The Place in Which the Suffering of Living is:

How Nurses Enact Compassion in Pediatric Intensive Care

by

Amy Lydia Neufeldt

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Abstract

In pediatric intensive care units, nurses enact compassion as they enter in with patients and families to the place where the suffering of living is and take action to make that suffering even a little bit easier to bear. This study sought to answer the question: how do nurses enact compassion in their clinical practice in pediatric intensive care?

This study used interpretive description to explore the practice knowledge nurses have regarding how compassion is enacted in the unique setting of pediatric intensive care. Seven semi-structured interviews with registered nurses who worked in pediatric intensive care units in Alberta were conducted and then analysed using reflexive thematic analysis.

Two non-linear phases of *Opening the Door* and being *Inside* were the main themes that provided an overarching metaphor of opening the door and stepping inside the physical room and the experience with patients and families.

Participants offered narratives describing ways of enacting compassion that opened the door including introductions between the nurse, the patient, and the family as well as the nurse introducing the patient and family to their healthcare environment. Making offers of varying natures such as offering a physical comfort, information, or family involvement helped to alleviate suffering, but also invited patients and families to begin to open up about their experiences and needs. Finally, enacting compassion involved the nurse's self - attending to one's own attitude. In view of the humble fragility of human life, entering in to places of devastating loss required courage and an understanding of the gravity of the situation along with a keen awareness of trying to understand how the patient and family were experiencing the situation. In the inside space - the place where the suffering of living is - nurses were with patients and families in a deeply engaged way. Sometimes that involved creating a calm space,

comforting through physical touch, speaking emotional support, or gently guiding. Other times, compassion was enacted by staying present when there was nothing more to say. Throughout these acts of compassion, nurses built trust and spoke truth while balancing the complex dynamic of time.

This study offers a novel distinction between compassion that opens the door and compassion that is dependent upon being inside or trusted. Among ways that nurses invited patients and families to open the door, novel contributions include *Introduction to the Healthcare Environment* and *Making an Offer.* In the vulnerable place of being inside the patient or family experience with them, the most novel themes were *Being the Calm in Their Storm* and *Guiding*. Both focused on the role of nurses to support patients and families in the disorienting experiences they encounter in pediatric intensive care. The narratives given by participants in this study provide powerful exemplars of how nurses in pediatric intensive care can enact compassion in unique ways in a challenging setting. As nurses balance the many demands on their limited time, the way they integrate life-saving tasks with compassion can become a beautiful dance in the midst of the suffering.

Keywords: compassion, engagement, clinical practice, PICU, nursing

Preface

This thesis is an original work by Amy Lydia Neufeldt. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Exploring How Nurses Enact Compassion in Pediatric Intensive Care”, No. 00117798, 21 March 2022.

To the one who showed me what compassion was in my own suffering.

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To those who participated in this study, words of gratitude are insufficient. I only hope readers can benefit half as much as I did from their beautiful practices of compassion.

My practice as a nurse and much of who I am has been shaped by the patients and families in the PICU who have allowed me to enter into their journeys.

Many thanks to my family. I am grateful to my parents Dave and Karin for their faithful prayers and encouragement. And to my brother Clayton and his wife Tasha for celebrating with me each step of the way and for sharing the podcast about compassionomics.

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Chapter 1: Introduction and Background

Compassion is sharing in the suffering of another person in combination with taking action to alleviate their suffering (Gerace, 2020; Oxford English Dictionary, 2021; Schantz, 2007; Sinclair et al., 2016; Soto-Rubio & Sinclair, 2018; Trzeciak & Mazzarelli, 2019; von Dietze & Orb, 2000). In the context of healthcare, compassion features prominently in organisational and hospital values statements (Alberta Health Services, 2021) as well as both codes of ethics for nurses and physicians (Canadian Medical Association, 2018; Canadian Nurses Association, 2017). While compassion is core to professional and organisational guidelines, healthcare settings vary widely and each setting poses unique challenges that influence how compassion is expressed. In the Pediatric Intensive Care Unit (PICU), there is much suffering and therefore a significant need for compassion. Although there has been a great deal of research on compassion fatigue and self-compassion in PICUs, there has been little to no research about compassion itself in this setting. The aim of this research project is to explore how nurses enact compassion in their clinical practice in the PICU setting.

Literature Review

Literature on the topic of compassion is abundant and spans thousands of years of medical, philosophical, religious, psychological, sociological, anthropological, and other literature. Even since beginning this project three years ago, the number of publications on the topic of compassion has grown exponentially (Malenfant et al., 2022). This section will first provide a brief overview of the meaning of compassion as it is commonly used in medical literature currently, followed by a discussion on the place of compassion within nursing literature, and finally a brief discussion of compassion in PICUs.

Defining Compassion

Etymologically, compassion comes from a Latin root meaning “to suffer with another” (Oxford English Dictionary, 2021) and conceptually is tied to taking action to alleviate the suffering of another person (Soto-Rubio & Sinclair, 2018). According to many authors,

compassion requires both the "willingness to actively 'suffer with'" (Sinclair et al., 2016, p. 202) someone who is suffering, and action intended to lessen the suffering - with a clear distinction that one is not required to remove all suffering in order to be compassionate. Sometimes this "action" is clear and tangible like administering analgesia, but often it is the way in which one interacts with a patient - suffering *with* them - that serves to help alleviate their suffering (Hodges et al., 2020; Malenfant et al., 2022; Sinclair et al., 2021; Trzeciak & Mazzarelli, 2019).

Sympathy, empathy, and compassion can be differentiated in the literature, and these nuances have been confirmed to be consistent with how these terms are understood by patients (Sinclair, Beamer, et al., 2017). Although it has changed over the years, sympathy is currently seen as a pity-based emotional response that identifies someone else's suffering while remaining relationally distant from that person (Sinclair, Beamer, et al., 2017; Soto-Rubio & Sinclair, 2018; von Dietze & Orb, 2000). Sympathy can be experienced as patronising or demoralising by the sufferer and is often motivated by pity or obligation. Sympathy can be conflated with a condescending attitude wherein the one who is suffering is in some sense below one who is not (Schantz, 2007) which contrasts sharply, as will be seen, with compassion which recognizes suffering and dependence as part of the shared human experience (Jones, 2015; Larkin, 2016; Soto-Rubio & Sinclair, 2018; von Dietze & Orb, 2000).

There are two main types of empathy: cognitive and affective (or basic). Cognitive empathy is a more objective response of trying to mentally identify and understand the thought processes of another person (Fernandez & Zahavi, 2020). Affective empathy is understood as a more subconscious neurological response of mirroring another person's emotions and thereby "feeling with" one who is suffering (Fernandez & Zahavi, 2020; Sinclair, Beamer, et al., 2017). Empathy is increasingly associated with an emotional response but also carries the connotation of understanding the other person and experiencing a relational connection between people (Soto-Rubio & Sinclair, 2018). Neurobiological research has found that empathy can lead to a phenomenon known as "empathetic distress" which, as the name suggests, is a distress

response associated with empathetic feeling toward another's suffering (Singer & Klimecki, 2014). Empathetic distress can lead to stress, burnout, and withdrawal thereby compromising the health of the healthcare providers and the care they are able to provide to patients (Trzeciak & Mazzarelli, 2019).

Finally, compassion, the subject of this study, involves both "suffering with another" who suffers *and* an intentional act to alleviate that suffering (Käppeli, 2008a; Ledoux, 2015; McNeill et al., 1983; Schantz, 2007; Sinclair, Beamer, et al., 2017; Sinclair et al., 2016; Soto-Rubio & Sinclair, 2018; Trzeciak & Mazzarelli, 2019; van der Cingel, 2009; von Dietze & Orb, 2000). In the philosophical literature, compassion has been written about for thousands of years, often tied to Aristotle's *Nicomachean Ethics* and discussed in the context of virtue (Hawking, 2017; Nussbaum, 1996; von Dietze & Orb, 2000). This idea of compassion being part of a person's character, or tied to virtue, remains in the current conceptualizations (Sinclair et al., 2021; van der Cingel, 2014) and is seen as a precursor to practising compassion in the clinical setting (Sinclair et al., 2016). It is important to make the distinction that a virtue is different from a personality trait that someone may or may not be born with - evidence suggests that compassion *can* be learned, but only if the person wants to learn it (Trzeciak & Mazzarelli, 2019). This ties back to the initial description of compassion involving the intention to alleviate suffering. It is this focus on alleviating suffering - of taking action - that most importantly differentiates compassion from empathy, and the emotional engagement *with* the sufferer that differentiates it from sympathy (Singer & Klimecki, 2014; Soto-Rubio & Sinclair, 2018; von Dietze & Orb, 2000).

Clearly differentiating between terms is not only important for the purpose of clear communication, but also because of the impact of these different processes on healthcare providers. Empathy and compassion operate by different neurocognitive processes (Singer & Klimecki, 2014). Empathy responds to the suffering of another by focusing on one's own feelings which often leads to a desire to withdraw or protect oneself from that experience of

suffering, leading to burnout and empathetic distress (Singer & Klimecki, 2014; Soto-Rubio & Sinclair, 2018). Compassion, although including a similar “feeling with” another person as empathy, moves beyond those potentially distressing feelings to look for actions that could alleviate the other person’s suffering (Oxford English Dictionary, 2021; Soto-Rubio & Sinclair, 2018; Trzeciak & Mazzarelli, 2019; von Dietze & Orb, 2000). This focus on action, a central aspect of compassion, stimulates neurological pathways associated with positive feelings and social connection (Singer & Klimecki, 2014).

In healthcare research, the idea of “compassion fatigue” has been widely used despite evidence challenging the concept. Compassion fatigue has been conceptualised in different ways, but is generally perceived as a negative consequence of being compassionate and is often explored in conjunction with moral distress, secondary traumatic stress, and burnout. In situations where compassion fatigue is understood as one’s compassion being blocked for some reason, this is better understood as moral distress since one is being prevented from doing what one believes is the morally right thing to do (Sinclair, Raffin-Bouchal, et al., 2017). This is consistent with how moral distress is understood and this kind of so-called “compassion fatigue” needs to be recognized as moral distress and addressed through conversations regarding ethics. In situations where compassion fatigue is understood as a response of depersonalization to a difficult or traumatic situation, so-called “compassion fatigue” is better understood as secondary traumatic stress or empathetic distress. Using the term “secondary traumatic stress” more accurately acknowledges the relationship between the healthcare provider’s feelings of depersonalization and some trauma to which they have been exposed (Sinclair, Raffin-Bouchal, et al., 2017). Empathetic distress, as discussed above, results in the person disconnecting from interpersonal connections and therefore from taking action to alleviate suffering, making it merely emotional unlike compassion. Empathetic distress can indeed have negative effects on those who are empathetic, but it must be emphasised that these negative outcomes come from empathy not compassion.

"Burnout" is another term often used to describe these negative feelings of disconnection that result from work stress associated with secondary traumatic stress or empathetic distress. Instead of compassion *causing* fatigue and burnout, being compassionate is instrumental in *overcoming* the disconnection of burnout and secondary traumatic stress (Singer & Klimecki, 2014; Trzeciak & Mazzarelli, 2019). Emerging research indicates that treating patients with compassion is actually beneficial for the healthcare providers themselves by helping prevent and even overcome burnout (Singer & Klimecki, 2014; Trzeciak & Mazzarelli, 2019). In today's healthcare environment, burnout abounds and the suggestion to be *more* compassionate can be perceived as an additional burden on nurses who are already struggling to keep up with existing demands on their time. Yet, the interpersonal connections formed through compassion are a powerful antidote to the disconnection of burnout (Trzeciak & Mazzarelli, 2019). By recognizing and acknowledging the humanity of patients, nurses also recognize their own humanity and reconnect with the powerful sense of meaning that comes from acting in such a way as to help another human in their time of suffering (Pramilaa, 2018; Singer & Klimecki, 2014; Soto-Rubio & Sinclair, 2018).

Compassion in Nursing Literature

The understanding of compassion described above positions compassion as a concept which holds both the "art" and "science" of the nursing profession - recognizing the importance of science in developing interventions that can more effectively alleviate suffering and the art of engaging in a genuine relationship with patients which itself serves to alleviate suffering. Within the nursing literature, compassion features prominently. Many influential theories of nursing promote compassion as essential to nursing practice including those of Martha Rogers, Jean Watson, and Simone Roach (George, 2002; Roach, 2002). Not only does compassion influence nursing theory, but it is also the dominant professional value found in nursing Codes of Ethics around the world (American Nurses Association, 2015; Canadian Nurses Association, 2017; Elliott, 2017; Indian Nursing Council, n.d.; International Council of Nurses, 2012; Nursing and

Midwifery Board of Ireland, 2018; Schmidt & McArthur, 2018). These documents guide nurses as they provide ethical nursing care to patients, clients, communities, and families - ethical care that requires compassion. Together, the prevalence of compassion in both nursing theories and nursing ethics indicates that compassion is a crucial part of nursing.

Throughout early nursing literature and grand nursing theories, the emphasis has been on the concept of “caring” as the essence of nursing practice (Brykczyńska & Jolley, 1997). Compassion has often been promoted as an *element* of the nursing work of caring. In Roach’s influential nursing theory, “The 6 C’s of Caring,” compassion is one of the six “c’s” that characterise nursing practice (Roach, 2002). Watson, too, situated compassion as an essential part of caring in her Theory of Human Caring (Costello, 2018). Hockley (2016) suggested that what is referred to today as “compassion” is analogous to the understanding of “caring” in nursing practice that was promoted during her training in the 1970s. This may be the case to some extent, but descriptions of “nursing care” often focus on tasks and interventions that nurses provide. In contrast, the deep sense of “suffering with” that is encapsulated in Roach’s and Watson’s descriptions of compassion cannot be reduced to tasks that one performs as part of care. The use of the word compassion also allows one to draw on broader philosophical literature to understand the vulnerability and humanity of learning to suffer with those who are suffering.

As recently as 2015, there was criticism that the concept of compassion remained poorly defined in nursing literature (Ledoux, 2015). This criticism was not completely unfounded, but it is somewhat blind to the broader historical context in which compassion has been understood. Käppeli provides an overview of the historical understanding of compassion within healthcare contexts which were predominantly Christian and Jewish (Käppeli, 2008b, 2008a). This historical review reveals that healthcare and religion were often deeply intertwined, which is also seen within the nursing profession. Religious nuns had a significant role in the development of the nursing profession and even Florence Nightingale, who is often seen as the founder of

modern nursing and promoted it as a secular profession, was motivated by her own religious convictions and inspired by the nursing work of nuns. Indeed, the training she received was at a palliative care facility run by a pastor and his wife as an expression of faith (Bork, 2002). As nursing has moved away from its religious roots, Käppeli found that compassion has continued to be understood in a way that is consistent with this spiritual heritage. This spiritual perspective provides the often-quoted perspective that compassion is something that “asks us to go where it hurts, to enter into places of pain, to share in brokenness, fear, confusion, and anguish… Compassion means full immersion in the condition of being human.” (McNeill et al., 1983, p. 4). Later in the same book, the authors devote a chapter to the idea that compassion also requires some kind of action to alleviate suffering which continues to be reflected in current understanding of compassion and was expressed historically through the actions of developing facilities to take care of the sick who had no family to care for them (Hem & Heggen, 2004).

In the last ten to fifteen years, there has been a great deal of research exploring the concept of compassion in healthcare settings. Researchers have explored what compassion means in a variety of cultural and practice settings as well as including perspectives of healthcare providers, patients, and caregivers (Malenfant et al., 2022). Many studies have described the barriers and facilitators of compassion. Others have focused on describing how compassion is conceptualised in various contexts and by different groups such as patients and caregivers. Although not specific to the nursing discipline, a recent model of compassion in the pediatric setting provides an excellent framework with which to understand the interaction between healthcare providers, patients, and families (Sinclair et al., 2021).

Compassion as an Ethical Responsibility

Trzeciak and Mazzarelli are two physicians who recently published a review of healthcare literature regarding compassion (Trzeciak & Mazzarelli, 2019). Although the review does not focus on the nursing context specifically, it does provide compelling evidence that being treated with compassion makes a significant difference to patient outcomes including

measurable improvements in pain, survival rates, and quality of life even in the midst of a poor prognosis. In one study, patients who perceived a healthcare provider to be compassionate during medical emergencies were significantly less likely to develop subsequent post-traumatic stress disorder following the event (Moss et al., 2019). It is an ethical responsibility of nurses to practise in a way that is informed by evidence in promoting the health and well-being of patients and families, so aside from compassion being identified as an ethical imperative itself, the health benefits of compassionate care further underscore the ethical responsibility of compassionate practice for nurses (Canadian Nurses Association, 2017).

Promoting the health of patients is a professional responsibility of nurses and the benefits of compassion to patient outcomes may be enough to prompt compassion, but there is more. Part of the understanding of the term "compassion" is that it is humanising - that is to say that it treats people in a manner that is consistent with recognizing them as human beings. It can be easy in the healthcare setting generally, and the ICU environment specifically, to focus on tasks and on maintaining or monitoring the patient's bodily functions. In that clinical focus, one can forget the *person* in the bed and, in the case of the PICU, the family around them. Compassion, however, involves interacting with one another on the basis of shared humanity (Davis, 1981; Hammarström et al., 2020; Hem & Heggen, 2004; Käppeli, 2008a; Nin Vaeza et al., 2020; Roach, 1991; Soto-Rubio & Sinclair, 2018; van der Cingel, 2009; von Dietze & Orb, 2000).

Compassion in the PICU Context

The setting for this study is the PICU, a unique practice setting that typically focuses on life-saving interventions for the most critically ill children. In the PICU, nurses care for children from age one month to seventeen years while also attending to the needs of their parents. In contrast to the overwhelming amount of research on compassion in nursing, research specific to the compassion of nurses in the PICU setting is surprisingly absent. When search terms were limited to include compassion, nursing, and PICU, only one search result was returned across

three databases that was not regarding self-compassion, compassion fatigue, or compassion satisfaction. Research focused on exploring the meaning of compassion has had fairly consistent results across contexts (Malenfant et al., 2022), so the theoretical understanding of compassion that PICU nurses have may not be significantly different to how compassion is understood in other contexts. Despite a similar understanding, the way in which compassion is enacted by nurses in PICUs may very well have unique aspects in its expression.

Much of the research in the context of intensive care units (ICUs) more broadly is on quantitative research intended to identify and develop interventions that help people's bodies recover from critical illness. Yet, people are more than only bodies and treating them in a way that recognizes that – a way that treats them as humans – is compassionate (McNeill et al., 1983). In an effort to combat dehumanising attitudes, there have been initiatives in the last few years toward humanising ICUs (Nin Vaeza et al., 2020) and patient-centred care in ICUs (Jakimowicz et al., 2018). Although not explicitly stated, both of these initiatives contain themes consistent with compassion and seem to reflect patient experiences of depersonalization in ICUs (Reis et al., 2016). Although these initiatives may promote compassion in ICU, they are not focused on understanding compassion itself and often do not even mention compassion. As discussed above, compassion has a humanising effect (Bradshaw, 2011; Davis, 1981; Hem & Heggen, 2004; Monks & Flynn, 2014; Nin Vaeza et al., 2020; Roach, 1991; van der Cingel, 2009; von Dietze & Orb, 2000; Zaman et al., 2018) which positions this research as complementary to these initiatives of patient-centred humanising care in ICUs.

In (2019), Roze des Ordons et al. published the results of a qualitative study comparing compassion in the ICU setting with compassion in the palliative care setting. She proposed a 'pattern language' involving four dimensions of compassion that may be present regardless of the setting: relational, situated, dispositional, and involving activity. Although clinicians from both the ICU and palliative care were involved, no ICU nurses were included in interviews. This pattern language is no doubt helpful to understand and identify compassion, but more

understanding is needed regarding specific ways nurses in ICUs can express compassion. For nurses in PICUs, there is typically a 1:1 assignment meaning that one nurse is with one patient for twelve consecutive hours, often multiple days in a row. While the workload of tasks can still be very heavy, spending this much time with one patient is rarely the case outside the PICU setting and has the potential to create unique opportunities for nurses to enact compassion toward patients and their families.

