EXPLORING NURSING PRESENCE AS EXPERIENCED BY PARENTS IN PEDIATRIC ONCOLOGY

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ABSTRACT

Background: Family caregivers of children living with cancer are overwhelmed with feelings of fear, anxiety, powerlessness, isolation, and distress when their children undergo cancer treatment. Using the family-centered care framework, nurses are placed in a unique position to support family caregivers undergoing this complex health experience through nursing presence. Nursing presence has been linked with improved physical and mental well-being for patients during hospitalization. Although there is existing nursing literature on the role of nursing presence in nurse-patient relationships and its benefit during hospitalization, there is a gap concerning the experience of nursing presence from the perspective of parents of children with cancer.

Purpose: The purpose of this qualitative study was to explore nursing presence as experienced by parents of children with cancer during cancer treatment. The research question guiding this study was: *How do parents of children receiving cancer treatment experience and describe nursing presence in a pediatric oncology unit?*

Methods: This study was conducted using a descriptive phenomenological approach as described by Giorgi. The study included 10 participants of children with cancer aged birth to 14 years receiving treatment for cancer at a local hospital in mid-Western Canada. Purposive sampling was utilized in the selection of participants. One to two in-depth face-to-face and Zoom video call interviews with the participants were conducted using a semi-structured interview guide. The five stages of analysis as described by Giorgi were used to analyze the data.

Findings: Based upon the participant's descriptions, a structure of nursing presence in pediatric oncology emerged which included six constituent features: An attitude of presence, a source of encouragement, clinical experience and expertise, therapeutic communication, family

involvement, and a sense of home away from home. Most notably, nursing presence was experienced by parents as characteristically by both the 'being' and 'doing' of presence, each of which were equally important.

Conclusion: The experiences described by parents provided rich and nuanced insights into what it meant for parents to experience nursing presence in a pediatric oncology setting. This study provides a structure for this meaning making and expounds on its constituent features, to describe what nursing presence resembled when experienced by parents of children with cancer.

Practice Implications: This study informs nursing practice, policy, and education in ways that are likely to enhance the care and subsequent well-being of pediatric oncology patients and their families.

Key words: Nursing presence, pediatric oncology, descriptive phenomenology, family-centered care, parents

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DEDICATION

This work is dedicated to the loving memory of my father Morrison Mcharo and my mother Charity Mcharo. We did it.

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LIST OF ABBREVIATIONS

ALL- Acute Lymphiod Leukemia

CANO/ACIO- Canadian Association for Nurses in Oncology/ Association Canadienne des infirmieres en oncologie

ER- Emergency Room

FCC- Family-Centered Care

IPFCC- Institute for Patient- and Family- Centered Care

PICC- Peripheral Inserted Central Catheter

PPE- Personal Protective Equipment

CHAPTER 1

1.0 Introduction

The changing face of our healthcare today has posed a threat to nurses' relationships with patients. Marked with different communication styles than prior generations, preferring to communicate via text, email, and other technology assisted methods, versus face-to-face communication, the interpersonal interchange that traditionally took place at the bedside is at risk of erosion (Turpin, 2014). The everyday tasks, the lack of time, and the perceived need to maintain distance from patients in order to remain professional and get the job done have prevented nurses from having therapeutic relationships with their patients (Melnechenko, 2003). Furthermore, due to social distancing and use of personal protective equipment (PPE) the Corona virus pandemic has taken away the intimacy of non-verbal communication and physical contact that many patients and their caregivers rely on for comfort (Brown, 2020). Many health care professionals have had to focus more on procedures and methods than on being there and being with their patients (Covington, 2005). As a result, nursing presence, once regarded a critical component in the delivery of quality nursing care (Gardner, 1992) is at risk for decline.

The purpose of this research was to explore nursing presence, as experienced by parents of children with cancer during treatment. Childhood cancers are life-threatening diseases that are universally distressing and potentially traumatic for children and their families at diagnosis, during treatment, and beyond (Kazak & Noll, 2015). As children undergo cancer treatment, parents are highly involved in their medical care and see themselves as active members of the health care team. Some parents cope well with the experience while others report psychosocial difficulties. The quality of relationships between the family and the health care team may shape parental adaptation to their child's cancer experience (Salvador, 2019). Genuine relationships

create meaning and trust which facilitate healing for the child and their parent, while enhancing the nurse's clinical experience (Doona et al., 1997). In part, these quality relationships may be grounded in nursing presence.

This research originated from the results of my work as a Master of Nursing student in the Adventist University of the Philippines. Throughout my nursing education, it was emphasized that good nursing practice addressed the physical, mental, and spiritual dimensions of a person. Holistic nursing care was the ideal form of nursing. However, during my Master's program I found there was no literature addressing spiritual nursing care in the emergency room (ER). There were numerous studies on spiritual nursing practices in long term care and for patients with chronic illnesses (Ferrel et al., 2013; Ho et al., 2018; Mcharo & Polancos, 2016). Spiritual nursing in the ER did not appear to be a priority. On the contrary, my personal experiences working in the ER as a student nurse and later as a nurse intern contradicted this assumption. I had experienced intimate and authentic encounters between nurses and patients. In the ER, I had observed nurses look a patient in the eyes, hold their hand and tell them "everything is going to be okay," or that tap on a family member's shoulder that was in someway reassuring and provided hope. I had experienced a nurse walk in a waiting room, where a family anxiously sat waiting to receive some news on the progress of a loved one, and instinctively felt the nurse's compassion and empathy, and realized that somehow, we were all one at that moment and having the same encounter. For me, that was a spiritual experience. The ability to feel and be with the other in such difficult times had to be spiritual.

Therefore, for my Master's thesis, I explored practices and barriers of spiritual nursing care among nurses in the ER. Presence emerged in my findings as one of the practices (Mcharo & Polancos, 2016). Most responses from my participants were based on religious practices such

as prayer and reading of religious scripture. Out of 17 participants, only one stated they used "presence" as a spiritual care practice in the ER. This was the first time I was hearing of "presence" as spiritual care. As I conceptualized this study, I was reminded of an experience working in a pediatric ward of a Teaching and Referral Hospital in Kenya. An 11-year-old male patient was adamant about receiving his intrathecal chemotherapy treatment unless I was in that treatment room. I do not recall saying or doing much while with him. However, I remember placing my hand on his shoulder as he cried and received his treatment. I asked myself "was this nursing presence?" In retrospect, I had no idea that I would be conducting research exploring "being there" as one of my roles working with those pediatric patients.

I must acknowledge that my history and Christian background may have tremendously contributed to my interest in this nursing phenomenon and influenced my way of being and thinking. Great memories of my childhood are clouded with trauma and endless need. Being the last of four children, and having a father who struggled with mental illness, I did not understand much of what was happening at the time. But I remember being sad, anxious, and afraid. Although the situation at home was tough and things were uncertain, I knew I was loved. Our close relationship as a family was what we had. Growing up in a Christian home and going through my experience, I believe that God's presence has been with me throughout my life, showing up when I had no one else to turn to. Therefore, I try as much as I can to be present for others. A presence that comforts, encourages, and reassures. I have also come to value relationships. My friends and family have been a source of joy and comfort in my life. It is my hope that this study contributes to the development of presence as a concept in nursing, and aids in improvement of quality relationships in health care, specifically, in pediatric oncology.

In this chapter, a background of nursing presence is provided to appreciate the evolution of the concept in nursing. A philosophical framework guiding the study is discussed to help understand my epistemological and ontological positions and the theoretical framework proposed for this study is presented. A detailed discussion of the theoretical framework guiding this study is found in a later chapter. The purpose, research question, relevance of the study, and an introduction to the method of inquiry of this study are also included. The chapter concludes with a description of the organization of this manuscript-style dissertation.

1.1 Background

According to Statistics Canada (2019), cancer is ranked the second leading cause of death in children aged between 1-14 years. A diagnosis of cancer and management of its symptoms during cancer treatment is overwhelming for children and their parents. The limited control and understanding of the hospital environment and treatment, may lead to anxiety, distress, and diminished hope for patients and family caregivers (Crespo et al., 2016). As children undergo cancer treatment, some parents cope well with the experience while others report psychosocial difficulties. The quality of relationships between the family and the healthcare team may shape parental adaptation to their child's cancer experience (Salvador, 2019). To best support families undergoing complex health care, pediatric nursing has adopted a philosophy of family-centered care (FCC) (Feeg et al., 2018). FCC requires a collaborative relationship between families and professionals with goal of promoting health and well-being of individuals and families while they re-establish their control during hospitalization (IPFCC, 2019). In part, these collaborative relationships may be grounded in nursing presence. The term presence has been used in numerous health disciplines and is considered a trait found in nursing care that when practiced

may facilitate healing and improve satisfaction for the patient, family caregiver, and the nurse (Kostovich, 2012).

1.1.1 Presence

The word presence is derived from the Latin noun praesen: Prae meaning in front; and sens, meaning being (Doona et al., 1997). As a noun that has existed in the English language since the Middle Ages, "presence" has acquired various shades of meaning dependent on the context or discipline in which the word is used. The disciplines in which presence has been used include psychology, sociology, counselling, education, and management (Turpin, 2014). Other disciplines as examined by Lombard and Ditton (1997) are communications, cognitive science, computer science, and engineering. Terminology such as caring, empathy, therapeutic use of self, support, nurturance (Finfgeld-Connett, 2006), awareness, stillness, consciousness (Tolle, 1999), compassion (Seale, 2016), and mindfulness (Baldini et al., 2014) are amongst the few that either overlap or are used together with presence. Although presence is a concept that cuts across disciplines, its evolution in nursing is rooted in religious mysticism and philosophical existentialism (Smith, 2001).

1.1.1.1 Presence and Religion

Presence was originally used as a liturgical concept referring to the spiritual presence of a supreme being (Osterman & Schwartz-Barcott, 1996). Religion has used God as a metaphor for the universe of what is unknown and unknowable. Judaism, Islamism, and Christianity have used the concept of presence for centuries as exemplified by passages from the Bible and the writings of the Christian mystics (Smith, 2001). Smith (2001) demonstrates how presence is understood as a manifestation of the divinity to worshipers in the books of the Old Testament, and how the divinity manifested itself in the person of Jesus in the New Testament. Jesus himself however,

also communed with a presence that was beyond him (The book of John 17). Although the manifestation of this divine presence in religion is not sensory, to the conventional believer, God is the ultimate reality, and "present" everywhere, knowable through scriptural interpretation and is enhanced by faith and active participation in religious exercises such as communal prayer, meditation, and singing (Sheridan, 1999). Thus, in the biblical stories of Jesus's healings, the concept of presence arguably takes on a therapeutic function and thereby an antecedent with nursing presence is established (Smith, 2001).

1.1.1.2 Presence and Philosophy

Presence has closely been identified with three existential philosophers including Marcel (1951), Heidegger (1972), and Buber (1958), who have discussed the concept at length. Marcel, a French philosopher, speaks of presence as communion, a mystery of shared togetherness enabled by availability, intersubjectivity, and mutuality (Grumme et al., 2016). In his lecture on the question of being, Marcel (1951) states:

> The fact is that we can understand ourselves by starting from the other, or from others, and only by starting from them… Fundamentally, I have no reason to set any particular store by myself, except in so far as I know, I am loved by other beings who are loved by me. (p. 8)

Interpersonal relationships are a fundamental concern of his philosophy. According to Marcel, it is the existence of others that gives one an awareness of his own existence. Marcel's contribution to the understanding of presence was his belief that humanity is defined by one's capacity to be open and receptive to others (Smith, 2001). While Marcel reflected on presence and mystery, Heidegger reflected on presence and being (Grumme et al, 2016).

The German philosopher, Martin Heidegger, was concerned with the question of being (Sheridan, 1999). Therefore, he began his quest for the meaning of being with an exploration of how human beings are conscious of their existence (Smith, 2001). In his work, *Time and Being*, Heidegger (1972) identifies the mode of existence as "being-in-the-world which constitutes human being is the being of a self in its inseparable relations with a not-self, the world of things and other persons in which the self always and necessarily finds itself inserted" (Heidegger, 1972, p. 88). Heidegger (1972), also reflects on presence and being, stating that "being gives itself as presencing" (p. 32). Normal 'being' in Heideggerian view, means complete involvement in a dynamic interaction where subject and object are not separable, and only by stepping back and disconnecting from that involvement can a person perceive the elements of the situation (Sheridan, 1999). Similar to Marcel, Heidegger's self is affirmed in its consciousness of others. Blackham (1952) on Martin Heidegger reiterates:

> My being-in-the-world, in this sense of being constituted by my projects and by my relations with the objects which I make use of and develop as tools for realizing them, involves my being-with-others who are also in the world in the same sense. Here again, the existence of others is not merely accidental, nor a problem for thought, but is a necessity for thought, is constitutive of my being and implied in it. (p.90)

Dealing with philosophical basis for being, Heidegger rejected the cartesian thought of a dual reality, mental and physical domain, to explain the nature of human existence, using instead subjectivity of interpretation to describe being (Grumme et al., 2016). Though presence is not a concept overtly treated in Heidegger's work, the frequent definition of presence as "being there" used in nursing seems to have been inspired by associating the concept of presence with

Heidegger's notion of Dasein which literally means "there-being" (Smith, 2001). Being is, therefore, the most consistently used word for defining and describing presence.

For Buber, being is the very personal, individual, unique attribute, quality, or spirit which makes one human and is dependent upon the relationship between the "I" and the "thou" (Gilje, 1992). In his existential writings, the Jewish philosopher, Martin Buber (1958) described his philosophy of relationships characterized by two types of relations, subject to object (I-It) and subject to subject (I-Thou). An I-It relationship implies objectification of the other person and can never be presented with the whole being while an I-Thou relationship is characterized by true interest in the uniqueness of the other person to whom one is relating (Buber, 1965; Westerhof et al., 2013). Both relationships are essential, and a constant movement takes place from the I-Thou to the I-It relationship and vice versa. However, the I-Thou relationship is one of openness, directness, mutuality, and presence (Hanson & Taylor, 2000). It is in the I-Thou relationship where one becomes a presence, dialogue transcends communication, and both are embodied in communion (Grumme et al., 2016). According to Buber, in the I-Thou relationship, the individual takes a stand to be present with the other; that is, they join in the other's experience as it is being shared (Buber, 1965). It is in the I-Thou relationship where the whole person is being given in the relationship. Influenced by the work of Buber, Paterson and Zderad (1988), developed the humanistic nursing practice theory that proposed nurses consciously and deliberately approach nursing as an existential experience. Humanistic nursing embraces more than a benevolent technical competent subject-object one-way relationship guided by a nurse on behalf of the other. Rather it dictates that nursing is a responsible searching, transactional relationship whose meaningfulness demands conceptualization founded on a nurse's existential awareness of self and of other (Paterson & Zderad, 1988).

1.1.1.3 Presence and Nursing

Central to the concept of presence in nursing are interpersonal relationships. According to Smith (2001), Hildegard Peplau was the first nursing theorist to identify the nurse-patient relationship as being central to all nursing care after developing the nurse-patient relationship theory in 1952. Peplau defined nursing as a "significant, therapeutic, interpersonal process," (Peplau, 1952, p. 16). For Peplau, both verbal and nonverbal communication was cornerstone of therapeutic work. At a time when the nursing profession was growing, Peplau along with other nurse scholars of the 1950s and 1960s emphasized how theory development should be a goal for the discipline (Smith, 2001). Within this context of theory development in nursing, existentialism and the concept of presence formally entered nursing through the writings of Vaillot (1966) who had an educational background in both philosophy and nursing. Existentialism is an umbrella term applied to philosophies centering on the individual and that individual's relationship with the universe and/or the divinity (Smith, 2001). Vaillot (1966) argued that existentialism was the philosophy that nurses needed onto which their practice could be anchored. Vaillot used the term "commitment" as opposed to "presence" and her writings perceived the two terms as closely related. Vaillot (1966) describes a committed nurse as one whose:

> Involvement with her patient is but an overflow of her inner plenitude, of her richness of being. To be sure, the very fact that she gives of her self renders her vulnerable to the potential suffering inherent in any close human relationship, but this gift of self is, in itself, a source of personal growth for the nurse. (p.501)

Guided by the work of Vaillot, Ferlic (1968) explicitly mentioned the concept of presence. Citing the work of Buber and Marcel in her article "Existential Approach in Nursing," Ferlic (1968) describes presence as an interaction between the patient and the nurse of "mutual

giving and receiving" in a "situation" (p. 31). Ferlic's chief aim was to demonstrate that Marcel's and Buber's philosophies were applicable to nursing practice and nursing education (Ferlic, 1968), and also made a case for existentialism as the best philosophical foundation for the profession (Doona et al., 1997).

With existentialism as a philosophical foundation for the profession, Paterson and Zderad (1988), two psychiatric mental health nursing theorists, developed their theory of humanistic nursing that was based on Marcel's existentialism. Humanistic nursing prescribes that nursing is "responsible searching, transactional relationship whose meaningfulness demands conceptualization founded on a nurse's existential awareness of self and of other as opposed to a benevolent technical competent subject-object one-way relationship guided by a nurse on behalf of the other" (Paterson & Zderad, 1988, p. 3). Paterson and Zderad (1988) also reflected on the work of Buber and stated "nurse and patients can view themselves and the other as objects and as subjects or in any variation or combination of these ways… such subject-object or "I-It" relationships differ essentially from subject-subject or "I-Thou" relationships," (p. 27).

Presence as demonstrated in humanistic nursing entails a kind of "being with" and "being there" that determines the quality of presence experienced (Paterson & Zderad, 1988, p. 14). Paterson and Zderad (1988) described presence as being available or open in a situation with a wholeness of one's individual being. Based on the philosophies of Marcel and Buber, the significance of existentialism and presence, in the work of Vaillot (1966), Ferlic (1968), and Paterson and Zderad (1988) provided a foundational synthesis of the concept of presence, providing nursing with a philosophic concept for its unique practice. The concept of presence in nursing has since evolved and gathered several meanings and definitions. Hines (1992)

acknowledges that the struggle in describing presence in nursing literature is thought to be related to the simultaneous events that occur during presence.

In nursing literature, some authors have used presence as an instrument of care, also referred to as “presencing” (Benner, 1984) while others have applied an existential understanding of presence (Gilje, 1992). However, presencing has sometimes been used to refer to a deeper existential understanding of presence (Pettigrew, 1990). While presencing may have been used to describe the doing of presence, Doona and colleagues (1997) argue that “techniques are a creation of science whereas presence is the creation of philosophy” (p. 11). Nursing practice encompasses action and interventions for the clients which is based in physical science while “being with” is based in philosophy. The two distinctions should not be ignored because presencing is a result of reference to presence in a utilitarian way than an existential philosophical way (Doona et al., 1997). The use of the term presence and presencing demonstrates the different understandings and application of the concept in nursing literature and the confusion that can arise. Nevertheless, the word presence is more commonly used than presencing, and different nursing literature has endeavoured to fully capture the nurse actions during presence.

1.1.2 Purpose and Research Question

The overall purpose of this dissertation was to explore nursing presence as experienced by parents of children with cancer during cancer treatment. The specific aim was to draw on parents’ lived experiences in order to determine the essence of nursing presence when a child was in treatment of cancer. The research question that guided this inquiry was: *How do parents of children receiving cancer treatment experience and describe nursing presence?*

1.1.3 Relevance to Nursing

Although nursing presence is foundational for professional nursing practice (Gardner, 1992) and has known positive outcomes, how parents of children with cancer experience nursing presence remains unknown. Exploring nursing presence in a pediatric oncology setting will enable us to understand the essence of the phenomenon as it is experienced by parents in a specific setting. Furthermore, describing the essence of presence in a pediatric oncology setting will make the concept tangible and less ambiguous, thus, enabling us to identify how it can be cultivated amongst pediatric nurses. Research on nursing presence may contribute to provision of quality care and may promote healing by developing better relationships between nurses and family caregivers. Therefore, understanding presence will potentially provide a remedy for depersonalization of healthcare, allowing family caregivers to have a better hospitalization experience such as an enhanced quality of life, feelings of safety and security (Cantrell, 2007), coping, self-esteem, and decreased stress (Finfgeld-Connet, 2006) as their child goes through the cancer journey. Because nursing presence has been found to improve patient satisfaction (Godkin, Godkin & Austin, 2002; Penque & Kearney, 2015), this study provides a foundation to explore the development of new models that may improve care provided to parents of children with cancer and, thus, influence policy. To address the gap in understanding nursing presence as experienced by parents of children with cancer, I used a descriptive phenomenological approach based on the philosophy of Husserl (1962) as described by Giorgi (2009) for the method of inquiry.

1.2 Philosophical Framework

In order to deepen the understanding of parents' experiences of nursing presence, critical realism (Bhaskar, 1978) was used as a philosophical lens during this study. Critical realism is a

philosophy of science that has grown out of weakness of positivism and relativism, aiming to hold onto the insights of both while trying to avoid the pitfalls of either (Clark, 2003; Denzin & Lincoln, 2005; Schiller 2015). This philosophy holds that the world is made of layers, where reality exists and is not limited to our human interpretation and construction of it (Littlejohn, 2003). Importantly, while seeking the truth, critical realism recognizes that different representations of truth can exist, and it can embrace knowledge from a wide range of approaches. Critical realism uses a unique, stratified ontology to distinguish between three different domains of what we hold to be true namely, the: a) real, which is independent of the thought, awareness, and even existence of human beings; b) actual, where human beings experience a portion of events caused in the real domain; and, c) empirical, the final layer that consists of human experiences associated with the actual domain (Schiller, 2015).

I closely relate with a critical realist ontology because it acknowledges the underlying importance of personal factors (experience and meaning) and contextual factors (place and cultural norms) in influencing health outcomes, and the interplay of these factors (Sword et al., 2012). I must acknowledge that my Christian background may have tremendously contributed to my interest in the phenomenon of nursing presence and shaped my thinking. I grew up in a Christian home believing in God. My idea of God and truth is influenced by Christian teaching. Consequently, I believe in a *presence* of God that is beyond the physical. Therefore, a critical realist ontology informs my way of being, and has influenced this study. As a critical realist, my epistemology acknowledges that there are multiple ways of knowing (Carper, 1978) that are constructed from a combination of one's own experience, perceptions, and standpoint. There is a deeper reality than that which we can observe and experience. Human beings are described as "in-the-world" and nurses are guided to recognize the complexity and uniqueness of each

person's relating and experiencing (Mitchell & Cody, 1992, p. 57). Nursing presence is a concept engrained in nurse-patient relationships (Gardner, 1992) and may be influenced by unique subjective experiences. As I explored nursing presence in this research, I recognized that parents may be informed by their history, past experiences, cultures, or daily practices that are taken for granted which inform their reality. Critical realism helps uncover these layers from different realities and develop a richer and more informed essence of nursing presence.

