent to garner new knowledge that is relevant, practical, and readily accessible to knowledge users (CIHR, 2012).

Knowledge Dissemination and Diffusion

My plan for knowledge dissemination first involves a report of my study findings to key stakeholders: staff and personnel in Alberta Kidney Care (AKC). Following the finalization of my thesis, I hope to present my findings to key stakeholders in AKC by means of an online presentation and a written report, detailing the primary findings of my study and potential follow-up initiatives. In terms of knowledge diffusion, I am also planning to present my study findings, via conference presentations and publications, to the wider professional and academic community in nephrology nursing. I hope to specifically present and publish with the Canadian Association of Nephrology Nurses and Technologists (CANNT), in the annual CANNT conference and the *CANNT Journal*, respectively.

Knowledge Application

This type of end-of-grant KT alludes to the operationalization of acquired knowledge, or knowledge-to-action initiatives (CIHR, 2012; Straus & Leung, 2010). As HD nurses appear to enact negotiations in care that differ in scope, however, it is difficult to develop overarching recommendations and moreover comprehensive KT initiatives that utilize study findings to improve support for HD nurses in care provision. To provide an example, the negotiations of *nursing perspectives ↔ patient perspectives* and *organizational considerations ↔ patient-*

centered care relate to negotiations in care at the nurse/patient-level and systems-level, respectively. Well-designed interventions to alleviate specific negotiations in care would thus require tailoring for that particular scope. The former would involve initiatives that focus on building the nurse-patient relationship; alternatively, the latter would require system-level changes, like modifications to the booking model for HD treatments. Though these KT activities have potential for application, more information is needed prior to implementation in practice. These KT activities may thus benefit from further study, perhaps in the form of a quality improvement project, to discern how best to address specific negotiations in care with tailored interventions. In keeping with my KT plans for knowledge dissemination, I plan to communicate these potential quality improvement projects—in tandem with my study findings—back to key stakeholders within AKC.

Overall, however, interventions that focus on equipping HD nurses with strategies to effectively navigate negotiations in care may prove to be the most feasible option. These interventions can include negotiation-targeted initiatives, such as educational sessions about professional boundaries and the therapeutic nurse-patient relationship in the context of chronic care (*professional boundaries ↔ therapeutic relationship*). Other interventions can also center around addressing the moral distress that HD nurses experienced in care provision, which was observed across all narratives of negotiations in care. Counselling sessions offered on a by-need basis, regular de-brief sessions, and peer-to-peer support groups for HD nurses in relation to patient care are some example initiatives that may aid HD nurses as they continue to care for patients in this care setting. In presenting my study findings to key stakeholders in AKC, I also hope to further discuss and bring forward these possible avenues for KT pertaining to the findings of this study.

Moving Forward in Hemodialysis Nursing Care Provision

At the beginning of this chapter, I chose a quote by Maya Angelou that has tremendous significance to me—a summation of my learnings in researching a topic of personal importance. As a researcher and as a colleague, I feel immense gratitude to the HD nurses who participated in my study and disclosed their joy, struggles, and overall experiences in caring for chronic HD patients. In my gratitude, I feel beholden to share the collective experiences of the HD nurses interviewed for this study, and to ultimately work towards initiatives that can address and alleviate their recounted negotiations in care provision.

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Appendix A

Research Study Timeline

Exploring the Perspectives of Hemodialysis Nurses in Care Provision: An Interpretive Descriptive Study	Timeline																
	September 2020 – December 2021																
	Sept 2020	Oct 2020	Nov 2020	Dec 2020	Jan 2021	Feb 2021	Mar 2021	Apr 2021	May 2021	Jun 2021	Jul 2021	Aug 2021	Sept 2021	Oct 2021	Nov 2021	Dec 2021	2022 —
Stakeholder Engagement, Recruitment, and Data Collection																	
Identify and engage key stakeholders from Alberta Kidney Care-North and -South programs	X	X	X													X	X
Obtain ethics approval (Conjoint Health Research Ethics Board)	X	X															
Recruitment process: distribute electronic media to raise awareness of study		X	X														
Data collection: semi-structured interviews and interview transcription		X	X	X	X												
Data Analysis																	
Data analysis: ongoing interview transcription and data analysis		X	X	X	X	X	X	X	X								
Preparation and Dissemination of Findings																	
Preparation and finalization of findings into thesis format with supervisor and supervisory committee										X	X	X	X	X			
Thesis defense and submission to university repository															X	X	
Dissemination of primary findings to key stakeholders from Alberta Kidney Care-North and -South programs																	X

Research Study Budget

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Appendix C

Sample Journal Entries

November 2020

- *Second interview (P2).* This interview was done via ZOOM with video enabled (as per participant preference)—as I anticipated, I enjoyed this interview format more (as compared to the via phone); I felt I could engage with the participant more and I was more comfortable in reading their facial expressions to take cues for interviewing. The main takeaway I had from this interview was the struggle and frustrations the participant expressed in their HD nursing care—particularly around wanting to comfort patients or address their emotional and psychological needs but feeling as though they did not have the time in practice or the skills in counselling to do so. This resonates with what P1 stated in their interview...as well as my own experiences in HD care, to be honest. I can especially appreciate P2's reported advice to new HD nurses—to not stress the “small stuff” about specifics on the HD machine, etc., but to keep both the “big picture” of patient care and the HD machine in mind. In my new role as an educator in HD care, this is what I always hope to convey to my orientees as well.
- *Third interview (P3).* This interview was done via ZOOM with via enabled as per patient preference. For the same reasons re: the interview with P3, I prefer this means of interviewing better. From this interview, what really struck me was this was the first time the patient mentioned professional boundaries and how they can get blurred in chronic care. I remember thinking about it from the interviews with P1 and P2; although I thought they alluded to that concept, it was P3 who explicitly mentioned it. P3 is also the first person to bring up the concept of moral distress—specifically around providing care to

patients who do not show up for HD treatment or have their own views regarding medications and do not adhere to recommendations. In retrospect, I feel as if I should have pursued or explored the topic of moral distress more with P3...but I was very focused on their experiences instead with juggling rapport-building/emotional and personal investment in nurse-patient relationships with their views on professional boundaries.

- *Meeting with Supervisor.* Eloise and I had a meeting to touch base with how recruitment and interviewing is going. My main concerns were my rate of recruitment (I only have one interview lined up right now) and the fact that none of my participants were mentioning their perspectives on supporting patient coping/resilience in care provision unless directly asked. I did not include it in my interview guide as I did not want to lead participants. After discussing with Eloise, however, I think I will add more direct questioning about supporting patient coping/resilience in care...perhaps with an initial preamble about what patient coping/resilience is and why it's important (e.g., high incidence of depression and anxiety in HD patients, etc.). I will also ask my unit manager—and moreover the other unit/patient care managers—to re-send out the recruitment material to keep pace on recruitment and interviewing. In addition to the rate of recruitment, only RNs have been reaching out to me to participate in the study; to date, I have not had any LPNs expressing interest in participating or being interviewed for the study. I thought I was quite clear in the recruitment emails/material that both RNs and LPNs are eligible for the study, but perhaps I need to be more direct—in sending out another recruitment email, I will change the wording somewhat to explicitly mention that RNs and LPNs are eligible. If I have any further issues with recruitment in the next little

while, I may consult my supervisory committee further about their thoughts on how to bolster things!

- *Fourth interview (P4)*. This interview was done via ZOOM with video enabled as per participant preference. As I discussed with Eloise, I did directly ask about the participant's thoughts on care provision and patient coping/resilience...I thought P4 had a beautiful reply about just trying to be compassionate throughout care provision, because you never really know what someone is going through. What really stood out for me though during this interview was P4's story about a patient they became close to over chronic care and then the patient passed away—as P4 was close with the patient, they were invited to the patient's funeral, which P4 attended. P4 stated that they still miss the patient to this day, despite them having passed on a few years ago...and P4 also intimated that because of that, they could never form that type of attachment to patients again and now tried to keep their emotional distance. Overall, this anecdote made me sad—to think that meaningful nurse-patient relationships are possible but because of the emotional toll it takes when patients inevitably pass on, nurses feel the need to pre-emptively protect themselves. Again, it is something I can relate to, as I also attended the funeral for an HD patient that I had cared for since I was a nursing student. From the interviews I've had to date, it is evident that there is a pervasive struggle that HD nurses face in care provision that is tied up in the unique way HD is set-up—in its chronicity of care, the movement of patients from different kidney services, etc.
- *Fifth interview (P5)*. This interview was done via phone. My main takeaway from this interview was P5's in-depth focus on getting to know patients and developing a deep rapport with them; they brought this topic up even before I specifically asked about HD

nursing care provision and supporting patient coping and resilience. I felt that P5's responses very much echoed that of P2's responses, where they both differentiated between two aspects of HD nursing care—the medical, HD side of things in addition to the psychosocial aspect of it. In reviewing both transcripts, both P2 and P5: (a) acknowledged the importance of both sides of HD nursing care, but (b) also alluded to the notion that the psychosocial aspect of HD care provision falls by the wayside for a whole host of reasons. Another notable item that P5 brought up was something previous participants had not mentioned: the notion that system policies/practices at times conflicted with meeting HD patients' needs outside of the HD setting. P5's anecdote about a homeless patient being given food—food otherwise reserved for diabetic patients' glycemic emergencies—really stood out to me. I don't recall the previous participants alluding to something like this. In retrospect, system-level properties of care, like nurse-patient ratios, were mentioned by P1 and P2 and could affect patient care, but the example that P5 brought up directly contrasted system care directives and their desire to provide holistic patient care. It would be interesting to see if other participants also bring this topic up in their respective interpretations, prompted or no.

December 2020

- *Twelfth interview (P12)*. This interview was done via phone. With this interview, in tandem with P10 and P11, I think I've reached data saturation—at least with this particular set of interview data I've collected from participants anyways. P12's interview data very much brought me back to the interviews with P1, P2, and P4—the underlying albeit resounding theme of distress and the struggle of participants in developing

meaningful connections with patients who (a) may not be feeling the best at times—and thus are vulnerable in their sadness, anger, and frustration—and (b) patients who are mostly, irrevocably, in the last stages of their lives. What really resounded with my own experiences, and that of P4's, from P12's interview was the admission that it's relatively easy to forget that your patients are really sick—they may be stable, but they are sick nonetheless; when HD patients' health begins to deteriorate, their health can deteriorate quickly because of their predisposition, and it can be jarring when they do pass on as you are so used to seeing them, caring for them, a few times a week. I felt that there was no new data that came from this interview, but the data that I did glean from it was quite powerful in relating the struggle of HD nurses when they do achieve that meaningful connection with patients in their care.

