

Patient-Centred Hemodialysis Nursing Care: An Interpretive Description

**A DISSERTATION SUBMITTED TO
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Abstract

Background

Patient-centred care originated in the 1950s, gained popularity in the 1990's, and is a professional regulatory, clinical practice guideline, governmental health policy, and perhaps organizational expectation of every nurse in Canada. The term is used liberally on the Health Canada website, and in 2011 the Canadian Institutes of Health Research launched the Strategy for Patient-Oriented Research. Also in 2011, the Canadian Nurses Association (CNA) and Canadian Medical Association (CMA) jointly identified patient-centred care as the first principle to guide healthcare transformation. In 2018, patient-centred care was adopted by Accreditation Canada through the addition of patient surveyors. Patient-centred nursing care could benefit people with end-stage kidney disease (ESKD) however the philosophical ideals of the approach may not consistently align with the everyday reality of hemodialysis nursing.

Purpose of Study

The study purpose was to describe the experiences and perspectives of hemodialysis nurses in their provision of patient-centred care.

Methods

A qualitative interpretive description design was used, with purposive sampling of hemodialysis nurses from hospital and satellite hemodialysis units in urban and rural areas registered with the College of Nurses of Ontario and currently employed full or part-time for more than three months. Semi-structured interviews were held, and transcripts were analyzed.

Results

Ten RNs participated and five themes were constructed through interpretation of their comments during interviews: Knowing, Applying, and Sustaining, plus Promoters and Detours of Patient-Centred Hemodialysis Nursing Care.

Conclusions

Patient-centred hemodialysis nursing care is a complex process with multiple promoters such as therapeutic relationships, reflective nursing practice, collaboration, and the satellite unit context. Nurses needed to navigate detours that interfered with the provision of patient-centred care related to patients, nurses, and unit, organizational, and system processes. Various interconnections occur within patient-centred hemodialysis nursing care, and certain ethical aspects require consideration.

Implications for Nephrology Care

Implications and recommendations for nephrology nursing education, practice, policy, and future research are identified.

Dedications

This dissertation is dedicated to all hemodialysis patients and nurses

“Hemodialysis is no bed of roses”

Cummings, 1970, p. 72

Special dedication to my loved ones

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Chapter One: Introduction

Patient-centred care is a concept that originated in healthcare in the 1950s and gained popularity in the 1990's when health professionals began to view recipients of their services as partners who were active in decision making (O'Connor et al., 1998; Stacey et al., 2020). Viewing patients as partners has raised awareness of the benefits of a patient-centred approach and shifted healthcare practice in many settings (Jakobsson et al., 2020; Ocloo et al., 2020; O'Rourke et al., 2019; Vennedey et al., 2020;). Research about patient-centred care has found benefits for patients such as those with cancer (Radwin et al., 2009), mental health issues (Maassen et al., 2017), chronic conditions (Sav et al., 2015), and dementia (Fazio et al., 2018). Providing patient-centred care is beyond any one profession (Gilbert, 2005) – it is essential to communicate the perspective of patients “across disciplines, specialties, and settings” (Thorne & Truant, 2010, p. 119).

Although the notion of a care provider and recipient relationship is foundational for patient-centred care, a common definition of the concept is lacking. This lack of standard terminology can lead to confusion about language and reasons for choosing specific terms. Tension in complex patient-centred care language includes interchangeable use and interpretations of terms such as person-centred, client-centred, or relationship-centred (Leplege et al., 2007; McCormack & McCance, 2017). Examination of types of centredness in healthcare found that *patient* was used most frequently (Hughes et al., 2008). The dynamics of stigma may shape nursing practice, and “language about others” uses power to “reduce a person to a problem or disease” (Hartrick Doane & Varcoe, 2005, p. 317), such as identifying a person as a patient. This may help explain the use of person-centred by some authors as a way to acknowledge

the whole person, not objectifying them by focussing on their symptoms (Harding et al., 2015; Britten et al., 2016). However, based on the belief that a patient is a person needing or receiving health care, and not “merely a patient” (Britten et al., 2016, p.410), the term *patient-centred care* is used throughout this dissertation. Alternate terms are sparingly used to prevent distorting the terms chosen by institutions and authors.

The United States (U.S.) and United Kingdom (U.K.) were early adopters of patient-centred care. In the U.S., the importance of the patient’s point of view as central to the therapeutic process influenced the psychotherapy of Carl Rogers in the 1950’s; he named it *client-centered care* (Rogers, 1951/2003, p. 7). It diverged from the traditional clinical model of seeing the patient as a “passive body” to a holistic person who knew more about their ailments than therapists and were “able to set their own goals” (Leplege et al., 2007, p. 1561). In 1960, Abdellah and colleagues published the book *Patient-Centered Approaches to Nursing*, but the topic was dormant until the Planetree and Picker movements promoting it were founded by patients in 1978 and 1986 respectively (Picker Institute, 2024; Planetree, 2023). In the U.K. at the same time, the possibility of “patient-centered medicine” was introduced (Balint, 1969), which led to the development of a conceptual framework for patient-centred physician-patient relationships (Mead & Bower, 2000). In the U.K., the National Health Service promotes person-centred care and nursing frameworks were developed (McCormack & McCance, 2006; 2017). In the 1990’s, Kitwood pioneered person-centred care and created a framework that has been extensively adopted globally (Mitchell & Agnelli, 2015; Terkelsen et al., 2020).

Canada has a short history in relation to patient-centred care. Nationally, the movement began in earnest when the federal government promoted Interprofessional Education for Collaborative Patient-Centred Practice (Curran, 2004; Gilbert, 2005). Documents on the Health Canada website have been archived for several years but some are accessible, such as final summary notes of a research workshop held in Ottawa in 2006 that noted the need for common definitions for several terms, including patient-centred (Government of Canada, 2007). Multiple searches of the Health Canada website during this study found liberal use of the term patient-centred but no definition of the concept. Another milestone towards care centring on the patient was when the Canadian Institutes of Health Research launched the Strategy for Patient-Oriented Research in 2011, which has the vision of improving health outcomes and enhancing patient care through research while improving healthcare system cost-effectiveness. In the same year, the Canadian Nurses Association (CNA) and Canadian Medical Association (CMA) together identified patient-centred care as the first principle to guide healthcare transformation, which requires effective communication and collaboration within and between healthcare professional disciplines along the continuum of care (CNA & CMA, 2011). In addition, patient-centred care was adopted by Accreditation Canada in 2018, which incorporated patient surveyors. In the background of a Canadian article regarding a bilingual qualitative survey with open-ended questions completed by Deans of academic programs in health and social care for ten professions, it is noted that “Canada has the longest standing collective experience” in the development of accreditation standards that are relevant for interprofessional education (Azzam et al., 2022, p. 2), which promotes patient-centred care.

An important benchmark in Ontario occurred in 2006 when patient-centred care became an expectation of every nurse in Ontario because it was articulated in the College of Nurses of Ontario (CNO, 2019) Practice Standard: Therapeutic Nurse-Client Relationship. The definition *client-centred care* drew from the 2002 version of the Best Practice Guideline of the Registered Nurses' Association of Ontario (RNAO), which was replaced, renamed, and redefined as *Person-and Family-Centred Care* (RNAO, 2015). Those important changes are not reflected in the most current CNO Standard (2019).

Statement of the Problem

Patient-centred care lacks a clear definition, which contributes to how it is operationalized in the care context. These two issues provided seeding for this study, because they became noticeable to me as a senior front-line nurse when 'patient-focussed' care was introduced in the 1990's. Nurses on our acute hospital adult medical unit were provided twice-weekly education on the 'new' concept, which one colleague described as "patient-focussed hocus pocus" (personal communication, 1995). Widely discrepant interpretations became quickly apparent about what it meant to provide nursing care that put the patient at the centre. Some colleagues seemed to have completed their work early, such as bed baths and distributing medications, which they described and documented as patient refusal. In contrast, other colleagues offered patients a choice of time for their care. Presence or absence of patient-centred care has been personally experienced as a patient and professionally as a Registered Nurse. My interest in the concept has not waned, and my current research has arisen from twenty years of experience in hemodialysis, including as Clinical Educator, where I noticed that the philosophical ideals of patient-centred care inconsistently aligned with the everyday

reality of hemodialysis nursing. Hemodialysis patients require complex nursing care. They could benefit from their care being patient-centred – evidence suggests it is not.

Under the Ontario Ministry of Health and Long-Term Care (2015), the Ontario Renal Network (n.d., a) promotes *Person-Centred Care* in collaboration with Cancer Care Ontario (2017) – unfortunately, no framework for this model of care is available. Patient-centred nursing care could benefit people with end-stage kidney disease (ESKD), which is incurable but treatable by kidney replacement therapy such as hemodialysis. Over the past decade there was a 24% increase in incident patients receiving renal replacement therapy (dialysis or pre-emptive kidney transplant) (N = 4,921 in 2012 versus N = 6,091 in 2021) (excluding Quebec because long-term trending is not available) (Canadian Institute for Health Information [CIHI], 2023). Three-quarters of the 29,809 Canadians on dialysis at the end of 2022 received institutional hemodialysis (CIHI, 2023).

Hemodialysis nurses provide treatments for a broad variety of patients in a broad variety of settings. In hospital hemodialysis units, Registered Nurses (RNs) provide treatments for one acutely ill patient in an inpatient or emergency room, while RNs and Registered Practical Nurses (RPNs) provide treatments for two or more chronically ill patients in the hemodialysis unit in the hospital (in-centre) or a satellite. Satellite units may also be rural, with nurses providing treatments for two or more chronic patients per session – acutely ill patients are transferred to hospital. Canadian hemodialysis patients described feeling they were “on an assembly line”, which researchers interpreted as causing “tension ... (with) whole person care” (Allen et al., 2011, p. 131). These comments suggest nursing care that is not patient-centred.

Research Aim

The aim of the study was to explore the experiences of Ontario hemodialysis nurses in providing patient-centred care.

Research Questions

The main research question was: How do hemodialysis nurses describe providing patient-centred care? Sub-questions were:

1. How do hemodialysis nurses describe care that is or is not supportive of patient-centred care? Are there differences and similarities across settings?
2. What facilitates hemodialysis nurses in providing patient-centred care? What interferes with hemodialysis nurses providing patient-centred care?

Conceptual Definition

Patient-centred care and hemodialysis nursing are the main concepts of interest for this study. There is no consensus on a definition of patient-centred care, therefore a conceptual definition developed by nursing research was selected that identified three patient-centred care elements – holistic, collaborative, and responsive – facilitated through a therapeutic relationship based on mutual trust and respect (Sidani & Fox, 2014). Holistic care addresses all health domains (bio-physical, cognitive, emotional, behavioural, social, spiritual), health promotion, illness prevention and management. Collaborative care refers to patient involvement in decision making that includes timely discussion with health professionals of accurate information, with options for treatment explored and implemented. Responsive care recognizes and responds to individual patient needs, values, expectations, experiences, and knowledge. The therapeutic

relationship involving mutual trust and respect facilitates implementation of the three elements holistic, collaborative, and responsive care (Sidani & Fox, 2014). All three elements must be implemented simultaneously (Sidani et al., 2014).

Hemodialysis Nursing

Hemodialysis nursing is a nephrology subspecialty requiring specific educational and experiential knowledge (Bonner, 2006). Hemodialysis nursing has been identified as the prototype of specialist nursing because it is one of the first practice areas reflecting advanced roles for nurses beyond traditional parameters (Arikan et al., 2007; Hoffart, 1989;). Physicians initially managed hemodialysis treatments with nursing assistance, but as patient numbers increased in the 1960's, nursing roles expanded to manage treatments – constant physician presence was no longer economically feasible or necessary (Hoffart, 1989). Hemodialysis nursing is unique due to the “sophisticated technology” and intense, continuous, and long-term contact with patients (Lewis et al., 1992, p. 546). The Canadian Nurses Association (CNA) organizes Nephrology Certification in nine categories, with the hemodialysis category being the largest (24.6%) with 68 competencies (CNA, 2014, p. 4). Certification is based on standards and practice recommendations developed by the Canadian Association of Nephrology Nurses and Technologists (2021).

The provision of patient-centred hemodialysis nursing care occurs in settings from urban to rural. According to Statistics Canada (2017), the word urban is understood intuitively to mean an area with concentrated and dense population, the opposite to rural. However, this leads to challenges due to broad interpretations, therefore two changes occurred in 2010: 1) the term 'urban area' was replaced by

'population centre', which was defined as having a population of at least 1,000 with a density of 400 or more people per square kilometre, with all areas outside population centres defined as rural; and 2) three population centre sub-groups were created to reflect the urban-rural continuum: small population centres (population 1,000 to 29,999), medium (30,000 to 99,999), and large (100,000 and over) (Statistics Canada, 2017). A Province of Ontario definition of urban is elusive but draws from Statistics Canada (Ahmed, 2019). Comparable to patient-centred care, there is no consensus on a definition for rural, and the conceptual definition is drawn from the Rurality Index for Ontario (RIO), developed with three broad, weighted components: 1) community population; 2) density; and 3) travel times to the nearest basic and advanced referral centres (Kralj, 2009). RIO scores are ordinal measures from 0-100 reflecting a “*relative ranking*” of rurality, with a higher score indicating a higher degree of rurality (Kralj, 2009, p. 6, italics original). RIO scores can be determined using an online postal code tool (Ontario Medical Association, n.d.) and cross-checked against information from the Ontario Ministry of Health (2022).

Dissertation Format

This dissertation is presented in six chapters. The study was introduced in this chapter through provision of background information and identification of the problem, research aim and questions, and guiding conceptual definition. In Chapter Two, relevant literature is examined in three streams: patient-centred nursing care, hemodialysis nursing, and patient-centred nursing care in hemodialysis, with gaps identified. In Chapter Three, the methodology and methods are described, including research design and setting, sampling strategy, data collection and analysis, and steps taken to ensure

that ethical standards were followed, credibility assured, and reflexivity apparent. In Chapter Four, results are described in themes constructed through analysis and interpretation of what participants shared about their experiences of patient-centred care during interviews. In Chapter Five, a discussion of findings is provided and in Chapter Six, a summary is provided, implications for practice, policy, and future research are discussed, dissemination plans are described, and strengths and limitations of the study are identified. References and appendices complete the dissertation.

Chapter Two: Review of the Literature

In this chapter the foundation on which the study is built is provided through a description of the search strategy and summary of relevant literature about patient-centred hemodialysis nursing care. In line with the interpretive description approach, this standard review supports the need for this study by presenting what is currently known while reflecting on what does and does not exist (Thorne, 2016). Literature directly bearing on the problem is included, with attention to major findings. Comments are provided about the overall strengths and weaknesses in the body of current knowledge rather than exposing flaws in prior research that the current study will try to correct, which does not align with the requirements of interpretive description (Thorne, 2016). The search for relevant literature occurred throughout the dissertation process.

Search Strategy

The search strategy was developed to find high quality peer-reviewed research evidence to determine the current state of knowledge regarding the perceptions and experiences of hemodialysis nurses of patient-centred care. Inclusion criteria included quantitative or qualitative research about patient-centred care and hemodialysis nursing for adults, available in English, with no date range to capture historical developments. Articles were excluded that focused on other renal replacement modalities such as home dialysis (hemodialysis or peritoneal), kidney transplant, or supportive care. Literature without a specific patient-centred nursing care model or definition was reviewed and included where relevant.

The search strategy began using a targeted vocabulary, displayed in Table 1 below, which was built to access the highest number of papers using MeSH headings

and combinations of keywords or their variants, including patient-centred (e.g., person-centred, client-centred), nephrology (e.g., renal), nephrology nursing, end-stage renal or kidney disease, renal replacement therapy, and hemodialysis. The goal was to identify as many studies as possible without restricting the potential pool of papers to screen or having an excessive number of irrelevant studies (Arksey & O'Malley, 2005; Daudt et al., 2013; Elliot et al., 2019). The intent was to identify and consolidate literature while identifying gaps, rather than providing a critical evaluation of individual articles (Grant & Booth, 2009). The search was completed in the MEDLINE (OVID), CINAHL (EBSCO), and ProQuest databases to ensure comprehensive retrieval of nursing literature with the following inclusion criteria:

1. The primary topic was patient-centred hemodialysis nursing care for adults.
2. The paper was a published peer-reviewed report of qualitative and/or quantitative data collected through any study design.
3. Theoretical discussion and conceptual analyses of the two main streams of patient-centred care or hemodialysis.
4. Full-text English version was available.

Grey literature was searched using the same keywords on targeted Canadian websites such as Health Canada and Accreditation Canada and for specific health professions, mainly nursing. Particular interest was given to grey literature in Ontario, especially the Ministry of Health and Long-term Care, and professional organizations such the College of Nurses of Ontario and Registered Nurses' Association of Ontario. Samples of search results are available in Appendix A. In addition, relevant articles accessed over the past three decades by this researcher were added if they did not

surface during searches, and automatic electronic searches were established with keywords to ensure awareness of new articles. Literature scans were also completed of the websites and journals of the Canadian Association of Nephrology Nurses and Technologists (CANNT) and the American Nephrology Nursing Association (ANNA).

| Patient-centred care | Hemodialysis | Rural |
|---|--|---|
| MeSH | MeSH | MeSH |
| Nurse-Patient Relations/ Patient-Centered Care/ Patient Participation/ Patient Preference/ Patient Satisfaction/ Professional-Patient Relations/ | Renal Dialysis/ Renal Replacement Therapy/ Nephrology Nursing/ | Hospitals, Rural/ Medically Underserved Area/ Rural Health/ Rural Health Services/ Rural Nursing/ Rural Population/ |
| Keywords | Keywords | Keywords |
| collaborative cultural competence holistic patient centred patient-focused relational responsive therapeutic relationship patient satisfaction patient experience patient perspective | end-stage kidney disease end-stage renal disease hemodialysis nephrology nurse nephrology nursing renal nurse renal nursing renal dialysis renal replacement therapy | non-metropolitan non-urban rural rural clinic town village |

Screening

Manual screening of the literature began by reading titles and abstracts, which reduced the number of articles for full-text reading because they did not meet inclusion criteria. Full text reading resulted in an expansion of articles to screen based on emerging results, for example by searching for specific articles identified in reference lists of high-quality articles, and frequently cited work from authors with known expertise relevant to this study. The literature is reviewed in three streams, beginning with the two

main concepts, patient-centred nursing care and hemodialysis nursing, and ending by combining the two concepts to present literature about patient-centred hemodialysis nursing care.

Patient-Centred Nursing Care

The first main concept in this study is patient-centred nursing care. Patient-centred care has been evident in nursing research for over 60 years (Abdellah et al., 1960) and guided framework development based on patient values (Bilodeau & Tremblay, 2019; McCormack, 2003; McCormack & McCance, 2006 & 2017). Patient-centred care re-emerged recently as a strategy to reform healthcare, but:

... is so fundamental to nursing's theoretical, ethical, and philosophical core that arguably it constitutes the central idea from which nursing has distinguished itself from all other healthcare professions over time (Thorne & Stajduhar, 2017, p. 24).

As noted in the introduction, tension related to patient-centred care language was addressed through examination of types of centredness in healthcare that found the term *patient* was used most frequently (Hughes et al., 2008). Ten themes were identified as common to all types, and their interconnectedness provided strength: respect for individuality and values; meaning; therapeutic alliance; social context and relationships; inclusive model of health and well-being; expert lay knowledge; shared responsibility; communication; autonomy; and professional as person (Hughes et al., 2008, p. 468). Types of centredness differed due to contextual and background variations, such as being in a hospital or long-term care setting, and for practical reasons such as using family-centred care in pediatrics (Hughes et al., 2008). Patient-

centred communication was identified as being critical for improved patient healthcare outcomes and satisfaction (McKeown et al., 2023, p. 132).

The conceptual definition for this research is drawn from an integrative literature review of 178 papers in which nurse researchers described patient-centred care as a complex intervention with “holistic, responsive, and collaborative” components facilitated by the therapeutic patient-healthcare professional relationship (Sidani & Fox, 2014, p. 138). Subsequent cross-sectional research on self-reported survey data from 382 nurses, physicians, and social workers in 18 urban and suburban hospitals across Ontario (Sidani et al., 2018). Findings indicated differences in how they valued and practiced these elements, which may negatively affect collaborative care if the level of patient-centred care is inconsistent between different groups of professionals (Sidani et al., 2018). This is supported by findings from a qualitative study in Australia of ten surgical patient perceptions of patient-centred care that it was fragmented between different health professionals (Marshall et al., 2012) and from another study from the U.S. with 107 employees (leaders, middle managers, front line providers and staff) at four Veteran Health Administration medical centres that found varied conceptualizations of patient-centred care (Fix et al., 2018). Some participants felt patient-centred care was aligned with a specific discipline, especially nursing – these authors suggest this may limit the adoption by nurses of important factors in patient-centred care such as sharing power (Fix et al., 2018). A systematic review of twelve instruments from Sweden, Canada, Turkey, U.S., Finland, and Australia measuring patient perceptions of patient-centred nursing care found no single, consistent definition or gold standard for different settings and populations (Koberich & Farin, 2015). This observation was reinforced by

an Australian integrative literature review of 17 articles exploring definitions of person-centred care in nursing, which also found no common definition but core themes of people (uniqueness and partnerships), practice (influenced by system and professional factors), and power (patient and professional) (Byrne et al., 2020). These findings are important for this study because they indicate that although there is no consensus on a standard definition and nurses may have different interpretations than other health professionals, they still enact the core values of patient-centred nursing care.

There is also no consensus in the literature about many aspects of patient-centred nursing care, including whether it is beneficial or not. Research reporting that it is beneficial includes findings that when care was patient-centred, patient ratings of satisfaction with care improved (Cudney et al., 2024; Manias, 2019), patient participation in their healthcare improved which in turn improved patient safety (Hwang et al, 2019), individuality and continuity were maintained for patients with dementia through meaningful activities in a safe environment (Nicholson, 2017), and communication, documentation, and patient safety improved (Jakobsson et al., 2020).

Nurses have championed patient-centred care, such as in a 2-year Australian case study where a nurse navigator developed a trusting relationship and successfully provided support for home-based care for a patient with chronic respiratory illness, in spite of his significant social and clinical issues (Byrne et al., 2021). Canadian nurses also championed patient-centred care, in a 6-month multi-site randomized controlled trial that evaluated an individually tailored nurse-led hospital-to-home transitional care intervention (in-home visits, telephone follow-up and system navigation) for patients with multimorbidity; the intervention was effective and patient experiences improved (Markle-

Reid et al., 2021). These studies draw attention to nursing engagement and nurse-patient relationships over time for patients with chronic illnesses and reinforce the benefits of patient-centred nursing care in different contexts and patient populations.

No studies reported that patient-centred care was not beneficial, but several drew attention to negative aspects, misuse, and barriers. For example, a Canadian institutional ethnography noted that the nursing profession accepted patient-centred care with little criticism, describing it as a complex textual tool that was adopted by healthcare organizations to reshape nursing processes to organize their work with patients managed as customers (Rankin & Campbell, 2006). This meant that organizations used the rhetoric of patient-centred care to reduce staffing and promote healthcare as a business. This is the antithesis of patient-centred care.

Continuing with this discourse, a Canadian examination of the politics of patient-centred care found that manager, physician, and nursing groups used patient-centred language to their own advantage against the other groups, such as when nurses were encouraged to consider patient-centred care as part of the distinct history of the profession (Kreindler, 2013). It was argued that rhetorical choices, such as use of the word 'person' rather than 'patient' may actually "marginalize the experience of persons whose illness renders them vulnerable" (Kreindler, 2013, p. 1144).

Another example of barriers to patient-centred care is in the previously mentioned study from Australia, where tension developed due to hospital processes such as discharge protocols and limits to the nurse navigator role (Byrne et al., 2021). Barriers were also noted in the United Kingdom, where interviews with 26 clinicians found there were practical and ethical uncertainties and tensions from various sources

at patient and professional levels in providing patient-centred care for people with long-term conditions (Entwistle et al., 2018). In Canada, patient-centred care has not been promoted or utilized in federal policy strategies, resulting in gender disparities and a lack of improvement in the healthcare experiences of women (Abbatichio et al., 2024; Gagliardi et al., 2020).

In addition to barriers and lack of/misuse, patient-centred care can be poorly understood and difficult to operationalize in different nursing environments, which was the reason for a systematic research program by Jakimowicz in Australia. The work of Jakimowicz is important for this study because it is the first research on patient-centred care in a specific setting, the intensive care unit (ICU), and because ICU nurses have been described as providing care for patients whose illness severity is comparable to that of patients on hemodialysis (Arikan et al., 2007). The professional activities of hemodialysis RNs have often been reported as similar to ICU RNs (Doré et al., 2018).

An early project by Jakimowicz and Perry (2015) was a concept analysis of patient-centred nursing in the ICU, where defining attributes in 28 reviewed studies were found to include patient identity, biomedical nursing practice, plus compassionate and professional presence. When these attributes were combined with antecedents and consequences specific to the ICU environment, patient-centred care was different in comparison to other areas of healthcare, and a foundation was provided for operationalizing patient-centred ICU nursing (Jakimowicz & Perry, 2015). A later integrative review of 23 studies of patient-centred care in ICUs unfortunately found few facilitators, such as teamwork and nursing values, but many barriers, such as workload, ethical issues, and poor communication with physicians (Jakimowicz et al., 2017). A

further qualitative study with 21 ICU nurses from two units found they could provide patient-centred care only if they were able to attain balance on a “compassion continuum” while meeting various complex personal and professional (regulatory, workplace, collegial) expectations (Jakimowicz et al., 2018, p. 1607). A new approach to achieve light sedation in an ICU in Belgium that focused on patient comfort identified patient-centred care components such as frequent appropriate communication, time and space orientation, noise reduction, and night sleep promotion (Vincent et al., 2016).

The findings from these studies are important for this research because they provide information related to patient-centred care in the specific setting of ICUs, drawing attention to the lack of comparable or contrasting information in different hemodialysis settings. They also identify factors important in the provision of patient-centred nursing care, such as communication and ethics.

Meaningful trust in the context of chronic illness is another dimension of patient-centred care - this trust develops over time as patients and healthcare professionals get to know each other, as found through a case study in Slovakia (Tomagova et al., 2024). Patients must also develop self-trust as they navigate their chronic illness, which can be undermined by unsupportive relationships with healthcare practitioners who do not demonstrate reciprocal trust, as noted in an exploratory essay based on qualitative research of patient perspectives (Grob et al., 2023). Secondary analysis of qualitative data (64 patient and 66 health practitioner interviews) from a U.K. mixed methods study of partnerships between patients and healthcare professionals, found trust to be a central mechanism that enabled relationships to be built; patients needed to feel comfortable before becoming engaged and disclosing details of their illness experiences

(Westlake et al., 2022). Relationships between patients and nurses are dynamic and transform over time and through repetitive contact and can become mutually beneficial and meaningful (Luchsinger et al., 2019; Morse, 1991). These relationships could be strengthened through, and be a way to facilitate, a patient-centred approach to hemodialysis nursing care.

Collectively this literature addresses patient-centred nursing care primarily in hospital acute care settings and raises questions of whether difficulties with patient-centred nursing care relate more to operationalizing it in different contexts rather than defining it. In addition, it raises questions about what, how, and when individual patient and nurse factors might affect the interpretation and provision of patient-centred care in different settings, such as varied hemodialysis units in urban and rural settings. In view of the different types of 'centred care' in different contexts as identified by Hughes and colleagues (2008), it leads to the question of whether there is more than one type of patient-centred care. Based on the literature I would argue that there are at least two types – the managerial type which health care organizations broadly adopt (Byrne et al., 2021; Rankin & Campbell, 2006) and the relational type which reflects the nurse-patient therapeutic relationship (Jakimowicz et al., 2018; Markle-Reid et al., 2021).

In the reviewed papers some authors noted methodological limitations, such as Sidani and colleagues (2018) who noted an imbalance across professional groups and social response bias, and Jakimowicz and colleagues (2018) who noted a lack of generalizability, although their findings aligned with other studies. One study noted that funding was received from a pharmaceutical company, but disclaimed any influence (Vincent et al., 2016). These limitations add credence to the need for the present study.

This was a brief review of literature related to patient-centred nursing care. Similar to patient-centred care, there are many different points from which to view hemodialysis nursing, such as the development of patient/nurse relationships, differences in urban and rural in-centre satellite units, and specific ethical concerns. These views are developed in the next section.

Hemodialysis Nursing

Hemodialysis nursing is a nephrology subspecialty requiring specific educational and experiential knowledge (Bonner, 2006), and as previously mentioned, is the prototype of specialist nursing (Arikan et al., 2007; Hoffart, 1989), uniquely different from nursing in other units (Lewis et al., 1992). Nurse researchers have hypothesized that patient-centred care could improve during longer stays on one hospital unit due to the ability to develop better communication and strengthen the relationship between patients and nurses (Koberich et al., 2016). This could also be very applicable to the circumstances in hemodialysis units due to the unique repetitive nature and length of time patients are present for treatments several times each week.

Tension with language in patient-centred care was also previously mentioned, and somewhat similarly, language relating to kidney health has been described as inconsistent and conceptualized differently by patients and healthcare professionals. Research from focus groups involving 54 patients with chronic kidney disease and 13 caregivers from Australia, the U.S., and the U.K. found that patients were unfamiliar with words such as *renal* rather than kidney and were shocked and scared by words with negative connotations such as “end stage”, which they interpreted as indicating impending death, not realizing it meant the end of their kidney function, not their life

(Tong et al., 2020, p. 939). Effective communication is a cornerstone of providing patient-centred nursing care, which these researchers supported by recommending education to promote health literacy, help patients to face the reality of having a chronic incurable disease, plan for the future, self-advocate, and communicate with their family members. A Patient Editor response to the Tong and colleagues (2020) article was published in the same journal issue, noting that much of the terminology used by kidney professionals caused anxiety and created barriers for patients to understand their disease and prognoses, calling for professionals to think about how they communicate with patients, and the specific language that they use (Conway, 2020, p. 907).

Shifting from language issues to the perspectives of hemodialysis nurses about patient care, a Canadian nursing PhD student recently noted that there is very limited literature addressing this (Ortiz, 2021). The literature that is available provides conflicting views. One view about hemodialysis nursing in a recent ethnographic study that included 27 interviews with patients (12), RNs (12), and clinical support workers (3) in the U.K. described direct patient care in the hemodialysis unit as active or passive (Wood et al., 2019). Active care involved direct staff member and patient engagement, such as when patients were being assessed by nurses or connected/disconnected to the machine, while care was considered passive when the nurse was visible in the same room but occupied, for example providing active care to another patient. The clinical and urgent aspects of care always were the priority. These findings are important for this study because Wood and colleagues (2019) heard the voices of hemodialysis nurses, added layers to the idea of patient-centred hemodialysis nursing

care occurring through active and passive direct care episodes, and highlighted the patient-nurse therapeutic relationship.

Hemodialysis nurse perspectives of their lack of satisfaction with their work environment were reported in an exploratory study with 101 RN participants from 45 outpatient hemodialysis facilities in the United States (Gardner & Walton, 2011). The researchers found that nurses were striving to be heard and recognized, wanted to prevent problems, and were frustrated and dissatisfied by not being recognized as valuable team members, feeling that administration did not value their opinions. The nurses reported lacking resources to promote quality patient care, including adequate staff, and felt “isolated, overwhelmed, under-utilized, and disconnected” from their expectations of being a professional nurse (Gardner & Walton, 2011, p. 249). Several recommendations were made to improve the working environment, with a call for timely action. These findings are not only specific to North America and are supported by research findings in Australia and New Zealand that examined relationships between work environment, job satisfaction, stress, and burnout in 417 hemodialysis nurses (Hayes et al., 2015). Nurses experienced frequent contact with patients in an intense, complex work environment, where the highest levels of stress were due to workload and the lowest from conflict with nursing colleagues, 52.5% had emotional exhaustion and 58% had low levels of feeling personally accomplished (Hayes et al., 2015). Despite that, the overall practice environment was perceived positively by the nurses, who appreciated fair and equitable management flexibility, such as in daily work assignments. The authors suggest that the high emotional exhaustion levels of in-centre

nurses were related to the higher patient acuity and workloads, lack of support, and conflict with doctors (Hayes et al., 2015).

Since this current study includes rural settings, research literature in that context is relevant. Patients in rural settings were found to have concerns that smaller towns lack anonymity, causing fear of stigma and ostracism and resulting in less reaching out and discussion of sensitive health topics (Bauer et al., 2019; Calopedos et al., 2019). A systematic review and meta-analysis from the U.K. of 40 articles regarding nurses' decisions to work in rural and remote settings found they had concerns about personal and professional lives being blurred, and challenges in maintaining anonymity because everybody in the community knows other people's problems (MacKay et al., 2021).

Challenging patient behaviour was found in an examination of a rural hospital-based hemodialysis unit in Australia, through focus group interviews with five nurses who reported facing patient aggression and lack of self-management (Jacob et al., 2020). Patients were reported as being rude, inappropriate, and verbally or physically aggressive, but the nurses dismissed or justified the challenging behaviours as being due to the patient illness (Jacob et al., 2020). Patients also created logistical challenges, intentionally or not, such as by not attending appointments in a timely manner and demanding care at specific times. Additionally, if patients became too dependent on nurses when long-term relationships developed, they could manipulate the nurses and undermine their confidence, potentially contributing to burnout (Jacob et al., 2020). In spite of this, all participants said that they maintained their commitment to professional care regardless of patient behaviours and that the priority was always patients, the core of patient-centred care. Teamwork was appreciated by the nurses, such as taking turns

with challenging patients, and support from unit managers and administration such as developing patient-specific strategies to manage particular behaviours (Jacob et al., 2020). This challenging behaviour is demonstrated in that study in a rural setting, but it has been prevalent across hemodialysis units for decades, such as verbal and physical abuse toward nurses from patients as found through semi-structured interviews with ten hemodialysis nurses in Ireland (Murphy, 2004). Another type of patient behaviour is not adhering to the difficult regimen for attending and completing all hemodialysis sessions, taking all medications as prescribed, following fluid restrictions, and maintaining the prescribed diet (Kim et al., 2010; Morgan, 2000). Many factors contribute to non-adherence. For example findings from a Canadian study where eight patients receiving hemodialysis were interviewed described access to safe and reliable transportation as a factor that can affect whether they attend and complete a full hemodialysis treatment (Kamboj, 2019).

Hemodialysis may be provided in a satellite unit, which is referring to a location outside of the main hospital unit, which can occur in rural or urban settings. A U.K. investigation through interviews with 25 patients and 12 nurses regarding their experiences in satellite units found that patients felt more secure because of the relationships that develop between them and staff, while repetition and routine help them learn to arrange their lives around hemodialysis (Bevan, 2007). Patients could feel safer and more relaxed than in the hospital unit due to the close proximity of other patients and nurses who were easily visible and ready to intervene if necessary (Bevan, 2007). Another benefit of the satellite setting in contrast to the hospital was that nurse autonomy and confidence was promoted in the satellite due to having more freedom to

use their knowledge and skills and make decisions about patient care without having to constantly explain their actions (Bevan, 2007). Through interviews, 17 Canadian patients also described the satellite hemodialysis environment as more relaxed and quieter than the main “chaotic, factory-like, noisy, and uncomfortable” unit (Wilson & Harwood, 2017, p. 385). This environment with closer proximity promotes patient-centred hemodialysis nursing care. However, the perspectives of eight nurses in a suburban satellite hemodialysis unit in Australia indicate they felt their status was lower than the hemodialysis nurses in the acute hospital unit (Bennett, 2011). Through interviews and observations it was found that they needed confidence to provide quality interpersonal and technical care (Bennett, 2011). This may negatively affect their ability to provide patient-centred hemodialysis nursing care.

The power differential between clinical staff and patients and their families has led to hemodialysis nurses trying to give back the power to patients and their families, as found through interviews with ten nurses from five hospitals in Norway (Aasen et al., 2012). This was achieved through repeated contact during treatments, by nurses building rapport, engaging with patients, promoting self-care, providing education, and involving them in management of their chronic kidney disease and hemodialysis care. These findings draw attention to some ethical aspects in hemodialysis nursing. Ethical issues have been mentioned as a barrier to patient-centred care, such as by Jakimowicz and colleagues (2017), and there is potential for the same barrier to happen in hemodialysis. Due to the frequent, regular proximity hemodialysis nurses have with patients, they are uniquely positioned to deal with the everyday ethical issues that arise.

Ethical issues arose decades ago in nephrology when the first patient received maintenance hemodialysis, related to patient selection for the scarcely available new treatment by the “Life or Death Committee” (Alexander, 1962, p. 105) also known as “The God Squad” (Jonsen, 2007, p. 238). Early research noted a paucity of prior studies on the perspectives of nurses on ethical conflicts experienced in dialysis settings, which were examined in a descriptive pilot study in the United States (Redman et al., 1997). Results showed that no ethics instruction was received by 32% of participants in their basic nursing education and 64% in post-graduate coursework, and that the majority (69%) of ethical conflicts reported involved discontinuation or non-initiation of dialysis, half of which were disagreements with physicians about dialysis for terminally ill patients (Redman et al., 1997, p. 2-3). The authors were most struck by the finding of a lack of formal resolution of ethical conflict by two-thirds of the respondents: 44% tried to simply cope, 18% ended with the patient’s death, and 5% of the nurses removed themselves from the situation (Redman et al., 1997, p. 3). However, 11% of the issues were resolved by simply raising an ethical question, 9% by referral to an ethics committee, and 5% by an ethical decision (Redman et al., 1997, p. 4). These findings are relevant and interesting and have not been reported in more current literature.

Later studies concerning ethical issues in nephrology have examined patient perceptions about quality of life (Al-Arabi, 2006; Lindqvist et al., 2000) and end-of-life issues (Davison & Simpson, 2006). A particular focus has been patient decision-making about choice of treatment (Giles, 2003; Polaschek, 2007; Silen et al., 2008), with doubts being raised that patients are even involved or offered choices (Landreneau & Ward-Smith, 2006; 2007; Mehrotra et al., 2005). Silen and colleagues (2008) examined the

perspectives of 13 nurses in three hospitals through interviews about decision making regarding life-sustaining treatments for dialysis in Sweden. The nurses thought that a lack of communication, collaboration, and consensus between physicians and nurses with regard to decision making resulted in poor collaboration between staff, patients, and their families (Silen et al., 2008). Physicians reacted with irritation when nurses questioned them about decisions regarding treatment withdrawal, however nurses could help physicians by conveying information from patients and family members (Silen et al. 2008). Many nurses felt that patients were ignored and not well informed, especially early in their disease course, and therefore were not involved in decision making; this could result in patients receiving treatment even if they did not want it (Silen et al., 2008). The authors suggested improved communication across professional boundaries and clarity in nursing roles in decision making. Through case study in the U.S., decision making and communication were demonstrated as still being important ethical concerns for hemodialysis nursing (Vickey & Frechman, 2022).

The recent pandemic contributed to ethical dilemmas such as adaptations to ensure patient safety, patients skipping treatments and experiencing increased anxiety during lockdowns (Nigri & Silva, 2022; Shi et al., 2023). In a multi-country review (Australia, India, USA, UK, Africa), Ducharlet and colleagues (2021) reported increased moral distress and injury in nephrology healthcare providers during the pandemic due to issues such as being unable to provide necessary patient care due to increased constraints on limited healthcare resources, compromised end-of-life care and care quality in comparison to pre-pandemic standards, and managing conflicting

responsibilities. Strategies to manage moral distress included recognizing its existence, responding when it occurs, and steps to minimize it in the future (Ducharlet et al., 2021).

Ethical issues in nephrology have arisen for seven decades and continue – implementation of patient-centred hemodialysis nursing care could be beneficial. This stream of literature is very relevant for this research because it draws attention to the complexity and uniqueness of nursing care in the hemodialysis setting. Strong nurse-patient relationships that develop due to the repetitive, consistent, and in many cases long duration of treatments combined with a patient-centred approach could significantly and positively impact patients' coping with the burdens of chronic kidney disease and hemodialysis. Consideration must be given to the shortcomings that arise because some of these studies are about nephrology nursing or dialysis in general rather than specifically hemodialysis, and to the practice differences and skill mixes in other countries compared to Canadian healthcare settings. These methodological weaknesses further support the need for this current study.

The final shift in this literature review will combine the two main concepts of this study by focussing on research literature about patient-centred hemodialysis nursing care. Three streams of this literature will be identified and followed: the first is that patient-centred care is not occurring, the second is that it is occurring but not articulated as such, and the third is that it is occurring and articulated.

Patient-Centred Hemodialysis Nursing Care

In the previous two sections, literature was presented about nursing in relation to patient-centred care and the specialty area of hemodialysis, which provided some background to understand this final section where the two concepts are combined. The

nurse-patient relationship is the cornerstone of patient-centred hemodialysis nursing, and several studies contribute collectively to understanding the development of those relationships. This is very relevant to examining patient-centred hemodialysis nursing care and provides further significance for conducting this study. In Canada, Ortiz (2021) drew attention to the centrality of the nurse-patient relationship in the context of the provision of hemodialysis care through interviews with 12 hemodialysis nurses.

Relationships between patients and nurses was described decades ago as either unilateral or mutual, based on various factors, with four levels of the latter: clinical, therapeutic, connected, and overinvolved (Morse, 1991), and is very applicable in hemodialysis nursing. A connected relationship develops beyond one that is clinical and therapeutic, perhaps due to the duration of time and complexity of patient needs. Connected relationships required mutual negotiation and commitment, and while nurses maintained their perspective as a professional and advocated for patients, they saw them first as a person and second as a patient, a factor that is important in determining what type of relationship developed (Morse, 1991). In turn, patients respected nurses and developed trust in their technical competence and interpersonal psychosocial skills (Morse, 1991). This description of relationships being connected is an appropriate description of patient-centred hemodialysis nursing care.

Nurse-patient relationships in outpatient hemodialysis were found through interviews with 22 nurses in one hospital in the U.S. to exist in a complex combination of the patient, nurse, and illness, and were similar to a “psychotherapeutic patient/therapist relationship” due to the long-term nature of hemodialysis (Morehouse et al., 2001, p. 297). In a Korean study of interviews with 14 hemodialysis nurses in two centres, Kim

and colleagues (2016) found that they felt pity for patients due to their restricted lifestyles. The nurses developed and tried to maintain trusting and comfortable therapeutic relationships over prolonged time periods but were challenged by patients who constantly complained, expected immediate attention, and behaved in an abusive way (Kim et al., 2016). They came to realise that as they cared for patients and helped them resolve problems, they had psychologically matured and felt appreciative and humbled when reflecting on their own lives, as well as on life and death (Kim et al., 2016).

Managing chronic kidney failure can lead to the need for hemodialysis. A Canadian review noted that patient-centred care would benefit patients with chronic kidney disease but requires improvement because the scientific/technical focus has kept attention away from “the more human aspects of the disease” (Bear & Stockie, 2014, p. 6). This comment raises doubts that patient-centred hemodialysis nursing care is occurring. One study points directly to a lack of patient-centred care in nephrology nursing. This grounded theory study of nephrology nursing expertise in one Australian renal unit involved six non-expert and 11 expert nurses and revealed that of the three stages (non-expert, experienced non-expert, expert), being “patient-focused” happens only when the expert level is reached (Bonner & Greenwood, 2006, p. 482). However, this finding is taken with some scepticism because while it is understandable that new nurses focus on developing nephrology skills, nurses who are new to the hemodialysis context typically have some years of clinical experience and may have previously developed patient-centred practice. One can be a non-expert nephrology nurse but an expert in being patient centred.

Other research raises doubts about patient-centred hemodialysis nursing care through findings of high pressure in hemodialysis units due to heavy workloads, understaffing, and noisy, cramped environments that affect care quality, with little or no time to talk with patients or meet their emotional needs (Murphy, 2004; Vitri et al., 2001; Wai et al., 2020). These findings indicate long-standing issues reinforced by a later national study of nephrology settings in the U.S. that surveyed 929 nurses (74.4% hemodialysis) and found that patient safety concerns were due to issues such as poor communication and non-compliance with policies such as infection prevention (Kear & Ulrich, 2015). Nurses described “an assembly line mentality”, citing pressure to get patients “on and off the hemodialysis machines” in a hurried working environment (Kear & Ulrich, 2015, p. 117). In a follow-up study with 1,070 nurses (hemodialysis = 73%), long and intense work hours were reported: 35% worked shifts longer than 12 hours and 79.9% had on-call duty after a regular workday (Ulrich & Kear, 2018).

Research through interviews with 10 Ontario hemodialysis nurses also found that they considered work processes to be akin to the fast pace of an “assembly line”, referring to changeover periods when treatments for multiple patients end and then begin for a new group of patients, which is impacted by factors such as nurses work shift requirements and pressure from patients (Wilson et al., 2010, p. 38). This is one contributing factor to hemodialysis nurses remaining in the stage of “perpetual novice” where there is a delay or even an end in the transition to expert cannulator in spite of working in the hemodialysis unit for a number of years (Wilson et al., 2010, p. 39).

Findings from the above studies describe hemodialysis work conditions that are not conducive to patient-centred care – an overworked exhausted nurse may not be

able to engage with a patient or develop their skill competency to provide the highest quality of care. These findings are reinforced by Thomas-Hawkins and colleagues (2020) in the U.S., who examined the relationships to patient safety in outpatient hemodialysis units of RN staffing, workload, and nursing care left undone (e.g., patient surveillance and monitoring of dialysis treatments, documentation of nursing care) through surveys with 104 participants. They found that transitions during patient shift changes in hemodialysis units were noted as being unique because they occur multiple times daily and have a high potential for care interruptions, miscommunication, and error, and only 34% of the nurses in the study rated them as being safe (Thomas-Hawkins et al., 2020). Results showed that high patient-to-RN ratios, high RN workloads, and inadequate care processes were directly or indirectly associated with negative patient safety outcomes. Addressing those two key factors would improve safety during patient shift changes (Thomas-Hawkins et al., 2020), and would promote patient-centred care.

Limited evidence that the concept was integrated into nursing practice was found in a qualitative case study exploration of person-centred care in a large urban hemodialysis program in western Canada (one in-hospital unit and two satellite units, including nocturnal and home hemodialysis) (Lewis et al., 2019). The 49 participants interviewed included patients (20), family members (6), nurses (9), nephrologists (6), social workers (3), and managers (5). There were numerous barriers at individual, unit, and organizational levels and themes that varied across services, such as the in-hospital unit having higher time constraints, patient acuity, and instability than the

satellite units. Participants reported there was little support for person-centred care, but acknowledged its principles were occasionally applied (Lewis et al., 2019).