1.3 Theoretical Framework

After a diagnosis of cancer, parents get deeply involved with their child’s health care demands to perform daily medical tasks including treatments and medications, manage the side effects of treatment, meet multiple health professionals, and care for the child during periodic hospitalizations (Feeg et al., 2018). Therefore, exploring nursing presence within a family-centered care (FCC) framework informed this study, since parents are in the frontline of their child’s care having direct contact with their nurses and other health care providers. FCC is a healthcare delivery framework based on the promotion of a relationship between family caregivers and health care providers acknowledging the important role of the family in patient care (Feeg et al., 2018). This relationship results in a mutual therapeutic benefit between the family caregivers and the nurse. A more detailed discussion on nursing presence in FCC is presented in Chapter 3.

1.4 Organization of the Dissertation

This dissertation is organized and presented in a Manuscript-style format in which three manuscripts are described and integrated into the whole dissertation. The first chapter includes an introduction to the overall dissertation research including a background to the concept of study, and the philosophical and theoretical framework. Chapter Two contains the first

manuscript titled: Nursing Presence in Pediatric Oncology: A Scoping Review. This manuscript was published in the Journal of Pediatric Oncology Nursing. A scoping review was conducted in order to understand the current state of knowledge related to nursing presence in pediatric oncology. Findings in this chapter include several themes related to nursing presence and can be used to improve quality of care when applied in pediatric oncology nursing. In this chapter, the gaps in nursing literature are identified and justification to address the research question in this dissertation is provided.

Chapter Three is a presentation of the second manuscript titled: Improving Family Nursing Care through Nursing Presence and Family-Centered Care which has been submitted to the Journal for Specialists in Pediatric Nursing. This chapter demonstrates how nursing presence is linked to family-centered care (FCC), the theoretical framework guiding this study. FCC is an approach to ensure that families are involved in their child's care and is centered upon relationships between the nurse and the patient's family. In this chapter, the role of nursing presence in the FCC model as described by the Institute for Patient- and Family-Centered Care is examined. A case study identifying the intertwined relationship between nursing presence and FCC in pediatric oncology is presented.

The final manuscript is presented in Chapter Four and is titled: Exploring Nursing Presence as Experienced by Parents in Pediatric Oncology. This manuscript was submitted to the Journal of Pediatric Nursing. In Chapter Four, descriptive phenomenology, the method of inquiry used in this dissertation, is described and an in-depth analysis of data collected is presented. This chapter provides a description of the essence of nursing presence as described by parents in pediatric oncology and each constituent of its structure is presented. A model illustrating the structure of nursing presence as described by parents in pediatric oncology is presented,

demonstrating the findings in this study. A discussion of the findings is also included in this manuscript.

Lastly, Chapter Five offers an analysis of all three manuscripts in relation to the objectives of the study. This chapter offers an integration of the findings in relation to the theoretical and philosophical framework used to guide this study. This final chapter also provides the implications of the findings to nursing education, research and practice, and an overall conclusion of the dissertation. All manuscripts included in this dissertation have been revised to suit the formatting guidelines of each peer-reviewed journal.

1.5 Chapter Summary

Nursing presence is foundational in nursing practice and plays a significant role in establishing meaningful relationships inherent to FCC. Although nursing presence is foundational for professional nursing practice and has known positive outcomes, how parents of children with cancer experience nursing presence remains poorly understood. Guided by a critical realist philosophical lens, this study aimed to address this gap in knowledge by using a descriptive method of inquiry. This knowledge will provide a new understanding of nursing presence and, thus, will enhance the care provided to parents of children with cancer.

CHAPTER 2

2.0 Review of Literature

Nursing presence has been regarded as a significant concept in nursing practice that has known positive outcomes for patients and nurses (Mohammadipour, 2017). Although nursing presence has contributed to improvement in care and satisfaction of patient and nurses (Kostovich & Clementi, 2014; Penque, S., & Kearney, G., 2015), little is known about its contribution in pediatric populations. A scoping review was, therefore, conducted to identify available research on nursing presence in pediatric oncology, in order to draw conclusions regarding the overall state of research in this population (Arksey & O'Malley, 2005). What follows is a scoping review by Mcharo, Bally, and Spurr (2021) published in a peer-reviewed pediatric journal. This is the final edited and published version.

2.1 Manuscript 1

Mcharo, S. K., Bally, J., and Spurr, S. (2021). Nursing Presence in Pediatric Oncology: A Scoping Review. *Journal of Pediatric Oncology Nursing*, 1-15. https://doi.org/10.1177%2F10434542211041939

This manuscript was completed in collaboration with Dr. Bally and Dr. Spurr, my co-supervisors in this dissertation. This manuscript was titled: *Nursing presence in Pediatric Oncology: A scoping Review.* My contributions included: conceptualization, conducting the literature searches and critical appraisals, data analysis, writing of the initial draft and incorporating feedback from Dr. Bally and Dr. Spurr on subsequent drafts, and preparing and formatting the manuscript to meet journal guidelines. Dr. Bally and Dr. Spurr contributions included: Conceptualization, review and editing, providing critical feedback, and supervision. None of the articles retrieved in this scoping review had a direct inquiry into nursing presence in

pediatric oncology. This manuscript aligns with and supports the dissertation by identifying the gap in nursing knowledge from which the research question that guided this dissertation was developed.

2.2 Abstract

Background: Nursing presence creates meaningful and trusting relationships that facilitate healing for the patient and enhances the nurse's clinical experience. Although nursing presence has been linked to better health outcomes especially in chronic illnesses and end-of-life, little is known about its contribution in pediatric oncology.

Purpose: The purpose of this scoping review was to explore how nursing presence is understood and expressed in pediatric oncology.

Methods: Arksey and O'Malley's (2005) framework was used to guide the review, with Clark and Braun's (2013) thematic analysis process used for collating, summarizing, and reporting the results. Key search terms were developed for searches between January 1999 and July 2020 in CINAHL, MEDLINE, and Psych INFO databases. Initially, 4357 studies were identified with a final sample of 9 articles meeting specific inclusion and exclusion criteria. Gray literature retrieved from the search was used to inform the review.

Findings: Most notably, there is a limited understanding of nursing presence in pediatric oncology setting. However, findings revealed five themes that can be identified with nursing presence: Being With or Being There, Therapeutic Relationships, Communication, Family-centered Approach, and Perceived Outcomes of Nursing Presence. Nurses in pediatric oncology are in an ideal position to provide nursing presence in order to improve the quality of care in pediatric oncology settings.

Discussion: There is a need to establish a comprehensive evidence-based understanding of the construct of nursing presence in pediatric oncology that health care providers can utilize to enhance their clinical practice and health research.

Key Words: Nursing Presence, Oncology, Pediatric, Scoping review

2.3 Nursing Presence in Pediatric Oncology: A Scoping Review

Nursing presence creates meaningful and trusting relationships that facilitate healing for the patient, and enhances the nurse's clinical experience (Turpin, 2014). McKivergin (2009) describes nursing presence as a multidimensional state of being available, emphasizing the quality of being with a patient rather than doing for the patient. Although nursing presence is foundational for professional nursing practice (Gardner, 1992) and has been linked to better health outcomes (Finfgeld-Connet, 2006; Kostovich & Clementi, 2014) especially in chronic illnesses and end-of-life (Speakman, 2018), little is known about its contribution in pediatric oncology setting.

2.4 Background

Cancer remains one of the leading causes of death among children in Canada and the United States (Public Health Agency of Canada, 2012; Canadian Cancer Statistics Advisory Committee (CCSAC), 2019; Lin, Jay, & Howard, 2018; National Cancer Institute (NCI), 2020). In 2019, nearly 1000 children under the age of 14 were diagnosed with cancer in Canada (CCSAC, 2019). In the United States, an estimated 11,050 new cases of cancer will be diagnosed among children aged birth to 14 years in 2020, and about 1,190 children are expected to die from the disease (NCI, 2020). Having a child with cancer is an overwhelming physical, emotional, and psychological experience for both the child and the parents (NCI, 2020; Kars, Duijnstee, Pool, van Delden, & Grypdonck, 2007). After a cancer diagnosis, children and parents are faced with new health care demands such as performing daily medical tasks, managing side effects of treatment, and regular hospital visits (Feeg et al., 2018). These new demands are accompanied by feelings of insecurity, loss of control, fear, and despair for parents and their ill child (Alves et al., 2016). A stable environment and support from nurses are believed to have a beneficial impact on

such debilitating effects (Nicastro & Whetsell, 1999). Nurses are in an ideal position to provide support by developing a therapeutic relationship with the child and their parents through clinical expertise, interpersonal skills, and nursing presence (Anderson, 2007).

Nursing presence is a holistic and reciprocal exchange between the nurse and patient that exists within the context of a therapeutic relationship (Hessel, 2009). According to Kostovich et al. (2016), nursing presence occurs when the nurse performs physical tasks and psychomotor skills while concurrently establishing an emotional connection with the patient. Nursing presence is sometimes used to characterize nurse's physical presence, while at other times, it is used in a highly metaphysical way to depict a nurse's psychological and spiritual presence (Easter, 2000; Osterman, 1996). It is through nursing presence that values such as listening to patient's fears, dreams, and pain are lived out (Rankin & DeLashmutt, 2006) while a sense of mutual openness, love, quality interpersonal nurse-client relationships, and comfort are experienced (Hosseini et al., 2019; Melnechenko, 2003; Stockmann, 2018). In this paper, we adopt the definition of nursing presence according to Doona et al. (1997) as an "intersubjective encounter between a nurse and a patient in which the nurse encounters the patient as a unique human being in a unique situation and chooses to spend herself on the patient's behalf, while at the same time the patient invites the nurse into their presence" (p.12). This definition provides an element of individual choice for both the patient and the nurse to enter into this experience, enabling this study to reveal that which may facilitate that choice for family caregivers of children with cancer.

Although studies suggest nursing presence has contributed to improvement in care and satisfaction of patient and nurses (Kostovich & Clementi, 2014; Penque, S., & Kearney, G., 2015), and has positive financial consequences (Doona et al., 1999; Godkin et al., 2002), little is

known about its contribution in pediatric populations. Furthermore, in defining presence, nursing literature mainly focuses on the nurse and patient, excluding caregivers, such as parents. However, when talking about the art of pediatric oncology, Cantrell (2007) suggests that nursing presence can help alleviate the negative effects created by a cancer diagnosis and empower parents and their ill child as they go through hospitalization and treatment of cancer.

Thus, a scoping review was chosen as a means to develop and disseminate a broad understanding of the state of the existing literature on nursing presence in pediatric oncology. Additionally, an enhanced understanding of the gaps in the extant literature will be used to develop a foundation for, and direct future research in pediatric oncology.

2.5 Methods

This study was guided by Arskey and O'Malley's (2005) framework for conducting scoping reviews. Scoping reviews are used to identify the main sources and types of evidence available, especially in areas where little might be known, and to represent this evidence by charting or mapping the data (Phillips, Kenny, & Esterman, 2014; The JBI Reviewers' Manual, 2015). Scoping reviews are also conducted to identify gaps in current research literature, in order to draw conclusions regarding the overall state of research activity in a particular area of study (Arskey and O'Malley 2005; The JBI Reviewers' Manual, 2015). Arksey and O'Malley's (2005) framework provided a rigorous scoping review process to support transparency, and enabled replication of the search strategy, thus increasing the reliability of the findings (Phillips et al., 2014). Arskey and O'Malley (2005) suggested six stages in their framework which included: a) identifying the research question; b) identifying relevant studies; c) study selection; d) charting data; e) collating, summarizing and reporting the results; and f) an optional consultation stage. Additionally, the review was reported using guidelines from the Preferred Reporting Items for

Systematic reviews and Meta-Analyses extensions for Scoping Reviews (PRISMA-ScR) (Equator Network, 2021).

2.5.1 Stage 1: Identifying the Research Question

This scoping review aimed to explore nursing presence as it is understood and expressed in pediatric oncology settings. The research questions used to guide this scoping review were: a) What is known about nursing presence in pediatric oncology settings? and b) What are the characteristics and outcomes of nursing presence in pediatric oncology care settings?

2.5.2 Stage 2: Identifying Relevant Studies

The leading author and an experienced health science university librarian worked together to identify key concepts and search terms to capture literature that related to nursing presence in any pediatric oncology setting. Arksey and O'Malley (2005) suggested a broad definition of key words for search terms be used to cover the extensive literature that is available. The librarian was consulted for the initial search strategy to identify the kind of terms that might be appropriate for searches among the different data bases. This approach was used to improve the validity of the study since librarians have the skill required for designing and executing sensitive search strategies (Arksey & O'Malley, 2005). This input was useful in the refinement of key search terms and identifying appropriate databases (see Table 1).

Table 2.1

A list of MeSH headings and Boolean operators used in the search strategy

1. (youth or child* or "young adult" or adolescent or infant or neonate or neonatal).tw.
2. ((child or family or pediatric or adolescent) adj1 health).tw.
3. (Pediatric* or Paediatric*).tw.
4. 1 or 2 or 3
5. ((chronic or "long term") adj1 care).tw.

6. "oncology".tw.
7. "cancer".tw.
8. 5 or 6 or 7
9. ((Listening or Caring or Therapeautic or Nursing or Compassionate) adj1 Presence).tw.
10. presenc*.tw.
11. Nursing presence.tw.
12. (mindfulness or "mindful presence").tw.
13. empath*.tw.
14. compassion*.tw.
15. nurturance.tw.
16. silence.tw.
17. therapeutic touch.tw.
18. (("nurse-patient" or "nurse-client" or "therapeutic") adj1 relationships).tw.
19. 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
20. 4 and 8 and 19
21. limit 20 to (english language and yr="1999 -Current")

To eliminate threats to validity, a comprehensive and detailed search strategy was documented to allow replicability of the study (Arksey & O'Malley, 2005). A clear documentation of the search strategy is a vital component of the scientific validity of any scoping review (The JBI Reviewers Manual, 2015). Techniques for searching included the use of search tools such as medical subject headings (MeSH) and Boolean operators to narrow, widen and combine literature searches (see Table 1).

Although nursing presence is a foundational nursing concept, its application and development within the discipline of nursing has evolved over the recent years (Smith, 2001). Nursing presence has only recently been measured and attracted attention to its practical intervention (Kostovich, 2012; Snyder, Brandt, & Tseng, 2000). Therefore, the authors decided to review relevant articles from January 1999 to July 2020 in order to capture foundational

literature and recent studies conducted on nursing presence. A snowball search was also conducted by searching the references of key articles, and clear inclusion and exclusion criteria set at the initial search of the relevant sources (see Table 2) (Arskey & O'Malley, 2005).

Table 2.2

A list of inclusion and exclusion criteria

Criterion	**Inclusion**	**Exclusion**
Time period	January 1999- July 2020	Studies outside these dates
Language	English	Non- English studies
Type of article	Original research, published in a peer reviewed journal	Articles that were not peer reviewed or original research
Age of participants	Birth to 16years	Adult population
Study focus	Publications that cover nursing presence in pediatric oncology Allied concepts such as compassion, empathy, and caring, that highlight nursing presence.	Publications that cover nursing presence in other settings Allied concepts that do not highlight nursing presence
Clinical Setting	Pediatric oncology, palliative and end of life care related to pediatric oncology	Settings outside pediatric oncology and palliative and end of life care related to pediatric oncology.

Journal articles included in this scoping review were peer-reviewed and focused on nursing presence or allied concepts and pediatric oncology settings. Specifically, articles with allied concepts were retained because there were attributes describing nursing presence. Relevant articles that appeared from the database searches that were not peer reviewed were used to inform the study. Articles that were not written in English were excluded.

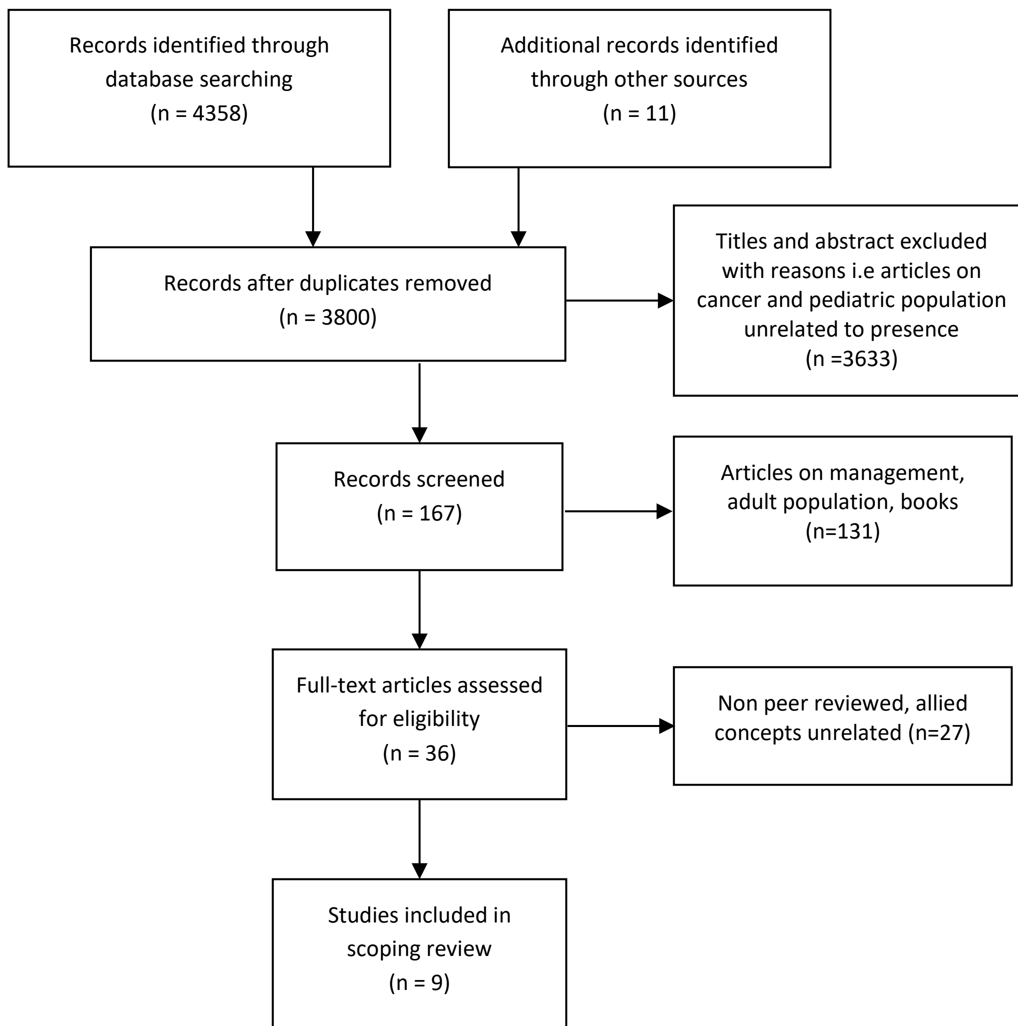
2.5.3 Stage 3: Study Selection

A total of three databases were used for this scoping review including MEDLINE and CINAHL since they are the principle resources for literature search in nursing (East Carolina University Libraries, 2021; The University of Melbourne, 2021). PSYCINFO was also included due to its resource for locating scholarly research findings in psychology and health disciplines (American Psychological Association, 2021) which is essential when considering nursing presence. In addition to searching electronic databases, Canadian Agency for Drug and Technology in Health's (C.A.D.T.H.'s) Grey Matters tool was used to search for relevant grey literature (CADTH, 2018). Grey literature is information produced outside of traditional publishing and distribution channels that may be inaccessible via bibliographic databases and does not go through peer review process (CADTH, 2018; Simon Fraser University Library, 2020). Key words identified were used throughout the search process. To begin, the primary researcher independently reviewed all articles and consulted the other authors when uncertain on whether to include or exclude an article. The initial search identified 4,357 articles. After removing 568 duplicates, the titles and abstracts were reviewed by the leading author with ongoing consultation amongst all authors. Rayyan (Ouzzani et al., 2016) was used for the title and abstract screening process. This round of screening revealed a large number of articles that did not meet the inclusion criteria since most focused on cancers unrelated to pediatric populations or focused on pediatric populations with other diseases (N=3633). All articles focusing on nursing presence plus those that focused on allied concepts such as compassion, caring, and empathy which highlighted nursing presence were retained for analysis (N=167). Guided by the inclusion and exclusion criteria, full-text articles were assessed by the leading author in consultation with secondary authors and reaching consensus. Nine articles were

identified as being relevant to the research aim and question. Grey literature that was not peer reviewed was used to inform literature in the discussion (see Figure 1).

Figure 1.1.

PRISMA flow diagram for article selection



2.5.4 Stage 4: Charting Data

To implement the fourth stage of Arskey and O'Malley's (2005) framework, a Pinch Table (see Table 3) was used to summarize the nine research articles and included author, year, purpose, population and sample size, methodology, findings, and a critique of the study.