April 2021

- *Notes on Analysis.* Looking back at my previous journal entry, I felt like some of the thinking work I had to do was relatively easy—like reformulating my research question and clarifying the concept/definition of what a ~~“balancing act”~~ “negotiation in care” is and how can arise (constraints and limitations in care provision!). What I've been finding the most difficult thing so far, however, is distancing (but not separating) myself and my own HD nursing practice from that of study participants'. From my last meeting with my committee, a feedback/reflection from the committee regarding my findings was the notion that care constraints are not the only contributors to negotiations in care; it can also be HD nurses' education/perceptions/approach to practice that can lead to these necessary negotiations. Perhaps the best example of this would be HD nurses'

perceptions of what professional boundaries constitutes, and how professional boundaries can change—and perhaps need to change—in the unique context of chronic patient care and developing that therapeutic nurse-patient relationship to be an effective relationship. I think this was difficult for me to hear/realize as I am an HD nurse myself; I strive to the best that I can be in my practice, and as such learning that I may not have been providing the best patient-centered care that I could have been...that was challenging for me to accept and process. However, I ultimately felt like I needed to process this and make peace with it in my own practice before I could resume and organize my analyses in an impartial way—from being so close to interview data, I knew my committee's assessment of this was accurate, but it was hard for me to accept this, never mind write it down as part of my analyses. It took some time and I had to step away from things for a bit—I baked, took walks and bike rides, thought about things over teas and coffees—after a few weeks, I felt I had come to terms with this and could accept that there were specific ways I could improve my practice as an HD nurse.

Appendix D

Sample Analysis and Coding Notes

Sample Interview Transcript (Participant 1)

Interview Transcript – Participant 01		Interview Transcript – Participant 01	
Interviewer (I), Participant (P)		Interviewer (I), Participant (P)	
1	I: Okay, so thank you so much for participating in the study. Just a few	43	
2	interview questions, I started recording now.	44	I: Could you please describe your experiences so far in caring for patients on
3		45	chronic hemodialysis treatment?
4	P: Okay.	46	
5		47	P: Sure. Um, it's different from I'm accustomed to...because, even in nursing
6	I: [Participant 01], can you tell me your nursing designation?	48	school you know of those clinical experiences but you don't get to know,
7		49	like you don't see people on a regular basis for years at a time? So that's a
8	P: Registered Nurse.	50	big piece that I find different from the type of care I'm used to. Usually
9		51	there's an accident, or you have a gall bladder attack, or diverticulitis or
10	I: And what is your age?	52	something like that, and we fix you up and send you home...but this is
11		53	different in the sense that you really get to know these people and their
12	P: 29.	54	families and what they've gone through and their past medical history,
13		55	you're sort of with them. And that's how I find hemo to be very different
14	I: What gender do you identify as?	56	from any other nursing experience I've had. Even in home care, you don't
15		57	typically spend that time with people—they might have a wound or
16	P: Female.	58	something that you have to help them manage and it heals or they get an
17		59	amputation and then they're sort of off your list again.
18	I: And how many years have you worked in hemodialysis?	60	
19		61	I: Oh, okay.
20	P: Uh, just over two now.	62	
21		63	P: Yeah, so I guess, uh...it's different. You get to see people, even on—they
22	I: Okay. Have you worked in other clinical areas or settings?	64	can't hide their bad days. Like, I remember we had this one lady who came
23		65	in and she must have had a fight with her husband [laughs]...
24	P: Yeah, I used to work in burns and plastics...burns and plastics and has a	66	
25	little bit of [general surgery] overflow. [laughs] Very different world.	67	I: Oh, no.
26		68	
27	I: Oh, and how long have you worked in that area?	69	P: [laughs] He called the unit, yeah, he called the unit and was, like, "Tell so-
28		70	and-so that I love her," and you're like, "Oh, no, now I'm sort of dragged
29	P: I worked there since graduation and then I moved to Alberta, maybe, a	71	into the middle of this, [laughs] should I go tell her or should I say, "You
30	year and a half into that position. Then I took a management role in a home	72	should just call her or talk to her after treatment", so...it's a different beast,
31	healthcare company...um, Bayshore, I don't know if you know them	73	I feel like.
32	but...and then I didn't really...I prefer to be bedside nursing, I prefer to do	74	
33	that. And so then I took a job with AHS and it happened to be hemo.	75	I: Mm.
34		76	
35	I: Oh, okay. Great. And I'm sorry, that was two years in hemodialysis?	77	P: Even if I imagine you've been in hemo for, like, 20 years, like...people get
36		78	transplanted out and then come back when their transplant begins to fail,
37	P: Yeah.	79	or something like that...or [peritoneal dialysis] is working well for a couple
38		80	of years and then it fails, so...I could see knowing somebody for the entire
39	I: Great, we're lucky to have you in hemo. Yeah, so I'll get right into the	81	length of your career.
40	research study questions.	82	
41		83	I: Yeah, I think for other senior nurses, I think they've told me that [laughs].
42	P: Sure.	84	

chronicity / regularity of
care = in-depth "knowing"
of patients, families,
medical history

↳ unique to HD

exposed / involved in
pt's "bad days"

↳ "can't hide"

↳ "charged into the
middle"

— unwilling
participant,
level of
involvement?

enduring relationship
w/ pts through
the years

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

85 P: Oh, really. Yeah, and even if it's, like...when you talk about genetics and
86 predisposition...then you're meeting their children. Like that...that's pretty
87 wild. They're affected by the same sort of disease that...yeah, so I mean,
88 that's the big...I mean, in terms of nursing care and patient care, a lot of it is
89 the same...that's the only piece that I've picked up on so far that's
90 shockingly different from what you learned in school, any your clinical
91 experiences, like my previous job...that's the piece that I would say is a lot
92 different and unique to hemo...or kidney care in general, I guess.

93
94 I: Could you...so what you would say has been the easiest aspects of caring
95 for this patient population?

96
97 P: Like the easiest?

98
99 I: Yeah, or...what do you feel is most important to you in day to day care.

100
101 P: Uh, yeah, okay...I'll answer the first one. I feel like those are separate.

102
103 I: Oh, okay. No, that's good.

104
105 P: I mean [laughs], is it okay if I split up that question.

106
107 I: Mhm.

108
109 P: I feel like the easiest part of care is the routine tasks. Like, it's easy to
110 initiate hemodialysis, it's easy to the dressing on a central line or those, ah,
111 nursing tasks that are easy. They're routine, there's a set guideline that you
112 follow, that's definitely those. The hard piece is that piece that's unique to
113 hemo, which is that you get to know these patients. So it's, it could be
114 challenging to hear, "Oh, remember my daughter who I told you, blank-
115 blank-blank? Well now there's this awful thing that's happened," or "Now
116 there's this really great thing has happened," or...somebody might say
117 something to you like, "I want to stop hemodialysis but I just want to make
118 it until my grand, my granddaughter is born, I just want to meet my
119 granddaughter." And you're like, "Oh, my god." Or they're like, "I just want
120 to make it to my son's graduation," stuff like that. Those are, that is a
121 challenge. And I'm, I'm only 29, I don't have a ton of life experience to...to
122 be really of a valuable person to talk to about these kinds of things. So I find
123 that that's the challenging piece, like, how do you support patients dealing
124 with complex life issues. Um...and you, you don't have any real experience
125 dealing with those issues. That's, that's the challenging piece, and then the,
126 so I guess, the therapeutic communication piece for these types of patients

↓
enduring
relationship cont.
↳ expanded to
pt families
i.e. (genetic
predisposition)

] easiest vs. most important
(separate entities)

↓
routine
tasks
(w/ PDD to
rely on)
(technical
care)
(vs. getting to
know Pts)
↳ helping Pts
deal w/ "complex
life issues"
↳ how to (not
pg)
deal w/ some
strategies?
↳ young age
= life experiences
= advice?

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

127 can be extremely complex. Whereas the nursing care itself, like the
128 technical care, that's easy. You can look up bloodwork, titrate medications,
129 or change HD prescriptions but...that is challenging to talk to people dealing
130 with pretty heavy life situations and life decisions.

131
132 I: Yeah. Have you developed any strategies, I guess, to manage those
133 difficult conversations you were talking about?

134
135 P: Um...I think the strategy, for now, until I become like, the...there's a few
136 nurses on the unit that are really good at this, maybe because they're older
137 and they have a few more like experiences...that's what I tell myself
138 anyways [laughs]...um, I just think that, now all I can do is be a listening ear
139 for them. And maybe they don't want to talk about some of the stuff at
140 home because maybe it involves some of the people at home? So like,
141 sometimes I feel like they talk about tough decisions on the unit like
142 wanting to stop hemodialysis but their family member doesn't want them
143 to, so they can't really talk about it home, so...all I really can do is be a
144 listening ear and, you know, I can point them in the direction of the
145 multidisciplinary team, like social work or whatever. But I don't feel like I
146 have developed any real strategies...[laughs] beyond that.

147
148 I: Yeah.

149
150 P: Just, just listening. You know, you're a nurse...you just want to provide,
151 or like, do something, you know? You want to fix things. That, that's
152 challenging when you feel like there's no good answer or no real...good
153 option I can provide you other than just...to listen. It's kind of sad.

154
155 I: No, I mean, I can understand, especially for chronic issues. It's such a
156 short span of time you're with them, right?

157
158 P: Yeah, there's that as well. You could be...it feels really [sigh]...like,
159 disingenuous to listen to somebody tell you something very personal about
160 their...granddaughter or whatever it is and then you're, "Okay, yeah, we'll
161 chat more, I'll just put on your neighbouring patient and then I'll come
162 back." Sometimes you don't get back there for an hour and half or
163 something and you feel like, "Oh, maybe they don't want to continue to talk
164 about it," but you told them you would, so now you're navigating this kind
165 of murky water of like, "Should I bring it up?" or "Maybe I'll just leave it and
166 see if they bring it up again,"...or maybe now they have their headphones
167 on...