In the case of pediatrics, there has been relatively little research about compassion (Sinclair et al., 2020). Sinclair et al. (2021) recently developed a model of compassion based in pediatric oncology which provides a conceptual understanding of compassion in pediatric healthcare. This model shows that compassion in pediatrics is similar to adults, but with a greater emphasis on awareness of suffering and actions to alleviate suffering which has informed this research question. In the pediatric context there has also been a long history of advocacy work toward family-centred care for over fifty years (Bagnasco et al., 2017; Bamm & Rosenbaum, 2008; Jolley & Shields, 2009). In the family-centred care model, parents are viewed as part of the care team and are involved in every aspect of care (Jolley & Shields, 2009; Kuo et al., 2012).This ideal of involving the patient and family in care, whether called "partnership" (Franck & O'Brien, 2019; van den Hoogen & Ketelaar, 2022) or "collaboration" (Bamm & Rosenbaum, 2008), has been influential in shaping the interactions between nurses, patients, and families in pediatric nursing.

Compassion is not a solution for system-level problems that have a negative impact on patient care such as inadequate or unsafe staffing, but it is always possible to see patients as people and treat them in a way that is consistent with respecting their humanity. PICU nurses and patients both need the reconnection compassion brings. By describing some of the practical ways in which PICU nurses enact compassion, others can be encouraged to be more cognizant of compassionate actions that can be incorporated into their own practice.

Compassion is essential in healthcare and central in nursing. Suffering with children and families in PICUs and taking action to alleviate their suffering is the work of PICU nurses. Knowledge developed through this study is intended to support nurses as they improve their ability to enact compassion in the PICU setting.

Chapter 2: Methods

This study used the interpretive description methodology which was developed for exploring practice-based questions of applied disciplines such as nursing (Thorne, 2016). Interpretive description allows researchers to develop knowledge that applies in practical ways to clinical situations, which aligns closely with the research question. The research question for this project was seeking to describe the practical knowledge of pediatric intensive care nurses as they enact compassion in the setting of PICU. The aim of interpretive description is to "make visible and accessible the practice wisdom of a passionate and thoughtful expert practitioner for whom a similar understanding had been acquired through extensive reflective observation and pattern recognition, … illuminating relevant insight" (Thorne, 2016, p. 188). The nurses who participated in this study shared rich stories and reflections full of insight into how nurses enact compassion in PICUs and interpretive description provided a suitable methodology to inform the research question.

Participants and Recruitment

Following approval from the University of Alberta Research Ethics Board, I connected with a gatekeeper from each participating unit. Gatekeepers provided guidance in regard to usual recruitment practices for each unit and facilitated the distribution of recruitment materials. In some cases, this was a research coordinator and in others it was a clinical nurse educator. Each gatekeeper sent out a recruitment email including the recruitment poster to the nursing staff. Recruitment posters were also posted on each unit in appropriate locations identified by the gatekeepers. One gatekeeper also requested that I present the study in a staff meeting. One gatekeeper sent out a follow-up email a few weeks after the initial recruitment email, which was consistent with their unit practices.

According to Thorne (2016), a variety of sample sizes may be appropriate within the interpretive description methodology. Thorne provides the guidance that for studies exploring a commonly occurring phenomenon where the focus is on exploring a subjective experience, a

small sample size is appropriate. In this case, compassion is a topic with which nurses are likely to be familiar, therefore a small sample size of five to eight was planned. Eleven people responded with an expression of interest in participating. Two initially expressed their interest by email and the others used the intake form.

Participants

Participants were all registered nurses who, at the time of the interview, were working as bedside nurses in a pediatric intensive care unit in Alberta. The experience of participants ranged from 7 months to 15 years working in the PICU and from 4.5 years to 18 years working as a nurse. Most of the participants identified themselves as White or Caucasian and female. In terms of age, the largest group was nurses in their twenties, but nurses in their thirties and forties also participated. I had worked directly as a coworker with six of the seven participants, and with ten of the eleven nurses who volunteered to participate. The pre-established relationships the writer had with many of these participants may have contributed to their willingness to participate, but I did not initiate conversations about recruitment for the study with coworkers.

Informed Consent

The consent form used can be found in Appendix A. For zoom interviews, this consent form was emailed to each participant prior to the interview and reviewed at the beginning of the interview. Then the consent of each participant was recorded once they had the opportunity to ask any questions. For interviews conducted in person, two copies of the consent form were brought to the meeting. Each participant was given time to review the consent form and ask any questions, the form was then signed and the participant was provided with their own copy of the consent form. Once the hard copies were scanned into the secure server, they were destroyed.

Data Collection and Management

Data were collected through semi-structured interviews. Of the seven participants, four chose to have the interview online through Zoom and three chose to have in-person interviews.

Two of the interviews were conducted in public locations and one in the participant's home. For the in-person interviews, participants chose a meeting place in which they were most comfortable. The interview guide in Appendix B was used for all of the interviews. Due to the iterative nature of interpretive description, I sought to maintain an attitude open to refining the questions throughout the research process, but no significant changes were required. The order in which the questions were asked varied for each interview depending on the responses of the participants and how the questions linked naturally to what participants said. I also asked probing questions throughout the interviews to obtain greater depth in the responses and clarify responses.

Zoom interviews were recorded onto an encrypted and password protected computer hard-drive and then uploaded to a secure University of Alberta server within 48 hours. A digital voice recorder was used to record in-person interviews. Following each interview, the recording was transferred onto an encrypted and password protected computer hard-drive and uploaded to the secure University of Alberta server using a password-protected internet connection within 48 hours of the interview. Local files on the computer and voice recorder were then deleted. I then completed transcription within the secure University of Alberta server.

Data Analysis

Within the interpretive description methodology, data construction is understood to be an inductive process (Thorne, 2016). The process is also meant to be approached iteratively wherein the data are reviewed and reworked multiple times until suitable themes are developed – questioning logic and looking for alternative explanations along the way (Thorne, 2016). This project used reflexive thematic analysis as described by Braun et al. (2019) which was based on Braun and Clarke's popular description from 2006. Reflexive thematic analysis facilitates an inductive approach to data analysis that is consistent with the interpretive description methodology (Vaismoradi et al., 2013). It is a systematic approach to exploring and understanding conceptual patterns of meaning across the data in an iterative and inductive

process (Braun et al., 2019). Thematic analysis also supports mapping of connections between themes (Kyngäs, 2020). The six phases of thematic analysis as described by Braun et al. (2019) were followed but, as noted by Braun et al., it was not a strictly linear process.

During the first phase of familiarisation, I transcribed each interview. While transcribing, I identified phrases or stories that stood out as especially meaningful or illustrative. Throughout all the stages, I reflected on my own responses, both positive and negative, to insights and stories shared by participants. Data collection and the initial two phases of analysis happened concurrently as I worked on transcription and initial coding of the first interviews during the same timeframe as when later interviews were being conducted. Anonymization was done as part of creating the transcripts to protect the identities of participants.

The second phase of generating codes happened after transcribing each interview. Each transcript was imported into NVIVO and I went through each interview systematically, assigning initial codes to phrases and stories. Each interview transcript and initial coding were reviewed with my supervisor. In the thesis proposal, I had intended to use some a priori themes from the literature to support early code identification. Some of the concepts that were familiar from the literature were identified in early coding, but the analysis was approached inductively and no a priori themes were used. This approach was more consistent with the methodology of interpretive description and the method of reflexive thematic analysis.

Once the interviews, transcription, and initial code generation were complete the third stage of analysis began, which was constructing themes based on the previous analysis. According to Braun, et al. (2019), the goal of this stage is to develop “a coherent, insightful story about the data” (2019, p. 854). Through discussion with the supervisor and review of initial codes, prototype themes were developed. During this stage, the NVIVO software available within the secure server stopped working. Initial code generation and some initial theme construction were done in NVIVO, but after that time the file would only function as a read-only file despite numerous efforts. Early coding was still accessible to reference, but the remainder of

the analysis had to be completed outside of NVIVO. This unexpected change in strategy for analysis prevented systematically completing all of the analysis in one file, and meant I had to adapt to using new tools in the middle of the analysis process. However, moving analysis out of the software did allow additional flexibility in how I worked with the data, particularly in creating and modifying visual maps of themes.

The fourth stage was revising the themes. During this stage, researchers typically refine the themes further and may construct visual maps to explore relationships between themes. I created and re-created visual maps multiple times as part of both constructing and revising the themes. A variety of other tools were also used to explore how themes could be constructed to reflect the stories told by the participants. The interviews and initial codes were reviewed multiple times throughout the third and fourth steps of analysis.

The penultimate step of reflexive thematic analysis is defining the themes. The work of defining the themes was primarily done through writing about them, and much of that writing was used in the final report which meant that the step of defining the themes was closely intertwined with the final step of writing. Defining the themes was also done in close collaboration with my supervisor through discussion. The main themes of opening the door and being inside stood out early on in analysis, but other themes and sub-themes changed significantly throughout the analysis.

The final step of producing the report included further refining, clarifying, and organising the themes through the process of writing the report. This process was supported by committee members who prompted further synthesis and clarification of the results. There is a recognition within interpretive description that it is important to understand both generalities and particulars (Chiu et al., 2022). The overarching metaphor and themes in the results primarily speak to the generalities of how various participants described the practice of enacting compassion in PICUs. Each narrative of compassion included in this final thesis was offered as an example of a theme, or generality, and each narrative exemplar embedded that practice in the particulars of

a unique patient, family, nurse, and clinical situation. Through the narratives included in the final report, readers can access a variety of ways nurses might practically integrate the generalities into particular situations.

Throughout the final phase of writing the report, the complexity and beauty of stories as shared by participants became apparent. Although a narrative approach was not part of the proposed process for analysis, the final writing of the report reflected some aspects of this approach. Stories shared by participants are seen as reflecting the emotions, attitudes, and beliefs of the speaker, not simply a sequence of events (Holstein & Gubrium, 2012). It is not only the events of the story but also *how* the story is told by the narrator that is central to what is being said through the story (Daiute, 2014). The narratives told by participants in this research study were complex and multi-faceted involving multiple observations, previous experiences, and reflective thought processes in the recounting of each narrative. In order to help readers understand the actual practice of enacting compassion in its complexity, I sought to preserve the authentic voice of each narrative as much as possible in the final report which is consistent with a narratively-informed final written report (Daiute, 2014). While I draw extensively on individual participant narratives as exemplars, every participant offered examples of enacting compassion relating to most themes that are explored in the findings of this research.

Braun, et al. (2019) acknowledged that despite outlining six steps, the process of data analysis is typically non-linear and that the defined steps overlap and are sometimes repeated later in the process. That was consistent with the process of data analysis for this research project. Although the process was followed as closely as possible, often analysis merged slowly from one stage into the next. For example, during the transcription and code generation of the last few interviews, I began to identify connections with earlier interviews. Sometimes the information shared in previous interviews informed questions asked in later interviews, which was a practice supported by the supervisory committee. Another example was that Braun, et al. (2019) described the use of visual mapping as part of the fourth stage of analysis, but I

employed this strategy at a variety of stages of analysis and in a variety of ways. The technique of mapping was employed early on in collaboration with the supervisor, and then continued throughout the analysis process as a tool to clarify and define the themes.

In terms of data saturation, Thorne (2016) acknowledged that there is always more to be learned which could make data collection and analysis an endless process. While recognising that infinite variation is possible, the goal of this study, in keeping with the methodology of interpretive description, was to arrive at themes that provide an insightful description that can inform clinical practice in meaningful ways. Rather than asking whether the data is saturated, Thorne recommends asking instead if there is coherence, logical connection between the research question and conclusions, and meaningful in-depth understanding of the phenomenon. The supervisor and supervisory committee confirmed in collaboration with the writer that these distinctives were met at which time recruitment was closed. My concurrent clinical practice within the setting of PICU helped maintain a focus on practical application. During clinical practice, I often had this research in mind, and noticed that it shaped my own practice throughout the time during which the research was being completed. Reflexive thematic analysis provided a helpful process by which to develop themes that had potential to inform practice.

Researcher's Positioning

Within interpretive description, data is understood as being co-constructed by the participants and the researcher. As such, the researcher's own positioning is an important element of data construction. In order to make explicit my own role in data construction, I will describe my own position. In terms of demographics, I am from a family of German immigrants to Canada. I have lived and worked in Canada for most of my life but have had several experiences volunteering overseas in a variety of cultural and practice settings.

I currently work as a registered nurse in the PICU in a part-time position and this experience had a significant impact on the research. I have been in this role for seven years and

thus have significant practical experience in this setting and with the research topic. My own clinical experiences and observations were instrumental in leading to this research question, and informed the conduct of the research process including interviews, interpretation of data, and subsequent writing. Having a concurrent nursing practice in the area of research also helped maintain a focus on developing knowledge that had practical application, which is the target of interpretive description research.

Six of the seven participants knew me as a coworker before signing up to participate in the research study. The pre-established relationships I had with many of these participants may have contributed to their willingness to participate, but I did not initiate conversation about recruitment for the study with coworkers. When coworkers asked about the study, general information about participation was given, such as that it would be a one- to two-hour interview and that it could be conducted online or in person. Participants who expressed interest to me in person were asked to follow up by expressing their interest through the intake form found in Appendix C or through other communication methods indicated in the recruitment materials. This was done to avoid any undue pressure on coworkers to participate. Other researchers have had difficulty recruiting nurse participants from our unit, but there were eleven volunteers for this study, so it is possible that the existing working relationship with me may have contributed to the willingness of volunteers to participate. Some participants shared that they felt more comfortable signing up to participate because they knew me and felt I was easy to talk to. Other participants reflected that there was a certain vulnerability in sharing their experiences and perspectives with someone who would encounter them and their practice in the future. When these topics came up during the interviews, I was careful to reiterate that the participants did not have to say anything they were not comfortable with sharing.

In addition to knowing many of the participants, many of the stories that they told were about patients who I knew and had cared for myself. Some participants relied heavily on my pre-existing knowledge and used phrases like “you know Sally” and then proceeded to give an

example of compassion without describing Sally's situation in the interview, which was pertinent to the example. As a novice researcher, my ability to identify these situations improved as I conducted more interviews. In later interviews, I was better able to identify these situations in the moment and ask the participant to describe the situation briefly in their own words so that the appropriate context could be included in the interview data. There were some moments in which my pre-existing knowledge of a situation or unit norm informed the probing questions I asked during the interviews. My understanding of a situation helped me identify where there was perhaps more behind what was initially said by the participant and often prompted the asking of the question "could you say a bit more about that?" There were moments when my pre-existing knowledge of policies or the physical layout of the unit allowed the interview to keep moving forward instead of needing to ask participants to describe, for example, current visitor restrictions on the unit. While this did streamline the interviews in some moments, it is possible that having more in-depth descriptions from the participants of the context may have added to the richness of the data.

As someone who was personally familiar with the research context and with nursing practice in this setting, cutting down stories into shorter excerpts proved to be difficult. The way participants intertwined multiple examples with more general reflections revealed rich insight into the practice of compassion in PICUs. Because of my personal involvement, details that may have seemed peripheral to others often seemed like important context to me as they informed the enactment of compassion in a particular example. Having seen in my own clinical practice the impact one small moment or action can have – a word, eye contact, tone – I struggled to cut down examples into shorter excerpts. Participants shared in ways that were rich and multi-faceted, often weaving together multiple examples and personal reflections. As a result, a conscious decision was made to include longer excerpts to convey the complexity of the practices as depicted in particular situations and in the voices of participants.

Throughout the research process, I kept a reflexive journal to identify my own responses to what participants shared. I did have pre-existing knowledge of the phenomenon and I found myself challenged to think differently about compassion at times when participants shared examples or descriptions that did not fit with my own experiences. I shared these observations with my supervisor and reflected on how to recognize and question my own views and assumptions to better understand what was shared by participants. Many of the stories that participants told inspired me to make changes to my own practice - to enact compassion more effectively. I found myself putting into practice things participants had shared and noticing the positive impact those actions had on patients and families.

There is one final acknowledgement to make on my own positioning as a researcher. Prior to commencing this study, one of my closest friends had a child admitted to Pediatric Cardiac Intensive Care at the Stollery for many months. This gave me new insight into experiences of parents and children in PICUs and revealed to me the enormous impact the bedside nurse can have on experiences of patients and families. Walking with her as a friend through her time in the PICU and subsequent grief was instrumental in my own interest in pursuing this research question. Parents spend long hours, days, weeks, months, and even years with PICU nurses and compassion can make an inestimable difference to their experience and bring comfort in times of great sorrow.

Chapter 3: Opening the door

Compassion involves both entering into another person's suffering with them and taking action to alleviate that suffering. This research question and the insight shared by participants were focused on the actions by which nurses in PICUs enact compassion. Across the interviews, there was an emphasis on the nurse developing a connection or relationship with the patient and family. In the context of pediatrics, the entire family is often considered to be the patient. This is especially true in PICUs since patients are often sedated which limits interactions with the patient directly, so throughout this analysis, compassion toward patients is often indistinguishable from compassion toward families. Many of the compassionate actions that participants described could be appropriate for families, patients, or both.

The metaphor of opening the door and walking through it will provide a framework to understand how compassion was described by PICU nurses. Laura described this metaphor as follows:

> Someone has to open the door. So you can open the door, but it doesn't… even mean they're going to look up from their chair.… [but] you have to make the offer. And sometimes families do it too, sometimes I'm not even thinking about opening the door yet, and they ask "I'm so sorry to interrupt, but can you answer this?" and you realise "Oh yes, hold on, they've opened the door, they need something, they're asking for me to come be with them." And then you can shift gears – it's not always nurse-led. It's a two-way street for opening the door and walking through it.

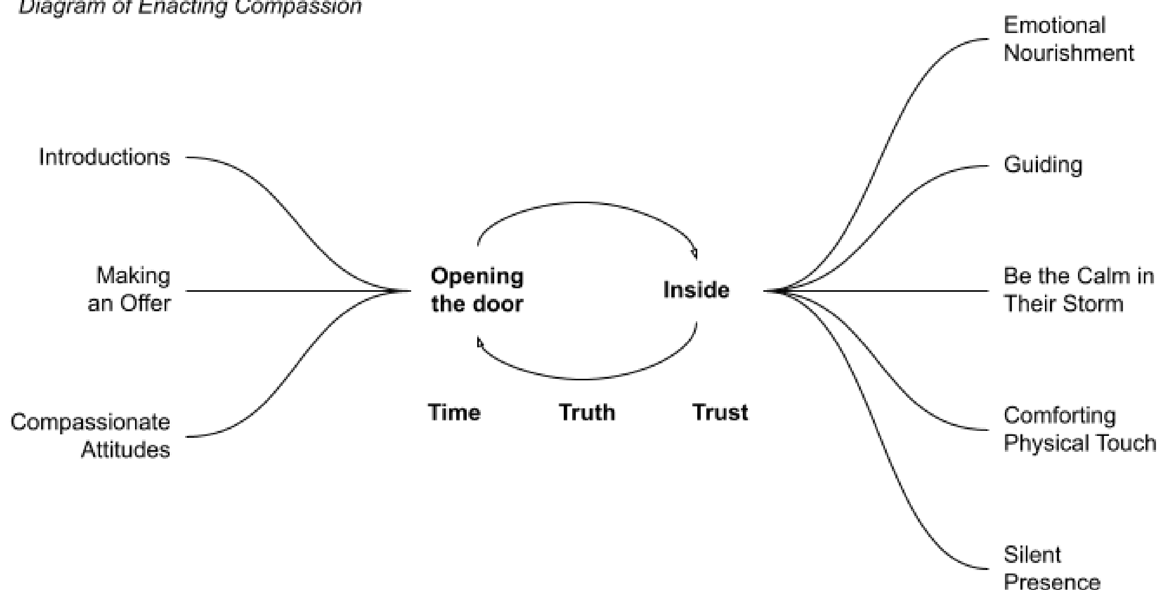
This description highlights the reciprocal nature of a compassionate nurse-patient relationship. Both the nurse and the patient or family have a role in opening the metaphorical door. Yet, even if the family seems not to respond to the nurse's efforts to open the door, it is the nurse's responsibility to make the offer – to try to open the door regardless of the response. In most cases, a patient or family is unlikely to physically prevent a nurse from entering the

room, but they might keep the metaphorical door closed through non-verbal communication like not making eye contact or giving one word answers. Participants described the creativity and perseverance it takes for a nurse to get the patient or family to open up in some situations, while in other situations the door is opened very quickly. In either case, the act of trying to open the door is itself enacting compassion.