Table 2.3

Summary of Literature Search

	Author/Year	**Problem/Purpose**	**Population/ Sample size**	**Methodology**	**Findings/critique of study**	**Implications for nursing**
1.	Anderzen-Carlsson, Sorlie , & Kihlgren, 2012	To examine adolescents' perspectives on dealing with cancer related fear	6 adolescent girls aged 14-16years no longer on active cancer treatment, but receiving regular check ups (Sweden)	Qualitative descriptive design	Results revealed two perspectives, namely, participants had their own personal battle with fear, and fear was a shared experience with significant others. Participants described it was not good to be alone as companionship helps in dealing with fear as well as prevents it from occurring.	Findings suggest it is easier for adolescent cancer patients to undergo fearful procedures when professionals show an empathic attitude that could be seen as related to social support, also described as "being there" for the patients.
2.	Furingsten, Sjogren, & Forsner, 2015	To describe caring as represented in healthcare workers' experiences for dying children	Four nurses in general acute pediatric care settings (Sweden)	Phenomenological approach	The essence of caring for a dying child in acute pediatric care unit is likened to a musically attuned composition comprising five constituents: presence, self-knowledge, injustice in dying, own suffering and in need of others.	Caring in ethically demanding situations can be facilitated through presence, a supportive atmosphere, self knowledge and time-assets readily available to nurses.
3.	Kars, Duijnstee, Pool, van Delden,	To gain insight into the lived experience of parenting a child	23 parents of care dependent children (≤12) on treatment	Grounded theory approach	Study revealed 'being there' as the core concept. Parents 'being	Nurses should organise and manage their care

	& Grypdonck, 2007	with leukemia during treatment	for ALL, from a pediatric oncology unit (Netherlands)		there' was a fulfillment to their parental duty, a response to the perceived vulnerability of the child. 'Being there' served two purposes: protection and preservation. Six aspects of 'being there' were identified; trusting relationship, presence, emotional support, advocacy, routines and effacing oneself.	giving in a way that enables and encourages parents to 'be there'. At the same time and in partnership with parents, they need to be alert for the less constructive parts of 'being there': an overly protective relationship or 'burning out'.
4.	Monterosso & Kristjanson, 2008	To obtain feedback from parents of children who died from cancer about their understanding of palliative care, their experiences of palliative and supportive care received during their child's illness, and their palliative and supportive care needs.	Parents of 24 children 2-17 years at the time of death from five Australian tertiary paediatric oncology centers (Australia)	Qualitative design comprising of in-depth interviews	Findings highlight critical aspects of the importance and therapeutic value of authentic and honest relationships between health professionals and parents, and between health professionals and children. Also highlighted was the need to include children and adolescents in decision making, and for the delivery of compassionate end-of-life care that is sensitive to the	In order to provide good care to both parent and child with cancer, there is a need for health professionals to better understand the concept of palliative care, and factors that contribute to honest, open, authentic and therapeutic relationships of those concerned in the care of the dying child. .

					developmental needs of the children, their parents and siblings.	
5.	Pavlish & Ceronsky, 2009	To explore oncology nurses' perspectives of palliative care through narrative analysis of participants' descriptions of life experiences	33 oncology nurses in three urban medical centers (USA)	Focus groups and use of categorical-content method of narrative analysis	Findings revealed five primary nursing roles: teaching, caring, coordinating, advocating, and mobilizing. In all five roles, seven professional attributes were described: clinical expertise, honesty, family orientation, perceptive attentiveness, presence, collaboration, and deliberateness	Nurses must carefully document the manner in which these attributes make a difference in patients and families. High-quality palliative care standards from a variety of professional palliative care organizations may improve oncology nurses' role development and performance.
6.	Snaman et al., 2016	To explore the communication between hospital staff members and patients and families at the time patients were still receiving cancer-directed treatment and experienced health decline near the end of life	Twelve bereaved parents (USA)	A focus group with semantic content analysis used to analyze the transcript.	The common themes to parents' responses to the prompt about typical ways the medical team communicated were ''patient inclusion'' and ''explanation of medical plan.'' Common themes to prompts about positive and negative aspects of communication were ''strong relationship between family and	Certain techniques should be used by clinicians as they work with children with cancer and their families, specifically patient inclusion in medical discussions and treatment decisions, relationship building, communication indicating caring and empathy,

					staff," for positive communication, and ''variations in care with a negative impact'' was used most frequently in describing negative communication.	additional support by an interdisciplinary team, and pairing bad news with a plan of action.
7.	Steele, et al., 2013	To determine how to improve care for families by obtaining their advice to health care providers and researchers after a child's death from cancer	36 mothers, 24 fathers, and 39 siblings from 40 bereaved families (USA and Canada)	Content analysis qualitative study	Five major themes emerged: a) improved communication with the medical team, b) more compassionate care, c) increased access to resources, d) ongoing research, and e) offering praise for the medical team, hospital, and research. Interwoven within the five themes was a subtheme of continuity of care.	Findings highlight the importance of continually assessing communication preferences of individual family members throughout the illness, and their preference for continuity of care. Findings also suggest siblings should be included when possible and encourage families to express their wishes and advocate for their needs.
8.	Thienprayoon, et al., 2020	To identify and define parent/caregivers prioritized domains of family-centered care in home-based hospice and palliative care (HBHPC)	39 Parents of children who had been enrolled in pediatric HBHPC programs (USA)	A qualitative study employing grounded theory methodology	Compassionate care emerged as a domain of HBHPC. The HBHPC team, through their physical and emotional presence, decreased the emotional and physical isolation engendered by the child's illness.	Parents prioritize compassionate care as a new domain of quality in pediatric HBHPC. Although parent/caregiver define each domain differently from healthcare providers,

						it is our responsibility as nurses to deepen our understanding and perspective of quality pediatric HBHPC within each domain.
9.	Woodgate, 2006	The aim of this study is to detail the degree and type of social support from the perspectives of adolescent participants with cancer.	15 adolescents between 12 and 18 years of age diagnosed with cancer (Canada)	A longitudinal qualitative research design guided by the philosophy of interpretive interactionalism.	The degree and type of social support was represented by 3 subcategories: 1) supportive relationships-from healthcare team, special friend, and family-that helped adolescents maintain a sense of being in the world and made them feel connected as well as loved and cared for; 2)being there-to comfort me, to hold my hand, to keep me from feeling lonely, to help me feel like I have a life, to keep me positive, and for me despite everything, and; 3) there are positive and negative consequences of being there	In determining what are the most appropriate support resources to offer adolescents, nurses need to consider what resources will best strengthen key relationships in the adolescent lives. Nurses also need to practice, and teach adolescents and their families that "being there" does not always have to involve "doing", but "being there" in mind and spirit by providing psychosocial-emotional support may be more valuable than the act of physically doing something.

2.5.5 Stage 5: Collating, Summarizing and Reporting the Results

Scoping studies do not formally appraise the quality of research reports, nor attempt to make recommendations from the evidence about the most effective intervention, but provide a comprehensive, descriptive account of the available research (Coughlan, Cronin, & Ryan, 2013). A thematic construction was used to present a narrative account of the existing literature as suggested by Arksey and O'Malley (2005). Specifically, Clarke and Braun's (2013) thematic analysis process was used because it works with a wide range of research questions, and can also be used to analyze diverse types of data, from secondary sources such as media, journal articles, transcripts of focus groups, or interviews.

The analytic approach to Clark and Braun's (2013) thematic analysis is divided into six phases: 1) familiarization with the data, which was achieved by reading and re-reading the nine articles and immersion in the data extracted from each article; 2) coding, which entailed extracting significant statements from the articles that directly related to nursing presence or related concepts; 3) searching for themes, where words were identified that could bring meaning to the codes when put together and to identify similarity in the data; 4) reviewing themes, which involved collapsing themes extracted from the articles and reflecting on whether they told the same story presented in the data; 5) defining and naming themes where names coined to capture the essence of each theme were developed; and 6) writing up, where the analytic narrative was woven together, contextualizing it in relation to existing literature while reflecting on the research questions. All the six phases were initially conducted with the leading author, with consistent consultation and discussion with the secondary authors.

2.5.6 Stage 6: Consulting

Findings of this scoping review were presented to a group comprised of PhD students and their academic supervisors in the college of nursing. Presenting the findings to this committee assisted in validating the results and provided an opportunity for reflection and feedback. Consulting amongst the co-authors also provided feedback that informed all aspects of the scoping review. Bedside nurses were not consulted in this review because the intention of the study was to identify the state of existing literature and direct future research in pediatric oncology.

2.6 Results

Nine studies published between 2006 and 2020, which predominantly used qualitative methodologies, were included in this scoping review (Anderzen-Carlsson et al., 2012; Furingsten et al., 2015; Kars et al., 2008; Monterosso & Kristjanson, 2008; Pavlish & Ceronsky, 2009; Snaman et al., 2016; Steele et al., 2013; Thienprayoon et al., 2020; Woodgate, 2006). The studies were conducted globally including the United States 33.3% (N=3), Sweden 22%.2 (N=2), Netherlands 11.1% (N=1), Australia 11.1% (N=1), Canada 11.1% (N=1), and 11.1% (N=1) conducted in both USA and Canada. Study populations were comprised of parents 55.5% (n=5), nurses 22.2% (n=2), pediatric patients 22.2% (n=2), or siblings of pediatric patients 11.1% (n=1). A general overview of the included studies is presented in Table 3. Most of the findings implicitly highlighted nursing presence (Anderzen-Carlsson et al., 2012; Monterosso & Kristjanson, 2008; Steele et al., 2013; Thienprayoon et al., 2020; Woodgate, 2006), with some having introduced the concept as a section of their results (Furingsten et al., 2015; Kars et al., 2008; Pavlish & Ceronsky, 2009; Snaman et al., 2016). None of the studies specifically examined nursing presence and its application in pediatric oncology. However, several grey

literature resources explicitly discussed nursing presence in pediatric oncology (Cantrell 2007; Rushton 2005). Guided by the research questions and informed by available research on nursing presence, findings were adequate to provide several themes identified with nursing presence including Being With or Being There, Therapeutic relationships, Communication, Family-centered Approach, and Perceived Outcomes of Nursing Presence.

2.6.1 Being With or Being There

Findings from this scoping review reported the importance of "being with" from nurses who cared for palliative patients and their families (Pavlish & Ceronsky, 2009; Furingsten et al., 2015), and "being there" from parents of children with acute lymphoblastic leukemia (Kars et al., 2007), and adolescents diagnosed with cancer (Woodgate, 2006). When describing oncology nursing roles and professional attributes in palliative care, nurses identified presence, also described as "being with," as "a kind of calmness and peacefulness that you bring into the room so they (patient and families) really feel you are there for them" (Pavlish & Ceronsky, 2009, p. 408). Nurses also recognized presence as one of the explicit meanings of care for dying children (Furingsten et al., 2015). When caring for dying children, nurses voiced presence depended on an honest relationship, courage to involve and support the family, and mutual trust between those involved (Furingsten et al., 2015).

Kars et al (2007) explored the concept of "being there" for parents with a child diagnosed with leukemia. Presence emerged as a way of "being there," depicting a literal and a figurative availability founded on a trusting relationship (Kars et al., 2007). Parents of children with leukemia described "being there" for their children as placing oneself in the service of the child, even when nothing is left to be done, creating feelings of safety, comfort, and relieved suffering (Kars et al., 2007). Through the act of "being there," adolescent patients felt that they were not

alone in having to go through the cancer experience (Woodgate, 2006). Health care team members, families, and friends "being there" was seen by adolescents as the key element of a supportive relationship (Woodgate, 2006). Results from this study described being there or being with a patient as a connection based on mutual trust and honesty that evoked altruism and led to caring relationships between the nurse, patient and their family (Pavlish & Ceronsky, 2009; Furingsten et al., 2015; Woodgate, 2006; & Kars et al., 2006). Also described as compassionate behaviours (Anderzen-Carlsson et al., 2012; Furingsten et al., 2015; Monterosso & Kristjanson, 2008; Snaman et al., 2016; Steele et al., 2013; Thienprayoon et al., 2020; Woodgate, 2006), attributes of being there or being with identified in the study included being gentle in approach (Anderson-Carlsson, 2012; Furingsten et al., 2015; Steele et al., 2013), allowing patients and their families to safely show and express their feelings (Furingsten et al., 2015; Woodgate, 2006), spontaneous acts of kindness (Monterosso & Kristjanson, 2008, Thienprayoon et al., 2020), being a physical presence of comfort at a difficult time showing emotion and empathic listening (Kars et al., 2007; Pavlish & Ceronsky, 2009; Snaman et al., 2016; Woodgate, 2006), and reassurance (Kars, et al., 2007; Steele et al., 2013).

2.6.2 Therapeutic Relationships

Articles from this review uncovered that being with or being there played a key role in developing and nurturing of authentic therapeutic relationships between patient, families and nurses (Anderzen-Carlsson et al., 2012; Furingsten et al., 2015; Monterosso & Kristjanson, 2008; Snaman et al., 2016; Steele et al., 2013; Thienprayoon et al., 2020; Woodgate, 2006). Parents valued authentic relationships with their health care providers when dealing with pediatric oncology patients due to the stress levels encountered when a child is diagnosed with a chronic illness (Monterosso & Kristjanson, 2008; Snaman et al., 2016; Steele et al., 2013). When

providing suggestions to health care providers about how to improve care for families with children at end-of-life, bereaved parents and parents of children still in home-based hospice and palliative care acknowledged that health care providers who valued authentic relationships were more compassionate and recognized the special population they worked with (Steele et al., 2013; Thienprayoon et al., 2020). Results also revealed that adolescent patients valued the authentic relationships and support they received from nurses, referring to them as "second family" (Woodgate, 2006). One study showed that adolescent participants who had established authentic relationships with nurses found it easier to communicate their fears dealing with cancer allowing them to cope better, as opposed to nurses that were hard-handed or acted in a harsh manner (Anderzen-Carlsson et al., 2012). However, siblings of pediatric patients at end-of-life cautioned health care providers about getting too attached to their patients and families. In the study by Steele et al. (2013), one 13-year-old sibling recommended:

> "You can get close to your patient, but don't get really, really close… just close enough to know their name and what they do. Because if you are really, really, really close… then you'll be sadder in life, 'cause you'll be treating them like they are your own" (p. 255).

Participants in this study feared that health care providers may be overwhelmed by their patients' and families' experience of suffering during the illness or death (Steele et al., 2013).

2.6.3 Communication

Two attributes of communication were identified in this scoping review. Non-verbal communication was established in the four articles that had presence as their findings (Furingsten et al., 2015; Kars et al., 2008; Pavlish & Ceronsky, 2009; Snaman et al., 2016), while open and honest communication was an implicit attribute identified as fundamental to

developing authentic therapeutic relationships (Monterosso & Kristjanson, 2008; Pavlish & Ceronsky, 2009; Snaman et al., 2016; Steele et al., 2013). Characteristics of non-verbal communication such as listening carefully, speaking last (Pavlish & Ceronsky, 2009), soft gentle touch or holding hands (Furingsten et al., 2015; Kars et al., 2008), and remaining attentive (Snaman et al., 2016), were identified as attributes to presence. In addition, silence was also mentioned as a meaningful form of non-verbal communication. One study revealed that adolescents considered a passive act of being physically present, without necessarily carrying out some specific duty, or say anything, was considered an act of presence that provided comfort to patients and their family (Woodgate, 2006). Findings also revealed that parents valued honesty from health care providers because it was important for them to be entirely informed about the state and prognosis of their children in order to make informed decisions and to remain 'realistic' (Monterosso & Kristjanson, 2008; Steele et al., 2013). In addition, although parents acknowledged the difficulty in communicating bad news, even after therapeutic relationships had been established with health care providers, they preferred health care providers to be more comprehensive and straight-forward concerning medical communication and continuity of care in order to adequately prepare for the possibility of a poor outcome. Open, honest, clear and comprehensive communication was considered an essential factor in therapeutic relationships between nurses and families of children in end-of-life patients (Monterosso & Kristjanson, 2008; Steele et al., 2013).

2.6.4 Family-centered Approach

Four studies in this review clearly suggested presence in pediatric oncology was founded on a family-centered approach where therapeutic relationships were not only focused on patients but parents as well (Furingsten et al., 2015; Kars et al., 2008; Pavlish & Ceronsky, 2009; Snaman

et al., 2016). Five of the remaining articles implied a family-centered approach with care provided to patient and their families (Anderzen-Carlsson et al., 2012; Monterosso & Kristjanson, 2008; Steele et al., 2013; Thienprayoon et al., 2020; Woodgate, 2006). Oncology nurses described presence in their care as encompassing a process of working with patients and their families to relieve pain and suffering and achieve holistic comfort and well-being (Furingsten et al., 2015; Pavlish & Ceronsky, 2009). Another study identified patients and families as coproducers of health together with clinicians, assigning them the responsibility to identify their own needs and preferences in the care process, and to evaluate the performance of those who serve them (Thienprayoon et al., 2020). Two studies revealed that parents believed they are the experts who knew their child best and were aware of their thoughts and feelings (Kars et al., 2007; Monterosso & Kristjanson, 2008). Therefore, meaningful connections between nurses and parents played a significant role in the treatment and management of a child with cancer because parents were their advocates and primary decision makers.

For older pediatric patients, findings revealed actions that facilitated building connections with patients and their families included being knowledgeable about patients' preferences or being attentive to their needs (Pavlish & Ceronsky, 2009), health care providers interacting with siblings and allowing them to spend time with the sick patient (Steele et al., 2013), and allowing family and friends to stay with patients during clinic appointments and hospital stays (Woodgate, 2006). For infants and pediatric patients unable to express themselves, a connection with health care providers was achieved when healthcare providers aligned their interests with those of parents. Three studies identified that parents expressed their need for health care providers to listen, acknowledge, and seriously consider their perspectives especially when making undesired decisions (Monterosso & Kristjanson, 2008; Snaman et al., 2016; Steele et al., 2013). Parents

expressed the need to feel supported and cared for throughout their child's illness as they undertook managing both medical and parental-care tasks. Three studies revealed that parents needed nurses to be available as they went through unexpected stressful events and were overwhelmed with their child's distress and a sense of powerlessness. (Kars et al., 2007; Monterosso & Kristjanson, 2008; Steele et al., 2013). In addition, one study showed that parents appreciated nurses who were there following the death of their children, following up with the family and helping those parents start to adjust their losses (Monterosso & Kristjanson, 2009).

2.6.6 Perceived Outcomes

Perceived outcomes emerged as a theme and identified consequences of being with, therapeutic relationships, communication, and family-centered care. Findings revealed hope as an outcome which helped patients and their families cope with the cancer diagnosis (Furingsten et al., 2015; Kars et al., 2007; Monterosso & Kristjanson, 2008; Snaman et al., 2016; Thienprayoon et al., 2020; Woodgate, 2006). Therapeutic relationships that were formed provided comfort and a source of support for patients and their families, decreasing the emotional pain experienced from their child's suffering. Three studies showed that a lesser burden was perceived for the child since the cancer experience was a shared process between the patient, parents, and nurses (Kars et al., 2007; Thienprayoon et al., 2020; Woodgate, 2006). One study showed that a child derived power and stability when they were not alone, developing the ability to manage unpleasant situations (Kars et al., 2007). Pediatric patients gained more self-confidence because of the recognition and praise received from nurses in relation to their determination and persistence in dealing with the cancer treatment regimens (Woodgate, 2006). Two studies revealed ease in having difficult discussions about goals of care and possible outcomes as a perceived outcome (Monterosso & Kristjanson, 2008; Snaman et al., 2016).

Mutual trust and a caring bond formed between nurses and parents made it easier to communicate unpleasant news because a therapeutic relationship had been formed. Furthermore, parents believed it was equally as difficult to convey sad news as it was to receive it (Monterosso & Kristjanson, 2008; Snaman et al., 2016).

One negative outcome was identified in the study by Woodgate (2006). Adolescent patients expressed they had a harder time dealing with lesser amount of attention received from nurses and other health care providers as they became healthy and required less monitoring (Woodgate, 2006). Although being with the patient and communication helped to facilitate a therapeutic relationship, adolescent patients experienced feelings of loss and abandonment when they had to end their close relationships with the nursing team as they neared the end of their treatment regimen. Conversely, the feeling of abandonment by adolescent patients speaks to the overwhelming support and care offered by nurses and other health care providers during their illness.

This study discussed articles that explicitly described presence in their findings, and those which had implicit attributes of presence as informed by available literature. The following discussion will explore Being With or Being There, Therapeutic relationships, Communication, Family-centered Approach, and Perceived Outcomes of Nursing Presence, as the five themes that emerged in the results.

2.7 Discussion

The purpose of this scoping review was to develop and disseminate a broad understanding of the state of the existing literature on nursing presence in pediatric oncology and to develop a foundation for future research in pediatric oncology. The results suggest that nursing presence has received minimal attention in pediatric oncology. Following the review of

literature, none of the articles retrieved in the search set out to examine nursing presence in pediatric oncology. However, four articles included nursing presence as an important concept in their findings. Informed by available literature on nursing presence, the authors felt that five of the nine articles had attributes of presence that were not directly expressed. Although these articles set out to discuss other dimensions of oncology care, they implied a nursing presence offered by health care providers. Being With or Being There, Therapeutic relationships, Communication, Family-centered Approach, and Perceived Outcomes of Nursing Presence were common themes that interlinked the included articles.

At the core of nursing practice is the nurse-patient relationship (Moyle, 2003). The term “being with” and ‘being there” was applied to describe a physical and emotional connection between nurses and the patients which was used to establish this relationship. Findings from this study suggest a multifaceted form of being characterized by observable and non-observable events such as active listening, touch, being empathetic, providing a safe space, and offering words of encouragement. Kostovich et al. (2016) confirms this finding suggesting that nursing presence is a fluid unified cognitive, affective, behavioural, and spiritual experience. Although other studies suggest that this characteristic of nursing presence makes it challenging to define and measure (Covington, 2003; Kostovich, 2012), findings in this review show that participants could distinguish the experience of being and doing. While it is true that physical closeness is sometimes required for the establishment of relationships, findings demonstrate that being with transcends being by the bedside of the client. In being with, patients and families feel at peace, cared for, and supported as their child undergoes the cancer experience. This scoping review established nursing presence, also widely described as being with (Hosseini et al., 2019;

Stockmann, 2018; Turpin, 2014), as a significant concept in pediatric oncology and further exploration on the concept is needed.

Retrieved studies showed that ‘being there or being with’ and ‘compassionate behaviours’ had synonymous attributes used to describe nursing presence and are essential in forming therapeutic relationships. Based on the findings of Sinclair et al. (2016) and Sherwood (1997), it is clear nursing presence, compassion, and caring have many overlapping components. However, all components appear to encompass a connection characterized by authenticity, openness, and intimacy in relationships that go beyond expert nursing practice. Attempts have been made to converge these concepts (Finfgeld-Connet, 2008), while other calls have been made to delineate and differentiate presence from these nursing phenomena (Covington, 2003; Finfgeld-Connett, 2006). More research is encouraged to pursue delineating or converging nursing presence from compassionate care in the context of pediatric oncology. Critical authentication of concepts such as nursing presence and compassion, and identification of differences and inter-relationships are essential in order to gain an enhanced understanding of the discipline and to inform best practice in the pediatric oncology care (Finfgeld-Connett, 2008). While participants identified compassionate behaviours as significant in developing authentic relationships, some cautioned about compassion fatigue, a term used to reflect the inevitable experience of the emotional exhaustion that comes from continuous compassion directed toward those in crisis (Rourke, 2007). Additional research is needed to determine if nurses in pediatric oncology experience fatigue when providing nursing presence in order to come up with effective ways of preventing it to continue providing comprehensive, holistic, and safe care.