→ supporting pt coping
+ resilience
~ being a "listening ear"
~ navigator for appropriate/
more involved HCPs to
be participating in pt
care re: issues

nursing care = "fixer"

↓ barriers to optimal
care
~ routine of work
~ timing/time
~ privacy (next page)

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

169 I: Yeah.
170
171 P: There's just a curtain dividing them from another patient, and now, "Hey,
172 remember that really personal thing that you brought up earlier before
173 everyone got here? Well, now I have some time to listen and there's just a
174 curtain dividing you...you want to talk about it?" Like, ugh, it's tricky.
175
176 I: Yeah. So I guess, listening to your experiences...you mentioned before, I
177 said something like "What are the easiest or most important aspects of
178 caring for chronic HD patients?" and you said, "The most important thing is
179 different from the easiest thing,"...what would you, could you speak more
180 to that? What would you say is the most important aspect...
181
182 P: Oh yeah, I guess I didn't really answer that. What's the important...I
183 guess it depends which hat you're wearing, if you're wearing the nursing
184 hat, well, care, having the highest standard of care is most important. So
185 you need to make sure, you know, their bloodwork is aligned with their HD
186 values, let the nephrologists know, that they're feeling as asymptomatic as
187 possible, you know, as best we can, for where they're at in their disease
188 process. But if you wear your human hat, you might think, like, well, all of
189 that is important and something we're working on but it might just be less
190 important than a patient feeling hurt or supported...I can't say if one is
191 more important than the other because it might be patient-specific.
192
193 I: Mm.
194
195 P: The patient may be dealing with insomnia and they may have this
196 baseline level of, like, "You know what, I've been dealing with insomnia for
197 years now and nothing seems to work, um...but let me tell you what my
198 granddaughter did on the weekend." So it doesn't feel they want to...your
199 nursing side is like, "Well, let's see if we can dig a little deeper, maybe
200 there's something new we can do," or maybe, "You haven't heard of all of
201 the things that we can do," but...you don't get the sense that they want to
202 dive into that? They want to tell you about...whatever their husband or son
203 or family members' been doing? So I don't know if I can say what's...more
204 important, it might just be more patient-specific and that might change
205 over time. You might think, like, the insomnia doesn't appear to be bother
206 her as much but she wants to talk to you more about...different foods to
207 try, more of what she's eating...um, but then next month the insomnia
208 might be affecting her differently so now that is a priority for her. So I don't
209 know, what...I guess it's patient-specific, really, that would be the most

nursing = different roles
("hats")
→ nursing vs. human "hats"
separated by participant
(are they really different?)
= boundaries vs. (professional) therapeutic relationship
balancing act? 
does chronicity of care
affect the urgency
w/ which things
are addressed? 
medical needs vs. psychological concerns
HCP perspectives
of pt QoL benchmarks
vs
Pt perspectives of same


Interview Transcript – Participant 01
Interviewer (I), Participant (P)

210 important part of the care. Like is it the emotional, psychological side of
211 things or is it the physical side of things.
212
213 I: Yeah...so in wearing those different hats that you said...involves the care
214 that we provide our patients...like, what hat do you feel like you wear the
215 most?
216
217 P: I would say the nursing one. You tend to go back, sort of, to your training
218 and your education and think, "How can I support, ah, support them
219 through this?" Maybe...and I'm just throwing out, like, kind of random
220 examples...but, "Maybe these issues that you're having at home may be
221 better solved if you're getting a good night's sleep, maybe you'd be a bit
222 more approachable," you know? Maybe something like that, you know? So
223 that is where we usually, at least for me anyway, I tend to fall back on, "Oh,
224 there's a medical reason for why you're feeling this way, maybe I can help
225 to fix it to change something else."
226
227 I: Mm.
228
229 P: And that, I don't know if that's the answer, or if that's my
230 training...maybe a social worker may view this entirely different than how I
231 see it, but. It makes you feel like you're doing something too, maybe
232 [laughs] maybe it's more of a nursing problem. You know, like you're
233 helping, even though...you are helping, though maybe not necessarily how
234 a patient wants to receive it.
235
236 I: Mm. Like referring to social work but maybe you could have tackled that
237 difficult conversation just as well, that kind of thing?
238
239 P: Um...or, maybe you're thinking, "Oh, I can help your itching and your
240 restless legs and then maybe you'll have better sleep and then better
241 relationships..." You know what I mean?
242
243 I: Mm.
244
245 P: Maybe there's not one thing, maybe, "Oh, would you like to speak to a
246 social worker? It sounds like you're having a hard time," and they're like,
247 "No, I don't want to do that," and you think, how can nursing assist with
248 this problem if talking isn't one?
249
250 I: Yeah.
251

nursing "hat" most
frequently worn
→ easiest?
→ designated role
in that setting?

HCP perspectives vs.
Pt perspectives

talking?
nursing vs. sw
re: therapeutic
conversation

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

252 P: You can sort of go back to the...
253
254 I: Symptom management?
255
256 P: Yeah, exactly, symptom management, and that's a pretty big one. But I
257 guess some people don't want to be helped that way, so I don't, I feel like
258 I'm being off-track here, but.
259
260 I: No, it's great. [laughs]
261
262 P: Is it? [laughs] Um. But so, I guess, I don't know the most important thing
263 is, in summary. And I think that I tend to, other people as well, fall back on
264 your training to help you.
265
266 I: Mm. So, I think...kind of similar, but what do you think could improve the
267 care that you provide patients on chronic HD treatment?
268
269 P: I, I wish...and I know that budget is a problem and then time is a problem
270 and there's all these constraints, but...I wish it didn't feel as "assembly-line"
271 as it's beginning to feel. Like, they're recently taking away staff members
272 and making ratios higher and it starts to feel assembly-line-like and I don't
273 like that as much. I don't, I almost wonder, actually, if it's going to result in
274 more admissions to hospital...not because, maybe nursing is missing things,
275 like...maybe nursing is doing everything they can, like they looked at the
276 bloodwork and it looks fine, the patient denied any concerns because they
277 can see that you're very busy, but...I wonder if you had more one-on-one
278 time with your patients if things would get caught earlier and issues that
279 would cause admission would be less. I wonder that sometimes.
280
281 I: Mm. So you said...it's starting to begin to feel more like "assembly-
282 line"...is that related to the increased nurse-patient, sorry, patient-nurse
283 ratios recently, or...
284
285 P: Yeah, I would say, yeah. Yeah. It just seems like you have more patients
286 in the same amount of time so you have to be pretty regimented
287 throughout how you approach your day and sometimes that can feel like,
288 "On to the next one. I've completed everything on one, on to the next one."
289 And I think it takes away from the assessment piece in the beginning. And I
290 know that there's funding issues and what have you but I just wonder if, in
291 big picture, that would be, if we're seeing more money spent in Emergency
292 Room admissions, or...what have you. Like, maybe they didn't have any
293 questions to ask you about a particular type of food and now we're seeing

not knowing how to help
so going back to nursing
diagnoses/care plans
nursing hat & human hat



constraints/limits
to optimal care
- time (nurse:pt ratios ↑)
- resources
("assembly-line")

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

294 more people eating phosphorus, and now they're having more parathyroid-
295 bone disease, ah, more parathyroid stuff going on. It just makes me
296 wonder—if you can spend more time with your patients, like say, if you
297 could prevent...or maybe you couldn't, maybe this is, maybe I have no idea
298 and this wouldn't help at all, but. I do wonder that.
299
300 I: Yeah? In your personal practice, do you feel like the increased patient
301 ratios...it affects your, how will I frame this...I guess, are you less happy with
302 the care you're providing with all of the recent changes going on?
303
304 P: Sadly, yes, like I...I understand why it's important to, ah, work within a
305 budget and it's universal healthcare so we have to work as a team and
306 provide care in a way that's not going to cause other issues, um...but, I
307 would say I'm extremely dissatisfied. It makes, it puts you in a pretty
308 precarious position, um...to have, you know. I just wonder if it's going to get
309 worse or is this the extent of it, or...because now, I would say, if we were a
310 well-oiled machine we're running full-tilt now. Like it's...I don't know how
311 much more you could push us, but...um, yeah, it definitely impacts the care
312 that I...for sure, I would say.
313
314 I: Mm. So very closely related, but I guess, in an ideal world what would
315 effective, optimal, quality nursing care for the chronic hemodialysis patient,
316 what would that look like for you?
317
318 P: Um. I think that the key part to that would be...having more time in the
319 initial assessment piece, like...not feeling like you have to rush through,
320 um...and maybe that's just a structural thing too but not feeling like you
321 have to rush through and get three people put on the machine and like,
322 check three people's bloodwork and assess blood pressure issues, and...get
323 all the basics done before you can really sit down and talk to them about
324 how they've been feeling over the last week or their last monthly
325 bloodwork or that sort of thing. Like in an ideal world you could sit there
326 with the patient one-on-one for longer. And I think they would be more
327 likely to open up too if they see you had, um, some time to talk. Yeah, so I
328 guess time would be, more one-on-one time with your patients, I think
329 would be...would make me a lot happier [laughs].
330
331 I: Mm. Do you think more training is also required, ah, for nursing staff? I
332 think you mentioned before that one of the challenging things you found
333 when you became a hemodialysis nurse was that therapeutic
334 communication piece.
335

importance/important
to ideal nursing care?
- more time/time

pts more willing to share if
they perceive nurses
to be more receptive?

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

336 P: Yeah, that's true. Like more...like, actually that'd be a good idea. We
337 could have more in-services with social work...maybe not necessarily social
338 work but somebody who's...well-versed with helping people manage...like, I
339 don't know if these kidney patients need psychiatrists or therapists on a
340 regular basis at all but somebody who, ah...you know, has experience with
341 dealing with these kinds of illnesses, like helping people navigate through. I
342 think that would be really nice, especially if we had something like annual
343 or semi-annual, to kind of sit down and talk about, "These are the things
344 that, um, kidney patients are dealing with and these are the ways that
345 we're trying to help them," or "These are the things that you can offer
346 them," sort of thing. Like, I know that our, in our position we have the
347 Empathy Project? Like...although the reason that they're doing it is good,
348 it's actually just further exacerbating the problem of, um, one-to-one time
349 with patients, it just makes it feel like it's another task that you have to get
350 done in a...you know, sort of quickly...before you have to take people off
351 machines or on machines...it didn't actually, I feel like, you get to touch on
352 those issues.

353
354 I: Mm. Has, um, have patients expressed any frustrations regarding
355 less...has any patients expressed that they would like more nursing time?
356

357 P: Ah, not directly to me, the only...I just hear comments, like, um, they'll
358 say things like, "Oh, how are you doing?" and I'm like, "No, I'm good, I'm
359 good," or, "You look like you're run off your feet," or "You're really busy
360 today," or, um, even things like, "Oh, Spot 5 is really busy, you're really busy
361 in Spot 5," or something like that. Like, it just makes you feel kind of bad,
362 almost like the good ones don't get as much attention as the ones that are
363 having problems...I shouldn't say the "good ones", I guess, I mean just the
364 people whose treatment seems smoother. So when you hear that stuff you
365 almost feel, bad, like, "Ugh, I should sit down with [patient] and see how
366 [patient] is doing," on a deeper level than, "Have you lost any fluid over the
367 last, since your last treatment," and asking about symptoms and...ah, things
368 directly related to the treatment? More things that are indirectly related?
369 Well, I guess you get a little bit of time at monthly bloodwork when you can
370 sort of have a good assessment as to how things have been going over the
371 last six weeks, but...then you have to do that for all of your patients and all
372 of the paperwork associated with that, then all of the physician notes to
373 get...any kind of medications and things and what have you, and then it
374 almost, you're just looking at, you're just treating numbers now. Instead of
375 sitting down with them again. So...it's just hard.