There are some limitations of the "opening the door" metaphor that need to be identified at the outset. This metaphor might unintentionally communicate a linear process of first opening and then being inside. Many of the actions that participants described as part of opening the door were not only done at the beginning of their relationship with a patient or family – they were also done on an ongoing basis to maintain that connection. As patients and families open up more vulnerable parts of their experience and needs to a nurse, and if a nurse responds in a way that is not consistent with the aim of compassion to alleviate suffering, that can sever the connection that has been built – closing the metaphorical door. Inversely, as those vulnerable parts of a patient's or family's experience are shared, the nurse can enact compassion in new ways that respond to those newly revealed needs thereby inviting further openness in the relationship. "Opening" is not done only at the beginning, but continually throughout the nurse-patient relationship, as will be illustrated throughout the examples participants shared. Opening the door is both enactment of compassion while also opening up new different ways of enacting compassion that become possible in the inside space of being with the patient or family. A visual representation of the main themes can be found in Figure 1.

Figure 1

Diagram of Enacting Compassion



Reagan described opening the door in a situation when it seemed impossible. A child of about seven years old would scream at nurses any time they entered the room and would rarely stop screaming until they left the room. The child seemed to be screaming because she wanted the nurse to leave. When a nurse is constantly being screamed at to leave, the patient is communicating a lack of openness to the nurse's presence let alone any connection. Even in this situation, Reagan explained how he continued to try, in ways that were consistent with her physical and developmental needs, to connect with her and he was eventually able to develop a bit of a connection with her which opened up the opportunity for him to give her analgesia for her pain and even wash her hair.

> If you really really worked hard, you could connect with her a little bit. She would still scream every time you walked in, but she would stop screaming as you were doing things and then you could sometimes sit on the end of the bed.… [Being willing to] take time and the effort to create some common ground and boundaries with her.… [One example of

> setting boundaries was when] she would say ‘pain’ and then you’d … try to get her Tylenol and she goes “no” … that was a frustrating experience…. Lots of times [nurses] just don’t want to take the effort to take 25 minutes to get them to take a Tylenol.

Reagan responded to this patient with patience and persistence. By the end of the week, she allowed him to be in her room without screaming, and even allowed him to wash her hair. Bathing is a very personal activity and Reagan provided this as evidence that the patient had opened up a little bit over the course of the week – she became open to care that was adamantly refused earlier in the week before he had been able to connect with her. Reagan went on to further explain how he practically integrated broader knowledge about the patient’s underlying needs in the way he worked to open the door over the course of the week.

> I would sit there until she [stopped screaming]... She’d go to grab the popsicle and I was like “no, you have to say please.” Kids like boundaries... [I’ll say to them] “If you want something, you are a big boy or a big girl and you can talk to me like you know how and when you’re ready to talk to me, let me know.” And they do. … then they respect you and they don’t try to walk over you. It’s in kids’ nature…. [You can] work to a kid’s strengths in their developmental stage in their life…. If they’re used to just screaming all the time until they get attention, that’s not solving anything especially when they can talk and communicate. And, yeah, sometimes it is about saying no… [or] giving them an option of how things are done… and giving them some control. Compassion to those kids is being able to get on their level and communicate efficiently in a developmentally appropriate way… understanding that developmental milestone… [and] giving them that bigger factor of *what do they need* and in a way that’s more appropriate for them.

Identifying unmet needs and meeting them was a key part of how participants described compassion throughout both phases of opening the door and being inside. Often a general knowledge of the child's developmental stage and hospital experiences informed the actions of participants to open the door. In this exemplar, the actions Reagan took met the needs of the child for boundaries, for persistence to help her take Tylenol, and for a patient nurse who would stay engaged despite her screaming. Participants reflected that sometimes the things children need, like structure and boundaries, are not the things that they seem to want and that compassion in the PICU involves helping meet those developmental and otherwise hidden needs. Enacting compassion in this way is particularly relevant in the PICU due to the diverse stages of development for these patients. By providing what patients and families need, nurses can develop connection and openness with them and once patients and families open up about their own experiences, more individualised needs can be understood and met by nurses.

Throughout this section, we will explore strategies shared by participants that PICU nurses used to open the door. Many of the ways of enacting compassion in this section focus on the beginning of the relationship, but remain applicable throughout the nurse-patient relationship. This chapter will explore how participants described nurses compassionately opening the door through introductions, noticing and meeting needs, and adjusting their own attitudes. The next chapter will explore how nurses enact compassion beyond the door, within the inside space.

Introductions

This section is an overview of the first theme but also functions as an introduction to how nurses enact compassion in PICUs. In a parallel way, facilitating introductions with patients and families is often a first step in showing compassion. Even while acknowledging that it may seem basic and not worth mentioning, participants repeatedly emphasised the importance of introductions. Their introductions were not limited to providing one's name and role, even though that was often where it began. The introductions described by participants included

getting to know each other more deeply as well as introducing the patient and family to the healthcare environment.

Introduction to Each Other

Introductions are typically mutual – both parties introduce themselves, beginning with giving their names. Patients and families often remember the names of nurses who were meaningful to them. Some participants shared their own experiences of being in the hospital as patients and, even many years later, they often named a specific nurse who had demonstrated exemplary compassion. Just as patients remember the name of a nurse who had a big impact on them, when nurses remember patient and family names it shows that the nurse sees them as a person too, not merely a diagnosis or a body in a bed. Going beyond that, participants explained that remembering names of patients, family members, and even favourite stuffed animals is a powerful way of showing compassion.

Participants described their initial introductions to patients and families in similar ways to each other, often modelling what they would say in the interaction. One example was this description Avery gave: "There's all the basics like introducing yourself like 'I'm Avery, I'm wearing this yellow gown, you have no idea what I look like. I'm going to be your nurse today.'" The *way* participants modelled introducing themselves involved not only giving their name and role, but often also an expression of understanding the patient and family experience. In this example, Avery acknowledged that the patient did not know what she looked like which could be a barrier to connection. Starting the relationship off with an introduction in this way is a small action, but one that begins knocking at a closed door by offering something of oneself, and an expression of understanding.

Knowing the names of parents also offers the practical benefit of being able to communicate effectively in stressful situations. Avery explained it this way "I think it's a huge asset when you're in a stressful situation and you know their name, you can be like 'Okay, so-and-so, we're with you' or 'this thing is happening' and you're able to speak directly to them and

they know ‘oh, she sees me. She’s acknowledging me or respecting me.’” Using the names of the people who are important to the patient may be a small gesture, but it is one that communicates compassion to patients and families because it shows a deep respect for them as a person.

Introductions go beyond exchanging names; they are often the beginning of a relationship in which people can be known for who they are beyond their name. Participants described getting to know patients and families for who they were as a key part of showing compassion. Some examples participants gave included asking to see pictures or videos of the child from outside the hospital, recognising a special blanket or stuffed animal and asking where it came from, and encouraging families to print off a picture of their child to put up around the room if the child was going to be in the PICU and sedated for a long time.

Participants shared that familiarity with *who* a patient was, that is, their preferences, moods, routines, and values, could often facilitate new ways of enacting compassion. For example, when Avery found out that Max and Ruby was a child’s favourite show, she had to try three different consoles to find a working DVD player to play Max and Ruby so that child could watch her favourite show. Jamie explained seemingly small actions like these that were specific and personalised to a *particular* patient and family “show you care more, they’re not just ‘a fresh trach,’ they’re that person’s child - they had a life before this, they’ll have a life after.” These individualised actions show that the nurse sees them as a person and recognizes that they exist within a broader context of their life, interests, and personality.

Pointing again to the reciprocal relationship that is integral to compassion, participants gave many examples of compassion in which they chose to share information about themselves as part of how they invited patients and families to open up. In some cases, sharing about oneself served to establish common ground in shared experiences or interests. Reagan gave the example of finding connection with families who, like him, were not from the city. He reflected that

> A lot of times people aren't from this city… and it's funny how [the city] just draws people together and how so many people are here that wouldn't normally be here, so that's one of my biggest ways of starting to open a conversation.

Establishing something in common like not being from the city can *open* a conversation and also begin to *open* the door of connection. When people start talking about their home, nurses are given insight to better understand what being in the hospital is like for that patient and family. Understanding their home context helps the nurse better understand the patient and family's experience of hospitalisation, such as missing close family members who are far away. Participants described showing compassion by finding or creating points of commonality, explaining that establishing common ground helped open the door by giving the nurse a better understanding of the patient and family's experience and by developing a sense of connection and trust with the nurse.

Participants gave many examples of sharing about themselves in order to establish common ground. In the example above, Reagan shared his own experiences of moving to the city with patients and families. Sharing about oneself was also described by participants as having two roles beyond establishing common interests - that of meeting a need and that of establishing common humanity. Jamie reflected on how her practice had diverged from what she was taught in nursing school. Despite being taught to "never talk about yourself," she saw a need to be honest with families instead of evading questions that are a normal part of getting to know one another. She explained that "it always needs to be focused on the patient and family, but sometimes they just want to be distracted. You're in there all day, they just want to make conversation and think about something else." The nurse's availability to have normal conversations in the midst of abnormal situations meets a need for conversation and for distraction. Kelly further reflected on the impact of showing compassion by sharing about oneself:

> There's professional boundaries, but I also think that there's a therapeutic use of self-disclosure because I think that that again humanises the relationship, takes away the hierarchy, brings them some kind of normalcy and humanness. Instead of being a robot, it shows that you have a life too. And I think parents also enjoy that because then they know that it's not just, … a job for you, that there's actually some type of yourself in there too.

The qualifier "therapeutic" here is key - this is not venting as one would with a friend. It is sharing that is focused on the formation of a therapeutic relationship. Just as nurses seek to get to know patients and families, often patients and families also want to get to know nurses. When a nurse shares about themself, patients and families may be better able to trust that nurse and are often more willing to open up. The act of introducing not only one's name and role to patients and families, but also sharing one's very *self* is humanising for both the nurse and the patient.

Participants repeatedly highlighted the importance of bringing one's self into practice as an integral part of enacting compassion. Darcy said that "by simply not going through the motions, by really just kind of putting your whole self into it," nurses could really "elevate" the patient and family's experience. Not "going through the motions" but instead engaging your self - putting your whole self into it - is being compassionate. It requires a human nurse, not a robot, to interact with the very human patient and family. Reagan expressed it this way: "if you're not doing care compassionately, you're kind of just an empty shell doing tasks" which highlights that doing care compassionately *is* engaging in a way that involves one's self.

Engaging with one's true self, as opposed to putting on a performance or going through the motions, is being genuine. Many of the compassionate actions described by participants involved expressing their sincere interest in the patient and family - in getting to know them as well as in their well-being. In this next quote, Kelly highlighted the importance of being genuine as she described the compassionate actions of her coworker as follows:

> One of the things that sets her aside from other people is even when she's not taking care of patients, if she's just walking away for her break and she sees the parents there, she says a quick "hi, how are you? How's your chicklet doing?" and shows that she genuinely cares…. Families really appreciate that because it also, reciprocally, helps establish a relationship and trust…. When I feel like somebody's being authentic, I feel like I can let my guard down….being authentic is genuinely having the best interest of the patient and the family and letting that shine through your nursing practice."

Being genuine or authentic in caring about the patient and family was a recurring theme in participant responses as they described creating an environment in which the patient and family could "let their guard down" or, in the language of the metaphor, open the door. Although that "guard," or closed door, could perhaps keep those inside safe, it may also limit connection. In the example above, connecting with a former patient to whom they were not assigned for the day was a caring gesture that the family knew was not required. Ways of enacting compassion that open the door were described by participants in actions that showed that the patient and family's well-being was genuinely important to the nurse regardless of obligation. Participants described a variety of ways of navigating introductions involving using names, getting to know the patient and family, and genuinely sharing about oneself. The ways nurses introduce themselves and begin to get to know patients and families can be an important part of how compassion is shown in PICUs.

Introduction to the Healthcare Environment

Participants also described the role nurses had in introducing families to the healthcare environment and to the journey ahead of them. Many families are in a setting that is completely new and often overwhelming to them; they have no idea what being in the PICU will be like for them. Avery described saying to parents "this is now your environment, so let me introduce you." For some families who were familiar with the healthcare setting, as Avery described, "it's

not a big deal a lot of the time. Even if their kid's quite sick, they're almost too calm and [it is clear that] they've done this a few times." Whereas other families were described as confused, disoriented, and overwhelmed by participants - needing an introduction to a basic where to stand in the room in the midst of urgent medical interventions. Participants also gave examples of helping orient parents to the environment beyond the room - where the water machine, coffee shop, or parking office was - to this healthcare setting that was new to them.

The phrase "meet them where they're at," or a close variation thereof, was repeatedly used by many participants which reflects these themes of introduction and location. When we meet someone for the first time, it is customary to introduce oneself. In the chaos that is an unexpected PICU admission, patients and families are meeting a host of staff, but also 'meeting' a new experience and a new journey to which they must also be introduced. Often the journey they are facing is filled with hard things and nurses often have a better understanding of what their journey may hold than they do, so it is the responsibility of the nurse to provide that introduction and help families begin to understand. Participants gave examples of introductions that displayed an awareness of the place in which the family was and included the compassionate action of introducing them to their environment . A seemingly simple and easily forgotten action of introducing yourself and the healthcare journey to patients and families plays a key role in opening the door of meaningful connection and showing compassion to patients and families in the PICU.

Making an Offer

Offering something, whether material or immaterial in nature, to patients or family members was a prominent way nurses described enacting compassion. In the initial quotation establishing the metaphor of opening the door, Laura used the phrase "make the offer" to describe the action of offering, or inviting, an open door. Whatever the nurse offers, the act of offering something often fulfils two purposes. The first is to meet a need and the closely-related second is to invite further openness. In some cases, such as the initial quote, the expression of

need by patients and families was described as them opening the door. In other cases, participants described having insight into an unspoken need as a result of the nurse's expertise and experience. In both contexts, participants described ways that offering something to meet a need was compassionate by both meeting the need itself and by inviting the patient or family to open the door as these actions showed that the nurse noticed and cared about their needs. Many of the ways nurses work to open the door occurred in an ongoing manner throughout the relationship - as the patient or family allows the nurse inside their experience, the nurse may then be able to *offer* different things to meet needs that could not have been understood previously. This section will focus on how nurses might offer physical provisions, information, choice, or family involvement as ways of inviting patients and families to open the door.

Many of the examples participants gave of compassion were things that met a physical need. Offering something tangible like a glass of water or a kleenex box to a distressed family was described as a practical way of showing one's compassion and helping open conversation. Reagan shared the following exemplar:

> We keep our units cool for infection prevention, automatically the hospital's cold. Families are always freezing and I just give them warm blankets if I notice they're cold. They just light up - every time. It's just a small comfort in a really terrible situation and we don't have a lot we can offer a lot of the time, but that's the biggest thing I try to do for families is warm blankets and bedding.... Sometimes it just opens a conversation which is really funny. [I will say] 'oh, I noticed you might be a little cold, would you like a warm blanket I brought' and they're like 'oh my god, thank you so much!' and you're like 'no worries' then you kind of like 'are you doing okay? Do you need anything?' And it is an icebreaker to be able to open a conversation.

Reagan called offering these tangible comforts an "icebreaker" to help open the door to conversation. Participants reflected that actions like this offer physical comfort and they also

show that the nurse is aware of and responsive to what the family is experiencing. Through seemingly small and mundane actions, nurses can show their attention and receptivity to the patients and families - nurses show that they see and notice what is going on. Participants gave many examples in which compassion was enacted by paying attention to what patients and families needed and then offering something to meet that need. Physical needs are sometimes more easily identified through observation or experience, so offering physical comfort can be a particularly powerful action early in the relationship before other hidden needs can be identified. Since compassion involves taking action to alleviate suffering, offering ways to alleviate physical suffering is offering compassion and this action can also open up a conversation about how the patient or family is doing beyond basic physical needs.

Another way participants described offering something to meet a patient or family's need was offering information. Participants spoke repeatedly about the importance of helping families understand what was going on and of explaining to patients what one is doing, even patients who were unconscious. Instead of waiting for people to ask what is going on, which can feel vulnerable, an expression of compassion was offering information proactively. Hayley shared her observation of a coworker showing compassion in this way.

> She was so patient and gentle and she explained everything and you could just see the parents calm down as she was explaining…. She explained it in a way that they understood … she was very calm, it was slow, she took pauses. I noticed she'd say something and then she would right away explain it instead of being like 'do you understand?' or 'do you know what that means?' … I wonder how many times we put parents on the spot and they kinda get flustered so by saying 'she had A happen, and that's when B, C, and D is going on in her body.'... She offered the information without needing to be pressed for it or parents need to say 'I don't understand.'

Many participants described offering information to patients and families without being asked as another expression of compassion. They recognized that parents might be hesitant to ask questions, so offering information was a normal practice described by many participants that showed compassion. In this narrative, as with others, when parents understood what was going on, they were able to be calm and to open up more to the nurse.

Another way of offering something that a patient needs is offering choice. Many participants described offering patients a choice in their care, while recognizing that was not always possible. For example, when a child did not want to take their medication Jamie responded by saying "Okay, you have to take it. Do you want to take it now or in five minutes?" Although this is typically thought of as a parenting strategy, Jamie pointed to research that supports that being given a choice can improve the experience of adults too. Likewise, Laura reflected that "many people need to hear 'what do you need in this moment?' and giving them some options because in those moments they don't even have the brain capacity to think of what they need until you say it sometimes." Offering a choice between limited options supports the need for choice even if someone does not know what they need. As nurses seek to show compassion by identifying and meeting the needs of patients and families, offering basic choices like now or later, or which colour of popsicle the child would like gives children and family members back some sense of control. Participants reflected that offering choice in this way shows respect and understanding which can help to open the metaphorical door.

Throughout all of these examples, engaging with families and showing compassion toward them has been inextricably intertwined with showing compassion toward the patient. Kelly explained that "if you're not tying the family into the care that you're providing, it's almost a disservice because it's probably the most traumatic time in their life and we very much can have long-lasting impacts on families." In such a difficult time of life, the way nurses in PICUs engage with families can help alleviate some of their suffering.

One of the practical ways to engage with families is to offer them the opportunity to be involved in the care of their child. Kelly shared that parents "are so scared to touch their kid, but they love the kid." When children are critically ill, they can be too unstable for normal physical touch from their parents. Kelly identified the fear that parents can have, and the importance of helping them fulfil their desire to show their love to their child in other ways. She shared the example of involving a patient's mother and grandmother in giving a bath and reflected that "they're used to having their kid at home and doing this stuff with their kid by themselves. They miss that stuff…. Giving opportunities to let them get involved" is a way of showing compassion. Offering parents the invitation to be involved in ways that are appropriate shows an understanding of their relational needs and demonstrates compassion.

Reagan reflected further on how involving families in care is not only an act of compassion itself, but it can also help open up difficult conversations. He observed that

> as they're busy and their hands are busier, they tend to open up with you more…. while you're doing the bath the conversation just comes quite naturally. [I will ask:] "would you like to hold [your child] today?" Or "is there any outfit you want to put on [while the child is dying]?" It just comes naturally as you're doing the bath because you're busy so it's not … I hate that therapeutic, I'm on this side, you're there, 45 degree angle [textbook] conversation…. I just don't think it works well especially in end-of-life situations and so I find just doing something with the family like doing some footprints or handprints or some photos or whatever, it takes away that pressure of the conversation a bit and the families generally… just offer up the information quite naturally.

Involving parents in a tangible activity of care helped alleviate some of the pressure of the difficult conversation, and doing that *together* helped the parent "open up" about their end-of-life wishes. For a parent to enter a conversation about the end of their child's life head-on can be too overwhelming, but while they are actively caring for their child, conversations can be had

more naturally. As Kelly mentioned earlier, sometimes there can be fear or overwhelming emotions so it is important that family involvement is offered, but not forced. If parents are not ready or emotionally able to participate in or watch various parts of care. Even if parents decline the offer, the act of offering involvement to families is compassionate toward both the child and the family.

Throughout all of these examples of things to offer patients and families, the ability of the nurse to offer something that is needed and appropriate depends on the nurse noticing the patient or family. This involved noticing body language, noticing a child's developmental age, and noticing the temperature in the room to name a few. These things, participants shared, were often more easily observed when they were physically present in the room. Participants spoke about how when nurses are physically outside the room, it often communicates a lack of being present metaphorically. In contrast, participants offered physical presence by being inside the room as a way of showing that they were attentive and open to the patient and family which, reciprocally, invited openness on the part of the patient and family.

Participants felt that there is a time where it is appropriate to leave and to allow the family to have some privacy or to have quiet time. Often, participants described being able to identify intuitively from the family's body language if they wanted the participant to stay in the room with them or provide other types of support. Intuition about what is needed develops over time and with practice, but it cannot develop if nurses consistently choose to be outside the room. Sometimes explicitly offering presence is appreciated by families and gives them the opportunity to choose. Laura reflected on her experience with being present during end-of-life care.