Effective communication in pediatric oncology serves to build relationships, exchange information, enables family self-management, provides validation, manages uncertainty,

responds to emotions, supports hope, and aids in decision making (Sisk et al., 2020). Communication encompasses content and manner in which information is passed from health care providers to the patient and their families (Foronda, MacWilliams, & McArthur, 2016). It was evident that parents valued honest and timely discussions with their caregivers as this gave them a sense of control and helped them in making informed decisions for their children who had life-threatening conditions. Through communication, nurses can recognize and embrace the patients needs while offering adequate information about the patients' illness and treatment. Patients and their families feel safe, confident, and reassured when they are informed about their child's care (Steele et al., 2013). Silence was also considered an effective form of non-verbal communication that displayed an authentic presence. Kemerer (2016) affirms that silence can enhance therapeutic relationships by providing a presence that demonstrates understanding and respect for the patient. Findings is this review revealed communication as an essential attribute to nursing presence in pediatric oncology. When applied skillfully, communication can be used to support the patient and their family in acknowledging and processing the changes occurring in their child's health.

According to Kuo et al. (2012), family-centered care is considered a standard for pediatric health care. Family-centered care puts the nurse in a suitable position to practice nursing presence. Because family caregivers play an important role in treatment and management of their child's care, it is critical for nurses in a pediatric oncology setting to make therapeutic connections through nursing presence as their relationships are more than often long term and involve frequent interactions. This scoping review demonstrated that a family-centered approach plays a key role in developing therapeutic relationships needed when patient and families are overwhelmed with unexpected stressful events and emotional anxiety during the

cancer experience. While new to literature on nursing presence, these finding are consistent with Institute for Patient and Family-centered Care (n.d.) which confirms that a family-centered approach improves patient and family experience of care, leading to better health outcomes. In addition to a partnership in management of an ill child, therapeutic relationships in a family-centered approach provides support when a family's well-being is negatively impacted due to ongoing demands of caregiving. Recognizing that families are often psychologically stressed and have difficulties coping should encourage nurses to use presence with a family-centered approach to support family members' well being.

Lastly, it was evident that nursing presence could possibly enable nurses to have difficult discussions with patient families, easing their nursing experience and improving their efficiency in care. Nursing presence has been found to improve nurses' well-being through self awareness, self-confidence, renewed energy, and gratification (Kostovich, 2012). For patients and their families, it was evident that nursing presence enhanced their physical and mental well-being by finding comfort in feeling heard, understood, less isolated and vulnerable. Other studies have also found that nursing presence decreases patient's stress and anxiety that could be as a result of uncertainty during their illness and provides a sense of safety, peace, emotional comfort, and hope (Kostovich, 2012; Stockmann, 2018; Turpin, 2014; Zyblock, 2010). Novel findings from this review reveal that nursing presence can improve patient health outcomes and should be incorporated when caring for pediatric oncology patients and their families. In our analysis of the literature, it is evident that a potential outcome for the child who is transitioning from care may include the experience of loss and abandonment. While a change in the intensity of presence is anticipated as a child becomes well, this finding supports the need for future research to explore

these experiences and to inform nursing care needed to manage this transition and the accompanying feelings of loss of relationship.

Although several studies have examined nursing presence in adult care settings (Hosseini et al., 2019; Mohammadipour et al., 2017; Penque & Kearney, 2015), there is a scarcity of research of presence in pediatric oncology. Because no study was retrieved that explicitly explored the nature of nursing presence in pediatric oncology setting, this scoping review attempted to answer the research questions informed by available literature on the concept. Findings in this study demonstrate that nursing presence enhances family-centered care by facilitating better therapeutic relationships between nurses and family caregivers of pediatric oncology patients. This is new to nursing literature. Family caregivers and nurses in pediatric oncology have better healthcare experiences when there are healthy therapeutic relationships facilitated by nursing presence. However, these findings set the stage for more scientific research in exploring family caregivers experiences of nursing presence to broaden our conceptualization of nursing presence in pediatric oncology setting. Research investigating the essential attributes of nursing presence in pediatric oncology care is required to develop a baseline understanding of the concept that is applicable when caring for children and their families.

2.8 Conclusion

Informed by available literature, this scoping review revealed that nursing presence in pediatric oncology has scarcely been explored. Nurses in pediatric oncology are in a suitable position to provide nursing presence facilitated through being with the patients, therapeutic relationships, verbal and non-verbal communication and a family-centered approach. There is a need to establish a comprehensive evidence-based understanding of the construct of nursing presence in pediatric oncology using sound qualitative and quantitative research methods. Health

care providers can utilize this evidence in their clinical practice and future health research to improve quality of care in pediatric oncology settings.

2.9 Chapter Summary

As outlined in this scoping review, there has been no research that specifically explores nursing presence as experienced in pediatric oncology. This chapter includes a presentation of the state of nursing literature in regards to nursing presence in a pediatric oncology setting, what is understood about the phenomenon, and of the gaps in nursing literature. Out of 4358 retrieved articles, only nine articles addressed nursing presence, while none of them explicitly investigated nursing presence. Therefore, this scoping review was instrumental in determining and informing the research question of the overall research, considering there was no literature exploring nursing presence in pediatric oncology. Findings in this chapter included the role of family-centered approach in the treatment and management of a child with cancer. Therefore, in this dissertation a family-centered theoretical framework was used to guide the development of the research question. Although family-centered care (FCC) is based on relationships between nurses and families of ill patients, there is no literature identifying the role of nursing presence in formation of relationships in a family-centered care model. The following chapter expounds on a FCC model, and identifies the role of nursing presence in formation of relationships while using a family-centered approach.

CHAPTER 3

3.0 Theoretical Framework

Nursing presence exists within the context of a relationship that is formed through reciprocal communion between the nurse and patient (Delashmutt, 2007). Similar to nursing presence, family-centered care (FCC) is a mode of healthcare delivery that is centered upon relationships between the nurse and the patient's families. Studies indicate that healthcare services provided in a family-centered manner lead to better health outcome (Crespo et al., 2016). Therefore, FCC was used as the theoretical framework to guide this dissertation research because when caring for pediatric patients and their families, all interventions happen in the context of a nurse-family relationship. The following chapter demonstrates the role of nursing presence in family-centered care framework.

3.1 Manuscript 2

Mcharo, S. K., Spurr, S., Bally, J., Peacock, S., Holstlander, L., Walker, K. (2022). *Application of Nursing Presence to Family-Centered Care: Supporting Nursing Practice in Pediatric Oncology* [Manuscript submitted for publication]. College of Nursing, University of Saskatchewan.

This manuscript titled: *Application of Nursing Presence to Family-Centered Care: Supporting Nursing Practice in Pediatric Oncology,* was submitted to the Journal for Specialists in Pediatric Nursing for publication. In this manuscript, we discuss how nursing presence is integrated in the family-centered model. Each author contribution are as follows: Mr. Mcharo, conceived the idea and wrote the initial draft; Drs. Spurr and Bally conceived the idea, provided critical review, and revisions to content of the manuscript; while Drs. Peacock, Holtslander, and Walker provided critical review and revisions to content of the manuscript.

3.2 Abstract

Purpose: In pediatric care settings, family-centered care (FCC) is an integral way to ensure family involvement in their child's care and has been known to improve health outcomes and families' psychosocial well-being. Similarly, nursing presence is deemed beneficial in the formation of authentic nurse-patient relationships and is known to facilitate healing and improve satisfaction for the patient and their family. The objective of this article is to explore how nursing presence supports FCC by closely examining the four concepts of FCC as described by Institute for Patient- and Family-Centered Care: dignity and respect, information sharing, participation, and collaboration. A case study is also presented to demonstrate how nursing presence can be applied in FCC, when caring for a pediatric oncology patient.

Conclusion: Nursing presence is essential in FCC since it plays a key role in the formation of relationships, a fundamental element in the four concepts. Attributes of nursing presence can be interwoven in the FCC framework and have positive clinical, social, and emotional outcomes for the patient and family. Although literature has explored associations between FCC and nursing presence, there is need for more scientific research to justify this argument in order to support the improvement of quality of family nursing care and strengthen the FCC model.

Practice Implications: The four concepts of FCC lay a foundation for a model of care that can be enhanced by nursing presence, potentially providing a remedy for depersonalization of healthcare by improving nurse patient relationships in pediatric care settings. Nursing presence becomes less ambiguous when enacted in a FCC framework, revealing attributes that may be cultivated in family nursing to improve therapeutic relationships among nurses and family caregivers.

Key Words: Family-centered care, nursing presence, pediatric oncology

3.3 Application of Nursing Presence to Family-Centered Care: Supporting Nursing Practice in Pediatric Oncology

Family-centered care (FCC) is a method of care delivery that encourages pediatric nurses to focus on the humanist aspect of their patients and fosters the art of nursing (MacKay & Gregory, 2011). Researchers indicate that the provision of health care services in a family-centered manner leads to better health outcomes, higher levels of parental satisfaction with services, better parental and child psychosocial well-being, wiser allocation of resources, and increased professional morale and job satisfaction (Crespo et al., 2016; Watt et al., 2013; Wright & Leahey, 2013). According to the Institute for Patient- and Family- Centered Care (IPFCC, n.d), there are four core concepts of FCC: dignity and respect; information sharing; family participation in care; and family collaboration. Family caregivers and their ill child experience reduced anxiety, less depression, and higher psychological and emotional well-being when programs and services are delivered in a family-centered manner (Holm et al., 2003; Watt et al., 2013). When caring for families, all interventions happen in the context of a nurse-family relationship and are enacted primarily through therapeutic conversation (Bell, 2013). FCC puts nurses in an ideal position to develop therapeutic relationships with children with cancer and their loved ones because they often have the most frequent contact during diagnosis and treatment (Cantrell, 2007; MacKay & Gregory, 2011).

Similar to FCC, presence is considered a trait found in family nursing care that facilitates healing and improves satisfaction for the patient, family caregiver, and the nurse (Kostovich, 2012). Presence has been described and used in numerous health disciplines as a way of being with another when there is a physical, psychological, or therapeutic need (McMahon & Christopher, 2011; Turpin, 2014). In nursing, presence entails a holistic kind of "being with" and

"being there" that determines the quality of presence experienced (Paterson & Zderad, 1988, p.14). Central to the concept of presence in nursing is interpersonal relationships (McMahon & Christopher, 2011; Turpin, 2014) which are the heart of the matter in family nursing (Bell, 2011). MacKay and Gregory (2011) view presence as essential in developing nurse patient-family relationships in pediatric populations. Understanding the role of nursing presence helps identify its practical use in the four dimensions of FCC and demonstrates how it can be applied to improve provision of quality patient and family care. While seemingly intuitive that nursing presence underpins FCC, the evidence to support this is surprisingly scant. Nursing literature has extensively described FCC (Kuo et al., 2012; MacKay & Gregory, 2011; Wright & Leahey, 2013) and nursing presence (McMahon & Christopher, 2011; Turpin, 2014) and demonstrated their benefits. However, there remains a gap in the understanding of nursing presence and its contribution to FCC. Specifically, there are no articles that discuss these two concepts in the context of family nursing care. In this paper, we explore how nursing presence supports FCC by closely examining the four core concepts as described by IPFCC (n.d) and use a case study to present the implications for family nursing in pediatric oncology care. By illustrating the application of nursing presence in FCC and identifying their relationship, intuitive practice in FCC approach is made manifest, thus contributing to nursing knowledge and demonstrating potential to improve family nursing practice.

3.3.1 What is Nursing Presence?

An experience of nursing presence occurs when both the nurse and patient are mutually open to one another, and the nurse spends himself or herself on behalf of the patient so as to meet the patient's needs (Turpin, 2014). Nursing presence creates the opportunity for nurses to go where the patient is in life, to learn about their experiences of health as defined and lived, and to

work with patients as they choose the meaning of the situation (Hickman, 2013; Melnechenko, 2003). Health care providers have tended to focus more on procedures and methods than on being there and being present with their patients (Stockmann et al., 2018). The everyday tasks, the lack of time, and the perceived need to maintain distance from patients in order to remain professional have prevented nurses from having therapeutic relationships with their patients (Bell, 2013; Melnechenko, 2003). Nursing presence is reflected when the nurse, patient, and family acknowledge each other in a moment of vulnerability as unique human beings, seeing the other as a whole and not just attending to the tasks to be accomplished.

Nursing literature sometimes uses nursing presence to characterize nurses' physical presence; while, at other times, presence is used in a metaphysical sense to depict a nurse's full physical, psychological and spiritual presence (Finfgeld-Connett, 2006). Although use of the term 'nursing presence' demonstrates different understandings and application of the concept, nursing research has endeavoured to capture the multiple levels of nursing presence and their subsequent nurse actions (Easter, 2000; Godkin, 2001; McKivergin & Daubenmire, 1994; Osterman & Schwartz-Barcott, 1996). These multiple levels entail physical, psychological, and therapeutic ways in which nursing presence can be experienced. It is in the quality of being present that the physical, psychological and spiritual characteristics are distinguished (Godkin, 2001; Osterman & Schwartz-barcott, 1996).

Nurses know when their presence is essential in caring for their patients, and patients readily distinguish between nurses who are present for them and those who simply perform nursing tasks (Doona et al., 1997). Gilje (1992) added that an experience of nursing presence results in an experience of love, meaning and purpose, hope, disclosure, and an expansion of consciousness. In this paper, we define nursing presence as a genuine authentic way of being

with the other that goes beyond physical presence. Nursing presence is when the nurse makes room “internally” for the patient, being willing to be involved and to be there whole heartedly (Pettigrew, 1990). This definition captures that which may be termed a humanistic orientation and demonstrates an intersubjective connection between the nurse and patients’ family. This intersubjective connection articulates a nurse-family relationship that embodies the philosophy of FCC (Curley, 1997).

3.3.2 What is Family-Centered Care?

FCC is a health care delivery approach based on the promotion of partnership between family caregivers and health care providers (Rosenbaum et al., 1998). Traditionally, the family has been described in a language of biological ties and legal status (Holstein & Gubrium, 1999), however literature supports the notion that people commonly subscribe to a broader definition of family that is socially constructed and focus more on emotional ties rather than on blood lines (Sharma, 2013). For this paper we use the International Family Nursing Association (2017) definition of family as “a group of individuals who are bound by strong emotional ties, a sense of belonging and a passion for being involved in one another’s lives” (p. 3). We use this definition of family because it is inclusive and accepting of diverse experience of family and overlooks blood ties.

To be effective in the implementation of FCC, it is as important to understand the needs of the family who are partners in their child’s care as it is to understand the needs of the child (Feeg et al., 2018). FCC emphasizes a respectful and supportive approach between family caregivers and health care providers in the care of the ill child (Watt et al., 2013). At the very heart of FCC is the recognition that the family is the constant in a child’s life and their involvement in diagnosis and treatment of childhood cancer cannot be overlooked. Because FCC

is built on partnerships between parents and health care providers, the Institute for Patient-and Family-Centered Care (2019) identified the aforementioned four core concepts of patient and family-centered care: dignity and respect; information sharing; family participation; and family collaboration.

3.3.3 Presence in FCC

Grounded in the philosophy of FCC are the beneficial relationships between families and health care providers to recognize the importance of the family in the patient's life (Feeg et al., 2018; Wright & Leahey, 2013). Similar to FCC, the essence of nursing presence reflects the relationship between the nurse, the ill child, and the family caregiver as being a journey towards a mutual goal of comfort, growth, and well-being. Nursing presence demonstrates caring, assists coping by providing psychological support, and diminishes intensity of feelings such as fear, powerlessness, anxiety, isolation, and distress, by providing a physical and psychological anchor for the child with cancer and their family caregivers (Cantrell, 2007). A nurse's presence can help alleviate the negative effects of hospitalization and empower the family caregivers, their ill child, and their health care providers to grow through their experiences. Authentic connection within the relationship provides a sense of safety for the nurse, patient, and caregivers as they attempt to discover meaning in the human experience of health and illness (MacKay & Gregory, 2011; Wright & Leahey, 2013). Although nursing literature has described presence and FCC as important, it has not explored the role of nursing presence when using a family-centered approach of care. Authentic relationships are established when nurses are willing to talk openly and be involved with their patients whole-heartedly (MacKay & Gregory, 2011).

In order for nurses to provide compassionate care and better support pediatric oncology patients and their family caregivers, it is important to examine how FCC can be facilitated

through nursing presence. FCC encourages therapeutic relationships between family caregivers and the nurse. Therefore, understanding how nursing presence enhances FCC will help in establishing meaningful relationships, thus improving care for pediatric patients. In the following section we discuss how nursing presence enhances FCC and how it is interwoven in the four concepts. A case study is presented to demonstrate nursing presence in a FCC approach for a pediatric oncology patient.

3.3.4 Dignity and Respect

FCC requires that health care providers listen to and honour patient and family perspective and choices (IPFCC, n.d). Nurses are effective in their listening when they engage in therapeutic conversations with their patients and have a sincere intention to capture what truly concerns them, and when nurses simultaneously understand the experiences their patients express (Kourkouta & Papathanasiou, 2014; Wright & Leahey, 2013). Every conversation and interaction that a nurse has with a patient is significant and effects change in their own and their patient and family biopsychosocial-spiritual structures (Wright & Leahey, 2013). Therefore, active listening is paramount and essential attribute of nursing presence (Penque & Kearney, 2015; Turpin, 2014; Wright & Leahey, 2013). When nurses are present and actively listen to their patients and families, then they are better able to view issues from their perspective and relate to them as unique human beings, empathize, and be caring enough to honor their choices. Furthermore, FCC acknowledges that patients and their families have unique family values, beliefs, and cultural backgrounds which influence their choices of care (IFNA, 2017; IPFCC, n.d). Therefore, nurses need to work toward a professional, respectful relationship with their patients and family, incorporating their preferences and values in goals and plans of care. These

relationships that enable a mutual respect of acceptance and expression are grounded in nursing presence (Cantrell, 2007; Kostovich & Clementi, 2014).

Nursing presence fosters authentic relationships that are characterized by open, honest, and respectful interactions (Cantrell, 2007; Monterosso & Kristjanson, 2008). Using therapeutic conversations, active listening, and developing authentic relationships, nursing presence bridges cultural backgrounds and biases, ensures patient and families needs are met, and provides patients with comfort and satisfaction (Davidhizar, 2004; IFNA, 2017; Penque & Kearney, 2015). Being attentive to family and patient-specific needs is reassuring to the family, eases anxieties, and aids in having difficult discussions about goals of care especially in pediatric oncology (Pavlish & Ceronsky, 2009; Snaman et al., 2016). Nursing presence allows the nurse to recognize the patient and their family's individuality and takes time to understand and respect their values, preferences, dignity, and ideas in order to come up with plans of care that will meet their needs.

3.3.5 Information Sharing

Information sharing in FCC requires that health care practitioners share open, objective, complete, and accurate information with patients and families in a timely manner (IPFCC, n.d; Kokorelius et al., 2019; Kuo et al., 2012). Families experience stress when little or conflicting information is given, when their observations differ from those of their nurses, or changes in treatment plans are not communicated (Griffin, 2006). It is essential that authenticity and trust is established between nurses and patient and their families for FCC to be effective. When sharing information, nurses should promote family conversations that support the family in defining the health goals and outcomes (IFNA, 2017). Nursing presence achieves this goal by facilitating honest and open interactions between nurses and their patients (Finfgeld-Connett, 2008; Turpin,

2014). Through presence, nurses create a comfortable mutual environment allowing them to be open, vulnerable, and comfortable to share difficult information. Open and honest information sharing enables patients, families and the health care teams to be on the same page with realistic goals in mind (Monterosso & Kristjanson, 2008; Pavlish & Ceronsky, 2009), empowers family role enactment, and influences the family's self confidence, sense of control, and feeling of connection to their child (Griffin, 2006).

Sharing appropriate information also fosters a sense of trust and helps families to make informed disease related decisions (Kokorelias et al., 2019). Although nursing presence is demonstrated by open and honest communication in FCC, it is simultaneously characterized by caution when sharing information (Furingsten et al., 2015). Snaman et al. (2016) suggested that too much information sharing may lead to more confusion and stress and, therefore, patients and their families should be protected from information overload. Nursing presence allows nurses to be cognizant of the totality of a patients' and family experience allowing one to develop an in depth understanding of the whole situation, sensing what shared information is useful (Doona et al., 1999).

FCC requires health care practitioners to communicate and share complete and unbiased information with patients and families in ways that are affirming and useful (IPFCC, n.d). Nursing presence influences how nurses use verbal and non-verbal ways to pass information to their patients and families. Passive actions, such as the act of being physically present at a difficult time, and active behaviours, such as use of a gentle tone of voice, carefully chosen words, eye contact, and therapeutic touch (Finfgeld-Connett, 2006; Hickman, 2013; Turpin, 2014) are identified as attributes of nursing presence and these are credited for being positive aspects of communication that improve health outcomes (Snaman et al., 2016; Turpin, 2014).

Because FCC is known to better facilitate sharing of information and insights among nurses and patients and their families, nurses should also practice presence to share information in a compassionate manner with their patients and families.

3.3.6 Family Participation

In the concept of family participation, health care providers support and encourage families to participate in caregiving and decision-making at the level they deem comfortable (IPFCC, n.d). FCC encourages families to be involved in patient care discussions, making sure they are available to raise concerns about the health care plan and progress (Clay & Parsh, 2016). Nursing presence involves being open and receptive to families as they become vulnerable sharing their concern and fears about their child, while exposing their humanness (Pettigrew, 1990). Families need to feel they are free of judgement, can contribute to their best ability, and their observations are needed and welcome. When families participate in care, they can help identify missing information about their child, recognize and speak up about errors in care delivery, and alleviate feelings of powerlessness and discomfort (Clay & Parsh, 2016; Griffin, 2006). Like nursing presence, family participation also results in improved patient safety and clinical outcomes for their ill child (Boztepe & Kerimoğlu Yıldız, 2017; Horn & D’Angelo, 2017; Stockmann et al., 2018). Although FCC encourages families to participate in their child’s care, family members may experience a negative impact on their own well-being as part of ongoing demands of caregiving. However, nursing presence fosters cultivation of trusting, caring, and collaborative relationships between families and HCP that enables them to recognize when families are psychologically stressed and having difficulties in coping, affecting their participation in patient care (Doona et al., 1997; Hosseini et al., 2019; Turpin, 2014). It is when nurses are present in these established relationships, that families simultaneously receive

emotional support, enabling them to actively participate in their child's care (Kokorelias et al., 2019).