376

↑ Counselling, guiding or
services for pt
w/ therapeutic
communication

↑ time + ↑ quality of
one-on-one time

pt perceive
nurses'
availability /
openness

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

377 I: So I think...I also wanted to, ah...these are very good aspects of nursing
378 care that I wanted to touch on but another thing that I'm also interested in
379 with my study is how hemodialysis nurses...what are your experiences with
380 supporting patient coping and resilience in this population?

381
382 P: Supporting patient coping and what, sorry?

383
384 I: Resilience?

385
386 P: Oh, resilience.

387
388 I: Yes. I think you touched on it in different, in different areas of your
389 responses but I wanted to ask it outright, I guess.

390
391 P: Sure, so my experience with patient, um...

392
393 I: Yes. So what are your experiences with supporting patient coping and
394 resilience...

395
396 P: Supporting or reporting?

397
398 I: Supporting.

399
400 P: Supporting. Ah, oh. Mm, difficult...challenging. I was chatting with our
401 manager about it, and she said there was this, ah, learning thing I could go
402 to, that The Kidney Foundation thing or SARP puts on...and it's essentially
403 this thing where a woman talks about how to talk to people about ending
404 their treatment, like ending their hemodialysis treatments. So, yeah, there's
405 been some pretty, ah...I guess, like how to support patients through it, how
406 to support patients through some of this challenging stuff is really to refer
407 to the multidisciplinary team for a lot of stuff that is...out of our grasp. So
408 knowing the multidisciplinary team is pretty helpful. And there's a couple
409 resources you can give patients but I don't know, they don't seem to be,
410 they don't seem to...in my experience anyway, they don't seem to want any
411 pamphlets that you can offer them on symptom management, or, I don't
412 know, sometimes even recipes they can try. They don't seem to—not all,
413 but I would say the majority—they don't seem interested in that kind of
414 thing? Which make you wonder about this...lack of investing in yourself, like
415 is there a depression piece here too...and I don't feel like there's good
416 support for that. Like, I don't feel or know...I have asked the social workers
417 but they don't really have a good answer for this, but...I don't really know if
418 there is a group, like I wish there was a—and maybe there is and I'm wrong

desired coping
w/ respect to
concepts of
- pt coping
- pt resilience

Challenges to care /
Pt support from nursing

peer-to-peer
support vs.
HCP-directed?

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

419 and I just don't know—but I wish there was a support group, almost, that
420 could happen. They're all already at the hospital anyways maybe they can
421 have something downstairs after or before dialysis where they could just
422 talk about...like a kidney support group that could be optional. Like there
423 could be a women's version if that would be helpful, and a men's version,
424 or maybe it could be co-ed...but somewhere where they can talk to people
425 who have similar things going on. Even some patients ask me, like, "I'm
426 thinking of getting a fistula," and they know how it works and stuff like that
427 but they're more wondering...like we give them a pamphlet, and we go,
428 "We go in, we take your vein and your artery and we attach it here," like
429 they know that stuff, more like...what's it like after, what does it mean
430 when they say, "It's blown, what does that mean for me," like those type of
431 things it would be helpful to talk to other people who gone through it, and
432 not nursing to help manage those issues.
433
434 I: Do you make that suggestion in terms of...like, with the recent budget
435 cuts, or do you think that would help patients more in...receiving that kind
436 of information?
437
438 P: I think it would help patients...simply help patients navigate through
439 some of the stuff that we're telling them. Like, we're telling them to change
440 everything they eat, and not take in too much water, and change their
441 lifestyle in all these ways, and it...and you give them all these things to read
442 but I think it would be nice for them to be able to talk to someone who has
443 gone through it and listen to their experiences so that it feels less like,
444 "Here's a textbook," and more like human interaction. You know? Even,
445 um, like...fistulas are a big one right now because that's what recently
446 happened to me but...even for just like talking about, "Oh, I got this fistula
447 that never matured." Like, "Oh, really, was the surgery really bad?" And,
448 "No, the surgery wasn't too bad." "What was the recovery like?" "No, it
449 wasn't too bad, I did the same stuff that I normally did but then this never
450 really worked so I just stuck with the line". Or, "I got a fistula done, I have
451 steal syndrome in my hands and it's horrible, I want them to close it and I
452 want to go back to a central line," like I want them to be able to talk to both
453 sides. I just wonder if they almost had like, a support group through kidney
454 care, if they would, if it would affect the mood. Or like the...you know? Like
455 when I sort of said, "Oh, you can give them these pamphlets on how to
456 manage symptoms and they don't really seem to want them," [laughs] or
457 maybe they don't use the suggestions on there and it makes me wonder
458 about if there's a depression piece here because there's a lack of wanting to
459 take care of yourself, I don't know. Then I wonder if they had someone they
460 could kind of chat with about this stuff, if that would help with their care,

emphasis on
peer-to-peer
support
→ acknowledgment
of personal
limitations vs.
nursing scope?
→ life experiences

"human
interaction"
vital to
offering pt
support

* why would
peer support
possibly be more
effective/helpful
to supporting pt
coping + resilience
vs. HCP?

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

461 you know what I mean? Like that would help them want to try new things
462 or do new things or hear about new research that we tell them about...I just
463 wonder if that will affect them, their lives, I guess...their everyday life if they
464 had a group to talk about...who all are suffering from similar things. And
465 maybe there is one but I never feel like I've heard of one or, I don't suggest
466 anyone that they can go to...
467
468 I: No, I thought...I thought there was one as well...I know some nocturnal
469 patients, they access that service...but then I stopped hearing about it, I
470 would say, two years ago? So I'm not even sure right now as well.
471
472 P: Like I know there's exercise programs you can do but, um, it's pretty hard
473 to get to those, like they're pretty limited. Like in the community you can go
474 to a class with a kinesiologist and, but yeah, I've never heard...but maybe
475 that's, I've only been around for two years now in hemo but maybe that's
476 why I never seem to hear about one, or. Yeah, I wonder if that would take
477 some of the burden away, you know what I mean? From nursing as well, it
478 sounds kind of horrible, but, um...if people could have, if they could feel
479 more supported in their everyday life then...not just feel like nursing has to
480 be all the things for them when they come in, you know, like, it's "Okay,
481 provide treatment and you need to discuss bloodwork," and "Let's get
482 pharmacy in here because your blood pressures are great," and "Your
483 phosphate's pretty bad, let's talk to the dietitian," you know, and then, "So
484 how, how's the rest of your week been going?" They're, "Not good, my
485 brother died on Tuesday." Like, oh man. [laughs]
486
487 I: [laughs]
488
489 P: That was literally my week last week, last week I had a lady and I was like,
490 "Oh, how's your day going, how've you been feeling," and she goes, "It's my
491 brother's funeral today," and it's...oh, man. All the patient teaching goes
492 out the window when they want to talk to you about their brother, how he
493 was like, and what happened, and his kids...and how his funeral is today but
494 she can't be there, and...
495
496 I: It's terrible when it's...it's just a question you ask because it's part of your
497 list of questions and you know you have two minutes with them and then
498 they bring up something like that.
499
500 P: Yeah, it's like...well, you're going to see them Friday, and it was on
501 Wednesday that they said, "You know, my brother died," and I know that
502 they understand that we have other patients and that we're busy but you,

Strong contrast
btw medical/physiological
needs versus
life / psychological needs

limited time

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

503 you feel like you have to—and you want to—chat with them about it but it
504 almost produces like this guilt, this nursing guilt...or even not nursing, just
505 human, like you feel bad. But at least it's Friday and you feel bad about
506 Wednesday because you didn't get to spend much time with them as you
507 wanted...yeah, I almost feel like...it's not good for our mental health, I don't
508 know.

509
510 I: Mm.

511
512 P: Like, I know I haven't had a ton of experience in kidney care but...maybe,
513 maybe if you have more experience you'd feel like, well...and I haven't been
514 in that position so I feel maybe people don't necessarily want to chat about
515 things all the time like I think they do, but...[laughs] Yeah. It makes me feel
516 like they do, anyway.

517
518 I: In my experience, if it helps, that part of nursing care for our population
519 never gets easier...but I feel, I don't know. [laughs] But I feel like you
520 wouldn't be as good as a nurse sometimes if things were...easy. I don't
521 know if that makes sense.

522
523 P: But yeah, then you worry about it, then you hear about nurses that
524 appear to be kind of...like, they're good nurses and they're doing their job
525 and they're friendly and they're knowledgeable, but...they almost feel like
526 they're checked out or they're burned out...and you worry, like, "Is it
527 getting easier because I'm less affected by these horrible things," or "Is it
528 getting easier because I feel better to support them through it," I don't
529 know. That's sort of the...that's a little frightening if you think about that.
530 [laughs] Hopefully it's not the burnt out...nurse syndrome or whatever they
531 call it. Hopefully it's that you're getting better equipped to deal with it.

532
533 I: Yeah.

534
535 P: Yeah.

536
537 I: So [Participant 01], I only have one last question here. I think...if you were
538 to travel back in time to when you first got the job...or, sorry, the nursing
539 job in hemo...what patient care advice would you give yourself...starting
540 out.

541
542 P: Um...good question. I think when you start you're so focused on, like,
543 how to operate the machine and all the technical aspects of accessing
544 someone's blood and all these things, and that's sort of your focus. Like,

limited time
— psychological impacts
on nursing as well

What makes a good
HD nurse?
balancing
personal mental
health
vs.
emotional investment
= support (more
effective)

advice for new
HD nurses
↳ shift focus
from more
technical
aspects of care
vs.
focus on human
approach to care

nursing
care

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

545 "Oh, no, what if this happened on the machine, how do I make sure that my
546 patient safely gets all their blood back," or, "How, how do I do
547 troubleshooting, how do I troubleshoot this or troubleshoot that," and not,
548 do harm in any of this?

549
550 I: Mhm.

551
552 P: But that will come regardless and there's enough people around to help
553 you that you don't have to worry about, you don't have to be stressed
554 about that, you just need to ask for help. So that's one that...I thought was
555 more serious than it is...it's not that big of a deal. And then once you do it a
556 few times it's pretty ingrained in there. Um...so maybe that piece that, just
557 remind the nurse, I guess, or like me, whatever, whoever it would be, that
558 you're going to get to know these people over the entire length of your
559 career or so...just think about that approach, kind of, when you approach
560 care and less maybe of a regimented assessment and more of like, ah...I just
561 want so almost like an approach, like they're your child or your friend...you
562 do kind of become friends with them, I guess, um...I guess, it doesn't need
563 to be as, it can be, you can make it more of a happier time, you can make it
564 more relaxed. You can make jokes and you know, talk about personal stuff
565 within reason, and not...you don't necessarily need to be so focused on the
566 bloodwork numbers, or the treatment, that will be just second fiddle to
567 you, like that will be so easy to you in the end.