> Sometimes family members *do* want to be left alone with their child and some family members feel really uncomfortable being left alone with their child who just passed away. Sometimes they want the reassurance of someone sitting in the corner so they can ask questions when they come up. … giving them permission

> too, because a lot of times people don't feel they can ask you to leave or that they can ask you to stay.

Some families may want the privacy of time alone while others may want the reassurance of someone nearby. Although the end-of-life phase is unique, being present inside the room with most patients facilitates good care and connection. Jamie shared an example of a nurse sitting outside the patient's room on the computer when the family arrived. The family found that the patient had moved herself into an unsafe position and had clearly been that way for quite some time. If the nurse had been inside the room, she could have noticed the change in position and repositioned the patient immediately. As machines and monitors become more integrated into nursing care, the vigilant observation of a PICU nurse is difficult to replace. In that situation, the lack of attention firmly closed the door of relationship with the family where the nurse's physical presence in the room and careful attention could have maintained or further opened the door.

The action of offering something that meets a need of a patient or family member is an act of compassion. When nurses are attentive to physical, psychological, developmental, and social needs of patients and families, it allows families to feel that their needs matter which helps them open up more to the nurse. The examples described in this section do not provide an exhaustive list but instead offer suggestions of ways to engage families. By offering the means of alleviating some suffering through, for example, physical comfort, information, choice, family involvement, or their own presence, nurses show compassion to the patients and families in their care.

Compassionate Attitude

Since this research question is about actions, it may seem strange to have a section about attitude. Yet, one of the actions that participants often described was adjusting their own attitude in ways that helped them be more compassionate toward patients and families. Participants felt that the mindset with which a nurse enters the room can have a significant

impact on the way interactions unfold with patients and families. Using the previous section as an example, it becomes very difficult for a nurse to offer something that alleviates a need without an attitude that is attentive to notice that another person's need. After an overview of how participants described their experience of changing their attitude, this section will explore the specific attitudes that participants embraced to facilitate compassion toward patients and families.

A change in attitude is not something that can be seen by an observer, and yet it impacts the actions that are taken. Sometimes, an attitude shift happens in just a second, and that second puts the nurse's focus back on showing compassion to patients. Many participants described the crucial role self-awareness and reflection had on changing their attitude - on re-centering them on, as Darcy put it, "why you came into the profession and how you show compassion for your patients." Darcy went on to describe her thought process to adjusting her attitude from being frustrated or disengaged to an being focused on and able to show compassion to a patient:

> It has a lot to do with reflection and being able to reflect on experiences…. When it's 0800 am and you're already frustrated…. And you [ask yourself] "how do I get myself through the next 11 hours plus two more shifts after this?" but also remember that when I come to work, yes, I'm kind of doing this for myself, but *really*, we're there for our patients … Being able to reflect on even a simple moment and just say… "Okay, I need an attitude adjustment." … If you're … with a hard patient and you're really struggling and you can tell that your communication with the family is becoming not great or, for me, a big sign is that you don't want to go in the room as often. … I'll let myself debrief and [decide that] tomorrow I just have to come back with a different attitude. Or maybe I need to try and understand why this is so hard and frustrating to me.

Although each person's internal process is unique, examples given by multiple participants were similar to Darcy's example. They first acknowledged that something was hard for them and then asked similar reflective questions about why something was difficult for them or what else could be going on that helped participants choose to "come back with a different attitude." When nurses had open and engaged attitudes, participants observed that better collaborative relationships with families were built. Adjusting one's attitude may occur before a nurse even gets to work, or it might occur at any point in the shift when there is the awareness of a need for an attitude adjustment. Some of the attitudes nurses chose that facilitated compassion were attitudes of seeking to understand, being courageous, and honouring shared humanity.

Seeking Understanding

Seeking to understand is closely related to getting to know patients and families as has been discussed in previous sections. It is, however, a different action to try to get to know someone than to actively choose an attitude of openness and trying to understand someone in situations when the other person's actions might seem rude or offensive. Jamie, echoing other participants, encouraged entering a room "with an open mind. Try to empathise and find out why they are how they are - what's going on or what has been hard for them." Engaging patients and families with an open mind can invite the patient and family to reciprocate with openness about what their experience has been. Participants reflected that making judgments is helpful and necessary in some situations, but sometimes judgements are made prematurely or without understanding the full context which can be harmful. It can, however, be difficult to maintain this attitude, as Avery noted upon reflecting on a situation when another nurse was upset about a parent who had been rude to her.

> Without knowing the whole story, [the nurse] was like 'oh, she was such a jerk to me' and it's like… can [you] just take a moment to say 'okay, what else is going on here?' that's a huge part of compassion … - [understanding] what else is

> going on in their life … Everybody has a story about what else is going on. I think a lot of our lack of compassion is when we don't know the whole story.

In this situation, when the nurse understood that the mother had recently lost multiple family members and was now single-parenting her own children and her nieces, the mother's exasperation at being moved to a hospital further away could be understood. Her response could be seen in the context of her grief and the major logistical nightmare it caused in an already overwhelming situation. The mother's response was understood as an expression of her struggle and desperation instead of as "being a jerk." Participants gave many similar examples in which understanding a person's life experiences and difficulties allowed the nurse to respond to difficult situations with compassion. As Laura shared, "I love hearing about people's real authentic life and their struggles because [when I know] what's going on, it makes them more of a human…. Knowing more makes you more compassionate." Laura tied knowing about people's life to both seeing them as a human and being more compassionate. An attitude of shared humanity will be explored more fully later, but it is closely intertwined with getting to know people's authentic lives and seeing them as more than a body - as a whole person, which facilitates compassion.

Participants also shared a variety of experiences in which, despite the best effort of the nurse to communicate compassionately and understand, families remained hostile toward staff. Sometimes participants felt that a reputation developed among nursing staff that a family was "difficult" or "crazy." Participants reflected on these situations and described ways of navigating the challenges while maintaining compassion.

> You tell your buddy "hey, I'm having a hard time with this today," and then even just telling that person sometimes lets you move beyond it…. It's really important to speak about people consistently - that integrity piece. Are there conversations where you talk about a patient or family away from the bedside? Yes. Because I think it's part of how we process and work through our days. That is part of why

> the team is helpful. But I don't like introducing a word like "these parents are 'crazy'" because the language that we use is so important…. I think when we talk about parents as "crazy," we start to create this story that we are then more prone to live out… "we don't want to slime each other." … The narrative that we tell ourselves or that we tell others can actually have a really big impact on the way that we care for people and the way that the team perceives them and all of those things…. Every person is valuable. We make those assumptions, but what is behind that? … It's one thing to say "that mom is crazy" [but another to say] "I am having a really hard time with that mom because she's doing this thing and I don't understand it." Or "that's just something that is really irritating to me." It is a very different statement.

Avery framed things that were difficult as things she did not understand or things that were difficult for her instead of labelling the patient or family. This attitude facilitated a better understanding of the patient and family's situation but also better understanding of the nurse's own response. Participants reflected that the way nurses spoke about patients away from the bedside also affected the attitude other nurses had interacting with that patient or family. Negative labels can propagate negative attitudes that prevent nurses seeking to understand. The words and actions of nurses away from the bedside can help others better understand the family and treat them in a more compassionate way. Jamie explained it this way:

> People forget what families are going through and how hard it is…. I don't think there's anything wrong with venting. But I do think it does feed into negativity…. Attitudes can be infectious and a negative attitude … actually prohibits compassionate care…. People don't go in with an open mind anymore and they almost keep to themselves or don't want to empathise [or] find out why they're a difficult family or what's going on, or what's been hard for them…. It's good to maybe have your one person to vent to [instead of sharing it in the breakroom].

Facing one's own feelings can be difficult, but it helps keep infectious negative attitudes from spreading. If something has happened and a nurse needs to debrief, talking to one person privately was felt to be an appropriate context for that conversation. "Don't slime each other" can be a helpful maxim to avoid perpetuating negative stereotypes. When nurses choose an attitude of understanding instead of judgement, they and their coworkers are better able to create an environment in which nurses seek to understand struggling patients and families and show compassion even in difficult circumstances.

Choosing Courage

Courage is another attitude that participants described as being part of enacting compassion. In PICUs, patients and families are often experiencing something life-altering and conversations about end of life or long-term disability are difficult for both the family and the nurse. Yet, participants often described compassion as having the courage to engage in those hard conversations. Having these conversations could be considered part of being inside the room and experience with the patient and family, but the way in which those conversations are approached and *opened* by the nurse was considered essential. Reagan shared the following reflection explanation of how he broaches end-of-life conversations with families planning to withdrawing patient care:

> You kind of just have to go for it sometimes. The families generally already kind of know you're going to have a conversation with them, so you just start talking to them and then you bridge the gap. Sometimes you just hit it straight on and just say "we all know this is happening tonight, what does that look like to you? What does this experience look like to you?" … It's actually quite terrifying. It's never gone poorly…. If they're kind of abrupt, … I just say 'I totally understand if you're not willing to talk about this right now, but I just wanted to open up the

conversation so when you are ready, you've kind of thought about some of the things that are important to you."

Reagan described this action of opening the conversation as "terrifying" despite it never having gone poorly. He interpreted a family's abrupt response as a closed door, which he respected by allowing them more time to think about their wishes. Participants described overcoming these kinds of fears by choosing a courageous attitude and opening the hard conversation in spite of their fear. Avery described her approach of looking for opportunities and responding with courage as responding to "a sense of there's an opening here, [with] choosing a bit of courage to go for it and to ask the hard question." It would often be easier for the nurse to avoid hard conversations, but compassion is tied to stepping in to people's suffering with them and helping meet their needs. Families need to have those conversations about their wishes for end-of-life care, and often have no idea how to talk about a subject as distressing as the death of their child. A courageous attitude helps nurses overcome fear - their own and the family's - by taking the much-needed compassionate action of opening hard conversations.

An Attitude of Honouring Shared Humanity

Underlying many of the ways of "opening the door" discussed thus far is an attitude of seeing people's humanity and, in light of that, treating people with respect and dignity. The healthcare environment in general and the intensive care environment in particular, tend to be dehumanising environments - treating patients as bodies with problems to be fixed instead of whole people. Scattered throughout the interviews were many uses of phrases similar to "treat them like a human," "every person is valuable," and "what would I want if that was me?" Participants' use of these phrases revealed an underlying belief that on the singular basis of someone being a human, people deserve to be treated with compassion. Actions described as compassionate were often represented as reflecting this sense of shared humanity.

A few participants described compassion as "the human side of nursing." They often drew a contrast between an attitude focused on tasks and a compassionate attitude that saw

the patient and family as humans. In some cases, like the example earlier, understanding the context of a person helped participants see them as human. In other examples the underlying belief that all humans are worthy of being treated with dignity and respect prompted participants to want to better understand their context. In either case, being aware of a patient's humanity was expressed through actions themselves and the way in which those actions were done. Participants emphasised gentleness and tenderness throughout stories of nurses stroking an infant's head, snuggling them, rocking them, reading them stories, holding their hands, and "being very loving" toward patients. All of these actions attempted to recognise the child as more than a body - as a person who needs love and interaction. Avery shared her observation of the actions of a compassionate mentor nurse:

> She would always speak to her intubated patients. She taught me gentleness and to, regardless of the state of that person, to *really* respect their dignity. And explaining everything that we were doing, especially painful procedures. … Always [having] an attitude that… we can make assumptions about what they experience and what they don't, but we're not going to. We're going to treat them with so much respect and dignity, and as they wake up, that continues regardless [of the patient's cognitive awareness], make sure to be so gentle and careful…. A huge part of kindness and compassion is just to say "I see you. You matter." Even if they're not awake, to still maintain that. And if they are awake, it doesn't matter.… Regardless of their outward identity, are we acknowledging and respecting them and giving them that dignity, that basic human right. To be seen – and it doesn't take much for somebody to feel that respect from you – that's the basis of any compassion is that you value that person for who they are.

Although Avery acknowledged that "the ICU can be so inhumane," behaving in this way toward patients helped restore their human dignity. Participants reflected that seeing patients as fellow human beings prompts nurses to find ways to show them that

they are seen, known, and respected – to show compassion. When nurses are able to shift from a mindset of getting the tasks done to an attitude that says "I see you. You matter," that invites patients and families to open up as their deep human need of being seen and respected is met. Hayley shared the following example of how protecting a patient's privacy helped the mother be willing to open up and start talking with her.

> Mom made a comment about 'I really like how you do that, that's really respectful toward her' [by keeping the patient covered as much as possible during an in/out catheter]. I was like oh, [I'm] just doing my job.… Then mom started opening up a bit and … started to share about how she was really struggling…. I don't think we intentionally leave the curtains open when we're doing private things, we just don't pay attention to that. We get in our task-focused mode.… [we] forget that it's a person.

Hayley felt she was 'just doing her job,' but she had developed the habit of inserting a catheter in a way that respected the dignity of patients by protecting their privacy. The mom noticed that Hayley's manner was respectful to the patient. This *way* of doing a task was an act of compassion. For Hayley, it was no longer something she had to think about - compassion had become her usual practice, but the action was still impactful to the family. The attitude of respect that Hayley showed to the patient, even without consciously thinking about it in that moment, helped the mother open up in a way that she had not with other nurses.

Some participants shared that despite sustained effort to understand certain patients or family members, "sometimes you just don't like your patient." In these situations, nurses looked to the patient's humanity as the basis on which the child still deserved to be treated with dignity and respect. Like the example above, when practices that show compassion are an established habit in the practice of a nurse, it becomes much easier to continue those practices in difficult situations. Nurses develop habits of actions, like talking to a patient or protecting privacy during

catheter insertion, but they also develop habits of attitude. Reagan gave the following example of his habitual attitude for engaging with patients.

> I really try to leave how I personally feel about that child and family at the door. While I'm taking care of that family, I'm 100% committed to that child, making their experiences the best I can…. I take a deep breath, and [say to myself] 'okay, let's go.' … It's not fair to that child to treat them any differently as you would any other child. And some days it's harder than others. And sometimes you just have to close the door and chart on the outside of the room for a bit. But you just do it.

In many examples, like this one, being inside or outside of the physical room was intertwined with being inside or outside the metaphorical room. In situations where it was more challenging to maintain an open attitude and be present with the family emotionally, it was often also more difficult to be in the room physically. Even in difficult situations, participants expressed that every human deserves to be treated with dignity - it is not dependent on liking someone. Behaving in a way that honours the patient as a fellow human is compassionate and humanising, and it helps patients and families be willing to open up.

Many participants used some variation of the question "what would I want if that was me?" to identify compassionate actions. This question is rooted in an understanding that both the nurse and the patient are humans - "trying to connect with them on a human level" as Reagan called it. In the introductions section, we discussed looking for common ground in interests or experiences but in this theme, there is an underlying assumption that there is a shared experience of being human. Common ground can be found on the basis of humanity even between people who are very different, and this gave participants insight into how to treat patients and families with compassion in every situation. Kelly expressed it this way

> I say "treat everybody how you would treat your mom," because I treat my mom a lot better than I treat myself, then that kind of grounds your practice. If you treat

> everybody like your mom, … you're going to acknowledge "oh, my mom's probably freaked out, and this would be happening to her right now" and so maybe let's take a little extra time to explain it.

An attitude of treating a patient like a loved one grounds nursing practice in honouring shared humanity - even without knowing a person. Practically, this attitude also prompted excellence in practice through seemingly small things like being sure that small details in medication administration are done correctly. The careful attention to detail in some examples was a way that participants described their belief in the inherent value of that human patient and their desire for the wellbeing of that person influencing their actions. For some participants, excellence in these task aspects of clinical practice can also be seen as an expression of compassion.

The idea of *shared* humanity respects the patient's human dignity by drawing on one's own humanity. In order to reflect on what one would want in a situation, one is required to mentally put oneself in that situation - in many cases, that requires imagining oneself in horrific situations. Facing the humanity in another person who is facing death or the death of their child can be painful because, as humanity is shared, it also points to the uncomfortable fragility of one's own life and one's own lack of control. Laura expressed it this way:

> Working where we work makes me think always about how thankful and grateful I am for each moment and try not to get too hung up on, no matter how protective I am or careful I am, things can still blow up. And no matter how risky, you are never going to be safe. I felt that especially when I got pregnant. I was very scared of miscarriage; I was very scared of the next step. Once I hit the second trimester, I was like "I can breathe now!" but then I still couldn't breathe because then I was scared of anatomy scans and late term loss and so on. And then I realised once you birth your child, you're still never safe, so just leaning in to the unknown. Leaning into being thankful for the day you have. Being grateful, but

> just like each day knowing it could all be taken away … you realise you could be in a terrible terrible car accident and just kind of walk away from it or you can have one little slip and fall and you can be brain dead. And just it all is so.. You have no control.

Part of being human is the unknown; is the lack of control. In PICUs, nurses see this reality every day. Participants, like Laura, reflected on how experiences as PICU nurses impacted their experiences of motherhood. Facing the uncertainty of human life cannot be boxed up and left at work. It shapes people as nurses and humans; it impacts how nurses live their own lives even outside of clinical practice. This reality can be difficult for nurses in PICUs, but it also helps better understand patients and families as they find themselves face this sobering reality in a new way, or possibly for the first time. As participants reflected on their own humanity, many shared an approach similar to that shown by Laura in this next quote.

> Give yourself grace to feel sad and give yourself grace to feel upset and angry… people get so hung up on feeling bad about how they feel or feeling insecure about how you felt. Maybe you [should] just let yourself feel it and not beat yourself up about how you felt. Then maybe you can go through that experience a bit more gracefully. And I think that's what we see too with families who have tragedy but they're graceful about it because they're not questioning how they feel, they're just allowing themselves to feel it.

Being compassionate in the midst of hard days, hard situations, and hard emotions can often be painful. Then, out of the sense of one's own humanity, one is able to treat patients and family in a way that honours their humanity too; able to treat them with value and dignity. Avery explained her awareness of a person's value, as connected to taking action to lighten their suffering: "Every person is valuable – I'm going to make them all smile." While smiling may not always be possible in the PICU, having this attitude helps nurses *look* for ways to brighten that patient or family's day - ways to show compassion.

For nurses, as fellow humans, sometimes an act of compassion toward another person can involve the act of adjusting one's own attitude. In a context where tensions are high and situations are heartbreaking, attitudes of understanding, courage, and honouring shared humanity help nurses engage compassionately with patients and families.

This chapter has focused on a variety of ways that nurses enact compassion in PICUs. Introductions, making an offer, and adjusting one's own attitude are all ways of enacting compassion that have been framed as part of opening a metaphorical door. So, then, what is on the other side of that door? What happens once the door is opened?

Chapter 4: Inside

In the previous section, we explored the ways that nurses show compassion by opening the physical and metaphorical door to connect with patients and families in PICUs. Although both the nurse and the patient/family participate in opening the door, it is the nurse who walks through the door and enters in to the space of the patient. Even though the family is unlikely to prevent the nurse from physically entering the room, they may very well remain closed emotionally and be unwilling to share themselves and their experience with the nurse. Once the patient opens up, the nurse is able to enter the inside space. This section will first explore what the metaphorical inside space, and then explore five overarching themes encapsulating ways in which participants described enacting compassion within the inside space.

To step “inside” is to step into the experience of the patient or family with them. Examples given by participants included both physical and metaphorical ideas of the space where patients and families are. In the physical sense, it often meant stepping into the physical room. In the metaphorical sense, it meant stepping into the patient or family’s experience with them. The phrase “meeting them where they’re at” stood out; every single participant used this phrase at least once to describe how to be compassionate. This phrase, like the metaphor of opening the door and being inside, uses language of location. It assumes a *place* in which the patient and family can be met.

In order to meet someone in the place where they are, one needs to understand *where* to meet them. Unless the nurse has some understanding of the place in which the family is, it may be difficult to step into that space. The place in which the patient or family is also changes constantly. As the place in which the family is situated changes over time, the nurse needs to remain attentive to where they are at and continue stepping into their current experience. Even families who at first glance seem to be in the same situation, will likely experience it differently and therefore potentially be in a different metaphorical place. Additionally, as mentioned in the

Opening the Door chapter, the process of opening the door and stepping inside is always ongoing - there may always be some part of the experience of the patient or family into which the nurse has not and cannot enter. This next excerpt is just one of many examples in which participants adjusted their response based on the response of the family so that they could remain in the same place as the family. Kelly shared as follows:

> I hadn't taken care of that patient in a couple of weeks…. The last time I'd taken care of her, she got extubated…. I had heard through the grapevine she got intubated and ended up going down the trach route. [The next time] I took care of them, the parents came in at 7:15, but I genuinely wanted to hear about their experience: "what happened? What led to this route? I know it's been a couple weeks…" Having a previous relationship with them made it a bit easier…. Families kind of grow on you, so I genuinely was like 'ooh, that sucks.' And they're like 'no, we're okay with it because this just means like this is one step closer to the next milestones' and I said 'fair, that's awesome.'"