Some studies may give rise to an initial thought that findings do not suggest patient-centred care is happening due to the focus on acute clinical issues, however holistic care, which is taking care of the whole person, does include attention to the biophysical domain and patient safety (Sidani & Fox, 2014). One example is evidence indicating that hemodialysis nurses focus on ensuring patient safety during frequent treatment complications such as painful muscle cramps, clotting (circuit or vascular access) and “crashing” due to severe hypotension (Kuo et al., 2020, p. 4). Twenty-five patients and eight patient advocates across the U.S. participated in one of three focus groups and/or survey. The researchers suggested that patient-centred safety outcomes such as reducing avoidable patient suffering could occur through patient-nurse collaboration to prevent and manage unstable hemodialysis sessions, such as through shared decision-making about fluid management to prevent cramping (Kuo et al., 2020).

Interest in improving patient-centred care for in-centre hemodialysis is evident in findings from two papers on the perspectives of patients, caregivers, and healthcare professionals in seven Canadian academic centres (Rossum et al., 2020; Sass et al., 2020). There were 45 challenges noted; two challenges in the top 10 were a lack of individualized dialysis education and information on treatment complications (Rossum et al., 2020), which are central in patient-centred care. A lack of privacy, discomfort during sessions, and scheduling difficulties were identified as individual patient challenges (Sass et al., 2020). Although these barriers represent a lack of patient-centred hemodialysis nursing care, the aim of this large project was to promote it. Both papers

noted a limitation that the project was completed in large urban centres, leaving out small units and those in rural settings, and inclusion of only English-speaking participants (Rossum et al., 2020; Sass et al., 2020). In addition a low survey response rate of 31.5% was noted (Rossum et al., 2020).

Some literature provides evidence that patient-centred hemodialysis nursing care is happening, although it is unfortunately not articulated or defined as such. Supportive hemodialysis nursing care was found to have a major impact on patient comfort, anxiety reduction, and adjustment to hemodialysis for new patients in a Canadian study in an urban university academic hospital of perceptions of 36 patients aged 19 to 87 (Gregory et al., 1998). Hemodialysis nurses were constantly present and easy to access and were competent with technical and interpersonal aspects of care, which promoted patient satisfaction. Hemodialysis nurses valued, accepted, and cared for patients “in a humanistic manner” (Gregory et al., 1998, p. 778), demonstrating care that was patient centred. Similarly, 11 hemodialysis patients interviewed in Norway felt they were cared for and safe in the unit, and that nursing care was important (Andersen-Hollekim, 2020). Patients felt informed but not fully involved in treatment choices and were appreciative when they were seen as “more than a patient” such as by health professionals acknowledging their life outside the hospital (Andersen-Hollekim, 2020, p. 2300).

Patient-centred hemodialysis nursing care is also demonstrated but unnamed in a 15-month Canadian pilot study with 14 patient participants that was a quality improvement project comparing the standard central venous catheter (CVC) dressing practices to the “shower and no-dressing” technique (Lawrence et al., 2014, p. 67). Bathing is challenging for many patients with long-term CVCs, and patients were known

to ignore unit policies and nursing advice and arrive for hemodialysis with wet dressings. This inspired the study about potential changes to the dressing technique to make it easier for people on hemodialysis and improve their quality-of-life experiences (Lawrence et al., 2014). This is decidedly a patient-centred approach. Three years after the pilot shower and no dressing study the bloodstream infection rate was 0.0786 per 1000 catheter days compared to the program rate of 0.153 (Lawrence et al., 2014). Participants expressed an improved quality of life and satisfaction with the dressing protocol, and some cost savings occurred due to use of fewer supplies and reduced nursing time. Additionally, the nursing role became less task-focussed on dressing changes and there was more collaboration because nurses participated in the project with patients by teaching them the technique, coaching, and monitoring the exit site (Lawrence et al., 2014). This is further evidence of patient-centredness.

Another study where patient-centred nursing care is apparent without being articulated occurred in Sweden using a qualitative descriptive approach with ten hemodialysis patients, who described nurses as being trusted; patients relied on them to provide safe practice in a warm, kind, and caring environment, making them feel connected and maintaining some quality of life (Jonasson & Gustafsson, 2017). The authors noted that the number of participants was limited, and findings were very specific to the specialized setting, making generalization difficult. Similarly, patient-centred hemodialysis nursing care was demonstrated but not articulated in a grounded theory study that found reduced fear and anxiety for ten patients transitioning to hemodialysis because of improved knowledge from orientation provided by nurses in a recent Canadian study in one urban hospital program (Wai et al., 2020).

In contrast, patient-centred hemodialysis nursing care was articulated in Canadian research that reported qualitative data from 17 patients (Wilson & Harwood, 2017) and quantitative data from 252 nurse and physician vascular access experts in six countries (Wilson & Harwood, 2018). Successful cannulation involves more than needle insertion, and both studies agreed patient-centred care has a positive impact. Patient-centred care was not defined or linked to a model but was described as occurring when nurses listened and talked in a friendly manner while cannulating (Wilson & Harwood, 2017), and discussed what to expect while sitting in a chair beside the patient (Wilson & Harwood, 2018). This provokes a vastly different and more positive image than an assembly line (Allen et al., 2011, Kear & Ulrich, 2015).

Patient-centred hemodialysis nursing care was also articulated in another Canadian study that examined the experiences through semi-structured interviews with seven hemodialysis RNs relating to the assessment and management of patient pain in multiple outpatient hemodialysis units of one large tertiary care centre (Fothergill Bourbonnais & Ford Tousignant, 2020). The source of pain was found to be either directly related to hemodialysis treatment, or due to comorbidities such as arthritis or diabetes, and pain management in the presence of hemodialysis was seen as complex. Nurses described using patient-centred strategies to promote patient comfort and meet their needs and communicated strategies to team members because interprofessional collaboration was seen as important (Fothergill Bourbonnais & Ford Tousignant, 2020).

Interprofessional collaboration is deeply connected to patient-centred care in general and of vital importance in hemodialysis nursing care. For example, a case study in the U.S. found that nurses can advocate for patients through effective communication

with other health professionals (Vickey & Frechman, 2022). Interprofessional collaboration and communication was noted as challenging relating to discussing goals of care and palliative care for people receiving hemodialysis in Taiwan, Japan, Republic of Korea, and China (Chu et al., 2024).

The Canadian Interprofessional Health Collaborative (2010) based at the University of British Columbia developed a national competency framework in collaborative practice, which has six domains. The second domain is patient-centred care that values patient engagement (University of British Columbia, n.d.). Four indicators under the heading PATIENT/ CLIENT/FAMILY/COMMUNITY-CENTRED CARE (capitalized in original) begin with:

Support the participation of patients/clients and their families, or community representatives as integral partners with those health care personnel providing their care or service planning, implementation and evaluation (University of British Columbia, n.d., p. 3).

This framework was embedded in a large academic hospital in Toronto, Ontario which acknowledged that teams (clinical and non-clinical) are unique in how they use the framework to promote collaborative practice (McLaney et al., 2022). There is no indication that the framework has yet been adopted by a nephrology team in that organization, and no literature was found that demonstrated use of the framework by a nephrology team. The Canadian Interprofessional Health Collaborative is a partner in a global network of interprofessional research, which recently published a 113-page discussion paper on the topic of interprofessional education and collaborative practice, with the goal of “compassionate person-centered care” such as by strengthening the

relationships between patients and members of interprofessional healthcare teams (Lackie et al., 2024, p. 6).

Chapter Conclusion

There are challenges reviewing the literature about patient-centred hemodialysis nursing care. To begin with, the word *dialysis* may be used without specifying whether it is hemodialysis or peritoneal, which are vastly different treatments. Another challenge is the minimal amount of research about hemodialysis nursing. A simple CINAHL search using the keyword *hemodialysis nurse* produced six results, but the search for *intensive care nurse* yielded 146, and *hemodialysis nursing* had 363 while *intensive care nursing* found 19,008 citations. Another challenge is that many nephrology nursing studies do not identify different nursing roles (e.g., staff nurse, team leader, nurse educator), or specify how much education and clinical experience nurses have, which may influence their understanding and provision of patient-centred hemodialysis nursing care.

The overall impression from the aggregate body of literature reviewed in this chapter is that patient-centred hemodialysis nursing care is not a well-developed or solidly integrated concept. It is notable that the reviewed literature spans the globe – nursing, hemodialysis, and patient-centred care have been researched in many countries, including Canada, Australia, the United States, Brazil, Japan, Portugal, China, the United Kingdom, and Sweden. There are some similarities in basic care and nursing values, but there are many differences from one country to the next due to different healthcare and political systems, services, and priorities, such as nursing roles, scope of practice, and skill mix, as well as patient care delivery. All hemodialysis care in Canada is provided by registered nurses (RN/RPN), which may not occur in other

countries, making study findings not comparable if care providers are not nurses. In addition, there are inconsistencies in terminology, few models to guide nursing practice, limited supports, and multiple barriers. Hemodialysis nurse perspectives on providing patient-centred care may be different and distinct in various patient populations (acute/chronic, adult/elderly) and contexts (rural/urban, hospital/satellite), and due to individual differences in nurses (length as a nurse/hemodialysis nurse, age, education, practice experience, personal health experiences).

Much is unknown about hemodialysis nurse perceptions of providing patient-centred hemodialysis nursing care. Researchers have called for studies of patient-centred care in different practices and contexts to further understand the disconnect between “the rhetoric” and actual experiences (Van Humbeeck et al., 2020, p. 1052). Research is also needed about how patient-centred care “is valued and operationalized” by nurses (Byrne et al., 2020, p. 18). This study will address some of these information gaps. The methodology and methods for this study are described in the following chapter.

Chapter Three: Methodology and Methods

In this chapter the methodological approach and methods will be described in the following order: research design, setting, sampling and recruitment, data generation and analysis, ethics, credibility, and reflexivity.

Research Design

Much is known about patient-centred nursing care and nephrology nursing practice separately, however, as substantiated in Chapter Two, there is a gap about patient-centred hemodialysis nursing care. This study aimed to address this gap by asking the main research question: How do hemodialysis nurses describe providing patient-centred care? Sub-questions included: How do hemodialysis nurses describe care that is or is not supportive of patient-centred care? Are there differences and similarities across settings? What facilitates hemodialysis nurses in providing patient-centred care? What interferes with hemodialysis nurses providing patient-centred care?

Interpretive description aims to answer questions relevant to practice disciplines that will extend understanding of complex clinical experiences and provide useful applications for practice (Thorne et al., 2004; Thorne, 2016). This requires a specific goal for practice (Polit & Beck, 2017), such as promoting patient-centred hemodialysis nursing care, and provides a flexible approach to research that always begins with “what is already known, believed, or accepted within a discipline about the phenomenon in question” (Thorne, 2020a, p. 16). Therefore, my firm grounding in nursing resulted in selecting interpretive description as the best approach to develop knowledge about the provision of patient-centred care from the perspectives of hemodialysis nurses.

Interpretive description was influenced by traditional qualitative research methodologies, borrowing heavily from grounded theory, however rather than theory generation it focuses on understanding a phenomenon better by developing rich description that draws on the theoretical and practical knowledge of the researcher (Thorne, 2008; Thorne, 2016). Interpretive description is situated within a professional discipline, which differs from conventional qualitative research approaches that are more theoretically situated (Thorne, 2016; Thorne, 2020b). A researcher taking an interpretive description approach aims to capture subjective experiences of participants while also drawing an understanding about patterns and commonalities from the whole dataset that can be used to inform clinical practice (Thorne et al., 2004; Thorne, 2008).

Thorne (2008, 2016) described scaffolding as an analytic framework to begin building a study design, with two critical elements: 1) reviewing the literature, and 2) theoretically locating oneself as a researcher within a discipline and as a person with experiences, ideas, values, beliefs. This demonstrates reflexivity by acknowledging the influence of personal and professional knowledge and experiences on the entire research process. In interpretive description the researcher's discipline is considered "as theory" because it shapes the topic of interest, what is observed, and what sense is made of the findings, including implications and recommendations (Thorne, 2008, p. 68, quotations original).

Regarding the first element of scaffolding, reviewing the literature on current knowledge was addressed in the prior chapter. Regarding the second scaffolding element, it begins with acknowledging that I am firmly located in the nursing discipline. This research is built on my 54 years of nursing knowledge and experience as a front-

line nurse providing direct and indirect patient care across a broad variety of adult settings, active participation in various professional associations and groups, and ongoing professional education. In interpretive description research, clinical expertise is the place to start (Hunt, 2009, p. 1285), and locating myself as a researcher within my ideas begins by noting that initial seeding for this study occurred when I was a senior front-line nurse, and 'patient-focussed' care was introduced in the 1990's. Variations in how nurses had interpreted and operationalized patient-centred care were unexpected, surprising, and confusing.

My theoretical allegiance aligns to the qualitative interpretive paradigm through my respect for and belief in subjective personal experiences providing the starting point to develop knowledge about complex interpersonal relationships (Leavy, 2020). Nursing occurs within these complex relationships at various levels, such as with patients, other nurses, other healthcare professionals, employers, and regulatory bodies. Details of epistemology in qualitative research include being conducted in a naturalistic context (e.g., hemodialysis unit), valuing experiential knowledge that is subjective (e.g., hemodialysis nurses), acknowledging that human experience is socially constructed with multiple realities, and viewing the researcher as the instrument through which the research occurs (Thorne, 2016).

My ontological viewpoint aligns with that of interpretive description. Ontology influences a research approach because it is concerned with how reality is viewed through different lenses that guide knowledge development (Patel, 2015; Scotland, 2012). Interpretive description details socially constructed reality within human experiences that can align or be contradictory (Thorne, 2016, p 82). This approach is

the best way to illuminate patient-centred hemodialysis nursing practice as participants may describe similar experiences, such as attentive listening, but their realities may not align because they are standing in different contexts, see and hear things from different angles, and may have different reactions. Individual and collective knowledge developed pragmatically through this study can be applied in everyday patient-centred hemodialysis nursing practice. Pragmatism based on the educational philosophy of John Dewey (1938) is very relevant for nursing, and this research, because it provides an explanation of learning by experience, with outcomes based on actions (Hallett, 1997). Dewey (1938) argued that gaining knowledge and skill in a situation enables a person to gain understanding and effectively manage subsequent situations throughout life. Dewey (1938) described education as being theory-based and practice as experience-based – continuity and interaction are the two interconnected principles of experience. Being pragmatic means that things are dealt with sensibly and realistically in a way that is based on considerations that are practical rather than idealistic or theoretical, wherein actions have results and consequences (Merriam-Webster, 2024). Pragmatism informed this research project because nurses learn first in a theoretical way and in turn apply it, learning more – this includes how knowledge is developed about patient-centred hemodialysis nursing care.

Research Setting

The Canadian Organ Replacement Register (CORR) Directory indicates that hemodialysis occurs across Ontario in a variety of settings: urban independent facilities, one urban traveller's centre, urban hospital *in-centre* units, and urban or rural hospital-based *satellite* units (CIHI, 2024). This study focused only on the hospital and satellite

hemodialysis units across Ontario, which provided an opportunity to compare and contrast patient-centred hemodialysis nursing care in different contexts. It was anticipated that there would be four different contexts: urban or rural that was either in-centre or satellite, however it was discovered that rural in-centre units do not exist because rural hospitals are too small to support the infrastructure required for a full nephrology program. Therefore, settings included urban in-centre or satellite units, and rural satellite units.

Sampling and Recruitment

Purposive sampling is a qualitative data collection method where people with experience in and deep understanding of the circumstances of interest are selected as participants (Thorne, 2008, 2016; Yilmaz, 2013). Hemodialysis nurses from hospital and satellite hemodialysis units in urban and rural areas were included in the study if they were registered with the College of Nurses of Ontario and currently employed full or part-time for more than three months to ensure they had completed their orientation and joined unit staff. Exclusion criteria included not being a front-line hemodialysis nurse, such as vascular access, home dialysis (hemodialysis and peritoneal dialysis), transplant, and inpatient nephrology nurses. Selection of participants for this research was intended to reflect and represent the sample pool of hemodialysis nurses in Ontario – the size of the pool is not possible to determine. During recruitment an email from CANNT stated, “We currently have 139 active members in Ontario. Of those 124 have identified as nurses” (CANNT, personal communication, February 8, 2022). Anonymous demographic information provided by CANNT indicated that 32 nurses self-identified as working in in-

centre (hospital) hemodialysis units, there were no satellite or rural practice contexts, and other practice roles included Clinical Educator and Vascular Access Nurse.

Initial contact occurred through the Ontario Vice President of CANNT, who sent an email to members with basic information introducing them to the study and methods to contact the researcher. This resulted in only three nurses expressing interest, and after email contact two volunteered to participate and completed the interview process. The recruitment process was therefore revised to include direct contact with regional programmes in the hopes that the invitation to participate would be distributed to nurses across their units. This resulted in successful recruiting of five participants. Two regional programmes required further follow-up to their local Research Ethics Board prior to proceeding, which did not result in any recruits. One participant was recruited through direct invitation during an item writing meeting for the nephrology certification exam with the CNA. Two additional participants were recruited by asking interviewees if they knew other hemodialysis nurses who might be interested in the study, known as the snowball technique for accessing an unknown population (Showkat & Parveen, 2017).

The COVID-19 pandemic negatively impacted this study because it contributed to a slow rate of participant recruitment which required varying strategies to overcome. A follow-up email to a nephrology Nurse Practitioner in a large regional programme resulted in a request to delay the attempt to recruit until the peak of the pandemic was anticipated to have passed. The invitation to participate was redistributed two months later throughout their large program, again with no results, which was understandable considering the demands and uncertainty of the COVID pandemic at the time.

There are no rules to determine sample size in qualitative research, which can be affected by the study design, sampling strategy, and amount and quality of information provided by participants (Cresswell & Cresswell, 2018; Polit & Beck, 2017; Thorne, 2008 & 2016). Sample size is a topic heavily debated in qualitative research: if too small, analysis will be difficult due to limited variation and depth of findings, and predetermining the sample size is not possible due to the complexity of qualitative research variations (Morse, 2015). Numbers may range from one participant to 30 or more (Cresswell & Cresswell, 2018).

The minimum sample size set for this study was 12, which aimed to include at least three nurses from each of the four settings to allow for perspectives and experiences from different contexts: urban and rural hospitals, in-centre and satellite units. This is in line with other research using an interpretive description approach, such as the perspectives of Canadian hemodialysis nurses in supporting patient coping and resilience by Ortiz (2021), and nurse-physician interprofessional collaboration in the emergency department by Dreher-Hummel and colleagues (2021), each with 12 participants. The goal was not saturation, which does not fit with an interpretive description approach for research in nursing because of the requirement of the discipline to keep the door open for any new thematic variations and diversities due to the endless possibilities of variations in experiences (Thorne 2016; 2020c). Achieving saturation is a very subjective activity (Thorne 2016).

It was recently argued that many qualitative nursing scholars claim to have reached saturation with no supporting explanation, which is a problem because they “uncritically uphold a research reporting convention that has so little basis in substance”

(Thorne, 2020a, p. 4). The concept of “information power” of an interview sample has been suggested as an alternative to saturation (Malterud et al., 2016, p. 1754). Sample specificity means that a smaller sample is adequate if participants have characteristics with high specificity and are sharing experiences no one else has described previously (Malterud et al., 2016). This would support the recruitment of a smaller number of participants for a study of hemodialysis nurses because their area of expertise is highly specific, and they also have experience in varied settings such as inpatient acute and outpatient chronic care. In addition, regarding the quality of the interview dialogue, if communication with the researcher is strong, clear, and focused, purposive sampling of six to 10 participants who have diverse experiences can provide enough information power (Malterud et al., 2016). In this study, after it was discovered that there were no rural in-centre units and there would be three different types of settings rather than four, the target sample became nine participants while maintaining the goal of three participants per context. There were 10 participants, three from each setting (urban acute hospital units and satellite units both urban and rural), plus an additional one. Participants were engaged during interviews and communicated their experiences about providing patient-centred hemodialysis nursing care strongly and clearly. The 10 interviews provided sufficient information to analyze for the knowledge being sought, therefore no further interviews were held.

Data Generation

Data sources for this study included interview transcripts, demographic survey, and reflective and analytic memoing. Data was generated through individual virtual interviews, with the understanding that subjective experiences of providing patient-

centred care may not be effectively verbally conveyed (Thorne, 2016). The pandemic was a barrier to some other forms of data generation that could not be completed while distancing, such as document reviews and observation. Data generation began by obtaining demographic details using the tool in Appendix D, which was reviewed in advance of an in-depth individual interview at a day and time convenient for each participant. An email was sent with a participant-specific link and password to access the call as a method to maintain confidentiality and ensure privacy. Interviews ranged in length from 34 to 85 minutes. The semi-structured interview guide in Appendix E was pilot tested with two participants, who spontaneously raised the negative impact of the COVID-19 pandemic, therefore a question about that was added. Participants were asked if they were agreeable to being contacted for a second interview to clarify any ambiguous data that may be affecting analytic interpretation. In interpretive description this strategy is considered more productive than asking them to check transcripts as in some conventional approaches (Thorne, 2016). No second interviews were held due to pandemic-related restrictions and respect for participants by not adding to their burden.

During interviews I remained aware of maintaining my role as being curious to learn rather than being an expert hemodialysis nurse, while avoiding inadvertently encouraging participants to respond in a particular way (Thorne, 2008). Data from each interview was audio and video recorded by the platform, with the video portion being discarded immediately after the interview, which was included in the informed consent process. The video conferencing platform Zoom enabled verbatim interview transcription that was saved in a text format then prepared for analysis. Every effort was made during transcript preparation to ensure congruence with participant statements, with

notes written during repeated readings. Transcripts were read for the first time while simultaneously listening to the audiotape, with initial corrections made to certain words, phrases, and statements, and adding punctuation and identification of the speaker as the participant or researcher. Each transcript was read a minimum of four times while simultaneously listening to the audiotape to ensure accuracy. Some transcripts required further reading/listening actions to clarify what the participant had said verbatim. One final reading was done with each transcript prior to printing and advancing to the stage of analysis, however analysis had actually been occurring during transcript preparation. Preparing the transcripts allowed me to be fully immersed in and engaged with the data, which Thorne (2008) encourages as a way to attend to what is contained in each statement, although it can be a complex experience. Electronic versions of each transcript were saved in a locked, password-protected computer and a locked external hard drive, accessible only to the researcher. The hard copies were anonymized using the pseudonyms selected by each participant and are also only accessible to the researcher.

Reflective notes were another source of data generated and were written following each interview and throughout the study to capture personal thoughts to aid analysis and interpretation, and maintain awareness of bias (Thorne, 2016). Researchers bring bias into a study, as do participants, therefore consideration was given to what might be privileged or silenced from their perspectives, and my own (Thorne, 2008). As transcripts were read, notable quotes were highlighted in the text to illustrate and texturize findings in the research report (Thorne, 2016), and to note participant expressions such as pauses or emotions. These data bits help support and clarify the analysis (Thorne et al., 2004).

Analysis

Every data set contains an unlimited number of interesting elements and possibilities for interpretation (Thorne et al., 2004). The analysis process in interpretive description includes multiple strategies aimed at finding themes, patterns, and relationships by engaging with the data, and researchers use their interpretive lens to determine what data should be included in analysis and results (Thorne et al., 2004). The processes of data generation and analysis occur concurrently, constantly informing each other (Thorne & Truant, 2010). In addition, “*constant comparative analysis*” is used to compare, contrast, and understand patterns and relationships within the research data to root out knowledge (Thorne, 2016, p. 109, italics original). Thorne (2016) describes the interpretive space as one to stand in and reflect by gazing from different angles. In this study, experiences of patient-centred hemodialysis nursing care were viewed from different nursing and contextual perspectives, such as from novice and expert nurses, and nurses who worked in satellite and/or in-centre units. Transcripts were examined to explore how patient-centred hemodialysis nursing care is experienced and described from the perspectives of nurses. An open mind was kept to what was being said, while understanding patient-centred care elements from the literature and without rigidly following a pre-conceived framework. Certain words, phrases, and sections of text drew attention in each transcript and were highlighted, which was the beginning of sorting and organizing meaningful data.

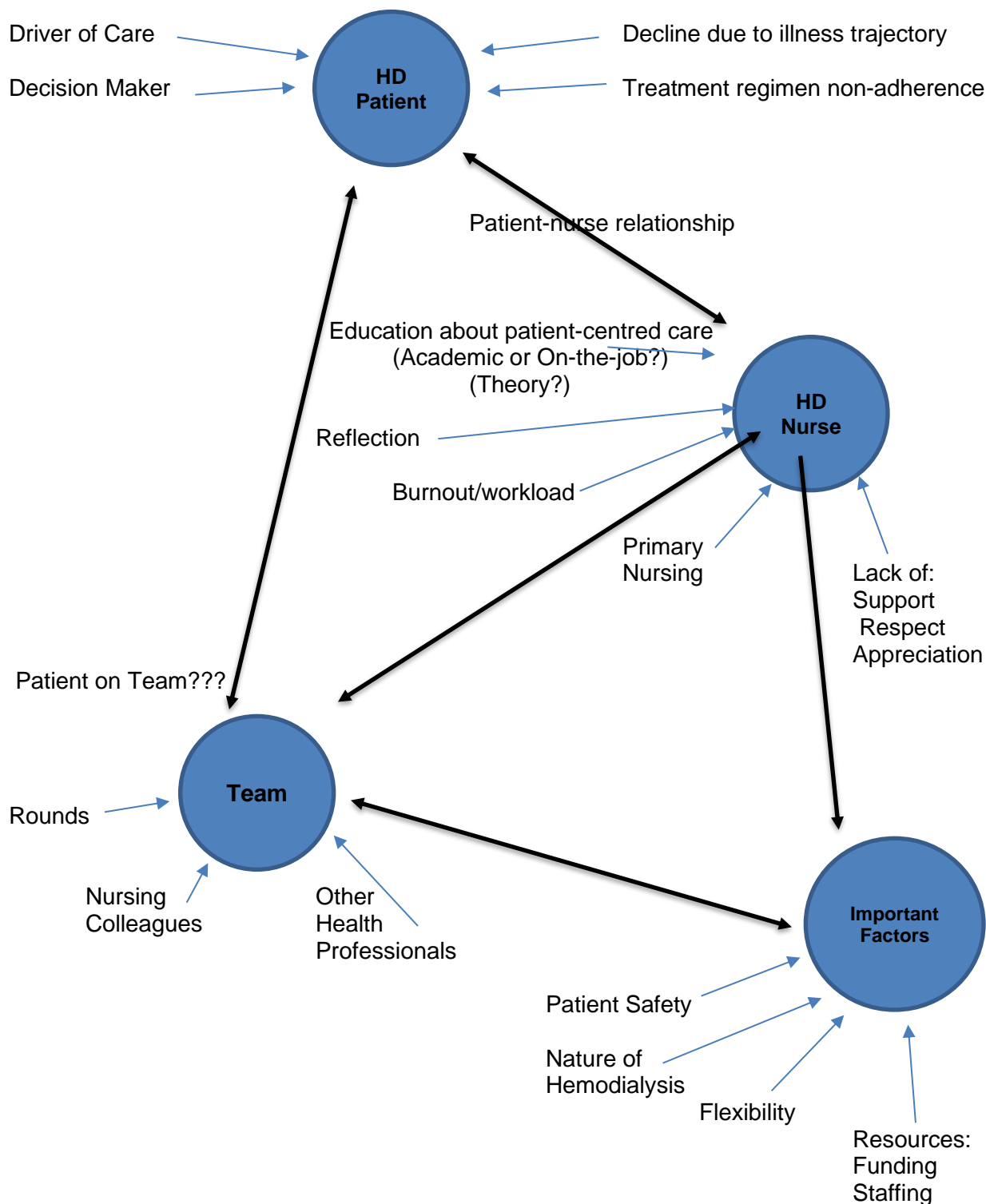
Attention was paid during analysis to the variations that occurred due to differences in hemodialysis patients (acute/chronic), nurses (education, experience), and care contexts (hospital/satellite; urban/rural). My high sensitivity to the language

spoken within the hemodialysis subculture benefited analysis and interpretation, in line with the disciplinary knowledge expectations promoted by Thorne (2016). Analysis was aided by opportunities during interviews to ask questions of participants to seek clarification (theoretical leads) while being open to potentially different understandings.

Analysis in interpretive description is influenced by the particular orientation of a professional discipline (Thorne, 2016). My hemodialysis nursing orientation allowed for important and relevant information to be identified on each transcript. Taking care to maintain the meaning and context, sections of transcripts were cut and pasted into a table format to begin the sorting, which Thorne (2016) likens to sorting laundry. This involves looking for patterns, recurrent ideas, and themes within and between transcripts to reach a point where no new information, ideas or patterns are seen in the data (Thorne, 2016). Each transcript had unique content in addition to reinforcing what other nurses had said. Questioning what is happening and being learned during inductive analysis have supported the interpretive description approach since it began (Thorne et al., 1997). Repetitive immersion in the data over several weeks included regularly stepping away from the transcripts and returning, which enabled meanings, patterns, and relationships to be identified, reflected on, and challenged (Thorne, 2016). Constantly questioning why a participant made a particular statement rather than something else, and what it meant was essential during analyses, to allow a range of possibilities to be considered and conceptualized as relevant new knowledge for clinical practice (Thorne et al., 2004). In line with the interpretive description approach, themes were constructed based on understanding and interpreting what participants described about their experiences.

The goal in interpretive description is to understand something better, such as patient-centred hemodialysis nursing care, by finding out under what conditions it works, what it feels like when it occurs, what those experiencing it think is important, and how it makes sense to people who experience it (Thorne, 2016). An audit trail (memos) was undertaken to contribute to the ability see any relationships that were possible within the data that may shift as the data set grew and evolved (Thorne, 2016). Organizing and clarifying these relationships were also explored visually (Thorne, 2016), such as in Figure 1 below that provides an example of initial potential data relationships.

Figure 1: Potential Data Groups in Patient-Centred Hemodialysis Nursing Care



(Adapted from Braun & Clarke, 2006)

Ethics

Patient-centred care is grounded in the ethical values of respect for persons (McCormack & McCance, 2017; Rushton & Edvardsson, 2018), and all scholarly research is based on ethical and legal principles (American Psychological Association, 2020). This research adhered to the ethical principles and articles of the Tri-Council Policy Statement *Ethical Conduct for Research Involving Humans* (Government of Canada, 2018). Respect for people was demonstrated throughout this study by processes such as informed consent, maintaining confidentiality by using pseudonyms, and reporting results honestly, including multiple perspectives and contrary findings (Gaudet & Robert, 2018; Cresswell & Cresswell, 2018). Approval from the York University Research Ethics Board was obtained. An appropriate informed consent process included implied consent when the nurse contacted the researcher via email in response to the invitation to participate and giving potential participants time to weigh benefits and risks prior to deciding whether to participate. Once contact was made by the nurse and they agreed to participate, the researcher sent an email with two attachments: the informed consent document from York University, Faculty of Graduate Studies (2017) in Appendix C and the demographic information document in Appendix D. The participant was asked to print, sign, and photograph a copy of the consent and send it electronically to the researcher, along with the completed electronic copy of the demographic document. The confidentiality of all study documents was promoted by asking each participant to select a pseudonym, which was used throughout the study, beginning with using them to maintain anonymity of the transcripts, and throughout any documents generated for the research. Additionally, any identifying information such as hospital names was removed from transcripts.

Credibility

Research findings are subject to the interpretive understanding of the researcher, who decides all details such as what data is generated, which data are relevant, how data will be conceptualized and structured in written form and diagrams, and how findings are disseminated (Thorne et al., 2004). Credible evidence provides reasonable grounds that it can be believed or trusted, and one way to do this is by ensuring that the researcher's interpretive lens is apparent throughout the research (Thorne et al., 2004). In addition, results that are rigorous and credible will pass testing by thoughtful clinicians wherein experts with clinical knowledge and experience with the phenomenon find that the results are plausible, confirmable, and provide new understandings and relationships (Thorne et al., 2004). This valuable experiential knowledge was later referred to as the *thoughtful practitioner test* (Thorne, 2016).

| Evaluation criteria | Beyond evaluation |
|---|--|
| 1. epistemological integrity: research question aligns with the epistemology stated, logically followed by data sources and interpretive strategies | 5. moral defensibility: there are convincing claims about the necessity of obtaining the knowledge from participants, and the purpose for having the knowledge |
| 2. representative credibility: knowledge claims are consistent with sampling from more than one angle | 6. disciplinary relevance: the knowledge contributes appropriately to disciplinary science |
| 3. analytic logic: evidenced by a transparent audit trail | 7. pragmatic obligation: health researchers must consider that their findings will be applied in practice |
| 4. interpretive authority: trust that the interpretations of the researcher provide fair, bias-free information from the data | 8. contextual awareness: new knowledge is located in the society that constructs it, with invisible shared assumptions of the researcher and researched; reality may shift |
| | 9. probable truth: research is done to create meaning, not to seek absolute truth |

(Thorne, 2016, pp. 233-238)

Much has been argued about terms and processes to ensure quality nursing research in view of quantitative research being traditionally dominant over qualitative (Morse, 2015; 2018). In an early discussion of analytic challenges for interpretive description, credibility of findings through “integrity to the interpretive process” was promoted rather than “rigid adherence to the ‘gamesmanship’ of rigor” (Thorne et al., 2004, p. 8). Enhancing credibility in interpretive description involves nine criteria:

1. Enhancing credibility through epistemological integrity is demonstrated by the research question aligning with the epistemology stated and being logically followed by data sources and interpretive strategies. This is supported during analysis when the researcher’s interpretive strategies and relationship with ideas are effectively conveyed and referenced (Thorne, 2016). In this study, the research question about patient-centred nursing care in hemodialysis aligns with the epistemology of nursing, because “the intellectual underpinnings of nursing disciplinary knowledge can provide an effective framework where qualitative technique can be aligned” based on an “understanding of disciplinary nursing logic” (Thorne et al., 2016, p. 452). Data sources and interpretive strategies logically followed to reach the goal of understanding current nursing knowledge about patient-centred hemodialysis care, and to identify and begin to address any noticeable gaps.

2. Enhancing credibility through representative credibility is demonstrated when knowledge claims are consistent with sampling from more than one angle of vision (Thorne, 2016). This was demonstrated in this study by purposively interviewing 10 hemodialysis nurses to provide different angles of vision based on their varying demographic characteristics (age, gender, length of experience as a nurse, length of

experience as a hemodialysis nurse) and the different hemodialysis practice settings (urban/rural, in-centre/satellite).

3. Enhancing credibility through analytic logic was demonstrated in this study by maintaining a transparent audit trail (Thorne, 2016). Excerpts of entries from the ongoing audit trail are available in Appendix F. The researcher has been transparent about working in the hemodialysis clinical area for many years.

4. Enhancing credibility with interpretive authority indicates that readers can trust that the interpretations of the researcher provide fair, bias-free information from the data (Thorne, 2016). The goal in this project was to make visible the experiences and represent the voices of front-line hemodialysis nurses in an honest, open, and respectful way by interpreting what I had learned from what they said. For my interpretations to be believable and justifiable, my approach to scientific rigour guiding this study meant understanding potential theoretical and practical threats to validity and ensuring that certain actions occurred to enhance credibility. For example, being transparent about the assumption that participants trusted me as the researcher when sharing their experiences because they all knew through information provided during recruitment that I was an experienced hemodialysis nurse and prior nurse educator. Perhaps they shared more deeply because they could leave some things unsaid during interviews since they did not need to explain hemodialysis practice in detail due to my background. However, the opposite may have occurred if they thought I understood something which perhaps I had no experience with, which was managed by being honest with them and asking questions. I emphasized throughout the study that it was about their voices and experiences, not mine. The quality of the data analysis and interpretation was

influenced by my relationship with the participants, how engaged we were in conversing during the interviews and therefore how much data was recorded, and what data relevant to the research questions were prominent.

5. Enhancing credibility through moral defensibility is demonstrated through convincing claims about the necessity of obtaining the knowledge from participants, and the purpose for having the knowledge (Thorne, 2016). In the first chapter the statement of the problem setting the stage for this study identified that patient-centred care is beneficial for patient outcomes, and that all Registered Nurses, including those in hemodialysis units, are expected to provide it, whether or not their organization mandates it. However, there is little knowledge about whether hemodialysis nurses can and do provide patient-centred care, and the participants in this study helped by shedding light on their experiences. This is relevant to current and future hemodialysis nurses and healthcare administrators, with implications for nursing practice, education, policy, and research.

6. Enhancing credibility through disciplinary relevance is demonstrated by the knowledge from the study contributing appropriately to disciplinary science (Thorne, 2016). Since little is known about front-line hemodialysis nursing practice, and even less about whether or not patient-centred care is occurring, this study makes an important contribution to nursing science.

7. Enhancing credibility through pragmatic obligation means that health researchers must consider that their findings will actually be applied in practice (Thorne, 2016). The goal of this research was to first find out what is happening with regards to patient-centred hemodialysis nursing care, then to share it with others through implications and

recommendations that will be applied in ethical clinical practice, as well as education, policy development, and research. It is hoped the findings will add clarity to the topic and be a starting point for conversations about promoting the concept of patient-centred care as a reality and not just rhetoric.

8. Enhancing credibility through contextual awareness means that new knowledge is located in the society that constructs it, with invisible shared assumptions of the researcher and researched, and acknowledging that reality may shift (Thorne, 2016). This is referring to an awareness of the interwoven complex histories of nursing, hemodialysis, and patient-centred care in a constantly shifting social world filled with people from diverse backgrounds with different viewpoints, education, political beliefs, and so on. The shifting that has occurred in nursing alone over the past few decades is remarkable, for example education has transitioned from schools of nursing in hospitals with apprenticeships to a more academic profession requiring a university degree. In addition, nursing competencies have expanded into many specialty areas, such as hemodialysis, with advanced post-graduate courses at colleges. There are so many invisible assumptions in the area of nursing education alone, and very little opportunity to bring things out in the open for respectful discussion, such as differences between nurses from the 'old school' and the more modern approaches, although all have to work together in the same clinical settings. There have also been advancements in nephrology care in general and hemodialysis specifically.

9. Enhancing credibility through probable truth is demonstrated by research being done to create meaning, not to seek absolute truth (Thorne, 2016). This study made no claim to be seeking an unreachable 'truth', but rather an understanding of hemodialysis

nurses' diverse experiences providing patient-centred care. Knowledge gained through this study is a contribution to nursing as a respectful understanding of how some nurses provide care interpreted through the experiences and education of another nurse, with acknowledgement of the complexity of patient-centred nursing care.

Reflexivity

A practice that was attended to was reflexivity, which aims for critical self-awareness of my personal influence on the entire research process, including anticipating the needs of the intended audience (Thorne, et al. 2004). Reflexive steps taken in this study include:

- adhering with integrity to the standards of the interpretive description process, which includes extensive reading and re-reading of theoretical and research papers
- recognizing that my perspective on patient-centred care was influenced by personal experiences as a patient and professional nurse from a specific background
- listening attentively and respectfully to what participants were actually saying
- being a “curious learner” during interviews while ensuring that I remained a “judgmentally neutral facilitator” who encouraged participants to share their thoughts as fully as possible (Thorne, 2016, p. 140).

In this chapter the methodology and methods for the study were outlined using the interpretive description approach. The results are presented in the following chapter.

Chapter Four: Results

In this chapter the results are organized beginning with participant details followed by presentation of themes constructed from their descriptions of providing patient-centred hemodialysis nursing care. Direct quotes from participants are utilized as data exemplars, with the goal of finding any hidden meanings in what may seem chaotic (Thorne, 2016) such as busy hemodialysis units. Participants in this study shared meaningful and memorable experiences, but their initial responses to interview questions potentially held deeper meanings requiring consideration (Thorne, 2016). Analysis was undertaken through the interpretive description approach described previously, which privileges the clinical origins and practice consequences of the knowledge developed (Thorne et al., 1997; Thorne et al., 2004). Knowledge was developed through induction and researcher interpretation of the results (Thorne, 2016).

The Participants

Ten RNs participated in the study and demographics are displayed in Table 3. Their ages ranged from 29 to 66 years (mean = 46.7), noticeably beginning at a higher age than membership statistics from the College of Nurses of Ontario (CNO) that includes 5.6% in the age group 18 to 24 (2022) – this study had none in that age group. Eight nurses worked full-time (80%) and two worked part-time (20%), in contrast to the most recent membership statistics from the CNO of 67.9% and 25.2% respectively (2022). Ontario membership gender statistics are not available but the seven females (70%) and three males (30%) in this study contrast with 91% and 9% reported by the Canadian Nurses Association (2022). Eight nurses provided front-line care, one was a Clinical

Educator who provided front-line care with new nurses during orientation, and another managed six rural satellites and occasionally provided front-line care.

| Pseudonym | Age | Gender | Education | Length as Nurse/HD Nurse | C Neph (C) | FT / PT * | Setting In-centre/satellite | | Rx Acute (A) Chronic (C) | Patients per session | On call |
|-----------|-----|--------|-----------------|--|------------|---------------|--------------------------------------|--------------------------------------|--------------------------------|----------------------|-------------------|
| | | | | | | | Urban | Rural | | | |
| 1 Zian | 48 | F | BScN | 25/23 years | | FT | in-centre 27 stations + satellite 17 | | A+C | 1 A 3 C | Once per month |
| 2 Rose | 29 | F | BScN | 3/2 years | Since 2021 | FT | in-centre 48 stations | | A+C | 1 A 3 C | 1-2 in 6 weeks |
| 3 Jarvis | 58 | M | BScN | 25/23 years | | FT | in-centre 30 stations + satellite 24 | | A+C | 1 A 3 C | 10 times per year |
| 4 Gerry | 46 | M | Graduate degree | 21/12 yrs. Clinical Educator since 2013 occasional frontline | Since 2010 | FT | in-centre 35 stations + satellite 20 | | A+C | 3 C | no |
| 5 Cher | 66 | F | Diploma | 46/20 years | | FT | in-centre 30 stations + satellite 24 | | A+C | 1 A 3 C | no |
| 6 Goldie | 44 | F | BScN | 15/15 years | Since 2006 | FT | | 6 satellites 31 stations RIO* = 3 | A (stable) +C | 3 C | no |
| 7 Hefei | 51 | F | BScN | 11/6 to 12 months | | PT | in-centre 30 stations + satellite 24 | | A (not off-unit) +C | 1 A 3 C | Not yet |
| 8 Jay | 45 | M | Diploma | 19/6 years | | PT but FT hrs | | 4 station satellite RIO = 74 | A (stable) +C | 2 C | no |
| 9 Joanne | 29 | F | BScN | 6.5/<6 months | | PT | | 6 station satellite RIO = 71 | C | 2-3 C | no |
| 10 Alice | 51 | F | BScN | 22/21 years | Since 2018 | FT | | 6 station satellite RIO = 62 | C | 3 C | no |

*FT is Full Time PT is Part Time *RIO is Rurality Index for Ontario

The nurses all provided care for people receiving outpatient chronic hemodialysis treatments, but only urban nurses also provided acute and inpatient hemodialysis, which contributed to constantly fluctuating daily assignments based on unlimited variation in patient needs. Rural nurses also provided care for patients who they described as 'stable acute'. Each nurse provided care for one to three patients at one time per shift depending on unit size and patient acuity (one acutely ill, two or three chronic) although in some urban settings COVID-19 necessitated adjustments. Six nurses were not assigned on-call

duties, three urban nurses had various on-call scheduling patterns from once every six weeks to ten times yearly, and the newest urban hemodialysis nurse had not yet acquired enough clinical experience to be assigned the independent on-call role. Two urban and two rural nurses had earned the nephrology specialty credential of CNeph(C) from the Canadian Nurses Association, described as indicating commitment to lifelong learning, patient advocacy and professional practice, and continuing competence. There were no indications this had any impact on their patient-centred hemodialysis nursing care.

Despite the diversity across the demographic variables, descriptions of patient-centred hemodialysis nursing care were similar among the participants. Variations between nurses have many causes, and it is challenging to interpret which, how, and to what degree specific individual nurse factors influenced their patient-centred hemodialysis nursing care, such as age, gender, education, experience, personality, beliefs, and values, as well as the culture of their unit, team, and organization. As an example, Rose was one of the youngest participants with three years experience as an RN and less than two years in hemodialysis and provided sensitive and well-articulated responses. This could be due to her basic nursing education that included theory and assignments about patient-centred care, the advanced nursing education she was receiving in nurse practitioner studies, because she had earned CNA certification, because of the collaborative team that she was part of, or due to her personal valuing of patient-centred care. In contrast, Cher had different factors such as being the oldest participant and only one with a college diploma but had the most clinical experience with 46 years as an RN and 23 in hemodialysis, worked in a different urban unit than Rose, and was equally as

articulate. Patient-centred nursing care is of course not unique to hemodialysis, but nuances in that specific context and different settings were shared by participants.

Settings

The nurses in each distinct type of hemodialysis unit are identified in Table 4; one rarely worked in the urban satellite, one occasionally worked in a different urban satellite, one worked occasionally in a rural satellite, and there were no rural in-centre units. The number of stations (beds or chairs) in urban in-centre units ranged from 30 to 48 and for satellites there were 24, while rural satellite stations ranged from four to six.

The Rurality Index for Ontario (RIO) scores for two urban settings were zero (population ~537,000 and ~2.8 million), and for one smaller urban area the index was three (population ~166,000), with populations approximated based on various websites due to lack of clarity and current census data. The RIO scores for rural settings where the participants worked ranged from 62 to 74 on a scale of 0 (urban) to 100 (remote).

| Table 4: Participants in Each Hemodialysis Setting | |
|--|---|
| Urban in-centre | Rural in-centre |
| Zian, Rose, Jarvis, Gerry, Cher, Goldie, Hefei | 0 – these units do not exist |
| Urban satellite | Rural satellite |
| Zian, Rose (rarely), Jarvis, Gerry (occasionally), Cher, Hefei | Goldie (occasionally), Jay, Joanne, Alice |

Themes

Patient-centred hemodialysis nursing care from participant perspectives is described in this section. Following analysis of interview transcripts the overall interpretation is that patient-centred hemodialysis nursing is a complex iterative process with multiple influencing factors. This complexity included numerous values woven

throughout participant descriptions. Some of the information participants shared follows the current discourse regarding patient-centred care, however their descriptions provide details specific to their perspectives in hemodialysis. Inductive analysis of their described experiences provided nuance and depth to understand how this is demonstrated in their everyday practices through alignment with the three patient-centred care elements of the conceptual definition – holistic, collaborative, and responsive – facilitated through a therapeutic relationship based on mutual trust and respect (Sidani & Fox, 2014). The conceptual definition was used as a guide for the research rather than using a pre-determined framework, which might distort findings if they are forced into a framework developed by another researcher. Five themes of interest were constructed from findings as the transcripts were interpreted:

Theme One: Knowing Patient-Centred Hemodialysis Nursing Care

Theme Two: Applying Patient-Centred Hemodialysis Nursing Care

Theme Three: Sustaining Patient-Centred Hemodialysis Nursing Care

Theme Four: Promoters of Patient-Centred Hemodialysis Nursing Care

Theme Five: Patient-Centred Hemodialysis Nursing Care Detours

Although the themes are presented individually they are not stand-alone topics but interact with each other in cycles. Nurses would make adjustments as they became more experienced with patient-centred hemodialysis nursing care. The data shows that participants, who are members of an applied discipline, experienced cycles of gaining knowledge, applying what they learned, and sustaining it in daily practice. Experiences described by participants were interpreted to promote understanding of how these cycles contributed to following the philosophy of patient-centred care in their different

work settings. The first three themes are a continuous process and the final two are factors that influence the first three themes. The words 'facilitates' and 'interferes with' were used in the second research question in an attempt to determine what factors might influence patient-centred hemodialysis nursing care. These words were adjusted during interpretation to 'promoters' and 'detours' to reflect nursing experiences.