568
569 I: Mhm.

570
571 P: It's, it's...so I almost want to say like, "Don't be too stressed out about
572 that." Even if you say, like tomorrow, "Oh, we're going to have this new
573 dialysis machine that we're going to start to use," um, I don't think I would
574 be so nervous about it, like, okay, we're going to learn how to use it, but I
575 don't think you need to be as stressed as you initially think you do...when it
576 comes to that kind of stuff. Also because you have the support of other
577 nurses around you, it's not like you're actually acting alone, and once
578 you've nailed it down, it won't, it won't matter if you have the support of
579 other nurses or not because it will be so easy to you. So maybe just that—
580 the machine isn't as scary, maybe, as you think it might be. I remember
581 when I was starting out, I was like, "Oh my god, how do you get air in it and
582 what will we do if I got air in the machine!" [laughs]

583
584 I: Mhm. [laughs]

585

always available:
support from other
HD nurses re:
technical aspects of care
but
human approach to
care harder to
develop?
↳ more personal?
↳ cannot be
(by other substituted or
HD nursing replicated?
staff)

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

586 P: It sounds scary when you think about it like that, "Oh, you can kill
587 somebody with this machine." Um, so, I think...there's a lot of safety,
588 there's so many safety measures that are in place in the machine, it would
589 be really hard for you to hurt somebody with it. I mean, it's very serious,
590 but whoever built these are fairly sophisticated. I think just taking away,
591 um, the fear of someone just starting out. I mean, for example, if you run
592 out of water, "Oh my god, it's the 'Insufficient Water' alarm," but like, the
593 machine is smart, it'll go into bypass mode and you'll have a certain amount
594 of time to decide what you want to do. You don't have to freak out about it
595 or...even sometimes you'll get a temperature alarm, and you think, "Oh my
596 god, I have a temperature alarm, the blood will—this will cause horrible
597 effects to the patient, like, I need to get the blood back, blah blah blah," but
598 you still also have the time. It's not as, ah, it's not as immediate as you think
599 it has to be, so it takes away the stress, I think.

600
601 I: Yeah. So I guess on a related note, do you think your nursing practice has
602 kind of evolved in a way since you started?

603
604 P: Ah, yeah...I think it's less...serious, it's less "business as usual", you know?
605 It's more like...I think one of the nurses said to me that worked a while on
606 the floor, and this is, like, a little bit extreme, but she was like, "A lot of
607 these patients have a horrible life, they hate coming here, we remind them
608 of their death, essentially," um, "And this is not a happy place for them,"
609 and she just went on about how horrible it is for them to come to our unit,
610 um...for some of them. And I never really thought about it that way. Like,
611 "Ugh, you have to come in again, and this treatment is preventing you from
612 having this type of lifestyle that you want, maybe not, and you see us
613 again," and...it could, it can almost conjure up these negative feelings? So
614 she, she's like, "It's really nice to come and just, like, you know, make them
615 laugh and, you know, make them feel like...almost like they're kind of your
616 friend that's coming to hang out with you again." Like, she more of looks at
617 like, yes, the treatment is very serious but when you see them it doesn't
618 have to be very serious. Like, you can ask them about...I don't know, funny
619 shoes they have on, or like, she just seemed to be more...relaxed about it,
620 and she's said, "You can make this a fun atmosphere even if the reason
621 they're here isn't fun." And I thought that was kind of nice.

622
623 I: Yeah. So I think, [Participant 01], that's all the questions I have for you. I
624 really liked that last...I really like the happy note that we ended on. [laughs]

625
626 P: Yeah. [laughs] It's sort of nice in a morbid way, right?

627

HD tx
vs.

HD tx is not just
about tx, it shouldn't
be to support pt
Coping + resilience —
it should be about
(also) giving pts something
to look forward to
QHD run...
→ long-term tx w/ minimal
health impairments,
if any
(does not "fix" CKD
but prevents it from
becoming worse)

Interview Transcript – Participant 01
Interviewer (I), Participant (P)

628 I: But it is true, I guess, like the work we do...it's not like...we're not curing
629 anybody, which is the hard part.

630
631 P: Exactly, yeah.

632
633 I: Well, we're at the end of my questions. Is there anything else that you
634 wanted to say specifically that I didn't ask you about or...

635
636 P: Um, I don't think so...I think, even if you didn't ask me I just went off on a
637 tangent, kind of...I'm pretty unorganized so I'm sorry for that. [laughs]

638
639 I: No, it's fine. [laughs]

640
641 P: The only thing I would add, um, yeah, it turns out that maybe I'm more
642 passionate about this than I thought. But yeah, it's not often that I get to
643 talk to other hemo nurses about this sort of thing, so yeah, this is great.

644
645 I: Okay, so I'm just going to stop recording, okay?

646
647 P: Okay.

February 2021 Coding Notes

"Gestalt"
Initial (thoughts for myself, others)
PBA (post close meeting)

Initial
- "receptivity to care" or ongoing assessment
→ idea that despite established rapport that may already be in place, every day and/or HD unit is different

Initial
- Unique to HD: chronicity + repeated contact (vs. acute care)
→ uninvolved participant in depth of involvement sometimes
→ overshooting (info, emotional) = struggle in defining + maintaining professional boundaries while cultivating therapeutic relationship

Initial
- Challenges/barriers to optimal care
→ pt behaviour → lack of appropriate resources such as counselling services, psychological support, nurses not trained to address some effectiveness
→ time (differs b/w participants) → interfere, optimizing
→ coping (nurses) w/ emotional attachment/invariable decline or death of HD pts

Initial
- Easy/obvious aspects of HD care/nursing
↳ routine of the work, HD machine-related care e.g. troubleshooting, associated skills
↳ rapport - building/getting to know the pt

Initial
- Thoughts on pt support + coping on HD
→ VARIES b/w participants re. perspectives
→ striving to know pts past medical (superficial?) hx, i.e. what makes chronic HD pts happy, outside of HD, what gives their lives meaning?
↳ tying back into optimizing health/QoL for something/someone other than self
→ focus more: pts who are alone (living, social supports)

Observations
differences w/ respect to role + experience
e.g. current role (with tech nurse specifically)
e.g. past experience in surgical/medical wards

Observations
- thoughts from participants required additional caring/leading to address some
- acknowledgment overall that awareness present re. poor medical health + QoL in this pt population

Why are negotiations necessary?
- time (limited)
- emotional investment/resilience of nurses
- sharing of one's self
- skill level/scope of practice

Balancing Act
Possible theme/overarching?

negotiations
what's best for the pt... (nursing)
HCP perspectives
vs.
Pt perspectives (autonomy, knowledge of self, experience, w/ OLB + HD)

negotiations
medical care (e.g. optimizing HD adequacy)
vs.
psychological - counselling care

negotiations
professional boundaries (setting, maintaining)
vs.
rapport - building for therapeutic relationship

negotiations
"protocol" (e.g. calling security)
vs.
"what will help the pt the most at this time?"

Receptivity to Care
(ongoing assessment)

↑
process-related?
...or iterative?
1L

April 2021 Coding Notes

Study Research Question

Initial (proposal): What are HD nurses' perspectives on supporting patient coping and resilience when caring for CKD patients on chronic HD treatment?

- Interview questions were kept quite open-ended up until interview to prevent “leading” of participants in specifically discussing how patient coping and resilience was supported in nursing care provision. As Participants #1-3 did not organically bring up this concept, it was specifically asked about by the interviewer in subsequent interviews with Participants #4-12.
- As participants were explicitly asked how they supported patient coping and resilience in their care provision, common concepts emerged:
 - o HD nurses already largely recognized that patients on HD treatment were likely to have persistent mental health concerns such as anxiety and depression
 - o HD nurses strived to provide ongoing support in various ways:
 - Becoming a supportive companion with patients throughout their journey (i.e., disease trajectory)
 - Helping patients find inner strength and personal reasons to continue coming to HD (e.g., personal health, more time with loved ones)
 - Recognizing the different nuances of acute vs. chronic nursing care, focusing on rapport-building in tandem with medical care
 - Ongoing assessment of receptivity to care
 - Attempting to alleviate the burden/negative connotation of HD by establishing meaningful relationships
- Throughout all participant interviews, regardless of whether the topic of supporting patient coping and resilience was explicitly asked about, HD nurses expounded on “balancing acts”, or negotiations in care, that they experienced in care provision

Revised (post-interviews): What negotiations in care do HD nurses experience in striving to support patient coping and resilience for CKD patients on chronic HD treatment?

- From interview data, HD nurses commonly related struggles and conflicts in care provision, especially with respect to endeavouring to support patient coping and resilience; as the most pervasive theme related throughout the interviews, this theme necessitated a revision to the study research question
 - o Element of moral distress in care provision is pervasive
 - Common examples:
 - Needing to focus on HD versus offering patient support when emotional issues are shared, e.g., recent loss of a loved one
 - Dealing with patient mortality/loss after a significant therapeutic relationship has been established over time
 - Witnessing patients' health slowly deteriorate over time with repeated albeit understandable non-adherence to recommended medical treatment

Overarching Theme: Overall, HD nursing care involves ongoing negotiations in care.

- Provision of HD nursing care involves active negotiations in different, various aspects of care.
 - o In striving to support and care for patients, nurses appear to often be caught in “balancing acts” of perceived conflicting views, beliefs, and practice direction (policies).
- Why are negotiations necessary in HD nursing care? Limitations/constraints:
 - o Time
 - Despite chronicity of care, nursing staff only have patients for <4 hours per treatment, requires prioritization of urgent or task items, counselling and psychological support takes much more time than other tasks
 - o Nurses' perceived personal emotional capacity and resilience
 - o Nurses' perceived professional constraints (e.g., professional boundaries)

- Nurses' perceived skill level and scope of practice (e.g., life experiences, counselling skills)

Themes: What specific negotiations in care do HD nurses relate experiencing in care provision?