Family-centered rounds are one of the ways families participate in decision making and care of their patients (Boztepe & Kerimoğlu Yıldız, 2017; Sharma et al., 2014). Family-centered rounds is described as a model of communicating and learning between the patient, family, health care providers, and students, where work rounds are conducted at the patient's bedside and the patient and family share in the control of management plan (Sisterhen et al., 2007). Families recommend that nurses should be present during family-centered rounds since they frequently look to nurses to continue to explain what they heard in the rounds and to assist them in interpreting the outlined plan (Kuo et al., 2012; Latta et al., 2008). Therapeutic relationships fostered by nursing presence are useful to enhance this process. Nurses who practice presence will establish better relationships and deeper connections with their patients and families (Hosseini et al., 2019); this allows their patients to comfortably interact with them, and revisit issues discussed in family-centered rounds without fear of judgement. The benefits of family-centered rounds include active participation of the family, improved communication, and shared decision making between health care providers and families (Boztepe & Kerimoğlu Yıldız, 2017; Muething et al., 2007). Family participation in FCC is enhanced when nurses are present and are attuned to the needs of their patient and family while striving towards a common goal.

3.3.7 Family Collaboration

FCC calls for patients, families, health care providers, and health care leaders to collaborate in policy and program development, implementation, and evaluation; in facility design; in professional education; and in research; as well as in the delivery of care (IPFCC, n.d). Nurses are often involved in all aspects of the family and patient's health care and collaborate in

different areas such as patient education, research, nutrition, pharmacy, supplies, therapists, institution management, and social work (Pavlish & Ceronsky, 2009). Nursing presence in family collaboration is two-fold. First, nursing presence allows nurses to determine when collaboration is needed between families and other health care services offered in order to improve patient and family health care (Doona et al., 1999; Godkin et al., 2002; Turpin, 2014). As mentioned in dignity and respect, information sharing, and patient participation, attributes such as therapeutic relationships, good communication, and shared decision-making enhances the process of collaboration amongst patient families and their health care providers. This collaboration facilitates families' access to services available to them. Secondly, nursing presence positively contributes to institutional development, improve patient satisfaction and the bottom-line (Godkin et al., 2002). These outcomes encourage health care providers and institutions to research, educate, and develop models that will implement nursing presence and improve patient care (Carol Toliuszis Kostovich & Clementi, 2014; McMahon & Christopher, 2011). Therefore, family collaboration can be achieved when models have procedures and policies that are identified as important since they support families' contribution to patient care and have positive patient outcomes (Kokorelias et al., 2019).

Nursing presence may play a significant role in the development of these policies in order achieve this goal. A table summarizing the attributes of nursing presence and expected outcomes when applied in the four concepts of FCC is illustrated in Table 1. Although different attributes have been placed under each concept, it is essential to acknowledge that some attributes of nursing presence, as well as expected outcomes, may be shared across the four concepts; this demonstrates how presence is a significant concept that underlies FCC.

Table 3.1

Attributes of Nursing Presence and Expected Outcomes when Applied in FCC

FCC Concept	**Presence Attributes that Enhance FCC**	**Expected outcome of FCC**
Dignity and Respect	-Active listening -Sincere intention -Non-judgemental acceptance -Acknowledgement of unique personhood -Open, honest, and respectful interactions	-Cultural sensitivity -Improved patient comfort and satisfaction -Patient and family reassurance -Reduced stress and anxiety -Promotes having difficult discussions
Information Sharing	-Open and honest communication -Authenticity and trust -Being physically present at difficult times -Gentle tone of voice -Carefully chosen words -Eye contact -Therapeutic touch	-Establishes a comfortable non-judgemental environment -Establishes trust -Promotes setting realistic goals -Improves confidence and sense of control -Encourages informed decisions -Empowers families on their roles
Family Participation	-Openness and acceptance -Vulnerability -A non-judgemental attitude	-Identifying missing information and errors in care -Alleviates feelings of powerlessness and discomfort -Improved communication, patient safety, clinical outcomes, and coping -Establishes deeper connections -Promotes shared decision making and active participation in patient care
Family Collaboration	-Good communication -Acceptance -Therapeutic relationships	-Facilitates access to healthcare services -Contributes to institutional development -Improves patient satisfaction and clinical outcomes Improves institution revenue

3.4 A Case Study

Caring for a child with cancer is significantly challenging to families. After a diagnosis of cancer, families become deeply involved with their child's health care demands to perform daily medical tasks including treatments and medications, managing the side effects of treatment, meeting multiple health professionals, and caring for the child during periodic hospitalizations (Bally et al., 2014; Feeg et al., 2018). This impacts the family's health and well-being (Bally et al., 2020). FCC has been considered paramount to ensure health care meets caregivers' and children's needs and supports them throughout the course of the disease (Crespo et al., 2016). The following case provides a scenario where nursing presence in FCC can be demonstrated in pediatric oncology:

> Philip (he/him), an 11-year-old boy was diagnosed with a relapse of Acute Lymphoid Leukemia (ALL) after spending nearly two and half years cancer-free. Philip's mother, Jen (she/her), was informed by the health care team that the relapse of leukemia was widespread and needed a more aggressive treatment plan that would include chemotherapy, immunotherapy, radiation, and stem cell transplant. In order to understand her experience and respect her values, Lucy (she/her), Philip's nurse, asked Jen to talk about what this relapse meant for her and her family, and the experience of being Philip's mother. After several exchanges and much reflection, Jen voiced a sense of gratitude and personal growth during her experience with Philip's illness and was thankful for their conversations.
>
> Lucy asked Jen if she and Philip would be interested in including any of the integrative health programs such as acupuncture, aromatherapy, massage or yoga to his treatment plan. Unfamiliar with any of the therapeutic practices, Jen was willing to

collaborate, but the final decision would be subject to Philip's response. Jen selected options that, as an individual, felt comfortable in performing and Lucy supported Jen during new or altered care activities. Together they planned opportunities for Jen to participate in her son's care. Jen also shared information with Lucy highlighting facts about Philip's level of tolerance to daily activities. Jen had successfully coped with previous hospitalizations and had firsthand knowledge of all the intricate details of managing her son's illness from home. As an experienced nurse, Lucy also shared that she had attended to parents whose children's cancer had relapsed and was familiar with varied and accompanying social, physical, and emotional challenges. Jen's insights into her son's responses along with Lucy's insights into cancer treatments and coping were incorporated into Philip's plan of care. Through collaboration, Philip and his family received optimal care.

3.5 Discussion

The case study demonstrates a therapeutic relationship formed between the nurse and family caregiver; wherein the nurse saw the patient as a human and a partner in care, rather than "just a patient". FCC provided an opportunity for Lucy to establish an authentic relationship with her client through therapeutic conversations and a genuine willingness to listen so as to understand, and encourage family participation in order to provide better care. Consequently, FCC allowed Jen to experience nursing presence as Lucy attended to her and her sick child. Patients and families of children with cancer place value in relationships (Monterosso & Kristjanson, 2008; Wright & Leahey, 2013) and nurses need to invest in building authentic relationships. The case study shows the four principles of FCC in play; together with the importance of authentic relationships in family nursing in pediatric oncology grounded in

nursing presence. Using the four concepts of FCC, the following discussion demonstrate how presence is applied in the case study to facilitate FCC.

3.5.1 Dignity and Respect

Lucy invited Jen to an open and honest conversations about her experiences as a mother to a child with ALL. Jen accepted the invitation, showing some degree of trust and rapport by being vulnerable and engaging Lucy in an open conversation. In FCC, it is through therapeutic conversations that nurses and family influence each other and nurse-family relationships are actualized (Bell, 2013; Wright & Leahey, 2013). Relationships are established when nurses are present, respectful, and actively listen to their patients and families (MacKay & Gregory, 2011; Steele et al., 2013). Conversations between Jen and Lucy resulted in an acceptance of the other, empathy, identifying need, and respect of choices and values. Family nursing in pediatric oncology requires nurses to listen, respect, and tune into their patients and families so that they may be able to come up with care plans that are sensitive to their unique needs and desires. Lucy respected Jen's decision sufficiently to let Philip decide what therapeutic practices to participate in and supported her through the activities she felt comfortable with although these were novel to her. Jen felt safe to be vulnerable in her lack of knowledge. When nurses are present, they develop perceptive attentiveness for their pediatric oncology patients and family, sensing their needs and being able to help when things feel out of control (Pavlish & Ceronsky, 2009).

Jen and Lucy each made unique contributions; yet simultaneously respected and acknowledged each other's understanding about Philip and the situation at hand. Jen was familiar with having a child with ALL, making her an 'expert' of her child's experience during the initial illness, while Lucy was familiar with ALL care and treatment, and had attended to several other pediatric oncology patients whose situations resembled Philip's. When caring for a child with

cancer, it is critical to acknowledge a family's individuality and consider their social, religious, or cultural preferences in the plan of care (Kuo et al., 2012; Pavlish & Ceronsky, 2009). Although Lucy had attended to other ALL patients, it was essential that she acknowledged Philip and his family as a unique patient with different sets of values and cultural beliefs. Jen appreciated Lucy's acknowledgement of her individuality, and respect for her family values by not treating her as she had other ALL patients. Nurses practicing FCC are not only called to respect their patient and family's individuality, but to elicit information about families' beliefs in order to come up care that will meet their cultural needs, and personal preferences and values (Kokorelias et al., 2019). Being present facilitated formation of an authentic and meaningful relationship that allowed Lucy and Jen to have an open and honest conversation. As a result, Lucy was able to identify and respect Jen's care preferences, while Jen felt seen and understood. The relationship formed through presence led to provision of better care.

3.5.2 Information Sharing

Open and honest communication was demonstrated when Jen was informed about the severity of the recurrence and possible treatment. Although this news may have been devastating for Jen, she appreciated the honesty. It was important that Jen was fully informed about her child's relapse. When caring for children with cancer, open, honest, and complete sharing of information is essential in FCC (Furingsten et al., 2015; Monterosso & Kristjanson, 2008; Pavlish & Ceronsky, 2009; Snaman et al., 2016; Steele et al., 2013). Open and honest sharing of information demonstrates respect to oncology patients and their families and is also essential to a trusting therapeutic relationship. Nursing presence is facilitated by an honest relationship when caring for a child with cancer (Furingsten et al., 2015). When sharing information, there is a compassionate jointly-held understanding between health care providers and patient families

about what information needs to shared and what information to withhold (Monterosso & Kristjanson, 2008). According to Doona et al. (1999), nursing presence enhances the ability to discern this dilemma. Although there may have been difficulty informing Jen about the news of the relapse, families of children with cancer still maintained that it needed to be heard but a delicate balance must be maintained (Steele et al., 2013). Therefore, while using FCC approach, it was essential that Jen be provided with the necessary information, granted all available options, and encouraged to participate in decision making in order to develop a sense of control for her child's care. As a result, Jen developed more trust for Lucy and health care team, improved her coping and gave her more confidence in the care process.

3.5.3 Family Participation

Family participation in the case study was displayed when Jen, although unfamiliar with other therapeutic practices, was encouraged to be involved in her child's care at the level she chose and felt comfortable with. Jen also participated in the plan of care by providing insights and sharing her 'expertise' from her caring for Philip at home. Families are usually unfamiliar with clinical and therapeutic practices and education about care provision and the disease are essential in FCC (Boztepe & Kerimoğlu Yıldız, 2017; Kokorelias et al., 2019; Muething et al., 2007). Educating families about their child's cancer diagnosis empowers them to make informed decisions, enabling them to participate in their child's care (MacKay & Gregory, 2011). Nursing presence enabled Jen to feel safe and allowed her to be comfortable to voice her lack of knowledge and concerns; while at the same time, this allowed Lucy to see past Jen's weaknesses and encouraged her to participate in ways that she felt comfortable with. Through FCC, family nurses enable patients and their families to feel safe by being present and actively listening, fostering their participation in their child's care (MacKay & Gregory, 2011; Wright & Leahey,

2013). Therefore, family participation in pediatric oncology not only provides safety for the family to express themselves but also the participation in their child's care provided a sense of control. Family participation may provide an opportunity not only for nurses but also for family members to deeply connect and understand each others' experiences.

3.5.4 Family Collaboration

The case study demonstrated that Lucy's invitation of Jen into collaboration with the health care team provided options about different therapies to be incorporated in the patient's care. Patient collaboration was also demonstrated when both Lucy and Jen shared their expertise and incorporated both their experiences into Philip's plan of care. Although families and nurses each have their own health care system (Wright & Leahey, 2013), families desire active involvement in decision making and prefer discussions about their child's care rather than decisions being passed on (Boztepe & Kerimoğlu Yıldız, 2017; Griffin, 2006). An experience of openness, and safety through presence enabled Lucy to acknowledge Jen's contributions as she shared her experiences with previous hospitalizations and managing Philip's at home. Because her experiences and contributions were acknowledged, Jen felt accepted as a member of the healthcare team, giving her a sense of control in her child's care.

When collaborating with patient family in FCC, nurses should view the parent as an expert since they are more familiar with their child (MacKay & Gregory, 2011). Presence encourages nurses to invite families into collaboration in order to ease traumatic experiences that come with hospitalizations and enables them to empathize and see the whole picture. Understanding Jen's experience may have helped Lucy determine whether there were other needs for collaboration with social or counselling services, finances, or educational resources, and ensured they received these services (Steele et al., 2013). Collaboration in FCC calls on

health care providers to forge trusting relationships not only with patients and family, but with the interdisciplinary teams, in order to optimize patient care and improve patient outcomes.

3.6 Conclusion

As demonstrated, the attributes of nursing presence can be interwoven in the four concepts of FCC; dignity and respect, information sharing, patient participation and patient collaboration, and have positive clinical, social, and emotional outcomes for the patient and family. Nursing presence is essential in FCC since it plays a key role in the formation of relationships, a fundamental attribute in the four concepts of FCC. Although literature has been explored to reveal associations between FCC and nursing presence, there is need for more scientific research to justify this argument. Evidence-based understanding of the role of presence in FCC will improve quality of family nursing care and strengthen the FCC model.

3.7 Chapter Summary

As discussed in this manuscript, nursing presence closely aligns with the dimensions of a family-centered care framework. As such, this theoretical framework is particularly useful to better understand and apply nursing presence in a pediatric oncology setting. This theoretical framework was a logical choice to support the research question that guided this research: *How do parents of children receiving cancer treatment experience and describe nursing presence?* Because nursing presence is experienced in the context of a relationship, a FCC theoretical framework is suitable to guide this study since nurse-patient family interactions occur in a family-centered context. Generally, parents of sick children are highly involved in their child's care. Therefore, their involvement and contribution to the research presented in this dissertation was essential, while staying true to the FCC theoretical framework. The following chapter is a

presentation of the findings of the research project, including identification of the structure of nursing presence as described by parents of children with cancer.

CHAPTER 4

4.0 Research Findings

The purpose of this research was to explore how parents of children with cancer experience nursing presence. A descriptive phenomenological approach was used to address the research question guiding this study. Phenomenology is a philosophy and a research methodology (Beck, 2013). As a philosophy, phenomenology is used to understand that which can be experienced through the consciousness one has of whatever is "given"-whether it be an object, a person, or a complex state of affairs (Giorgi, 2009 p.4). As a research methodology, phenomenology is designed to explore and understand people's everyday lived experiences (Shosha, 2012). The phenomenological term 'lived experience' is synonymous with this research approach.

There are two distinct approaches to phenomenological research, namely, descriptive and interpretive phenomenology. Descriptive phenomenology was developed by a German philosopher Edmond Husserl (1858-1938), who established a rigorous and unbiased approach that aimed to arrive at an essential understanding of human consciousness and experience (Fochtman, 2008). In an attempt to define a philosophical method that would provide insight into the experiences of conscious objects, Husserl developed phenomenology as a research process which was different from the empiricist natural sciences (Christensen, Welch, & Barr, 2017). Husserl believed that subjective information should be important to scientists seeking to understand human motivation because human actions are influenced by what people believe to be real (Lopez & Willis, 2004).

Interpretive phenomenology, also known as Heideggerian phenomenology, was developed by Heidegger (1889-1976), a student of Husserl. While Husserl's work on

phenomenology focused to achieve an "untainted description of consciousness," Heidegger considered this impossible and instead focused his work on interpretation rather than description (Burns & Peacock, 2019, p.2). Interpretive phenomenology is focused on subjective experiences of individuals and groups and seeks to find meaning of phenomena embedded in lived experiences (Shosha, 2012). Interpretive phenomenology allows the researcher to bring their own understanding and experiences to the research process because it recognizes that humans cannot be separated from their culture, relationships or history; thus, have a preunderstanding that cannot be put aside (Burns & Peacock, 2019).

In this dissertation, descriptive phenomenology according to Giorgi (2009) was used to guide this study. Descriptive phenomenology aligns with critical realism, the philosophical framework underpinning this study. Critical realism asserts that there is a reality independent of us, and our knowledge of this reality is subjective (Schiller, 2015). Descriptive phenomenology was therefore chosen to investigate the subjective reality, the experience of nursing presence, that is shaped by social, political, cultural, or economic factors, and influenced by personal experiences and meanings created. The methodology section of this chapter is presented in greater detail for a better understanding of the method of inquiry used for this research. In this chapter, the main findings are presented in a manuscript format followed by a discussion of the results. Following discussion of the findings, strengths and limitations are identified and relevance to clinical practice is highlighted.

4.1 Manuscript 3

Mcharo, S. K., Bally, J., Spurr, S., Walker, K., Holstlander, L., Peacock, S. (2022). Exploring Nursing Presence as Experienced by Parents in Pediatric Oncology. *Journal of Pediatric Nursing, 66*(86-94). https://doi.org/10.1016/j.pedn.2022.05.021

This manuscript titled: *Exploring nursing presence as experienced by parents in pediatric oncology*, has been submitted to Journal of Pediatric Nursing for publication. In this manuscript, a discussion of the study findings is presented in relation to the research question. Author contributions to this manuscript are as follows: Mr. Mcharo contributed in conceptualization, methodology, investigation, formal analysis, writing-original draft, and funding acquisition; Drs. Bally and Spurr contributed in conceptualization, methodology, formal analysis, writing- review and editing, supervision, and funding acquisition; Drs. Walker and Holstlander contributed to the conceptualization, writing- review and editing; and Dr. Peacock contributed to conceptualization, expert support with the use of the methodology, and writing- review and editing.

4.2 Abstract

Background: Nursing presence has been viewed as a valuable way to create therapeutic relationships and has been linked to better health outcomes for patients and families. However, whether nursing presence can be described and how parents in pediatric oncology experience this phenomenon remains unanswered. Therefore, the purpose of this study was to explore how parents of children with cancer describe and experience nursing presence.

Methods: This study used Giorgi's phenomenological approach to explore nursing presence as experienced by parents of children with cancer. Ten participants from a pediatric oncology clinic in Canada were interviewed. Giorgi's approach was used to analyze these data.

Findings: Based upon participants' descriptions, a structure of nursing presence emerged which included six constituent features: An attitude of presence, a source of encouragement, clinical experience and expertise, therapeutic communication, family involvement, and a sense of home away from home. Most notably, nursing presence as experienced by parents was characterized by the 'being' and 'doing' of presence which were equally important.

Conclusion: The experiences described by parents provided rich and nuanced insights into what it meant to experience nursing presence in a pediatric oncology setting. This study provides a structure for this meaning making and expounds on its constituent features, describing what nursing presence resembles when experienced by parents of children with cancer.

Practice Implications: This study informs nursing practice, policy, and education in ways that are likely to enhance care and the subsequent well-being of pediatric oncology patients and families.

Key Words: Presence, pediatric oncology, descriptive phenomenology, family-centered care

4.3 Exploring Nursing Presence as Experienced by Parents in Pediatric Oncology

A diagnosis of cancer and management of its symptoms during cancer treatment is overwhelming for parents and their sick children. Parents often see the diagnosis as a threat to the child's life and to the family's security; posing a great challenge not only to their physical health but also to their emotional, social, and psychological well-being (MacKay & Gregory, 2011). Support of the family through family-centered care and nursing presence is essential in these times of crisis; this is especially so during the COVID-19 pandemic where public safety demands restrict the physical presence of families for hospitalized patient (Hart et al., 2020; Mcharo et al., 2021). Family-centered care is a model of health care delivery that emphasizes collaboration between families and healthcare professionals (Thienprayoon et al., 2020). Parents play a significant role in their child's medical care and consider themselves as active members of the multi-disciplinary team, decision makers; they are experts in their children's caregiving (Kuo et al., 2012; MacKay & Gregory, 2011). Family-centered care puts the nurse in an ideal position to practice nursing presence and develop beneficial therapeutic relationships with parents and their loved ones (Mcharo et al., 2021).

Nursing presence is described as a foundation for professional nursing practice, characterized by being available with the whole of oneself and open to the experience of another through a mutual interpersonal encounter (Gardner, 1992; Kostovich, 2012). Nursing literature uses presence to depict both a nurse's bodily presence, and in a metaphysical sense encompasses a nurse's full physical, psychological, and spiritual presence (Turpin, 2014). Over the years, nursing presence has been viewed as a valuable way to create therapeutic relationships that facilitate healing, and has been linked to better health outcomes for patients and family caregivers (Doona et al., 1997; Finfgeld-Connett, 2006; Mohammadipour et al., 2017). For

example, the intensity of feelings such as manifest in fear, powerlessness, anxiety, isolation, and distress, are diminished when parents experience nursing presence; thus improving patient satisfaction and healing (Kostovich, 2012).