In this situation, Kelly stepped into what she thought was the place where parents were based on previous conversations. Once she brought up the topic, though, she allowed the parents' response to re-shape her understanding of the place in which they were. Instead of parents being upset or disappointed by the patient having a tracheostomy as she anticipated, they viewed it as a step forward that could be celebrated. Kelly was then able to celebrate with them and be 'inside' their positive experience of moving forward. Since the child's tracheostomy turned out to be positive for the family, it might not be considered compassion because compassion refers specifically to suffering with another person and the family did not experience the tracheostomy as suffering. However, Kelly adjusted her response to remain in the same place as the family. She anticipated a need for compassion because she knew getting a tracheostomy had been a hard topic for the family in the past. Kelly's example of continuing to stay attentive to the place in which the family was helped her stay present with them in their

experience. Ongoing attention to the place in which the family is allows the nurse to be able to step inside that place. Wherever the patient or family is, that is the space in which the nurse meets them.

Much of the time in PICUs, patients and families are experiencing some of their hardest days. It is often stressful, overwhelming, terrifying, confusing, and even devastating. These hard places can be particularly difficult for nurses to choose to step into, but they are also the spaces in which there is suffering that invites a compassionate response with intent to alleviate that suffering. Just as each person is unique, so too is their experience of suffering. Participants shared their insights into what this inside space is like and the experience of being in it. Avery described the impact of being forced into an uncomfortable situation can prompt people to pay attention to life and to ask existential questions normally left unacknowledged.

> We have a culture that's so focused on comfort that we don't necessarily pay attention to who we are and where we are…. But then in these moments where somebody's really sick and you're in the hospital, it somehow makes you so present and you have to face it…. It doesn't matter what you do for work, or how healthy you are, or really anything, because the moment your child is sick and you're in the ICU, none of those things really matter.

Participants shared that many of the things that fill people's lives seem to fade into the background and may even seem meaningless when one is facing the loss of one's child. Patients and families often feel vulnerable as usual coping mechanisms and routines are stripped away which can prompt deep questions of meaning, identity, and purpose. Laura described being in this space as a vortex of uncertainty with uncomfortable dark emotions - a space that nurses hold and sit in with patients and families. This is a different type of suffering than post-op pain, as this pain cannot be treated with medication. Nurses often have the unique privilege of being present with patients and families in those painful inside spaces. Avery

described an overarching description of the way a nurse might enact compassion in such a space.

> Helping people be comfortable in the, maybe not even comfortable in that space, but introducing people to the space where the suffering of living is…. Compassion is a huge piece about allowing people to be in that space and helping them to be in that space.

This quote provides an apt description of this inside space: “the space in which the suffering of living is.” This is the space into which nurses step with families and in which nurses suffer with patients and families. As much as people may prefer to avoid it, some suffering is inherent in human life. While this may seem bleak, it is also very real. Nurses enact compassion by being inside this suffering space of patients and families with them.

Compassion is, however, defined as taking action to alleviate suffering in addition to suffering with another person. As participants suffered with patients and families, they gained a lived understanding that was more than a cognitive understanding of the suffering. That deep understanding, in combination with experience and perspective led nurses to compassionate actions for each patient’s unique suffering. Hayley reflected that “oftentimes, people don’t know what they need when it comes to compassion. If we can recognize a need and try to give that to them, then they feel a sense of respect and dignity but also love.” As she reflected further on the experience of suffering, Kelly described a relationship between understanding a patient’s unique suffering and how a nurse might enact compassion in a way that is tailored to the situation.

> Suffering is feeling distressed, alone, worried, scared and by showing types of compassion and communicating and caring, you can help alleviate those feelings of suffering. It would depend on the person’s experience of suffering too. I go back to the simplest thing like a bed bath. Is the family having a hard time because they haven’t been able to hold their kid in how many weeks? And can I help provide that? To me compassion is filling the needs of the suffering. Is it a

> kid who's passing away, parents are suffering because they're already grieving, they're grieving the loss of life, they're grieving their thoughts [of] the life that they had envisioned for their kid. So how do you care for that? I think compassion is assessing the suffering and then providing caring tasks, or not, maybe they just need to be alone, or maybe they need someone to listen, or maybe they just need that extra uninterrupted time because their kid's entire life has been in the hospital and they *just* want time with their kid without someone walking in and out the door all day.

People are often unfamiliar with this space of suffering and, if permitted, nurses can enter in and be with families in that painful space. From that position beside the patient and family - inside the suffering with them - nurses can offer unique actions to support them in their suffering. All of the ways of enacting compassion in this section focus on meeting the patient and family where they are, and just as there are different aspects of a physical room such as the lighting or the furniture, so too are there different aspects of the metaphorical place where people are, and therefore different ways of meeting them in that place. This remainder of this section will explore how nurses can enact compassion through providing emotional nourishment, guiding, creating calm, comforting physical touch, and being present.

Emotional Nourishment

Emotions are an important part of the place in which a person is. Patients and families in PICUs experience a wide range of emotions from complete devastation over unexpected death to elation at unexpected recovery and everything in between. Laura described this emotional aspect of enacting compassion as "like an emotional nourishment." She went on to explain:

> Feeding people is always so important to me and hosting them and giving them nourishment and healthy food and loving them that way. So I think that compassion seems like loving them in a different way - like giving them that kind of emotional nourishment.

Like our physical bodies need the nourishment of healthy food and the provision of that is a way of loving them, so too is “emotional nourishment” a much-needed way for nurses to fulfil the emotional needs of patients and families. Reagan similarly described compassion as “acknowledging feeling and emotion, … showing emotion toward someone in understanding.” This section will focus on the emotional nourishment nurses give to patients and families in PICUs as acts of compassion.

Participants gave many examples of compassion that highlighted how they and others engaged with the emotions of patients and families. They often gave examples of dismissing a patient or family’s emotions as uncompassionate, and then provided compassionate counter-examples that entered into those hard emotions with the patient or family member. Jamie gave an example of quietly giving her four-year-old patient a pep-talk, saying “you’ve got this, you can do it, I know you’re strong, you’ve been through this before.” This kind of encouragement is vastly different to dismissing the child’s emotions; it instead acknowledges. Participants observed that patients and families seemed to experience some relief when their valid emotions were acknowledged and understood instead of dismissed or silenced. Acknowledging the emotions of a patient or family is one action through which participants described showing compassion. In the following instance, Jamie provided an example of how she enacted compassion with a patient who needed to mobilise.

> I was like “today you’re getting up and walking, you don’t have a choice.” The compassion [is] shown that way if it’s like “I know this is hard, I’m sorry it’s hard. We’re still doing it. You can not like it. And I know that it’s hard, but it’s still going to happen.” Not to say “oh it’s not a big deal, you’re fine.” [But instead to say] “I get that, I get that you don’t want to do this, I get you’re scared. You still have to do it.

This act of acknowledging that it was hard and scary demonstrated understanding according to participants. To say that something “it is not a big deal” or “you’re fine” was felt to silence the person who was experiencing something that was hard for them. There were,

however, examples where *first* acknowledging the patient's emotions then allowed the nurse to provide encouragement or direction such as "I know this is scary, but you are going to be okay." Like in other examples, Jamie did not allow the patient's fear or it being "hard" prevent much-need mobilisation, but her acknowledgement of the patient's feelings expressed compassion and transformed the experience for the patient. As Avery said, "just that acknowledgement of where that person is at goes a long way for them to feel cared for." In this next example, Jamie showed how her understanding of the place the patient was in emotionally shaped her response.

> She really wanted us all to have a Strawberry Frappuccino. Her parents bought something else and she was so upset because they didn't bring the things she asked for…. The other nurse, who was her nurse, was like "ooh, it's fine…. This is a really good drink, we don't mind." … But I knew that this [is not] what she wanted us to have… so I was like "I wish I would've gotten a strawberry frappuccino, that was such a good choice, I wouldn't choose to get this" and the patient was nodding…. I just recognized: [that] to her it was a big deal because she couldn't go down there and buy her nurses the drinks herself and that's what *she* wanted *us* to have…. [I thought about] why *is* she upset? She's upset because she hasn't left this room and she loves her nurses and she wanted us to have a treat, but she wanted to pick the treat because it's from her and then she didn't even get that one small thing she wanted to give us…. She [wanted to feel that she] had a choice and she didn't get that, and that's why she was upset. When they came up with not the strawberry frappuccinos, I remember her tearing up - she was *so* disappointed that they didn't get what she had asked them to get. And then [all the other nurses] were like "don't cry, it's fine." … but it's not about that…. I saw her face and how sad she was and I didn't want to minimise

> her disappointment. She had valid feelings and I knew where they were coming from.

The way Jamie responded reflected a deep understanding of the patient's experience. In response to the child's disappointment, others tried to dismiss her negative emotions by saying they liked the drink they had been given. Jamie, however, saw that those responses minimised and dismissed the patient's feelings which unintentionally upset the patient more. She understood where those valid feelings were coming from: it was not about the drink, it was about control. Instead of dismissing the emotions, Jamie put herself inside the experience with the child and expressed similar feelings of disappointment; she validated the child's feelings. This response supported the child emotionally and served to alleviate the child's disappointment. Jamie validated that the gift that the patient had wanted to give would have been a good gift - that the things *she* wanted were indeed important.

It can sometimes be difficult for nurses to see beyond relieving a child's disappointment as quickly as possible but this example, like others, reflects that deeper emotional needs are often present. Distraction or dismissing those emotions can sometimes worsen the suffering because the person remains alone in those emotions, feeling misunderstood on top of the existing feelings. Identifying these emotions can be difficult for patients and families, but as nurses, acknowledging and validating the emotional place someone is in is compassion. Sometimes people feel self-conscious about the way they are expressing their emotions or even the emotions they are feeling, so normalising people's responses is another way nurses can enact compassion. Laura reflected as follows:

> [Families] get self-conscious and [our role is] reminding them this is normal…. crying is totally normal and not crying is totally normal… just validating whatever your experience is…. Not that many people go through it, but we see it at least sometimes. We can help normalise it for them whereas their family and friends will not be able to normalise that for them. We are probably the only people

> outside of social work and therapists who will actually be able to say “this is totally the right response for you. This is exactly normal and okay whether you’re totally paralyzed with fear or smiling about happy memories or collapsed on the floor, they’re all just variations of normal.”

PICU nurses are in a unique role of walking through these situations with a variety of families and are therefore able to support families by validating and normalising their emotional responses. In contrast to other health professionals such as therapists or social workers, nurses support families in real time, as powerful emotions and experiences are unfolding in the moment. Nurses, however, are part of these tragic moments *with* families. In contrast to other medical professionals, bedside nurses in the PICU focus solely on one patient and family which allows them to be present for the moments of recounting memories or collapsing on the floor. Nurses provided the needed emotional support in these moments by validating and normalising the emotional experiences of families and patients. In this next example, Laura again did not dismiss the hard feelings of guilt. She went beyond even normalising and instead stepped further into the feelings of guilt with the father in a way that ultimately helped relieve guilt.

> This one parent said “My child wanted to do blank before bed and if I would’ve said no, he would’ve still been alive.” And I said “but you said yes. And you gave your kid exactly what they wanted. And they got to have the exact thing they wanted to do with their father before they passed away. And we don’t know, they could have passed away in their sleep, they would have not had that [experience of doing the thing they wanted to do with their father]. How terrible, but also how beautiful that you were able to give your child this one thing that they really wanted.”... It’s so hard to … sit in that and then relieve some of the guilt. There’s nothing most people can say in those moments. There’s not much that you can say to say “it’s not your fault” and that’s so weak. To say “it’s not your fault,” it doesn’t hold a lot of weight. But to say “and what if you wouldn’t have done that?

> Maybe everything would have still happened the same way and you would have missed out on this beautiful option - you would have missed out on this beautiful moment [of playing together] that you had."

Laura did not dismiss the father's question of "what if…?" She gave him space to ask it and sat in that guilt with him. Instead of giving a trite response of "it's not your fault," she was able to relieve some of the father's guilt by helping re-frame and remember the special time they had playing together. Acknowledging, validating, normalising, and encouraging are just a few examples, but these ways of enacting compassion provide much-needed "emotional nourishment" to patients and families in the midst of their suffering.

Compassionate Guiding

Another way of enacting compassion that participants described was guiding patients and families along their healthcare journey. The language of place or location was peppered throughout descriptions of how nurses enact compassion in PICUs. The place in which patients and families are is ever-changing. As nurses meet patients and families in the place where they are, there is often a need for nurses to guide patients by helping them understand the place in which they are and the path in front of them. The language of healthcare as a journey was often used by participants and this section will explore how nurses can enact compassion by guiding patients and families along their journey - walking with them the place where they are to whatever the next place might be. Avery described the act of guiding in this way:

> [None] of us like to feel helpless. We don't know which way is up. It's so discombobulating when you end up in the hospital…. Part of seeing who they are, having compassion, preserving dignity, is being like: I see you. And now let me help you locate yourself in this…. The parents of a brand new baby [feel like]: what's going on? So much is happening! Then [my response] is like "here's our little starting box. And then from there you can take steps as things start to progress and [you] understand more." … It's like "this is where you are on a map

> and here's the trail…. If you choose 'A', this is what the topography is like, these are the hazards you should expect to face, this is more likely the weather pattern." You can help orient people to their options.

Many of the examples of compassion thus far have focused on the nurses understanding the unique position and experience of each family. Nurses, however, also carry pertinent understanding about the clinical and emotional journey that may be ahead of the patients and families. Often, this is the first time this family has been in this situation, but nurses have likely had the experience of walking with other families through similar situations. When things are overwhelming and disorienting for families, nurses who understand the "landscape" of the illness and hospitalisation can help families understand the place in which they are and the path ahead. In this next example, Hayley had spent a lot of time with this family in the preceding weeks and noticed a change in the mother's attitude which allowed her to provide much-needed guidance.

> One night I could sense in the room [that] something was off [with mom] - it was bad vibes. [I thought]: She's been living at the bedside for months, she just needs to get a break…. So I said to mom "I'm going to make you a hot chocolate, you're going to go down to the healing garden, we're going to do the bedtime routine, and then you're going to come back and go to sleep." Because I had been there for so long and knew how parents liked [things done], the mom burst into tears. She was like "you think I'm losing it, don't you?" and I was like "I think this is an unimaginable situation that you've been put in and you have been here for [two months], and I think you need a break. You need to take care of yourself because this is a marathon and you're treating it like a sprint." She [agreed]. … When she came back from having that break, she was [much more positive] to interact with.

Hayley had an intimate knowledge of the unique patient situation: the patient's bedtime routine, the mother's priorities in care, and even the nature of the mother's struggle. She also brought knowledge of the marathon journey ahead of this family, the tendency of parents to not give themselves the care they need to continue on that journey, some of the ways parents tend to behave when they need a break, and ways families do take breaks. With these pieces of knowledge, Hayley helped this mother locate herself - in a place not of losing it but of needing a break. She also helped orient the mother to the long, difficult, marathon-like journey ahead that required pacing and endurance. By taking charge, doing the parts of the bedtime routine that were important to mom, and providing direction, Hayley guided this mom through feeling like she was "losing it." This mother's emotional and physical suffering was alleviated through Hayley's hot chocolate and guidance. This is just one example, but it shows how the nurse integrates a wide variety of information in the action of guiding.

Most participants, like Hayley, identified a need for guidance through noticing body language, intuition, and understanding the context. Many parents do not know how involved they are allowed to be in PICUs, especially at the beginning. They may not know how to change a diaper when their child is attached to a tangled spaghetti-like mess of monitoring cords and intravenous lines - or if that is even allowed; they may not know whether or not their child is stable enough to be held; they likely recognise when their child needs urgent interventions, but they often do not know what their place is in that situation or even where to physically stand so they will not be in the way. Examples participants gave of guidance were often in practical matters like these. In the case of families with children who have chronic illnesses and are accustomed to being in the PICU this type of guidance may not be needed, but participants emphasised that explaining and talking through what is happening is still important even if it is not new to families or patients. Providing ongoing guidance about what is happening and what might happen next helps alleviate anxiety for patients and families and was consistently part of how participants described compassion in the PICU setting.

Like the mother in the example above, participants gave many examples in which patients and families did not know what they needed, often reflecting that the loss of one's child is something a parent typically dares not think of. Laura, like other participants, reflected that "so many people … don't even have the brain capacity to think of what they need until you say it sometimes." Families often do not know how to interpret things like vital sign changes that indicate that the end of the child's life is imminent. Laura gave a number of examples of how she has guided parents through the rough terrain of the end of their child's life:

> Saying 'this is the time' if you think that it's a good moment where [the child] is stable, encouraging [parents] to take a [break]…. Or you see a vital signs change and you say "now is the time to call your family and friends." … "Now is the time to not be leaving the room just in case something happens" because you would never want to encourage a family member to go shower and then have the child pass away… but also giving permission for them to go to the bathroom and not be afraid that they left at the wrong time…. To give compassion – to read what they need in that moment… and offering what they're really looking for.

These examples highlight the knowledge the nurse has of the clinical and the emotional situation. Participants emphasised identifying what people really needed and were looking for especially when they themselves did not know. Laura recognised, for example, the fear parents had of leaving at the wrong time and guided them as to when and how to meet their basic needs in the midst of their grieving process. Although she used the word "offering" which echoes the theme "making an offer" in the previous chapter, her examples were offers of guidance. The things she said were aimed at guiding people through the process of saying good-bye to their child, not at opening up a relationship. Laura went on to give another vivid example of giving practical guidance to families through the process of the end of the life of their child.

> Guiding some of that… can be so powerful so they get those experiences that they didn't even know they should ask for…. I had a friend [who's newborn baby

> passed away] …One of her biggest things was “I never saw my child’s bum. I never got to inspect every inch of her … I got to hold her, I got to do some things, but I really regret that I didn’t get to love on every piece of her” which I would’ve never really thought about, but perhaps if there’s a moment I might say “do you want to bathe your child?” or “do you want to inspect her little fingers right now?” … might take more moments to say “should we take some photos? … What’s powerful?” Because they won’t even think about it until later. They will probably always have more regrets, but giving them the opportunity to have hand prints or keepsakes is helpful…. Three days is nothing when you’ve carried that child for nine months, and had expected … a whole lifetime for them…. They don’t even know what’s possible.

Making memories by giving a bath, preserving memories by taking photos, and inviting other family members to be present are things parents may not think of. Laura, again, gave an example of seeing a bigger picture of the journey ahead of the parents, considering what might be powerful to them in the coming years as they grieved their child and trying to give them those memories and keepsakes. With the guidance of a nurse who has learned from walking the same path with other families, things that would have been regrets of “I wish I had…” can be memories and mementos. Parents can have the opportunity to inspect every inch of their baby in the three precious days they had. Participants gave many examples that similarly integrated their knowledge of what was happening medically with what was important to the family and what would be important in the future to guide parents through what they did not even know was possible and what they did not know they needed.

One last example of guiding is from Avery. In a unique but similar way, she guided this family to meet their specific needs – the needs of both the patient and the father. Avery wove together her overarching goal described in her initial introduction with the family’s background and their behaviours she noticed clinically. All of that then informed the actions she then took,

and the outcome of those actions that then reaffirmed the impact this act of guiding had on the patient and family. At the conclusion, Avery described the insight that this particular situation gave her into the need families and patients have for guidance.

> Giving some sort of that direction and purpose [to the family] as part of the team and saying "This is your job, this is your role." Trying to include them in that *is* compassionate and empowering – it's both. It just is like "you matter here. And without you, we couldn't give this care." I remember this one dad: they're refugees and he didn't have work and he was just having a really hard time. His daughter would be okay for a bit and then she'd start looking over – lots! And she'd be like "where is my dad?" and "he's not here." He was just on the [parent cot bedside the patient bed], and she would get this sad lip…. I went up to her dad who had been napping for a few hours and probably didn't sleep much at night because it's the ICU, but I said "hey, she really needs you. Can you hold her?" And he held her for a few hours and she fell asleep in his lap. [There was] just this big grin, and this is a kid who's been in the hospital way too much and just [has] a flat affect, [is] not really interested in engaging with me as the nurse. [She had] a big grin when her dad picked her up. And then he had this big grin. And then the next day he was standing up more at the bedside and he helped me change the diapers and he just started to do these little things and they didn't stay in PICU long after that. I was like man, he needed a job! Which is a really funny thing – he needed that empowerment; to be seen for who he could be in this situation. Being in the hospital's so disempowering. Oddly enough, people need a job – and that's compassionate. You need a place, you need to know how to be there because it's so unlike the rest of our lives.