- Nursing perspectives ↔ patient perspectives
 - At times differing perspectives on what is best for the patient, such as concepts of quality of life, health trajectory, etc.
 - Example: adherence to central catheter dressing on at all times to prevent infection
- Medical care ↔ psychological care
 - Medical care = optimizing dialysis adequacy, addressing abnormal bloodwork, wound care, etc.
 - Psychological care = counselling, emotional support, etc.
 - Biomedical versus Biopsychosocial model of care
- Professional boundaries ↔ therapeutic relationship
 - Rapport-building is foundational to establishing a meaningful, therapeutic relationship but how much of themselves should nurses share of personal info and emotional investment, to build genuine rapport?
 - What does chronicity of care mean for professional boundaries?
 - Do nurses determine their professional boundaries from education (e.g., nursing school/training), professional bodies (e.g., CARNA), personal comfort level (e.g., personal privacy), or a culmination of several sources?
 - Setting boundaries is expressly more difficult in HD care due to repeated contact and chronicity of care
- Organizational considerations (?) ↔ patient-centered care
 - Following practice policies/protocols (e.g., calling security immediately for patient behaviour issues, etc.) versus nursing judgments (e.g., calling security immediately; may aggravate certain patients, other strategies such as allowing venting/walking away more effective)
 - Nurses' negotiations in providing care within system constraints (e.g., being unable to reschedule HD appointments to accommodate patients' lives/quality of life due to lack of available times and spots)

Other Considerations

- Interpretive Description: using a nursing framework to provide analyses with direct application to practice
 - Objective of research is to illuminate what struggles and conflicts HD nurses engage in care provision for this complex patient population
 - How will the research findings help nurses in their day-to-day practice?
 - ...that will help nurses care for HD patients and foster coping/resiliency?
 - ...that will help alleviate the conflicts, struggles, and sources of moral distress HD nurses experience in care provision?
- Notes on further recommendations for research
 - Increase sample diversity/representation of HD nurses in provincial program
 - Examining negotiations in care and tailor interventions accordingly
 - Highlight barriers to care that HD nurses recount in trying to support patient coping and resilience in care
 - Expound on specific sources of struggles, conflicts, and moral distress in HD nursing care
 - Tailored interventions: education, self-care, proposals for further research on more complex issues (e.g., system-level changes such as possibly creating an open booking system for patients to self-manage HD schedule)

Themes	Notes	Transcript Example/Reference
Nursing perspectives ↔ patient perspectives perspectives on what is best for the patient	<ul style="list-style-type: none"> - Nursing perspectives of what is best for the patient may not align with patient perspectives - Often deals with nursing recommendations of care that patients may not adhere to for reasons of perceived quality of life/outcomes of past medical experiences/patient values and preferences - HD nurses as experts in HD while patients are experts of their body/what will improve their quality of life 	<ul style="list-style-type: none"> - My experiences can be very rewarding but also very frustrating [...] you get patients who are very involved in their care, ah, and then you get patients who are not involved in their care at all, and those can sometimes get a bit on the frustrating side. Um, especially when you, you get into that as well and you get what I think are self-destructive patients who don't show up for dialysis days and, you know, then you become worried about them (Participant 02)
Medical care ↔ psychological care medical care = optimizing dialysis adequacy, medications, addressing bloodwork, etc. psychological care = counselling, emotional support, etc.	<ul style="list-style-type: none"> - Time = primary limitation for this negotiation in care provision; although patients are typically at dialysis for a 3-4 hr treatment every HD run, nurses also spend a lot of this time not in direct patient contact (patients are sleeping for majority of run; nurses spend a lot of time in rounds, break, break relief, patient research, etc.) - Skill level and scope of practice = another constraint that contributes to this negotiation; nurses may not feel comfortable/the most appropriate healthcare provider to be offering counselling services and psychological support to patients on a meaningful level; however, oftentimes nurses must try and attend to these patient issues (limited social work personnel available, limited to no healthcare providers available that are properly trained in psychological care) <ul style="list-style-type: none"> o May also be related to life experiences; nurses feel that they have no similar experiences to draw advice from to give to patients - Prioritization given to medical care when faced with a limitation or constraint 	<ul style="list-style-type: none"> - So I find that that's the challenging piece, like, how do you support patients dealing with complex life issues. Um...and you, you don't have any real experience dealing with those issues. That's, that's the challenging piece, and then the, so I guess, the therapeutic communication piece for these types of patients can be extremely complex. Whereas the nursing care itself, like the technical care, that's easy. You can look up bloodwork, titrate medications, or change HD prescriptions but...that is challenging to talk to people dealing with pretty heavy life situations and life decisions (Participant 01) - ...she said, "Well, my husband died two days ago and I'm making his funeral arrangements." And of course that was heartbreaking for me...but at the same time, you know, I gotta get the patient on, I gotta get the next patient on. And I felt horrible that, you know...I did end up afterwards providing her with some support, but I felt horrible that in that moment, I felt she needed to talk...I mean, I would to, I should have given her a hug for crying out loud, um...but that...the, the dialysis itself was stopping me from providing her—like, getting her on dialysis was preventing me from providing her the support that I wanted. And that really stuck out me, like...one of those heartbreaking moments when, you know you want to do more but you know just can't. (Participant 02)
Professional boundaries ↔ therapeutic relationship professional boundaries = nurses' perspective on social	<ul style="list-style-type: none"> - Most pervasive theme throughout interviews - When asked about giving advice to new HD nurses re: patient care provision, many participants encouraged new HD staff to switch focus from HD 	<ul style="list-style-type: none"> - ...I've had a few patients like...really want to get to know me—in a polite way—but they ask like really personal questions too. And, um...they're like, "Oh, are you married? Do you have any kids?" And I know it comes from a place of, they're just being genuine and friendly, um, but from my experience, once you kind of open that door you can't really go back. Um, so I try my best to um...maintain a therapeutic relationship, you know, I try to be a little

<p>and emotional boundaries that cannot be crossed</p> <p>therapeutic relationship = meaningful, restorative rapport that may require more investment with chronicity of care</p>	<p>machine/nursing tasks to recognizing/provision of more holistic care to patients</p> <ul style="list-style-type: none"> ○ Remembering that there is a patient, a human being attached to the HD machine - Predominant constraints: emotional capacity/resilience of nurses, nurses' willingness to offer personal info/preferences of personal privacy, and professional constraints (e.g., professional boundaries) - Deals with nurses' ongoing negotiations of how much to share of one's self with patients in order to develop that therapeutic relationship <ul style="list-style-type: none"> ○ Chronicity of care/repeated contact with patients increases pressure not only to develop therapeutic relationship but to also share one's self, e.g., patients remember nurses' shared personal information and follows up with nurses in subsequent HD runs - Also relates to nurses becoming more strict with drawing professional boundaries due to negative/distressing past experiences in care provision with emotional over-investment - "Nursing hat" versus "human hat" 	<p>vague, turn it around on them, give them an opportunity to chat... (Participant 03)</p> <ul style="list-style-type: none"> - ...so one day he just decided that he was going to turn his life around, you know. He started exercising, started eating properly, and, ah, you know, he just, it was just a miracle to see such a huge shift in his thinking and, ah...I was kind of going through an emotional period in my time, he was a good listener, so, we became connected not only through the dialysis but through, ah, what was happening to each of us, which was...and that's where I learned my lesson that you can't do that, you know? [...] I miss him terribly to this day because he's no longer with us [...] Him, I won't forget, just because of that one connection that we had, and maybe because I was the first to put him on [...] He's in my memory forever, he just gave me things for me that were very nice that are a reminder of who, what he did for me as well, and...that's why you don't get attached to your patient, yeah. (Participant 04) - ...it's hard to accept that all of these people, that we are taking care of, are sick people. And it's a, it always comes as a shock when somebody passes, right? [...] So...it took me a long time to accept the fact that these are not healthy persons, people...our patients are not, they're very sick people, they're stable for a certain amount of time and they're having their ups and downs...but you never know what's happening or when something is going to happen. I think that's the hardest part for me...because I get attached, I get to know them, um...and, I, I believe it, it takes a heavier toll on us after we know them, after we establish this professional and therapeutic relationship with them and then, for whichever reason, they're passing away or becoming...to me, anyways, that's the hardest part. (Participant 12)
<p>Organizational considerations ↔ patient-centered care</p> <p>organizational considerations = policies, procedures, system-level constraints (e.g., capacity issues)</p>	<ul style="list-style-type: none"> - Heavily involves concept of "ongoing assessment of receptivity to care" - Most often mentioned in interviews in relation to patients with behavioural issues ("purple-folder patients") - Efforts to provide optimal nursing care via highly tailoring care based on patient presentation at that particular time, during that particular HD run 	<ul style="list-style-type: none"> - Like at Foothills, we used to have a guy...and he was homeless, and he was spending a lot of time in shelters or out on the streets. And he will come hungry and shaking. And our guideline was not to give cookies, because he was not diabetic. But, if you think about it, if a starving patient comes in, does he care about dialysis or does he care about that one juice and few cookies that he gets? I always gave him juice and cookies if he asked for it. [...] I don't know whether it was right or not, but guidelines are guidelines. Like, it was only for diabetics, and for other patients at that time, we had a little bit limited supply. But I used that supply and I gave it to him. [...] So you kind of have to prioritize what the patient's needs are. So from a renal perspective, maybe giving cookies is not a good thing...but we have to look at what is the

<p>patient-centered care = nurses' perspectives on what constitutes patient-centered care that may not align with organization- or system-level care directives</p>		<p>best, or what is the most needed necessity for this patient. We have to look from the patient's side. (Participant 05)</p> <ul style="list-style-type: none"> - ...people always label those patients as "non-compliant", "Oh, he never comes, he only comes for 2 hours," but we forget to realize the reason behind his coming late, which is really very sad. [...] And whenever we say stuff like, "Oh, [Patient SM], you're always so late, you're not getting good dialysis," he said, "Oh, I had work, I was working in Red Deer, I'm just coming back," you know, he'll say, "I have to send my kids to university, I need money, I'm saving money for my children," and then I felt...he forgot to live his life, he focused on, more on his family's life, cutting down his treatment time and at the end...he should get a kidney, I was thinking, a new kidney, and then he will live longer and meet his goals. But, it didn't happen...he had to quit, stop dialysis...at one point he was so frustrated with his life, obviously missing the dialysis treatment jeopardized his health. (Participant 07) - Sometimes, we...have to understand what's going on with them the most, you know, rather than just saying, "Oh, you know, this is crossing the boundary," you know, sometimes, we have to understand them, what's going on with them...so, you know, let's just give some time for them. Um...rather than just saying, "Oh, no, this behaviour is not accepted," you know, or...sometimes, I see that in our unit, people call security for no reason, you know [...] sometimes just give them some time to settle, you know...we can say, "I can see that at this time you're distressed," you know...but that's all a short solution you know, it's...not, we're not dealing with the problem, actually. Um...and I don't know if the, even the doctors are not trained to do that, give psychological support, right? (Participant 08)
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Appendix E

Study Setting Details

Participant recruitment for this study occurred at a provincial level, with recruitment taking place from the two renal programs in Alberta, Alberta Kidney Care-North (AKC-N) and Alberta Kidney Care-South (AKC-S) (AHS, 2020a). AKC-N has 21 in-center HD sites across urban and rural settings, with HD sites in Edmonton ($n = 4$), Drayton Valley, Edson, Hinton, Lac La Biche, Lloydminster (Saskatchewan), Peace River, Fort McMurray, Grand Prairie, Red Deer, Rocky Mountain House, Slave Lake, Vegreville, St. Paul, Stettler, Westlock, Wetaskiwin, and Whitecourt (AHS, 2020a). In turn, AKC-S has 13 in-center HD sites, also across urban and rural settings, with HD sites in Calgary ($n = 7$), Lethbridge, Blairmore, Drumheller, Fort Macleod, Medicine Hat, and Olds (AHS, 2020a). In AKC-N, there are 99 full-time equivalent nursing staff across its in-center HD sites in Alberta, with 34.3% ($n = 34$) of nursing staff LPNs and the remaining 65.7% ($n = 65$) RNs (A. Stalker, personal communication, July 14, 2020). In AKC-S, there are 261 full-time equivalent nursing staff across the in-center HD sites, with 37.9% ($n = 99$) of nursing staff LPNs and the remaining 62.1% ($n = 162$) RNs (J. Scarrett, personal communication, June 29, 2020). As of March 2020, there are 2,860 patients on renal replacement therapy across both AKC-N and AKC-S: of these patients, 22.3% ($n = 638$) are on PD and 70.7% ($n = 2021$) receive some form of in-center HD treatment, with most on conventional HD treatment (A. Stalker and J. Scarrett, personal communication, July 9, 2020).