All participants used the word 'patient', which they felt was the most appropriate and frequently used word in the hospitals and units where they work, although they were familiar with other terms. Jarvis said:

I don't like the word client because it's a very business-based kind of word to me. Yeah, patient is relatable to a hospital patient care setting ... customer is ... in America maybe, just because hospital settings are owned and are administered or run by insurance corporations but ours is not.

In contrast, Gerry was the only participant who comfortably used other terms, and he spoke quickly and confidently when sharing his thoughts:

So client and patient I use interchangeably. Customer I use a little bit differently. As cringe worthy as this is, I'm a big supporter of customer service when it comes to health care. I think customers need to be listened to, I think they need benchmarks. I think there needs to be, we need to sell in a way, the care that we're giving to people, not monetarily, and then they need to exercise elements of consumerism and pick and choose to an extent, what they would like for their lifestyle and what they do not like. Then there needs to be feedback: How was that? Should we be doing anything differently? They need an apology if things

aren't being kept up to the benchmark, and then they need the alternatives if we're not able to meet our standard of care.

He acknowledged that he finds some of the words 'cringe worthy' and tempers his thoughts when stating that only some elements of consumerism are exercised as he shares some thought-provoking alternative angles on how patients can be viewed. He questioned where the division line is between customer and patient, adding that:

We know that not everyone needs equal pieces of the pie. Some people are sicker than others. Some people need more resources. So that's where the customer service model kind of falls apart, is that we're sharing one health care system and we're all not getting the same piece.

Patient-centred nursing acknowledges that care needs to be customized, and the broad range of patients receiving hemodialysis provide unlimited opportunities for this.

Participants helped shed light on how this happens in their varied clinical settings.

Theme One: Knowing Patient-Centred Hemodialysis Nursing Care

Patient-centred hemodialysis nursing care begins with knowing. Participants acquired knowledge about patient-centred care either in their basic nursing education or in their workplace. Participants were asked if they had heard of the term 'patient-centred care' or variant, and they all had; they were also asked if, when, and where they had received education about it. Rose, Gerry, Jay, and Joanne first learned about it in their basic nursing education but were unable to articulate a specific theory. Rose said that:

The first time I probably heard it was, I would say, definitely formal education. I would say during my nursing studies I became a little bit more cognizant of it, because I was waiting to be in a place where I would deliver patient-centred

care... There were different models ... theory, it definitely was not only taught to us, but it was unpacked ... there were quite a few reflective assignments on this idea, this notion of patient-centred care ... but maybe it just didn't really resonate. I just wasn't as mindful of it ... I found as a dialysis nurse specifically ... the delivery of patient-centred care ... was more just through the nature of the therapeutic relationship and the consistency, the time that these patients spent ... it was hard not to deliver patient-centred care.

In the workplace, practical knowledge about patient-centred care can be acquired in settings such as hemodialysis that naturally lend themselves to it, such as Rose explained. She had gained theoretical knowledge about patient-centred care in her basic nursing education, and it finally made sense to her in the clinical setting when she transferred from an inpatient unit to hemodialysis, where it felt natural for her to provide it as she developed therapeutic relationships with patients over time. Goldie could not recall how she first gained knowledge about patient-centred care, but also thought it was natural in the hemodialysis setting, indicating practical experiential knowledge:

It's kind of like, just how it goes in dialysis, it's just accepted, that that's the way it goes ... our delivery of care in dialysis ... is very different to conventional hospital type treatment ... I feel like it's very flourishing, the patient-centred care.

Rose worked in an urban in-centre unit, while Goldie worked in the rural setting. Alice, a rural nurse, agreed with them both that there was something about the hemodialysis setting that was naturally patient-centred when she stated that:

Especially in hemodialysis, when I think of patient-centred care I think of things that are individualized, tailored, unique to that specific person. But dialysis is

unique for that person, like that's where we are different, like everybody's, time, everybody's dialyzer, whatever, their prescription is, is always unique for that. She is referring to the notion that all patients have a hemodialysis prescription, which maintains their life, possibly for years, which is subject to adjustments based on their response to the treatment. Between hemodialysis treatments patients must maintain a precise regimen at home with restricted dietary and fluid intake and prescribed medications. There is no cure for their end-stage kidney disease.

Nurses who had not learned about patient-centred care in their basic education acquired their initial theoretical knowledge about it in workplace corporate or unit processes such as orientation or in-services. Cher said:

It first started as a corporate thing. And then the nurse educators and the managers started introducing the term in their meetings or in their communications with the staff ... There was no course per se, but I do remember when people were asking about it, the manager or the educator or someone on the unit would try to define what the term meant ... we sort of questioned what it was, but we've never been given a formal in-service.

Alice, like Cher, acquired knowledge about patient-centred care in her workplace, from the new Team Leader who had learned it in university and was very engaged:

At work, of course, we, they, throw that word around a lot, but it really started to mean something to me in the last two years since my new Team Lead took over ... When you approach the patient, the first thing that should go through your head is ... 'nothing about me without me' ... She brought that to a staff meeting ... from that day forward, we started to change different things ... Instead of doing

our rounds behind the desk ... we sit on stools, right in front of the patient, everything we are saying about them they hear, and we go through their chart. When patient-centred care began to 'mean something' to Alice as she began to learn about it, she understood it better as she began applying it in the clinical setting, demonstrating the acquisition of practical experiential knowledge that reinforced her initial learning. Her experience was similar to how it resonated for Rose when she joined the hemodialysis staff. The descriptions from Cher and Alice demonstrate variation in what and how nurses acquire knowledge about patient-centredness at work, and the importance of strong leadership to promote changes.

In the workplace, theoretical knowledge needs to be reinforced by practical experiential knowledge within the hemodialysis context. Gerry discovered that his prior knowledge of and experience with patient-centred nursing had to be adjusted and adapted to hemodialysis, because he had expected to:

Take the same set of rules I use with inpatient nephrology to hemodialysis [but] could not ... none of that is explained in the hemodialysis nephrology textbook and it's not what you expect coming from an inpatient unit.

His comments draw attention to varied knowledge requirements for tailoring patient-centred care in specific patient populations in different settings, and a gap in nephrology nursing education that leaves nurses on their own to figure that out.

Gerry had learned of patient-centredness in his basic nursing, and it was noted that he was searching for the appropriate words to describe his thoughts:

It came up in nursing school and it, it, to me it resonates as allowing the patient to be captain of their ship, allowing them to make decisions, involving them in

their care, being transparent with the information that's given to you so that everyone could be on the same page.

When asked if he thought that patient-centred care continued when he joined the workforce he said:

Not so much. I still think that patient-centred care is in the working is, um, I still think there's a legacy, a bad legacy in nursing, where it's traditionally, I think paternalistic is the wrong word, but the patient's told what to do, and assume a sick role to be taken care of, especially when it comes to something as complex and intricate as hemodialysis. People look at a dialysis machine and the complexity of the illness and come to conclusions that the patient does not know what they're, does not know enough about what's going on to make decisions themselves ... It shouldn't really be the medical staff or nursing staff saying, "Well we've done our assessment and we've decided that this is what you need". Allowing the patient to decide actually will have better life longevity, fewer complications, and to me that's what patient-centred care is.

He seems to understand the concept but used some words, such as 'allowing', that could be interpreted as paternalistic, and even mentioned that word, without realizing his contradiction. Being paternalistic does not align with the philosophy of patient-centred care, and on further analysis it was noted that this language slippage occurred in nurses who had acquired knowledge about patient-centred care prior to entering the workplace, as well as those who had learned about it after working for several years and potentially had to change prior care processes that may have been paternalistic. For example, Zian said:

Every now and then also you have to inform them what their care plan is ... And sometimes like you need to tell the patient that please just go on palliation rather than just giving dialysis ... and you want to tell them please decide, or can we decide for you? ... because we know that this is not going to have a very good life anymore, no more ... like it's the end of the road sometimes but it's hard to tell them ... There should be like a concept map for each and every patient chart to say this one is happening or an algorithm that says OK this patient goes to this one [another appointment or physician], is there any follow up?

Zian had not learned about patient-centred care in her basic nursing education but made several statements indicating her knowledge of the concept from her workplace. Similar to Gerry, her language slips at times with some words that could be interpreted as hinting of paternalism (e.g., inform, tell them, decide for you). Additionally, her suggestions to use an algorithm or concept map do not align with the philosophy of patient-centred care. Her comment does point to advocating for the best patient care, but that may be what a nurse thinks is best, not the patient, which also does not align. Gerry and Zian both demonstrate a lack of clarity about patient-centred hemodialysis nursing care.

Theme One Summary

Acquiring theoretical knowledge about patient-centred care is the initial step required for hemodialysis nurses. Participants shared three different ways that they had learned about the concept – in basic nursing education or at work through corporate or unit processes, and also through the nature of the hemodialysis setting.

Participant comments indicated that knowing patient-centred hemodialysis nursing care is continually evolving as they gain practical knowledge through their experiences caring for more patients. The process is iterative and there would understandably be variation in how much each nurse knows of patient-centred care in hemodialysis due to various factors such as years as a nurse and in the specific clinical contexts where they have worked prior to hemodialysis. This is important to note because nurses must have a minimum amount of experience, typically two years of acute nursing care, before they will be hired for a hemodialysis position. They may have been proficient in providing patient-centred care in a different unit but realize that they need to adapt their nursing practice to the hemodialysis context. In addition, there would be variation in their experiences of nursing processes such as therapeutic relationships and reflective nursing practice. These two factors can promote the ability of nurses to know patient-centred hemodialysis nursing care and make adjustment(s) where warranted. Further information about these two factors is provided in Theme Four.

The education received by participants did not consistently and effectively align with the philosophy of patient-centred nursing care and created challenges for nurses to articulate it. When some first received education about patient-centred care, it was not linked to a specific theory they could articulate, notably in the workplace, and standardization was missing in how they came to know patient-centred care.

In the next theme, findings are presented about participant experiences of applying patient-centred hemodialysis nursing care. This builds on the knowledge they initially gained.

Theme Two: Applying Patient-Centred Hemodialysis Nursing Care

Once theoretical, practical, and natural knowing of patient-centred hemodialysis nursing care has occurred, applying it in daily clinical practice occurs. Participant comments drew attention to a different part of the iterative cycle because applying leads to more knowledge being acquired through experience. The description from Jarvis sheds some light on this – he initially learned about patient-centred care during organizational orientation and engaged with it by applying his new theoretical knowledge in his bedside practice. His thoughts demonstrate his progression:

[From] ... it was pretty fancy ... like very professional, very high-end elite kind of place for people ... when they say the 'patient-centred' thing ... [To] ... there might be some practices that I might do to, let's say, enhance the communication process ... it focuses on specific and individual needs of each patient ... for patient-centred care to be implemented, it has to be flexible and ... unique to the specific patient ... [who says] "I make my own decision, it's centred to my specific need for that particular time, I just don't feel like sitting ... for four hours".

Jarvis applied what he had learned about patient-centred care and reinforced it as he gained practical experiential knowledge. He was paying attention to what patients said and was being flexible, collaborating more with them by attuning his practice to them.

Participants described improved quality of patient care due to flexibility with treatments which occurred when care was patient centred. As Gerry explained:

Now we're a little bit more flexible, now we're not insisting patients [come for] short [treatments] three times a week. If once a week is doing it and that's what they want, we support that as well ... to me that's where the patient voice has

spoken ... as opposed to medical literature alone speaking ... when they want off, they need off.

When he uses the words “now” and “as opposed to medical literature alone”, he is referring to a shift from previous practices that strictly insisted patients stay for each prescribed treatment and amount of time, which may be four or more hours three or more times per week. Responsive patient-centred care aligned to patient preferences would provide some flexibility, but that creates tension between what patients are willing to do and what nephrologists prescribe, with nurses in a difficult position in the middle. It is a complicated balance for nurses, trying to keep patients and nephrologists happy. Through their knowledge and experience they understand the importance of following the full hemodialysis prescription as determined by the nephrologist, including the time, and, by being patient centred, also understand the treatment burden on the patient.

Gerry described additional patient benefits when hemodialysis nursing care is centred on them:

... [helping] patients cope and deal with coming into dialysis because I think that's where nursing has its way in ... the psychosocial aspect to hemodialysis, especially when it comes to patient-centred care, is the major missing piece ... [and] ... rounds are done in front of the patient, going from patient to patient [and] patients have a direct contact to the Nurse Practitioners ... actually making it happen ... having the feedback from the direct patient clientele themselves makes a big difference.

These actions engage patients and benefit them by acknowledging and respecting the importance of their needs, values, and preferences, which could improve their coping,

which could reduce their anger, tension, and struggles with nurses, other healthcare professionals, and perhaps family members.

Further support for the benefits of applying patient-centred care come from Jay, who quoted a phrase from a movie when describing his thoughts:

Patient-centred care to me is the ability to have a plan of action in terms of the disease or the condition or the whatever but also be able to intertwine it with the actual person and make it so that you can put emphasis on the areas that are needed with specific patients ... Patch Adams ... said 'When you treat disease you win some and you lose some, but when you treat a person you never lose'.

That's kind of what it revolves around.

He is describing actions that the nurse takes to individualize care, reinforcing the notion of the processes of knowing and applying that are integral to the provision of patient-centred hemodialysis nursing care. His understanding of the concept is apparent, as is his comfortable engagement with the approach.

Patient needs are constantly changing as they progress down their trajectory of chronic kidney disease – the trajectory is always unrelentingly downwards because hemodialysis is a treatment, not a cure. They may have episodic inpatient experiences along the trajectory, with treatments provided by the nurses from the chronic unit, who provide support by applying patient-centred care. Participants mentioned this inevitable decline, such as Alice, who said that from the first hemodialysis treatment nurses must:

Find out what their disease understanding is so we can start from square one and help them to understand that this is a life sustaining treatment that you will get out as much as you put into this treatment, and that this is just a treatment.

Like we can treat you, but we are not curing you, the disease is still progressive and that you will have limited life expectancy. Like we try from the very beginning in a gentle way but try to help them to understand that this is life limiting.

This demonstrates applying a patient-centred approach, as the nurse is finding out first what the patient knows, then respectfully helping them understand their disease and treatment, while providing treatment and supporting them as their illness progresses.

Applying patient-centred hemodialysis nursing care demonstrates having the knowledge and technical ability to provide the care while engaging with the patient in a comforting interpersonal manner. This is beneficial to patients and nurses, and the following comment from Rose makes a direct connection:

I think that's where the patient-centred care came through ... I think we became partners in their health, in their journey. And I know in this again something that was so rewarding about this ... was you know we'd have patients who would look us in the eye and say ... "It's because of you, it's because of all of you, that I'm still here". Not just because we have the skill set to do this work, but because we're a smiling and welcoming face.

Participants offered other evaluative statements indicating how providing patient-centred hemodialysis nursing care feels to them, such as enjoyment when it is occurring. None of the participants mentioned any unpleasant feelings. Goldie felt she had "accomplished something", while Joanne enjoyed knowing that:

The care that you're providing them is enabling them to have a good next couple of days ... it's nice to see that some of them are still working and ... able to carry on with daily activities.

When speaking about the benefits of patient-centred care for herself as well as colleagues in their rural unit, Alice commented that:

I really like the change that we've made ... I grumbled about this initially because it sounded like a whole lot of extra work ... since we have kind of broken it down into how we're going to do it and, and there's something that supports us with the paperwork [online documentation], it's a lot easier ... so now we're all doing it.

Rose, Goldie, Joanne, and Alice all received feedback from patients directly or indirectly that their care was helping them, and that made the nurses feel good about what they were doing. When nurses enjoy what they do, such as providing patient-centred hemodialysis nursing care, they feel a sense of accomplishment, which can create a positive feedback loop confirming the benefits and making them want to continue. In the hemodialysis setting the unique repetitiveness of treatments multiple times per week for several hours can promote this.

Patient Safety

Participants linked applying patient-centred hemodialysis nursing care to patient safety. Zian made a direct link when sharing her experience:

So luckily, I was one of the policy makers in our hospital there, being a quality improvement nurse going for the accreditation ... we were all geared towards the patient-centred care with a greater outcome with regards to patient care really ... patient safety goals, which is, the centre of it actually is a patient-centred care approach.

Rose explained that she risked sacrificing patient safety if she had to rush because a patient asked to have their treatment started early or wanted early discontinuation:

I did feel pressured like as a nurse. Well you know I really want to make sure that their needs are met and to get them on time, but then I can't sacrifice patient safety by rushing either, so I'd have to remind myself of those pillars of my practice and not just "Oh I made them happy because I put them on 20 minutes earlier" like ... Well no, I'd rather ensure that you're on safely, even if it's 5 minutes past their time... now we're rushing to take them off and now we're cutting back on their treatment.

Her actions to make a patient happy could be seen as applying patient-centred hemodialysis nursing care but she had to balance that with patient safety. There are unique patient safety issues in hemodialysis nursing, such as critical timing of treatment parameters.

Cher thought that certain factors of providing hemodialysis created conflict between patient-centred care and patient safety because hemodialysis patients require regular rather than haphazard treatments to sustain their health and life:

We're not a walk-in clinic ... they can't expect to have their dialysis when they want to have their dialysis ... that kind of dialysis is not safe for the patient. So the treatment that we provide, we try and provide at least 12 hours per week for a kidney that works 24/7 ... that's why we need to have scheduled appointments, so that they can get their scheduled treatment time. So, if it revolved around when they wanted to, and if they wanted to, and how long they wanted to that's, that's a patient safety issue.

Rose and Cher are drawing attention to tensions between applying patient-centred hemodialysis nursing care and maintaining patient safety. There must be a seamless

balance between what the patient wants and what the nurse knows – strict safety protocols might seem to limit patient choice or preference.

From a different angle, Jay described an experience when nurses did not feel that it was safe to provide care to a specific patient in the rural hemodialysis satellite where he works:

Like it's happened before where, you know, we did not feel safe dialyzing a patient ... the patient had taken a turn in terms of mental cognition ... pulling at stuff and, like if she pulls that line out, what do you do, right, and stuff like that.

Patient safety is at stake in this example because “that line” is a central venous catheter connected to the hemodialysis machine with the blood of the patient circulating in tubing at 400 millilitres per minute. If she pulled it out, she could exsanguinate very quickly.

Delving deeper, Rose, Cher and Jay are applying patient-centred hemodialysis nursing care through their efforts to ensure patient safety, although they did not articulate the link between the two.

Theme Two Summary

Participants provided varied examples of applying patient-centred hemodialysis nursing care and apparent throughout was their concern about doing their best for patients, including keeping them safe. It was not just what they said, it was how they said things – respectfully, gently, and always putting patients first, often standing in the middle and acting as their buffer. Participants spoke primarily about providing patient-centred hemodialysis nursing care in the chronic context, rarely mentioning it in relation to acute treatments. This may be because most acute treatments occur in inpatient rooms where the hemodialysis nurse is a temporary provider, and the acute unit nurse

is assigned to all other care. Participants may also have considered patient-centred hemodialysis nursing care as seamless if the inpatient was a known chronic patient.

The experiences shared by participants have an undercurrent of tensions that they struggled with when trying to balance their basic nursing values such as patient safety with the realities of maintaining patient schedules, so the unit runs smoothly. They ensure that patients have enough knowledge, and their expectations remain realistic, monitoring them during treatment so they do not pull out their venous access, all while providing care in a patient-centred approach that may be mandated through unit or organizational policies. Another underlying tension is having the knowledge that there is no escape from the downward health trajectory for each patient while keeping them happy and giving them hope during treatments.

Theme Three: Sustaining Patient-Centred Hemodialysis Nursing Care

Sustaining patient-centred hemodialysis nursing care occurs after knowledge has been acquired and applied, continuing the dynamic iterative cycle. There are endless variations of patient experiences of hemodialysis treatments, which provides excellent opportunities for nurses to sustain care that is patient centred by supporting their highly complex medical and psychosocial needs. Sustaining patient-centred hemodialysis nursing care requires collaboration, which is fundamental to all effective healthcare processes. Nurses do not provide patient-centred care alone or in a vacuum – it is a relational and interactive dynamic process. This process has contextual uniqueness in the hemodialysis setting that promotes even more knowledge acquisition through different collaborative experiences over extended timeframes. Participants collaborated with numerous people, primarily in two different ways: with patients and perhaps their

families, and with other healthcare professionals within or beyond nursing (intra- and interprofessionally), and within or beyond the unit and nephrology program. This can include other units such as the emergency department or any inpatient setting, and the infection prevention and control department. In addition to all the requirements of providing hemodialysis treatments, nurses must ensure that patients attend specific appointments outside the unit, such as the vascular surgery department for creation of a fistula, or radiology for insertion of a central venous catheter.

Collaboration with Patients

Collaboration with patients promotes and sustains patient-centred hemodialysis nursing care because it welcomes active involvement in their care such as through timely sharing of accurate information by health professionals and discussion of treatment options. Gerry and Zian actually described the provision of patient-centred care as collaboration with patients, which infers that they are an integral part of the healthcare team. Participants made statements that indicated they thought the patient was in charge of and directing their care, such as being part of the “circle of care”, “driving the bus”, and being “the guide”, which promotes collaboration and patient-centred care. Hefei suggested this means that hemodialysis nurses should:

Put your foot in their boots ... think how the patient thinks ... just empty your brain ... sometimes it's like bending yourself [to] what they feel ... especially for new patients ... it takes time ... People just starting hemodialysis, they are followers ... see something, they just do something. But for the [seasoned] patient, they want to be leader ... they want you to follow them ... for the patient-centred care I say, no matter [if] you are a leader or follower I'll do whatever you choose me to do.

This was her way of describing listening respectfully to the patient to try understanding what they are experiencing from their perspective as if she were them, and skillfully applying her knowledge, skill, and judgment to shape her care in a therapeutic and individualized way. This is a patient-centred approach because she was customizing her care actions based on her assessment of individual needs and collaborating with patients, whether they were new or seasoned. Perhaps the seasoned patient was trying to collaborate as a partner rather than being the leader, and the new patient was reaching out for support and help as a follower in the beginning as they were being introduced to their new reality. They may collaborate as more of a partner as they become accustomed to their new routine, or the opposite, require more support from nurses as they try to cope with the burden of life changes due to hemodialysis.

Collaborating with the patient provides a way to gain knowledge, apply, and sustain patient-centred hemodialysis nursing care. Cher thought collaboration meant:

Planning their care for the day with the patient ... I think it's communication between the patient and the nurse. It's all based on communication ... the nurse has to talk to the patient and listen to them ... Instead of saying, "This is what I'm going to do with you today", the term should be, "how would you like your care today?" ... I think we provide care based on, just based on our old model of care.

This suggests a supportive relationship with patients that makes them feel as if they can communicate their concerns to nurses and receive respectful responses to questions. It also involves collaborating with patients to plan what care activities the nurse will provide that day and when, in contrast to the 'old model' of telling the patient what and when. Effective communication processes are crucial within collaboration, all nursing

practices, and indeed all healthcare. Participants identified two equally important types of communication as integral to patient-centred hemodialysis nursing care that align with collaboration: with members of the healthcare team, and with patients and family members, with nurses bridging the gap, in the middle again.

Sustaining patient-centred hemodialysis nursing care includes collaborating with a patient, which may involve assistance from a family member, an experience that Hefei described. While providing hemodialysis for a new patient from out of province, which had some challenges due to a language barrier, Hefei really listened to the concerns expressed by a family member, and her actions demonstrated patient-centred care:

I remember one patient ... was visiting Toronto from Montreal, then suddenly kidney failure, but then she has to be on hemodialysis. She's visiting her granddaughter here, so her granddaughter came in, and was very anxious. I remember that part because she said, "My Grandma has to go back to Montreal, she cannot do dialysis here ... Grandma doesn't speak English" ... You are the nurse at the bedside, you listen to them all the time ... and become their voice.

Hefei was able to collaborate with the patient because her granddaughter translated to facilitate effective communication. Hefei provided patient-centred care by listening, problem-solving, and being the voice for the patient as she helped with arrangements to transfer the grandmother to a hemodialysis unit back home. Hefei went beyond the provision of that day's hemodialysis treatment and considered the bigger picture for the grandmother, helping make plans for the future so her treatments could continue uninterrupted at a location convenient for her back home, promoting her comfort.

Collaborating with patients includes teaching them, to ensure that they are well-informed about their treatment. This was again demonstrated by Hefei, who was surprised by the differences in the way patients on hemodialysis process information when compared to those on the surgical unit where she previously worked, and the main target was being discharged home to recuperate. In the hemodialysis unit:

They [patients] are slow. The passing information, processing information is very slow in hemodialysis so it's not like on a surgical floor or, you know, trauma unit. Very quick. You tell them, they get it. But here, you tell them, you have to repeat, repeat, repeat ... still not get it!... sometimes you have to use a different way to talk. I don't know, it's like a brain slow down, population difference ... multiple things [are] going on and information is overwhelming.

The patient population, as Hefei mentioned, is uniquely different – patients are reliant on hemodialysis to maintain their life and have no ability to recuperate. Her awareness of the situation being overwhelming led her to take the time to ensure they understood the information, providing patient-centred care. She also demonstrated empathy when she used a different way of talking. This teaching is important because patients receiving hemodialysis must manage self-care at home – although they come to the unit several times per week for lengthy treatments, they must support this through their actions when they are at home. Collaboration requires effective communication.

Alice mentioned collaboration with patients during bedside rounds when they provided information that she recorded through electronic nursing documentation, one of the changes in the rural satellite since patient-centred care was implemented:

We make it a running dialogue ... weekly progress notes ... the things that they've talked about, changes in their goals of care, anything that's over and above their treatment things ... We do rounds at chairside now, we sit around on stools, right in front of the patient, everything we are saying about them they hear, and we go through their chart, each time we go through their medications ... They don't have to participate but a lot of times they do because they like to, you know, be a part ... by doing this it's changed the dynamic as well on the unit. Our patients are starting to ask about their blood work ... [and] medications, "What does this do?", "Why am I on this?" ... like really thoughtful questions are coming out of this ... patients are becoming more engaged, because when you're behind the desk talking about them, it's like it's being done to them, not with them.

Her comments demonstrate how continuity of care is being sustained through patient-centred hemodialysis nursing care. The running dialogue and changed dynamic with patients becoming more engaged also resulted in nurses being more engaged with them, gaining more knowledge about each patient, contributing to the iterative cycle.

Weekly rounds provide an important vehicle for collaborating with patients and ensuring that they are actively involved in their own care. Hefei used her nursing ingenuity to create a custom template to ensure that no important information from patients was missed, promoting effective communication because:

Some doctors do the rounds very, very careful, they listen, they do things ... but some doctors rush through even not five minutes they pass to the patient, to next one ... when doctors start doing rounds, I go to my patient ... I say the doctor will be here in ten minutes, think about any questions you want to ask ... if they didn't

get their question answered then I have to email doctor, right? So I don't want to write too many emails.

These preventive measures could eliminate potential problems due to delays in important information being communicated to the patient and helping reduce their worries about unanswered questions. Hefei would not need to email the nephrologist with patient questions then phone the patient after they left the unit to share a response. Collaboration with patients occurs even when they are at home, another reason patient-centred hemodialysis nursing care is unique – the ongoing nature of treatment and monitoring that depends on nursing and crucial patient self-care at home.

Some participant statements indicated that patients may have no interest in collaborating, such as when they are unhappy having to receive hemodialysis treatments. Rose described how difficult this can be for patients:

Even if they gave informed consent, they weren't happy definitely about being on dialysis ... they were just so gravely upset ... just so much anxiety about being hooked to a machine ... that's where the patient-centred care came through, and that's, you know, I think we became partners in their health, in their journey.

Rose has described collaboration as becoming partners with patients, which may help mitigate their unhappiness and anxiety – being completely dependent on a machine for life requires much nursing support. Cher described providing this support:

A new acute hemodialysis patient who knows nothing about their treatment, has anxiety, scared to death, all of a sudden, they're, they went from having a normal life now they're tied to a machine, and they have all these stress levels. So,

education and communication with the patient and telling them what you're doing and why you're doing it, why are you doing a blood pressure every 15 minutes ... [and] the seasoned patient, who says "Forget it, man, I've been on dialysis for 10 years, we do my way, or no way. I don't want blood pressure every 15 minutes; I want it every hour. I only want three and a half hours, take me off".

There are understandable differences between new and experienced patients, and nursing collaboration with them through effective communication promotes a patient-centred approach. Additionally, collaboration through patient-centred hemodialysis nursing care can provide benefits for patients when they are making important decisions and providing informed consent throughout their care trajectory.

Decision Making. Based on participant perspectives, collaborative decision making can sustain patient-centred hemodialysis nursing care. Hemodialysis patients must make life-changing decisions from the moment they are diagnosed with chronic kidney disease and at many junctures along their illness trajectory. Rose and Joanne described similar thoughts that demonstrate patient involvement in different ways, described as being in their circle of care to contribute their opinion, or actively choosing:

Rose: The patient – they are part of that circle of care, and their opinions and their perspectives matter, and it should matter, and that should always be factored in when decisions are collaboratively being made about their care.

Joanne: I think it's the patient having a choice in their treatments, being involved in the decisions ... a say in what's going on ... [and] the healthcare team working around that and trying to adapt so that the care is really around the patient and what works best.

In some units there are formal processes in place to ensure that patients participate in decision-making, such as meetings at critical points coinciding with decline in kidney health that Goldie explained. At her hospital, a nephrology program educator has an online discussion with a patient as their kidney health declines to a certain point and important decisions must be made about their goals of care:

I think patients should be given all the options and they should be allowed to choose ... peritoneal dialysis, hemodialysis, transplant ... and what options are available for them ... Some people don't like having all the options and they're very specific about when they want to talk about the options. But I think it's worth the risk to upset people, like, you know it's never going to be a fun conversation.

This may be a good approach if there is time for preparation but would have been more patient centred had she said 'helped' rather than 'allowed to', which hints of paternalism. Having an educator do an online discussion at an arbitrary point in the patient trajectory prior to them making an important decision infers a distance because the patient may not have previously met the educator, education should be occurring throughout the patient trajectory, and it excludes the front-line nurses. Patients may have questions after the discussion, and how would they be answered? If the front-line nurse needed to ask the educator for follow-up, this could delay the patient having important information in a timely manner. This would also put front-line nurses in the middle again.

Rose discussed some patient struggles with choices, such as if they should have an arteriovenous fistula surgically created, which could be supported by a patient-centred nurse. She mimicked two patients with what she said were their rightful thoughts:

“Oh, well doctor so and so wants me to have a fistula, and you know I don't want it” [and] “Well doctor so and so wants me to have a graft, and it's just something that I don't want, I want my line, I want to keep my CVC line. It's my body, it's my choice, my body it's my choice”, and that came up a lot. Or you know, “I don't want my dialysis to increase from three to four hours – I want three hours. I don't care. You know that's what I want – this is my life, right?”.

The solution Rose suggested for the struggles of both patients was discussion to find some “common ground” and collaboration between the team and patients to ensure the most appropriate care was in line with their wishes. That would be a patient-centred approach, benefitting patients and perhaps reducing the tension, demonstrating again how nurses are in the middle to create a buffer for patients.

Most participants referred to prominent topics such as modality choice when discussing the importance of collaborating with patients to make decisions, and some also saw importance in everyday decisions made by patients. There can be a delicate balance between nursing and patient knowledge, and between patient preference and patient safety. Who gets to decide what is risky or not? Jarvis provided an example of how seemingly less critical decisions are made in-the-moment by a patient:

Patient B doesn't want to have a blood pressure, standing up, standing blood pressure, in spite of let's just say the sitting blood pressure after retransfusion is 95 systolic but he insists that he goes, because he just feels like drinking coffee at Starbucks, I mean down at Tim Horton's ... after I explained the negative impact on his care.

To the patient, drinking coffee at the hospital food court was more important at that moment than the potential impact on his health due to his low blood pressure, which may drop even lower when standing, a common occurrence that Jarvis was well aware of and trying to prevent. Supporting everyday patient decisions that do not put them at risk is part of providing patient-centred care, as long as the patient has been provided with the appropriate information to make the decision and is cognitively intact.

Jarvis provided a different example of repeatedly having to remind patients to keep their masks on during their hemodialysis treatment in the pandemic:

Patients who are not necessarily compliant with masking ... I have to argue with the patient to keep reminding them ... the mask has to cover the nose ... That overrules that patient care, patient-centred care kind of thing, because they don't want to mask up.

His thoughts indicate that he thinks he is not being patient-centred when ensuring that patients remain masked. It does not go against the principles of patient-centred care to ensure that patients wear their masks, but actually supports it by keeping them safe and protected. This demonstrates the tension about whether patient choice outweighs their safety. Collaborating in a patient-centred manner may help maintain the balance.

In contrast to everyday decisions, some developed over time, which Gerry explained as being patient-centred and beneficial to patients when:

... walking them along their renal journey as the situation changes. So it's not a single conversation, um, the same with goals of care ... goals of care isn't just that one conversation. It's the "Now this is going on with you, what would you like to do? Before, you were thinking this way – has that changed at all?".

Goldie also mentioned decisions made over time when beginning a conversation with a patient about the possibility of requiring a central venous catheter at some point:

I wanted her to think about it because this was a real big reality that that fistula could go and then you're faced in this moment where I don't want anybody to be surprised, so I was kind of happy that she was mulling it over for a little bit.

Both of these descriptions involve applying and sustaining patient-centred hemodialysis nursing care and demonstrate the trust and collaboration that has developed over time through relationships with patients. This would also promote their ability to gain practical experiential knowledge about what patients know, value, and want from their care.

Goldie shared a challenging decision-making experience of a long-term rural patient with no family to support him:

[He] got to a point where he was struggling to drive himself, and really didn't want to move closer to the dialysis unit ... he ended up withdrawing treatment ... the last six months, he would not feel well a lot, so he wouldn't come, couldn't, he didn't have the tolerance for the drive, driving himself, which of course, only made him feel worse, right, having a lot less dialysis and then he ends up hospitalized and brought to the city.

Goldie sounded sad but resigned to the situation. Patients make the decisions, and nursing support such as through attentive listening would be beneficial. Decision-making processes are complex, with various ethical implications requiring consideration. Collaborating with patients when decisions are being made can lead to them providing informed consent, which is fundamental to patient-centred care.

Informed Consent. Being well informed is a crucial aspect of decision making and providing informed consent, and participants expressed concern that patients were not well informed prior to hemodialysis initiation. It was unclear if not being well informed was due to a lack of patient teaching or to poor patient retention of what was taught, perhaps in a pre-dialysis clinic. Zian expressed concern that patients were not well informed, particularly when they are new to hemodialysis treatments:

Most often than not because, when I receive an initial interview with the patient I ask all these things, or in the second hemodialysis of the patient, I ask all those things if it's mentioned to the patient, and sometimes they say "No, I don't know that one" or "No, that's not happening".

Zian suggested education as a way to promote patient-centred hemodialysis nursing care and thought it would improve patient awareness of what was to come. When asked specifically whether a formal informed consent was signed prior to hemodialysis initiation, Zian replied, "Yeah, we have like a pamphlet or educational materials for them". This vagueness does not indicate effective patient-centred hemodialysis nursing care involving a process to ensure that consent was informed – a pamphlet handed to a patient is not sufficient to ensure proper informed consent.

Rose described ensuring that informed consent was obtained prior to the initial hemodialysis treatment which, for an acutely ill patient lacking capacity at that time, might require a substitute decision maker. Alice shared that at her rural satellite unit:

It's the physician that actually goes through and tells them everything that's going to happen and then there's a consent at the bottom that says that they consent to treatment, and that they consent to have their chart shared with other members

of their circle of care ... Everybody's got to sign a consent to do anything these days.

It is important that every patient has provided appropriate informed consent and also that every hemodialysis nurse is fully aware if they have, or not. However, Gerry shared that on his unit:

We don't keep a consent on their chart. It is documented ... the conversation is documented by the navigator in the pre-dialysis clinic ... She is someone that puts a lot of effort and passion into the role that she does and has very firm vision on where she wants to see patients going when they come into the kidney care clinic, which was previously called the pre-dialysis clinic.

Although consent is obtained, this comment raises concern in two different ways. The first is the lack of awareness of consent by the nurses actually providing the treatment because the consent is kept in the clinic files rather than the hemodialysis patient chart. The second concern is that the navigator has a 'very firm vision on where she wants to see the patients going' – a patient-centred approach would prioritize the patient's vision of where they want to go and would not be pre-determined by someone else, which raises the question of whether this could be considered 'informed'.

When sharing some thoughts about the decision-making and informed consent processes, Alice said:

My personal bugbear is that you, you have like an 89-year-old patient ... and they don't want to go on dialysis, and their family, you can get families in the room, and they are like, "Oh no no! Dad's gonna start!" He just said he doesn't want to, what are we doing? And then you have this person who you wonder why

they're not compliant, because they don't want to be there. It upsets me. I think you need to go by what people say, they're allowed to make these decisions.

She is speaking in a way that is very patient centred as a nurse who witnesses the conflict when family decisions override patient choice, and the resulting non-compliance because the patient does not want to be there. She tried advocating for the patient but apparently was not successful. After the initial informed consent is obtained, it is implied each time a patient arrives on the unit and sits through hemodialysis treatment, but it can be challenging for nurses when they know it is not what the patient really chose.

Collaboration with Other Healthcare Professionals

The second type of collaboration identified by participants was with other healthcare professionals, primarily members of the nephrology team including other nurses, as well as the social worker, nephrologist, dietitian, vascular access nurse, and pharmacist. They drew attention to the critical importance of nurses on nephrology teams as the link between the patient and other members of the team because of their extended time with patients. This provides the opportunity to notice any problems and share with the team – as Jay described it, nurses “get the ball rolling”. Nurses in the middle as go-betweens is helpful, however, patient-centred care would be strengthened if patients were doing the sharing of information and concerns directly. That would also provide opportunities for questions and answers to clarify any of their thoughts and/or concerns, which would be more collaborative. However, when nurses share patient voices with other members of the healthcare team, there is an element of concern because it presents patients as external contributors rather than important collaborators.

Clinical collaboration can be promoted through documentation in various forms, which Alice referred to when using the electronic Primary Nursing template, accessible to all members of the healthcare team:

The physician can come and take a look at our notes if he wants to, right before he does his note for clinic ... so he can take a look at all the things that we have come up with that we think should be addressed at the next clinic, and it's right there in that note.

The “we” she is referring to is the patient and herself as the Primary Nurse, and “the things” that arose during their discussions in their collaborative dyad.

Intraprofessional Collaboration. Collaboration with other nurses within the hemodialysis unit, and in any unit across the hospital where treatments are provided, can support individual nurses in providing patient-centred care. Rose and Hefei both shared how they welcomed and appreciated collegial support from nursing peers in the different urban in-centre hemodialysis units where they worked. Rose described this as:

I can recharge by having breaks, by working with collaboratively like-minded nurses that support the, you know, the unified goal of caring for patients holistically. And so those are, yeah, those are all a range of factors that help support the delivery in patient-centred care.

Hefei had been a hemodialysis nurse for one year and had a strong background on inpatient orthopedic, trauma, and nephrology units. She shared that:

I have so many years experience but when I went to hemodialysis I feel like, oh my god I'm a new nurse now ... The teamwork, it really, really helps me to

provide patient-centred care ... like a base ... Nurses with two hands, how much you can do?

Comments about having breaks, working with nurses whose practice aligns with their own, and having help by collaborating demonstrate how Rose and Hefei feel supported in sustaining patient-centred nursing. In stark contrast, others had experiences worse than a lack of collaboration with nursing colleagues to the point of uncomfortable friction. Cher described how this might occur with hemodialysis nursing colleagues:

Let's say you're supposed to do some dressing on your shift and then you left it for the night nurse. You're going to hear about it ... like "Now I'm supposed to do the dressing when you had all this staff on days?" So they're not going to care that you're going to say, "Well the patient didn't want the dressing done till this evening". They're going to say "You, the nurse, didn't want to do the dressing today ... now I have to do it on nights" ... [patient care] depends on you and your colleagues ... you have to be comfortable with the people that you're working with, to know what to do at the bedside.

Collaborating intraprofessionally can be challenging due to the work processes in very busy urban in-centre hemodialysis units such as where Cher primarily worked. A great deal of overlapping occurs in the daily nurse assignment, where shifts are primarily twelve hours, but there may be an eight-hour day or evening. This is most noticeable in the afternoon when there is a chaotic mix of day and evening nurses providing treatments in the unit as well as numerous 'off-units' for inpatients and in the emergency department, plus covering each other for their meal breaks. Cher noted another type of friction with some nursing colleagues who do not collaborate because they:

... want to provide care the way they want to provide care. They're, they're in charge. "You will receive care the way I want to provide it to you". Very little do they communicate with the patient, and if the patient does try and communicate, they get harassed or annoyed ... They're more busy talking about their workload, [and] about other things than talking about their patient care... They're more busy watching videos or whatever on their phone, it's, it's become a virus. Nurses sitting at the desk, watching Netflix on their cell phones.

Hemodialysis patients require close vigilance, therefore this is a patient safety issue. Cher's descriptions are of nurse behaviours that are centred on themselves rather than patients. This does not demonstrate collaborative patient-centred hemodialysis nursing care. Another way that patient-centred care can be hindered by a lack of collaboration by nursing colleagues was described by Jay, who stated:

It's always been like nurses tend to eat their young, right? ... For every great, experienced nurse ... [there] is the one that you do not approach. Young or old, doesn't matter ... when two nurses aren't getting along, um, that doesn't really create a positive environment.

A final example of patient-centred care being hindered by uncollaborative colleagues was mentioned by Gerry, who shared that a nurse might:

... tell their colleague "I need to have a conversation with this patient, can you cover my machines?", that also doesn't always work, either because that affects break times, or it comes across as favoritism. And then it's, it's also, um, their peers as well ... [if a] nurse says "I've had this conversation with this patient. How's this for an idea?", that very act alone kind of puts them in a different peer

perception. I think, I think it's difficult in a huge team that works in a goldfish bowl to voice opinions without feeling attacked.

Nursing friction undeniably interferes with quality patient-centred care, particularly in a hemodialysis unit where close proximity allows patients to witness this unprofessional behaviour. Patients are in the unit frequently for extended times and may see this repetitively, losing confidence in nurses who should be collaborative with each other rather than adversarial.

Interprofessional Collaboration. As mentioned in the introduction, interprofessional collaborative patient-centred care was promoted at the beginning of this century by Health Canada. Although many of the original documents are archived, there are numerous papers and projects involving interprofessional collaboration, and most nurses are familiar with it. Interprofessional collaboration is unique in the hemodialysis setting because of the repetitive and long-term nature of team interaction, and patient involvement in setting goals of care. Participants all shared experiences of interprofessional collaboration, primarily with physicians and social workers, which could impact their ability to apply and sustain patient-centred hemodialysis nursing care. Alice spoke of interprofessional collaboration with notable respect for different perspectives:

[They] make that [patient-centred care] a priority as well ... all of the Allied Health, bringing to the table different kinds of things that make us think more about that patient and their rights ... they all come with that kind of background too in different ways, and nursing ... everybody being on board.

In contrast, some of the nurses felt that interprofessional collaboration does not always run smoothly due to some tensions and dynamics that caused unease. Jarvis drew attention to some of these in the urban unit where he worked:

It's surprising to me that some of the medical, the nephrologist staff are not as friendly to nursing staff, as opposed to let's just say pharmacists, or social workers ... I'm really surprised that the social workers don't also do rounds with [the] nurse practitioner and pharmacist and doctors, which I think they should.

He pointed first to the tension related to the unfriendly behaviour of physicians towards the nursing staff, which is not a new concept across nursing in general, and second to the dynamic on the unit which left social workers out of the interprofessional rounds. He notably did not mention that the front-line hemodialysis nurses were also not included in regular rounds. This is the opposite of everybody being on board as Alice described and would not contribute to hemodialysis nurses being able to apply and sustain patient-centred care. Typically weekly rounds occur in the hemodialysis unit with patients, and monthly rounds in a meeting room outside of the unit, without patients.

Sustaining patient-centred hemodialysis nursing care also requires support at unit and organizational levels. When asked if their organization and unit promoted patient-centred care, several participants thought they did. Rose and Cher both identified hospital Nursing Council as an example of a way to sustain patient-centred care as a link between the organization and individual units. Jay thought that:

You'd be hard pressed to find a hospital right now with the mission and values thing that doesn't incorporate something along those lines ... it's definitely promoted from our leaders and in our staff ... You need good leaders ... good

managers ... team lead and nephrologists ... good staff ... [support] for our own mental health, our own, I use the term 'freshness', you know what I mean? If you're a happy nurse and ... if your mental health is good and being looked after I think that is what is going to make you a better patient-centred nurse.

Theme Three Summary

Sustaining patient-centred hemodialysis nursing care can be promoted through collaboration with patients, which can affect their decision-making and provision of informed consent. Family members may also be involved. Sustaining is also promoted through collaboration with members of the healthcare team, including other nurses and other professions. Collaboration requires effective interpersonal communication as well as appropriate unit management and organizational support. The processes of applying and sustaining overlap, in turn contributing to additional knowing, primarily practical and experiential. Although some nurses struggled to articulate patient-centred care and made some statements that do not align with the philosophy, they seemed to understand the concept, engage with the approach, and tried to apply and sustain it in their daily practice. In addition, participants mentioned a variety of factors that promoted knowing, applying, and sustaining patient-centred hemodialysis nursing care. These factors are described in the next theme and weave throughout all three themes in the processes presented up until this point.

Theme Four: Promoters of Patient-Centred Hemodialysis Nursing Care

Participants made comments pointing to a pattern of four factors which promoted their ability to gain knowledge about, apply, and sustain patient-centred hemodialysis

nursing care: therapeutic relationships, reflective nursing practice, primary nursing, and the satellite unit context. These factors are presented individually but work together in varying combinations, which contribute to a compounding effect.