Despite the investigations of presence in nursing literature, there is limited research exploring this concept amongst pediatric oncology patients. A few studies have looked at implementing nursing presence and its positive outcomes in terms of the reduction of incidence of falls and pressure ulcers (Kostovich & Clementi, 2014), together with increase in patient satisfaction with care (Penque & Kearney, 2015). Quantitative measurements of nursing presence include measuring presence from both the nurse and the patient perspectives (Hines, 1992; Kostovich, 2012). Several qualitative studies have explored the nature of presence as described by adult patients (Edvardsson et al., 2017; Mohammadipour et al., 2017), as well as nurses and family caregivers of adult patients (Osterman et al., 2010; Reis et al., 2010). To our knowledge, there are no published reports examining the nature of nursing presence as experienced by parents of children with cancer. Therefore, the purpose of this study was to explore and understand nursing presence as experienced by parents of children with cancer during cancer treatment. The specific aim of this research was to draw on the parents lived experiences to help identify how we might use presence to improve nursing practice in pediatric oncology. The research question that guided the study was: *How do parents of children receiving cancer treatment experience and describe nursing presence?*

4.4 Methodology and Methods

As both a philosophy and a research methodology, descriptive phenomenology supports those who use it to understand that which can be experienced through the consciousness, at the same time explore and understand people's everyday lived experiences (Giorgi, 2009; Shosha,

2012). Descriptive phenomenology is used when little is known about an issue and the aim of the study is to make clear and understand the most essential meaning of a phenomenon of interest from the perspective of those directly involved in it (Giorgi, 1997). The main methodological consideration of this approach is the requirement to explore, analyze, and describe a phenomenon maintaining its richness, breadth, and depth so as to gain a 'near-real picture' of it (Matua & Van Der Wal, 2014). This method allows nurse researchers to bring out essential components of lived experiences taken for granted by a specific group of people, revealing their hidden essences which care givers can then use (Lopez &Willis, 2004; Matua & Van Der Wal, 2014).

In order to utilize descriptive phenomenology, one needs to understand the philosophical underpinnings of the method. Three important philosophical underpinnings of Husserl's phenomenology as indicated by Fochtman (2008) are intentionality, essences and phenomenological reduction. For Husserl, intentionality is the consciousness of something as something (Christensen et al., 2017). It is the "key feature of consciousness" (Giorgi & Giorgi, 2003, p. 250). Intentionality is the directing of the mind towards objects which may be physical objects, thoughts, concepts or feelings that are often taken for granted and perceiving them as they are. Intentionality, therefore, helps us uncover the essence of phenomena. Phenomena are seen to be made up of essential structures which can be identified and described if studied carefully and rigorously enough (Finlay, 2009). These essential structures are known as the essence, which is determined by means of free imaginative variations (Giorgi, 2009). Free imaginative variations is a process which requires that one mentally remove an aspect of the phenomenon that is to be clarified in order to see whether the removal transforms what is presented in an essential way (Giorgi, 2009; Giorgi & Giorgi, 2003). However, Jackson, et al.

(2018) states that Husserl's phenomenology requires the researcher to suspend personal beliefs about the research phenomena, while seeking to describe the participants' experiences. This is known as phenomenological reduction, or epoche. Phenomenological reduction involves bracketing or putting aside one's presuppositions and what one knows about the phenomena being studied so that one can see it without imposing past knowledge or experience upon the phenomenon (Fochtman, 2008). The phenomenological reduction in no way denies what is naturally believed in or posited by our natural consciousness, but rather it is a deliberate effort to "suspend" or "put in abeyance" that attitude to examine it in depth (Watson, 1988, p. 82). A researcher who wants to employ descriptive phenomenology should be familiar with its philosophy since it provides the foundation for the method (Beck, 2013)

Descriptive phenomenology was best suited to address this study for three reasons. First, because of its descriptive orientation, it was well suited to the exploration of parents' experiences of nursing presence. Nursing presence is a human experience that appears in the consciousness and is related to human health and illness (Watson, 1988). Descriptive phenomenology seeks to understand anything that can be experienced through the consciousness one has of whatever is 'given'-whether it be an object, a person, or a complex state of affairs-from the perspective of the conscious person undergoing the experience (Giorgi, 2009). In addition, nurses often seek an objective understanding of situations that are subjectively constituted (Giorgi, 2000). Nursing presence is an "intersubjective encounter" between the nurse and the patient (Doona et al., 1997, p 12) and it, therefore, calls for an objective method of inquiry into subjective experiences. Descriptive phenomenological method is instrumental in researching subjective human experiences that are foundational to sound nursing science (Lopez & Willis, 2004). Second, descriptive phenomenology was best suited for this study because it looks to a phenomenon as

experienced by the participant from a holistic, not cartesian dualist perspective (Jackson, et al., 2018). Within the participant's lived experience, nursing presence as a phenomenon is inextricably linked with the subject and so underpins the view that access to a phenomenon is through the participant. Finally, descriptive phenomenology provides room for critical realism, the philosophical framework used to guide this study. Critical realism recognizes the importance of the interplay between personal and situational or contextual factors (Sword et al., 2012) that may influence parents experience of nursing presence. Critical realism views events as being a product of many factors coming together and given the right context (Clark et al., 2008).

A descriptive phenomenological approach as described by Giorgi (2009), was used to conduct this study. Phenomenology is the study of lived experiences and is instrumental in researching phenomena related to human health and illness conditions such as loss-grieving, anxiety, hope, despair, and related human experiences of existence (Watson, 1988). Specifically, descriptive phenomenology aims to establish a rigorous and unbiased approach that aspires to arrive at an essential understanding of human consciousness and experience (Fochtman, 2008; Giorgi, 2009; Jackson et al., 2018). Our purpose in using descriptive phenomenology was to reveal the essence of nursing presence, as it is experienced physically and through consciousness. This method allowed the capture of invariant aspects of nursing presence, and to identify the essence of the phenomenon as described by parents in pediatric oncology (Giorgi, 2009).

4.4.1 Sampling and Participants

Purposive sampling was used to select participants from a local children's hospital oncology unit. Participant selection criteria included parents of children who had been diagnosed with any cancer and who were aged birth – through 14 years (inclusive), and who were of any

gender, ethnicity, and sexual orientation. Study participants were also required to have had at least one interaction with a nurse and to be fluent in English. Those who did not meet these criteria were excluded from the study. The nurse in charge of the unit was informed of the study criteria and assisted in recruiting participants by establishing first contact, then connecting the researchers to the prospective participants. A total of ten participants met the criteria and were included in the study. No participant withdrew from the study. As suggested by Giorgi (2009), the sample size was small so that each experience could be examined in depth and to better appreciate the variation of the phenomenon. Recruitment and data collection continued until a rich and in depth understanding of participant experiences with nursing presence was obtained.

4.4.2 Ethical Consideration

The study was approved by the Behavioural Research and Ethics Board at the University of Saskatchewan and operational approval was obtained from the Saskatchewan health region. The participants received information about the purpose and procedures of the study and were invited to participate through an informed and signed consent. Participants were advised that: their participation was voluntary; they could stop the interview, refuse to answer any question, and withdraw from the study at any time; their interview content was confidential; and, that research results would be published with their confidentiality maintained. All participants received an honorarium of 50 dollars after the interviews were conducted to show appreciation for their participation.

4.4.3 Data Collection

Data were collected between February 2020 and April 2021. A semi-structured interview guide was developed by the authors of this study based on their knowledge in this area (Brinkmann & Kvale, 2015). A total of 12 interviews were conducted. The initial seven

interviews were face-to-face and conducted at the hospital while the rest were done via Zoom (a cloud-based videoconferencing service that offers secure recording of sessions) (Zoom Video Communications Inc., 2016). The switch from face-to-face interviews to Zoom videoconferencing was done to implement physical distancing due to COVID-19 (Public Health Agency Canada, 2021). To initiate the telling of their experiences, the first question for the participant was “in as much detail as possible, please describe for me the situation in which you experienced nursing presence” (Giorgi, 2009). Follow up questions used such as “you spoke about such and such, can you please tell me more about that?” These follow up questions were intended to direct the participant to speak to the phenomenon of interest and extract aspects of the account that were presented but not fully and expressly described by the participant (Giorgi & Giorgi, 2003). All interviews were audio recorded and lasted approximately one hour. Any information that needed additional clarification was noted and, in such cases, participants were contacted again to elaborate on the descriptions of their experiences (Englander, 2012). Three out of ten participants had two interviews in order to provide more detail on the responses provided in their first interview. The initial two audio recordings were transcribed by the first author and later an experienced transcriptionist was hired to transcribe the recordings.

4.4.5 Data Analysis

Giorgi’s phenomenological analysis (2009; 2012) was used to transform the raw data to reveal the *essence* of the phenomenon of nursing presence. The method was implemented using the following steps:

1. The first author worked most closely with the data and read through each interview several times to get a sense of the whole. The second and third authors provided extensive support and peer debriefing during each stage of the data analysis process. The

fourth, fifth, and sixth authors contributed to the decisions regarding design and methodology, and further assisted in the last phases of the analysis, providing fresh perspectives and insights in the methodology and discussion of the findings.

2. Participants' data were divided into parts known as meaning units, where the first author would read the data and place a slash every time a transition in psychological meaning was experienced. Meaning units comprised of a sentence or paragraph.
3. Using the words spoken by the participants, the meaning units were transformed into expressions that were more revelatory of the psychological significance of what the participant said. This was a process that used free imaginative variation (Giorgi, 2009).
4. All meaning units of similar content were organized under the same category, also known as constituent feature. The respective direct and psychologically more sensitive transformations of the meaning units were then reviewed with the help of free imaginative variation and an essential structure of nursing presence was written.
5. The essential structure comprising of several constituents was used to help clarify and interpret the raw data of the research.

4.4.6 Rigor of the Study

A reductive approach was taken, where the researchers were reflexively self aware, and presuppositions were bracketed by writing memos from data collection through to analysis in order to avoid imposing past knowledge or experience upon the phenomenon (Giorgi, 2009; Tufford & Newman, 2012). The authors maintained journals, logs, and auditable records so that the specific research process could be assessed with a critical other. Throughout the iterative data analysis process, the method and emergent findings were discussed and critiqued by the study authors.

4.5 Findings of the Study

A total of 10 participants aged 26-48 years were interviewed (see Table 2). Two participants were from rural communities, while eight came from urban centers. All participants were parents of a child in treatment for a variety of cancers, and the sample was comprised of fathers (n=2) and mothers (n=8). Three different ethnic backgrounds were represented in the study; European (n=7), First Nations (n=2), and African (n=1). The average age of the participant's children was six years.

4.5.1 The Essence of Nursing Presence in Pediatric Oncology

As indicated, the aim of descriptive phenomenology is to find a general structure of an experience that implicitly contains all of the key meanings that contribute to the determination of the structure (Giorgi et al., 2017). This aim is achieved by reviewing all the transformed meaning units during the data analysis in order to determine the essential ones that will form the basis of the structure. The interviews in this study resulted in 361 meaning units from the ten participants. Based upon all data, the following structure captured the 'being' and 'doing' of nursing presence as experienced by parents of children in pediatric oncology emerged:

> Nursing presence has an intrinsic attitude characterized by a nurse's genuine concern for parents and their children in their period of distress. Through emotional and physical acts of kindness, parents feel seen as human allowing them to experience comfort and safety in their vulnerability. Nursing presence also has an extrinsic attitude experienced when nurses are skilled and competent in their care. When the patient family is involved in their child's care and information is shared in a respectable manner, parents feel appreciated and aligned with the care team. As a result, feelings of safety and belonging are experienced by parents leading to improved trust and therapeutic relationships.

As a result of the analysis, the explicit understanding and experience of nursing presence as described by parents is described in six constituent features which are captured in the essential structure: (a) An attitude of presence, (b) A source of encouragement, (c) Clinical experience and expertise, (d) Therapeutic communication, (e) Family involvement, and (f) a home away from home.

4.5.2 An Attitude of Presence

The research findings show that participants described an attitude of presence that was manifested through "seemingly insignificant" gestures. Parents experienced presence when nurses showed genuine concern and acknowledged them as 'human beings' rather than patients. Showing genuine concern and acknowledging patients was achieved through remembering their names and greeting them; recalling their personal stories and finding out how they were doing before procedures; being physically present in their distress without necessarily saying anything; stopping by their rooms during hospital visits even when not assigned to them; and keeping in touch after treatments. Presence was experienced when nurses would attempt to know parents or their child on a personal level, engaging them in conversations in which they were comfortable. This was described by a parent who stated (P8):

> …So if we're there because we're getting routine chemo, it's relating to him. Talking to him about his dog and, you know, remembering his brother's name and – and those little details. Because we have a Great Dane dog and – she was like two months old when he got sick, so they've been just the best of friends. So they – oh how's Minnie? And oh, is Kev at school today? And so he feels good going in.

Other gestures of kindness, such as grabbing a snack or a seat to make parents comfortable, portrayed presence that was pleasant and enhanced their hospital experience.

Parents also felt presence when nurses went out of their way to make the hospital experience more tolerable for their sick child. One parent stated (P3):

> There's one nurse that we've had a few times during the night. Super hard time with the pumps. He's got three different pumps going, right, so they're all beeping at different times. This nurse, goes and puts it into her phone to set up alarms on her cell so she comes into the room before the pumps start beeping. So, it lets him sleep longer and more calmly right because he already wakes so many times to go pee. And then with all the beeping on top makes it hard.

Parents described the kind gestures as seemingly trivial but these had a great impact on their hospital stay. The findings also describe moments that parents did not experience nursing presence, negatively affecting their experience of care. When nurses did not portray an attitude of presence, there was a breach of trust and relationships compromised, thus affecting their nursing care. One parent (P9) stated:

> We could hear them talking outside of our curtain, but no one walked in to ask if everything was OK. It took my husband going out there and saying we need help. It was so stressful and really bothered me that there was that much distress coming from behind the curtain … and I knew they were out there, and they could hear us, and no one could just peek their head in and say, do you need help. It was so disappointing.

Findings showed that parents had an easier time describing experiences they felt a lack of presence compared to when they did. Nonetheless, it was evident that parents experienced an attitude of presence when nurses went out of their way and took some form of action, whether great or small, to enhance their hospital experience.

4.5.3 A Source of Encouragement

Parents described they experienced nursing presence when nurses were supportive and provided reassurance. Participants stated they felt presence in the humane attitude, empathy, and genuine concern when nurses not only performed their tasks but went ahead and comforted them in their distress. This support was experienced through words of affirmation and comfort, providing suggestion for solutions when nurses observed parents' internal conflict, or spending a little extra time with parents. As one parent (P10) stated:

> Like they took him back to the OR three, four times and they couldn't find the reason he was having all these complications. So it was really good to have someone to just sit with you. She sat on the bed and she talked to me and told me, don't worry, like, we always have this. And he'll be ok. You're taking such good care of him. And, she just, yeah. She just talked to me, like, as a human being. Like, it just, yeah. It was really, really good.

When nurses were present and a source of encouragement, therapeutic relationships were formed allowing parents to be more vulnerable in sharing their fears and concerns. These relationships and intimate conversations with parents made it easier for nurses to identify their need and provide the support required.

4.5.4 Clinical Expertise and Experience

Findings showed that presence had a dimension of nursing clinical experience and expertise. For example, parents experienced presence when attended to by nurses they felt had the experience and expertise to care for their sick children. Value was placed on nursing skills such as accessing intravenous catheters and careful handling of patients during routine procedures such as X-rays, chemotherapy, or blood work. Parents felt that nurses working in the oncology clinic or oncology wards had more experience, hence, were experts in inserting

intravenous catheters compared to those working in the emergency departments. Although parents had been informed that they could call on nurses from oncology to come insert their child's intravenous catheter's whenever they visited the ER, resistance was sometimes encountered causing tension and anxiety. One parent (P2) stated:

> …I didn't want her to access her port because she hadn't had enough experience accessing ports and I didn't want her to miss. And she did miss. She came in, she tried to access her, she missed, so I was not pleased. And so at that point we already knew she already had an infection – she had a fever – so I just said "Yeah, let's just take her up to the ward and they'll access her up there." They took her up to the ward, they got it on one try and it turned out to be a line infection… yeah, they got her accessed quickly there.

Parents felt nurses with more experience in such nursing skills not only reduced the risk for infection and pain experienced by their sick children during invasive or non-invasive procedures but were able to have better interactions with them and their child during the procedures. While presence was experienced when parents had confidence in nursing skills, they also highlighted the need for nurses to pay extra attention during procedures. Furthermore, findings also showed that competence, being perceptive, and taking action when not necessarily required promoted trust between nurses and parents. Parents reported experiencing presence when interacting with nurses who were anticipative and insightful, being able to prevent trauma or solve their concerns before they occurred. Parents also expressed presence when nurses could comprehend the 'bigger picture' and took action to make their hospital stay comfortable. Ensuring patients' comfort was perceived as kind and empathetic thus establishing trust and emotional safety for the patients. For example, as a parent (P1) suggested:

I mean in the old hospital you had to sleep on the floor, or you got a red chair. I mean she kept getting me red chairs. I know that's stupid, but it made a huge difference to me. Yeah, that sounds silly (laughs). Yeah, every time we got admitted. Yeah, it was huge. I think she felt that – I think she was very good at empathizing and putting herself in my shoes, like, you know, your daughter just has this awful diagnosis and the last thing you want to be doing is sleeping on a – like a one-inch mattress on the floor of a hospital, right? So just the kindness and the thoughtfulness of procuring that red chair was just so nice.

Parents had stronger relationships with nurses who were perceptive and appreciated their thoughtfulness. Nurses' consideration was sometimes experienced when they insisted parents take better care of themselves by offering them some respite. While there was no clinical expertise needed in being anticipative, nursing experience working with parents of children with cancer played a role in ensuring their hospital stay was less stressful.

4.5.5 Therapeutic Communication

Communication emerged as a constituent feature that described nursing presence for parents. Findings showed that parents paid attention to who, what, and how the information was provided. Nursing presence was experienced when significant information was passed along by those who were trusted by parents. Parents established trust and were more comfortable with those whom they had frequent contact. Nurses who attempted to establish rapport before sharing sensitive information were seen as more present. Describing when she received information from a student, a parent (P7) stated:

…you know, that was also, to me – I mean, I guess they have to learn too. So, it was probably a type of a teaching tool. But, you know, you hope that you hear it from them. It

> means more to hear it from them. Somebody that you have trusted and built somewhat of a relationship with, instead of a complete stranger. This is life altering news that you're getting. So, I think that would've been more respectful.

Parents expressed presence when information provided to them was accurate, honest, easy to understand, and timely. Although parents admitted that, at first, receiving the information was overwhelming and challenging to grasp, they were more assured when nurses were straightforward and had a plan of care. Parents felt that receiving timely and accurate information made them feel cared for, less anxious, and made it safer to care for their sick children. Parents also noted that *how* information was shared was equally as important as *what* was shared. Participants stated that nursing presence was experienced when nurses were patient in their care. This was experienced through answering parents unending questions, clarifying misinformation, using a friendly and respectful tone of voice, and carrying a pleasant attitude. Describing a nurse's interaction with her four-year-old child, one parent (P10) said:

> She came in, didn't say hi, or find out how our night was. Like she just started talking, 'oh, I heard he's combative and like he gave someone a black eye. So, I'm not going to tolerate that today.' Just like that. [Laughter]. So, then I'm sitting there and she's like, 'and I'm going to come back, get all his stuff done and weigh him and do this and do this.' She was just going on and on while I sat there. So, I asked, 'are you talking to him?' She responds 'yeah'. I was like, 'why?' She says, 'well, I heard he's combative.' Then I was like, 'ok, you know what? You cannot be his nurse today.'

Participants in this study expressed a lack of presence when nurses caring for their ill child was unsympathetic in their approach, as opposed to those who showed more understanding when their child was aggravated and uncooperative. Describing presence, parents were observant in

what was communicated not only through the verbal, but the non-verbal body language and attitude. An unpleasant attitude while sharing information damaged any experience of presence by creating a barrier and mistrust between the nurses and parents.

4.5.6 Family Involvement in Care

Parents experienced nursing presence when they were involved in their child's care through decision making and learning how to perform some tasks. Parents considered themselves as primary advocates for their child and felt presence when their observations, ideas, and concerns were heard and genuinely considered in decision making by nurses. Participants reported to have had a better experience when requests they felt to be reasonable, were respectfully granted. Describing her child's traumatic experience being poked and finally getting a PICC (Peripheral Inserted Central Catheter) line, one parent (P8) said:

> They were in there four times a day drawing blood and he was getting transfusions and they were blowing veins and he had nothing left. The nurse, advocated for him to get a [PICC]. And he had a [PICC] in for four of five days before he got his port put in. You know, they were going to pull the [PICC] when they put the port in as well, and I said, no, because if that port doesn't work or it's not functional. So, I told the nurse please leave that [PICC] in even if it's for my mental health- you can't keep poking this kid six, seven times a day. And so they were like, you know, whatever.

Parents not only felt presence when they were involved in nursing care at the hospital, they observed that it made the experience less traumatic for the child and less stressful for the nurse. Participants also identified patient teaching as nursing presence since they were equipped and prepared to perform their child's care in the nurse's absence:

…Probably when I'm at home, for example, all the stuff they've passed along to me and my wife. Like she has a feeding tube, her G-Tube, her port; all that, they've made sure we've understood how it works and helped to grasp it all. And so, anytime if … let's say her G-Tube comes out, they've shown us everything if it ever comes out at home. But one of them has shown us what to do to put it back in instead of here's your kid and "goodbye"…

Involving the family in their child's care and ensuring parents were comfortable in performing tasks through patient teaching gave parents a sense of control, allowing them to be actively involved in their child's care. Parents expressed presence when nurses involved them in decision making, provided them needed information, and equipped them with the necessary skills to look after their ill child when away from the hospital.

4.5.7 A Home Away from Home

Parents described nursing presence as a sense of belonging to the 'nursing family' during their hospital visits. The term 'family' and 'home' were repeatedly used by parents describing how they felt safe and accepted by the nursing team. Frequent visits, familiarity, and empathy from nurses provided companionship for parents, thus establishing trust and developing better relationships. Describing how a nurse was like family, a parent (P1) stated:

Yeah, I think she could see that we were pretty shaken and she just had empathy in general which is nice… She made a huge difference and a huge impact in our life and she made this a little bit more bearable and that's – you can't take that back, right? Like this diagnosis is awful. I mean it could be worse, of course, but those first few days, I mean the shock of it, having someone who cares about you as a family, that matters…

A genuine willingness of nurses to actively cater to patients' needs made parents describe them as 'family'. Nursing presence was experienced when parents felt safe and less stressed at the hospital because nurses were proactive in their child's care. Describing why he referred to nurses as family, P2 said "It's like a husband and wife, if she threw up, they're (husband) there to help. No questions asked, they just … they just do it." In addition, due to the COVID pandemic, parents state they saw nurses more frequently than their families, making them a steady source of support and comfort. One parent (P9) elaborated by saying:

> …especially through COVID, we see our nurses more than we see some members of our family. Like more than I've seen my parents or my brother, just because we have to keep our circles so tight. They [nurses] are a very steady presence in our lives. Yeah, they're our family…

Familiarity due to frequent hospital visits provided a steady source of support and comfort. Parents acknowledged it felt safer and easier for them and their children to relate to some nurses because they were not only familiar but pleasant and easy to relate to. Parents experienced nursing presence through warmth, trust, companionship, and safety provided to them by their 'nursing family'.