Appendix F

Introduction Email(s) to Key Stakeholders

Introduction Email #1 (September 2020)



Dear Colleague,

Kindly find attached details for the study “*Exploring the Perspectives of Hemodialysis Nurses in Care Provision: An Interpretive Descriptive Study*”, a provincial-wide research study being conducted by Mia Ortiz, a Master of Nursing graduate student from the University Calgary and a Registered Nurse working on Unit 27 Hemodialysis at Foothills Hospital in Calgary, Alberta (Alberta Kidney Care-South). The University of Calgary Conjoint Health Research Ethics Board has approved this research study (Ethics ID REB20-1031).

This research study aims to explore the perspectives of nurses surrounding care provision in chronic kidney disease (CKD) and hemodialysis (HD) care settings. It is the hope that this study will contribute to a better understanding of how HD nurses perceive care provision and potentially explore how care can be improved to enhance patient coping and resilience in chronic kidney disease and hemodialysis care.

HD nurses who have worked with chronic, in-center HD patients in Alberta for at least two years and are still working in their respective in-center HD site are eligible to participate in this study. Nurses will be interviewed about their perspectives and experiences in patient care provision as well as how nursing care affects patient coping and resilience in CKD and HD. Interviews will be one-on-one, approximately 30-90 minutes in length, and will be scheduled at a

time convenient for participants during non-work hours. Interviews will be conducted over phone or over an online meeting interface (ZOOM) with video on or off, all as per participant preference. Attached is the recruitment poster for the study as well as a sample script for the invitation email.

If you could kindly disseminate the invitation email and the recruitment poster for the research study to the eligible nursing staff at your respective in-center HD site, that would be greatly appreciated. If you have any further questions or concerns about the study, please contact Mia Ortiz via email (xxxxxxx@ucalgary.ca) or phone (###-###-####).

Thank you for your time and consideration.

Sincerely,

[Name of Unit Manager of Unit 27 Hemodialysis, Foothills Hospital]

Introduction Email #2 (November 2020)



Dear Colleague,

Thank you for your earlier support in disseminating the recruitment material for the study “*Exploring the Perspectives of Hemodialysis Nurses in Care Provision: An Interpretive Descriptive Study*”, a provincial-wide research study being conducted by Mia Ortiz, a Master of Nursing graduate student from the University Calgary. The University of Calgary Conjoint Health Research Ethics Board has approved this research study (Ethics ID REB20-1031).

As you may recall, this research study aims to explore the perspectives of nurses surrounding care provision in chronic kidney disease (CKD) and hemodialysis (HD) care settings. It is the hope that this study will contribute to a better understanding of how HD nurses perceive care provision and potentially explore how care can be improved to enhance patient coping and resilience in chronic kidney disease and hemodialysis care.

The recruitment for this study is still ongoing and is still inviting HD nurses who have worked with chronic, in-center HD patients in Alberta for at least two years and are still working in their respective in-center HD site to participate in this study. Nurses will be interviewed about their perspectives and experiences in patient care provision as well as how nursing care affects patient coping and resilience in CKD and HD. Interviews will be one-on-one, approximately 30-90 minutes in length, and will be scheduled at a time convenient for participants during non-work hours. Interviews will be conducted over phone or over an online meeting interface

(ZOOM) with video on or off, all as per participant preference. Attached is the recruitment poster for the study as well as a sample script for another invitation email.

If you could kindly re-distribute the invitation email and the recruitment poster for the research study to the eligible nursing staff at your respective in-center HD site, that would be greatly appreciated. If you have any further questions or concerns about the study, please contact Mia Ortiz via email (xxxxxxxx@ucalgary.ca) or phone (###-###-####).

Thank you for your time and ongoing support!

Sincerely,

[Name of Unit Manager of Unit 27 Hemodialysis, Foothills Hospital]

Appendix G

Invitation Email(s) to Prospective Participants

Invitation Email #1 (September 2020)



To whom it may concern,

As a hemodialysis nurse that is presently working in in-center hemodialysis care and has had at least two years in in-centre hemodialysis care with Alberta Health Services, you are invited to participate in a province-wide research study titled “*Exploring the Perspectives of Hemodialysis Nurses in Care Provision: An Interpretive Descriptive Study*”, which aims to explore the nursing point of view surrounding patient care in the chronic kidney disease (CKD) and hemodialysis (HD) settings. It is the hope that this study will contribute to a better understanding of how HD nurses perceive care provision and potentially explore how care can be improved to enhance patient coping and resilience in CKD and HD care. The University of Calgary Conjoint Health Research Ethics Board has approved this research study (Ethics ID REB20-1031).

This research study is the thesis project of Mia Ortiz, a Master of Nursing graduate student from the University of Calgary. Participation in the study will involve a 30 to 90-minute interview with Mia via phone or an online meeting interface (ZOOM) at a time convenient for you during non-work hours and will primarily explore your perspectives and experiences in CKD and HD nursing care. The study is ultimately hoping to interview 10-15 hemodialysis nurses from in-center hemodialysis sites across Alberta.

Your participation in the study is completely voluntary and will not affect your employment in any way. All information gathered from the survey and the interviews will be presented in summarized form only (e.g., final report, presentations, publications). Your participation will remain anonymous in that all identifiable information of participants will be removed from all discussion, dissemination, and presentation of study findings.

For more information about the study or if you are interested in participating, kindly find attached an electronic poster detailing the study as well as further contact information for Mia.

Thank you very much for your time and consideration.

Sincerely,

[Name of Key Stakeholder]

Invitation Email #2 (November 2020)



To all LPNs and RNs,

As you may be aware, there is a ongoing research study at this time entitled “*Exploring the Perspectives of Hemodialysis Nurses in Care Provision: An Interpretive Descriptive Study*”, which aims to explore the nursing point of view surrounding patient care in the chronic kidney disease (CKD) and hemodialysis (HD) settings. It is the hope that this study will contribute to a better understanding of how HD nurses perceive care provision and potentially explore how care can be improved to enhance patient coping and resilience in CKD and HD care. The University of Calgary Conjoint Health Research Ethics Board has approved this research study (Ethics ID REB20-1031).

At present, this provincial-wide study is still looking for hemodialysis nurses (LPNs and RNs) that are presently working in in-center hemodialysis care and have had at least two years in in-centre hemodialysis care with Alberta Health Services. Participation in the study will involve a 30 to 90-minute interview via phone or an online meeting interface (ZOOM) at a time convenient for you during non-work hours and will primarily explore your perspectives and experiences in CKD and HD nursing care. The study is ultimately hoping to interview 10-15 hemodialysis nurses from in-center hemodialysis sites across Alberta.

Your participation in the study is completely voluntary and will not affect your employment in any way. All information gathered from the survey and the interviews will be presented in summarized form only (e.g., final report, presentations, publications). Your

participation will remain anonymous in that all identifiable information of participants will be removed from all discussion, dissemination, and presentation of study findings.

For more information about the study or if you are interested in participating, kindly find attached an electronic poster with details of the study.

Thank you very much for your time and consideration!

Sincerely,

[Name of Key Stakeholder]

Appendix H

Electronic Recruitment Poster



Exploring the Perspectives of Hemodialysis Nurses in Care Provision: A Research Study

Hemodialysis nurses are in a unique position in caring for chronic, in-center hemodialysis patients. Of all members of the healthcare team, nurses spend the most consistent one-on-one time with patients in hemodialysis care. As such, exploring hemodialysis nurses' perspectives in care is invaluable to understanding optimal care provision for hemodialysis patients and exploring how care can be improved!

Researchers at the University of Calgary invite you to participate in a research study if:

- You are currently a hemodialysis nurse (Licensed Practical Nurse, Registered Nurse)
- You have had at least 2 years of nursing experience in in-center hemodialysis patient care

Participation in the study entails a 30- to 90-minute interview via online (ZOOM) or phone.



Please contact Mia Ortiz (Email: xxxxxxxx@ucalgary.ca, Phone: ###-###-####) for more information or if you are interested in participating!

The University of Calgary Conjoint Health Research Ethics Board has approved this research study (Ethics ID REB20-1031).

Appendix I

Research Study Consent Form



UNIVERSITY OF CALGARY

CONSENT TO PARTICIPATE IN RESEARCH

TITLE: Exploring the Perspectives of Hemodialysis Nurses in Supporting Patient Coping and Resilience: An Interpretive Description Study (Ethics ID REB20-1031)

FUNDER: This research study has no sponsor or funder.

PRINCIPAL INVESTIGATOR (SUPERVISOR): Dr. Eloise C. J. Carr, RN PhD

CO-INVESTIGATORS (SUPERVISORY COMMITTEE MEMBERS):

Dr. Shelley Raffin-Bouchal, RN PhD

Richelle Forest, RN MN

STUDENT RESEARCHER:

Mia Maris Ortiz, RN BN

Faculty of Graduate Studies, Faculty of Nursing

University of Calgary

2500 University Drive NW

Calgary AB T2N 1N4

Email: xxxxxxxx@ucalgary.ca

Cell Phone: ###-###-####

INTRODUCTION

Under the direction of the Principal Investigator Dr. Eloise Carr and the Co-Investigators of this study, I (the student researcher) will be conducting this study from the Faculty of Nursing at the University of Calgary.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

You were identified as a possible participant in this study because you are a professional nursing staff (a Licensed Practical Nurse or a Registered Nurse) that has worked in in your respective hemodialysis site in Alberta for at least two years and are currently working in hemodialysis care. Your participation in this research study is voluntary.