Therapeutic Relationships

The development of patient-nurse relationships provides the bedrock for all nursing care and is a strong promoter of patient-centred hemodialysis nursing care. Although there is not a great deal of literature about hemodialysis nursing, one repetitive concept is the unique development of therapeutic relationships with patients, which was demonstrated throughout this study. Rose shared thoughts about differences in these relationships in hemodialysis compared with her prior experiences on inpatient units:

As a dialysis nurse specifically, you know I was able to form a rapport with those patients and I got to know them ... You get to know these patients in a way that you don't get to know your other patients ... They could be patients for years, and so you see them multiple times throughout the week for hours at a time ... The bond that you form as a hemodialysis nurse ... I think it's very unique and it's very special.

Rose specifically mentioned what makes the therapeutic relationship in hemodialysis so unique – it is the only nursing setting where they interact with patients in such close proximity with such high frequency over such an extended length of time. Getting to know the patients so well and gaining more experience over time enables hemodialysis nurses to customize the care they provide, gaining more knowledge as they apply and sustain patient-centred care. Cher echoed Rose when she explained that:

In hemodialysis you get to know the patient, you get to know the family, you get to know [them] for a long term, so you build a relationship ... I don't know any other kind of nursing where you can do that.

Getting to know the patient as these nurses described is different from the nursing knowledge gained in an academic or practice setting. It is much deeper and well beyond being acquainted with another person. This unique relationship allows hemodialysis nurses to gain specific knowledge about patient personalities, values, preferences, and dislikes, promoting their ability to apply and sustain care that is patient centred over extended periods of time.

Joanne experienced a therapeutic interaction with a patient who confided his difficulty in sometimes aligning his self-administered insulin dose with his transportation, resulting in him missing some pre-dialysis doses. She acknowledged his dilemma while discussing this with him, then suggested a care plan adjustment to the Charge Nurse:

So that if he struggles with dexterity, he can bring in his pen and the cap and we can assist him ... and then he can self-administer his insulin and then we're not dealing with sugars of 35 during his treatments.

She demonstrated situational awareness and flexibility as well as patient-centredness by taking action to ensure high quality care based on his unique needs. She used her assessment skills and broad knowledge base, including care of a person with diabetes. Her critical thinking skills resulted in a plan to hopefully prevent future problems for the patient that nurses may have to deal with. The patient and nurses all benefit.

Jay described a different advantage of developing a strong relationship with patients over a span of time, which demonstrates that there is much more in the

provision of patient-centred hemodialysis nursing care than the technical aspects of treatments:

I'm not just focused on their dialysis and their central line and this and that ... You can often tell if something is off just by the first three minutes of them walking to the chair and getting that first blood pressure ... or wheeling them to the weigh scale ... that whole interaction is part of our assessment.

Jay spoke of nursing assessment, but his comments also draw attention to the unstated depth of nursing knowledge and breadth of information a nurse can assess about a patient in a short amount of time. As a hemodialysis nurse spends more time with a patient and gains more knowledge about their patterns and behaviours, their assessment could be quicker and more detailed, and would continue to deepen as the patient moves along the trajectory of their chronic illness. Additionally, his comments hint at how the therapeutic relationship strengthens over time – the ability to “tell if something is off” takes time to develop and would become more fine-tuned with repeated visits. This strengthening over time is unique in hemodialysis.

Also demonstrating more than the technical, variety within the hemodialysis patient population requires nursing sensitivity, presenting different opportunities to develop therapeutic relationships and deliver care that is patient centred. Gerry provided an example of variation when he mentioned challenges with patients living in the downtown core of a large urban centre due to:

... tensions between race, the police, and in this case, wellness, um, when, when someone's having a difficult time, or with getting to and from dialysis, sometimes the police are the last people they want to see ... We also have patients who

have addiction issues, which have all sorts of paraphernalia in their dwelling, so I can say that's part of it too.

Gerry shared this comment when describing his experience of hemodialysis nurses being cautious about sending police to do a wellness check at the home of a patient. This action is unfortunately common practice if a patient does not arrive for their strictly scheduled life-saving treatment and occurs after the nurse has made unsuccessful telephone attempts to reach the patient or a family member. This demonstrates a patient-centred nursing practice unique in hemodialysis – the effort nurses make to ensure each patient comes for every treatment. Under the surface Gerry is sharing how hemodialysis nurses worry about 'no-shows', and want to know why they have not arrived, that someone has checked on them, and hope they are found safe rather than unresponsive or worse. There are ethical considerations within the therapeutic relationship and this worry about patients when they are unexpectedly missing could develop into a moral dilemma. Also, if patients learn about hemodialysis nurse efforts on their behalf beyond direct care, it may surprise them and strengthen their relationships.

On a different note, Hefei described mixed patient reactions to receiving nursing care, and how hemodialysis care needs to be customized using nursing skills such as assessment and critical thinking. She offered the example of helping patients transfer from their wheelchair to the hemodialysis chair:

Some patients really appreciate [the help], and some patients feel offended ... [if] you do this for them ... [Some] welcome it as kindness, and some ... they feel like you invade their private, something like that ... so assessment, kicks in, you know you have to use your judgment to tell if the patient like this, or not like this. That's

why you know sometimes I feel like [it's] a culture difference, race difference ... especially new patients ... it takes time.

Hefei's comment is pointing to getting to know individual patients and what type of care they want from nurses, developing a therapeutic relationship. She provides some reasons for their different reactions, such as a culture or race difference, and whether they are a new hemodialysis patient, but there can be numerous others. Rose for example mentioned that some patients had language barriers and others had cognitive challenges, Gerry mentioned that some patients are sicker than others, while Jarvis and Goldie noted different patient personality traits. These patient differences create limitless opportunities for developing and strengthening therapeutic relationships and gaining knowledge about individual patients so that nursing care can be customized through a patient-centred approach.

The depth of the patient-nurse relationship in hemodialysis logically promotes the ability of nurses to know, apply, and sustain patient-centred care. They get to know patients very well, which may strengthen collaboration with patients. This may also strengthen their collaboration with other healthcare professionals when they are repeatedly in the middle between patients and them. This might also provide an avenue for nurses to gain respect from others on the team.

Reflective Nursing Practice

Patient-centred hemodialysis nursing care could also be promoted by reflective nursing practice. During interviews participants reflected in-the-moment on patient-centred care as they engaged in the research process and described various clinical

experiences. Some questions garnered quick responses while others required them to pause for deeper reflection. Rose shared that in her basic nursing education there were:

Quite a few reflective assignments on this idea, this notion of patient-centred care ... in hemodialysis, I saw them ... first and foremost as a person ... honestly, I think that is unique to hemodialysis and that supported my patient-centred care 100% ... Stop and think and be reflective in your practice and ... reflect: What am I doing? Why am I doing this? What is the patient saying? What are they telling me? What do I need to listen to? What's something that I think is best but maybe in contrast with what the patient is saying? ... really being aware of making space to hear that patient out and be their sounding board too for the rest of the team.

Her inquisitiveness is very sensitive to what the patient is saying and demonstrative of patient-centred care, with a subtle indication of not being paternalistic. Being in the middle as the team “sounding board” would contribute to patient-centred care and require reflection on how to effectively express patient thoughts to others on the team.

Goldie shared that her thoughts about the process of reflection changed when she began clinical work:

Self care is pretty important in delivering good care. I think knowledge, and being proactive in educating yourself, making yourself better. I feel like school ... you do a lot of self reflection and it's kind of forced and it's jammed down your throat ... but wow, you know, it's definitely a skill that I use daily, not just in my work life but in life, period. Lots of self reflection and how I can affect outcomes when I can only affect myself, like it's only me that can be changed in the situation.

This could be interpreted as how reflection helps her gain knowledge about her nursing practice and perhaps change her approach in clinical situations to obtain the best outcomes, which might be by being patient centred. If reflection on what she changed confirms a better outcome, it can add to her knowledge of patient centredness and promote her application and sustaining that type of care for future patients.

Gerry described reflection as the action of processing “what’s going on”, and draws attention to two challenges in providing patient-centred care:

There’s room for improvement when it comes to frontline staff delivering the care ... I think they're not put in a good position to do it and I think they should be ... their processing time, thinking time, reflection time is interrupted specifically with dialysis alarms or incoming patients.

The first challenge is an unspecified lack of support by nurses not being “put in a good position” to deliver care as he thinks they should. The second is the never-ending workload interruptions that are common in all nursing settings, but in hemodialysis specifically this involves patients and other people coming and going, in the midst of continuous machine alarms and other factors requiring nursing attention.

The experiences of Rose, Goldie, and Gerry demonstrate that reflective practice is significant for patient-centred hemodialysis nursing care because it encourages nurses to stop and think in the moment or at some time later about what they are doing, or have done, and why. Reflection involves critical thinking to assess what worked and what did not, which can promote their ability to gain knowledge through their practice and may result in adjustments to actions to ensure the highest quality of patient-centred

care. This can lead, for example, to a change in the way that they approach patients and, as Rose said, how they listen to what patients are saying.

Primary Nursing

Several nurses mentioned Primary Nursing as a way to promote patient-centred care. The main component in their descriptions was that one nurse was accountable for a small group of patients to ensure nothing was missing in their care and their voices were heard. This could strengthen the nurse-patient therapeutic relationship and continuity of care, benefitting patients and nurses, and could work in hemodialysis due to the long-term relationships between patients and nurses. Zian described it as the “new thing now of the ORN” (Ontario Renal Network) and in her unit each nurse has:

... at least three patients who you will follow ... at the kardex rounds. You present to the interdisciplinary team ... how the patient is currently, and right now what are the current situation? But before you go for that one [kardex rounds] you ask the patient what's been going on.

Alice described her responsibility as a Primary Nurse and how she documented it electronically:

Especially if you're the Primary Care Nurse, it's my responsibility ... I have to keep track of making sure that they have a medication reconciliation done every so often, that they have foot care, a foot care check whether they're diabetic or not ... The Primary Nursing template ... is pretty neat because it will draw out everything that you need to know for that patient. So, it will draw their recent labs and it'll pull it in, it'll pull in their medications ... [it] has everything about that patient for that month when you create that in your progress note.

She compared the rural satellite where she worked to the urban in-centre unit of their program where Primary Nursing was also in effect but did not function as well because:

The nurse may not see them again for like six months or something because they have so many patients ... [and is] relying on all the other nurses. So, they can't get as involved as we do.

Her description of keeping track indicates vigilance and continuity of care, and how a Primary Nurse could maintain ongoing knowledge about patient experiences. The progress note documents the information that the nurse collects for other members of the healthcare team, promoting communication and collaboration. Her comments draw attention to the notion that Primary Nursing functions best in the rural satellite setting.

The Satellite Unit Context

Until this point in the findings, the most notable promoter of patient-centred hemodialysis nursing care was the therapeutic patient-nurse relationship, however almost as notable was the satellite context, regardless of whether it was urban or rural. Each hemodialysis context is different due to organizational, unit, staff, and patient variations, and examining these in depth is beyond the scope of this dissertation. However, participants mentioned various factors related to the hemodialysis satellite context that contribute to the patient-centred hemodialysis nursing care. Gerry has experience in urban in-centre (hospital) and satellite units and thought that the satellite setting contributes to patient-centred care and provides benefits for patients and nurses. He quoted patients as saying:

“I feel like I'm not treated like an animal anymore” ... they said when in the in-centre environment they felt like they were just ... they didn't say assembly line, but that type of mentality.

It is unfortunate that a patient felt like that, but fortunate that it did not happen in the satellite. Gerry uniquely thought nurses benefitted in the satellite too because:

Staff is confined in that they're able to look each other in the face every day and they're able to appreciate who they are ... There's a certain magic happening at the satellite where you're understanding people in a completely different capacity.

His feeling of “magic happening” is an expressive statement summing up the difference between the in-centre and satellite settings for the provision of similar treatments. This is interpreted as a feeling that other nurses might also experience, as well as patients.

Magic is a strikingly exceptional word to use in healthcare.

Participants in rural satellite units explained that there is only one changeover per day and no evening or nocturnal treatments, which would reduce the daily chaos and workload when compared to that of in-centre units. As Joanne described it, the stable workflow helped patient-centred care because “you get in the routine and the groove of things”. Satellite units also do not support the nephrology needs of an entire hospital as urban in-centre units do, which dramatically reduces the non-stop daily action with many more patients, nurses, and other people coming and going, creating a calmer clinical environment for providing patient-centred hemodialysis nursing care. Other contextual factors that promote it are unit size, patient acuity, exclusive staff, and skill mix.

Unit Size. A notable variation in settings that promotes patient-centred hemodialysis nursing care is unit size. Participants reported that there were 30 to 48

patient stations (beds or chairs) in urban in-centre units and 24 in urban satellites, much higher than the four to six in rural satellites. Jay said the small size made patient-centred care in the rural satellite “definitely easier” because:

Every two days you see the same people, it's the level of attachment that you get to these patients, in terms of family, knowing their entire life ... I can sit down beside my patient, and I could talk to him for an hour or two, or I can sit in between both the two patients in that little pod ... Your charting was there, and your computer was there, and everything you needed was there.

He worked in a 4-station unit with two patients per nurse and describes a proximal intimacy not achievable in the in-centre setting, which would promote patient-centred care. He also explains how this setting promotes knowing patients more deeply. Alice reinforced his comment and added further details about the sharing of patient care, providing an example of intraprofessional collaboration and suggested it is easier in the satellite, promoting patient-centred hemodialysis nursing care:

It's a bit easier ... you have fewer amount of patients so that you can direct all of your time towards them, and because we share the patients, all three, like all the three people that are working, we can divvy up these jobs between us ... you can't have that kind of coordination [in in-centre] that we do in our satellite unit.

Patient Acuity. Patient acuity varies between settings, which can impact patient-centred hemodialysis nursing care. As noted previously, all participants provided care for patients receiving outpatient chronic hemodialysis treatments, but only urban in-centre nurses provided acute hemodialysis for inpatients and those in the emergency department. Participants in rural satellite units said there are no heavy patients there

because they are transferred to an acute hospital, but nurses who worked in urban in-centre and satellite units were able to compare if patient care is equally heavy, such as Zian. She inferred that patient-centred nursing care was different in the satellite because patients:

They're not, they're not heavy ... like it's just a very simple hook in and hook out ... they are more taken care of rather than the in-center because nurses there [in the satellite] have more time to talk to the patient.

Patient acuity affects patient-centred care because a hemodialysis nurse needs to prioritize the biomedical aspect of care for patient who is more acutely ill. This is of course appropriate but may come at the expense of addressing psychosocial aspects that are also important in a holistic patient-centred approach. It could be upsetting for a patient to be transferred far from home to an unfamiliar unit with unfamiliar staff where patient-centredness may not be a priority or occur as naturally as in the satellite.

Exclusive Staff. Hemodialysis patients have specific treatment days and times in a specific unit, but nursing staff are frequently changing for varied reasons. Having exclusive unit staff would contribute to patient-centredness by promoting continuity of care. Participants from all rural satellites and some urban satellites worked exclusively in those settings. In some urban programmes the nurses described being either exclusively assigned to the in-centre unit and rarely to the satellite, or assigned in both intermittently, which would not promote patient-centred care because of the lack of continuity. As Rose explained:

Because I was specifically stationed at the "C" campus I would not go to the satellite campuses unless they were short staffed, then they would make an

exception ... “Hey you know, we're short someone here at K do you mind working there instead?”.

Rose has the opportunity to develop patient-centred relationships with regular in-centre patients, but it would be difficult with satellite patients due to her unpredictable and sporadic shifts there.

Alice commented about another benefit promoting patient-centred hemodialysis nursing care in the satellite unit compared to in-centre unit of the same program:

Another thing about patient-centred care that we're pretty good at in our unit, as I think most satellites are, you get to really know the people's arms too [re: vascular access] ... so you can catch things quicker, you know these people.

She identified a crucial benefit of having exclusive staff – quickly noticing and addressing problems with a patients’ arteriovenous fistula or graft, which is their lifeline. Nurses would also get to know more about other patient details, not just their access, and develop deeper relationships with them, which could promote more collaboration with them, and strengthen their relationships.

Skill Mix. Participants described varying skill mixes in the satellite units, which may affect their workload, which in turn may promote patient-centred hemodialysis nursing care. Skill mix involves different patient, nurse, and environmental factors such as those in the practice guideline of the College of Nurses of Ontario (CNO, 2018a) incorporating the Three Factor Framework. Nurse factors determine the appropriate category of nurse to meet specific patient needs in a specific care environment, and include leadership, skill in decision-making and critical thinking, knowing when and how to apply knowledge, and having resources such as a senior nurse to consult with and

determine if care needs to be transferred. Patient factors include complexity, predictability, and risk of negative outcomes, while environmental factors include stability, predictability, and availability of practice supports such as an educator (CNO, 2018a). Gerry was the only nurse who mentioned this guideline, describing it as “you can do whatever you want with that, really”. This comment was not made or received negatively, but as a respectful understanding that standards and guidelines from regulatory bodies are very broad with respect to professional expectations. Differences in skill mix were evident in other participant statements. Some units had an all-RN staff with support from ‘Renal Aides’ or ‘Dialysis Technicians’, some considered RPNs to be ‘Renal Aides’ assigned only to basic clinical tasks such as taking patient weights and blood pressures, and others allowed them a broader scope of practice that included responsibility for vascular access. Alice described skill mix in the rural satellite:

It's two nurses and an RPN ... we kind of share. It depends if we have an RPN, so now she will usually take an assignment, but if they are beyond her scope of practice then of course it defaults back to the RN anyway ... if the person is unstable then the RPN can't look after them.

Her statement “it depends” is interpreted as meaning the assignment can vary from one day to the next, and there may not consistently be an RPN on the roster. Supporting staff may be responsible for some tasks that nurses would need to do if they are not there – when they are, it could lighten the nursing load, providing more time for direct patient contact and promoting patient-centredness.

Theme Four Summary

Four factors promoted the ability of participants to know, apply, and sustain patient-centred hemodialysis nursing care: therapeutic relationships, reflective nursing practice, primary nursing, and the satellite unit context. These could have an individual or cumulative effect if there were multiple factors active at any given time in any setting.

An additional notable factor is that a patient who is familiar to the nurse because they have been receiving chronic treatments may also visit the emergency room or become an inpatient due to experiencing an acute episode that is related or not to hemodialysis. This overlap of providing treatments in both acute and chronic settings is unique and can promote patient-centred hemodialysis nursing care.

In the next and final theme, detours, the opposite of promoters, are presented. These detours are factors that nurses are faced with from many angles, some of which they may be able to navigate around or mitigate, while others are more challenging, perhaps because they are out of their direct control.

Theme Five: Patient-Centred Hemodialysis Nursing Care Detours

Participant comments pointed to their determination to provide the highest quality of patient-centred hemodialysis nursing care that at times required them to navigate around some detours related to patients, nursing, or the unit, organization, or system. They often succeeded but sometimes could not.

Patient-Related Detours

Hemodialysis patients may inadvertently create some detours that nurses needed to navigate around in order to provide patient-centred care. Participants

described experiences when patients did not adhere to the strict and burdensome treatment regimen, including full completion of all prescribed hemodialysis sessions, potentially contributing to disruptive behaviours. Cher described how she tried to navigate this common issue:

I'm not going to argue with the patient if they want to come off 10 minutes early, I advise them, I teach them. We have a patient who comes in every day ... He has dialysis every day and every day he's like five kilos, five kilos over. I don't know, I don't know what this person does. I did so much patient teaching, "You're going to get cardiomyopathy, this is going to affect your heart, you're a young man". In one ear, out the other. In one ear, out the other. So, I tried patient teaching as much as possible.

When a patient receives repeated education about limiting his fluid intake but has ongoing difficulty adhering to that, Cher persevered in providing patient-centred care by repeating the message multiple times. Hefei spoke of the same issue when patients refused to come for an additional treatment to remove excess fluid because they had not followed their strict fluid restriction. She provided customized nursing support through a patient-centred approach by explaining and reinforcing the message:

What can we do? ... just respect them, give them suggestion ... I just explain, "if you feel short of breath, chest pain, or anything, go to emergency". That's what I can do. You know ... we support the decision, and how? Just give them resources, if anything happens, what are you going to do at home?

Joanne experienced different types of situations where patients want to shorten their hemodialysis treatments, and provided two examples:

We definitely try to accommodate in those situations where if they want to come off early because they have an appointment, you know, to me that's patient-centred ... (but) there's one patient who he's specifically ordered to have a three hour and 45-minute treatment, but he only ever stays three hours. He says "I've been doing this, you know, for this long. I only ever stay three hours" ... Doctors are also accountable ... so they're not going to change their medical opinion ...

And then the liability falls on the patient, right, if anything were to happen.

She sees it as patient-centred to reduce the treatment time if the patient provides what could be considered a valid reason such as having an appointment but does not seem to think it is also being patient-centred to support a competent patient who chooses to spend less time than prescribed without providing an explanation. Respecting competent patient decisions is part of providing patient-centred care, even when a healthcare professional disagrees with the choices made – hemodialysis nurses may struggle with this. It is also a matter that involves patient decision-making and providing informed consent. The solution which Jarvis suggested was having a document signed by the patient to ensure that when they want to shorten their treatment time, they accept full responsibility for their decision:

So I document 'Patient B chose to leave the department in spite of low blood pressure and with the spinning head' ... but ... if it truly comes to the legality of it ... it could be like my word against patient B kind of thing ... [A waiver] just solves everything. It gives you some sense of support, the sense of security that the patient agreed to having a three-hour dialysis as opposed to four.

He suggested potential solutions if a patient cuts treatment routinely such as discussing a flexible order with the nephrologist to keep the patient happy, and writing a nursing kardex care plan for treatment adjustments to ensure the patient reaches target weight.

Alice addressed the issue of non-adherence in a different way, describing how as a hemodialysis nurse she needs to respectfully challenge the patient and attempt to motivate a change. It is clearly an ongoing issue with all of the nurses, and Alice shared a potential solution of adding a new consent that is being trialled in her rural unit:

This is a regional program thing that when people call in now to say that they're sick and they're not coming in. We have three sheets of paper to go through with them on the phone ... this is what you need to know, these are the dangers of making this decision today, do you understand these conditions? ... we try ... to get them more dialysis. Before they get off the phone you have to offer them another treatment. And then you have to document.

The above examples indicate that hemodialysis nurses are determined to provide patient-centred care through actions to ensure the best treatment with timing that works for patients. Missing too much dialysis can be life-threatening, and although treatment is a patient burden, being under-dialyzed can cause fluid and toxin overload. This can cause patients to feel unwell and possibly lead to an extra treatment or unwelcome emergency department visit between scheduled treatments. This adds even more to the patient burden and nursing workload – hemodialysis nurses constantly strive to prevent this. In the findings related to patient safety, Rose mentioned a risk to safety when she had to rush if patients wanted treatment discontinued early. Patients are ultimately accountable for not adhering to their treatment regimen and must accept any liability,

which becomes an issue related to decision making and consent. It also must be noted that a static target weight may be difficult to achieve some days for various reasons.

Not adhering to the treatment regimen is one way that patients cope with the challenges of being on hemodialysis, which may contribute to the development of unexpected and disruptive behaviours when they are in the unit. Cher said that:

There's always surprises at the bedside in how people behave ... [such as] they don't like the nurse they're having so [they say] "That's it, I'm going home. I'm going home" ... [And] patients maybe who, who are just not very nice anymore, you know, like they just they come in to, just to, like, I don't think ... it's not that they come in to give you a rough or a hard time, but they're not happy. So no matter what you do, so they'll yell and scream and, you know, you don't want to call security because you know this person for such a long time you just hope they, they calm down but then you know a lot of times they storm out.

Along the same line, Rose shared that some patient requests were unrealistic, such as when they arrive too early for their scheduled treatment for an unknown reason and ask to have their treatment started before another patient or to "Put me on an hour before my time", which she described as repetitive problematic behaviors. The detour that Cher and Rose were determined to navigate around was to ensure that patient needs were met in a timely manner without sacrificing safety or displaying favoritism. They demonstrated patient-centred care by trying to understand that the causes of these behaviours stemmed from their chronic illness and events that may be out of their control such as their transportation to and from treatments, and helping them manage it through problem-solving, a basic professional nursing responsibility.

One other way that patients may inadvertently create a detour in patient-centred hemodialysis nursing care arises in the unique unit environment. Hemodialysis nurses may struggle with their own reactions to how patients react to situations that they see while they are having their treatment – urgent clinical events with varying severity occur daily. Gerry and Alice provided examples of a clinical scenario when patients witness complications other patients experience during treatment. Gerry said that:

The first thing the patient says to you is they shrug their shoulders when someone's just died next to them or had CPR done on them and they're like, "I'm going to be late, you need to start taking me off" ... To me that's even the saddest thing ... they were asking for the porter when somebody is dying right beside them ... and they probably at some point have just seen it way too many times or imagine it happening to themselves someday, stopped worrying, stopped caring.

Alice concurred as she described a similar situation that was "traumatic to those people watching ... they can hear everything and ... see. That's not right". Hemodialysis usually occurs in an open unit with very close proximity between multiple patients who have no choice but to witness treatment complications on a regular basis. Patients may have even experienced their own complications in the past, which may dredge up unpleasant memories. If they have not had such an experience they may worry that something they witnessed might happen to them. These events are rarely, if ever, discussed, creating challenges for nurses to help them cope, which is an important factor in patient-centred hemodialysis nursing care. Observing or experiencing rapid nursing actions to resolve complications might reassure patients.

Nursing-Related Detours

Notable nursing-related detours mentioned by participants that could interfere with patient-centred hemodialysis nursing care were a lack of support, respect, and appreciation from others. In addition, they needed to navigate around the detours of managing a heavy workload and experiencing burnout and moral distress.

Lack of Support, Respect, and Appreciation. Hefei described experiencing challenging clinical communication with healthcare team members, clearly articulating that this happened with different professions and on repeated occasions. She struggled to articulate how this made her feel and the potential ramifications for her self-confidence and future interactions with them, sounding deflated and sad:

Doctors, I think they are too busy, probably they didn't really pay attention to nursing practice for some things ... including the Nurse Practitioner, they really look, I feel like, the thing is, they didn't treat us as equal team member ... Some Nurse Practitioners, really just ... I don't know how to say. They don't really value your opinion or something ... you hesitate to voice, you know ... I still approach them but the feeling, you hurt. Hurt repeatedly.

This lack of positive feedback to nurses that they are respected and appreciated as valuable members of the team was also mentioned by Jarvis, specifically regarding the unfriendliness of nephrologists towards nurses, and his added comment about a lack of appreciation from management:

I just feel ... that there is a very big gap ... it's just as if you don't exist ... I don't know if it's a personality thing and that's surprising to me. And I just think that that's, like, like over time that I've been at this hospital, I think that they have to

have a better way of communicating with us kind of thing ... [and] management are not appreciative of the effort we put in.

Gerry supported what Jarvis said regarding a lack of respect for nurses when he shared his experience:

Nursing staff are still disregarded, that just is frustrating ... and then you report it to a manager or a doctor or a nurse practitioner or an educator, and one of the first questions that come out of their mouth is like, "Oh, it sounds like there was a lot of anger in that situation. What could you have done differently?", like somewhat accusatory, which sometimes isn't what is meant ... it's not usually the intent but we need to have better ways to have conversations and analyze and discuss and process what's happened in our hemodialysis unit.

This lack of support, respect, and appreciation for nurses is not confined to the hemodialysis setting, but the team functioning is unique when compared to other units because of the long-term nature of patient needs, and due to the overlap of acute and chronic treatments. It is unique that when an inpatient requires hemodialysis treatment, the nephrology department is consulted – the same nephrologists and nurses are involved, and collaboration needs to occur with the acute inpatient MDs and nurses. No other department functions in this manner, making the provision of patient-centred hemodialysis nursing care unique, particularly when a chronic patient is an inpatient.

Heavy Workload and Burnout. Some participants were experiencing heavy workload which may lead to burnout, which was another detour when providing patient-centred hemodialysis nursing care. Zian linked workload and burnout together when she said that:

Sometimes we do have burnout episodes ... [and] the interdisciplinary team is lacking time to talk to each other and ... it's heavier, it is very heavy ... especially now that we don't have enough nurses.

She is referring to what happens when there are not enough nurses and staff must pick up overtime – there are no agencies with hemodialysis nurses to fill the staffing gap. It is common in the urban settings that some nurses work full time at one hemodialysis unit and pick up extra shifts as a casual nurse at the unit in a different hospital.

In contrast to linking workload and burnout, Jay linked burnout to the negative way that nurses are treated, which in turn could directly and negatively affect their ability to provide patient-centred hemodialysis nursing care:

Not being appreciated and micromanaging leads to all of us staff being burnt out and surly and that's going to translate onto your patient care. At that point it no longer becomes patient centred I think. That's what we try to avoid at all costs.

Rose shared that during the pandemic she lost faith, became “disheartened” and experienced burnout because management:

... didn't acknowledge our work ... I just felt like a pawn ... we weren't being recognized and instead we were being in some ways policed not to have our masks off even for a moment to have our water bottles ... I'm going 10 hours straight ... working sometimes like 60 to 70 hours per week. I was going nonstop without taking vacations.

Similar to Hefei above, Rose sounded sad and deflated as she shared the experience of trying to make her way through her daily assignment in spite of feeling a lack of support:

It just felt even though if I wanted to deliver patient-centred care maybe my surroundings didn't support me in doing so ... I'm spread thin, pulled in multiple directions ... Maybe my needs aren't being met as an employee, as a nurse, to be able to deliver patient-centred care, if that makes sense.

Her way of managing the unpleasant feelings that arose from these experiences of not being able to provide patient-centred hemodialysis nursing care was to shift to a different position that was part-time rather than the full-time she had been doing. She assessed the new position as being very appealing because it offered her the ability to work virtually. The other participants did not mention how they specifically managed these negative feelings, but similar to Rose, expressed thoughts that heavy workload and burnout detoured them away from providing patient-centred hemodialysis nursing care. These negative feelings may contribute to the development of moral distress.

Moral Distress. Participants described some situations that caused them to experience what was interpreted as moral distress, although only Gerry used that term: [It was a] big surprise ... how much weight is put on the nurse to just make things work ... Nobody understands the complexity and arbitrariness of target weights and tolerance to dialysis treatments ... All the moral distress that goes along with not taking enough fluid and then having the patient die of pulmonary edema or show up in emerge and be admitted or taking off too much fluid and having them get sick from it or pass out in the lobby afterward on their way home ... Nurses almost have a post traumatic stress response to constant negative patient interactions.

His statements about moral distress and post traumatic stress demonstrate his thoughts about what can develop from the invisible weight that hemodialysis nurses carry every day because the results of treatment are fully on their shoulders. If they are not able to remove enough fluid from the patient during treatment to reach their prescribed target weight, which happens for various reasons, the nurse may feel as if they did not do what they should have done, and what was expected by patients, nephrologists, and others. This conflict between what should happen and what has actually happened can lead to the nurse experiencing moral distress, particularly if they have had prior similar experiences.

Hefei described an experience that is indicative of her developing moral distress and residue. She thought hemodialysis patient care was negatively affected when there was an emergency situation during the pandemic because:

You're too busy with all the isolation and gown, everything... It's a balance, your life and patient's life ... if I didn't follow up the policy, then I'm sick, then they say, "that's your fault". If I follow policy when I dress in code blue gown, two minutes go ... if you just jump in, they will blame you. It's the balance. You first, patient first? ... Hard to make a decision to be honest. As a nurse, I, I, don't know.

She sounded apologetic and emotional, which clearly left her feeling badly even long after. Her statement about needing to dress in a 'code blue' gown is describing that she would need to don an isolation gown and other personal protective equipment prior to entering the room if a patient with COVID-19 was in cardiac arrest where seconds can count for successful resuscitation. She was describing her struggle to balance prioritizing the patient or herself by wearing the approved equipment to protect herself.

She may have faced consequences from her employer if she did not follow the policy. Although Hefei was describing a situation during the pandemic, her experience could occur in any situation where a patient receiving hemodialysis is being isolated, which is a frequent occurrence. If the nurse is sitting outside the room observing the patient through a window, personal protective equipment must be donned prior to entering the room to manage a complication.

The gradual, inevitable patient deterioration was the least enjoyable experience sadly described by participants, which could contribute to moral distress and in turn create a detour affecting their provision of patient-centred hemodialysis nursing care.

Cher spoke sadly:

Patients ... that you've known a long time and then they start to get really sick, and they die. So that's, that's very sad and we've had a lot of deaths, recently. So, you've been with them for X number of years, and all of a sudden you hear they've been admitted to ICU and two days later they pass ... So you slowly watch this vital person that walked in, laughing, joking, slowly passing away. So that's not a good thing about hemodialysis. Also their surgeries ... you know they have amputations, they have a lot of ischemia to their legs, so you watch one leg being cut off then ... the other ... [then] they're septic ... the wound didn't heal.

Alice also spoke sadly when sharing comments about situations that were her least enjoyable, which could cause her to experience moral distress, potentially creating a detour in her provision of patient-centred hemodialysis nursing care:

The family doesn't see it coming, and they're not seeing the slow degrading things that are happening to this patient. And they keep thinking, "Oh well Dad's

going to get better". No they're not! He's just gone down another level ... They're here because they have to be, not because they want to be. So I find that hard ... some people just die badly.

Gerry shared a potential outcome that may occur when a nurse experiences moral distress. He said that when a patient dies the nurses:

... just nod their heads and they're like 'oh who goes in that station now?' and 'how do we adjust the assignment?'. [They] become completely desensitized ... and I don't know if that's the type of nursing we should be doing.

His comment about becoming desensitized infers disengagement from the provision of patient-centred hemodialysis nursing care, which can be due to moral distress. During the interview he raised a unique question about providing patient-centred nursing care:

Is there a risk to it as well? I have the feeling that some nurses don't want to get into it because it always opens things up that don't leave them necessarily in a better place ... maybe there's a feeling of hopelessness ... if we don't bring it up, then it won't be a problem.

This again points to disengagement from the provision of patient-centred hemodialysis nursing care, indicating that nurses could not successfully navigate around the detour to continue providing it.

Unit, Organizational, and System Detours

Cher described how unit and organizational structures and processes created detours that needed navigating around in order to provide patient-centred hemodialysis nursing care. Nurses tried to accommodate patient requests for shift changes:

So patient-centred care in my mind would be care revolving around the patient's needs, requests, schedule, availability, but the care that I think we provide in hospitals is more scheduled, and regimented, and then I'd have to say, "No you can't come tomorrow for your dialysis at 11 because you have to come in this morning at 7:30, because there's no room for you tomorrow at 11".

Changing shifts also might mean that a patient would miss structured weekly rounds with the nephrologist in charge of their shift and other members of the interprofessional team, which is crucial for continuity of care.

Managerial decisions can create detours at the unit level, which Zian described as occurring when hemodialysis unit managers are concerned only about the financial side of care. Resource decisions at organizational or unit levels affect daily nursing practice and were interpreted as another detour. Jay noted that:

The patient load has increased, their responsibilities have increased so that you don't have time to do that anymore ... It's all about the mighty dollar now and budgets ... the first place that they cut is the frontline staff ... The impact is huge.

Rose provided a concrete example of the negative impact of resource decisions on patient-centred care in the hemodialysis unit:

With funding changes they got rid of the unit-specific porter. And then we just tapped into the general portering system, so our calls would always be pushed back because we were considered outpatient ... so inpatient portering was always prioritized over ours.

Hemodialysis nurses rely on porters to transport patients by wheelchair between the hospital entrance and outpatient hemodialysis unit as they arrive for treatment and back

again after treatment to catch their transportation home, and waiting would cause delay.

Rose explained that nurses must fill the gap when a porter does not come for a patient:

Then we became porters, so then that was a safety issue where we're running to wheel them to the front and now we're not in the centre and I'm having my co-worker manage six patients when he or she maybe should only be responsible for three. But I really want to get this patient to the front, so they don't miss their transportation home so they're not here for another two or three hours.

She has pointed to safety risks placed on other patients as well as staff, not only because she is rushing, but also her need to leave the unit, resulting in temporarily doubling her colleague's workload, detouring from patient-centred hemodialysis nursing care. This is another example of nurses being in the middle and buffering the impact on patients, picking up the slack to ensure that they do not miss their transportation home.

Joanne mentioned the lack of WiFi in the rural satellite due to a lack of organizational resources and described one impact because it was not provided:

But I guess it's never been done. There was an incident I guess where the access nurse wanted to walk the cannulation, walk it through with the nurse but the patient had to provide his own cell phone, and use his own data.

Decisions that are made by others in managerial or organizational levels above nurses directly impact what they do at the bedsides of patients and create detours, making patient-centred hemodialysis nursing care difficult. This can also add to nurses feeling a lack of respect because they are not involved in discussions leading to these decisions.

Primary Nursing was presented in Theme Four as a promoter of patient-centred hemodialysis nursing care, but several participants mentioned some detours related to

that process. Zian drew attention to challenges in operationalizing the role of Primary Nurse due to decisions at the unit or organizational level, therefore it is either not implemented, or is implemented poorly. She explained that:

It doesn't work that much because the continuity of care for each patient ... like for example I like to work on day shifts and my other Primary Nurse patient is nocturnal and evening ... I don't see them ... the manager doesn't like you to have ... like I requested sometimes that I'm in the morning always, so can I have the morning patient? And then sometimes they don't agree with what you think it is that could be better for the patient, but they don't agree.

The first problem with operationalizing Primary Nursing is linking complicated nurse and patient scheduling. Nurse scheduling includes shift work, days off, and being assigned to in-centre or satellite unit or an acute inpatient or ER treatment. Patient scheduling is tightly regimented on morning, afternoon, evening, or nocturnal shifts. The second problem is disagreement between what the nurse sees as “better for the patient”, which is being patient-centred by having a morning patient assigned from her Primary Nurse group so she could provide their care, and the manager who controls the assignment.

Rose described how decisions were made at the unit or organizational level that shifted the Primary Nurse roles previously held by experienced front-line nurses to Nurse Practitioners. The same happened where Gerry worked, and he shared that:

I'm very pro Primary Nurse ... It's not the everyday interaction that does it, there's something more to it ... these things [patients] wouldn't discuss with anyone else on their health care team but looked for their Primary Nurse because they knew

that person ... would understand and knew who they were ... there needs to be more stories about what a Primary Nurse has done.

Gerry identified that unit or organizational decisions such as not supporting a Primary Nurse model may result in: “our well-trained RNs and RPNs are not working within their full scope”. Nursing scope of practice is broad, and participating as a Primary Nurse promotes this by developing knowledge and skills to assess patients, follow up on concerns, and coordinate care. It may be even more troubling when Primary Nursing had previously been the model of care and it is shifted away from the front-line nurses. Nurses can experience unpleasant feelings when they are unable to provide the best care possible in the manner that they welcome, which can contribute to moral distress, in addition to other factors. This can in turn affect patient care.

Reduced Access in Rural Units. Hemodialysis nurses in rural satellites may provide patient-centred care and satellite units could promote it, however participants drew attention to challenges providing it due to unit or organizational decisions. Joanne described how patients and nurses lack access to multidisciplinary team members, inferring that this may impede her ability to provide patient-centred hemodialysis nursing care. She also suggested a potential partial solution:

This is frustrating ... because I feel like our patients are at a disadvantage because of where they live geographically. In the sense, we don't have access to, you know, the access nurse, the clinical educator, the nephrologist ... So I feel like as a sort of backup that they (management) should at least provide WiFi and an iPad so that you know they're able to FaceTime with their nephrologist.

Jay drew attention to how reduced access in the rural satellite setting creates different potential challenges:

In terms of the challenges of hemodialysis number one would be just the straight up acuity of these patients ... The other thing challenging is just our setting, our rural setting, not having you know the nephrologist right there, so you're always kind of being on the lookout for something like that too because you don't want to ... I can't hook up a patient that's not hemodynamically stable.

Joanne and Jay are both drawing attention to the differences in care that they are able to provide in the rural satellite setting, which troubled them both. These differences do not occur in urban settings where access to members of the interprofessional team can occur much quicker, even urgently, which keeps care centred on the patient. Nurses in rural settings are generally providing care for patients considered more 'stable', but the condition of every hemodialysis patient can change dramatically in seconds. Delays in reaching another team member can directly affect how the nurse is able to provide patient care.

Joanne and Goldie identified different but related challenges due to a lack of resources that create detours in the provision of patient-centred hemodialysis nursing care in the rural setting:

If they need an extra run it's harder to do based on staffing because Tuesdays Thursdays Saturdays there's just one nurse, so we can only do two patients ... this is Northern Ontario, this is rural nursing.

This could cause nursing overtime or perhaps require the patient to be sent elsewhere for treatment, or have to wait for treatment, which could be very detrimental. Goldie

mentioned the inability to provide on-call hemodialysis, which was managed by the urban regional centre, and went on to speak of the impact on patient choices. She said:

They don't do it in rural areas, right, so it's usually an air flight to the more urban area, and then acutely launched ... Then as they become more stable, they go back to their home communities and recover or need chronic hemodialysis ... (but) if we don't have the capacity to do their dialysis ... if our community, like the rural area, is already full and there's no space for them physically, they have to move, it does happen ... well ideally you would maybe do peritoneal [dialysis]. That's kind of your only option.

Goldie has described how the rural setting could influence some lifestyle choices that hemodialysis patients must make such as where they live and what renal replacement modality they choose if they have the option. Peritoneal dialysis is contraindicated in some cases, such as patients with abdominal scarring from surgery. This healthcare resource inequality in rural settings does not promote patient-centred care.

COVID-19. Patient-centred hemodialysis nursing care was impacted by the multifaceted and seemingly endless detour of the unexpected COVID-19 pandemic in many ways, and some examples that participants mentioned were described previously. Hemodialysis patients are all very vulnerable to communicable diseases, requiring extra precautions and vigilance. Added strain on nurses came from the impact on patients that occurred due to organizational decisions affecting unit processes, and short-staffing that occurred when some nurses fell ill. Changing priorities pushed patient-centredness to the side. Participants described some impacts, such as Zian who spoke of

“overwhelming overtime” that was at times “forced”. Referring to patient-centred hemodialysis nursing care if a patient tested positive for COVID-19, Cher said:

Oh, forget it! ... you tell them what time they're coming. You tell them what room they're going to be in. You tell them that they have to wait downstairs until someone comes to pick them up... So we cohort them and tell them 'you're coming Monday Wednesday Friday', doesn't matter what their shift was before. It doesn't matter ... we had a time when we had like 10 COVID patients at one time, so everybody's time had to be slotted so that it was efficient enough for two nurses to look after the group of them at one time. [Patient care] was totally task focused. We just tried to get through ... your shift ... workload ... overtime and burnout and everything else ... the stress.

She was describing how patient shifts had to be rescheduled to accommodate the nursing assignment rather than keeping the shift that patients had become used to and arranged their life around. Patients also had to adjust their transportation between home and the unit three or more times weekly, which in urban centres was often problematic.

Jarvis described a different detour providing patient-centred hemodialysis nursing care due to COVID when supportive caregivers that patients depended on at their bedside during their long treatments required organizational approval. In the beginning there were “many unknowns” which created multiple detours that were constantly shifting. Rose explained that patient-centred hemodialysis nursing care got lost:

We weren't able to have loved ones support people who attend dialysis ... they were barred from entering the hospital ... [and important conversations stopped occurring] ... We were prolonging suffering ... I think we lost patient-centred care

altogether ... professionally I thought that many of them had lost their ability to consent to this treatment ... We stopped seeing nephrologists come by.

Other participants agreed with Rose about nephrologists and added that other team members were not visiting in the rural satellites, such as Alice who shared that:

It's also prevented a lot of the assistance that we received from the Allied Health because they weren't able to come in ... from other people in the unit as well ... Volunteers ... Chaplain ... it's been all nurses all the time, like we took on every role, basically.

Joanne described a lack of organizational support for patient-centred hemodialysis nursing care during the pandemic because patients who were coming to their rural satellite unit were inconvenienced actually getting into the unit:

A lot of our patients right now are very heavy and they're all in wheelchairs, so they need to come through the front entrance, which I guess the hospital doesn't want ... They need to come through the front entrance to get a wheelchair, and then go to dialysis whereas if they come through a side door there's a keypad lock, there's a curb that you'd have to go up, like, it's not even feasible.

Patient safety during the pandemic was repeatedly mentioned, especially the need for isolation and being unable to visualize all patients when the nurse was in an isolation room. Some hospitals added staff if possible, as Cher described:

The gowning and the ungowning, and the masking, it wasn't safe for the nurses, so the patient to nurse ratio became 2:1 rather than the usual 3:1 ... at times so many nurses were off with COVID, so we went to one to four.

She was referring to the lack of staff in the non-isolated treatment rooms, which made patient-centred hemodialysis nursing care difficult. That did not happen in the different urban unit where Rose worked:

They were, you know, moving nurses around ... I do appreciate that they did still stick to the ratio of one nurse to three patients ... so I think that is an example of really adhering to patient safety, and maybe more patient safety than patient-centred care, but maybe they could kind of be lumped together with regards to that ... they didn't sacrifice, they didn't say well you know let's prioritize our budget over patient safety and change the ratios to one to four.

Patient safety is fundamental for patient-centred care, and she was seeing patient-centred hemodialysis nursing care and patient safety as two separate concepts that “maybe” could be “lumped together” rather than understanding the strong linkage of the two as in the literature. Her comment demonstrates different managerial staffing decisions between organizations.

Resource difficulties during the pandemic were another detour for providing patient-centred hemodialysis nursing care as shared by Jay and Joanne. Jay spoke of flexibility when he shared that two patients at the rural satellite caught COVID-19 and:

We had to ship them to hospital S. There was no way that we could isolate them in our dialysis unit – it is basically two old hospital rooms with a with a hole cut in the middle so it's basically, you can imagine the size ... no way that we could isolate one patient, you know safely, or for the safety of the other patient.

Joanne had a similar experience when treatments were provided at the main hospital in a different city:

So we did have one patient, and he was sent, just, this is just the only one that I know about who did get it, yes so he went, he needed to get his treatments in [XXX] about an hour and 45 minutes [away] ... because we weren't able to provide the isolation in our satellite unit ... he was admitted twice, so he was admitted, discharged and then readmitted within I think 48 hours.

Having COVID-19 as well as being forced to have hemodialysis so far from home would be doubly disruptive and upsetting for the patient and create a double detour for patient-centred hemodialysis nursing care. However, there was no other option – the inability to provide treatment in an isolation room would put other patients at unacceptable risk.

Theme Five Summary

In contrast to the interested way participants spoke about experiences with patients, they sounded somewhat deflated, frustrated, and distanced from unit and organizational patient-centred care practices, somewhat surprising in urban settings where it has been promoted for more than two decades. Perhaps this was because they did not feel supported, or because they were minimally involved, if at all, in making decisions about various managerial, organizational, and system processes that they needed to navigate around in their daily work. It is doubtful, for example, if any frontline nursing staff was invited to strategic planning meetings to decide to adopt a patient-centred approach and how to implement it, or how resources are distributed.