It was compassionate to give this father the job he so needed – it was compassionate to the father and to the daughter who longed for his attention. Often, patients and families are in a

place of overwhelm. The guidance of a nurse can help them understand where they are and the path ahead. A nurse's compassionate guidance is coming alongside patients and families in the midst of their difficult journeys, walking with them, and helping them find their way forward.

Be the Calm in their Storm

Compassion is not only enacted in the relationship with the patient or family, but also in the physical space inside the patient room. Participants spoke about the prevalent experiences of stress and anxiety among patients and families in PICUs. As Kelly reflected, "suffering is feeling distressed, alone, worried, and scared and by showing compassion, … you can help alleviate those feelings of suffering." While the other themes focus on interacting directly with the patient and/or family which include ways of alleviating anxiety, this theme focuses on how nurses actively shape the environment inside the room to create a calm environment that alleviates some of the suffering from stress. Jamie shared the following reflection on how the demeanour of the nurse impacts the patient and family's experience.

> If you're not calm, your patient's not going to be calm, your family's not going to be calm. Humans are wired to sense stress – humans and animals. Our survival depends on it; it's instinctual. So if you come in not calm, it will be apparent…. You have to be the calm in their storm because you're the person they're looking to to keep calm in the room.

The place in which patients and families are was described as often being stormy. It can be chaotic, fear-filled, and overwhelming. In that place, families look to nurses to keep calm in the room which included nurses keeping themselves calm but also tending to the physical environment of the room to ensure that the room is a space that facilitates calm. Reagan described compassion this way:

> Just simple things like making your kid look good in bed. It doesn't have to be this grandiose end-of-life experience. Sometimes it's just the little things that make a really big difference to a lot of people in showing compassion… If the kid

> has hair, I'll put a barrette in their hair and I actually keep … random stuff like barrettes and little hair ties or little slippers or little socks…. I'll go get one of the donated [handmade quilts] and tuck it into the end of the bed and tuck the kid in nicely and it's not all dishevelled. Sometimes the kid moves and they're psycho two seconds later, but you still try. You just lay the blanket on them cute or you wrap them nicely and bundle them up well and clean the sheets if there's stuff on them. [There are situations when] it's not really safe, but [most of the time] just clean the sheets! Clean out that NG canister that's rotting in the corner even though it's not full.… You can make the lines look neat, you can organise your bedside cart. In general a lot of people find calm when it's clean and organized.… Clean, tidy environments are comforting for people [and] the family's a lot calmer when things are neat and tidy.

This quote contains many specific examples of actions nurses take to create a calm environment which is comforting. Reagan, like other participants, emphasised keeping the patients themselves neat and tidy, as much as possible, and adding small, personalized touches like quilts or barrettes when appropriate. These small actions rely on paying attention to the details in the environment around the patient to identify ways to make the space more calming for those in it – it is a way of enacting compassion that involves being engaged in the physical space and not only focusing on tasks that need to be done.

Through examples given by participants, the responsibility of the nurse to establish a calm environment inside the patient's room sometimes required an active role of advocacy. In some examples, the nurse took the role of gate-keeper to keep certain conversations outside the room or to prevent interruptions during a much-needed quiet time. This next exemplar shows how Reagan has learned to engage with parents who were fighting in a way that protected a calm environment for the child.

> If the mom and dad are fighting and arguing… I will ask them to leave. I saw a child actively withdraw into themselves a little bit more while their family was… fighting…. So now I just tell families: … 'this is a place of healing, this isn't an appropriate conversation to have. If you want to argue, please leave.' … I think they're just so in crisis, they don't even realise they're doing it in a way that's affecting the environment…. [I'll acknowledge] "I understand you're in a very stressful situation and you're dealing with a lot, but having an argument in here [is not appropriate]... It should be [a] calming [place]." … Before that I would've just left the room, closed the door. Whereas now, I'm like that's not okay because we have to advocate for our patients because sometimes they can't advocate for themselves.

There were many examples that highlighted the need patients and families both have for a calm environment. In most examples, the actions participants took helped the patient and the family both become more calm. In a few examples, similar to this one, the family had a difficult time being calm which negatively impacted the child. In these situations, nurses expressed a responsibility to protect the well-being of the patient which sometimes meant, if the behaviour persisted, asking the parent to step out until they could engage in a calm way. These examples were communicated as unusual exceptions in which the patient was awake and impacted by the behaviour of the parents, but they were notable and brought to the forefront how what is happening in the room impacts the well-being of the patient.

Participants also gave counter examples in which families who had spent a lot of time in the PICU were sometimes unexpectedly calm in a given situation. Even if the situation was life-threatening, some families were so familiar with what was happening that they were able to stay calm. Helping families understand what was happening was another key way participants enacted compassion that helped maintain a calm environment in the room. This was often done in a way that modelled calm to the parents and helped them regain their own calm. Participants

explained that being aware of the atmosphere in the room helped them enact compassion by establishing and maintaining the calm they knew their patient needed.

Participants often reiterated the importance of their own way of being in the room – that just as parents impact the environment in the room, so too do nurses. By remaining calm themselves, nurses were better positioned to bring comfort to patients and families. In the first quote of this section, Jamie described calm as something families look to the nurse to *be,* not to provide. In other words, calm does not seem to be something that is given or done, but a way of being and it is part of a compassionate way of being inside the room. Participants also shared strategies they used for maintaining their own calm such as taking a big deep breath. Jamie shared further in the following quote about how she navigates stressful situations in a way that helps her maintain calm.

> One of my mantras is 'I can only do one thing at once.' [even] when there's a million things going on…. And you can only do one thing effectively if you're only thinking about one thing. So I remember days where it's like 'do a blood gas, start epi, start norepi, push roc…' And I can only do one of those things. And sometimes I'll say 'what do you want first?' And then just do that one thing and just think about that one thing because it's so easy to get distracted and that's when, for me, when I start to get overwhelmed, [I will say to myself] 'Okay. If I'm pushing volume, that's all I'm doing in this moment - this. moment. I'm just. giving. [this].' And then once that's given, then think about the next thing. And that keeps me. Things are not calm, but it's so important to stay calm…. There's never a situation where it's not good just to be calm.

Even when the situation is not calm, using strategies like those described by Jamie can help the nurse stay calm and, in turn, help the family and patient stay calm. The reciprocal nature of compassion is again highlighted here; the calm of the nurse and the family are tied together. A

calm nurse and a calm environment can move patients and families from a place of stormy terror to a place of calm, enacting compassion by relieving the suffering of anxiety.

Comforting Physical Touch

Physical touch is inherent to many of the actions that characterise nursing care from pulse checks to repositioning. Almost every participant gave examples of compassion that highlighted physical touch, and most of the examples highlighted touch that was not procedural or clinical but was instead more personal and comforting in nature.

Bathing patients was an example of enacting compassion that every participant gave. Even though bathing patients every night is required by policy, and leaving patients unbathed was alluded to as a lack of compassion, in most cases participants emphasised the way in which the bath was done as an expression of compassion. In this next exemplar, the patient needed a bath and the mother was missing holding her child. Involving family in giving the bath was also an expression of compassion, but take note of how Kelly described the way she gave this patient a bath.

> Me and the mom and grandma, we all just bathed the kid together. I got one of the donated jumpers and I went 'Look! He looks like a baby now!"... You get rid of the dirt, and you do their ears and their necks - everyone always forgets the neck folds and the ears - then you put the lotion on. It's just something nice; it's pampering. In an ICU, bed baths are necessary, but putting on the lotion and making them feel nice and taking extra good care of their skin…. It's not lifesaving, it's not epi or norepi, and I think sometimes we forget about that stuff and that shows compassion because it's still remembering again that they're human, that they're little babies…. It's about the details.

Kelly tied the aspects of bathing that were especially thorough or comforting to humanising the child. It was about more than the child not having been bathed in a few days - it was about treating him like a baby. Her detailed description showed the careful attention she

gave to every part of his body as an expression of compassion. Darcy also reflected on the experience of giving a bath to a patient and the deep sense of human connection this action can have even, perhaps especially, if the patient is unconscious.

> I think PM care [or bedtime care, which involves giving the patient a bath,] is a really good example. It's you and your patient in that moment. Especially in ICU where you might have patients who you aren't able to have conversations with, but it's those moments of care and those moments of calm and tenderness. That's when the compassion really comes out. … it really does come back to working with the patient. When you're braiding someone's hair or getting them fluffed and buffed for bed or you're doing a bed bath. It kind of re-centers you into why you came into the profession and how you show compassion for your patients.

Bathing is an experience, or place, into which nurses enter because of their role and it is personal and intimate in nature. It can be something deeply humanising that is "inside" the patient's physical personal space. To ensure someone is clean and well-cared for physically is to treat them in a way that is consistent with their human dignity. For Darcy, this awareness re-centered her to her identity and sense of purpose. The act of bathing a patient *and* the care and tenderness with which nurses undertake this responsibility is an important way of enacting compassion.

Bathing was just one of many examples of how nurses showed compassion through physical touch. Many of the other examples were more individualised to a patient or family member. As participants told these stories, they often described the situation in detail, situating their use of a hug or touch on the shoulder within an explanation of how the situation informed their use of that action. Reagan explained that after the first step of making a connection, or opening the door, his next step was to try to understand how that particular person wanted to

receive compassion. He gave the following exemplar of how he responded when he found something that comforted the patient.

> Sometimes a child just wants their hand held, that's all they want. I've literally pulled the bed as close to the computer as I possibly could, turned the kid around in the bed, and just held their hand while I charted all night and that's compassion to that child.

Whatever the source of the child's distress, Reagan identified that holding their hand helped alleviate the suffering. Because of this action, that patient was able to sleep through the night without being given additional sedation. It took effort and creativity on the part of Reagan to move the patient, the crib, and the computer to make it possible to hold the child's hand, charting one-handed for the night. It was an action, however, that brought the child comfort through physical touch.

Some participants recounted existing research that indicates that compassion in general and physical touch in particular improve patient outcomes and even decrease the amount of analgesia they require. While comforting patients and families through the use of physical touch is a practice supported by research, some participants also described a perception in the practice setting of physical touch being perceived as unprofessional or a boundary violation. Participants also shared examples of how they successfully implemented specific types of physical touch that have been shown through research to help patients, such as the deep pressure of a hug or the motion of rocking. Jamie shared the following reflection on how she enacts compassion with families.

> It can be something so simple like sitting beside a family in the room on the couch with them rather than on your computer. Just even for ten minutes, and putting your hand on their shoulder. It's hard because touch is so frowned upon by a lot of people, but it can be very therapeutic. We see it sometimes as a violation of a boundary, but to put your arm around someone, to give someone a

> hug, [is an act of compassion].... I'd always give a hug if I felt it would be welcomed. A lot of times I would ask. When I see people touching the patient or touching the parent, that's an act of compassion. Healing touch…. I don't ever think twice before I would give a hug, or stroke a patient's head, or hold their hand…. it's important for kids to be held when they're upset and at work, I do see a lot of touch. … Stroking their head, or holding their hand, rubbing their backs, or even doing your care like putting lotion on. The touch is important.

Despite the perceived tension, Jamie and other participants emphasised the therapeutic value of "healing touch" and its integral role as part of compassion. Physical touch can be a powerful act of compassion that meets a very real need. Just as every patient is different, so too is every nurse. Some participants expressed that they were not comfortable with giving a hug to patients or families, but found other ways of connecting like giving a high-five. To expect every nurse to do things the same way paradoxically dehumanises nurses. This section offers examples of how nurses have shown compassion, but they are not prescriptive - each situation, nurse, patient, and family is different. These examples and reflections are meant to support PICU nurses in developing their own practice of compassion and to perhaps challenge them to adapt their own practice to more effectively show compassion.

In this last narrative, Avery highlighted how powerful physical touch can be to bring comfort to a patient. Her decision to use physical touch in this situation was not without risk, but Avery drew on her knowledge of the nervous system and previous experience with this patient to enact much-needed compassion.

> I'll never forget this one girl who I had on her fourth time in our PICU for a suicide attempt. The second time, she hadn't been my patient but I was in the room next door and she had grabbed a blanket [to harm herself] … The resident asked if she could hug her from behind and gave her a hug around her shoulders. And that was the thing that calmed her down. Then on the fourth time she was with

> us, she … started banging her head against the side-rail. There was the option of medication, absolutely. But I asked her if I could give her a hug and I held her until she stopped trying to hurt herself and started sobbing, and then eventually calmed down.
>
> I'll never forget - that was so powerful…. That's one of the ways that we calm our nervous system down, and how much better does that feel - a hug - versus somebody giving you drugs and all of a sudden you're out of it. Not always will that be appropriate or the best thing, but what a different way, and … [it was] less traumatic for me…. it had a way better outcome for both of us.

This is a powerful picture of Avery suffering with this patient in her suffering and taking action to alleviate it. She contrasted providing a pharmacological intervention, with its sedation and many side effects, with the comfort of physical touch - a hug. She recognized that a hug may not always be appropriate and therefore asked the patient if it was okay to hug her. Avery reflected that for her as the nurse, using physical touch was much less traumatic than previous experiences of holding patients down and sedating them pharmacologically. Avery acknowledged that this approach was a greater physical risk to herself. And yet, she was willing to try it for the sake of the patient, saying "compassion is a risk." Her decision to show compassion this way was informed by the fact that she had seen it work in the past and by her understanding of the physiological benefit of gentle firm pressure. In this example, as in many others, being compassionate to patients benefited both the patient and the nurse which reflects the beautifully reciprocal benefit of compassion. Avery's exemplar shows what it can look like to enter inside a patient's suffering *with* them instead of only trying to remove the suffering from the outside. A seemingly simple action like giving a hug can make a profound impact on a patient or family.

Silent Presence

Sometimes there are no words. In situations where nurses feel helpless, to *stay* is one of the most important things. To stay in a way that is *with* patients and families in midst of their suffering is distinctly different from merely being next to them. Some of the examples in this section do use words, but the examples explore ways nurses shared in the experiences of patients or families; ways nurses sat with and engaged with them; ways of staying with the patient or family inside hard places. Avery provided an apt description of how this looks, how it feels for nurses, and how it can affect patients and families.

> We like to make things better. But some things are. just. hard. That's what compassion in those moments is: to acknowledge the hard and not try and make it better necessarily, but to be present. I think we struggle with that because it feels helpless, it feels like we're not doing anything. And yet, it's one of the most important things we can do, because to be alone in that, and to feel alone in that, and to be almost more lonely with somebody sitting right next to you is worse than just somebody being with you. Being like "my words won't make it better, but I am here."

Sometimes the space inside is just hard. Although it can sometimes be avoided by nurses, a compassionate action is stepping into the physical and emotional space and being present with the patient and family. Nurses can be physically present without bringing their whole selves - without being present with the patient and family in a meaningful way. Participants reflected that other professionals come for a conversation or event and then leave, but part of the unique role of nurses in the PICU setting is staying with families in their devastation even when the others leave. Although conversations about a difficult prognosis are typically had with the physician, Darcy shared that

> Patients and families can tell when you are really engaged and it makes them feel more comfortable with us, makes them feel more comfortable on the unit,

makes them feel as though you really care…. By allowing yourself to not put walls up when you get to work, it really elevates the patient experience. We're the ones who are there, and we don't have the option to walk away…. If they just had a really hard conversation with the physicians, the physicians leave. [The nurse is] probably the one who stays, or the one who walks in to check on them after. Even after a hard or frustrating conversation with a family to [let them know that] "I'm still here and I'm still open and still willing to be there for you and your child."

Being "*here*", being present, being *with* the patient and family was felt to be part of what it means to be compassionate - to suffer *with* them. In difficult situations as nurses are the ones who perform post-mortem care and accompany the patient to the morgue, nurses often, as Darcy said, "feel the emotions with the families" - sharing in their grief and sorrow. Participants gave many examples in which nurses stayed present and engaged instead of leaving the room in hard moments. Jamie offered the practical advice to "always have the tissues. Just to hand them the box when they get the bad news is an act of compassion. Sit with them." Through these actions of sitting with and staying, nurses show compassion.

It is not only end-of-life situations in which being present and engaged can transform a patient's experience. Participants cited neurobiological research supporting the importance of attentive care, especially for infants. They shared examples of patients in whom they could see a clinical improvement when chronic patients had the attention they needed, whether from particularly attentive nurses, volunteers, or family members. Avery described some ways she provides that much-needed attention to patients that were echoed by other participants.

Just [give] as much attention as you can give. Sometimes charting falls behind. I read books and I held them and I gave them a good bath and we changed outfits and got the volunteer in.… [Ask yourself] how do you love on a little kid for twelve hours, whatever that looks like? Reading. Holding. [With teenagers], talk, play a

> game like go-fish or something, and just listen…. It's really presence. Whatever's appropriate for that kid or that adult. So much of it is presence which is kind of a hard thing to teach.

Presence is more than being physically present and doing the tasks. The examples participants gave went far beyond sitting inside the room while focusing on their phone or the computer. Examples highlighting compassion involved immersing oneself in giving the patient as much attention as possible - being present and attentive to that child with one's whole self, giving them the needed warmth and love. Jamie described the internal process behind this kind of engagement as follows:

> Compassion means really thinking about what another human is going through, but also their past experiences that have set them on the path and being able to relate to them in a way that you can *walk* alongside them in their journey and support them through it. Leaving your own biases…. Whatever we're experiencing that's making us negative, that family is experiencing it ten-fold and to be able to walk alongside them, you have to think of how they must be feeling…. You can feel empathetic,... but not *show* compassion toward them. Compassion would be more showing them that you are more supportive.

Participants talked about compassion as walking alongside people and showing them support through it. It is similar language to the act of guiding discussed above, but here Jamie focused not on the guidance being provided but on the thought process that facilitates walking alongside patients and families in the space they are in. It is still their journey, but the nurse shows compassion through gaining that background understanding of the place where they are and showing support in ways that are meaningful to that family's specific place in their journey. In this next narrative, Laura described journeying closely with a family over the few days before their child's death as she reflected on the ways she showed compassion by being with them.

> I think of those last 24-48 hours that we often have in critical care where the nurse is just holding space with a family. I would think of a particular patient… where I was the only one who was supposed to go in the room… as the child passed away, I was the one holding the family and they were holding me … and everyone else was outside of the room looking in and I was part of that moment…. We're not trying to fix anything… we're really just holding space to allow the family to have the most graceful transition into the next phase of letting their child go as gracefully as they can.

Laura introduced the context which was the last few days of a child's life, a familiar context for PICU nurses. She was uniquely positioned inside the room with the family while the rest of the medical team remained outside. As participants described being part of these moments with families, they were intimately part of this process with families as they held one another. Laura then went on to further explain the actions in that inside place - holding space instead of trying to "fix" something. She reflected further on the practice of "holding space."

> People who are able to hold space are able to sit in dark emotions, they're able to sit in the unknown. It's this little limbo kind of vortex where you're just sitting in it and you're really just honed in to this exact moment and holding the unknown with the other person. You're able to ignore what else is going on and sit in this kind of silent discomfort. And not needing to fix it - there doesn't have to be a result or an outcome…. Holding space to the possibility of recovery or the possibility of passing away or the possibility of a life without your child. And you're just sitting in it and letting them think about it and not needing to have, and like allowing them to feel sad or remember happy memories or remember like this sad moment where they feel like the last thing they said to their kid wasn't what they wanted.

By “holding space,” nurses can enable people to walk through their suffering and to better understand the space where the suffering of living is. This space that was ”held” was one of asking difficult questions; a space of sitting in uncertainty and lack of control; a space where the uncomfortable, negative, or bad emotions like guilt are present; a space that makes one face the fragility of life. The tension between responding to needs while at the same time not trying to “fix” something that cannot be fixed is a tension that nurses hold in PICUs. The way that nurses respond can help people feel love, respect, and dignity even in the midst of their suffering. Laura went on to further describe how she held space with this specific family.