WHY IS THIS STUDY BEING DONE?

This study is being conducted to explore hemodialysis nurses' perspectives on care provision with respect to supporting patient coping and resilience in the chronic, in-center hemodialysis setting. The study is part of my master's thesis in the Faculty of Nursing. To date, much is

known about the patient experience in this patient population, but little research has focused on nursing staff perspectives. With this study, it is my hope to increase understanding of nursing perspectives in chronic kidney disease and chronic hemodialysis care while illuminating opportunities to enhance support of hemodialysis nurses in quality care provision.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

It is anticipated that approximately 10 to 15 hemodialysis nurses will take part in this study through the University of Calgary, with recruitment occurring at in-center hemodialysis care sites in the Alberta Kidney Care-North and Alberta Kidney Care-South renal programs.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this study, you will be asked to participate in a one-on-one interview with me that will last approximately 30 to 90 minutes. You will have the choice to conduct the interview via (a) the online meeting interface “ZOOM”, with video on or off as per your preference, or (b) over telephone.

Your participation is voluntary. You will be asked questions about your perspectives surrounding nursing care provision in the chronic, in-center hemodialysis care setting as well as your experiences in supporting patient coping and resilience in this care setting. You do not have to answer any question you do not wish to answer, and you may stop the interview at any time. The interviews will be audio-recorded to make an accurate record of what you say during the interview and for the purposes of data analysis. You will also be given a grace period of two weeks following their interview to redact the interview data. After this two-week period, you cannot redact your interview data from the study due to the concurrent data collection and

analysis of this study. I may also re-contact you in this two-week period if further clarification is needed with any of your interview data.

HOW LONG WILL I BE IN THIS STUDY?

Individual interviews will last approximately 30-90 minutes. It is estimated that the study will take one calendar year to complete.

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

Although there are no foreseeable risks to you as a result of your participation in this study, you will be asked to explore and detail their nursing care experiences for patients in the interview. As such, you may experience some temporary psychological or emotional stress (e.g. anxiety) upon recollections of nursing care provision for specific patients during the interview process. Should you feel distressed and desire further counselling and wellness services following your interview, please consider accessing the Alberta Health Services Employee & Family Assistance Program (EFAP). As an employee of Alberta Health Services, you have free access to EFAP, which offers a wide array of counselling and wellness services to all Alberta Health Services staff.

Alberta Health Services: Employee & Family Assistance Program

- Main Website: <https://insite.albertahealthservices.ca/hr/Page964.aspx#efap-resources>
- Counselling Services Overview: <https://insite.albertahealthservices.ca/main/assets/hr/tms-hr-whs-efap-counselling-overview.pdf>
- Contact Phone Number: 1-877-273-3134

ARE THERE ANY POTENTIAL BENEFITS IF I PARTICIPATE?

There will be no direct benefit to you from participating in this study, although I hope that you will find the interview to be an enjoyable experience. Moreover, this study may help researchers learn more about nursing perspectives in chronic kidney disease and chronic hemodialysis care. This increased knowledge can be used to further insights into how nurses can be supported to provide care as well as how patient coping and resilience can be enhanced by nursing care in the context of chronic kidney disease and hemodialysis care.

WHAT OTHER CHOICES DO I HAVE IF I CHOOSE NOT TO PARTICIPATE?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. Your decision will not affect your employment.

CAN I STOP BEING IN THE STUDY?

Yes. You can decide to stop at any time. Let me know if you are thinking about stopping or decide to stop at any time. If you have already been interviewed, however, please note that you will be given a grace period of two weeks following your interview to withdraw the interview data. After this two-week period, I cannot remove your interview data from the study as data analysis will have already started.

WITHDRAWAL OF STUDY DATA

As mentioned previously, you will be given a grace period of two weeks following your interview to redact the interview data. After this two-week period, you cannot withdraw your interview data from the study.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not be paid for your participation in this research study.

WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?

Yes, information about you and your participation will be kept confidential. I will have sole access to the consent forms and audio-recordings of the interviews; I will also remove any personally identifiable information from the interviews during transcription. As interviews will be audio-recorded, audio-recordings of the interviews will be kept on one audio-recorder; the audio-recorder will be kept in a locked storage container at my residence at all times when not in use. Interview transcripts, which will have all personally identifiable information removed, and electronic copies of consent forms will be stored in an encrypted, password-protected file in my personal laptop computer, which also requires an additional password for initial access that only I know. When not in my use or close possession, my laptop will be stored at my residence. No data will be stored on ZOOM. I will make every effort to maintain the confidentiality of your research records, to the extent permitted by law (e.g., disclosed child abuse or neglect must be reported) and legal requests (e.g., court applications seeking disclosure of research data are possible).

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

To comply with university regulations, it is required that all research study data in electronic and paper files is kept for five years after data collection. After five years, I will destroy all study data by deletion. Transcript data collected for this study may be shared with other researchers for future studies that are unknown at this time. Any data shared with other researchers, will not include your name or other personally-identifying information. Any future use of this research data is required to undergo review by a Research Ethics Board.

RESEARCHER CONFLICTS OF INTERESTS

The research team have no conflicts of interests to declare in conducting this study.

WHOM MAY I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

Student Researcher: You may contact me at the email xxxxxxxx@ucalgary.ca or at the phone number ###-###-#### with any questions or concerns about the study or your participation in this study.

Conjoint Health Research Ethics Board (CHREB): If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?

Final findings of the study will be shared with all the study participants in the study once my thesis is completed and approved for submission to the university thesis repository. An abstract of the study will be prepared and shared with you.

WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?

Taking part in this study is your choice. You can choose whether you want to participate.

Whatever decision you make, there will be no penalty to you. You have a right to have all your questions answered before deciding whether to take part. Your decision will not affect your employment. If you decide to take part, you may leave the study at any time.

HOW DO I INDICATE MY AGREEMENT TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to take part in the study. In no way does this waive your legal rights nor release the research team or involved institutions from their legal and professional responsibilities.

SIGNATURE OF STUDY PARTICIPANT

Name of Participant

Signature of Participant

Date

SIGNATURE OF PERSON OBTAINING CONSENT

Name of Person Obtaining Consent

Contact Number

Signature of Person Obtaining Consent

Date

SIGNATURE OF THE WITNESS

Name of Witness

Signature of Witness

Date

A signed copy of this consent form will be given to you to keep for your records and reference.

Appendix J

Research Study Interview Guide

Interview Information

- Date:
- Time:
- Participant pseudonym:

Preamble to Interview

My name is Mia Maris Ortiz, I will be interviewing you today about your perspectives and experiences in caring for chronic kidney disease (CKD) patients on chronic, in-center hemodialysis (HD) treatment. Specifically, I am interviewing HD nurses to explore their perspectives in supporting patient coping and resilience during HD care provision. I intend to use information from these interviews to develop a better understanding of how HD nurses perceive care provision in the HD setting and potentially explore how care can be improved to enhance patient coping and resilience in CKD and HD.

This interview will be audio-recorded for the sole purposes of data collection and analysis; I will have sole access to any identifying information that ties you to this project, which I will remove when transcribing interviews to maintain your confidentiality.

Before I begin recording, I will review the consent form with you and address any questions or that you may have with participating in this project. [review consent form]

Do you have any questions about the project? [address questions, if any]

Can we begin the interview and start audio-recording?

Interview Questions

	Interview Questions	Possible Probing Question(s)
Demographics	What is your nursing designation? (e.g. Licensed Practical Nurse, Registered Nurse)	
	What is your age?	
	What gender do you identify as?	
	How many years have you worked in HD? Have you worked in other clinical areas or settings? If yes, in which clinical areas or settings?	
Research Study	Please describe your experiences in caring for patients on chronic HD treatment.	What are/were the easiest or least challenging aspects of caring for this patient population? ...the most difficult or most challenging aspects of caring for this patient population?
	Please describe your perspectives in caring for patients on chronic HD treatment.	What are/were the most important nursing priorities in caring for this patient population? ...the less important nursing priorities in caring for this patient population?
	What do you think could improve the care that you provide to patients on chronic HD treatment? OR	Examples: - Logistical factors (e.g. nurse to patient ratios, consistent patient assignments) - Additional training/education in a specific area (e.g. mental health support)

In an ideal world, what would effective, quality nursing care for chronic HD patients look like?	- Additional healthcare personnel or support staff (e.g. pharmacists, social workers, etc.)
What patient care advice would you give nurses who have just started in chronic HD care or are interested in becoming HD nurses?	How have you felt your nursing practice has changed or evolved from when you first started in HD care to now?
It has been noted in literature that CKD patients reliant on chronic HD treatment experience high burden of disease; depression and anxiety are quite common in this patient population. What are your perspectives on HD nursing care and supporting patient coping and resilience?*	How do you support positive coping skills and resilience for HD patients in your care?*
	What barriers, if any, do you face in care in trying to support patient mental health?*
	What factors aid you in supporting patient mental health in care provision?*

*Added in November 2020 for Participants 4-12.

Interviewer Notes (Post-Interview Journaling)

- Observations on participant engagement and behaviour during the interview (if video is available and information is not captured by audio-recording)
- Interviewer thoughts on specific participant responses
- Key themes highlighted by the interviewee regarding care provision in chronic HD

Appendix K

End-of-Recruitment Response



Dear [name of prospective participant],

My name is Mia Maris Ortiz; I am the student researcher for the study “*Exploring the Perspectives of Hemodialysis Nurses in Care Provision: An Interpretive Descriptive Study*” which I am conducting for my Master of Nursing thesis project as approved by the University of Calgary Conjoint Health Research Ethics Board (Ethics ID REB20-1031).

Firstly, thank you for your interest in participating in this study; I very much appreciate your time and consideration. However, I regret to inform you and that I am no longer accepting participants into the study due to resource constraints of the study. I thank you nevertheless for your support and continued commitment to quality nursing care in the chronic kidney disease (CKD) and chronic in-center hemodialysis (HD) setting. With this study, it is my hope to develop a better understanding of how HD nurses perceive care provision in the HD setting and potentially explore how care can be improved to enhance patient coping and resilience in CKD and HD care.

Warm wishes,

Mia Maris Ortiz, RN BHSc BN CNeph(C)

Faculty of Nursing, University of Calgary

2500 University Drive NW, Calgary AB T2N 1N4

Email: xxxxxxxx@ucalgary.ca, Phone: ###-###-####