Participants demonstrated determination to provide patient-centred hemodialysis nursing care by navigating around detours that were patient-related, nursing-related, or related to unit, organizational, or system factors, plus the unprecedented pandemic. Nursing resilience enabled them to be flexible while ensuring that all patients received

their prescribed treatments, providing patient-centred care as best they could under circumstances that at times were particularly challenging, which could result in them experiencing moral distress. At times the detours were insurmountable, and it became impossible to provide patient-centred hemodialysis nursing care, even with the best intentions. In certain instances, such as safety considerations, care centred on a group of patients rather than an individual one must be prioritized, which can be a delicate balance that forces difficult decisions.

Chapter Summary

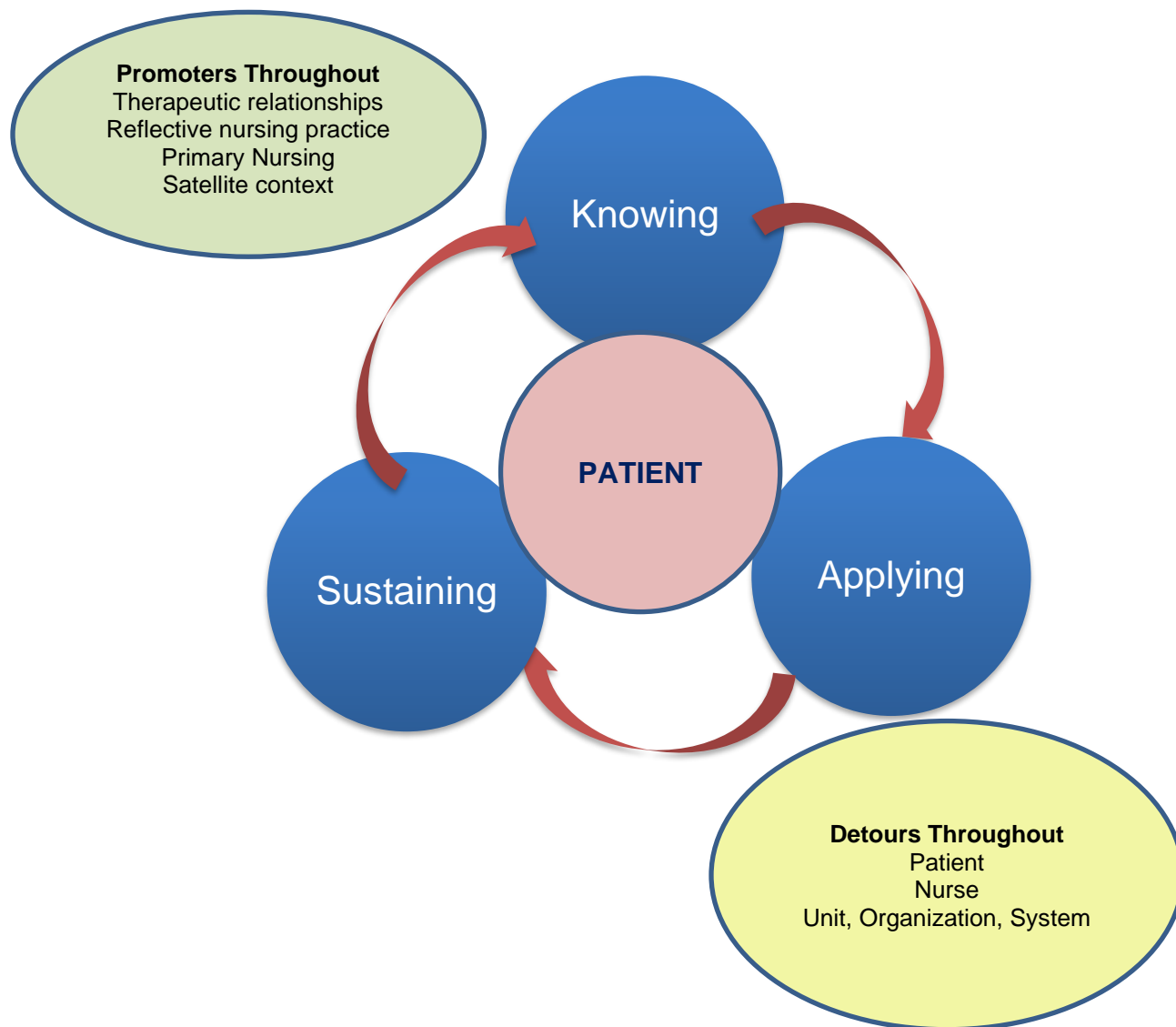
The goal of this study was to answer the main research question of how hemodialysis nurses describe providing patient-centred care. Through analysis and interpretation answers have been provided, adding to nursing knowledge. Patient-centred hemodialysis nursing care can be understood as occurring in different settings through a complex iterative process with multiple influencing factors. The first three themes constructed include nurses knowing, applying what they have learned, and sustaining the new knowledge in their daily practice. The last two themes were factors that promoted patient-centred hemodialysis nursing care or created detours that required nurses to navigate around. Nurses strive to do their best for patients and are usually successful, but at times detours are beyond their control and their best is not enough, interfering with the provision of patient-centred hemodialysis nursing care.

Participants drew attention to the link between patient-centred hemodialysis nursing care and patient safety and provided solutions in certain cases. An example was the risk of exsanguination if a patient with dementia pulled out her central venous catheter during treatment. A patient-centred solution might include discussions with

family to see if someone could sit with the patient each treatment to distract her and keep her hands busy, or if they could hire a sitter. Without private insurance the cost could be prohibitive for the family and the unit would be unable to provide that resource.

It was noticeable that the nurses lacked cohesiveness in what they understood should be happening if hemodialysis nursing care was patient centred, yet they could each articulate some meaningful experiences about understanding and providing it. The lack of uniformity in providing patient-centred hemodialysis nursing care is not apparent in other aspects of nursing care such as completing psychomotor tasks. For example, if they had been asked about hemodialysis tasks such as cannulation or initiating treatment for someone with a central venous catheter they would all have described the same basic process – the same should happen when they speak of patient-centred hemodialysis nursing care.

Figure 2 below provides a visual format of the themes constructed during analysis. Several versions were developed as thoughts shifted during analysis, and it was difficult to construct a diagram to detail the complexity. The promoters and detours can occur at any point in the process of knowing, applying, and sustaining patient-centred hemodialysis nursing care. In the next chapter these results are discussed in more depth and linked to academic literature.

Figure 2: Patient-Centred Hemodialysis Nursing Care

Chapter 5: Discussion

In response to the main research question of how hemodialysis nurses describe providing patient-centred care, findings from the prior chapter are thoughtfully reflected on in this chapter, further interpreted, and discussed in relation to current knowledge in the literature, guided by the interpretive description approach (Thorne, 2016). Patient-centred nursing care is uniquely nuanced in hemodialysis due to values, language, attitudes, and behaviours different than in other hospital units because “stalking death is hovering round every dialysis machine” (Aswanden, 2003, p. 193). Discussion is focussed in three interwoven threads: the process, the interconnections, and the ethical considerations of patient-centred hemodialysis nursing care.

The Process of Patient-Centred Hemodialysis Nursing Care

Conceptualizing patient-centred hemodialysis nursing as a complex dynamic iterative process with multiple influencing factors has not been previously articulated in the literature. Complexities within the daily practice context affect collaborative patient-centred care, such as communication breakdowns, lack of respect and trust, and not involving patients and their personal expertise (Metersky et al., 2022). The constantly evolving process of knowing, applying, and sustaining patient-centred hemodialysis nursing care was described in my study in various ways.

Knowing

There is a great deal of research about patient-centred care yet there is no consensus on a definition of this concept. The conceptual definition selected for my research has three patient-centred care elements – holistic, collaborative and

responsiveness – that are facilitated by a therapeutic relationship, based on mutual respect and trust (Sidani & Fox, 2014). Although this definition is useful, it does not provide guidance on how nurses gain knowledge about patient-centred care, or how to apply and sustain it.

Based on findings from my study, the first step in the process of patient-centred hemodialysis nursing care is knowing. Thorne (2023) described knowing in nursing as: [taking] generalized textbook knowledge into the particularities of ... the individual nurse patient dyad ... across any context ... We take those insights we gain from particular cases back into informing the general knowledge in this ongoing iterative of imagining how our knowledge will evolve ... [it] is flexible and infinitely adoptive ... that individualizing lens that who is this person today and what might they need differently than the one I had yesterday?

Participants integrated three different ways of knowing patient-centred hemodialysis nursing care: patterns of knowing, clinical knowledge, and knowing patients.

Fundamental patterns of knowing in nursing were developed and expanded over time to include different types such as empirics, esthetics, personal knowledge, ethics, unknowing, sociopolitical, emancipatory, organizational, and spiritual (Carper, 1978; Thorne, 2020d). This expansion of knowing in patient and family centred nursing care includes the concept of “procedural knowledge” (Judge, 2023, p.124), which is focused on nursing actions. According to Judge (2023), the display of combined procedural and experiential knowledge demonstrated nurses working collaboratively to provide different elements of care coordinated in response to a patient on an orthopedic surgical unit who had fallen. This included actions such as assessing and returning the patient to bed

safely, informing the physician and others, documenting in a timely manner and then returning to care for their assigned patients. This combination of procedural and experiential knowledge was described as a non-alignment between the busy demands placed on nurses every day with bureaucratic “aspirational” policies about care that is patient/family-centred (Judge, 2023, p. 126). My study results suggest the opposite of a non-alignment because nurses combined procedural and experiential knowledge by collaborating, supporting patient-centred hemodialysis nursing care. Therefore, it was not nurses versus bureaucracy, but nurses working within bureaucracy. This leads to potential implications for policy development within organizations and further research related to nursing practice, discussed in the next chapter.

Findings from my study demonstrate that the most notable pattern of knowing with relevance to patient-centred hemodialysis nursing care was through esthetics as participants artfully provided nursing care. Participants demonstrated situational awareness, perceptive depth, and responsiveness to individual patient needs, such as when one patient might want some help with transferring, but another patient might not. This supports Carper’s (1978) pattern of knowing through the art of nursing, esthetics, which involves situational awareness of the needs of each patient as a unique individual and results in collaborative nursing actions. She cited others, including Dewey, when noting that this involves a certain perceptive depth and responding to the “whole patient” rather than simply recognizing a certain patient need or behaviour (Carper, 1978, p. 17). This describes holistic patient-centred care and raises the thought that esthetics may be intrinsic, or natural, in an individual nurse, because in my study one of the findings is that patient-centred hemodialysis nursing care was “in the nature” of hemodialysis and

may start with the nurse. There are conflicting theories and limited knowledge about what motivates a person internally (intrinsically) which may indicate that an action is inherently enjoyable (Morris et al., 2022, p. 1801), such as providing holistic patient-centred care. Intrinsic factors of nurses related to demographics and personality have been found to have practical implications for the promotion of holistic care (Han et al., 2023). Intrinsic motivation for nurses can be due to their contribution to improving patient quality of life (Koivisto et al., 2021). Holistic care is one element of the conceptual definition of patient-centred care grounding my study, which addresses all health domains (bio-physical, cognitive, emotional, behavioural, social, spiritual), health promotion, as well as illness prevention and management (Sidani & Fox, 2014).

Clinical knowledge, which is inherent under 'illness management' in the holistic element of the conceptual definition (Sidani & Fox, 2014), is supported by my findings in that nurses build on their basic education through experiential knowledge gained in clinical settings, where they may integrate patient-centred care, adjusting care for individual patients in the unique hemodialysis setting. This demonstrates how experience and education are intertwined, which was noted many years ago by Dewey (1938). Similar to the esthetic way of knowing, clinical nursing knowledge is constantly evolving as nurses observe and treat actual patients and contributes to the process of patient-centred hemodialysis nursing care.

Knowing the patient, a central nursing value (Jenny & Logan, 1992; Whittemore, 2000), has been described as being basic to nursing and leading to individualized care (Radwin, 1995), directly aligning with patient-centred care. Every patient has their own story of previous, current, and potential future experiences (Radwin, 1995), and findings

from my study demonstrate unique long-term relationships with hemodialysis patients which include sharing experiences, getting to know them very deeply, and helping them set future goals. These actions demonstrate tailoring of nursing care and align with responsive and collaborative care in the conceptual definition (Sidani & Fox, 2014).

Variation in knowing patients between settings is supported in the literature by a nursing dissertation in the UK that examined patient and nurse experiences in satellite hemodialysis units, where they became familiar with each other, and reported findings that patients felt relaxed, knew what to expect from nurses, and gained confidence in their care (Bevan, 2007). The experience of being known was different and more in-depth when compared to the main hospital hemodialysis unit – nurses connected directly with them because the “nursing gaze is patient-centred” (Bevan, 2007, p. 297). The opposite of knowing each other well occurred in the main hospital unit where patients felt like they were “a commodity ... on a processing line in a factory” rather than an individual (Bevan, 2007, p. 257).

In my study, similar language of being ‘treated like an animal’ and on an ‘assembly line’ was used when comparing the hospital and satellite units. This type of language indicates care that is not patient centred, due to the herding and regimentation of patients through tightly administered schedules and attention to technology. It was recently reported that when nurses displayed a lack of interest in patients as human beings and were more interested in the technology in intensive care units it made patients feel “dehumanized” (Nielsen et al., 2023, p. 395). Patient-centred hemodialysis nursing care helps prevent this through fundamental respect for each patient.

Bevan (2007) found that hemodialysis nurses in the main hospital unit were seen as strangers who come and go because they are too numerous and busy, and only seen sporadically due to working many different shifts. In contrast to Bevan (2007), participants in my study did not express thoughts of being strangers but experienced knowing patients well because they did develop relationships with them in the hospital hemodialysis units, not just the satellites, even though they may not see them as often. That was due to the long-term nature of these relationships rather than the frequency of being together, and the updates to personal knowledge with each interaction, including changes to their treatment due to the changing nature of the patient's health along the downward health trajectory, and advancements in clinical practice and technology.

In my study, it was found that some participants demonstrated a lack of knowing or understanding about patient-centred hemodialysis nursing care, such as the suggestion to use algorithms and clinical pathways to direct care, which are not common in hemodialysis. Clinical pathways that are based on diagnoses can be useful but are usually based on a single medical condition and may be unsuitable for certain patients such as those with chronic diseases and multi-morbidity and may not promote patient-centred care (Røsstad et al., 2013). This is significant for patients receiving hemodialysis nursing care – each patient has a complex chronic disease trajectory involving multiple morbidity issues such as diabetes and hypertension and their care requires flexibility and communication that does not fit well into a static and rigid algorithm. This does not align with holistic, collaborative and responsive patient-centred hemodialysis nursing care. Although there are standardizations in hemodialysis care,

findings from my study overall demonstrate how nurses were flexible with each patient through an individualized collaborative patient-centred approach.

Applying

The first element in the process of patient-centred hemodialysis nursing care is the acquisition of knowledge, but that is insufficient as this knowledge needs to be operationalized and direction on how to apply it in daily practice is missing. Applying patient-centred hemodialysis nursing care occurs when knowing is synthesized into actual doing (Thorne, 2016). This has been described as the merging of “skills (knowing how) and theoretical assumptions (knowing that)” (Friesacher, 2017, p. 95). My study findings demonstrate how hemodialysis nurses apply their knowledge about patient-centred care in everyday practice through descriptions of experiences such as remaining focussed on patient safety and avoiding getting caught up in rushing through treatments. Other strategies included being flexible, shifting previous practices, and especially using effective communication in episodic and repetitive encounters with patients and other healthcare professionals. Core effective nursing communication through written, electronic, and verbal forms is a basic requirement for patient-centred care that includes collaborative practice and promotes patient safety (Davis Boykins, 2014).

Research found a significant increase in trends of patient-centred communication over the past decade, possibly due to patient experiences with chronic illnesses that require more visits with healthcare professionals, where they value relationships and share decision making (McKeown et al., 2023). Strong communication skills among healthcare professionals facilitate shared decision making and positive relationships

with patients and were found by patients and family members to be a valuable feature of patient-centred care (Cheng et al., 2018). Findings from my study support communication as crucial for applying patient-centred hemodialysis nursing care, enabling negotiation of individualized care.

Communication is a pillar of the national mission for nephrology nursing practice as it promotes the best possible nephrology care across the continuum (CANNT, 2021). Miscommunication commonly occurs in nephrology units due to issues such as language barriers, rushing, and poor listening skills including lack of attention to non-verbal cues (Payton, 2018). Experience with language barriers was mentioned in my study, which nurses managed by having family members provide translation. That strategy demonstrates application of collaborative and responsive patient-centred hemodialysis nursing care.

Certain words such as working in a “factory” to describe a hemodialysis unit context that focusses on “production, not human relations” were found to contribute to a predominantly paternalistic discourse (Aasen et al., 2012, p. 423). The words ‘assembly line’, ‘letting’, and ‘allowing’ in my study denote the opposite of collaborative, responsive patient-centred hemodialysis nursing care and are paternalistic words. A paternalistic view considers patients as passively receiving care with a voice that is limited (Metersky, 2020), and occurs when nurses are guiding patients rather than supporting their decisions (Zomorodi & Foley, 2009). Patient-centred care is necessary to counteract problematic paternalism that prioritizes healthcare professional authority (Pilnick, 2023).

Sustaining

Knowing and applying patient-centred hemodialysis nursing care leads to the third and final part of the process, which is sustaining this care. In my study, sustaining occurred through continuous collaboration of nurses with patients and sometimes their family members, and with other health professionals. This could be supported by initiatives such as the national competency framework in collaborative practice developed by the Canadian Interprofessional Health Collaborative (2010) based at the University of British Columbia which was described in the literature review chapter. No literature was found that demonstrated adoption of this framework by a nephrology team, but it could be an effective model for sustaining patient-centred hemodialysis nursing care as it encompasses holistic, collaborative, and responsive care (Sidani & Fox, 2014).

Regarding the process of knowing, applying, and sustaining patient-centred hemodialysis nursing care, overall findings from my study do not align with a study examining nephrology nursing expertise that found they could only be “patient-focused” if they reach the level of expert, defined by having more than five years of nephrology nursing expertise and post-graduate qualification (Bonner & Greenwood, 2006, p. 482). In my study non-expert nurses did provide patient-centred hemodialysis nursing care, which was attributable to their nursing education and experiences before joining the hemodialysis team – most hemodialysis units have pre-requisites of two years or more clinical experience before a nurse can join the nursing staff. It is unclear why this discrepancy exists – perhaps it was due to the criteria for defining an expert nurse

chosen by Bonner and Greenwood (2006), or practice differences between Canada and the United States where that study occurred.

In research about patient and family-centred care in hospitals, Judge (2023) found that nurses were “challenged to separate out ‘centring’ actions from everyday nursing care” because in the view of one of participant, “*everything she did*’ had patient care at its centre” (p. 154, italics original). This raises curiosity about why any separating out should be considered at all necessary rather than fully incorporating ‘centring’ throughout all nursing care. In my study participants did not separate centring actions out, which aligns with the participant in Judge’s 2023 study, but sustained centring actions as they collaborated with patients and advocated on their behalf with nursing colleagues and other members of the healthcare team. This would be an interesting topic to explore with future research.

Interconnections in Patient-Centred Hemodialysis Nursing Care

A second interwoven conceptualization of patient-centred hemodialysis nursing developed from findings of my study is that it involves dynamic interconnections between people. This aligns with an Indigenous African Nguni proverb that translates to the statement that “a person is a person through other persons” (Nwoye, 2017, p. 42). These interconnections begin with individual patients and nurses in a therapeutic relationship impacted by many other people including family members and those at the team/unit, organizational, and system (i.e., regulatory, healthcare, legislative) layers. This creates a complexity of strengths and challenges for ensuring that patient-centred hemodialysis nursing care can occur through collaboration, communication and specific strategies. Five interconnections will be discussed: patient-nurse, patient-healthcare

team, nurse-nurse, nurse-other health professionals, and nurse-unit/organization/system.

Patient-Nurse Interconnections

Findings from my study indicate that the fundamental core of patient-centred hemodialysis nursing care occurs in the dyad of the patient-nurse therapeutic relationship. Little happens in healthcare without going through the hands of a nurse (Allen, 2015), and research found that hemodialysis patients trust nurses with their life story (Fischer Gronlund et al., 2011). Patient-centred nursing care is therefore vital in all patient trajectories, especially for people with a chronic illness such as kidney failure – their downward trajectory can be lengthy. Factors such as different goals and cultural norms between patients and their families and healthcare professionals can facilitate or impede the “caring trajectory” (versus *illness trajectory*), creating unintended consequences (Allen et al., 2004, p. 1009). Hemodialysis nurses need to be aware that patients may cope with treatment stresses such as being machine-dependent through their emotions and may display irritation, avoidance, distancing, and sadness (Al-Nashri & Almutary, 2022; Hreńczuk & Flak, 2021; Johnson et al., 2019; Ng et al., 2021). They may fear the unknown and worry about having an incurable disease and impending death (Tong et al., 2020). In my study it was found that patient-centred hemodialysis nursing care helped patients cope with these emotions and stressors, such as with the anxious grandmother who became acutely ill when visiting Toronto and wanted to return home, and the man who became unable to drive to treatments, and the man who declined a standing blood pressure measurement so he could get a coffee.

Decades ago it was stated that relationships with patients were “the lion’s share” of hemodialysis nurse contributions (Cummings, 1970). Canadian nephrology nurses described their relationships with patients as long term, intimately close, continual, and raw in a way that “does not exist in any other nursing specialty” (Wyld, 2017, p. 105). In satellite hemodialysis units patients felt safe due to nursing clinical knowledge and proximity because they were visible and present, which provided reassurance (Bevan, 2007). Findings from my study reinforce Cummings (1970), Wyld (2017), and Bevan (2007) because all participants mentioned relationships through descriptions of direct and indirect proximity as they provided patient-centred hemodialysis nursing care. The patient-nurse therapeutic relationship in hemodialysis is particularly unique because it is the only setting where nurses interact with patients in such proximity with such high frequency over such an extended length of time. This can be considered a high ‘dose’ of nursing, which was the subject of nursing research that found optimal patient outcomes occur when the nurse ‘dose’ is correct (Manojlovich & Sidani, 2008; Sidani et al., 2010). Findings from my study demonstrate experiences where the nurse ‘dose’ is correct and where it is questionable, notably when staff shortages occurred and also during the pandemic. There is little current literature about nurse ‘dose’ except with regard to medications, which is an indicator for potential future research.

In my study patient-centred hemodialysis nursing care was described as a way to support patients who were anxious being dependent, ‘hooked’ or ‘tied to a machine’. Proximity to patients during hemodialysis has been described as a form of nonverbal communication because nurses are constantly watching patients while they are connected to the machine that allows them to tightly monitor and adjust treatment as

necessary (Moreira et al., 2017). However, technology changed nursing practice and created potentially negative outcomes due to “human-machine interaction” (Nagle, 1998, p. 79); the hemodialysis “production-line” required nurses to gain technological skills, “often to the detriment of caring” (Bevan, 1998, p. 730). Helping patients by repetitively engaging in intense therapeutic relationships while providing treatments requires hemodialysis nurses to manage their own emotional responses and maintain resilience through strategies that include personal reflection, self-care, and maintaining professional boundaries. Examples mentioned in my study were ensuring their own mental health and even changing their job to reduce stress.

Findings from my study indicate that the fundamental core of patient-centred hemodialysis nursing care is the patient-nurse interconnection, and also that patient and nurse factors can affect this relationship. Patients are the recipients of patient-centred hemodialysis nursing care – they are the reason for nurses and healthcare. Patient receptiveness to patient-centred hemodialysis nursing care may be negatively affected by numerous personal factors, such as stressors related to their chronic illness and treatment. Patients may not cope well with the number and variety of stressors as they begin hemodialysis and have difficulty making treatment decisions (Harwood et al., 2009). Patient perceptions of their quality of life were found to change dramatically as they proceeded down their trajectory after dialysis began, from thriving to getting by to being so poor that they became consciously aware of moving toward the end of their lives (Elliott et al., 2014). Participants in my study were fully aware of this inevitable decline due to end-stage kidney disease and that hemodialysis patients have no chance of remission or cure. This provided many opportunities for patient-centred hemodialysis

nursing care as patient needs shifted along the caring trajectory. Participants expressed sadness at seeing the constant decline of patients over time, describing varied experiences such as patients needing repeated amputations or stopping treatment when they could not manage driving themselves to treatments. These experiences can deepen the patient-nurse interconnection as nurses respond to shifting patient needs.

Most experiences of providing patient-centred hemodialysis nursing care in my study were in chronic settings, but some occurred during acute hemodialysis initiation. Both an unplanned and a “crash” emergency start point to a lack of nephrology care prior to treatment initiation that occurs during hospitalization with a central venous catheter to provide venous access (Molnar et al., 2016, p. 2). Patients receiving dialysis are at higher risk of hospitalization relative to the general population, particularly when treatment is initiated (Molnar et al., 2018). When a patient has an emergency start, priority is given to providing practical support in preparation for treatment rather than informational and emotional support, with time a major influence on the ability of the nurse to provide individual support (Sturesson & Ziegert, 2014). Emotional support is distinct from practical support and may be done simply by confirming the patients’ feelings and expressing understanding; nurses may lack knowledge and find it difficult to provide, or it may not be well received, which may depend on the phase of kidney disease that the patient is in (Sturesson & Ziegert, 2014), perhaps too ill to notice. This could interfere with receiving patient-centred hemodialysis nursing care and indicates that certain factors in providing it must be prioritized depending on the situation, conflicting with the statement that all three elements of the conceptual definition require simultaneous implementation (Sidani et al., 2014).

The other half of the patient-nurse interconnection is the nurses who provide patient-centred hemodialysis nursing care, and reflective practice is an influencing factor. Reflection is a core requirement of the Quality Assurance program of the College of Nurses of Ontario (CNO, 2023a). The argument that reflective practice is a factor promoting patient-centred hemodialysis nursing care is supported by my study because participants mentioned reflection as they spoke about their patient-centred care experiences. This aligns with the thought that reflection is a core element of professional accountability contributing to patient-centred care (Schwind et al., 2014; White et al., 2010). Findings from my study reinforce Ashker and colleagues (2012), who described reflection by the majority of hemodialysis nurses in their study as a way of coping with the stressors of work by using “deliberate, problem-focused efforts that are analytical to alter the situation” (p. 234).

Healthcare professional practices may be improved by “encouraging them to engage in a reflective/critical analysis of their interactions with patients” (Pomey et al., 2021, p. 1240). A systematic review about reflection and reflective practice in health professions education defined reflection as a “purposeful critical analysis of knowledge and experience, in order to achieve deeper meaning and understanding”, drawing from three different definitions of reflection beginning with Dewey in 1933 (Mann et al., 2009, p. 597). Reflection is incorporated into the undergraduate nursing curriculum “as part of their professional responsibility”, with the main focus being for them to develop self-knowledge that in turn contributes to patient-centred care within therapeutic relationships (Schwind et al., 2014, p. 344-5). Reflective practice is an interpretive,

subjective, and personal way of knowing, however “consciously or unconsciously”, nurses may not be “truly reflecting” on their practice (Mahon & O’Neill, 2020, p. 780).

The organizational work of Argyris and Schon was used to help frame Canadian nursing research about the challenges of patient-centred care in relation to patient choice in oncology to determine if it is happening in practice or just “rhetorical” (van Mossel et al., 2011, p. 280). Reflective practice involves “knowing-in action” and “reflection-in-action” (Schon, 1987, p. 1), which are applicable for nursing practice in hemodialysis and beyond and were apparent in my research. In professional practice there is high ground, and “the swampy lowland” where “messy, confusing problems defy technical solution” (Schon, 1987, p. 3). Knowing-in-action refers to intelligent action and skillfully completing a physical performance such as bicycle riding where “the knowing is *in the action*” (Schon, 1987, p. 25, italics original). Reflection-in-action is the “thinking what they are doing while they are doing it” that professionals may “bring to situations of uncertainty, uniqueness, and conflict” (p. xi). Reflection-in-action is different than other kinds of reflection because it has “immediate significance for action” (Schon, 1987, p. 29) and has “a central role in the description of professional competence” (p. 35). Reflection clarifies understanding of a problem and may lead to different action that finds a better solution (Schon, 1987). Professionals additionally share *knowing-in-practice*:

A professional’s knowing-in-action is embedded in the socially and institutionally structured context shared by a community of practitioners ... in the institutional settings particular to the profession ... (with a) common body of professional knowledge (Schon, 1987, p. 33).

If people achieve what they intended to do there is a match between actions and intentions, which are identified and governed based on a “master program [of] values” (Argyris, 2005, p. 262). Learning occurs through acting effectively, and also if a new outcome is produced for the first time by an action, which uses “a productive reasoning mind-set” also known as reflection (Argyris, 2005, p. 266). For learning to occur, people must “reflect critically on their own behavior, identify ... problems ... and then change how they act” (Argyris, 1991, p. 4). However, it may be difficult for someone to critically reflect on their personal work performance; they may react in a self-protective defensive manner (Argyris, 1991).

Student nurses “can only learn to be reflective practitioners when they are in practice” (Rolfe, 2014, p. 1182). This was demonstrated by a participant in my study who said that patient-centred care did not resonate in nursing school. She also made statements about her reflective practice, inferring that patient-centred care began to resonate and make sense after she had reflected on specific clinical experiences – she learned to be a reflective practitioner when she entered nursing practice.

A concept analysis of reflective nursing practice by Patel and Matersky (2021) noted three types of reflective practice revealed by the literature: reflection-in-action (Rolfe, 2014), reflection-on-action (Bolg et al., 2020; Schwind et al., 2015), and reflection-for-action (Thompson & Pascal, 2012). Participants in my study demonstrated all three of these types of reflective practice. As an example, regarding reflection-in-action (Rolfe, 2014), participant Hefei in my study quickly reflected in the moment when providing hemodialysis for a patient from a different province who only spoke French and took action to help begin preparations to repatriate her back home. Regarding

reflection-on-action (Bolg et al., 2020; Schwind et al., 2015), during interviews, all participants demonstrated that as they reflected on their practice prior to responding to questions. Regarding reflection-for-action (Thompson & Pascal, 2012), a participant in my study assumed he could practice in the hemodialysis unit in a similar way that he had on the nephrology inpatient unit where he transferred from. He was surprised to find that he could not, and had to process misunderstandings in his head, which is another way of describing reflection on his prior way of providing patient-centred care. This enabled him to change future actions as he adapted to the different patient population.

Reflective practice specifically supports patient-centred hemodialysis nursing care because it promotes critical analysis of what the nurse knows and experiences, allowing deeper understanding and development of personal knowledge that in turn can contribute to patient-centred care within therapeutic relationships (Mahon & O'Neill, 2020; Mann et al., 2009; Schwind et al., 2014). Nurses can reflect on patient-centred care experiences, identify problems, and change their actions if necessary to improve the care they provide. Critical reflection can result in improvement efforts – when health professionals reflect on their delivery of care, the normal process “ensures self-correction whenever practice becomes inconsistent with values and standards of care”, however when it fails “care erosion becomes likely” (de Vries & Timmins, 2016, p. 5), raising ethical concerns.

Patient-Other Health Professional Interactions

Engaging patients as partners in their healthcare is particularly important for people who live with chronic illnesses (Pomey et al., 2015), pointing to the importance of patient-centred care in patients with chronic kidney failure. Findings from my study

reinforce the crucial need for active involvement with the healthcare team by patients who require renal replacement therapy such as hemodialysis. A specific phrase of note mentioned by a participant is the motto “nothing about me without me” that was adopted in 2007 by the BC Ministry of Health when it launched a program based on evidence that patients who exhibit more engagement with their own health care “have better health outcomes, are safer and have an improved experience of care” (BC Ministry of Health, 2011, p. 3). This phrase is similar to “Nothing about us without us”, the mantra of the disability rights movement (Wolff & Hums, 2017). Some challenges and barriers to patient involvement occurred in my study when patients were reluctant or unable to participate actively in their care such as when they did not want to participate in chairside rounds, and when there was a language barrier. Nurses in my study managed this by discussing concerns with them and speaking on their behalf at rounds, and by involving family members as translators.

Patient interconnection with the team raises the question of whether or not they are members and to what extent. In a recent study of patient roles within healthcare teams, it was noted that literature has primarily viewed patients in the middle of a circle with professionals sitting around them, but the author advocated for interprofessional patient-centred team collaboration with all members “in the circle as equal partners” (Metersky, 2020, p. 128). Earlier research suggested that when patients were positioned in the centre of the team, they are present but not an active partner in the circle (Pomey & Lebel, 2016). Those are two debatable points: patients being an equal in the circle, and not being an active partner if they were in the centre. These points are not supported by my study because participants took specific steps to make sure

patients were active partners in their care by collaborating with them through patient-centred hemodialysis nursing care. One example is communicating with patients to ensure their voices were heard during rounds – patients did not need to be physically there to actively participate in their care. Figuratively placing patients as part of the circle of care rather than in a privileged position in the centre like the hub of a wheel raises concern. The circle of care exists only because there are patients – jobs/careers of everyone other than patients depend on them. With the patient in the centre everyone in the circle has a clear, direct line of sight to them and may be more attentive to what they are saying. If the patient joins everyone in the circle, others may not be able to see and hear them as clearly.

A patient is an active recipient of patient-centred care when they participate in their own health care as much as possible, which is reinforced by findings from my study. Since the 1990's, patient care has shifted from being “to” and “for” patients, to a more collaborative approach of “care with patients” (Clavel et al., 2021, p. 1925). Better outcomes may occur if members of the interprofessional team understand and use patient expertise gained from their experiences (Metersky, 2020). This is supported by findings from my study in descriptions of collaborating with patients in numerous activities fundamental to hemodialysis nursing care, promoting patient involvement during each treatment and self-management between treatments, which is crucial for preventing fluid and toxin overload.

Nurse-Nurse Interconnections

When nurses work together it can be termed intraprofessional collaboration, which the Canadian Nurses Association defined as “a relational and respectful process

among nursing colleagues that allows for the effective use of the knowledge, skills and talents of all nursing designations to achieve optimal client and health system outcomes” (CNA, 2020, p. 4). This could promote collaborative patient-centred hemodialysis nursing care. Intraprofessional collaboration in hemodialysis nursing is unique because of patient requirements and unit workflow. In most units nursing workflow involves covering for each other during breaks, but it is broader and more dynamic in hemodialysis, primarily because patients are there for a designated treatment time and many complications can occur. Complications due to fluid removal and electrolyte shifts during hemodialysis treatments, notably nausea, vomiting, severe cramps, and hypotension, must be rapidly detected by vigilant nurses who provide quick interventions (Costa et al., 2015). Intraprofessional collaboration in hemodialysis when covering for breaks requires an immediate response to patient complications, and when not covering involves helping another nurse needing assistance. Participants in my study were grateful for help from nursing colleagues, keeping patients at the centre of care. This provides a potential topic for future research regarding how patient-centred care occurs intraprofessionally.

Hemodialysis nurses welcome collegial interaction, including discussion and collaboration, which has been found to improve nursing practice, provide the opportunity to develop a collective voice, and improve nurse confidence as clinical leaders within the team (Gardner & Walton, 2011). In my study intraprofessional collaboration did occur, but occasionally did not, to the point of collegial friction or conflict, such as if a central venous catheter dressing change was not completed early during a regularly scheduled treatment but was left for another nurse to do. This may be due to patient

request or nursing workload. Timely dressing changes are important because the vast majority of patients on hemodialysis have initial treatments via a central venous catheter and nursing care has a “great deal of control” over the rate of access infections (Steward, 2017, p. 47). Collegial conflict is detrimental to patient-centred hemodialysis nursing care for many reasons, most notably because in the unique setting of large open treatment rooms, multiple patients can witness the lack of collaboration.

Hemodialysis nurses also collaborate with nurses in other units, including critical care; it was noted that the specialty expertise of critical care and nephrology nurses can be comparable (Martin, 2002). Research found that improved collaboration between ICU and dialysis nurses resulted in improved clinical outcomes for patients with acute renal failure and promoted patient-centred care through improved communication between them (Sclauzero et al., 2006). In my study only the urban participants provided hemodialysis in the ICUs, as well as all other units in their hospitals, and had many opportunities to collaborate with nurses in those units.

Nurse-Other Health Professional Interactions

Interprofessional collaboration is also important for patient-centred hemodialysis nursing care and was a fundamental part of the framework for the Canadian initiative at the turn of the century mentioned in the introduction, Interprofessional Education for Collaborative Patient-Centred Practice (Curran, 2004; Gilbert, 2005). Interprofessional collaboration has been described as a necessity for the delivery of patient-centred care (Metersky et al., 2022). It has also been described as necessary in the complex care of patients on hemodialysis because it is neither realistic nor appropriate to expect that a single health professional can address all patient symptoms (Baragar et al., 2023).

Collaboration with members of other healthcare professions was described in my study, most notably by participants with physicians and social workers. In contrast to the finding from Bevan (2007) that nurses were able to practice autonomously without the typical restraints from management and medical staff that inhibited them, findings from my study indicate that the absence of medical and allied healthcare professionals was a drawback in the rural satellite settings because patient care may be delayed and did not promote patient-centred hemodialysis nursing care.

Further findings from my study indicate that at times there were sources of tension when providing patient-centred hemodialysis nursing care that placed nurses in the middle between the patient and other healthcare professionals. They needed to maintain balance with patient care and unit/team priorities, sometimes with family members, and some system issues such as those related to the pandemic. Maintaining balance of the complex personal and professional (regulatory, workplace, collegial) expectations was noted in the literature review regarding ICU nurses (Jakimowicz et al., 2018). In Swedish research, hemodialysis nurses felt that nephrologists did not listen seriously to them, but ignored and ridiculed them when advocating for patients; nurses felt guilty for being unable to effect change, blaming physicians (Fischer Gronlund et al., 2015). Canadian research found that hemodialysis nurses may feel they are “being pulled in two directions” (Wyld, 2017, p. 3), aligning with the argument that nurses face “double-sided” tension due to conflicting responsibilities (Freisacher, 2017, p. 92).

In other Canadian research it was found that interprofessional oncology teams use patient-centred discourse however practice with a “professional-centred approach” such as healthcare professionals presenting patient viewpoints in meetings where

patients were absent (Bilodeau et al., 2015, p. 108). Some nurses in my study presented the patient viewpoints during rounds, but that does not necessarily mean it was professional-centred – they could present the patient voice through patient-centred hemodialysis nursing care. A Canadian case study of person-centred care in an urban hemodialysis program found there were numerous barriers at organizational, unit, and individual levels that included time constraints, heavy workloads, and difficulties with team members not working together (Lewis et al., 2019). Some of these issues were also found in my study, notably a lack of interprofessional collaboration due to a lack of respect for hemodialysis nurses from managers, nephrologists and Nurse Practitioners.

Nurse-Unit, Organization, and System Interconnections

Decisions that are made by the unit, organization, or system directly impact the provision of patient-centred hemodialysis nursing care. In my study, it was notable that participants were more engaged with that approach when leaders in the unit and organization promoted and supported patient-centred care.

Job Satisfaction. When hemodialysis nurses are comfortable with decisions that control their everyday work, such as providing care in a patient-centred way, they may be more satisfied with their jobs. The ability to provide holistic, respectful, empathetic patient-centred care contributes to hemodialysis nursing job satisfaction (Hayes et al., 2015). Hemodialysis nurses who are satisfied with their jobs may be happier at work and promote patient relaxation such as during fistula or graft cannulation (Wilson & Harwood, 2017) – this promotes patient-centred care.

In my study it was found that experiences of rewarding interactions with patients and job satisfaction helped promote patient-centred hemodialysis nursing care – participants felt appreciated. They spoke mostly about patient interactions but mentioned some issues at the unit level that created challenges, such as having to manage non-nursing tasks due to a lack of support staff, rushing during care provision, and burnout. Findings also included experiences where nurses did not feel respected, notably by managers, nephrologists, and Nurse Practitioners. Almost and Mildon (2022) indicated that meaningful respect for nurses is a key to retention and requires recognition of their knowledge, values and experience, actively seeking their input on decisions affecting them, and ensuring quality practice environments.

High levels of hemodialysis nurse burnout are linked to various factors such as a lack of autonomy, power, support and resources, and high workload (Doré et al., 2018; Harwood et al., 2010a, 2010b; O'Brien, 2011). My study reinforces several of these factors, such as burnout, lack of support and workload. In Canadian research of hemodialysis RNs, only half felt that their manager demonstrated concern about their well-being and commitment to make changes toward workplace improvement, which could promote a positive nursing work environment (Doré et al., 2018). This may be affected by a lack of clinical support services, which can create a barrier for learning because nurses needed to perform non-nursing tasks to keep the unit functioning (Wilson et al., 2015). Hemodialysis nurses have reported often feeling rushed because their unit did not have enough staff to manage the workload (Ulrich & Kear, 2015).

Primary Nursing. The findings in my study support the importance of Primary Nursing to promote patient-centred hemodialysis nursing care, which began in the

1970's as a model of "relationship-based practice" (Manthey, 2003, p. 369). This model would support patient-centred hemodialysis nursing care, but as my study noted, it is fully dependent on managerial support at the unit level because it does not function well when nurses are assigned in different care settings or on different shifts than their primary patients. Primary Nursing breakdowns were noted to occur if nurses are not assigned regularly to the same group of patients (Morse, 1991). In my study it was found that Primary Nursing promoted patient-centred hemodialysis nursing care in satellite units, especially in rural units, but not in hospital settings. Primary Nursing promoted patient-centred care because each patient had one hemodialysis nurse ensuring continuity of care on a broad scale such as monthly foot assessments and bloodwork reviews, and developed stronger relationships as they looked out for them over the long term. In some hospital units Nurse Practitioners now monitored some care and participants who had previously been Primary Nurses missed having that responsibility. No literature was found linking Primary Nursing and patient-centred care.

Satellite Units. At the healthcare system level, a notable finding from my study promoting patient-centred hemodialysis nursing care was the creation of satellite units. The satellite hemodialysis program in Ontario began in 1995 in response to a shortage of hemodialysis facilities and some patient treatment decisions being made based on the distance they lived from the closest unit (Blake et al., 2000; Prakash, 2006). The first satellites were placed between 1995 to 2002 in regions where there were already several patients receiving hemodialysis living, with the goals of reducing their travel time (Prakash, 2006), which is a patient-centred approach. In my study the satellite settings were influenced by factors such as unit size, patient acuity, exclusive staff, reduced

access, and skill mix. These differences helped answer the sub-question about differences and similarities across settings.

The smaller size of satellite hemodialysis units contributed to patient-centred care because the nurse-to-patient ratio was lower. Appropriate nurse staffing is essential in order to achieve optimal patient outcomes (De Kleijn et al., 2020), and research findings show that the level of RN staffing has a direct impact on patient outcomes in chronic hemodialysis units, with higher patient to nurse ratios resulting in necessary patient care tasks not being completed, leading to increased rates of intradialytic complications such as hypotension and treatment non-adherence through shortened or skipped treatments (Thomas-Hawkins et al., 2008).

In my study it was found that patient acuity was lower in satellite units because acutely ill patients, including those new to receiving hemodialysis, did not receive treatment there. Patients new to hemodialysis have higher acuity and require more nursing care time, especially the elderly and those with comorbidities, but may become more stable over time and participate in some of their own care such as applying pressure to their fistula after treatment, requiring less nursing time (De Kleijn et al., 2020). This occurred in my study when many patients began their treatments in the main hospital unit and then shifted to the satellite units, both urban and rural. Findings in my study indicated that patient problems in satellites at times could not be managed there and required patients to be transferred to the main hospital unit, with some returning if the problem resolved. In the literature this was termed a “fallback event” where the patient is transferred to the regional centre for problem management and dialysis on an outpatient or inpatient basis (Lindsay et al., 2009, p. 603). These events

were primarily due to vascular access problems or non-dialysis medical problems such as ischemic heart or lung disease and ended with the problem being resolved and the patient returning to the satellite (Lindsay et al., 2009). Findings from my study support those reasons and, in addition, transfers to the main hospital occurred when patients tested positive for COVID-19 when the satellite site could not provide hemodialysis in an isolation room. Thus fallbacks in my study referred to necessary “transfers” when the satellite sites were not equipped to provide more complex care and points to the necessity of support throughout the healthcare system for patient-centred hemodialysis nursing care to occur.

Skill Mix. Skill mix decisions are determined by individual units that are influenced by departmental and organizational strategic plans, which can affect nurse-unit and organizational interconnections. There can be subtle effects on patient-centred nursing care due to skill mix variations in hemodialysis units. One example in my study is that workloads were different and unpredictable if RPNs worked in the unit. Results from a three-year nursing project in 23 different settings across Ontario revealed measurable differences between the way that RNs and RPNs made decisions, with statistically significant differences found between perceptions of the two groups of the frequency that they made decisions and difficulty making them (Royle et al., 2000).

Hemodialysis nurses in recent Canadian research were repeatedly dissatisfied about care directives from the organization regarding patient behaviour, constraints on time to provide hemodialysis, and rigid patient scheduling which interfered with patient-centred care (Ortiz, 2022). The health, safety, and work environments of nephrology nurses vary widely, and threats to patient safety related to the work environment have

been described in some practice settings due to organizational culture, management practices, workforce deployment, and work design (Kear & Ulrich, 2018). Patient safety was mentioned directly and indirectly in findings of my study and was linked to promoting patient-centred hemodialysis nursing care.

COVID-19. At the organizational and system level, findings from my study indicated that patient-centred hemodialysis nursing care was negatively impacted by COVID-19 in a broad variety of ways regardless of setting, including confusing and poorly communicated changes affecting care delivery. Decisions were made by organizations based on guidance from the healthcare system and special pandemic management group. This interfered directly with the provision of patient-centred hemodialysis nursing care, such as specific mention of patient scheduling being changed to cohort patients who tested positive, with their usual routines tossed aside – as one participant stated, patient-centred care was forgotten. These decisions also created difficulties for patients, such as mobility challenges getting to the hemodialysis unit because the usual wheelchair-accessible door was taken out of service.

Findings from studies about the impact of the pandemic in hemodialysis care are beginning to be reported, such as Canadian research about the critical importance of nursing care in preventing or managing the higher incidence of acute kidney failure in patients with COVID-19, which could prevent complications in the short or long term (Fortin & Boucher, 2021). Research found a higher incidence of hemodialysis circuit clotting in patients with COVID-19, and acute kidney injury was found to be a “severe complication of COVID-19” (Batlle et al., 2020, p. 1380). Hemodialysis nurses would definitely play an important part when providing patient-centred treatment for a patient

experiencing acute kidney injury and would need to be particularly vigilant for complications during hemodialysis such as circuit clotting.