> I was invited to be a part of [that family’s grieving process]. The child was alive for a week and the whole time we knew that he would not leave the hospital alive. I got to learn about their culture and I learned about the family and I got to learn about the siblings. Then I got inducted into this special sacred space that they were holding this vigil and [I learned] about what was important to them. Especially as he started to make those final steps toward passing on, we would clarify [their cultural practices].... You can ask too if they want you to stay or if they want you to go. I think that one’s even more relevant when a child has passed away. Sometimes family members *do* want to be left alone with their child and some family members feel really uncomfortable being left alone with their child who just passed away. I think sometimes they want the reassurance of someone sitting in the corner so they can ask questions when they come up.

Laura was part of this “sacred space” of the child’s last days and moments with the family. Similar to many other examples, she got to know this family - who they were, their cultural practices, and how they wanted to walk the journey toward death. Recognising that some families want privacy and others are comforted by the presence of the nurse, participants often shared a practice of asking families what they prefer which gave families freedom to have privacy when needed. In this narrative, Laura was invited to be inside every moment with them.

From a place of knowing who and what was important to this family, Laura was able to support the family in ways that were uniquely appropriate for them.

Participants reflected that becoming invested with the family in this way is vulnerable for the nurse. It is a place in which nurses also experience grief and loss alongside the family. And yet, participants paired the acknowledgement of how hard it can be for nurses with recognising the reward of being able to make a difference to suffering patients and families in those vulnerable places. They spoke of the difficult compassionate moments also being the ones that "fill your cup."

Many participants gave the example of bringing their patient off the unit as something that was fulfilling to them as nurses. Examples included taking patients to the indoor hospital garden, to an outdoor courtyard, and to other outdoor spaces. In an interesting paradox, taking patients *out* was part of being *inside* their experience and meeting an often unrecognised need. One final exemplar from Avery shows this paradox of being physically *outside* the patient room is the place where the nurse can sometimes be most *inside* the experience with someone - in this case, the mother. In this situation, the trauma team in the Emergency Room was doing chest compressions on the child while the mom sat outside the room.

> The mom was too terrified to go in the room, so she was sitting outside of the room… so just going and sitting with her. [It] is not a comfortable thing to do when the child is grey and they are doing chest compressions and you [see that it is] probably not going to go well. I'll never forget that moment, just saying "Hey. I'm a nurse. Here we are. This is the best team you could have. I'm sorry. This is impossible and I don't know the outcome, but we're here with you." I don't know exactly what I said, but you don't want to say "it'll be okay." [What's] really important is to be careful of your words in those really tough moments. Don't promise anything that's not true…. I asked her the basics like "do you want to be in the room? Or not? Okay. And that's okay. I can be with you here. Can I get

> you anything?" No. which [was] not surprising. I asked "is it okay if I sit with you?" and I probably asked "can I put my hand on your back?" Just a little bit of that gentle touch. Kind of that reminder of presence. Then I did say a few things like "I'm Avery. She's in good hands." and "I'm sorry, this is so hard" or something like that. Just very simple. And then I tried to just not say anything, which is surprisingly difficult…. It's in these moments when there just is nothing [to do] that you have to be okay with that…. Just trying to say "there's somebody with you." "I'm not going to leave you alone." and "I think it's good for you to be right here. You don't have to be in there, this is good." Trying to be very calm and present and not say too much.

In this space where the suffering of living is, trying not to say or do anything was felt to be surprisingly difficult by participants. And yet, this was how she showed compassion: sitting with the mom, putting a hand on her back as a reminder of presence, being silent, watching a grey child receive chest compressions with the mom. Even though she was *outside* the patient room, Avery was *with* that mother in her grief - in her journey of watching the death of her child. Compassion is not about being inside the physical room, but about being inside the experience of the patient and family with them. One participant recounted saying to parents: "we're in this. We're in the right place. Let's do this - together." She said *we.* An attitude of "we're in this together," whatever this is, is showing compassion in the PICU.

In this section, we have explored how nurses enact compassion within this inside space where the suffering of living is. From a place of understanding the patient and family deeply, the tender ways of showing compassion explored in this chapter become possible. Within the inside space, actions of providing emotional nourishment, guiding, creating calm environments, comforting physical touch, and staying present are ways nurses can bring comfort to patients and families in PICUs - ways of showing compassion.

Chapter 5: Time, Truth, and Trust

Time, truth, and trust. These three themes are intertwined with each other and the aspects of how compassion is enacted that have already been discussed. This section will be broken into three subsections, each of which focus on one of these themes. It will, however, quickly become evident that the themes are closely interrelated as few examples include only one of these. As one spends more time at a bedside, often more trust is built and there are more opportunities to be honest. Together these three themes are woven throughout the ways nurses enact compassion in PICUs as they engage in the process of opening the door and being inside the experience of patients and families.

Time

Time is, chronologically speaking, one of the most dependably consistent phenomena in our world - one second, one minute, and one hour are always the same length regardless of what happens in that time. And yet there is an elastic quality about time - what is happening in those seconds, minutes, and hours makes a profound difference to how the same amount of time is experienced. When a patient is rapidly decompensating and a nurse is pushing fluid while waiting anxiously for the physician to arrive, one minute can feel like an eternity. Inversely, when the end of a shift comes on a busy day, it often feels like the time passed very quickly. Time is an intrinsic part of human life - part of every action and interaction. Time poses natural limits on the actions of nurses both through the limited duration of a shift and through the limitation of what can feasibly be accomplished in the time that one has. Participants gave many examples highlighting that PICU nurses enact compassion within a unique context of extended one-on-one time with a particular patient and family. Participants also gave many examples in which the enactment of compassion was brief - taking just a few moments. This section will explore how participants described enacting compassion in both time contexts.

Participants shared many examples in which their deep engagement with a particular patient and family was built over time - patients who were in the PICU for many months or even

years. In the next exemplar, Laura reflected on how her own perspective of a situation changed depending on her engagement with the patient and family. For background information, being the primary nurse for a patient means that almost every shift that nurse is at work, they are taking care of the patient for whom they are a primary nurse. As a result, a primary nurse typically spends far more time with their patient than any other healthcare provider. ExtraCorporeal Membrane Oxygenation (ECMO) is the most extensive form of life support.

> I primaried a kid who was [a] super chronic ex-prem kind of kid who had lots [of medical problems]. She went on ECMO and then came off ECMO… and people would walk by the bedside and say "what are we doing? Why are we keeping this kid alive?..." And even I would probably buy into it if I wasn't at the bedside. When I'm at the bedside, I'm protective of the kid. I'm protective of holding the space. And when I'm not, when you don't have any buy-in, when you're not invested, it's different. You judge the situation differently. And from the outside you might say - I *have* said things like "that's millions of dollars we've spent for what?" But if I was at the bedside, I would say "we're giving the parents time to make a decision" and "we're giving parents time to come to terms with the fact that their child might be dying or not living the life that they were expecting" or that "we're giving the parents a chance to see if there is going to be a recovery or not." I have a different perspective when I have buy-in and when I don't have buy-in. I'm just looking at it as an outsider and I don't have compassion for it because I don't know any of it….

As the primary nurse of this patient, Laura positioned herself inside the experience *with* the family and patient in contrast to other nurses who did not have the same understanding. She contrasted the possibility of buying in to the questions being asked by her coworkers from the perspective of an outsider, she had bought in with the family. By using the language of "buy-in," there is an association with investment. Not a financial investment, but an investment of one's

self. As nurses walk with families like this over many months through many crises and, in some cases, the child's eventual death, they come to care about and understand the family deeply. There is an expression of compassion that comes through a depth of understanding that is only possible when long hours are spent together. From the position of an insider, as Laura was, nurses are often better able to understand care decisions that may not make sense to staff who either did not spend as much time with the family or who did not allow themselves to enter in to the experience of the family. Underneath seemingly cavalier statements about a patient's poor prognosis *is* a desire to keep the child from suffering, but those judgements are, as Laura pointed out, often made from the position of an outsider. A compassionate stance is one in which the nurse acts toward the patient and family in a way that shows the understanding of an insider.

The relationships nurses had with many of these long-term patients were exceptional. It was clear from the examples that were shared that participants had walked along that patient in their inside space of suffering - they deeply understood and had been present with the patients and families in profound ways. Nurses who had been "inside" with these patients and families had insight into the situation that often did not make sense to nurses who had spent less time with the same families.

Even when patients are not in the PICU for a long time, participants frequently used the phrase "taking the time" to describe enacting compassion. Avery, for example, said "that's where compassion comes in… take[ing] the time to… give a bath, then dry them off and give a warm blanket. Just those extra little things nobody says you *have* to do, but it's just that much more comfortable." Participants often used the phrase "taking the time" in conjunction with actions further described as humanising, whether the action was listening for an extra ten minutes, reading a story, or looking at photos of the patient. These actions of compassion were portrayed as a contrast to "simply going through the motions." A shift in attitude from "going through the motions" to "really taking that extra ten minutes" was presented as part of the

contrast between when the nurse was and was not compassionate toward a patient or family. Interestingly, however, participants also described that their attitude could change in just a second. The resulting attitude of compassion did not necessarily require extra time, but it changed the way the tasks were done from being merely tasks to being acts of compassion. Even in situations where the nurse was engaged and wanted to enact compassion, participants shared that inadequate staffing was a significant barrier that did prevent participants from being able to sit with and listen to families or do the other "extras."

Time is often perceived as a scarce resource for nurses and participants acknowledged that "you can only do so much within your 12 hour shift." Even in the midst of limited availability of time, participants often found ways of enacting compassion. Again and again, participants emphasised the humanising impact of talking to patients regardless of their cognitive status. Explaining what they were doing to a patient did not take extra time. Reciprocally, verbalising what one is doing is a common grounding strategy that can help the nurse stay focused and calm in stressful situations. Maintaining a calm attitude can help the nurse use the available time more effectively, making it a way of showing compassion that actually gives the nurse more time *and* benefits the patient. Jamie gave the following exemplar of enacting compassion in a creative way such that it did not take any more time.

> I just think "how can I make this day better? What am I capable of? How do I make things easier? What will this person really want? Today, my patient was incontinent and I was like "okay, let's shower him." That was his first shower in two weeks. We washed his hair and we stood there and sprayed him off, and he was happy. It doesn't take much longer to do that but I'm sure he felt so much better for it. And it would've probably taken just as long with packs of wipes.

By advocating to give the patient a real shower instead of using wipes, Jamie relieved some of the dehumanizing influence of being incontinent. Her awareness of his experience – the humility of being incontinent – informed her decision to give him the dignity and enjoyment of a shower.

She was also able to enact compassion in this way within the same bounds of time. There are often creative ways, like in this example, of doing things a little bit differently to enact compassion that do not require more time.

In some situations, "taking" time away from life-saving actions even for one minute would result in those life-saving actions not being done as well or in as timely a manner as required for that child's to remain alive. And yet, performing those life-saving actions may be considered to be another form of compassion in that it *is* meeting the patient's needs – physiological in this case – with excellence. Even in situations requiring urgent action, participants gave examples of taking "just a moment" or "a few seconds" to briefly update family. Laura reflected on this kind of situation in the following excerpt.

> It's kind of an ebb and flow. If the kid's really sick, of course you might take moments to say "hey" but again, that's only when you have a moment that you… crouch down and you say "I'm here, I'm busy, but I'm here for you. I'm taking care of your child. If you can drink water, try and drink it, and I'll be back. And you can wave and ask your questions, but I'm going to have to keep doing stuff. But I'm here." And if something beeps and you stand back up and you move back on to bedside nurse, that's like two different – it's the same human, the same nurse, but it's like two different parts of you that you can't always really juggle at the same time.

> When I talk about [what it's like to be switching back and forth so quickly], I'm like *yes!* This is the work, this, *this* is ICU nursing. In the moment,... it depends on the situation…. If the family is… pulling me in and out of those moments, if the alarms are ringing off and then the family's asking me 8000 questions, and then the alarm's ringing off again, and then the family's asking me more questions, it's really hard to focus on either very well…. [sometimes] it's kind of this beautiful

> dance versus [sometimes it is] chaotic, [being pulled side to side], and you don't feel like you did anything good.

Laura described this back-and-forth of juggling, of an ebb and flow, of a beautiful dance, of balancing the child's physical survival *and* emotionally supporting the family. Her powerful imagery expressed an experience echoed by other participants. There *is* a time for focusing on whatever is alarming, on the unstable vital signs, and doing what needs to be done. There is also a time, even if just for a moment, to acknowledge the family and to say with words and actions "I am here," to invite questions and input when appropriate. Like dancing a dance, balancing these tensions is an expert skill that can be developed over *time.* In her example, Laura took just a few moments to crouch down by the parents and connect. Although the amount of time she could take was extremely limited, it is often possible to take just a few seconds to support the patient and family and acknowledge their experience – to show them that they are seen.

Time is an integral and dynamic part of how nurses enact compassion in PICUs. As Reagan said, nurses "show compassion in such a different way as a nurse than most other medical people do. We're at the bedside for twelve hours and the physician is at the bedside for two minutes so it's just a different role." The long hours nurses spend at a bedside influences how compassion is enacted by nurses in unique ways and the deep relationships that can be formed. Even when there seems to be less than no time, small acts of compassion are always possible. The image of a dance is so very fitting: while dancing, one must keep time with the music, people who are dancing to the same music together respond to one another. Like dancing, perhaps compassion is a skill that one can grow in with practice and focus. Time, whether non-existent or in excess, shapes the ways nurses in PICUs enact compassion. With practice, nurses can learn to dance the dance and find timeless moments of compassion in the midst of any circumstance.

Truth Telling

Throughout the examples of enacting compassion given by participants, truth telling was often represented as an act of compassion. Participants also used the word “honesty” to refer to the practice of truth-telling, so that is how it will be used here. Participants emphasised being honest about themselves, about mistakes, and about the clinical situation. Even in situations when it was difficult, truth was an important aspect of enacting compassion.

In the chapter *Opening the Door* the way the nurse engaged with patients and families was an important part of enacting compassion - being authentic or genuine is a way of being that is honest. This involved both expressing a sincere interest in how the other person was doing, but also sharing honestly about oneself. Participants shared that as they were honest with patients and families about who they were, that often helped build trust and open the metaphorical door. Participants enacted compassion by showing themselves to be truthful in the way they interacted with patients and families,

Another way participants emphasised being honest about oneself was regarding the limits of one’s own knowledge. Avery shared the phrase “expose your ignorance” and then explained that “you’ll be safer for it, don’t try to pretend…like ‘I don’t know the answer to that, I’ll ask the doctor.’” Pretending is hiding what is true about one’s own knowledge or lack thereof. Being honest about what one does not know ultimately protects the patient and family by ensuring that things are done well and that they get the answers they need.

Another situation in which participants emphasised being honest was being honest when they had made a mistake. Compassion is closely tied to a sense of shared humanity and one part of being human is making mistakes. Avery reflected on a situation in which some things had not been done as well as they could have. In this situation, she described compassion in the following way:

> There’s this piece of honesty and saying “Hey, this is not how this is supposed to go.” Apologies… [when you make a mistake,] you’re going to say “sorry” and …

> just admitting those things because when you can be human, in a way that's respectful.

Other participants similarly emphasised that as humans, mistakes do happen but navigating those mistakes in a compassionate way requires being honest about them. Even when the nurse's impulse might be to hide something or to be defensive in justifying actions, the compassionate action is to apologise when a mistake has been made and to understand where the family is coming from. This is a reminder again of the courage mentioned as part of opening the door. Participants repeatedly explained that honesty about mistakes paired with a genuine apology can make a difference in the experience of patients and families in PICUs. Although difficult, being truthful about mistakes is an important way of enacting compassion.

As humans, not only do we make mistakes, but there are also limitations to what can be done. Being honest about the limitations of healthcare and the circumstances in which the patient and family are situated was another way participants highlighted the telling of truth as an act of compassion, as Avery shared in the following quote.

> A huge part of having compassion is trying to acknowledge people's current reality and not trying to deny it. Not pretending it will get better. Not saying we can fix it all - and, in fact, being better at knowing when we shouldn't offer [to fix it].

It can be difficult to recognise when nothing more can be done, but the truth of the situation must be told and to do so is an act of compassion. Although making these decisions and delivering news to families is the role of the physician, nurses are often present during and after the conversation. Many participants gave examples of compassion shown by physicians in that type of situation. Being kind, calm, and tender in the way truth is spoken is certainly part of enacting compassion, but participants also emphasised that when bad news is softened too much, families sometimes do not fully understand the gravity of the situation which makes matters worse. Reagan gave an example in which the physician addressed the fears the

parents had of killing their child by withdrawing care by saying “it’s not *if* your child dies, because they are going to die. It’s when. And how we can make that a positive death experience”. The physician communicated the real future possibility of the child getting to the point of rotting in bed if they did not withdraw care. Simon reflected that the physician communicated in a way that was “was straight-forward but compassionate and I think we beat around the bush a lot of the time and we try to sugar-coat a lot of situations that we deal with.” Participants expressed that giving families the needed truth in a straight-forward way is part of enacting compassion.

A wide variety of other examples were given in which having “open honest communication” with patients and families was described as a way of enacting compassion. Procedures such as inserting a new intravenous catheter or ambulating can be painful, but they are necessary and to refrain from doing painful but necessary things was described by participants as uncompassionate. However, the way that nurses communicated about something painful but necessary was an important part of how participants described being compassionate during painful procedures. Jamie shared the advice: “don’t say something’s not going to hurt and then it’s going to hurt. [Say] ‘I’m sorry, but…’” When painful or hard things *do* need to happen, participants described it as compassionate for nurses to communicate honestly about that pain in a way that also expressed their care. Participants shared that this approach was founded on their knowledge of existing literature that when children know what is going to happen, even when it is painful, that knowledge helps the child build resilience and trust through the difficulty instead of creating more anxiety. When there was dishonesty or deception, either by the nurse or the family, it was perceived by participants as a lack of openness. Referring again to the overarching metaphor for enacting compassion of opening the door and being inside, communication that is “open and honest” is a key part of establishing a reciprocal relationship of openness. As will be seen in the next section, honesty is part of establishing trust which is also integrated into the enactment of compassion.

Trust

As the participants discussed compassion, they often referred to trust in various ways. The Cambridge English Dictionary (n.d.), provided the following definition of trust which is reflective of how participants used the word: “to believe that someone is good and honest and will not harm you, or that something is safe and reliable.” Unlike other themes, the theme of trust does not focus on the actions of the nurse, but on how the patient and family perceive the nurse. Participants often portrayed trust as an outcome of compassion - when they treated the patient and family in a way that was compassionate, trust was given. Participants gave many examples of compassion that involved protecting patient safety, but trust was also embedded in the intersection between opening the door and being inside. This section will first address enacting compassion through protecting patient safety and then explore how trust was woven throughout both opening the door and being inside the suffering of patients and families with them.

There are many policies and practices established for the purpose of protecting patient safety in PICUs and decision-making often heavily prioritises the physical safety of patients. While participants described enforcing policies intended to keep patients safe as part of compassion, they also described making exceptions as a common way of enacting compassion, sometimes framing policies as barriers to compassion. Avery reflected that “policy has its place, absolutely, I respect it. And then sometimes you’re like I need to be human. And that’s where compassion comes in.” In contrast to rigid adherence to policy, seeing patients as humans sometimes prompted making exceptions to policies or unit norms. Compassion often took the form of advocacy in these situations.

Reagan shared the following exemplar of enacting compassion. He described his process of advocating for an exception to be made to established safety practices. For context, children who are on this type of life support are, for their safety, typically kept very sedated. They are not allowed to be held by their families because of the very high risk of life-ending

complications – 5mm of movement in the wrong direction can end the child's life. In the situation below, the decision had been made to withdraw care since there was no longer a possibility of recovery.

> I talked to [Mom about] what does [withdrawing from care] look like for you?... and the one thing she said [was] "I would love to hold my child, both of us, the mom and the dad, at least once before [the child] passed." … I said to the physician "we're withdrawing care in an hour or two, what is the point? So what if the [life support] cannula comes out? So what if the breathing tube comes out? So what if the central line comes out? Does it really matter at this point?" Once I said that, they [agreed]. I guess as long as the family knows the risks, why do we care? Yes, their chest is open, but does it really matter? This is what the family wants and we're at the end of the line already! And they understand the risks of holding a child with an open chest, but that's what they want and why can't we facilitate it then? At first [the physicians] were like "no" and I was like "well, why not?" and they were like "well, their chest is open" and I was like "so? The heart's not going to fall out of the chest, the skin is closed. It's not getting any worse." After some pushing, [they agreed]. I think sometimes advocacy can be compassionate.