Analysis of participants' data provided six constituent features of the structure of nursing presence as experienced by parents in a pediatric oncology setting. These constituent features captured both an intrinsic and extrinsic dimension of nursing presence. Parents described intrinsic attributes of nursing presence that reached to their socio-emotional being, characterized by a genuine concern and care. Parents also paid attention to nursing skills, determining the extrinsic attributes that made them feel safe and involved. These attributes were intertwined to form the totality of nursing presence, leading to positive hospital experience for the parents.

4.5.8 Nursing Presence as Described by Parents in Pediatric Oncology: A Model

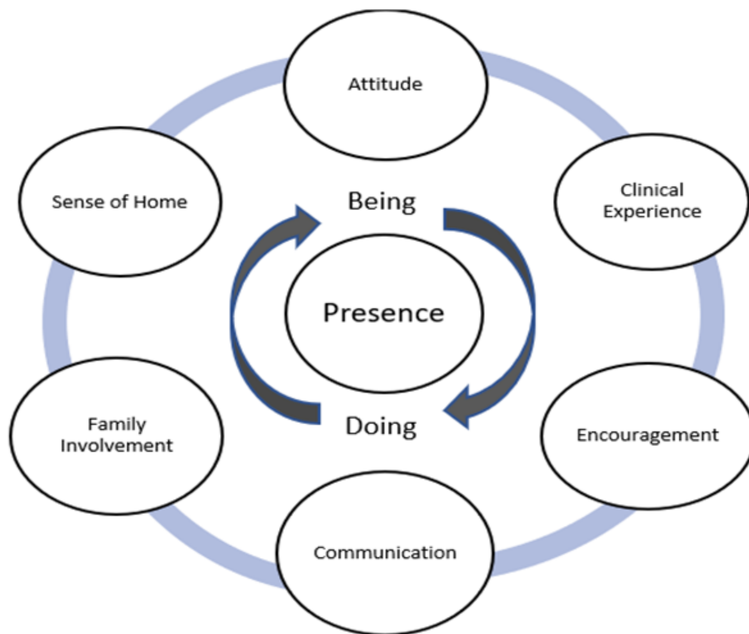
A model describing the structure of nursing presence was developed for a richer description of the findings (see Figure 2.1). The model incorporates the six constituents described by parents in this study: An Attitude of Presence, Clinical Experience and Expertise, A Source of Encouragement, Therapeutic Communication, Family Involvement, and A Sense of Home away from Home. In the model, each constituent is essential. According to Giorgi (2009), a constituent is essential if the structure of the experience collapses once it is removed, and inessential when the structure does not collapse. The constituents in this model are arranged in a circle, suggesting equal level of importance and their interconnectedness. In the middle of the model is nursing presence, the central idea of the structure, encircled by 'being' and 'doing'. 'Being' and 'doing' encircling presence suggest their significance in the experience of nursing presence, while the arrows emphasize how 'being' and 'doing' are interconnected and of equal importance in the process. It is in the flow between 'being' and 'doing' that the outer constituents of the model also tend to overlap in their experiences which is illustrated in the model by the arrows.

Findings demonstrated that nursing presence calls for both 'being' and 'doing', and the two dimensions are intricately interwoven as described by parents of children with cancer. This finding is consistent with Kostovich et al (2016) who described nursing presence as multidimensional, encompassing a physical and a metaphysical presence that meets the emotional and social need of a patient. This study affirms that parents of children with cancer experienced nursing presence not only when their socio-emotional needs were met, but also the physical needs of their ill children during treatment. Parents experienced nursing presence when

nurses were able to physically cater to their child's needs while being emotionally available for them.

Figure 2.1

Model: Nursing Presence as Described by Parents in Pediatric Oncology



4.6 Discussion

To reiterate, the purpose of this study was to use a descriptive phenomenological approach to describe the essence of nursing presence as experienced by parents of children with cancer. Nursing presence was experienced when nurses were genuinely concerned, saw the child as a normal human being, and listened and remembered their stories. Parents and their child felt seen, heard, and understood when nurses showed genuine interest in them as human beings and not their illness. These results are similar to Woodgate (2006) who found that adolescents with cancer experienced nursing presence when nurses were interested in them as people; instead of treating them as if their lives evolved around cancer and its treatment. In another study, by Monterosso and Kristjanson (2008), parents found comfort in relationships where nurses

demonstrated willingness to know their child as a person. Conversations held on a personal level made pediatric patients feel safer in the hospital environment and reduced their fear of the unknown that came with a cancer diagnosis (Anderzén-Carlsson et al., 2012). When a nurse has an *attitude* of presence, they see the patient as a person and pays attention to their stories since they have meaning attached to their daily lives. Although Browning and Waite (2010) argued that it takes courage for nurses to open their hearts and listen, presence provides an opportunity for nurses to listen and understand at a deeper level in order to connect with their patients and families on a shared humanity. Nursing presence also seemed to be conveyed in small actions by nurses; these did not go unnoticed by parents. Opening the curtain to acknowledge noise from the opposite side can appear to be minor or insignificant. According to Gottman (2012) it is these seemingly insignificant gestures that provide an opportunity to establish or betray trust, which are essential means for establishing and experiencing nursing presence. Paying attention to little things and acting in the smallest ways demonstrated that nurses saw parents and their patients as more than a diagnosis, a bed number, or a task to be accomplished.

Parents experienced nursing presence when nurses were a source of encouragement and comfort in their distress. Parents felt seen and encouraged when nurses expressed sincere commitment and interest, giving hope, and helping them cope with their child's illness. These findings echo a study by Steele et al (2013) which showed that parents needed to be encouraged that they were going to get through their difficult circumstances. Pediatric patients in Woodgate's (2006) study also experienced presence and valued nurses who were there to remind them of the importance of maintaining a positive attitude and getting on with life. Walsh (1999) described this nurse-patient interaction as '*being-with* as possibility' in a shared human experience. Patient encouragement is not merely a vague hope about an unforeseeable future, but

in ‘being with’, parents and nurses fight and strive for a *possibility* of what could become (Walsh, 1999). When caregivers take time to console patients, the aim of nurses in the presence is not to change or intervene, but to bear witness to the patient experiences in a non-judgemental manner and meet each other in their respective understandings of life (Mohammadipour et al., 2017).

Nursing presence was experienced when the care provided to parents was safe, desirable, and of good quality. This constituent feature of clinical expertise and experience explicitly revealed the ‘doing’ of presence that parents had considered significant. According to Wong et al. (2015), parents mainly bring their children to the clinic to seek a diagnosis, treatment, and reassurance. Therefore, when parents experience nurses with clinical expertise and experience, they feel reassured and confident that their child is in good hands. Similar results are discussed by Mohammadipour et al. (2017) where patients described a nurse practicing presence as one who not only provided humanistic care, but one who was objective and technically competent. Most parents of children with cancer have had to endure frequent hospital visits, recurrent hospital admissions, and patient teachings, and therefore tend to be familiar with what is expected or required of them. Uncertainty, tension, and anxiety may arise when what they know to be familiar is challenged. Clinical experience and expertise allowed the nurses to engage in more meaningful exchanges in order to prevent negative consequences that may arise. According to Godkin (2001), nursing presence enabled nurses who were professionally mature to see a ‘bigger picture’ by going beyond the scientific data; they knew the uniqueness of the individual patient, and sensed when and how to interact with patients.

Godkin and Godkin (2004) argued that patients are unable to easily recognise whether the nurses were technically skilled or not but could effortlessly identify those nurses who had shown

nursing presence. However, findings showed that parents in pediatric oncology can easily identify those nurses who they felt were less experienced and competent, as well as those who lack nursing presence. Although nurses are often trained to believe they are most effective when doing for a patient, nursing presence, being with the patient can be equally, if not more, therapeutic overall (Benner, 1984).

Parents were sensitive to not only who delivered the message, but what and how the communication occurred. Communication comprises of what is being communicated and how the content is being communicated which includes the tone, language, and style used to deliver the message (Foronda et al., 2016). Parents sought open and honest communication delivered in a compassionate manner; preferably by someone they have established trust and rapport. Findings in this study are consistent with Steele et al. (2013) where families emphasized the importance of open and honest communication throughout the care of the ill child.

According to Furingsten et al. (2015) nursing presence may fail to materialize if honesty is missing. When parents have a clear understanding of their child's medical status their overwhelming sense of powerlessness is reduced and they gain some sense of control, allowing them to make more informed decisions on behalf of their child (Monterosso & Kristjanson, 2008). Connected with openness and honesty, nursing presence was experienced when information was delivered in a compassionate manner. When nurses use a gentle caring tone, a pleasant attitude, and practice patience with patients and their families, they demonstrate nursing presence in their relational skills. Walsh (1999) described this as a genuine being-to-being communication that takes place against a background of shared humanity, which allows us to communicate on a deep level of humanity, showing concern and understanding. Although several studies have indicated challenges involved in communication for nurses such as giving

bad news, discussing end of life issues, or having conversations about sensitive issues (Sinclair et al., 2020; Steele et al., 2013) it is possible that nursing presence may provide a solution to having these difficult conversations by learning and practicing how to use presence to establish meaningful and trusting relationships that are comfortable enough to have these conversations. Further research is needed in this addressing nursing presence and having difficult conversations.

Parents of children with cancer wished to be included in the entire process of care so that they were able to support and comfort their ill child and reduce an overwhelming feeling of powerlessness. Nursing presence requires families to not only consent to but be empowered and actively involved in care decisions of their ill child. These results are similar to those of Mohammadipour et al. (2017), who found that nursing presence entails patients' involvement in care, which enables understanding and reduces anxiety and suffering.

Parents experienced nursing presence when they were helped to develop confidence and independence in their abilities to care for patients at home. Anderson (2007) stated that patients who benefit from nursing presence and received training required to realize recovery were less stressed and psychologically comfortable. Furthermore, the child's emotional trauma of being hospitalized, especially during episodes of discomfort is decreased if the parent is part of the care process (Roberts et al., 2015). With nursing presence, involving parents demonstrates that you see them as stakeholders and those who experience pain with their child. Nursing presence and patient involvement is useful to the parents and their children reducing anxiety and distress during the hospitalization.

Finally, parents likened the experience of nursing presence to a 'home', where they experienced trust, warmth, and safety with nurses as their 'family'. McGregor (2016) described a home as not only an enclosed private space, but a place where hearth, joy, protection, comfort,

refuge, and belonging are experienced. In this study, parents felt loved and cared for when they visited the oncology clinic. Because of lockdown restrictions, limited freedom of movement, and social distancing due to COVID, nursing presence gave parents a sense of being in the world during their hospital visits. Seeing familiar people made them feel connected and provided a sense of belonging. Similar results are described by Woodgate (2006) where adolescents considered nurses as their second family, and experienced presence when nurses were there to: provide comfort when they were not feeling well; hold a hand when experiencing physical or mental stress; keep them from feeling less lonely; encourage them to maintain a life other than the life that evolved around the cancer and it's treatment; keep them positive; and, provide love and care when they felt moody and acted differently. Although a hospital is a busy and stressful environment, when nurses practice nursing presence, parents have a special feeling with the hospital environment where they feel safe and experience warmth and comfort due to the relationships formed and quality care received.

4.6.1 Strengths and Limitations

This study has several strengths. A descriptive phenomenology approach was best suited for this study since it aims to provide a better understanding of anything experienced through the consciousness and determine its structure (Giorgi, 2009). Nursing presence is a human experience that appears in the consciousness (Watson, 1988) and its exploration using this method has illuminated the phenomenon as experienced by parents of children with cancer. In addition, nurses seek an objective understanding of situations that are subjectively constituted (Giorgi, 2000). Because nursing presence is an intersubjective encounter between the nurse and the patient (Doona et al., 1997), descriptive phenomenology was the most suitable method because it extracted subjective experiences that were analyzed by an objective method of inquiry.

There are some limitations to this study. All participants were recruited from one health facility. Although nursing presence is a human experience, parents from different health facilities may have provided different perspectives and strengthened the study. Furthermore, considering nursing presence is an intersubjective encounter, this study does not provide the experiences of nursing presence from the nurses' perspective.

4.6.2 Relevance to Clinical Practice

This study is the first to explore nursing presence as described by parents in pediatric oncology. Insights from parents in this study will inform therapeutic processes and ultimately enable the development of strategies to improve delivery of healthcare to pediatric oncology patients. A better understanding of nursing presence would facilitate continuous improvement in knowledge, attitudes, and abilities of nurses to care for parents and their sick children. Further research should focus on developing evidence-based approaches to guide the integration of nursing presence into pediatric oncology practice, research, and education. Nursing presence could inform new hospital policy, and practice standards to improve delivery of care to pediatric patients and their parents.

4.7 Conclusion

The experiences described by parents provides rich and nuanced insights into what it means to experience nursing presence in a pediatric oncology setting. This study provides a structure and expounds on its constituent features, describing nursing presence as experienced by parents of children with cancer. It was evident that nursing presence has both dimensions of being and doing, and both are equally significant for provision of quality nursing care. Nurses can use these findings to inform practice, policy, and education. However, further research investigating how to implement nursing presence is required to develop programs where

presence can be taught and nurtured given its value in provision of quality care in pediatric oncology care setting.

4.8 Chapter Summary

In this chapter, the findings of this study were presented in a manuscript format. More detail was presented for the methodology illustrating a better understanding of why descriptive phenomenology was used for this study. This manuscript included the identified gap in knowledge, the research question and chosen method, findings, discussion, strength and imitations, and the relevance to clinical practice. The findings contributed to nursing literature and extended understanding of nursing presence in pediatric oncology populations. While this study sheds light on this nursing phenomenon, additional research is needed to continue to further the understanding of nursing presence and develop and evaluate interventions to support children and their families during cancer treatment.

CHAPTER 5

5.0 Discussion and Conclusions

The purpose of the work contained in this dissertation was to explore nursing presence as experienced by parents of children with cancer during treatment. The research question that guided this inquiry was: *How do parents of children receiving cancer treatment experience and describe nursing presence?* The specific aim of this project was to draw on parents lived experiences in order to determine the essence of nursing presence when a child is receiving cancer treatment. In this chapter, I provide an overarching analysis of the preceding manuscripts in relation to the research purpose, aim, and question of the study. Implications of the findings to nursing education, research, and practice will also be discussed in this chapter. Lastly, concluding thoughts of this dissertation are illustrated

5.0.1 Manuscript 1: Nursing Presence and Gap in Nursing Knowledge

Nursing presence has been acknowledged as foundational in nursing practice and has contributed to improvement of care and satisfaction of patients (Penque & Kearney, 2015). The nursing literature has several definitions of nursing presence; some capturing the "being" of presence, others the "doing" of presence, while others entailing both the "being" and "doing" of presence. Although the contribution of nursing presence has been captured in different populations adult populations, especially in chronic illness and end-of-life (Speakman, 2018), very little was known about its contribution in pediatric oncology setting. Therefore, a scoping review (Mcharo et al., 2021) was conducted for the purpose of informing the overall objective and research question that guided this study. Completing this scoping review provided a better understanding of the state of the knowledge of this phenomenon in the pediatric oncology population, and important gaps in knowledge were identified as discussed below.

Results of the scoping review suggested that nursing presence had received minimal attention in pediatric oncology. In fact, out of the 4,358 articles that were retrieved from three databases, none of them set out to examine nursing presence in pediatric oncology. However, four of the nine final articles included in the scoping review included nursing presence as part of their findings, while the remaining five had attributes of nursing presence that were not made explicit (Mcharo et al., 2021). This finding provided more justification for exploring the nature of nursing presence in pediatric oncology. Nonetheless, informed by available literature on the concept of presence, five themes emerged that identified some attributes of nursing presence, namely, being with or being there, therapeutic relationships, communication, family-centered approach, and perceived outcomes of nursing presence (Mcharo et al., 2021). This scoping review established nursing presence as a significant component in pediatric oncology. However, the lack of evidence examining nursing presence warranted further exploration of the concept. Thus, the following research question was developed to guide the present study: *How do parents of children receiving cancer treatment experience and describe nursing presence?*

Another significant finding of this scoping review was that nursing presence enhanced family-centered care by facilitating better therapeutic relationships between nurses and family caregivers of pediatric oncology patients. Although it was not novel that nursing presence has to exist in the context of a therapeutic relationship (Hessel, 2009), nursing presence in the context of a family-centered framework was new to what has been explored in the existing nursing literature (Mcharo et al., 2021). This scoping review demonstrated that a family-centered approach plays a significant role in developing therapeutic relationships needed when patients and families are overwhelmed with uncertainties and emotional anxiety during cancer experience

(Mcharo et al., 2021). This finding led to the exploration of nursing presence in a family-centered care framework and provided a theoretical framework to guide this present study.

5.0.2 Manuscript 2: Nursing Presence in FCC- A Theoretical Framework

The second manuscript within this dissertation addressed the role of nursing presence in a FCC framework as described by IPFCC (n.d). According to Crespo et al. (2016), FCC has been considered paramount to ensure that health care meets parents' and children's needs and supports them throughout the course of the disease. Research indicated that health care services provided in a family-centered manner lead to better health outcomes, higher levels of parental satisfaction with services and better parental and child psychosocial well-being (Watt et al., 2013). The four core concepts of FCC according to IPFCC (n.d) were dignity and respect, information sharing, family participation in care, and family collaboration, and guided this present study. This FCC framework was used because when caring for patients and their families, all interventions happen in the context of a nurse-family relationship (Bell, 2013). Furthermore, a family-centered approach plays a key role in developing therapeutic relationships (Mcharo et al., 2021). Likewise, central to the concept of presence in nursing is interpersonal relationships (Turpin, 2014). According to MacKay and Gregory (2001), nursing presence is essential in developing nurse patient-family relationships in pediatric populations. Therefore, FCC provided a framework in which nursing presence could be applied and seemed ideal to be used in this present study. Furthermore, although nursing literature has extensively described FCC and nursing presence, there was no literature describing the role of nursing presence when using a family-centered approach of care.

The case study provided in this manuscript showed how the four principles of FCC integrate and demonstrated the importance of authentic relationships grounded in nursing

presence. To be effective in the implementation of FCC, it is as important to understand the needs of the family who are partners in their child's care as it is to understand the needs of the child (Feeg et al., 2018). Nursing presence plays a key role in the formation of authentic relationships that enable nurses to understand the need of the ill child and their family. Although this manuscript explored literature to reveal associations between FCC and nursing presence, there was need for more scientific research to justify this argument. An evidence-based understanding of the role of presence under a FCC framework in pediatric care was still necessary to improve quality of pediatric oncology nursing practice and knowledge.

Findings in this dissertation demonstrated how nursing presence can contribute to the FCC framework. One of the significant findings in this study, the 'being' and 'doing' of nursing presence, can be applied in the four dimensions of the FCC framework. The 'being' of presence can be applied in showing dignity and respect, sharing information, and parental participation and collaboration. When nurses use a family-centered approach in care, an attitude of presence can be used to promote more meaningful experiences and better health outcomes. Furthermore, all the six constituents can find a place in the four dimensions of FCC. For example, an attitude of presence, clinical experience and expertise can be used to demonstrate dignity and respect when relating to parents of ill children; a source of encouragement and therapeutic communication can be used as a more effective way of sharing information; and family involvement can be used in family participation and collaboration, giving back some control to parents and giving them a sense of home away from home.

5.0.3 Manuscript 3: The Essence of Nursing Presence in Pediatric Oncology

The third and final manuscript within this dissertation presented an in-depth description of the processes and findings of the present study that addressed the overall purpose and research

question of the study. A descriptive phenomenological approach according to Giorgi (2009) was used to conduct this present study. This methodology suited this study because it sought to explore parents' lived experiences of nursing presence. Descriptive phenomenology also provided room for a critical realist philosophical framework which was used to guide this study. Specifically, this study acknowledged that there is a *presence*, the reality, that nurses and parents of ill children experience in nurse-patient relationships while providing care. Meanwhile, it is the experience of this reality, nursing presence, that is dependent on the person and their background. Various social, political, cultural, economic, and/or ethnic factors may differently influence a parent's meaning and experiences of nursing presence, making presence a subjective experience. Using descriptive phenomenology enabled us to be rigorous and unbiased in determining the essence of nursing presence, revealing an objective understanding of an experience that is subjectively constituted by the parents. Research decisions such as ethical considerations, recruitment strategies, steps for data collection and analysis, and strategies to enhance rigour of the study were discussed in the manuscript. This manuscript concluded with a discussion of strength and limitations of the present study and implications for practice and research.

Findings from this study revealed the essence of nursing presence as experienced in a pediatric oncology setting, capturing the six constituent features: An attitude of presence, a source of encouragement, clinical experience and expertise, therapeutic communication, family involvement, and a sense of home away from home. A model was constructed to illustrate how the constituents are equally important to the structure and contribute to the central idea of presence. The constituents form a structure that provides deeper insights into how parents of children with cancer experience nursing presence, while demonstrating how they are interrelated

for a wholistic experience of presence. The model also demonstrates how the 'being' and 'doing' of nursing presence are intricately interwoven in pediatric oncology care as described by parents.

All constituent features that emerged in the findings had an aspect of 'doing', for example; an attitude of presence was manifested by a humane treatment of the patient and acts like remembering patients' names and recalling their stories; a source of encouragement was characterized by nurses not only performing their tasks but providing words of affirmation and comfort; clinical expertise and experience placed value on nursing skills and duration of experience; therapeutic communication focused on who, what, and how information was provided; family involvement in care required nurses to consider parents as members of the healthcare team and involve them in decision making; and a sense of home away from home involved frequent hospital visits and an effort to be familiar with the patients. Benner (1984) described this 'doing' of presence as presencing, where the nurse becomes an instrument of care. Underneath this 'doing' of presence experienced by parents of children with cancer is an underlying attitude that captures the 'being' of presence-a deeper humane understanding of presence (Pettigrew, 1990). Findings of this study were more consistent with Gardner (1992), who although described the presence of a nurse as an "intervention tool", acknowledged presence as the physical "being there" and psychological "being with" a patient, where the two are intricately interwoven in the reality of nursing care. The essence of nursing presence in pediatric oncology demonstrated that 'presencing' was essential in determining the experience of nursing presence. However, nursing presence changes the manner in which 'presencing' was carried.