Other research found an adverse effect on patient hemodialysis and medical regimens during the pandemic, with a significant rise in the level of non-adherence primarily attributed to psychological distress (Sultan et al., 2022, p. 6). It was found that hemodialysis units in different countries took actions during the pandemic focussing on quality and safety for patients and professionals (Nigri & daSilva, 2022). Participants in my study mentioned various actions that differed depending on their setting, such as cohorting patients who tested positive in the urban settings but sending positively tested patients to the main hospital unit from the rural satellites. It was noted in recent literature that moral distress is heightened when nurses face unprecedented challenges such as COVID-19 (Smith et al., 2023). Findings from my study support this, such as the nurse who was troubled caring for a patient in isolation and struggled with prioritizing herself by donning PPE or prioritizing the patient by rushing into the room without it.

Ethical Considerations in Patient-Centred Hemodialysis Nursing Care

Although not a main focus of my study, ethics became a substantive consideration for discussion because participants shared experiences demonstrating ethical dilemmas in their daily patient-centred practice. Nephrology nursing literature has addressed ethical concerns over many years (Redman & Fry, 2000; Russ et al., 2005). The argument that patient-centred care is morally [ethically] valuable and desirable for quality patient care is justifiable based on different ethical theories (consequentialist, deontological, and virtue-based) (Duggan et al., 2006). Principlism is also applicable, particularly respect for autonomy (Beauchamp & Childress, 2001;

Lindridge, 2017). The principle of autonomy considers cultural and personal traditions, preferences, values, family situation and lifestyle of each patient (Sine & Sharpe, 2011), vital for patient-centred care. All healthcare departments, including clinical ethics, are responsible for promoting and practicing patient-centred care (Lukich & Honan, 2024).

Although most concerns expressed by participants in my study related to everyday patient decisions, they acknowledged some major decisions patients faced or were facing and were troubled by a lack of informed choice. Ethics provides a “springboard” for ensuring patients are active partners in decision-making, which promotes patient-centred care (Ekman, 2022, p. 1). Patient-centred care is critical for patients with advanced kidney disease partly due to the major decisions they must make about treatment, such as whether and when to start hemodialysis (O’Hare et al., 2018). A lack of patient-centred care is noticeable in a study that found only 10 percent of patients receiving hemodialysis thought they had actually made a choice about initiating treatment, feeling it was “imposed, involuntary, even inevitable” including by patients who had received pre-dialysis clinic care that was intended to promote informed choice (Russ et al., 2005, p. 303). In hemodialysis units “while older patients generally accept dialysis treatment, given the alternative of death, they do not choose it” (Russ et al., 2007, p. 2239). Sixty percent of patients with chronic kidney disease in a Canadian study regretted their decision to start dialysis (Davison, 2010).

Prior to dialysis initiation nephrologists are responsible for ensuring patients provide valid, informed consent, however an international study (Australia, Canada, United States, United Kingdom) reported that ethical and legal requirements were routinely ignored, noting “the suggestion that nephrologists may eliminate actual choice

is extraordinary” (Brennan et al., 2017, p. 1001). In my study there was a troubling lack of awareness about informed consent prior to initial hemodialysis and for ongoing treatments. Participants were aware of informed consent, however lacked depth in understanding the required processes and/or what specifically happened in their own units. This is surprising in view of the Ontario Renal Network 2018 initiative promoting advance care planning, goals of care, treatment decisions, and informed consent, and has implications for patient-centred hemodialysis nursing care. Hemodialysis nurses should all be well aware of the critical importance of informed consent whether or not their organization promotes patient centredness. After initial informed consent, presumed consent occurs each time patients arrive for treatment. Review should occur annually and any time the patient condition changes, as goals of care may change. Promoting and respecting informed consent is a core value of the Canadian Nurses Association Code of Ethics for Registered Nurses (2017).

Other concerns in findings of my study that provided numerous opportunities for patient-centred hemodialysis nursing care were the notable turning points that patients faced – participants collaborated with them to drive their own care. Patient choices may be limited if dialysis was their only available option, however, once hemodialysis begins, they face many critical turning points as they adjust to their chronic illness and treatment regimen (Gregory et al., 1998). Turning points may include multiple hospitalizations for vascular access problems such as a clotted fistula or central venous catheter infection, shortness of breath due to fluid overload, or complications of multiple chronic conditions (Clark-Cutaia et al., 2020). Canadian research found that over a 10 year period, vulnerable dialysis patients (80% hemodialysis) visited emergency departments eight

times more frequently than the general population that were matched by age and gender (Komenda et al., 2018).

These areas of concern lead to discussion of two topics interpreted from findings of my study: reconsidering patient non-adherence as decision-making, and the experience of moral distress in hemodialysis nurses.

Reconsidering Non-Adherence as Patient Decision-Making

The most notable ethical concern for nurses in my study was daily management of decisions by competent patients to shorten or skip their hemodialysis treatment, even after an appropriate informed consent process – in nephrology literature this is considered non-adherence. An earlier term for this was non-compliance (Quinan, 2007), which was generally interpreted in literature as patients lacking knowledge or understanding or having “irrational beliefs” in contrast to available scientific evidence (Russell et al., 2003, p. 282). Drawing from experience with patients in a renal transplant unit who self-adjusted their medications based on their personal assessment, Bissonnette (2008) noted the evolution of terminology from compliance to adherence and then to concordance. Bissonnette (2008) noted that since the 1970’s, nursing scholars had been advocating for a more holistic and collaborative approach to compliance, advocating for a move away from that concept due to its undertone of paternalism and patient blaming. Bissonnette (2008) argued that there is an implied power imbalance between patients and healthcare professionals with regard to adherence and that there is no definition of it with a patient-centred approach; she added that shifting to concordance may be difficult since healthcare professionals lack knowledge of that term. Concordance was defined as “the process of developing a

mutually agreed treatment plan”; compliance as “the act of following an instruction”, and adherence as “the process of **sticking with a course of treatment**” (Snowden & Marland, 2012, p. 1355, bold in original). Snowden and colleagues (2014) suggest that concordance aligns with a patient-centred approach to decision making however noted confusion and inconsistent application due to different conceptualizations in nursing, medicine, pharmacy, and psychiatry.

The World Health Organization has not defined concordance, but in a critical review defined adherence in chronic illness as: “the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (Sabate, 2003, p. 3). Adherence is influenced by many factors that are patient (and family perhaps), provider, or health system related, and patients are engaged, active partners in their own care (Bosworth, 2017; Sabate, 2003). This indicates that “nonadherence is not specifically or solely a ‘patient problem’” (Schwartz et al., 2017, p. 35). Adherence can be promoted through patient-centred collaboration that improves shared decision making (Bosworth et al., 2017). Due to the lack of clarity about whether concordance is patient-centred, the confusing inconsistent application of that term, and lack of use in nephrology literature, adherence is the most appropriate term for this dissertation. Adherence denotes behaviour and is the accurate term to use with patient-centred hemodialysis nursing care because it refers to patients actively sticking with their prescribed regimen.

There is a heavy burden of sticking with their regimen experienced uniquely by patients receiving hemodialysis treatments as they manage their daily lives. Chronic

dialysis has been described as “a site of prolonged out-patient life support” (Russ et al., 2005, p. 313) that is so burdensome patients may decide against it. Research from Australia about factors influencing patient choice of treatment for end-stage kidney disease found that they were willing to shorten their life expectancy with conservative care rather than initiating dialysis so they could maintain their freedom and quality of life, and age was not a significant factor when choosing (Morton et al., 2012). If they did choose to begin hemodialysis, they were willing to give up seven months of life to reduce their number of treatments per week from four to three, and 15 months of life to decrease their travel restrictions from “very” to “somewhat” (Morton et al., 2012, p. E281). Hemodialysis patients must redefine quality of life because their lives are changed so completely and drastically – dialysis makes living “possible” and becomes “part of their daily schedule”, and they need to feel that the challenges are worth it (Elliott et al., 2014, p. 1500). Research about valuing life and considering stopping hemodialysis found that:

Patients often do not understand, in beginning treatment, what they have assented to, the commitment it will entail, or that it will be for the rest of their lives. Indeed, many do not gather until well into therapy that they are, as the son of one patient put it, “on full life support” and that without dialysis, they will die (Russ et al., 2007, p. 2241).

Hemodialysis patients not adhering to their treatment regimen is a global concern (Saran et al., 2003). Adherence to all four elements is required: dietary restrictions, fluid restrictions, medication treatment and hemodialysis treatment. Non-adherence to any one element may result in significantly higher hospitalization, health costs, morbidity

and mortality rates, and decreased quality of life (Alikari et al., 2015; Denhaerynck et al., 2007; Ozen et al., 2019). Although results from studies vary widely, up to one-third of patients skip or shorten their treatments, skipping one treatment per month increases the risk of death by 30%, and three episodes of shortening one treatment more than ten minutes also increases mortality but no statistics are available (Denhaerynck et al., 2007). However, this is not what patients are concerned about – they are in the moment and may decide to skip treatment due to pain or depression (Balhara et al., 2020), or shorten their treatment because they are simply tired of sitting so long in a hemodialysis chair. This demonstrates how making decisions is dependent on “the conditions under which they are made” (Sandman et al., 2012, p. 119). Research has found that patients receiving hemodialysis are not even sure how or why they got there, and obsessively watch the clock to see how much time is left until treatment finishes, where the “last hour is the longest” (Russ et al., 2005, p. 309). Rigorous adherence to their treatment regimen is more critical for the survival of people receiving dialysis than for people with the majority of other chronic diseases (Emmett & McIntyre, 2017). These issues help understand the concern participants in my study had for patients shortening treatments.

Findings from my study provide the opportunity to re-consider non-adherence to the burdensome treatment regimen in a different way, as a matter related to individual decision-making through patient-centred hemodialysis nursing care. The findings support this different angle of considering non-adherence because they demonstrate care being centred on patients such as through shifts over time in hemodialysis patient care from being very tightly regimented to being more flexible and listening to patient voices about concerns such as catching their ride home. This different angle of

consideration is related to a marked discrepancy noted many years ago in academic literature in the interpretation of non-compliance by healthcare professionals and patients, and between patients who are chronically ill and those who are not, which presents the argument that non-compliance was actually an intentional strategy to manage chronic illness (Thorne, 1990). Findings from my study align with that, such as the description of how patients more seasoned with hemodialysis were “driving the bus” or being “the guide” because they knew what worked for them. This is important to consider because patients receiving hemodialysis have reported feeling as if they are hopelessly, monotonously imprisoned by the treatment that can never make them better and might even make them worse, wondering when their suffering would be enough so that death had been “earned” (Russ et al., 2005, p. 309).

Canadian research about perspectives of patients on hemodialysis found that being non-compliant was a chronic illness management strategy, resulting in “adversarial” relationships with healthcare professionals (Allen et al., 2011, p. 131). Three points of tension were reported: i) between whole person care and “assembly line” treatment by staff always in a hurry; ii) between patient knowledge that developed by “observation and experience over time” and medical expertise; and iii) between collaborative decision-making and struggling to access clinical information that felt like it needed to be dug out rather than shared (Allen et al., 2011, p.131-133). These points of tension do not reflect patient-centred hemodialysis nursing care and were findings from my study. Regarding i), the phrase “assembly line” and experiences of rushing were mentioned by participants. Regarding ii), a participant mentioned that patient-centred care has resulted in a shift from previous practice, and it is no longer “medical literature

alone speaking” because attention is now being given to patient knowledge. Regarding iii), participant and patient voices were not always welcomed in collaboration, which meant vital information may be missing.

Patients may be labelled as difficult and non-compliant when they do not follow the advice of healthcare professionals (Cerit et al., 2020; Russell et al, 2003). In a dated critique of nursing literature concerning non-compliance in healthcare it was noted that factors potentially influencing patient decisions had not been acknowledged, that a generic “patient-centred model ... does not go far enough”, and that nursing literature has failed to clearly recognize and direct any change (Russell et al., 2003, p. 285). Three articles in the reference list address compliance in hemodialysis but decision-making was not mentioned (Lundin, 1995; O’Brien, 1980; Sherman, 1996).

Findings from my study contrast with Russell and colleagues (2003) because participants accepted their role in helping prevent complications and through their patient-centred approach listened to patients, did not use language that labelled them as non-adherent, respected their self-knowledge and decision-making, and provided information. This may be due to changes and advancements in nursing, nephrology care, and patient-centred care over the past two decades. It may also be due to the shift from a compliance to adherence paradigm, where the former is paternalistic, and the latter supports patient autonomy and ability to decide because, when provided with accurate and relevant information, they can consider the value of results from a decision (Sandman et al., 2012). Hemodialysis patient care is complex, and nurses have a key role in preventing complications from non-adherence (Clark-Cutaia et al., 2020).

Knowing the patient is essential for decision-making (Radwin, 1995; Whittemore, 2000), and participants in my study described their experiences of knowing patients. They tried to collaborate with patients such as by having discussions on their behalf with interprofessional team members about providing some flexibility for treatments. Thorarinsdottir and Kristjansson (2014) found that patients want to be respected and recognised by healthcare professionals as equal human beings, and want to discuss their healthcare choices, the most important factor in decision-making. Participants in my study did respect patients and helped with their self-management by discussion and providing education, which at times required repetition. Education provided by hemodialysis nurses can improve patient adherence (Dsouza et al., 2023). Some root causes of non-adherence were apparent in my study such as patient difficulties with transportation to and from treatment. Limitations of current strategies in the literature that continue to blame and mis-label patients does not address their problems or concerns and results in obscuring potentially manageable root causes.

A study of shared decision-making in nursing found a discrepancy between their beliefs that they were partnering with patients and their practice of subtle persuasion of patient choices to promote adherence, raising concerns of paternalism (Upton et al., 2011). A later scoping review also noted a discrepancy because nurses reported positive relationships with patients, but partnering was minimal or missing (Metersky, 2020). This discrepancy may interfere with patient-centred hemodialysis nursing care, as demonstrated in my study when a participant was describing the patient navigator in their program. The navigator nurse was partnering with the patient to decide on a renal replacement modality but actually had a firm vision of where she wanted patients to go.

A broad variety of factors affect patient health decisions, including the social context of their lives. Patients may be disadvantaged due to medical or demographic issues (age, gender, ethnicity, cause of renal failure) beyond their control that should not be interpreted as non-adherence (Gordon et al., 2003). Awareness of these different ways of considering patient decisions to shorten or skip treatment were mentioned by participants in my study, which demonstrates patient-centred hemodialysis nursing care. Without listening to patients and acknowledging and respecting their decision-making, hemodialysis nurses would continue prior practices. Nursing research on compliance has supported encouraging patients to follow doctors' orders, making nurses complicit in not acknowledging the importance of patient knowledge (Russell et al., 2003).

Ethical Dilemmas and Moral Distress

Nursing research has found that maintaining ethical fitness in practice demonstrates how nurses uphold commitments to patients (Storch, 2013), which is fundamental for developing therapeutic relationships and providing patient-centred hemodialysis nursing care. In my study challenges related to patient decisions could create ethical concerns or dilemmas, such as when patients decided not to follow their prescribed treatment. Ethical dilemmas can lead to moral distress, which occurs when nurses are not able to "act according to their moral judgment", which can lead to them feeling angry, frustrated, guilty, and powerless, and result in deteriorating morale and teamwork, decreased quality of care, and patient safety challenges (Rodney, 2017, p. S7). Moral distress can interfere with patient-centred hemodialysis nursing care. Root causes of moral distress can be situational factors such as inadequate staffing, or clinical situations such as futile treatment, aggressive treatment not in a patient's best

interest, or inadequate informed consent (Hamric, 2012). Organizational constraints can contribute to the moral distress experienced by nurses (Austin, 2012).

Nephrology nursing research noted that experiencing ethical conflicts is not surprising (Redman & Fry, 2000). When maintenance hemodialysis emerged in the 1960's it created "an ethically ambiguous realm" where life was sustainable "indefinitely without curing underlying disease" (Russ et al., 2007, p. 2237). Witnessing patient decline and feeling helpless to prevent it or alter the health trajectory may cause moral distress for nurses (Hardill, 2019). Canadian research found that the source of moral distress for nephrology nurses came from knowing that "what is to come can be unsettling and arduous" because of the "familiar predicted disease progression for patients with CKD [chronic kidney disease]" (Wyld, 2017, p. 86). Other Canadian research about hemodialysis nursing care found moral distress threaded throughout, which caused disengagement that presents like burnout, reducing the quality and safety of patient care (Ortiz, 2022, p. 90), a potential detour for patient-centred hemodialysis nursing care.

The nature of the hemodialysis environment, long-term relationships with patients, disease progression, and frequent "near-death" situations are emotionally stressful work issues for hemodialysis nurses (Ashker, et al., 2012, p. 232). Moral distress is persistent in hemodialysis nursing care related to patient ambivalence, treatment reluctance, and decisions about renal replacement therapy (Axelsson et al., 2020; Fischer Gronlund et al., 2015; Hallock, 2014; Ortiz, 2021). Moral distress may also arise if hemodialysis nurses did not receive end-of-life education during orientation, and the intensity of maintaining tight treatment schedules allows no time for them to

grieve the loss of a patient before another one is scheduled for treatment (Lee & King, 2014). Sudden cardiac death is the highest cause of mortality in patients receiving hemodialysis (Makar & Pun, 2017). Participants in my study had these experiences.

Over time moral distress may lead to moral injury, a relatively new term in healthcare denoting a deeply emotional long-lasting wound that includes a loss of hope and trust (Cartolovni et al., 2021). A similar term is moral residue, the long-term deep effect of moral distress (Hardingham, 2004; Smith et al., 2023). These concepts overlap and clarity is required (Cartolovni et al., 2021).

Chapter Summary

In this chapter study findings were linked to the literature, joining the academic conversation. Some findings support or are supported by findings from other studies, and some are expanded on, refined, or understood more deeply (Thorne, 2016). New knowledge from my study includes that patient-centred hemodialysis nursing care is a complex process and involves many interconnections of people. Ethical discussion included reconsideration of non-adherence as patient decision-making. Participants did not mention their own decisions when providing care, leaving them unintentionally invisible without acknowledging their own strengths in making clinical judgments and their advanced, knowledge, skills, and expertise (Daneau et al., 2023). Additionally, discussion occurred related to moral distress in hemodialysis nursing, which was experienced by participants.

Patients with chronic diseases want healthcare professionals to “pick up on you as a person” and respect them as a unique individual (Thorne, 1990, p. 203), which is a good description of patient-centred hemodialysis nursing care. My study hopes to draw

attention to the importance of prioritising patient-centred nursing care for patients receiving hemodialysis, to promote the highest quality of care. Patient-centred care is recognized by the Ontario Excellent Care for All Act (King's Printer for Ontario, 2010).

In the next and final chapter, my study will be summarized, implications and recommendations will be provided, and strengths and limitations will be identified.

Chapter 6: Summary, Implications and Recommendations, Conclusion

Interpretive description is an approach designed to generate new awareness about a clinical issue that can be translated into applied practice (Thorne, 2016). Using this approach, the aim of my study was to explore the experiences of Ontario hemodialysis nurses in providing patient-centred care, which was achieved by interviews with 10 participants from three different settings: urban in-centre and satellite units, and rural satellite units. The findings resulted in five themes that provide information about knowing, applying, and sustaining patient-centred hemodialysis nursing care, factors that promote it, and others that create detours for nurses to navigate around. Findings were further interpreted in relation to available literature, with the overall interpretation that patient-centred hemodialysis nursing is a complex iterative process with interconnections and ethical factors. Hemodialysis nurses strive to maintain care that is patient centred but are often in the middle between patients and others, primarily nephrologists. Providing patient-centred care depends on the individual nurse, their engagement with promoters, and perseverance in navigating detours. Participants spoke of their provision of patient-centred hemodialysis nursing care and shared experiences when some colleagues did not engage with the approach.

My study is important for two main reasons, the first of which is to join the conversation about nursing care, adding knowledge about patient-centred care and hemodialysis nursing. The second reason is that the findings contribute to the gap about patient-centred hemodialysis nursing care from the perspectives of the people who provide it. Although there is some literature that uses the term patient-centred care, to date there remains none directly addressing this topic in hemodialysis nursing.

Implications and Recommendations

Findings from Canadian research about patients managing chronic kidney disease support “the pursuit of strategies to support patient-centred care”, which could improve patient safety and continuity of care (Ravenscroft, 2008, p. 156). Findings from my study have implications that give rise to strategic recommendations to support patient-centred hemodialysis nursing care through education, practice, policy, and potential future research.

Nursing Education

Due to the expectation by regulatory bodies such as the College of Nurses of Ontario, various levels of government, and individual employers that nurses should provide patient-centred nursing care, it must be taken seriously. Therefore, mandatory theoretical and practical education about patient-centred care should be incorporated into basic and advanced nursing programs and courses and provided in places of employment.

The early version of the nursing metaparadigm introduced in the mid-1970's was based on the essential units in conceptual models of nursing and seen as an ontological orientation that would affect the development of nursing knowledge, with four primary inter-related theoretical concepts: nursing, person, environment, and health (Bender, 2018). This metaparadigm is still being taught in some basic nursing education programmes and could be used as an introduction to the course about patient-centred care. A recent proposal was advanced to add the domain of technology to the metaparadigm to support patient-centred care because “machines are enmeshed in daily human life” (Johnson & Carrington, 2023, p. 1).

Nursing education should also address the lack of clarity in conceptualizing and applying reflective practice (Kinsella, 2009), which was found in my study to be a promoter of patient-centred hemodialysis nursing care. Ensuring that nurses are knowledgeable about patient-centred care as well as skilled in its application could occur for example through combined theoretical education, role playing exercises, written assignments that incorporate clinical placement experiences, and discussion. There is also a shift and call for nursing curriculums to move beyond the individual and also look at posthumanism (Adam et al., 2021) – although patient-centred care aligns more with humanism, there could be new understandings.

As noted in the discussion section of ‘Knowing’ in the prior chapter, although there have been numerous definitions of patient-centred care developed through nursing research, there is no guidance on how to operationalize the process of knowing, applying, and sustaining it. This could begin by incorporating the topic into basic nursing education and workplace orientation sessions, to provide theoretical understanding of the approach before applying it in clinical practice. Applying and sustaining would vary between organizations and requires engagement from boardroom to bedside, with opportunities to continue learning and collaborating to ensure the approach flourishes. Further research and development is required before these steps might happen.

Findings from my study note a link between patient-centred care and patient safety, which is another topic that should be part of basic nursing education. This could be done by educators incorporating the Patient-Centred Safety Model as part of personalizing patient care – patient safety and patient-centred care are described as being in a “mutually synergistic relationship” (St. Onge & Parnell, 2015, p. 41). The

combination of the two would compound the individual benefits of each for promoting the highest quality of patient care. An example of promoting education about interprofessional patient-centred care is a graduate level course designed by a collaborative team that involved a community partner and professional nursing and social work perspectives and explored “advanced therapeutic communication (ATC)” (Schwind et al., 2016, p. 592). Regarding paternalistic language, nurses require education about maintaining the “thin line” between paternalism and advocacy which may occur when patients have difficulty communicating (Zomorodi & Foley, 2009, p. 1748). Nursing curriculum should acknowledge the history of paternalistic behaviour and language so steps can be taken to prevent it.

Specific to nephrology, findings from Canadian research identified “several areas for improvement relating to nursing education and practice in the HD [hemodialysis] clinical setting” (Ortiz, 2022, p. 83). Nursing schools provide education about basic nephrology topics such as anatomy, physiology, and renal failure, but no in-depth education about how to provide hemodialysis treatments. Advanced education for nephrology nursing care is provided in Ontario at the college level through post-graduate certification programs for RNs and RPNs, for example the certificate program at Humber College (2023), which is based on the nephrology nursing competencies of the Canadian Nurses Association (CNA, 2014) and includes five compulsory courses plus a 96-hour practicum. The program overview notes that nurses will learn how to develop collaborative and consultative partnerships, which aligns with the philosophy of patient-centred care.

Nurses require education in undergraduate and post-graduate courses, as well as in their workplaces about how to provide hemodialysis care that is patient centred, including how to help patients cope with the dramatic changes in their lives. Patients may have “profound confusion” about how they ended up on hemodialysis, which may have been presented to them as the only choice they could make because the alternative is death (Russ et al., 2005, p. 4). Hemodialysis nurses also must have education about the importance and involvement of family members/caregivers. They may be very supportive or find the strict treatment and self-management regimen that the patient must adhere to very stressful and disruptive to their relationships and households (Sousa et al., 2022). It is unknown if and how nurses are educated to address these issues and their consequences.

Nursing Practice

Findings from my study have implications for frontline nursing practice as well as for nurses in leadership positions that can be transferred into practice through “knowledge-to-action” processes (Graham et al., 2006, p. 14). Sustainable practice changes require many phases that include understanding factors specific to individual care providers, practice settings, and organizations (Castiglione & Ritchie, 2012). Four topics with nursing practice implications include respecting patient expertise, point of care, skill mix, and moral distress.

Respecting Patient Expertise. There is a shared boundary between patients and healthcare providers, and research has found that patients can participate in their own care at “different stages” (Edwards, 2002, p. 342). This could apply to hemodialysis

nursing practice as they provide care along the downward health trajectory by inviting patient participation in their care; for it to be patient-centred their role should be more than an “honorary” healthcare team member (Edwards, 2002, p. 347). However, patient perceptions of patient-centred care have been found to be lower when compared to healthcare professionals, possibly due to various methodological, clinical and/or contextual factors (Sidani et al., 2016).

Patients, supported by family members if appropriate, should be the hub that supports the spokes, in the centre of care. Literature is expanding about engaging patients as active partners in their care, which would support patient-centred hemodialysis nursing care, such as the Canadian work of Pomey and colleagues (2021) and Metersky and colleagues (2022). Literature regarding specific interventions to change nursing practices is very limited, however patient partners were recommended in the provision of education for healthcare professionals to promote patient-centred care (Metersky et al., 2023). This is important in hemodialysis because each patient experience is uniquely different, but their hemodialysis treatments may be similar.

Experiences and expertise of patients, especially related to chronic conditions, promoted patient-centredness and were found to add diversity and value when co-designing three new primary care clinics that would connect patients to community services (Hertel et al., 2019). Patient-centred care is enabled by knowing what patients and family members consider important in healthcare experiences based on their values, beliefs, concerns, and needs (Pratt et al., 2021). Patient-healthcare professional interconnections could be measured through use of a tool developed in Canada through collaboration between healthcare professionals, patients, and researchers (Pomey et

al., 2021). Dimensions of this tool include confidence, autonomy, decision-making, sharing information, personal context, empathy, and expertise; it was found to be useful in different urban and rural clinical settings (Pomey et al., 2021).

Point of Care. Practical implications at the point of care include ensuring that nurses have appropriate support and resources to allow them to gain knowledge about and be able to apply and sustain patient-centred hemodialysis nursing care. This requires having safe staffing levels with the appropriate skill mix and sufficient support staff. Additionally, hemodialysis nurses need their own support for the “emotional and mental encumbrances in care provision”, a finding that “has been repeatedly noted in literature for some time” (Ortiz, 2022, p. 83). Specific resources to support the emotional and mental well-being of hemodialysis nurses may include workplace debriefing sessions on the unit when there is a patient death, especially following a code blue incident, which could be provided by a representative from the clinical ethics department (Lukich & Honan, 2024). If ethics support is unavailable, support could be provided by a unit nursing leader such as the manager or educator. Organizations may also provide support through an off-site confidential Employee Assistance Program, such as the one available through Occupational Health and Safety at Health Canada (2023).

Skill Mix. At the system layer of regulatory requirements, skill mix was guided by the practice guideline that detailed the Three Factor Framework, which was replaced effective July 1, 2023, along with one other practice guideline and one standard, by a new Scope of Practice Standard (College of Nurses of Ontario, 2023b). There are links between patient-centred hemodialysis nursing care and professional accountability to

follow Practice Standards and Guidelines such as the College of Nurses of Ontario Therapeutic Nurse-Client Relationship (2019). There are also the national Nursing Standards of Practice of CANNT, which states that “patient-centred care is integrated throughout” (CANNT, 2021, p.5). There is little literature to contribute to meaningful discussion, which points to an opportunity for future research, for example examining how regulatory and specialty Practice Standards support and promote patient-centred hemodialysis nursing care.

Moral Distress. Moral distress can result in serious outcomes for nurses, including burnout causing them to leave the profession (Austin et al., 2005). Canadian nursing research found that moral distress may compromise patient care, and when the ethical climate in a hospital was perceived as being more positive, the experience of moral distress in nurses was “less intense” (Pauly et al., 2009, p. 568). Consequences when healthcare professionals experience moral distress range from feeling angry and frustrated, withdrawing from care, and reduced job satisfaction and nursing retention (Pauly et al., 2012). Coping strategies to manage moral distress include listening to patient concerns then reflecting and responding, “in a prepared state of mind”, seeking support from colleagues within a healthy team environment, having personal interests outside of work, and possibly working part time (Wyld, 2017, p. 99). The poem in Appendix G is an example of how this author coped with strong feelings after an experience 20 years ago involving intraprofessional conflict that affected care of a patient, which was later learned to be moral distress. The student nurse present at the time had learned what ‘un-patient-focussed’ care was from her preceptor, who made her crush a pill that is not supposed to be crushed and administer it orally to a sleeping

patient who was on 'choking precautions'. It happened long ago and my experience witnessing it during the provision of hemodialysis treatment brings back memories with each reading of how troubling it was – this is an example of moral residue or injury. Ethical problems in nursing care can be experienced as a moral dilemma, uncertainty, distress, or residue, and efforts must be made to support nurses in their work environments (Hardingham, 2004).

Policy

Findings from my study illuminate opportunities to improve policy at the organizational and system levels. At the organizational level, policies guiding patient-centred care within individual hospitals and units need to align with nursing values and actions, and not simply be bureaucratic aspirational literature and policies as noted by Judge (2023). Hemodialysis nurses must be involved in the development and implementation of all policies that affect the care they provide, including patient-centred nursing practice. This may be difficult to advocate for and ensure it occurs within the current healthcare system that is very troubled and in the press frequently, particularly critical nursing shortages (CNA, 2024).

At the system level, there is a glaring gap regarding patient-centred care in the Ontario Renal Network (ORN), which is responsible for directing nephrology care across the province. The ORN is not a stand-alone program but a division of Cancer Care Ontario (CCO) with a tab on the CCO website. Cancer care is decidedly different than nephrology care and specifically hemodialysis. The ORN (n.d., a) has adopted person-centred care from the CCO rather than developing a patient-centred approach for renal patients – there are subtle but important differences between 'patient' and 'person'

centredness (Pilnick, 2023). CCO adapted a person-centred care guideline from the United Kingdom (Bidy et al., 2015). A video promoting this guideline has been viewed by thousands of people in 92 countries (Moody et al., 2018). There is no mention of this on the ORN webpage, no participant mentioned it, and there is no evidence it has been utilized to promote patient-centred care in nephrology. On the ORN webpage there are no tools, articles, or links to anything that would support patient-centred hemodialysis nursing care. There are tools developed by two hospitals in Ontario – a treatment options grid, and a patient decision aid, which do not indicate that they are endorsed by the ORN (n.d., b). These tools may be utilized by nephrology nurses in a kidney care clinic setting to help educate patients about modality but are not useful to those in other roles. There are nine videos of patient and family experiences to assist patients but no videos to help healthcare professionals – one for shared decision making is unavailable.

After a decade in existence, the ORN has presented its third Renal Plan for 2019 to 2023, and one strategic goal is to be person-centred – it states this model of care relies on effective, compassionate communication between patients, caregivers, and healthcare professionals, but there is no model (CCO and ORN, n.d.). A link takes the reader to a 52-page review of advancing person-centred care in Ontario from CCO which has a few pages about ORN, but no model (CCO, 2017). There is nothing to support patient-centred hemodialysis care – how can nurses be expected to know, apply, and sustain a non-existent model of care? This gap does not support nephrology nurses, or any other healthcare professionals, in the provision of patient-centred care that would benefit patients and staff.

The ORN can provide more robust support for patient-centred care, such as that of the BC Renal network which has numerous online links including a patient goal-setting strategy. Patient-centred nephrology care in BC was highlighted during the province-wide Patient Experience Week April 23 – 29, 2023 involving patients, families, communities, nurses, physicians, support staff and administrative professionals (Provincial Health Services Authority, 2023). Another idea of patients as partners was promoted during Kidney Days, which aimed to answer the question: what is true patient-centred care? (BC Transplant and BC Renal Agency, 2012). The University of Alberta leads an initiative with the goal of living well with chronic kidney disease that supports patient-centred care through language based on providing the right care, to the right patient, at the right time (Kidney Supportive Care Research Group, n.d.). Patients receiving hemodialysis are on a downward trajectory, which may change how involved they are in their care, demonstrating a need for flexibility as demonstrated in my study.

Nurses are in a contradictory situation where they must provide care however may have minimal involvement in decisions surrounding hospital policy development and implementation, which are influenced by federal, provincial, and professional regulations – research findings indicate that they “aren’t asked” to participate (Bartmess et al., 2022, p. 24). Nursing should not be left out of planning opportunities affecting their profession and patient care but are often not invited to participate at organizational levels and higher. As an example, a multi-sector advisory committee of the Ontario Hospital and Medical Associations created a rural health hub framework to support a person-centred approach to local services, but nursing was not represented (Ontario Hospital Association, 2015).

Future Research

The phrase 'nothing about me without me' quoted in my study has also been used to promote the idea of including patients as partners in clinical research, in contrast to prior research that was performed on them as study subjects (Puckrein, 2016). It would be beneficial to gain knowledge about patient perspectives of patient-centred hemodialysis nursing care. Hemodialysis is a specified treatment, but every patient has a different experience – understanding these could significantly advance the practice of patient-centred hemodialysis nursing care. The provision of patient-centred care has not been studied comprehensively (Mathe, 2023), and there is a dearth of research about nephrology nursing and patient-centred hemodialysis nursing care, providing unlimited opportunities for future research. Findings from my study illuminate several topics of interest for potential future research such as patient-centred hemodialysis nursing care as it relates to nursing expertise and patient safety; nurse dose in relation to providing patient-centred hemodialysis nursing care; intra- and interprofessional collaboration in patient-centred hemodialysis nursing care; patient-centred nursing care in other nephrology settings such as peritoneal dialysis, home dialysis, and transplantation; and whether hemodialysis nurses separate 'centring' from their regular care. It would also be interesting to explore if and how regulatory and specialty Practice Standards support and promote patient-centred hemodialysis nursing care, and the effects of Primary Nursing.

There is potential for promising research opportunities regarding patient-centred care through the federal initiative Strategy for Patient-Oriented Research (SPOR) funded by the Canadian Institutes of Health Research (Government of Canada, 2023).

The aim is to engage patients, their caregivers, and families as partners in the research process, which could involve patients receiving hemodialysis.

Knowledge Dissemination

Knowledge from my study will be disseminated primarily in two ways. The first opportunity occurred through presentation of preliminary findings and analysis at the annual CANNT conference in October 2023, which generated welcomed supportive feedback from hemodialysis nurses across Canada about their experiences providing patient-centred care. They can be considered as “thoughtful practitioner[s]” with the potential to fortify the data (Thorne, 2016, p. 92, italics in original). Future abstracts will be submitted on topics such as reconsidering non-adherence as patient decision making. The second manner of dissemination is that a selection of topics from this dissertation will be used to prepare manuscripts for future publication in professional nursing journals, primarily in nephrology nursing such as those of CANNT, the preferred primary publication venue, and the American Nephrology Nurses Association. Both journals have specific length guidelines therefore the dissertation content would be divided into separate manuscripts. The initial topic submitted to CANNT could be a general overview of the process of patient-centred hemodialysis nursing care. This could be followed by a manuscript presenting promoters and detours of patient-centred hemodialysis nursing care, and then another presenting ethical considerations.

Strengths and Limitations

The main strength of my research is that it is the first to directly address patient-centred hemodialysis nursing care. An added strength is that this was accomplished

through an interpretive description approach grounded firmly in nursing – the researcher and participants were all hemodialysis nurses. Another strength is that the participants came from varied educational and experiential backgrounds and worked in different clinical settings (urban/rural, in-centre hospital/satellite) providing different angles for viewing and interpreting patient-centred hemodialysis nursing care across Ontario. Additionally, participant expertise was highly specific – they shared experiences not previously described, which provided information power (Malterud et al., 2016).

There are benefits when a researcher is a clinician because they are “better placed to interpret the findings because of an understanding of the context within which the participants worked” (Schluter et al., 2011, p. 1213). My background in urban in-centre and satellite hemodialysis units helped me understand the contexts where participants provided care, allowed me to ask more in-depth questions, and build rapport with participants.

One limitation of my study is that all participants were Registered Nurses (RNs), therefore it is unknown if there may have been different findings with Registered Practical Nurses (RPNs) working in hemodialysis units. Another limitation may be that all participants were from Ontario, and perhaps hemodialysis nurses in other provinces have different experiences providing patient-centred care. However, readers may find connections between some study findings and their own experiences. These limitations could guide subsequent studies in this field, such as by examining RPN descriptions of patient-centred hemodialysis nursing care and pursuing studies in other provinces.

Conclusion

A powerful statement from Thorne and Stajduhar (2017, p. 24) quoted in Chapter Two is worth repeating as this dissertation is being concluded. Patient-centred care:

... is so fundamental to nursing's theoretical, ethical, and philosophical core that arguably it constitutes the central idea from which nursing has distinguished itself from all other healthcare professions over time

In full agreement and support of that statement, my study aims to contribute to existing and evolving knowledge about nephrology nursing and patient-centred hemodialysis nursing care. This will hopefully benefit education, practice, policy, and future research.

It was recently stated: "Living is what we do minute to minute, memories are what we get to keep" (Kahneman, 2023). It is hoped that many wonderful memories are being created and kept by patients from every healthcare experience they have of receiving patient-centred hemodialysis nursing care.

References

- Aasen, E., Kvangarsnes, M., & Heggen, K. (2012). Nurses' perceptions of patient participation in hemodialysis treatment. *Nursing Ethics, 19*(3) 419-430. <https://doi.org/10.1177/0969733011429015>
- Abbatichio, A., Theodorlis, M., Marshall, D., MacKay, C., Borkhoff, C., Hazlewood, G., Battistella, M., Lofters, A., Ahluwalia, V., & Gagliardi, A. (2024). Policies in Canada fail to address disparities in access to person-centred osteoarthritis care: a content analysis. *BMC Health Services Research, 24*(1), 522. <https://doi.org/10.1186/s12913-024-10966-5>
- Abdellah, F., Martin, A., Beland, I., & Matheney, R. (1960). *Patient-centered Approaches to Nursing*. The Macmillan Company.
- Accreditation Canada (2018). Five benefits of patient surveyors. <https://accreditation.ca/news/5-benefits-patient-surveyors/>
- Adam, S., Juergensen, L., & Mallette, C. (2021). Harnessing the power to bridge different worlds: An introduction to posthumanism as a philosophical perspective for the discipline. *Nursing Philosophy, 22*(3), e12362. <https://doi.org/10.1111/nup.12362>
- Ahmed, W. (2019). Measuring Ontario's urban-rural divide. Policy paper for Ontario 360. <https://on360.ca/policy-papers/measuring-ontarios-urban-rural-divide/>
- Al-Arabi, S. (2006). Quality of life: Subjective descriptions of challenges to patients with end stage renal disease. *Nephrology Nursing Journal, 33*(3), 285-293.
- Alexander, S. (1962). They decide who lives, who dies. *Life, 53*(19), 102-125.

- Alikari, V., Matziou, V., Tsironi, M., Theofilou, P., & Zyga, S. (2015). The effect of nursing counseling on improving knowledge, adherence to treatment and quality of life of patients undergoing hemodialysis. *International Journal of Caring Sciences*, 8(2), 514-518.
- Allen, D., Wainwright, M., & Hutchinson, T. (2011). 'Non-compliance' as illness management: Hemodialysis patients' descriptions of adversarial patient clinician interactions. *Social Science & Medicine*, 73(1), 129-134.
<https://doi.org/10.1016/j.socscimed.2011.05.018>
- Allen, D., Griffiths, L., & Lyne, P. (2004). Understanding complex trajectories in health and social care provision. *Sociology of Health & Illness*, 26(7), 1008–1030.
<https://doi.org/10.1111/j.0141-9889.2004.00426.x>
- Allen, D. (2015). 'Organizing Work': Nurses invisible contribution to healthcare quality and safety. Inaugural Florence Nightingale Foundation Lecture, Manchester, UK.
https://www.youtube.com/watch?v=hFpYdGCi_Cl.
- Almost, J., Mildon, B. (2022). R-E-S-P-E-C-T: A key to nurse retention. *Nursing Leadership*, 35(2), 12-28. <https://doi.org/10.12927/cjnl.2022.26876>
- Al-Nashri, F., & Almutary, H. (2022). Impact of anxiety and depression on the quality of life of haemodialysis patients. *Journal of Clinical Nursing*, 31(1–2), 220-230.
<https://doi.org/10.1111/jocn.15900>
- American Psychological Association (2020). *Publication manual of the American Psychological Association*, (7th ed.). Author.

- Andersen-Hollekim, T., Solbjør, M., Kvangarsnes, M., Hole, T., & Landstad, B. (2020). Narratives of patient participation in haemodialysis. *Journal of Clinical Nursing*, 29(13/14), 2293-2305. <http://doi:101111/jocn.15238>
- Argyris, C. (1991). Teaching smart people how to learn. *Harvard Business Review* (May–June 1991) <https://hbr.org/1991/05/teaching-smart-people-how-to-learn>
- Argyris, C. (2005). Double loop learning in organizations: a theory of action perspective. In: K. Smith, M. Hitt, (Eds.) *Great minds in management: the process of theory development*, pp. 261-279.
- Arikan, F., Köksal, C., & Gökçe, Ç. (2007). Work-related stress, burnout, and job satisfaction of dialysis nurses in association with perceived relations with professional contacts. *Dialysis & Transplantation*, 36(4), 182-191.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19-32.
- Ashker, V., Penprase, B., & Salman, A. (2012). Work-related emotional stressors and coping strategies that affect the well-being of nurses working in hemodialysis units. *Nephrology Nursing Journal*, 39(3), 231-236.
- Aswanden, C. (2003). Discovering the culture of haemodialysis units: an ethnography. *EDTNA/ERCA Journal*, 29(4), 192-194.
- Austin, W., Lemermeyer, G., Goldberg, L., Bergum, V., & Johnson, M. S. (2005). Moral distress in healthcare practice: The situation of nurses. *HEC Forum*, 17(1), 33-48. <https://doi.org/10.1007/s10730-005-4949-1>

- Austin, W. (2012). Moral distress and the contemporary plight of health professionals. *HEC Forum*, 24(1), 27-38. <https://doi.org/10.1007/s10730-012-9179-8>.
- Axelsson, L., Benzein, E., Lindberg, J., & Persson, C. (2020). Processes toward the end of life and dialysis withdrawal: Physicians' and nurses' perspectives. *Nursing Ethics*, 27(2), 419-432. <https://doi.org/10.1177/0969733019848050>
- Azzam, M., Girard, M., Andrews, C., Bilinski, H., Connelly, D., Gilbert, J., Newton, C., & Grymonpre, R. (2022). Accreditation as a driver of interprofessional education: The Canadian experience. *Human Resources for Health*, 20(1), 65. <https://doi.org/10.1186/s12960-022-00759-4>
- Balhara, K. S., Fisher, L., El Hage, N., Ramos, R. G., & Jaar, B. G. (2020). Social determinants of health associated with hemodialysis non-adherence and emergency department utilization: A pilot observational study. *BMC Nephrology*, 21(1), 4. <https://doi.org/10.1186/s12882-019-1673-7>
- Balint, E. (1969). The possibilities of patient-centered medicine. *Journal of the Royal College of General Practitioners*, 17, 269-276.
- Baragar, B., Schick-Makaroff, K., Manns, B., Love, S., Donald, M., Santana, M., Corradetti, B., Finlay, J., Johnson, J., Walsh, M., & Elliott, M. (2023). "You need a team": Perspectives on interdisciplinary symptom management using patient-reported outcome measures in hemodialysis care—a qualitative study. *Journal of Patient-Reported Outcomes*, 7(3). <https://doi.org/10.1186/s41687-022-00538-8>
- Bartmess, M., Myers, C. & Thomas, S. (2022). Original research: 'It would be nice to think we could have a voice': Exploring RN involvement in hospital staffing

- polycymaking. *American Journal of Nursing*, 122(10), 22-31. <https://doi.org/10.1097/01.NAJ.0000884564.75005.a9>.
- Battle, D., Soler, M., Sparks, M., Hiremath, S., South, A., Welling, P., & Swaminathan, S. (2020). COVID-19 and ACE2 in Cardiovascular, Lung, and Kidney Working Group. Acute kidney injury in COVID-19: Emerging evidence of a distinct pathophysiology. *Journal of the American Society of Nephrology*, 31(7):1380-1383. <https://doi.org/10.1681/ASN.2020040419>
- Bauer, M., Fetherstonhaugh, D., Blackberry, I., Farmer, J., & Wilding, C. (2019). Identifying support needs to improve rural dementia and their carers: A consultation study in Victoria, Australia. *Australian Journal of Rural Health*, 27, 22-27. <https://doi.org/10.1111/ajr.12444>
- BC Ministry of Health (2011). Patients as partners: Nothing about me without me. First annual report. <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/primary-health-care/patients-as-partners-annual-report-2011.pdf>
- BC Transplant and the BC Renal Agency (2012). Walk a mile in their shoes: What is true patient-centered care? <http://www.bcrenal.ca/resource-gallery/Documents/Davis-Delivering-Patient-CenteredCare-bckd-2012.pdf>
- Bear, R., & Stockie, S. (2014). Patient engagement and patient-centred care in the management of advanced chronic kidney disease and chronic kidney failure. *Canadian Journal of Kidney Health and Disease*, 1(24). <http://www.cjkhd.org/content/1/1/24>.
- Beauchamp, T. & Childress, J. (2001) Principles of Biomedical Ethics: Fifth Edition. Oxford University Press.

- Bender, M. (2018). Re--conceptualizing the nursing metaparadigm: Articulating the philosophical ontology of the nursing discipline that orients inquiry and practice. *Nursing Inquiry*, 25(3), <https://escholarship.org/uc/item/7tb3224c>
- Bennett, P. (2011) Satellite dialysis nursing: Technology, caring and power. *Journal of Advanced Nursing*, 67(1), 149-157. <http://doi:10.1111/j.1365-2648.2010.05474.x>
- Bevan, M. (1998). Nursing in the dialysis unit: Technological enframing and a declining art, or an imperative for caring. *Journal of Advanced Nursing*, 27(4), 730-736. <https://doi.org/10.1046/j.1365-2648.1998.00603.x>
- Bevan, M. (2007). Experiencing dialysis: A descriptive phenomenological study of nurses and patients in dialysis satellite units. [Doctoral thesis]. University of Huddersfield. <http://eprints.hud.ac.uk/id/eprint/963/>
- Biddy, R., Griffin, C., Johnson, N., Larocque, G., Messersmith, H., Moody, L., Shamji, H., Stevens, C., Zwaal, C., Singh, S., and the Person-Centred Care Guideline Expert Panel (2015). *Person-Centred Care Guideline*. <https://www.cancercareontario.ca/en/content/person-centred-care-guideline>
- Bilodeau, K., Dubois, S., & Pepin, J. (2015). Interprofessional patient-centred practice in oncology teams: Utopia or reality? *Journal of Interprofessional Care*, 29(2), 106-12. <https://doi.org/10.3109/13561820.2014.942838>
- Bilodeau, K., & Tremblay, D. (2019). How oncology teams can be patient-centred? Opportunities for theoretical improvement through an empirical examination. *Health Expectations*, 22(2), 235-244. <https://doi.org/10.1111/hex.12847>
- Bissonnette, J. (2008). Adherence: A concept analysis. *Journal of Advanced Nursing*, 63(6), 634–643. <https://doi.org/10.1111/j.1365-2648.2008.04745.x>

- Blake, P., Mendelssohn, D., & Toffelmire, E. (2000). New developments in hemodialysis delivery in Ontario, 1995-2000. *Nephrology News Issues*, 14(11):72-4, 76, 79-80.
- Bolg, J., Dwyer, P., Doherty, D., Pignataro, S., & Renaud, A. (2020). The impact of critical reflective inquiry education on experienced nurses' insights into practice. *Journal for Nurses in Professional Development*, 36(2), 68–73.
<https://doi.org/10.1097/nnd.0000000000000606>
- Bonner, A. (2006). Uncovering the evidence of non-expert nephrology nursing practice. *International Journal of Nursing Practice*, 12(2), 51-56.
<https://doi.org/10.1111/j.1440-172x.2006.00550.x>
- Bonner, A., & Greenwood, J. (2006). The acquisition and exercise of nephrology nursing expertise: A grounded theory study. *Journal of Clinical Nursing*, 15(4), 480-489. <https://doi.org/10.1111/j.1365-2702.2006.01361.x>
- Bosworth, H., Fortmann, S., Kuntz, J., Zullig, L., Mendys, P., Safford, M., Phansalkar, S., Wang, T., & Rumptz, M. (2017). Recommendations for providers on person-centered approaches to assess and improve medication adherence. *Journal of General Internal Medicine*, 32(1), 93–100. <https://doi.org/10.1007/s11606-016-3851-7>
- Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Brennan, F., Stewart, C., Burgess, H., Davison, S., Moss, A., Murtagh, F., Germain, M., Tranter, S., & Brown, M. (2017). Time to improve informed consent for dialysis: An international perspective. *Clinical Journal of the American Society of Nephrology*, 12(6), 1001-1009. <https://doi:10.2215/CJN.09740916>

- Britten, N., Moore, L., Lydahl, D., Naldemirci, O., Elam, M., & Wolf, A. (2016). Elaboration of the Gothenburg model of person-centred care. *Health Expectations*, 20(3),407-418. <https://doi.org/10.1111/hex.12468>
- Byrne, A., Baldwin, A., & Harvey, C. (2020). Whose centre is it anyway? Defining person-centred care in nursing: An integrative review. *PLoS ONE*, 15(3), e0229923. <https://doi.org/10.1371/journal.pone.0229923>
- Byrne, A., Harvey, C., & Baldwin, A. (2021). Nurse navigators and person-centred care; Delivered but not valued? *Nursing Inquiry*, 28(1). <https://doi.org/10.1111/nin.12402>
- Calopedos, R., Bang, A., Baade, P., Yu, X., Ruthven, S., Patel, M., & Smith, D. (2019). Patterns of prostate-specific antigen testing by remoteness of residence and socio-economic status: An Australian population-based study. *Australian Journal of Rural Health*, 27(3), 216-223. <https://doi.org/10.1111/ajr.12504>
- Canadian Association of Nephrology Nurses and Technologists (2021). *Nephrology Nursing Standards and Practice Recommendations*. <https://cannt-acitn.ca/standards-of-practice/>
- Canadian Institute for Health Information (CIHI) (2024). Dialysis Centres in Ontario, 2022. Canadian Organ Replacement Register Directory-Dialysis Centres in Canada. [corr-edirectory-for-participating-centres-dialysis-en.xlsx \(live.com\)](https://www.cihi.ca/en/corr-edirectory-for-participating-centres-dialysis-en.xlsx)
- Canadian Institute for Health Information (CIHI) (2023). Annual Statistics on Organ Replacement in Canada: 2012 to 2021. <https://www.cihi.ca/en/annual-statistics-on-organ-replacement-in-canada-2012-to-2021>

Canadian Institutes of Health Research (2011). Canada's Strategy for Patient-Oriented Research. https://cihr-irsc.gc.ca/e/documents/P-O_Research_Strategy-eng.pdf

Canadian Interprofessional Health Collaborative (2010). A national interprofessional competency framework.

https://drive.google.com/file/d/1Des_mznc7Rr8stsEhHxl8XMjgiYWzRIn/view

Canadian Nurses Association (2014). Exam blueprint and specialty competencies:

Nephrology Nursing Certification. [https://hl-prod-ca-oc-download.s3-ca-central-](https://hl-prod-ca-oc-download.s3-ca-central-1.amazonaws.com/CNA/2f975e7e-4a40-45ca-863c-)

[5ebf0a138d5e/UploadedImages/documents/nephro_blueprint_2014_e.pdf](https://hl-prod-ca-oc-download.s3-ca-central-1.amazonaws.com/CNA/2f975e7e-4a40-45ca-863c-5ebf0a138d5e/UploadedImages/documents/nephro_blueprint_2014_e.pdf)

Canadian Nurses Association (2017). Code of Ethics for Registered Nurses.

<https://cdn1.nscn.ca/sites/default/files/documents/resources/code-of-ethics-for-registered-nurses.pdf>

Canadian Nurses Association (2020). Intra-professional collaboration. Position

Statement. <https://www.cna-aiic.ca/en/policy-advocacy/policy-support-tools/position-statements>

Canadian Nurses Association (2022). Nursing Statistics. <https://www.cna->

[aiic.ca/en/nursing/regulated-nursing-in-canada/nursing-statistics](https://www.cna-aiic.ca/en/nursing/regulated-nursing-in-canada/nursing-statistics)

Canadian Nurses Association (2024). CNA News Room: Latest health workforce data

confirms CNA's predictions of critical nursing shortages. <https://www.cna->

[aiic.ca/en/blogs/cn-content/2024/02/29/latest-health-workforce-data-confirms-cnas](https://www.cna-aiic.ca/en/blogs/cn-content/2024/02/29/latest-health-workforce-data-confirms-cnas)

- Canadian Nurses Association and Canadian Medical Association (2011). Principles to guide healthcare transformation in Canada. https://www.cna-aiic.ca/~media/cna/files/en/guiding_principles_hc_e.pdf
- Cancer Care Ontario (CCO) and Ontario Renal Network (ORN) (n.d.). Ontario Renal Plan 3. <https://www.ontariorenalnetwork.ca/en/renalplan>
- Cancer Care Ontario (CCO) (2017). *Advancing Person-Centred Care in Ontario*. https://www.ccohealth.ca/sites/CCOHealth/files/assets/AdvancingPersonCentredCareInOntario201617_0_0.pdf
- Carper, B. (1978). Fundamental patterns of knowing in nursing. *Advances in Nursing Science*, 1(1), 13-23. <https://doi.org/10.1097/00012272-197810000-00004>
- Cartolovni, A., Stolt, M., Scott, P., & Suhonen, R. (2021). Moral injury in healthcare professionals: A scoping review and discussion. *Nursing Ethics*, 28(5), 590-602. <https://doi.org/10.1177/0969733020966776>
- Castiglione, S., & Ritchie, J. (2012). Moving into action: We know what practices we want to change, now what? An implementation guide for healthcare practitioners. <http://www.cihr-irsc.gc.ca/e/45669.html>
- Cerit, K., Karataş, T., & Ekici, D. (2020). Behaviours of healthcare professionals towards difficult patients: A structural equation modelling study. *Nursing Ethics*, 27(2), 554-566. <https://doi.org/10.1177/0969733019858694>
- Cheng, F., Waddell, K., & Wilson, M. (2018). Determining the features of person-centred models of care that patients value. <https://macsphere.mcmaster.ca/handle/11375/23789#:~:text=to%20this%20item%3A-,http%3A//hdl.handle.net/11375/23789,-Title%3A%C2%A0>

- Chu, W., Tsai, H., Chen, Y., Hung, K., Cheng, S., & Lin, C. (2024). Palliative care for adult patients undergoing hemodialysis in Asia: Challenges and opportunities. *Journal of Hospice & Palliative Care*, 27(1), 1–10.
<https://doi.org/10.14475/jhpc.2024.27.1.1>
- Clark-Cutaia, M.N., Jarrin, O.F., Thomas-Hawkins, C., & Hirschman, K.B. (2020). The perfect storm: Stakeholder perspectives on factors contributing to hospital admissions for patients undergoing maintenance hemodialysis. *Nephrology Nursing Journal*, 47(1), 11-20. <https://doi.org/10.37526/1526-744X.2020.47.1.11>
- Clavel, N., Paquette, J., Dumez, V., Del Grande, C., Ghadiri, D., Pomey, M., & Normandin, L. (2021). Patient engagement in care: A scoping review of recently validated tools assessing patients' and healthcare professionals' preferences and experience. *Health Expectations*, 24(6),1924-1935.
<https://doi.org/10.1111/hex.13344>
- College of Nurses of Ontario (2018a). *Practice Guideline: RN and RPN Practice: The Client, the Nurse and the Environment*. Author.
- College of Nurses of Ontario (2019). *Practice Standard: Therapeutic Nurse-Client Relationship, Revised 2006*.
https://www.cno.org/globalassets/docs/prac/41033_therapeutic.pdf
- College of Nurses of Ontario (2022). Membership Statistics Report 2022.
<https://www.cno.org/globalassets/2-howweprotectthepublic/statistical-reports/registration-statistics-report-2022.html>
- College of Nurses of Ontario (2023a). QA Program. <https://www.cno.org/en/myqa/>

College of Nurses of Ontario (2023b). Scope of Practice.

<https://www.cno.org/globalassets/docs/prac/49041-scope-of-practice.pdf>

Conway, P. (2020). Nephrology nomenclature: How to accelerate patient anxiety, suppress engagement, and mire the advance of medical innovation. *Clinical Journal of the American Society of Nephrology*, 15, 9037-908.

<https://doi.org/10.2215>.

Costa, R., Dantas, A., Leite, É., Lira, A., Vitor, A., & da Silva, R. (2015). Complications in renal patients during hemodialysis sessions and nursing interventions. *Revista De Pesquisa, Cuidado é Fundamental Online*, 7(1), 2137-2146.

<https://doi.org/10.9789/2175-5361.2015.v7i1.2137-2146>

Cresswell, J.W., & Creswell, J.D. (2018). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, Fifth Edition. Sage Publications Inc.

Cudney, E., Reynolds Kueny, C. and Murray, S.L. (2024), Analyzing patient satisfaction in a rural wound care center. *The TQM Journal*, 36(4), 1074-

1091. <https://doi.org/10.1108/TQM-08-2022-0273>

Cummings, J. (1970). Hemodialysis – feelings, facts, fantasies. The pressures and how patients respond. *American Journal of Nursing*, 70(1), 70-76.

Curran, V. (2004). Interprofessional Education for Collaborative Patient-Centred Practice: Research Synthesis Paper. Health Canada.

<https://www.med.mun.ca/getdoc/58a756d2-1442-42ed-915b-9295b6d315c6/Curran--Resarch-Synthesis-Paper.aspx>

- Daneau, S., Bourbonnais, A., & Legault, A. (2023). Ending the invisible work of nurses: Reflection following a study about nursing support of relatives. *Aporia*, 15(1), 14-18. <https://doi.org/10.18192/aporia.v15i1.6503>
- Daudt, H., van Mossel, C., & Scott, S. (2013). Enhancing the scoping study methodology: a large, inter-professional team's experience with Arksey and O'Malley's framework. *BMC Medical Research Methodology*, 13(48). <https://doi.org/10.1186/1471-2288-13-48>
- Davis Boykins, A. (2014). Core communication competencies in patient-centered care. *The Association of Black Nursing Faculty Journal*, 25(2), 40-45.
- Davison, S., & Simpson, C. (2006). Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ Online First*, 333(7574):886. <https://doi.org/10.1136/bmj.38965.626250.55>
- Davison, S. (2010). End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clinical Journal of the American Society of Nephrology*, 5(2):195-204. <https://doi.org/10.2215/CJN.05960809>
- De Kleijn, R., Uyl-De Groot, C., Hagen, C., Franssen, C., Schraa J., Pasker-De Jong, P., & ter Wee, P. (2020). Changing nursing care time as an effect of changed characteristics of the dialysis population. *Journal of Renal Care*, 46(3), 161-168. <https://doi.org/10.1111/jorc.12326>
- Denhaerynck, K., Manhaeve, D., Dobbels, F., Garzoni, D., Nolte, C., & De Geest, S. (2007). Prevalence and consequences of nonadherence to hemodialysis regimens. *American Journal of Critical Care*, 16(3), 222–236. <https://doi.org/10.4037/ajcc2007.16.3.222>

- de Vries, J., & Timmins, F. (2016). Care erosion in hospitals: Problems in reflective nursing practice and the role of cognitive dissonance. *Nurse Education Today*, 38, 5–8. <https://doi.org/10.1016/j.nedt.2015.12.007>
- Dewey, J. (1938). *Experience and Education*. Kappa Delta Pi, First Touchstone Edition 1997, Simon & Schuster.
- Doré, C., Duffett-Leger, L., McKenna, M., Breau, M., & Dorais, M. (2018). Burnout and empowerment in hemodialysis nurses working in Quebec: A provincial survey. *CANNT Journal*, 28(1), 14-27.
- Dreher-Hummel, T., Nickel, C., Nicca, D., & Grossmann, F. (2021) The challenge of interprofessional collaboration in emergency department team triage - An interpretive description. *Journal of Advanced Nursing*, 77(3), 1368-1378. <https://doi.org/10.1111/jan.14675>
- Dsouza, B., Prabhu, R., Unnikrishnan, B., Ballal, S., Mundkur, S., Chandra Sekaran, V., Shetty, A., & Moreira, P. (2023). Effect of educational intervention on knowledge and level of adherence among hemodialysis patients: A randomized controlled trial. *Global Health, Epidemiology and Genomics*, Article 4295613. <https://doi.org/10.1155/2023/4295613>
- Ducharlet, K., Trivedi, M., Gelfand, S., Liew, H., McMahon, L., Ashuntantang, G., Brennan, F., Brown, M., & Martin, D. (2021). Moral distress and moral injury in nephrology during the COVID-19 pandemic. *Seminars in Nephrology*, 41(3), 253–261. <https://doi.org/10.1016/j.semnephrol.2021.05.006>

- Duggan, P., Geller, G., Cooper, L., & Beach, M. (2006). The moral nature of patient-centeredness: Is it "just the right thing to do"? *Patient Education and Counseling*, 62(2), 271–276. <https://doi.org/10.1016/j.pec.2005.08.001>
- Edwards, C. (2002). A proposal that patients be considered honorary members of the healthcare team. *Journal of Clinical Nursing*, 11(3), 340-348. <https://doi.org/10.1046/j.1365-2702.2002.00612.x>
- Ekman, I. (2022). Practising the ethics of person-centred care balancing ethical conviction and moral obligations. *Nursing Philosophy*, 23, e12382. <https://doi.org/10.1111/nup.12382>
- Elliott, B., Gessert, C., Larson, P., & Russ, T. (2014). Shifting responses in quality of life: People living with dialysis. *Quality of Life Research*, 23(5), 1497-1504. <https://doi.org/10.1007/s11136-013-0600-9>
- Emmett, J., & McIntyre, C. (2017). A dialysis patient's choice and a nephrologist's obligation: The need to understand and value the patient's perspective. *Seminars in Dialysis*, 30(1), 3-5. <https://doi.org/10.1111/sdi.12562>
- Entwistle, V., Cribb, A., Watt, I. S., Skea, Z. C., Owens, J., Morgan, H. M., & Christmas, S. (2018). "The more you know, the more you realise it is really challenging to do": Tensions and uncertainties in person-centred support for people with long-term conditions. *Patient Education and Counseling*, 101(8), 1460-1467. <https://doi.org/10.1016/j.pec.2018.03.028>
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centred care for individuals with dementia. *The Gerontologist*, 58(S1), S10-S19. <https://doi.org/10.1093/geront/gnx122>

Fischer Grönlund, C., Dahlqvist, V., & Soderberg, A. (2011). Feeling trapped and being torn: Physicians' narratives about ethical dilemmas in hemodialysis care that evoke a troubled conscience. *BMC Medical Ethics*, 12(8).

<https://doi.org/10.1186/1472-6939-12-8>

Fischer Grönlund, C., Soderberg, A., Zingmark, K., Sandlund, S., & Dahlqvist, V. (2015). Ethically difficult situations in hemodialysis care – Nurses' narratives. *Nursing Ethics.*, 22(6), 711-722.

<https://doi.org/10.1177/0969733014542677>

Fix, G., Lukas, C., Bolton, R., Hill, J., Mueller, N., LaVela, S., & Bokhour, B. (2018). Patient-centred care is a way of doing things: How healthcare employees conceptualize patient-centred care. *Health Expectations*, 21(1), 300-307.

<https://doi.org/10.1111/hex.12615>

Fortin, C., & Boucher, A. (2021). Acute kidney failure during SARS-CoV-2. *Nephrology Nursing Journal*, 48(5), 493-498. [https://doi.org/10.37526/1526-](https://doi.org/10.37526/1526-744X.2021.48.5.493)

[744X.2021.48.5.493](https://doi.org/10.37526/1526-744X.2021.48.5.493)

Fothergill Bourbonnais, F., & Ford Tousignant, K. (2020). Experiences of nephrology nurses in assessing and managing pain in patients receiving maintenance hemodialysis. *Nephrology Nursing Journal*, 47(1), 37-44.

<https://doi.org/10.37526/1526-744X.2020.47.1.37>

Friesacher, H. (2017). Nursing and critique: elements for a theory in nursing. In T. Foth, H. Remmers, D. Holmes, S. Kreutzer, M. Hülksen-Giesler (Eds.), *Critical approaches in nursing theory and nursing research: implications for nursing practice* (pp. 91-111). V&R Unipress GmbH.

- Gagliardi, A., Dunn, S., Foster, A., Grace, S., Khanlou, N., Stewart, D., & Straus, S. (2020). Is patient-centred care for women a priority for policy-makers? Content analysis of government policies. *Health Research Policy and Systems, 18*(1). <https://doi:10.1186/s12961-020-0533-z>
- Gardner, J., & Walton, J. (2011). Striving to be heard and recognized: Nurse solutions for improvement in the outpatient hemodialysis work environment. *Nephrology Nursing Journal, 38*(3), 239-53.
- Gaudet, S., & Robert, D. (2018). *A Journey Through Qualitative Research: From design to reporting*. Sage Publications Ltd.
- Gilbert, J. (2005). Interprofessional Education for Collaborative Patient-Centred Practice (IECPCP). *Nursing Leadership, 18*(2), 32-38.
- Giles S. (2003). Transformations: a phenomenological investigation into the life-world of home haemodialysis. *Social Work in Health Care, 38*(2), 29–50. https://doi.org/10.1300/j010v38n02_02
- Gordon, E., Leon, J., & Sehgal, A. (2003). Why are hemodialysis treatments shortened and skipped? Development of a taxonomy and relationship to patient subgroups. *Nephrology Nursing Journal, 30*(2), 209-218.
- Government of Canada (2007). ARCHIVED - Interprofessional Education for Collaborative Patient-Centred Practice (IECPCP): Research Workshop Final Summary Notes [Health Canada, 2006]. https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/health-human-resources/interprofessional-education-collaborative-patient-centred-practice.html#a1_1

- Government of Canada (2018). Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html
- Government of Canada (2023). Strategy for Patient-Oriented Research. <https://cihr-irsc.gc.ca/e/41204.html>
- Graham, I., Logan, J., Harrison, M., Straus, S., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *The Journal of Continuing Education in the Health Professions*, 26(1), 13-24. <https://doi.org/10.1002/chp.47>
- Grant, M., & Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal*, 26(2), 91-108. <https://doi.org/10.1111/j.1471-1842.2009.00848.x>
- Gregory, D., Way, C., Hutchinson, T., Barrett, B., & Parfrey, P. (1998). Patients' perceptions of their experiences with ESRD and hemodialysis treatment. *Qualitative Health Research*, 8(6), 764-783. <https://doi.org/10.1177/104973239800800604>
- Grob, R., Van Gorp, S., & Evered, J. A. (2023). "You have to trust yourself": The overlooked role of self-trust in coping with chronic illness. *The Hastings Center Report.*, 53(S2). <https://doi.org/10.1002/hast.1522>
- Hallett, C. (1997). Pragmatism and Project 2000: The relevance of Dewey's theory of experimentalism to nursing education. *Journal of Advanced Nursing*, 26(6), 1229-1234. <https://doi.org/10.1111/j.1365-2648.1997.tb00817.x>
- Hallock, A. (2014). An ethical approach to renal replacement decisions in the elderly. *Nephrology Nursing Journal*, 41(5), 513-518.

- Hamric, A. (2012). Empirical research on moral distress: Issues, challenges, and opportunities. *HEC Forum*, 24(1), 39-49. <https://doi.org/10.1007/s10730-012-9177-x>
- Han, K.-H., Sun, C.-K., Cheng, Y.-S., Chung, W., & Kao, C.-C. (2023). Impacts of extrinsic and intrinsic factors on psychiatric nurses' spiritual care attitudes. *Journal of Psychiatric and Mental Health Nursing*, 30(3), 481–491. <https://doi.org/10.1111/jpm.12878>
- Hardill, K. (2019). That look that makes you not really want to be there: How neoliberalism and the war on drugs compromise nursing care of people who use substances. *Witness: The Canadian Journal of Critical Nursing Discourse*, 1(1), 13-27. <https://doi.org/10.25071/2291-5796.15>
- Harding, E., Wait, S., & Scrutton J (2015). The state of play in person-centred care: A pragmatic review of how person-centred care is defined, applied and measured, featuring selected key contributors and case studies across the field. London: The Health Policy Partnership.
- Hardingham, L. (2004). Integrity and moral residue: Nurses as participants in a moral community. *Nursing Philosophy*, 5(2), 127-134. <https://doi.org/10.1111/j.1466-769x.2004.00160.x>
- Hartrick Doane, G., & Varcoe, C. (2005). *Family Nursing as Relational Inquiry*, Lippincott Williams & Wilkins.
- Harwood, L., Wilson, B., Locking-Cusolito, H., Sontrop, J., & Spittal, J. (2009). Stressors and coping in individuals with chronic kidney disease. *Nephrology Nursing Journal*, 36(3), 265-276.

- Harwood, L., Ridley, J., Wilson, B., & Laschinger, H.K. (2010a). Occupational burnout, retention and health outcomes in nephrology nurses. *Canadian Association of Nephrology Nurses and Technologists Journal*, 20(4), 18-23.
- Harwood, L., Ridley, J., Wilson, B., & Laschinger, H.K. (2010b). Workplace empowerment and burnout in Canadian nephrology nurses. *Canadian Association of Nephrology Nurses and Technologists Journal*, 20(2), 12-17.
- Hayes, B., Douglas, C., & Bonner, A. (2015). Work environment, job satisfaction, stress and burnout among haemodialysis nurses. *Journal of Nursing Management*, 23(5), 588-598. <https://doi.org/10.1111/jonm.12184>
- Health Canada (2023). Employee Assistance Services: Employee Assistance Program. <https://www.canada.ca/en/health-canada/services/environmental-workplace-health/occupational-health-safety/employee-assistance-services/employee-assistance-program.html>
- Hertel, E., Cheadle, A., Matthys, J., Coleman, K., Gray, M., Robbins, M., Tufte, J., & Hsu, C. (2019). Engaging patients in primary care design: An evaluation of a novel approach to codesigning care. *Health Expectations*, 22(4), 609–616. <https://doi-org.ezproxy.library.yorku.ca/10.1111/hex.12909>
- Hoffart, N. (1989). Nephrology nursing 1915-1970: a historical study of the integration of technology and care. *ANNA Journal*, 16(3), 169-178.
- Hreńczuk, M., & Flak, K. (2021). The therapeutic relationship between a nurse and a patient in the therapy of haemodialysis. *Renal Disease and Transplantation Forum*, 14(1), 43-46.

- Hughes, J., Bamford, C., & May, C. (2008). Types of centredness in healthcare: Themes and concepts. *Medicine, Healthcare and Philosophy*, 11(4), 455-463.
- Humber College, Faculty of Health Sciences and Wellness (2023). *Nephrology Nursing*.
<https://healthsciences.humber.ca/programs/nephrology-nursing-rn.html>
- Hunt, M. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research*, 19(9), 1284-1292.
- Hwang, J., Kim, S., & Chin, H. (2019). Patient participation in patient safety and its relationships with nurses' patient-centered care competency, teamwork, and safety climate. *Asian Nursing Research*, 13(2), 130-136.
<https://doi.org/10.1016/j.anr.2019.03.001>
- Jacob, A., Vafeas, C., Stoneman, L., & Jacob, E. (2020). Rural dialysis nurses' experiences with challenging patients: A thematic qualitative analysis. *Renal Society of Australasia Journal*, 16(1), 13-19.
<https://journals.cambridgemedica.com.au/rsaj/vol-16-no-1-march-2020>
- Jakimowicz, S., & Perry, L. (2015). A concept analysis of patient-centred nursing in the intensive care unit. *Journal of Advanced Nursing*, 71(7), 1499-1517.
<https://doi.org/10.1111/jan.12644>
- Jakimowicz, S., Perry, L., & Lewis, J. (2017). An integrative review of supports, facilitators and barriers to patient-centred nursing in the intensive care unit. *Journal of Clinical Nursing*, 26(23-24), 4153-4171.
<https://doi.org/10.1111/jocn.13957>

- Jakimowicz, S., Perry, L., & Lewis, J. (2018). Insights on compassion and patient-centred nursing in intensive care: A constructivist grounded theory. *Journal of Clinical Nursing*, 27(7-8), 1599-1611. <https://doi.org/10.1111/jocn.14231>
- Jakobsson, S., Ringstrom, G., Andersson, E., Eliasson, B., Johannsson, G., Simren, M., & Jakobsson, E. (2020). Patient safety before and after implementing person-centred inpatient care – A quasi-experimental study. *Journal of Clinical Nursing*, 29(3-4), 602-612. <https://doi.org/10.1111/jocn.15120>
- Jenny, J., & Logan, J. (1992). Knowing the patient: One aspect of clinical knowledge. *The Journal of Nursing Scholarship*, 24(4), 254-258. <https://doi.org/10.1111/j.1547-5069.1992.tb00730.x>
- Johnson, E., & Carrington, J. (2023). Revisiting the nursing metaparadigm: Acknowledging technology as foundational to progressing nursing knowledge. *Nursing Inquiry*, 30(1), 1–6.
- Johnson, S., Crane, P., Neil, J., & Christinano, C. (2019). Coping with intradialytic events and stress associated with hemodialysis. *Nephrology Nursing Journal*, 46(1), 13-21.
- Jonasson, K., & Gustafsson, L. (2017). You live as much as you have time to: The experience of patients living with hemodialysis. *Nephrology Nursing Journal*, 44(1), 35-41.
- Jonsen, A. (2007). The God Squad and the origins of transplantation ethics and policy. *The Journal of Law, Medicine & Ethics*, 35(2), 238-240.
- Judge, H. (2023). Understanding practices of patient and family centred care in hospitals. [Doctoral dissertation, University of Alberta].

https://era.library.ualberta.ca/items/0dc1d06a-ba12-4854-802a-c7ef10056108/view/84c625d6-c8e5-4143-84b6-8fad83e0ff0e/Judge_Harkeert_202306_PhD.pdf

Kahneman, D. (2023). Degree Honoris Causa address, York University Convocation in June 16.

Kamboj, N. (2019). An exploration of how persons requiring hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health. <https://ir.lib.uwo.ca/etd/6708>

Kear, T., & Ulrich, B. (2015). Patient safety and patient safety culture in nephrology nurse practice settings: Issues, solutions, and best practices. *Nephrology Nursing Journal*, 42(2), 113-122.

Kear, T., & Ulrich, B. (2018). A window into the world of nephrology nursing: Nephrology nurses' views of the health and safety of their work environments, the impact on patient care, and opportunities for improvement. *Nephrology Nursing Journal*, 45(5), 437-449.

Kidney Supportive Care Research Group (n.d.). Living well with chronic kidney disease. <https://sites.ualberta.ca/~kscrg/index.html>

Kim, S., Lee, H. Z., Hwang, E., Song, J., Kwon, H., & Choe, K. (2016). Lived experience of Korean nurses caring for patients on maintenance haemodialysis. *Journal of Clinical Nursing*, 25(9-10), 1455-1463. <https://doi.org/10.1111/jocn.13160>

King's Printer for Ontario (2010). Excellent Care for All Act, 2010. S.O. 2010, c. 14 <https://www.ontario.ca/laws/statute/10e14>

- Kinsella, E. (2009). Professional knowledge and the epistemology of reflective practice. *Nursing Philosophy*, 11(1), 3-14. <https://doi.org/10.1111/j.1466-769X.2009.00428.x>
- Koberich, S., & Farin, E. (2015). A systematic review of instruments measuring patients' perceptions of patient-centred nursing care. *Nursing Inquiry*, 22(2), 106-120. <https://doi.org/10.1111/nin.12078>
- Koberich, S., Feuchtinger, J., & Farin, E. (2016). Factors influencing hospitalized patients' perception of individualized nursing care: A cross-sectional study. *BMC Nursing*, 15(14). <https://doi:10.1186/s12912-016-0137-7>.
- Koivisto, J., Multisilta, J., & Haavisto, E. (2021). Surgical nurses' experiences with intrinsic work motivation: A focus on autonomy, competence and relatedness. *Hoitotiede*, 33(2), 102-111.
- Komenda, P., Tangri, N., Klajncar, E., Eng, A., Di Nella, M., Hiebert, B., Strome, T., Lobato de Faria, R., Zacharias, J., Verrelli, M., Sood, M., & Rigatto, C. (2018). Patterns of emergency department utilization by patients on chronic dialysis: A population-based study. *PLoS ONE*, 13(4): e0195323. 323. <https://doi.org/10.1371/journal.pone.0195323>
- Kralj, B. (2009). Measuring rurality – RIO2008_BASIC: Methodology and results. Toronto: Ontario Medical Association; 2009. <https://content.oma.org/wp-content/uploads/2008rio-fulltechnicalpaper.pdf>
- Kreindler, S. (2013). The politics of patient-centred care. *Health Expectations*, 18(5), 1139-1150. <https://doi.org/10.1111/hex.12087>

- Kuo, P., Saran, R., Argentina, M., Heung, M., Bragg-Gresham, J., Krein, S., Gillespie, B., Zheng, K., & Veinot, T. (2020). Cramping, crashing, cannulating, and clotting: A qualitative study of patients' definitions of a "bad run" on hemodialysis. *BMC Nephrology*, 21(67). <https://doi.org/10.1186/s12882-020-01726-8>
- Lackie, K., Khalili, H., Gilbert, J., Bookey-Bassett, S., Cutler, S., Dixon, K., Fricke, M., Greene, C., Harvan, R., Jessen, J., Langlois, S., Macdonald, L., Maxwell, B., McCarten, C., Najjar, G., Park, V., Saad, A., Syvaioja, K., Schneider, C. (2024). The transformative power of inclusion, diversity, equity, accessibility, and social justice in interprofessional education and collaborative practice – discussion paper. <https://interprofessionalresearch.global/>
- Landreneau, K., & Ward-Smith, P. (2006). Patients' perceptions concerning choice among renal replacement therapies: A pilot study. *Nephrology Nursing Journal*, 33(4), 397-402.
- Landreneau, K., & Ward-Smith, P. (2007). Perceptions of adult patients on hemodialysis concerning choice among renal replacement therapies. *Nephrology Nursing Journal*, 34(5), 513-519.
- Lawrence, J.A., Seiler, S., Wilson, B., & Harwood, L. (2014). Shower and no-dressing technique for tunneled central venous hemodialysis catheters: A quality improvement initiative. *Nephrology Nursing Journal*, 41(1), 67-72.
- Leavy, P. (2020). Introduction to The Oxford Handbook of Qualitative Research, Second Edition. In P. Leavy (Ed.), *The Oxford Handbook of Qualitative Research* (2nd edition). <https://doi.org/10.1093/oxfordhb/9780190847388.013.9>.

- Lee, V., & King, A. (2014). Exploring death anxiety and burnout among staff members who work in outpatient hemodialysis units. *Nephrology Nursing Journal*, 41(5), 479-485, 518.
- Leplege, A., Gzil, F., Cammelli, M., Lefevre, C., Pachoud, B., & Ville, I. (2007). Person-centredness: Conceptual and historical perspectives. *Disability and Rehabilitation*, 29(20-21), 1555-1565.
<https://doi.org/10.1080/09638280701618661>
- Lewis, R., Benzies, K., MacRae, J., Thomas, C., & Tonelli, M. (2019). An exploratory study of person-centered care in a large urban hemodialysis program in Canada using a qualitative case-study methodology. *Canadian Journal of Kidney Health and Disease*, 6, 1-15. <https://doi.org/10.1177%2F2054358119871539>
- Lewis, S., Campbell, M., Beckett, P., Cooper, C., Bonner, P., & Hunt, W. (1992). Work stress, burnout, and sense of coherence among dialysis nurses. *ANNA Journal*, 19(6), 545-554.
- Lindqvist, R., Carlsson, M., & Sjöden, P. (2000). Perceived consequences of being a renal failure patient. *Nephrology Nursing Journal*, 27(3), 291–298.
- Lindridge, J. (2017). Principlism: When values conflict. *Journal of Paramedic Practice*, 9(4). <https://doi.org/10.12968/jpar.2017.9.4.158>
- Lindsay, R., Hux, J., Holland, D., Nadler, S., Richardson, R., Lok, C., Moist, L., & Churchill, D. (2009). An investigation of satellite hemodialysis fallbacks in the province of Ontario. *Clinical Journal of the American Society of Nephrology*, 4(3), 603-608. <https://doi.org/10.2215/CJN.02890608>

- Luchsinger, J., Jones, J., McFarland, A., & Kissler, K. (2019). Examining nurse/patient relationships in care coordination: A qualitative metasynthesis. *Applied Nursing Research, 49*(3), 41–49. <https://doi.org/10.1016/j.apnr.2019.07.006>
- Lukich, N., & Honan, L. (2024). Here for the people: The argument for making clinical ethics more patient-centred. *Healthcare Management Forum*, <http://doi:10.1177/08404704241232041>
- Lundin, P. (1995). Causes of noncompliance in dialysis patients. *Dialysis & Transplantation, 24*(4), 174-176, 202.
- Maassen, E., Schrevel, S., Dedding, C., Broerse, J., & Regeer, B. (2017). Comparing patients' perspectives of "good care" in Dutch outpatient psychiatric services with academic perspectives of patient-centred care. *Journal of Mental Health, 26*(1), 84-94. <https://doi.org/10.3109/09638237.2016.1167848>
- MacKay, S., Smith, A., Kyle, R., & Beattie, M. (2021). What influences nurses' decisions to work in rural and remote settings? A systematic review and meta-synthesis of qualitative research. *Rural and Remote Health, 21*(1). <https://doi.org/10.22605/RRH6335>
- Mahon, P., & O'Neill, M. (2020). Through the looking glass: The rabbit hole of reflective practice. *British Journal of Nursing, 29*(13), 777–783. <https://doi.org/10.12968/bjon.2020.29.13.777>
- Makar, M., & Pun, P. (2017). Sudden cardiac death among hemodialysis patients. *American Journal of Kidney Diseases, 69*(5), 684-695. <https://doi.org/10.1053/j.ajkd.2016.12.006>

- Malterud, K., Siersma, V., & Guassora, A. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, 26(13), 1753-1760. <https://doi.org/10.1177/1049732315617444>
- Manias E. (2019). A patient-centred care and engagement program in intensive care reduces adverse events and improves patient and care partner satisfaction. *Australian Critical Care*, 32(2), 179–181. <https://doi.org/10.1016/j.aucc.2018.10.001>.
- Mann, K., Gordon, J., & MacLeod, A. (2009). Reflection and reflective practice in health professions education: A systematic review. *Advances in Health Sciences Education: Theory and Practice*, 14(4), 595–621. <https://doi.org/10.1007/s10459-007-9090-2>
- Manojlovich, M., & Sidani, S. (2008). Nurse dose: What's in a concept? *Research in Nursing & Health*, 31(4), 310-319. <https://doi.org/10.1002/nur.20265>
- Manthey, M. (2003). Aka primary nursing. *Journal of Nursing Administration*, 33(7/8), 369-370. <https://doi.org/10.1097/00005110-200307000-00001>
- Markle-Reid, M., McAiney, C., Fisher, K., Ganann, R., Gauthier, A., Heald-Taylor, G., McElhaney, J., McMillan, F., Petrie, P., Ploeg, J., Urajnik, D., & Whitmore, C. (2021). Effectiveness of a nurse-led hospital-to home transitional care intervention for older adults with multimorbidity and depressive symptoms: A pragmatic randomized controlled trial. *PLoS ONE*, 16(7). <https://doi.org/10.1371/journal.pone.0254573>

- Marshall, A., Kitson, A. & Zeitz, K. (2012). Patients' views of patient-centred care: A phenomenological case study in one surgical unit. *Journal of Advanced Nursing*, 68(12), 2664-2673. <https://doi.org/10.1111/j.1365-2648.2012.05965.x>
- Martin, R. (2002). Who should manage continuous renal replacement in the intensive care setting? A nursing viewpoint. *EDTNA/ERCA Journal*, 28(S2), 43-46.
- Mathe, T., Zucca, A., Sanson-Fisher, R., Hobden, B., Turon, H., Leigh, L., & Boyes, A. (2023). Rural versus urban cancer patients' receipt of patient-centred care: A cross sectional survey. *Australian Journal of Cancer Nursing*, 24(1), 14–23. <https://doi.org/10.33235/ajcn.24.1.14-23>
- McCormack, B., & McCance, T. (Eds.) (2017). *Person-centred practice in nursing and healthcare: Theory and practice*, Second Edition. John Wiley & Sons Ltd.
- McCormack, B. (2003). A conceptual framework for person-centred practice with older people. *International Journal of Nursing Practice*, 9(3), 202-209. <https://doi.org/10.1046/j.1440-172x.2003.00423.x>
- McCormack, B., & McCance, T. (2006). Development of a framework for person-centred nursing. *Journal of Advanced Nursing*, 56(5), 472-479. <https://doi.org/10.1111/j.1365-2648.2006.04042.x>
- McKeown, L., Hong, Y., Kreps, G., Xue, H. (2023). Trends and differences in perceptions of patient-centered communication among adults in the US. *Patient Education and Counseling*, 106, 128-134. <https://doi.org/10.1016/j.pec.2022.10.010>.
- McLaney, E., Morassaei, S., Hughes, L., Davies, R., Campbell, M., & Di Prospero, L. (2022). A framework for interprofessional team collaboration in a hospital setting:

- Advancing team competencies and behaviours. *Healthcare Management Forum*, 35(2), 112–117. <https://doi.org/10.1177/08404704211063584>
- Mead, N., & Bower, P. (2000). Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science and Medicine*, 51(7), 1087-110. [https://doi.org/10.1016/s0277-9536\(00\)00098-8](https://doi.org/10.1016/s0277-9536(00)00098-8)
- Mehrotra, R., Marsh, D., Vonesh, E., Peters, V., & Nissenson, A. (2005). Patient education and access of ESRD patients to renal replacement therapies beyond in-center hemodialysis. *Kidney International*, 68(1), 378–390. <https://doi.org/10.1111/j.1523-1755.2005.00453.x>
- Meland, E., Schei, E., & Baerheim, A. (2000). Patient centered medicine - a review with emphasis on the background and documentation. *Tidsskr Nor Laegeforen* (Journal of the Norwegian Medical Association), 120(19), 2253-6.
- Merriam-Webster (2024). Pragmatic. In Merriam-Webster.com dictionary. <https://www.merriam-webster.com/dictionary/pragmatic>
- Metersky, K. (2020). Patient roles within interprofessional collaborative patient-centred care teams: The patient and health care provider perspectives. [Doctoral dissertation, University of Western Ontario]. <https://ir.lib.uwo.ca>
- Metersky, K., Rahman, R., & Boyle, J. (2023). Patient-Partners as educators: vulnerability related to sharing of lived experience. *Journal of Patient Experience*, 10(4). <https://doi.org/10.1177/23743735231183677>
- Metersky, K., Axenciuc, R., Mitchell, E., & Nyathi, S. (2022). The need for clarification of terminology and labels in interprofessional care: A commentary. *International Health Trends and Perspectives*, 2(1), 80-87.

- Mitchell, G., & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard*, 30(7), 46-50.
<https://doi.org/10.7748/ns.30.7.46.s47>
- Molnar, A., Hiremath, S., Brown, P., & Akbar, A. (2016). Risk factors for unplanned and crash dialysis starts: A protocol for a systematic review and meta-analysis. *Systematic Reviews*, 5(1):117. <http://doi:10.1186/s13643-016-0297-2>
- Molnar, A., Moist, L., Klarenbach, S., Lafrance, J., Kim, S., Tennankore, K., Perl, J., Kappel, J., Turner M., Gill, J., & Sood, M. (2018). Hospitalizations in dialysis patients in Canada: A national cohort study. *Canadian Journal of Kidney Health and Disease*, 5, 1-10. <http://doi:10.1177/2054358118780372>
- Moody, L., Nicholls, B., Shamji, H., Bridge, E., Dhanju, S., & Singh, S. (2018). The Person-Centred Care Guideline: From principle to practice. *Journal of Patient Experience*, 5(4), 282–288. <https://doi.org/10.1177/2374373518765792>
- Morehouse, R., Colvin, E., Maykut, P. (2001). Nephrology nurse-patient relationships in the outpatient dialysis setting. *Nephrology Nursing Journal*, 28(3), 295-300.
- Moreira, A., de Azevedo, A., de Figueiredo, N., de Oliveira, L., & de Araujo, S. (2017). Proxemic behavior of nursing in the hemodialysis setting. *Acta Paulista de Enfermagem*, 30(4), 343-349. <https://doi.org/10.1590/1982-0194201700051>
- Morgan, L. (2000). A decade review: Methods to improve adherence to the treatment regimen among hemodialysis patients. *Nephrology Nursing Journal*, 27(3), 299-304.

- Morris, L., Grehl, M., Rutter, S., Mehta, M., & Westwater, M. (2022). On what motivates us: A detailed review of intrinsic v. extrinsic motivation. *Psychological Medicine*, 52(10), 1801-1816. <https://doi.org/10.1017/S0033291722001611>
- Morse, J. (1991). Negotiating commitment and involvement in the nurse-patient relationship. *Journal of Advanced Nursing*, 16(4), 455-468. <https://doi.org/10.1111/j.1365-2648.1991.tb03436.x>
- Morse, J. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, 25(9), 1212-1222. <https://doi.org/10.1177/1049732315588501>
- Morse, J. (2018). Reframing rigor in qualitative inquiry. In N. Denzin & Y. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research*, (5th ed., 1373-1409). Sage.
- Morton, R., Snelling, P., Webster, A., Rose, J., Masterson, R., Johnson, D., & Howard, K. (2012). Factors influencing patient choice of dialysis versus conservative care to treat end-stage kidney disease. *Canadian Medical Association Journal*, 184(5), E277–E283. <https://doi.org/10.1503/cmaj.111355>
- Murphy, F. (2004). Stress among nephrology nurses in Northern Ireland. *Nephrology Nursing Journal*, 31(4), 423-431.
- Nagle, L. (1998). The meaning of technology for people with chronic renal failure. *Holistic Nursing Practice*, 12(4), 78-92.
- Ng, M., Wong, C., Choi, K., Hui, Y., Ho, E., Miaskowski, C., & So, W. (2021). A mixed methods study of symptom experience in patients with end-stage renal disease. *Nursing Research*, 70(1), 34-43. <https://doi.org/10.1097/NNR.0000000000000479>

- Nicholson, L. (2017). Person-centred care: Experiences of older people with dementia. *Nursing Standard*, 32(8), 41-51. <https://doi.org/10.7748/ns.2017.e10558>
- Nielsen, A., Kvande, M., & Angel, S. (2023). Humanizing and dehumanizing intensive care: Thematic synthesis (HumanIC). *Journal of Advanced Nursing*, 79(1), 385-401. <http://doi:10.1111/jan.15477>
- Nigri, R., & daSilva, R. (2022). Hemodialysis in the context of COVID-19: Care, nursing protagonism and quality. *Revista Brasileira de Enfermagem (Brazilian Journal of Nursing)*, 75(Suppl 1): e20201077. <https://doi.org/10.1590/0034-7167-2020-1077>
- Nwoye, A. (2017). An Africentric theory of human personhood. *Psychology in Society*, 54, 42-66, <http://dx.doi.org/10.17159/2309-8708/2017/n54a4>
- O'Brien M. (1980) Hemodialysis regimen compliance and social environment: A panel analysis. *Nursing Research*, 29(4), 250–255. <https://doi.org/10.1097/00006199-198007000-00018>
- O'Brien, J. (2011). Relationships among structural empowerment, psychological empowerment, and burnout in registered staff nurses working in outpatient dialysis centers. *Nephrology Nursing Journal*, 38(6), 475-481.
- Ocloo, J., Goodrich, J., Tanaka, H., Birchall-Searle, J., Dawson, D., & Farr, M. (2020). The importance of power, context and agency in improving patient experience through a patient and family centred care approach. *Health Research Policy and Systems*, 18(1). <https://doi.org/10.1186/s12961-019-0487-1>
- O'Connor, A.M., Tugwell, P., Wells, G., Elmslie, T., Jolly, E., Hollingworth, G., McPherson, T., Bunn, H., Graham, I., & Drake, E. (1998). A decision aid for women considering hormone therapy after menopause: Decision support

framework and evaluation. *Patient Education and Counseling*, 33 (3):267–79.

[https://doi.org/10.1016/s0738-3991\(98\)00026-3](https://doi.org/10.1016/s0738-3991(98)00026-3)

O'Hare, A., Richards, C., Szarka, J., McFarland, L., Showalter, W., Vig, E., Sudore, R., Crowley, S., Trivedi, R., & Taylor, J. (2018). Emotional impact of illness and care on patients with advanced kidney disease. *Clinical Journal of the American Society of Nephrology*, 13(7), 1022-1029. <http://doi:10.2215/CJN.14261217>.