As with previous work (Kostovich et al., 2016), this present study confirmed that nursing presence is multidimensional, encompassing a physical and a metaphysical aspect that meets the

physical, emotional, and social need of a patient. Parents of children with cancer experience nursing presence not only when their socio-emotional needs are met, but also the physical needs of their ill children during treatment. Although Doona et al. (1997) disagreed with the later finding, arguing that nursing presence should be understood strictly as interaction instead of mere action, parents of children with cancer in this study described a 'doing' of presence in their experiences of nursing presence.

The purpose of this study was to explore how parents of children with cancer experience nursing presence as their children undergo treatment. Each manuscript prepared in this dissertation was foundational in addressing the stated research question: *How do parents of children receiving cancer treatment experience and describe nursing presence?* This study is the first to explore nursing presence in a pediatric oncology setting, providing a structure of nursing presence as experienced by parents of children with cancer. Insights from parents in this study will inform nursing practice, education and research, and ultimately enable development of strategies to improve delivery of healthcare to pediatric oncology patients. The following section will describe in more detail the strength and limitations of the study, and implications of the findings for nursing education, research, and practice.

5.0.4 Strengths and Limitations

Each manuscript contained within this dissertation together strengthened the findings of this present study. In the paper by Mcharo et al. (2021), using the existing literature to date, no study retrieved explicitly explored nursing presence in pediatric oncology. This finding revealed a scarcity of research of presence in this setting. Therefore, findings from the scoping review set the stage for more scientific research in exploring family caregivers' experiences of nursing presence to broaden our conceptualization of the concept in pediatric oncology. Furthermore, as a scoping review may

identify gaps in existing knowledge (Arksey & O'Malley, 2005; The JBI Reviewers Manual, 2015), the results of this paper highlighted areas for future research and, thus, inspired the present study.

The completion of the scoping review (Mcharo et al., 2021) revealed that nursing presence enhanced FCC by facilitating better therapeutic relationships between nurses and family caregivers of pediatric oncology patients. This was a new finding and supported the use of FCC as the theoretical framework to guide this study. The use of family-centered care as a theoretical framework strengthened this study. Theories interrelate concepts in such a way as to create different ways of looking at a particular phenomenon and provide guidelines that can be used in the ongoing process of improvement of nursing practice (Peterson & Bredow, 2017). Demonstrating the application of nursing presence in FCC enabled us to further develop and explore the interrelationships of the four concepts-dignity and respect, information sharing, patient participation and patient collaboration. Using FCC as a framework to explore the role of nursing presence also provided ways to identify and apply nursing presence to practice. Findings from this study may be used to test the FCC model, thus, strengthen the framework and contribute to the body of nursing knowledge.

As previously mentioned in the third manuscript, descriptive phenomenology provided a way in which nursing presence, experienced through consciousness, can be accessed, and its essence determined. The use of this method of inquiry strengthened this study. Because of the previous extensive reading I had done on nursing presence prior to conducting the study, phenomenological reduction allowed me to suspend impressions, conceptions, or beliefs surrounding what I had learnt about the phenomenon (Giorgi, 2009). In addition, descriptive phenomenology provided a way in which nursing presence, a subjective intangible concept, can develop a form and be objectively understood.

This study had several limitations. Because nursing presence is an intersubjective encounter between the nurse and the patient (Doona et al., 1997), data was only collected from

parents who had experienced presence. Therefore, I am unaware whether the nurses attending to these parents simultaneously experienced presence during those interactions. Another limitation of this study was that all participants were recruited from one health facility in mid-western Canada. Canada is a vast country with diverse cultures and experiences. Although nursing presence is a human experience, parents from different health facilities in other parts of Canada may have provided different perspectives, thus, strengthened the study.

The global COVID-19 pandemic was a limitation to this study. Because of the government response to the pandemic, public health guidelines, and a required renewal of ethics approval, participant recruitment was paused for about six months. Re-establishing rapport with participants became more challenging due to the duration of absence. It was perhaps due to this absence that some participants did not respond to emails to participate in a second interview. Furthermore, a switch to online interviews via Zoom video conferencing as opposed to face-to-face interviews during data collection may have presented a challenge in the researcher and participants' feeling comfortable during interviews. Establishing conversational rapport and having rich conversations about parents' experiences may have been altered by the discomfort caused by an online presence during data collection. Despite the limitations and disruptions of the COVID-19 pandemic, rich data were collected.

5.0.5 Implications for Nursing Education

The findings of this study have several implications for nursing education. Being the first study exploring nursing presence in a pediatric oncology setting, findings from this study contributed to nursing literature and provided a foundation for nursing education in this area. Although Doona et al. (1997) argued that nursing presence cannot be taught, this study identified the 'being' and 'doing' of presence which are a set of skills that can be nurtured since they are

rooted in knowledge and experience. The established structure of nursing presence has attributes such as being thoughtful and showing kind gestures, being respectful during communication, and involving patient family in their child's care, that practicing nurses and students can learn and implement in order to provide quality nursing care and improve health outcomes. These findings provide a foundation to equip nurse educators and other healthcare professionals on nursing presence, developing their capacity to practice and impart this knowledge. Because nursing is a well-paying and stable profession, many applicants are not entering the nursing discipline based on a higher calling to give of self, and may lack the personality, skillset necessary to become proficient in nursing presence (Turpin, 2014). Findings from this study provide an opportunity for nursing education to develop programs where presence can be developed and nurtured given its value in provision of quality care in pediatric oncology. Simulation scenarios and clinical laboratory experiences should incorporate therapeutic skill building alongside technical skills to reduce compartmentalizing nursing presence from hands-on tasks. Because students begin their nursing education with varying levels of relational skill ability, opportunities to build rapport with clients should be encouraged to improve recognition of patients' need for nursing presence.

5.0.6 Implications for Nursing Research

This study uncovered many possible future directions for nursing research. Because nursing presence fundamentally occurs in the context of a relationship between the nurse and the patient, additional research related to nurses' experiences of presence may help identify similarities or intersections in these experiences. Dyadic research approaches using different interview types, for example, conducting separate interviews of both the nurse and parent, separate interviews performed simultaneously by different interviewers, or joint interviews, would provide a wholesome meaning of their nursing presence experiences, thus, providing a

clearer picture of the phenomenon. Future research should also explore whether variables such as age, gender, culture, or different environments specifically an online verses physical presence could potentially influence the nature of presence. Determining how these variables influence nursing presence could help provide different approaches of implementing nursing presence and perhaps offer ways to facilitate better nurse-patient relationships. For example, it may be easier for a nurse and patient of the same age, gender, or culture to provide or accept the other's presence because of their commonalities.

Findings from this study suggested that 'being' and 'doing' of nursing presence were intertwined and equally important. Using quantitative designs, the six constituent features that emerged from this study: an attitude of presence, a source of encouragement, clinical experience and expertise, therapeutic communication, family involvement, and a sense of home away from home, could be separately measured or developed in relation to nursing presence. This would improve the structure of presence by developing each dimension, making it more tangible and easier for practicing nurses and students to grasp and utilize.

5.0.7 Implications for Nursing Practice

Although findings in this study described nursing presence as multidimensional with an aspect of 'being' and 'doing', the essence of presence in pediatric oncology makes the concept more tangible and less ambiguous, enabling it to be cultivated amongst pediatric nurses. With insights revealed in this study, nurses may form better relationships with patients and their families while using a family-centered approach to provide quality pediatric care. Nurses should remember to attend to their patients as unique human beings, remembering that it is in the small moments/details and seemingly insignificant gestures where trust is established, and nursing presence enacted. Nurses should accompany their much-needed nursing skills with an attitude of

genuine care and concern, making an effort to have better therapeutic communication and be supportive.

As demonstrated in this study, nursing presence occurs in the context of a relationship, and a family-centered approach provides an appropriate avenue to practice presence. Since nurse-patient interactions occur in a family-centered context, the use of nursing presence should be encouraged as it plays an important role in showing dignity and respect for the patient and families, communication, and patient and family collaboration and involvement in care; the four dimensions of FCC. Better therapeutic relationships are formed when nurses are present while using a family-centered approach. With this knowledge, nursing presence may potentially provide a remedy for depersonalization of healthcare, allowing family members to have a better hospitalization experience as their child goes through the cancer journey.

5.1 Concluding Thoughts

This dissertation provides an extensive discussion and exploration of presence in nursing as experienced by parents of children with cancer. During the course of this research journey, I have gained a new understanding of presence, and its application in and away from nursing practice. I found new insights into forming therapeutic relationships and the role of nursing presence in improving patient and family care. It was intriguing that parents remembered the specific positive and negative experiences of nursing presence; these stories had meaning to them. Listening to their experiences reminded me of how we take things for granted in our professional and personal lives, and that in genuinely paying attention to the other, life transforming experiences can be created. In most cases during the interviews, the parents did not remember the nurse's names, but they remembered how they made them feel-present with them

in their moments of despair. Nursing presence allows us to experience that which is fundamentally a human experience, which is to genuinely be with the other.

Thanks to this research journey, I have developed a sense of humility in my quest for knowledge. As described by Giorgi (2009), this journey has caused me to curiously interrogate in more depth what I once thought I knew in order to better understand that which I took for granted. Phenomenology offered an invaluable methodological approach to not only explore and understand the patient's experiences, but to explore my personal experiences and beliefs. Through this study, as I interacted with the participants and went through the data analysis, I was encouraged to be more reflective and self-aware, so as to be objective in my decision making. These are qualities needed in nursing that I will help nurture in nursing students as I continue to apply them in my nursing research and practice. The knowledge acquired in this study will be used to guide my future nursing practice, ensuring that patients and their families experience quality nursing care that simultaneously encompasses both "being" and "doing".

Nursing presence connects nurses and patient their families, allowing them to share feelings, perspectives, hopes, dreams, and their fears because even when admitted in hospitals undergoing cancer treatments, patients and their families feel at home when nurses offer their presence. I am grateful for the participants who were willing to share their experiences of an incredibly challenging and stressful time. I am also proud of the quality work that resulted from their sharing of experience. Their contribution to these findings provided a foundation to inform nursing practice and improve the care of other families undergoing similar experiences. Although the research question guiding this study has been addressed, I am excited to continue this journey of research, discovery, and enhancement of nursing practice in pediatric oncology.

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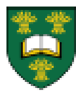
APPENDIX A: University of Saskatchewan Ethical Approval



UNIVERSITY OF SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB) 28/Nov/2019

Certificate of Approval

Application ID: 1560

Principal Investigator: Jill Bally

Department: College of Nursing

Locations Where Research Activities are Conducted: Saskatoon Health Authority (Jim Pattison Childrens Hospital-Acute care pediatrics and pediatric oncology)., Canada

Student(s): Solomon Mcharo

Funder(s): Western & North-Western Region Canadian Association of Schools of Nursing

Sponsor: Canadian Association of Nurses in Oncology

Title: Exploring Nursing Presence as Experienced by Family Caregivers in Pediatric Oncology using Descriptive Phenomenology

Approved On: 28/Nov/2019

Expiry Date: 27/Nov/2020

Approval Of: Behavioural Research Ethics Application

Consent form

Demographic form

Interview guide

Advertisement poster

Reference list

Recruitment Script

Acknowledgment Of:

Review Type: Delegated Review

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board (Beh-REB) is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2 2018). The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this project, and for ensuring that the authorized project is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month prior to the current expiry date each year the project remains open, and upon project completion. Please refer to the following website for further instructions: https://vpresearch.usask.ca/researchers/forms.php.

Digitally Approved by Patricia Simonson, Vice Chair
Behavioural Research Ethics Board
University of Saskatchewan

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APPENDIX B: Letter of Operational Approval

December 5, 2019

Dr. Jill Bally
College of Nursing
University of Saskatchewan

Study Title: Exploring Nursing Presence as Experienced by Family Caregivers in Pediatric Oncology using Descriptive Phenomenology
File Number: OA-UofS-1560

Authorization Granted By:

- Jonathon Melville, Manager, Acute Care Pediatrics, JPCH
- Melissa Speiser, Manager, Pediatric Day Medicine/Hemtology/Oncology Provincial Programs, JPCH

RE: LETTER OF AUTHORIZATION TO CONDUCT RESEARCH

Dear Dr. Bally,

This letter is to notify you that the above-listed research study has been reviewed and meets all criteria for Operational Approval within the Saskatchewan Health Authority (SHA).

Please note that Operational Approval is conditional upon continued review and approval by the Research Ethics Board (SHA, U of R or U of S). Should Research Ethics approval lapse or be revoked, Operational Approval will also be suspended. In addition, Operational Approval is issued based upon the details provided in the Operational Approval to Conduct Research Application Form. Should the resource utilization deviate from what was requested in the initial application, Operational Approval may be revoked and an amendment must be submitted for review. Any publications or presentations that result from this research should include a statement acknowledging the assistance of the Saskatchewan Health Authority.

This letter serves as your official authorization to conduct research; study activities may now commence.

If you have any questions, please contact the Research Approval Coordinator, Shawna Weeks, at 306-655-1442 or shawna.weeks@saskhealthauthority.ca.

Sincerely,

Dr. Elan Paluck
Director of Research
Saskatchewan Health Authority

APPENDIX C: Consent Form

You are invited to participate in a research project entitled: Exploring Nursing Presence as experienced by family caregivers in pediatric oncology

Principle Investigator: Solomon K. Mcharo
PhD(c), MSN, RN, College of Nursing, University of Saskatchewan,
Phone: (Insert new number), email: kasha.mcharo@usak.ca

Co-Supervisors:
Dr. Shelley Spurr
Phone: 306-966-8663, email: shelley.spurr@usask.ca
Dr. Jill Bally
Phone: 306-966-7391, email: jill.bally@usask.ca

Committee Members:
Dr. Lorraine Holtslander
Phone: 306-966-8402, email: Lorraine.holtslander@usask.ca
Dr. Shelley Peacock
Phone: 306-966-7375, email: shelley.peacock@usask.ca
Dr. Keith Walker (cognate)
Phone: 306-220-0614, email: keith.walker@usask.ca

Purpose: The purpose of this study is to find out more about your experience of nursing presence during your encounter with nurses at the hospital. Nursing presence is what is experienced when a nurse is attending to a client in a genuine and authentic way. It is a way of "being with" a client rather than "doing to" or "doing for" the client. Nurses are not present when their minds are preoccupied about something they did or should have done in the past or something they are going to do in the future.

Nurses, nurse educators, and nurse researchers can benefit from learning about your experiences and may be better able to provide better cancer care to other patients and improve on their practice. There is very little research in this area to date, and we believe that your personal experiences will contribute to a better understanding of the phenomenon, and to the development of quality health care. We know that your experiences and perceptions about nursing presence are key to this understanding, and therefore we are asking for your participation.

Funding: This project has been funded by Canadian Association of Nurses in Oncology (CANO)

Procedure: Once you agree and provide me with your consent to participate, I will arrange a room at the hospital or at the University of Saskatchewan college of nursing where we can meet when it is a good time for you. Your participation would involve having two or three interviews that will explore your experience of nursing presence upon encountering nurses during cancer treatment. You will be asked to answer questions about yourself and/or the child's illness (gender, age, child's diagnosis and medical care). Also, I will ask about your hospital experience

during treatment for his or her illness. At a later date, in a second interview, I will ask more questions arising from the first interview and share more about your experiences. With your permission, our discussions will be audio-recorded, but you may ask to have the recording device turned off at any time without giving a reason. The interviews will take approximately 1-2 hours, but will depend on your preference.

We anticipate that the total time of your involvement in this study may be about two to four hours. A 50-dollar gift card will be issued to you at the end of data collection as a display of gratitude for your participation. If you choose to withdraw from the study during the data collection, you will still receive a full value gift card.

Potential Benefits: Taking part in this study may not benefit you directly, although people find it helpful to talk about their experiences and share their stories. The information that you provide may be of help to others. This information will be used by health care professionals to provide improved and more effective health care for families in similar situations.

Potential Risks: While there are no true risks to participation, answering the questions may be time consuming, upsetting or tiring. You do not have to answer any questions that you do not want to answer, and you can end the interview or terminate your involvement in the study at any time, as you wish. If you get tired or feel upset, you can take a break at any time, or end the meeting. If you wish, with your permission, we will contact the social worker who coordinates care for the Saskatoon Health Authority for Acute Care Pediatrics or your family physician, or a similar alternative, in order to obtain additional support and assistance for you. If you are experiencing distress, you can call Saskatoon mobile crisis on 306-933-6200 who will be available 24/7.

Storage of Data: Your answers to the demographic and interview questions will be stored on paper in a locked drawer or password-protected computer at the College of Nursing for at least five years. This information will also be saved on the University of Saskatchewan secure cabinet on PAWS as backup to prevent data loss. Only the research team will be able to look at this information. To further safe guard your privacy, the consent forms and demographic forms will be stored separately from your data.

Confidentiality: The audio recording of our discussions will be transcribed, but your name or contact information will not be on any of the information. All information from this study will be reported in a way that no one can identify you, such as in conference presentations or publications. Although direct quotations might be used in reporting the results of this study, they will be presented in such a way so as to ensure that no one can identify you (that is with a pseudonym or code). Your name will not be used, and all identifying information will be removed from the report. However, given that the pool of eligible participants may be quite small, it is possible that participants could be identified on the basis of what they say, even with the removal of the identifiers.

Right to Withdraw: Your participation is voluntary, and you may answer only those questions with which you are comfortable. There is no guarantee that you will personally benefit from your involvement. The information that is shared will be held in strict confidence and discussed only

with the research team. You may withdraw from the research project, two weeks after your participation has ended, for any reason and without penalty of any sort. Please be advised that your participation, non-participation, or withdrawal from this study will not affect your child's access to health care services or how they will be treated. After the two weeks, it is possible that some form of analysis will have already occurred and it may not be possible to withdraw your data. You may withdraw by notifying me. If you choose to withdraw from the research project within the two weeks, any data that you have contributed will be destroyed beyond recovery at your request.

Questions: If you have any questions concerning the research project, please feel free to ask at any point. You are also free to contact the researchers at the numbers provided if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board (INSERT DATE). Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (306-966-2084). Out of town participants may call toll free at 1 (888) 966-2975. You can also contact the ethics office through their email at ethics.office@usask.ca.

Follow-Up or Debriefing: You may find out about the results of this research project by contacting me at any time. We estimate to have the results of this study by end of December 2020.

Consent to Participate:

(a) Written Consent

I have read and understood the description provided. I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time. A copy of this Consent Form has been given to me for my records.

________________________________ ________________________________

(Name of Participant) (Date)

________________________________ ________________________________

(Signature of Participant) (Signature of Researcher)

A copy of this consent will be left with you, and a copy will be taken by the researcher

APPENDIX D: Participant Demographic Form

Demographic Form

Date:______________________ Code Number: _________________________

Participant

Name (Optional): ____
Age: ___________ Gender: ___________ Years of Education: ______________
Religion (If any): ____
Marital Status: Married______ Single______ Widowed______ Divorced______
Occupation: ________________ Ethnicity: ___________________________
Rural Location: _____________

Pediatric Patient Data

Age:____________________ Gender:___________________

Year of Diagnosis:__________________________

Duration of Treatment:_______________________

APPENDIX E: Participant Interview Guide

Research has shown that a therapeutic relationship embedded in nursing presence is beneficial to patient and family caregivers of patients undergoing cancer treatment. The goal of this interview guide is to explore the care givers' in-depth knowledge and experiences of nursing presence. The topic I want to explore is the care givers experience of nursing presence in the hospital as their child receives cancer treatment. Do you have any questions, concerns, or comments before we begin?

Begin with a review of the consent form and address any questions

Interview Guide

The following are open-ended questions that will be used to guide the interview.

1. In as much detail as possible, please describe for me the situation in which you experienced nursing presence.
2. When you think of nursing presence what comes to mind? What does "being with" mean to you?
3. How do you understand and make sense of your experience when receiving nursing presence?
4. How has this affected you?
5. Is there anything else that you would like to say about nursing presence that we haven't talked about?

Prompting Questions:

Can you tell me more about…….
In what way………
What were you thinking when that happened…..

Goal for Second and Third Interview

The goal of a second interview guide is to follow up with the patient's descriptions of their nursing presence experience from the first interview. The researcher seeks clarity and detail of the participants experiences.

Interview guide

The following are open ended questions that would be used to guide the interview.

1. In the last interview you talked about… can you tell me more about this?
2. Other than your interactions in the hospital, can you tell me about another "being with" experience you have had?
3. In our last meeting we talked about nursing presence, how would you describe nursing presence?

Prompting Questions

What happened next…
Can you tell me more about this…
What did you feel when you saw this…

APPENDIX F: Recruitment Script for Nurses

Recruitment Script for Nurses

Hi, my name is ______________ (name of nurse). I would like to know if you are interested in participating in a study being conducted by a nursing graduate student at the University of Saskatchewan. The study is about how you experience nurses "being there" for you, as you receive care for your child. If you decide to participate, it is completely voluntary and you may say no if you do not want to take part. It will not, in any way, affect how you receive health services at this hospital. If you are interested in participating in this study I will ask Kasha who is the graduate student conducting the research, to come talk to you or I can provide Kasha with your contact information so that he can call you - he will tell you more about what your participation will include. Would you like to talk to him? *(If yes, go ahead and ask Kasha to come talk to the participant. If no, thank them and provide them a flyer (attached), and ask them to contact him directly if they change their mind).*

APPENDIX G: Advertisement Poster

PARTICIPANTS NEEDED FOR RESEARCH IN EXPLORING NURSING PRESENCE AS EXPERIENCED BY FAMILY CAREGIVERS OF CHILDREN WITH CANCER

I am looking for family caregivers of children with cancer to take part in a study to explore their experiences of nursing presence when their children are undergoing cancer treatment.

As a participant in this study you will be asked to participate in an interview and complete a short demographic questionnaire

Your participation may involve more than one session, each approximately 60min. Interviews will be made in person

For more information about this study, or to participate, please contact:
Kasha Mcharo, College of Nursing, University of Saskatchewan
Email: kasha.mcharo@usask.ca

(This email account is only accessed by myself and is password protected)

This study has been reviewed by, and received approval through, the Research Ethics office, University of Saskatchewan on 28-Nov-2019. REB 1560.