Ontario Hospital Association (2015). Rural health hubs framework for Ontario.

<https://www.oha.com/Documents/Rural%20Health%20Hub%20Framework%20Ontario.pdf>

Ontario Medical Association (n.d.) RIO Postal Code Look-up.

<https://apps.oma.org/RIO/index>

Ontario Ministry of Health and Long-Term Care (2015). *Patients First: A Proposal to Strengthen Patient-Centred Healthcare in Ontario*.

http://www.health.gov.on.ca/en/news/bulletin/2015/docs/discussion_paper_2015_1217.pdf

Ontario Ministry of Health and Long-Term Care (2022). Northern Health Programs: Communities by Rurality Index for Ontario (RIO) Score.

https://health.gov.on.ca/en/pro/programs/northernhealth/rio_score.aspx

Ontario Renal Network (2018). Advance care planning, goals of care, and treatment decisions & informed consent.

<https://www.ontariorenalnetwork.ca/sites/renalnetwork/files/assets/advancecareplanningfaq.pdf>

Ontario Renal Network (n.d., a). *Person-Centred Care*.

<https://www.ontariorenalnetwork.ca/en/about/our-work/person-centred-care>

Ontario Renal Network (n.d., b). Recommended resources for nurses.

<https://www.ontariorenalnetwork.ca/en/recommended-resources-nurses>

O'Rourke, D., Thompson, G., & McMillan, D. (2019). Ethical and moral considerations of (patient) centredness in nursing and healthcare: Navigating uncharted waters.

Nursing Inquiry, 26(3). <https://doi.org/10.1111/nin.12284>.

Ortiz, M. (2021). Exploring the perspectives of hemodialysis nurses in supporting patient coping and resilience: an interpretive description study. [Master's thesis, University of Calgary] ProQuest Dissertations Publishing, 28862950.

Ozen, N., Cinar, F., Askin, D., Mut, D., & Turker, T. (2019). Nonadherence in hemodialysis patients and related factors: A multicenter study. *Journal of Nursing Research*, 27(4):e36. <https://doi.org/10.1097/jnr.0000000000000309>

Patel, K. M., & Metersky, K. (2022). Reflective practice in nursing: A concept analysis. *International Journal of Nursing Knowledge*, 33(3), 180–187.

<https://doi.org/10.1111/2047-3095.12350>

Patel, S. (2015). The research paradigm – methodology, epistemology and ontology – explained in simple language. <http://salmapatel.co.uk/academia/the-research-paradigm-methodology-epistemology-and-ontology-explained-in-simple-language/>

Pauly, B. M., Varcoe, C., & Storch, J. (2012). Framing the Issues: Moral distress in health care. *HEC Forum*, 24(1), 1-11 <https://doi.org/10.1007/s10730-012-9176-y>

- Pauly, B., Varcoe, C., Storch, J., & Newton, L. (2009). Registered Nurses' perceptions of moral distress and ethical climate. *Nursing Ethics*, 16(5), 561-573.
<https://doi.org/10.1177/0969733009106649>
- Payton, J. (2018). Improving communication skills within the nephrology unit. *Nephrology Nursing Journal*, 45(3), 269-271, 280.
- Picker Institute (2024). Our history. <https://picker.org/who-we-are/our-history>
- Picker Institute (2024). The Picker Principles of Person-Centred care.
<https://picker.org/who-we-are/the-picker-principles-of-person-centred-care/>
- Pilnick, A. (2023). Reconsidering patient-centred care: Authority, expertise and abandonment. *Health Expectations*, 1-4. <https://doi.org/10.1111/hex.13815>
- Planetree Organization (2023). Our story: Humanizing healthcare for everyone. Everywhere. Every time. <https://www.planetree.org/our-story>
- Polaschek N. (2007). 'Doing dialysis at home': Client attitudes towards renal therapy. *Journal of Clinical Nursing*, 16(3A), 51–58.
<https://doi.org/10.1111/j.1365-2702.2006.01622.x>
- Polit, D., & Beck, C. (2017). *Nursing Research: Generating and Assessing Evidence for Nursing Practice*, Tenth Edition. Wolters Kluwer.
- Pomey, M., Clavel, N., Normandin, L., Del Grande, C., Philip Ghadiri, D., Fernandez-McAuley, I., Boivin, A., Flora, L., Janvier, A, Karazivan, P., Pelletier, J., Fernandez, N., Paquette, J., & Dumez, V. (2021). Assessing and promoting partnership between patients and health-care professionals: Co-construction of the CADICEE tool for patients and their relatives. *Health Expectations*, 24(4), 1230-1241. <http://doi:10.1111/hex.13253>

Pomey, M., Ghadiri, D., Karazivan P., Fernandez, N., & Clavel, N. (2015). Patients as partners: A qualitative study of patients' engagement in their health care. *PLoS ONE*, 10(4). <http://doi:10.1371/journal.pone.0122499>

Pomey, M., & Lebel, P. (2016). Patient engagement: The Quebec path. *Healthcare Papers*, 16(2), 78-83.

Prakash, S. (2006). Influence of satellite dialysis units on utilization and modality selection. [Master's thesis, University of Toronto].

https://tspace.library.utoronto.ca/bitstream/1807/121859/1/MR21194_OCR.pdf

Pratt, H., Moroney, T., & Middleton, R. (2021). The influence of engaging authentically on nurse–patient relationships: A scoping review. *Nursing Inquiry*, 28(2), 1-15.

<https://doi.org/10.1111/nin.1238812388>

Provincial Health Services Authority (2023). Patient Experience Week: A time to celebrate and encourage positive patient experiences.

<http://www.bcrenal.ca/about/news-stories/news/patient-experience-week-2023>

Puckrein, G. (2016). Nothing about me without me.

<https://patientresearchexchange.org/stories/detail/nothing-about-me-without-me>

Quinan, P. (2007). Control and coping for individuals with end stage renal disease on hemodialysis: A position paper. *CANNT Journal*, 17(3), 77–84.

Radwin, L. (1995). Knowing the patient: A process model for individualized interventions. *Nursing Research*, 44(6), 364-370.

Radwin, L., Cabral, H., & Wilkes, G. (2009). Relationships between patient-centered cancer nursing interventions and desired health outcomes in the context of the

- health care system. *Research in Nursing and Health*, 32(1), 4-17.
<https://doi.org/10.1002/nur.20302>
- Rankin, J., & Campbell, M. (2006). *Managing to nurse: Inside Canada's health care reform*. University of Toronto Press.
- Ravenscroft, E. (2008). *Patient perspectives on health care system navigation: The chronic illness multi-morbidity experience*. [Doctoral dissertation, University of British Columbia].
<https://open.library.ubc.ca/collections/ubctheses/24/items/1.0066327>
- Redman, B., & Fry, S. (2000). Nurses ethical conflicts: What is really known about them? *Nursing Ethics*, 7(4), 360-366.
<https://doi.org/10.1177/096973300000700409>
- Redman, B., Hill, M., & Fry, S. (1997). Ethical conflicts reported by Certified Nephrology Nurses (CNNs) practicing in dialysis settings. *ANNA Journal*, 24(1), 23-31.
- Registered Nurses Association of Ontario (2015). *Person- and Family-Centred Care: Clinical Best Practice Guidelines*. <https://rnao.ca/bpg/guidelines/person-and-family-centred-care>.
- Rodney, P. (2017). What we know about moral distress. *American Journal of Nursing*, 117(2 Suppl 1), S7-S10. <http://doi:10.1097/01.NAJ.0000512204.85973.04>
- Rogers, C. (1951/2003). *Client-centered Therapy*. Constable & Robinson Ltd.
- Rolfe, G. (2014). Rethinking reflective education: What would Dewey have done? *Nurse Education Today*, 34(8), 1179–1183. <https://doi.org/10.1016/j.nedt.2014.03.006>
- Røsstad, T., Garåsen, H., Aslak Steinsbekk, A., Sletvold, O., & Grimsmo, A. (2013). Development of a patient-centred care pathway across healthcare providers: A

qualitative study. *BMC Health Services Research*, 13(1).

<http://doi.org/10.1186/1472-6963-13-121>

Rossum, K., Finlay, J., McCormick, M., Desjarlais, A., Vorster, H., Fontaine, G., Talson, M., Ferreira Da Silva, P., Soroka, K., Sass, R., James, M., Tong, A., Harris, C., Melnyk, Y., Sood, M., Pannu, N., Suri, R., Tennankore, K., Thompson, S., Tonelli, M., & Bohm, C., (2020). A mixed method investigation to determine priorities for improving information, interaction, and individualization of care among individuals on in-center hemodialysis: The Triple I Study. *Canadian Journal of Kidney Health and Disease*, 7, 1-13.

<https://doi.org/10.1177%2F2054358120953284>.

Royle, J., DiCenso, A., Baumann, A., Boblin-Cummings, B., Blythe, J., & Mallette, C. (2000). RN and RPN decision making across settings. *Nursing Leadership*, 13(4), 11-18. <http://doi.org/10.12927/cjnl.2000.16289>

Rushton, C., & Edvardsson, D. (2018). Reconciling conceptualizations of ethical conduct and person-centred care of older people with cognitive impairment in acute care settings. *Nursing Philosophy*, 19(2). <https://doi.org/10.1111/nup.12190>

Russ, A., Shim, J., & Kaufman, S. (2005). "Is there life on dialysis?": Time and aging in a clinically sustained existence. *Medical Anthropology*, 24(4), 297-324.

<https://psycnet.apa.org/doi/10.1080/01459740500330639>

Russ, A., Shim, J., & Kaufman, S. (2007). The value of "life at any cost": Talk about stopping kidney dialysis. *Social Science & Medicine*, 64(11), 2236-2247.

<https://doi.org/10.1016/j.socscimed.2007.02.016>

- Russell, S., Daly, J., Hughes, E., & Op't Hoog, C. (2003). Nurses and 'difficult' patients: Negotiating non-compliance. *Journal of Advanced Nursing*, 43(3), 281-287.
<https://doi.org/10.1046/j.1365-2648.2003.02711.x>
- Sabaté E. (2003). Adherence to long-term therapies: Evidence for action. Geneva, Switzerland, World Health Organization.
<https://iris.who.int/bitstream/handle/10665/42682/9241545992.pdf?sequence=1&isAllowed=y>
- St. Onge, J., & Parnell, R. (2015). Patient-centered care and patient safety: A model for nurse educators. *Teaching and Learning in Nursing*, 10(1), 39-43.
<https://doi.org/10.1016/j.teln.2014.08.002>
- Sandman, L., Granger, B.B., Ekman, I., Munthe, C. (2012). Adherence, shared decision-making and patient autonomy. *Medicine, Health Care and Philosophy*, 15(2), 115–127. <https://doi.org/10.1007/s11019-011-9336-x>
- Saran, R., Bragg-Gresham, J., Rayner, H., Goodkin, D., Keen, M., Van Dijk, P., Kurokawa, K., Piera, L., Saito, A., Fukuhara, S., Young, E., Held, P., & Port, F. (2003). Nonadherence in hemodialysis: Associations with mortality, hospitalization, and practice patterns in the DOPPS. *Kidney international*, 64(1), 254–262. <https://doi.org/10.1046/j.1523-1755.2003.00064.x>
- Sass, R., Finlay, J., Rossum, K., Soroka, K., McCormick, M., Desjarlais, A., Vorster, H., Fontaine, G., Ferreira Da Silva, P., James, M., Sood, M., Tong, A., Pannu, N., Tennankore, K., Thompson, S., Tonelli, M., & Bohm, C. for the Can-SOLVE CKD Network (2020). Patient, caregiver, and provider perspectives on challenges and solutions to individualization of care in hemodialysis: A qualitative

study. *Canadian Journal of Kidney Health and Disease*, 7, 1-12.

<https://doi.org/10.1177%2F2054358120970715>

Sav, A., McMillan, S., Kelly, F., King, M., Whitty, J., Kendall, E., & Wheeler, A. (2015).

The ideal healthcare: priorities of people with chronic conditions and their carers.

BMC Health Services Research, 15(551). <http://doi.org/10.1186/s12913-015->

[1215-3](http://doi.org/10.1186/s12913-015-1215-3)

Schluter, J., Seaton, P., & Chaboyer, W. (2011). Understanding nursing scope of practice: A qualitative study. *International Journal of Nursing Studies*, 48(10),

1211-1222. <https://doi.org/10.1016/j.ijnurstu.2011.03.004>

Schon, D. (1987). *Educating the reflective practitioner*. Jossey-Bass, John Wiley & Sons, Inc.

Schwartz, D., Stewart, S., Aikens, J., Bussell, J., Osborn, C., & Safford, M. (2017).

Seeing the person, not the illness: Promoting diabetes medication adherence through patient-centered collaboration. *Clinical Diabetes*, 35(1), 35–42.

<https://doi.org/10.2337/cd16-0007>

Schwind, J., Beanlands, H., Lapum, J., Romaniuk, D., Fredericks, S., LeGrow, K., Edwards, S., McCay, E., & Crosby, J. (2014). Fostering person-centered care among nursing students: Creative pedagogical approaches to developing personal knowing. *Journal of Nursing Education*, 53(6), 343-7.

<http://doi.org/10.3928/01484834-20140520-01>

Schwind, J., McCay, E., Metersky, K., & Martin, J. (2016). Development and implementation of an advanced therapeutic communication course: An

interprofessional collaboration. *Journal of Nursing Education*, 55(10), 592-7.

<http://doi.org/10.3928/01484834-20160914-11>

Schwind, J., & Manankil-Rankin, L. (2020). Using narrative reflective process to augment personal and aesthetic ways of knowing to support holistic person-centred relational practice. *Reflective Practice*, 21(4), 473-483.

<https://doi.org/10.1080/14623943.2020.1777958>

Schwind, J., Santa-Mina, E., Metersky, K., & Patterson, E. (2015). Using the narrative reflective process to explore how students learn about caring in their nursing program: An arts-informed narrative inquiry. *Reflective Practice*, 16(3), 390–402.

<https://doi.org/10.1080/14623943.2015.1052385>

Sclauzero, P., Casarotto, S., Martingano, M., Morpurgo, F., Rocconi, I., Scala, K., Vescovi, M., & Galli, G. (2006). Improving quality of assistance and outcome in critically ill patients with acute renal failure. *Journal of Renal Care*, 32(3), 167-

170. <https://doi.org/10.1111/j.1755-6686.2006.tb00013.x>

Scotland, J. (2012). Exploring the philosophical underpinnings of research: Relating ontology and epistemology to the methodology and methods of the scientific, interpretive, and critical research paradigms. *English Language Teaching*, 5(9),

9-16. <http://www.ccsenet.org/journal/index.php/elt/article/view/19183>

Sherman, R. (1996). Noncompliance in dialysis patients. *Nephrology News & Issues*, 10(6), 36-38.

Shi, Y., Liao, Y., Zhou, Y., Liu, H., Lei, Y., & Luo, L. (2023) Anxiety, depression, and related factors in hemodialysis patients during the lockdown period of COVID- 19

- in China: a multicenter study. *Psychology, Health & Medicine*, 28(6), 1513-1519.
<http://doi.org/10.1080/13548506.2022.2100917>
- Sidani, S., Collins, L., Harbman, P., MacMillan, K., Reeves, S., Hurlock-Chorostecki, C., Donald, F., Staples, P., & van Soeren, M. (2014). Development of a measure to assess healthcare providers' implementation of patient-centered care. *Worldviews on Evidence Based Nursing*, 11(4), 248-57.
<https://doi.org/10.1111/wvn.12047>
- Sidani, S., & Fox, M. (2014). Patient-centered care: Clarification of its specific elements to facilitate interprofessional care. *Journal of Interprofessional Care*, 28(2), 134-141. <https://doi.org/10.3109/13561820.2013.862519>
- Sidani, S., Manojlovich M, Covell C. (2010). Nurse dose: Validation and refinement of a concept. *Research and Theory for Nursing Practice*, 24(3), 159-71.
<http://doi.org/10.1891/1541-6577.24.3.159>
- Sidani, S., Reeves, S., Hurlock-Chorostecki, C., van Soeren, M., Fox, M., & Collins, L. (2018). Exploring differences in patient-centered practices among healthcare professionals in acute care settings. *Health Communication*, 33(3), 716-723.
<https://doi.org/10.1080/10410236.2017.1306476>
- Sidani, S., van Soeren, M., Hurlock-Chorostecki, C., Reeves, S., Fox, M., & Collins, L. (2016). Health professionals' and patients' perceptions of patient-centered care: A comparison. *European Journal for Person Centered Healthcare*, 4(4), 641-649.
- Silen, M., Svantesson, M., & Ahlstrom, G. (2008). Nurses' conceptions of decision making concerning life-sustaining treatment. *Nursing Ethics*, 15(2), 160-173.
<https://doi.org/10.1177/0969733007086014>

- Sine, D., Sharpe, V. (2011). Ethics, risk, and patient-centered care: How collaboration between clinical ethicists and risk management leads to respectful patient care. *Journal of Healthcare Risk Management*, 31(1), 32-7.
- Smith, J., Korzuchowski, A., Memmott, C., Oveisi, N., Tan, H.-L., & Morgan, R. (2023). Double distress: Women healthcare providers and moral distress during COVID-19. *Nursing Ethics*, 30(1), 46-57. <https://doi.org/10.1177/09697330221114329>
- Snowden, A., & Marland, G. (2012). No decision about me without me: Concordance operationalised. *Journal of Clinical Nursing*, 22(9-10), 1353–1360. <https://doi.org/10.1111/j.1365-2702.2012.04337.x>
- Snowden, A., Martin, C., Mathers, B. & Donnell, A. (2014) Concordance: A concept analysis. *Journal of Advanced Nursing*, 70(1), 46–59. <https://doi.org/10.1111/jan.12147>
- Sousa, H., Bártolo, A., Ribeiro, O., & Figueiredo, D. (2022). A family-centred perspective on the arteriovenous fistula in end-stage renal disease: Findings from dyadic interviews. *Scandinavian Journal of Caring Sciences*, 36(2), 426-438. <https://doi.org/10.1111/scs.13055>
- Statistics Canada (2017). Population centre and rural area classification 2016. <https://www.statcan.gc.ca/en/subjects/standard/pcrac/2016/introduction>
- Steward, C. (2017). The relationship between bloodstream infections and hemodialysis catheters in hospital-based hemodialysis units. *Nephrology Nursing Journal*, 44(1), 43-47.

- Storch, J. (2013). Nursing Ethics, The Moral Terrain. In: J. Storch, P. Rodney, R. Starzomski (Eds.) *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice*, Second Edition, Chapter 1, 1-19. Pearson Canada Inc.
- Sturesson, A., & Ziegert, K. (2014). Prepare the patient for future challenges when facing hemodialysis: nurses' experiences, *International Journal of Qualitative Studies on Health and Well-being*, 9(1), 1-15.
<https://doi.org/10.3402/qhw.v9.22952>
- Sultan, B., Fouad, A., & Zaki, H. (2022) Adherence to hemodialysis and medical regimens among patients with end-stage renal disease during COVID-19 pandemic: A cross-sectional study. *BMC Nephrology*, 23(138), 1-9.
<https://doi.org/10.1186/s12882-022-02756-0>
- Terkelsen, A., Petersen, J., & Kristensen, H. (2020). Mapping empirical experiences of Tom Kitwood's framework of person-centred care for persons with dementia in institutional settings. A scoping review. *Scandinavian Journal of Caring Sciences*, 34(1), 6-22. <https://doi.org/10.1111/scs.12709>
- Thomas-Hawkins, C., Flynn, L., & Clarke, S. (2008). Relationships between registered nurse staffing, processes of nursing care, and nurse-reported patient outcomes in chronic hemodialysis units. *Nephrology Nursing Journal*, 35(2), 123-30, 145.
- Thomas-Hawkins, C., Flynn, L., & Dillon, J. (2020). Registered Nurse staffing, workload, and nursing care left undone, and their relationships to patient safety in hemodialysis units. *Nephrology Nursing Journal*, 47(2), 133-142.
<https://doi.org/10.37526/1526-744X.2020.47.2.133>

- Thompson, N., & Pascal, J. (2012). Developing critically reflective practice. *Reflective Practice*, 13(2), 311–325. <https://doi.org/10.1080/14623943.2012.657795>
- Thorarinsdottir, K., & Kristjansson, K. (2014). Patients' perspectives on person-centred participation in healthcare: A framework analysis. *Nursing Ethics*, 21(2), 129-147. <https://doi.org/10.1177/0969733013490593>
- Thorne, S. (1990). Navigating troubled waters: Chronic illness experience in a health care crisis. [Doctoral dissertation, The Union Institute of Advanced Studies]. <https://sigma.nursingrepository.org/handle/10755/620763/browse?type=author&value=Thorne%2C+Sally>
- Thorne, S. (2008). *Interpretive Description*. Left Coast Press.
- Thorne, S. (2016). *Interpretive Description: Qualitative Research for Applied Practice*, Second Edition. Routledge, Taylor & Francis Group.
- Thorne, S. (2020a). The great saturation debate: What the “S Word” means and doesn't mean in qualitative research reporting. *Canadian Journal of Nursing Research*, 52(1), 3-5.
- Thorne, S. (2020b). Applied interpretive approaches. In P. Leavy (Ed.), *The Oxford Handbook of Qualitative Research* (2nd edition). <https://doi.org/10.1093/oxfordhb/9780190847388.013.14>
- Thorne, S. (2020c). Untangling the misleading message around saturation in qualitative nursing studies. *Nurse Author & Editor*, 30(1), 1-9. <https://doi.org/10.1111/j.1750-4910.2020.tb00005.x>
- Thorne, S. (2020d). Rethinking Carper's personal knowing for 21st century nursing. *Nursing Philosophy*, 21(4), <https://onlinelibrary.wiley.com/doi/10.1111/nup.12307>

- Thorne, S. (2023). Making Qualitative Studies Matter. Inaugural presenter, Pan-Canadian Nursing Research Methods Webinar. Available at <https://www.youtube.com/watch?v=6XtUpwp9SMY>
- Thorne, S., Kirkham, S., & MacDonald-Emes, J. (1997). Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health*, 20(2), 169-177.
- Thorne, S., Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in Interpretive Description. *International Journal of Qualitative Methods*, 3(1), 1-11. <http://doi.org/10.1177/160940690400300101>
- Thorne, S., & Stajduhar, K. (2017). Rebuilding the roots of patient-centred care. *Nursing Leadership*, 30(1), 23-29. <https://doi.org/10.12927/cjnl.2017.25109>
- Thorne, S., Stephens, J., & Truant, T. (2016). Building qualitative study design using nursing's disciplinary epistemology. *Journal of Advanced Nursing*, 72(2), 451-460. <https://doi.org/10.1111/jan.12822>
- Thorne, S., & Truant, T. (2010). Will designated patient navigators fix the problem? Oncology nursing in transition. *Canadian Oncology Nursing Journal*, 20(3), 116-121.
- Tomagová, M., Čáp, J., & Podolinská, L. (2024). "Trust is built in an inner principle": An idiographic case study exploring the trust of a young man with chronic pancreatitis in healthcare professionals. *Central European Journal of Nursing & Midwifery*, 15(1), 1059–1067. <https://doi.org/10.15452/CEJNM.2024.15.0003>
- Tong, A., Levey, A., Eckardt, K., Anumudu, S., Arce, C., Baumgart, A., Dunn, L., Gutman, T., Harris T., Lightstone, L., Scholes-Robertson, N., Shen, J., Wheeler,

D., White, D., Wilkie, M., Craig, J., Jadoul, M., Winkelmayr, W. (2020). Patient and caregiver perspectives on terms used to describe kidney health. *Clinical Journal of the American Society of Nephrology*, 15(7), 937-948.

<https://doi.org/10.2215/CJN.00900120>

Ulrich, B., & Kear, T. (2015). Patient safety culture in nephrology nurse practice settings: Results by primary work unit, organizational work setting, and primary role. *Nephrology Nursing Journal*, 42(3), 221-236.

Ulrich, B., & Kear, T. (2018). The health and safety of nephrology nurses and the environments in which they work: Important for nurses, patients, and organizations. *Nephrology Nursing Journal*, 45(2), 117-139.

University of British Columbia (n.d.). National framework assessment of interprofessional teams.

https://health.ubc.ca/sites/health.ubc.ca/files/documents/CIHC_NationalFrameworkAssesmentTool_IPTeams.pdf

Upton, J., Fletcher, M., Madoc-Sutton, H., Sheikh, A., Caress, A.-L., & Walker, S. (2011). Shared decision making or paternalism in nursing consultations? A qualitative study of primary care asthma nurses' views on sharing decisions with patients regarding inhaler device selection. *Health Expectations*, 14(4), 374-382.

<https://doi.org/10.1111/j.1369-7625.2010.00653.x>

Van Humbeeck, L., Malfait, S., Holvoet, E, Vogelaers, D., De Pauw, M., Van Den Noortgate, N., & Van Viesen (2020). Value discrepancies between nurses and patients: A survey study. *Nursing Ethics*, 27(4), 1044-1055.

<https://doi.org/10.1177/0969733020906595>

van Mossel, C., Alford, M., & Watson, H. (2011). Challenges of patient-centred care: practice or rhetoric. *Nursing Inquiry*, 18(4), 278–289.

<https://doi.org/10.1111/j.1440-1800.2011.00523.x>

Vennedey, V., Hower, K., Hillen, H., Ansmann, L., Kuntz, L., & Stocket, S. (2020).

Patients' perspectives of facilitators and barriers to patient-centred care: Insights from qualitative patient interviews. *BMJ Open*, 10(5), 1-11.

<http://doi.org/10.1136/bmjopen-2019-033449>

Vickey, T. & Frechman, E. (2022). Continuation of hemodialysis in a patient with global hypoxic brain injury. *Journal of Hospice & Palliative Nursing*, 24 (2), E35-E40.

<https://doi.org/10.1097/NJH.0000000000000831>

Vincent, J., Shehabi, Y., Walsh, T., Pandharipande, P., Ball, J., Spronk, P., Longrois, D., Strom, T., Conti, G., Funk, G., Badenes, R., Mantz, J., Spies, C., & Takala, J. (2016). Comfort and patient-centred care without excessive sedation: The eCASH concept. *Intensive Care Medicine*, 42(6), 962-71.

<https://doi.org/10.1007/s00134-016-4297-4>

Vitri, N., Attias, M., Banayahu, M., Elharrat, K., & Hener, T. (2001). The social climate in chronic haemodialysis units as perceived by patients and nurses. *EDTNA/ERCA Journal*, 27(4), 178-180.

<https://doi.org/10.1111/j.1755-6686.2001.tb00173.x>

Wai, V., Chinybayeva, L., Chou, S., Luscombe, R., & Trask, M. (2020). The effects of priming (pre-orientation) on patients' transition to hemodialysis. *The Canadian Association of Nephrology Nurses and Technologists Journal*, 30(2), 18-26.

Westlake, D., Ekman, I., Britten, N., & Lloyd, H. (2022). Terms of engagement for working with patients in a person-centred partnership: A secondary analysis of

qualitative data. *Health & Social Care in the Community*, 30(1), 330–340.

<https://doi.org/10.1111/hsc.13406>

White, C., Perlman, R., Fantone, J., & Kumagai, A. (2010). The interpretive project: A creative educational approach to fostering medical students' reflections and advancing humanistic medicine. *Reflective Practice*, 11(4), 517-527.

<https://doi.org/10.1080/14623943.2010.505718>

Whittemore, R. (2000). Consequences of not "Knowing the Patient". *Clinical Nurse Specialist*, 14(2), 75-81.

Wilson, B., & Harwood, L. (2017). Outcomes for successful cannulation of the arteriovenous fistula: Perspectives from patients on hemodialysis. *Nephrology Nursing Journal*, 44(5), 381-388.

Wilson, B., & Harwood, L. (2018). Reaching consensus on outcomes for successful cannulation of an arteriovenous fistula: Patient and healthcare provider perspectives. *Nephrology Nursing Journal*, 45(4), 327-336.

Wilson, B., Harwood, L., & Oudshoorn, A. (2015). Understanding skill acquisition among registered nurses: The 'perpetual novice' phenomenon. *Journal of Clinical Nursing*, 24(23-24), 3564-75. <https://doi.org/10.1111/jocn.12978>

Wilson, B., Harwood L., Oudshoorn, A., & Thompson, B. (2010). The culture of vascular access cannulation among nurses in a chronic hemodialysis unit. *CANNT Journal*, 20(3), 35-42.

Wolff, E., & Hums, M. (2017). "Nothing About Us Without Us" – Mantra for a Movement. *Huffpost*. https://www.huffpost.com/entry/nothing-about-us-without-us-mantra-for-a-movement_b_59aea450e4b0c50640cd61cf

- Wood, A., Tocher, J., & Rodgers, S. (2019). Delivering direct patient care in the haemodialysis unit: A focused ethnographic study of care delivery. *Journal of Research in Nursing*, 24(8) 712-725. <https://doi.org/10.1177/1744987119883406>
- Wyld, K. (2017). The lived experience of moral distress for nephrology nurses who care for patients with chronic kidney disease. [Master's thesis, University of Calgary]. <https://prism.ucalgary.ca> doi:10.11575/PRISM/28234
- Yilmaz, K. (2013). Comparison of quantitative and qualitative research traditions: Epistemological, theoretical, and methodological differences. *European Journal of Education*, 48(2), 311-325.
- York University, Faculty of Graduate Studies (2017). Informed Consent Form template. <http://gradstudies.yorku.ca/current-students/thesis-dissertation/research-ethics/>
- Zomorodi, M. & Foley, B. (2009) The nature of advocacy vs. paternalism in nursing: Clarifying the 'thin line'. *Journal of Advanced Nursing* 65(8), 1746-1752. <http://doi.org/10.1111/j.1365-2648.2009.05023.x>

Appendix A: Sample Search Strategies from Literature Review

Sample 1: Database(s): Ovid MEDLINE(R) and In-Process & Other Non-Indexed Citations 1946 to January 19, 2021:

| # | Searches | Results |
|----|--|---------|
| 1 | "Patient Acceptance of Healthcare"/ | 48603 |
| 2 | Patient Acceptance of Healthcare.mp. | 48692 |
| 3 | Patient Participation/ | 26518 |
| 4 | "Patient Participation".mp. | 28119 |
| 5 | Patient Preference/ | 9007 |
| 6 | Patient Preference.mp. | 12819 |
| 7 | Patient Satisfaction/ | 83171 |
| 8 | Patient Satisfaction.mp. | 101673 |
| 9 | Preference, Patient.mp. | 61 |
| 10 | Satisfaction, Patient.mp. | 337 |
| 11 | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 | 183379 |
| 12 | Health Services Accessibility/ | 76712 |
| 13 | Health Services Accessibility.mp. | 77047 |
| 14 | Health Services, Indigenous/ | 3387 |
| 15 | Health Services, Indigenous.mp. | 3402 |
| 16 | Hospitals, Rural/ | 4923 |
| 17 | Hospitals, Rural.mp. | 4959 |
| 18 | Medically Underserved Area/ | 7096 |
| 19 | Medically Underserved Area.mp. | 7163 |
| 20 | Rural Health/ | 23512 |
| 21 | Rural Health.mp. | 38984 |
| 22 | Rural Health Services/ | 12994 |
| 23 | Rural Health Services.mp. | 13406 |
| 24 | Rural Nursing/ | 111 |
| 25 | Rural Nursing.mp. | 392 |
| 26 | Rural Population/ | 61004 |
| 27 | Rural Population.mp. | 64827 |
| 28 | Center*, Rural Health.mp. | 8 |
| 29 | Communit*, Rural.mp. | 100 |
| 30 | Health, Rural.mp. | 69 |
| 31 | Health Cent*, Rural.mp. | 17 |
| 32 | Health Service*, Rural.mp. | 11 |
| 33 | nonmetropolitan.mp. | 718 |
| 34 | non-metropolitan.mp. | 552 |
| 35 | nonurban.mp. | 481 |
| 36 | non-urban.mp. | 598 |
| 37 | Nursing, Rural.mp. | 8 |
| 38 | Population*, Rural.mp. | 121 |
| 39 | reservation.mp. | 2077 |
| 40 | rural.mp. | 170315 |
| 41 | Rural Communit*.mp. | 11967 |
| 42 | Rural Health Cent*.mp. | 767 |
| 43 | Rural Hospital*.mp. | 3916 |
| 44 | Service*, Rural Health.mp. | 5 |
| 45 | "small town".mp. | 1782 |
| 46 | village*.mp. | 31453 |
| 47 | 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 | 268416 |
| 48 | (Renal Dialysis or Renal Replacement Therapy or Nephrology Nursing or end-stage renal disease or hemodialysis or nephrology nurse or nephrology nursing or renal dialysis or renal replacement therapy).af. | 145924 |
| 49 | 11 and 47 and 48 | 56 |

Sample 2: Search Strategy from ProQuest November 27 2020

Adapted from PDF GENERATED BY PROQUEST.COM

| Set No. | Searched for | Databases | Results |
|---------|---|--|---------|
| S1 | (noft(Nurse-Patient Relations/) OR noft(Patient-Centered Care/) OR noft(Patient Participation/) OR noft(Patient Preference/) OR noft(Patient Satisfaction/) OR noft(Physician-Patient Relations/) OR noft(Professional-Patient Relations/)) AND PEER(yes) | Nursing & Allied Health Database | 11327 |
| S2 | (noft(active patient involvement) OR noft(client) OR noft(collaborative) OR noft(cultural competence) OR noft(culturally appropriate care) OR noft(culturally safe) OR noft(expert patient) OR noft(holistic) OR noft(patient centred) OR noft(patientfocused)) AND PEER(yes) | Nursing & Allied Health Database | 7480 |
| S3 | S1 and S2 | Nursing & Allied Health Database These databases are searched for part of your query. | 1662 |
| S4 | S1 or S2 | Nursing & Allied Health Database These databases are searched for part of your query. | 17145 |
| S5 | (noft(relational) OR noft(responsive) OR noft(therapeutic relationship) OR noft(patient satisfaction) OR noft(patient perception) OR noft(patient experience) OR noft(patient perspective) OR noft(patient view)) AND PEER(yes) | Nursing & Allied Health Database | 26708 |
| S6 | S4 or S5 | Nursing & Allied Health Database These databases are searched for part of your query. | 35454 |
| S7 | (noft(Renal Dialysis/) OR noft(Renal Replacement Therapy/) OR noft(Nephrology Nursing/) OR noft(end-stage kidney disease) OR noft(endstage renal disease) OR noft(hemodialysis) OR noft(nephrology nurse) OR noft(nephrology nursing) OR noft(renal dialysis) OR | Nursing & Allied Health Database | 4478 |

| | | | |
|-----|--|--|------|
| | noft(renal replacement therapy)) AND PEER(yes) | | |
| S8 | S6 AND S7 | Nursing & Allied Health Database These databases are searched for part of your query. | 513 |
| S9 | (noft(Health Services, Indigenous/) OR noft(Hospitals, Rural/) OR noft(Medically Underserved Area/) OR noft(Rural Health/) OR noft(Rural Health Services/) OR noft(Rural Nursing/) OR noft(Rural Population/) OR noft(nonmetropolitan) OR noft(nonurban) OR noft(rural)) AND PEER(yes) | Nursing & Allied Health Database | 5503 |
| S10 | noft(S) AND S9 | Nursing & Allied Health Database These databases are searched for part of your query. | 2253 |
| S11 | noft(S) AND S9 | Nursing & Allied Health Database These databases are searched for part of your query. | 2253 |
| S12 | (noft(S) AND S9) AND PEER(yes) | Nursing & Allied Health Database These databases are searched for part of your query. | 2253 |
| S13 | (noft(S) AND S9) AND PEER(yes) | Nursing & Allied Health Database These databases are searched for part of your query. | 2253 |
| S14 | (noft(S) AND S9) AND (subt.exact("adult") AND PEER(yes)) | Nursing & Allied Health Database These databases are searched for part of your query. | 1300 |
| S15 | (noft(S) AND S9) AND (subt.exact(("middle aged" OR "aged" OR "young adult") AND "adult") AND PEER(yes)) | Nursing & Allied Health Database These databases are searched for part of your query | 923 |

| Sample excerpt from EBSCO host | | Searching: CINAHL Plus with Full Text |
|---|---------|---------------------------------------|
| Search Terms | Details | |
| S1 "Nurse-Patient Relations/ OR Patient-Centered Care/ OR Patient Participation/ OR Patient Preference/ OR Patient Satisfaction/ OR Physician-Patient Relations/ OR Professional-Patient Relations/" | 15,409 | |
| S2 "active patient involvement OR client OR collaborative OR cultural competence OR culturally appropriate care OR culturally safe OR expert patient OR holistic OR Indigenous-centred OR patient centred OR patient-focused OR relational" | 14,878 | |
| S3 "responsive OR therapeutic relationship OR patient satisfaction OR patient perception OR patient experience OR patient perspective OR patient view" | 8,405 | |
| S1 AND S2 AND S3 | 246 | |

Appendix B: Introductory Letter

May 3, 2021

Dear Hemodialysis Nurse;

Re: Patient-centred Nursing Care in Hemodialysis

As a retired hemodialysis nurse I am planning a study with the aim of discovering and describing the perspectives and experiences of hemodialysis nurses about providing patient-centred care in hospital in-centre and satellite units across Ontario, in urban and rural settings. This invitation is being sent with the hopes that some of you from various settings will be interested and willing to participate.

If you accept the invitation I would send you an e-mail with two documents attached – a consent form and a form for you to provide information such as your age, how long you have been a nurse, how long you have been a hemodialysis nurse, what type of unit you work in, and so on. You will be asked to provide a pseudonym to ensure confidentiality is maintained. After receiving the documents I would contact you to arrange an interview over Zoom at your convenience, which would take approximately 30 to 60 minutes.

Your questions are very welcome – please feel free to contact me at bhil@yorku.ca for further information.

You do not need to be a member of CANNT to participate in this study, so please share this information with other Ontario hemodialysis nurses.

Thank you for your kind consideration.

Yours truly,

(Miss) Billie Hilborn, RN, CNeph(C),

BScN, MHSc (Bioethics), PhD student

Appendix C:**York University, Faculty of Graduate Studies****Informed Consent Form****Date:** May 3, 2021**Study Name:** Patient-centred Hemodialysis Nursing Care**Researcher name:**

Principal Investigator: Billie Hilborn, PhD Student, Faculty of Nursing, York University

Contact information: bhil@yorku.ca

Purpose of the Research:

The purpose of the research is to discover and describe the perspectives of hemodialysis nurses in providing patient-centred care.

What You Will Be Asked to Do in the Research:

Research participants are to answer each question to the best of their ability and knowledge and ask questions if unclear. The estimated time commitment is approximately one hour.

Risks and Discomforts:

No risks or discomforts are foreseen due to your participation in the research, however if answering a question causes discomfort, please inform the researcher.

Benefits of the Research and Benefits to You:

Benefits of the research will be to promote patient-centred hemodialysis nursing care, and benefits from participating will be to contribute to this project.

Voluntary Participation and Withdrawal:

Your participation in the study is completely voluntary and you may choose to stop at

any time. Your decision not to volunteer, to stop participating, or to refuse to answer particular questions will not influence the nature of the ongoing relationship you may have with the researchers or study staff, or the nature of your relationship with York University either now, or in the future. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality:

Unless you choose otherwise all information you supply during the research will be held anonymously and in confidence. Your identifying information will be held securely by the Principal Investigator and not included in any presentation or publication because a pseudonym will be used. Your responses to interview questions will be recorded, and the researcher will use handwritten notes to describe pertinent details. Hard copies of your data will be safely stored in a locked file cabinet, and electronic files will be securely stored on an encrypted storage device and maintained in password-protected computer files. Only the researcher and members of her dissertation committee will have access to this information. Data will be safely stored throughout the dissertation process then archived at the York University data repository in an anonymized manner. Confidentiality will be provided to the fullest extent possible by law.

The data collected in this research project may be used in an anonymized form by members of the research team in subsequent research investigations exploring similar lines of inquiry. Such projects will still undergo ethics review by the HPRC, our institutional REB. Any secondary use of anonymized data by the research team will be treated with the same degree of confidentiality and anonymity as in the original

research project. Findings will be reported through class and conference presentation(s), PhD dissertation, and article(s) published in professional journals.

Questions About the Research?

If you have questions about the research in general or about your role in the study, please feel free to contact me at bhil@yorku.ca or my supervisor, Dr. Mina Singh, at minsingh@yorku.ca. You may also contact the Nursing Graduate Program Director, Dr. J. Choiniere at York University at gradnurs@yorku.ca or 416-736-5271.

This research has received ethics review and approval by the Delegated Ethics Review Committee, which is delegated authority to review research ethics protocols by the Human Participants Review Sub-Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process or your rights as a participant, please contact the Senior Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

I _____ consent to participate in the study Patient-centred Nursing Care in Hemodialysis conducted by Billie Hilborn. I understand the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature _____
Participant

Date _____

Signature _____
Principal Investigator

Date _____

Additional consent for Zoom recording:

I consent to my interview being conducted and recorded through Zoom.

Participant

Date

Principal Investigator Signature

Date

Appendix D: Sample Demographic Questions

What pseudonym (fictitious name) would you prefer to use to maintain anonymity?

What is your age? _____ years

What is your gender? _____

Education

What is your highest level of education?

- College/trade school Bachelor degree Graduate degree

Registration:

- Registered Nurse Registered Practical Nurse

Length as a Nurse

- Less than 6 months 3-5 years
 6 months to 1 year More than 5 years: # of years _____
 1-2 years

Length as a Hemodialysis Nurse

- Less than 6 months 3-5 years
 6 months to 1 year More than 5 years: # of years _____
 1-2 years

Certification

Are you certified in Nephrology (CNephC) from the Canadian Nurses Association?

- Yes, continuously since _____ No
 Previously certified but did not renew

Current Employment Status

- Full-time (35+ hours/week) Part-time (1-34 hours/week)
 Other: Please specify: _____

Employment Setting

What type of hemodialysis setting are you employed in?

- Urban Hospital in-centre
 Rural Hospital satellite
 Other: Please specify _____

Treatments

What type of hemodialysis treatments do you provide?

- Acute Chronic Acute and Chronic Nocturnal

How many patients are do you provide care for each hemodialysis session? _____

On Call

Are you assigned to on-call hemodialysis?

- No Yes: how often? : _____

Appendix E: Interview Guide

Probing questions will be asked when needed:

1. What are your thoughts about providing hemodialysis nursing care?

Probes: what is important to you in this experience? What is surprising? What is challenging?

2. What do you enjoy most and least about providing hemodialysis nursing care?

3. Have you heard the term 'patient-centred care' before?

Probes: When? Where? Have you had formal education about it?

4. How does the organization where you work promote patient-centred care?

5. Based on what you think patient-centred hemodialysis nursing care should be, what helps you provide it?

Probes: what hinders you?

6. Is there anything else you would like to add?

Appendix F: Excerpts from Audit Trail

January 2022: Since the recruitment process through CANNT yielded poor results, other methods of recruiting were considered. In my proposal I had indicated that the College of Nurses of Ontario could be contacted, however that route was decided against since the option of ‘hemodialysis’ was not something nurses could select when renewing their annual license – they could only select ‘nephrology’ as an area of care. This had the potential to yield too many nurses who did not meet the inclusion criteria of being a front-line hemodialysis nurses who worked full or part-time and would create a great deal of completely unnecessary work. I therefore decided to use the list of Ontario hemodialysis units which had been accessed on the CIHI website and began generating contact information for all appropriate units with the idea of contacting hemodialysis unit managers to request that they distribute the invitation to nurses. This proved to be more difficult than anticipated. Several units provided phone numbers, and none provided email addresses. When contact was made by phoning some units I was directed to make the approach through the Communications Department or Research Unit, which was done.

February 2022: The second and third interviews occurred on January 31, 2022 and the fourth on February 1. The interview guide was adjusted after piloting in the first two interviews to add a question about the impact of COVID because both had mentioned it and when I asked the third he said I should add it as a question because it has had such an impact. An adjustment was made to the first question to address the awareness of ‘client’ and ‘customer’. The question of whether the organization promotes patient-centred care was moved up in the list to improve the flow. It was interesting as

interviews proceeded to see how differently the nurses answered the same question. It was also beneficial that I have a strong background in hemodialysis because it made comprehension of what they were talking about so much easier – I had the ‘insider’ knowledge of the language and the processes. Only hemodialysis nurses know what ‘changeover’ means and understand the tension that patients experience relating to transportation before and after treatment. The uniqueness of the setting is clear. At the same time I am an ‘outsider’ because I did not work in their units.

Monday March 20, 2023 – Happy Spring, which begins today at 5:50 pm!

I am working on a drastic revision to Chapter 4, which is very time-consuming because it entails incorporating relevant changes in the ‘track changes’ feedback from two committee members and combing through the existing version to move important quotes into the new themes. It is an interesting process because it is making me think more and solidify my thoughts. I remain comfortable with my interpretation and new themes and am trying to write the chapter from a more abstract stance, but it is difficult for my pragmatic brain.

Thursday February 1, 2024 – I have just sent the latest revision of the 5th and 6th chapters to my supervisor and will await her feedback before sending it to the committee members in advance of the next meeting on February 27th at 3. I am hoping that they will be pleased with the revisions and that I can move forward to the final defense to complete this process. I am still very engaged in my topic and have enjoyed learning how to do research and more specifically how to write the dissertation. So many revisions but with each one I have learned something, and the end result is improving.

Appendix G: Poem for Mr. Y

Why can't you see that I'm comfortably sleeping,
In spite of dialysis, on and off beeping?

My pain made me restless and grab at the lines
With my blood in the circuit. But now I'm just fine.

My pain is not here now. I sleep, quite content.
That 2 p.m. breakthrough was really potent!

Your clock says it's time for my 4 p.m. dose.
I wish that my wife had stayed here and was close.

My wife, had she stayed, would have said "Let him be -
He's comfortable, sleeping, quite peaceful to me!".

Don't wake me – I'm sleeping, I'm comfortable, see?
My pain is all gone now. Please, listen to me!!

My words are not yours, but my body speaks too –
My sleep is quite peaceful – a very loud clue!!

What happened to care being focussed on me?
I'm sleeping and pain-free! Oh why won't you see?

Pain Service says "Give him pills round the clock –
Plus a breakthrough injection when needed". Thanks, Doc!

But they're not in my bed, it is ME with the pain.
If you wake me right now, is there any real gain?

I'll take the pill later, when treatment has ended.
Your therapeutic window should not be offended.

My nurses, they argued, but I slept right through it.
Please focus on me! Wake me now? Please, don't do it!

The 'choking precautions' should make you think twice
About waking me now. If you do it, not nice!!

Oh please let me sleep, do not wake me just yet.
Your pill will be safe in that cup for a bit!

I'm sleeping and peaceful, in fact, quite serene.
Disturb me, oh please, no! – that's really quite mean!

August 3, 2004