Similar to other examples, Reagan did prioritise the safety risk associated with holding the patient – that the life-sustaining tubes could be pulled out resulting in the patient's immediate death. But he also recognised the uniqueness of the situation – that the patient was about to pass away in the next few hours and the parents wanted to hold their child. Even though it was not "safe" to hold the child, the child was already dying. The life-threatening risks no longer mattered as much and the priority was a good death – giving parents those experiences of holding their child. Participants, like Reagan, advocated in situations like these

for the needs of patients to be met that went beyond their physical needs, whether that was for the child to die outside or for the parents to hold the child.

There is a great deal of individual decision-making for nurses in protecting patient safety. Even in the same situation, nurses would have opposing perspectives on what the appropriate way to enact compassion was. Both perspectives attended to patient safety and advocated for compassion, but in different ways. As an example, contrasting views on clothing offered by two participants will be shared. Hayley gave the following perspective:

> A parent said “can I put their own pyjamas on them?” And in the PICU answer is no, and I was like yes! … I was like I don’t care, worst case scenario, [we] cut it off for CPR…. The way we do things in ICU is very regimented… [but] if wearing her purple sweater is going to make her [happy], I really don’t care, go do it.

For Hayley, the most important thing was making the patient feel happy. She was not unaware of the risk that the clothing might have to be cut off in an emergency, but that was a worthwhile risk. Other participants also gave dressing infants in onesies as an example of compassion with the rationale they felt that it was humanising. Reagan offered an opposing perspective:

> I refuse to put kids into clothes in an ICU. People will disagree with me, but I think if you’re in an ICU, a patient should not be in clothes. I will put them in a cute little gown, but I will not put a child in a onesie. They are in the ICU, I’ve had to cut one off a child in an emergency, so I [say] no! I literally [will say] “you’re in an ICU, you don’t get a onesie. Sorry bro, but I will give you a really cute hair clip and a blankie.”... Maybe [other] people think “well, the family bought these cute clothes, I want to put them in the cute clothes” and I think “they’re intubated! They are sick. You don’t know what’s going to happen in five minutes, that’s just another thing I have to worry about.” … [if it is] important to the family, I usually try and meet the family halfway and say “well, we won’t put it on but we can wrap it cutely on them”

For Reagan, the risk of having to delay life-saving treatment in an emergency in order to cut off a onesie was not worth the risk. He recognised the possible comfort that clothing might bring to the family and “met them halfway” by protecting the child’s safety *and* laying the clothing over the patient. Each participant’s evaluation of what was safe for the patient was different, but both prioritised what they thought was most important for the patient. As nurses integrate their knowledge of the clinical condition of the patient and the risks at any given moment, decisions like these are often dynamic – something that may be safe in the morning might no longer be suitable in the afternoon. Nurses, like situations, are dynamic and individual. As parents *entrust* their child into the care of the nurse, nurses might make different decisions about what is best, and a variety of actions can be seen as expressions of compassion depending on the intent and communication.

Many of the acts of compassion explored as part of “opening the door” build trust. They demonstrate to patients and families that the nurse is honest, safe, reliable, and will not cause harm. Once the nurse is trusted in this way, patients and families seemed more willing to open up and allow the nurse into their inside space. In that inside space, nurses continue to act in ways that are trustworthy and, over time, families would often open up even more parts of their experience to nurses. The phrase “they trusted us” was often used at the conclusion of a description of compassion, providing an indication that the actions had succeeded in opening the door.

Compassion often resulted in trust, but nurses are responsible to enact compassion whether or not patients and families are ever willing to trust the nurse. When the nurse is trusted different expressions of compassion become possible by being inside the patient or family’s experience with them. Participants sometimes framed their description of a particular action with the explanation that they were able to provide a certain type of support *because* the parent or child trusted them. Hayley shared the following narrative:

> [Mom] wanted to adjust a few things and … the resident was like "*sigh* I spent all afternoon talking to her about this." And I was like well, she might've just needed to talk through it again and the intensivist [responded that] "it's because she's seen you for five days now, you're the one that she wants to talk through."

This mom was willing to receive guidance from Hayley because of the trust that had developed over the preceding days. Even though the resident spent what felt to her like a long time discussing it with the mom, there was not the same level of trust which meant that the conversation did not have the same therapeutic effect as it did coming from Hayley. The same information was accepted from Hayley because of the trust that had been built. Here, we can see that time is intertwined with trust and truth – the time spent and built trust, and provided the opportunity for Hayley to speak truth. Hayley was able to meet the mom's need to feel heard in a way the resident could not.

As has been discussed, emotions are a big part of the experience of patients and families in PICUs and caring for those emotions is part of enacting compassion. Without trust, those vulnerable emotions are less likely to be shared with the nurse which means they cannot be acknowledged or validated as needed. Darcy reflected on the trusting relationship staff had with a particular patient who was on the unit for a long time.

> They were such kind people and willing to communicate with us…. [Staff would be] walking around cuddling his baby sister who was born during his stay on our unit. And you could just see the trust was the biggest thing - they really trusted us…. Things could not have gone more wrong for him, but they trusted us with his care, and with them too - they just trusted us with their experience…. From the moment that we knew we needed to withdraw on him, [the intensivist who] was working went in there and held mom's hand and said "okay. I think this is him telling us [that it is time to let him go]." You could tell that conversation wasn't

> had lightly. You could just tell that everyone was in that experience with the family.

The trusting relationship with this family went far beyond tasks. Family trusted staff to walk around the unit with their new baby while they ate dinner or snuggled with the patient. They trusted staff to do what was needed in their child's care and to guide them through the most difficult moments of having to withdraw medical intervention. There was a sense, as Darcy said, of staff being "in that experience with the family" - sharing in the delight of a new sibling and the sorrow of the patient's death. Trust facilitated the open communication and relationship that made it possible for staff to be inside with the family.

Trust is a key part of compassion and of the transition between outside and inside - between a nurse being positioned outside, endeavouring to open the door, and that door being opened for the nurse to step into the patient and family's experience with them. For the patient and family to share their vulnerable inside space with the nurse, they need to feel safe; they need to *trust* that the nurse will not cause more pain in their already tender place. Trust is embedded in this intersection between opening the door and being inside with the patient - it is embedded in enacting compassion.

Three 'T's Intertwined

Throughout this section time, truth, and trust have overlapped in a variety of ways. Each one impacts the ways nurses enact compassion in the PICU both as nurses open the door and are inside spaces of suffering with patients and families. One final narrative from Jamie depicts how time, truth, and trust are intertwined with the ways PICU nurses enact compassion.

> We had a patient for three days in a row. We were deep suctioning and I [said to the new staff member working with me] "you have to tell him, and you have to explain what you're doing" because she just started [suctioning]. And she was like "well, does it matter?" [because] he was delayed. And I was like "yeah, it does." And it was the best because I would say "we're going to do this, we're

> going to count to five and then it will be over. I promise you it will be over at five, but we have to do it." By the third day, he would open his mouth and let us. He knew and he had developed the trust and the capability. And I remember it was the best and [the new staff member] was like "wow, that really worked!" And I was like "Yeah, it does work." … If someone knows what's happening, how long it's going to last, you build the trust that they actually believe you. A lot of times, they'll cooperate better.... "We're going to count and then it will be over. I promise you." I think that's compassion too. And it's also just respect – respect for the person. It took three days and I remember on the third day, it was so easy, he was just totally cooperative. I remember her saying to me "wow" like yes, he trusts us now. That [extended time with one patient] makes a big difference too – having that relationship.

Like many other examples, Jamie felt that the extended time of three days and consistent honesty about suctioning along with her kindness resulted in the patient trusting her. Jamie reflected that compassion enacted in this way transformed the patient's experience of being orally deep suctioned from something terrible to something bearable. This is the goal of compassion; to act in ways that alleviate the suffering of the other person.

Time, truth, and trust, although not the most prominent aspects of enacting compassion, are a deep undercurrent beneath the visible actions. They shape each interaction nurses have with patients and families whether in an obvious way or in a more indirect way. The extended time nurses have with patients and families often provides opportunities for truthful conversations and the building of trust. Even when there is a lack of time, nurses learn to dance in the tension of pressing physical and emotional needs. As nurses are honest about themselves, mistakes, and the clinical situation, that fulfils a need patients and families have for truth. Being honest also builds trust. As nurses show compassion in ways that invite patients

and families to open up, the presence of trust allows nurses to enter in and be present with patients and families – truly suffering with them – and to bring some comfort into the space.

Chapter 6: Discussion

This chapter will explore the ways that the themes in this research study are consistent with and different to existing literature on compassion. The overarching metaphor of opening the door and being inside portrays similar concepts to those found in existing literature in a new way. Differentiating between compassion that opens the door and compassion that is dependent upon being inside or trusted is a new way of incorporating both aspects of compassion that are already established in the literature. The primary contribution of this work is to contextualise compassion into the PICU setting. Even themes such as touch or getting to know patients and families that are common throughout compassion literature were described in examples unique to the PICU, such as having families print off pictures of their sedated child to put up in the room. The examples given by participants in this study provide powerful examples of how nurses in PICUs can enact compassion in unique ways in a challenging setting. In this project, *Introduction to the Healthcare Environment, Making an Offer, Being the Calm in their Storm,* and *Guiding* are more unique in their expression of compassion than has been reported in the existing literature which may relate to the context of the PICU. Time, truth, and trust, woven throughout opening the door and being inside, will be discussed at the outset of this chapter to explore how these themes and the overarching metaphor reflect the broader literature on compassion. This will be followed by discussion of the actions of opening the door and finally being inside.

Overarching Themes

Time is one of the aspects of nursing in the PICU context that participants repeatedly referenced as unique. The extended one-on-one time PICU nurses have with a patient and family is unusual. In the broader literature, lack of time is one of the most commonly described barriers to compassion (Malenfant et al., 2022; Nijboer & Van der Cingel, 2019; Sharp et al., 2016; Singh et al., 2018; Straughair et al., 2019). Participants in this study did give examples that echoed this concern, expressing the practical impossibility of enacting compassion in

certain ways when they were expected to do more than they reasonably could. In contrast to the perception of not having sufficient time for compassion, there is a great deal of research suggesting that it takes less than one minute for expressions of compassion to make a meaningful improvement in patient anxiety and perception of care and that by choosing to “take” time for compassionate interactions, professionals in turn feel that they have more time (Bylund & Makoul, 2005; Roter et al., 1995; Trzeciak & Mazzarelli, 2019). Most of that research has been done with physicians in clinic settings, so the practical application for nurses in PICUs may be very different. And yet, participants also gave examples of enacting compassion in ways that did not require additional time such as explaining something to the patient while doing it or taking the patient for a shower instead of using wipes. Even when many hours are spent with a particular patient and family, the time can seem short when filled with urgent interventions but those many hours also provide the opportunity for small moments of compassion interspersed with the urgent interventions. The description of a dance provided a poignant image of how nurses might weave compassion in with other aspects of their nursing practice.

Truth-telling is another topic that is often discussed and even debated in the literature. The first aspect of truth-telling described in this study was disclosure of medical errors which is widely explored in the literature and, as emphasised by participants in this study, is considered to be an ethical obligation (Hobgood et al., 2002; Kaldjian, 2021). An accompanying apology is an act of compassion (Shuldham, 2019). There is ongoing debate in the literature regarding disclosing truth more broadly, such as in relation to a diagnosis or prognosis, and if or when truth might be omitted for a time as an act of compassion that understands how devastating the information might be and the suffering it will cause (Begley, 2008; Nolte, 2008; Tuckett, 2023). Participants in this study strongly advocated for clearly delivering diagnostic information to families sooner than later in order to minimise the suffering of the patient or family despite the hardship that may be caused by this information.

Trust was integral to the nexus between opening the door and being inside in this study. Existing research studies promote compassion as beneficial to patient care for a variety of reasons, one of which is the development of trust. When healthcare professionals were perceived as compassionate, patients and families were more likely to trust them and "open up" about more intimate or vulnerable aspects of their experience (Baguley et al., 2022; Trzeciak & Mazzarelli, 2019; van der Cingel, 2011). Throughout the research, including this study and others, small details patients shared with compassionate healthcare providers helped the healthcare provider give better care (Trzeciak & Mazzarelli, 2019; van der Cingel, 2011). This is consistent with the understanding in this study that enacting compassion opens the metaphorical door with patients and families. In other words, the results of this study suggest that compassion is not only what happens inside, but also includes ways of interacting with patients and families regardless of whether or not they respond with trusting and allowing the nurse to enter in to their experience with them.

The overarching metaphor in this study bears some visual and conceptual resemblance to the model of compassion developed by Sinclair et al. (2016) and the subsequent pediatric-specific model (Sinclair et al., 2021). The goal of this research question was not to develop a model of compassion, however the language used by participants in this project did reflect a similar conceptualisation of compassion involving a particular space in which the healthcare provider and patient interacted. In the above models, the space in which patients and healthcare providers interacted was called the "relational space" and was entered by patients as a result of their experiencing suffering. Similarly, participants in this project used language of suffering to describe the place in which the patient was that the nurse also chose to enter. This study added the perspective that sometimes nurses are not permitted to enter into the space in which the patient and family are, but that acting in a compassionate way helps facilitate entry to that space.

Opening the Door Themes

Many qualitative research studies in nursing described similar themes to those of opening the door including introducing oneself, getting to know patients as people, being attentive to their need, and the attitude of the nurse (Baguley et al., 2022; Sinclair et al., 2021; Straughair et al., 2019; van der Cingel, 2011). The act of *Opening the Door* is similar to the commonly used phrase “building rapport,” however there is not a clear conceptual definition of rapport as it seems to be used more colloquially (English et al., 2022). Within the theme of introductions, nurses getting to know patients and families has been very commonly described in the literature. Allowing the patient and family to get to know the nurse is less commonly included, but is indirectly addressed through the development of trust as described above and other research pertaining to reciprocity and the therapeutic use of self (Antonytheva et al., 2021; Fisher, 2020; Steuber & Pollard, 2018). The theme of introducing patients and families to their healthcare environment has not been clearly described elsewhere. It is possible that this has been previously subsumed in the broad concept of meeting patient needs because it includes helping families meet some of their practical needs. It is also possible that this way of enacting compassion is more prominent in PICUs because of how foreign that particular healthcare environment is to many patients and families. Regardless of the reason, this sub-theme importantly recognises that the patient and family are within a particular healthcare context. Helping patients and families make sense of their healthcare environment - introducing them to it - is a significant way for nurses to enact compassion in PICUs that incorporates an understanding of the patient and family experience that is beyond their own physical and emotional needs.

Making an Offer is another theme that, while broadly consistent with existing literature, contains some unique nuances. It could be suggested that this theme is, again, analogous to the ubiquitous concept of meeting patient needs which is overwhelmingly present in the vast majority of publications on compassion and core to models of compassion (Sinclair et al., 2021;

Straughair et al., 2019; Trzeciak & Mazzarelli, 2019; van der Cingel, 2011). Yet, this action of "offering" is somewhat more nuanced and may be more specific to the PICU context. Although it does rest heavily on the nurse having an awareness of patient and family needs, in situations where a nurse may not yet know what a patient or parent needs, offering something that they are free to accept or decline functions as an invitation to begin to open up about their experience which is consistent of the placement of this theme within *Opening the Door.* Many of the tangible things nurses offered to families were similar to examples from other research such as a cup of water, warm blankets, or fresh sheets but these tangible offerings were described by participants as compassionate actions that both bring comfort and open the door to deeper interactions.

One of the things participants in this study emphasised offering was information. Communication is commonly part of how compassion is described in the literature (Ghafourifard et al., 2022; Malenfant et al., 2022; van der Cingel, 2014). Communicating information often helps alleviate anxiety and is therefore a part of alleviating the suffering of anxiety. Across the literature, simply providing the information does not seem to be enough to be considered compassionate – rather, it is the manner in which information is given that is key (Malenfant et al., 2022; Trzeciak & Mazzarelli, 2019). The description of *offering* information was, however, unique in this context as it went beyond delivering necessary information about medications or the patient's condition. Likewise, participants recognised some patients and families have varying needs for information, so *offering* additional information throughout the course of doing daily tasks was one way participants enacted compassion that built trust and invited participants to open up more about what they may or may not understand.

Family involvement is at some level expected due to the prevalent practice of family-centred care in pediatrics (Alberta Health Services, n.d.; Coats et al., 2018; Jolley & Shields, 2009). In this context, the language of *offering* family involvement may therefore seem strange. In PICUs, families are often not able to be involved in the care of their child in ways they are

used to because of the acuity of their child's illness or their own emotional state. To *offer* involvement to families recognises that families may not be willing or able to be involved in a particular way at a particular time. For example, involving a family in bathing their child can be too scary for some families during critical illness but it can also be a powerful moment. Involving families in practical aspects of care can also effectively open difficult conversations such as how to navigate end-of-life care, as shared by Reagan. The description of family involvement in this way may be particular to the PICU setting, but it is a clear way that participants enacted compassion in this context.

The final section of *Opening the Door* focused on the attitudes of nurses that facilitate opening the door. There has been a great deal of nursing research focused on whether or not compassion can be learned and how to develop it among nursing students (Adamson & Dewar, 2015; Percy & Richardson, 2018). The first attitude, *Seeking to Understand*, has been mentioned in almost every publication on the topic of compassion and is in many ways considered to be an essential part of compassion (Andrade et al., 2022; Baguley et al., 2022; Hem & Heggen, 2004; Morgan, 2017; Ortega-Galán et al., 2021; Sinclair et al., 2016; Ziarat et al., 2023). There has also historically been a close tie between compassion and treating people in a way consistent with their humanity - in healthcare literature, compassion is often seen as having a humanising effect on patients, but is also seen as a result of seeing the other person as a fellow human (Chaney, 2020; Sinclair, Beamer, et al., 2017; Sinclair et al., 2021; Trzeciak & Mazzarelli, 2019; von Dietze & Orb, 2000). It is fitting, therefore, that in this study, seeing the patient as a human is both an attitude the nurse develops and an act of compassion toward the patient. The inclusion of courage as part of enacting compassion, while not unique (Hamric et al., 2015; Hawking, 2017), is less common and likely reflects the weight of some of the situations in which PICU nurses enter alongside patients and families. Despite much debate on the topic, Trzeciak and Mazzarelli (2019) presented a powerful case that compassion can indeed be learned on the condition that the learner wants to learn - it cannot be compelled or

required. The way participants in this study talked about their own practices of self-reflection and even "adjusting" their own attitude is reflective of this agency. In keeping with broader literature, participants described their attitude as an area in which they took action to help themselves consistently enact compassion toward patients.

Inside Themes

In their article, Schultz and Carnevale (1996) contrasted engaged and disengaged presence which is very similar to the theme in this study on being inside. Carnevale was a PICU nurse, among other roles, and this article richly described engagement between PICU nurses and a specific patient as well as the benefits of that engagement to the care and recovery of the patient. The word "compassion" did not appear in their article, but they nonetheless went into great detail about knowing the patient, feeling with them in their suffering, and allowing that to inform actions to alleviate suffering which is consistent with compassion. The word "sympathy" is commonly used in the article which may be reflective of its being a more prevalent term at the time the article was written (Chaney, 2020; Sinclair, Beamer, et al., 2017). Schultz and Carnevale posited that being disengaged treats both the self and the patient instrumentally, while being fully engaged with another in their suffering "requires both openness to the patient's suffering and openness to that in us which the patient's suffering evokes: our own fragility and fatality." (Schultz & Carnevale, 1996, p. 197) Like examples given by participants in this study, nurses who knew the patient were better able to identify needs and meet those needs in ways that were not possible for those who were not inside with the patient or family, or engaged with them. In the primary example given by Schultz and Carnevale, the patient was initially not responsive to the efforts of the nurse, but with prolonged engagement over a few days, the patient did open up and begin to engage with the nurses which enabled them to better alleviate his pain. This parallels many stories shared by participants in this study of being deeply engaged - inside their experience - with patients and families, and how engaging in that place also opens up the possibilities for further engagement.

Sinclair et al. (2016) also prominently used the phrase “engaged caregiving” to describe actions that demonstrated the sense of being with the patient in a deeply meaningful way that would parallel the way being “inside” was described by participants in this study. In a recent review, Malenfant et al. (2022) described being engaged with patients in their suffering as a key theme of compassion across many research studies. Studies exploring the impact of the conceptually similar “human connection” overwhelmingly suggest that this kind of deep engagement can contribute to remarkable physiological and psychological improvements - helping to alleviate psychological and physical suffering (Trzeciak & Mazzarelli, 2019). Together, these findings suggest that enacting compassion involves a person being positioned closely with the patient and family. Participants in this study gave many examples of specific ways to enact compassion in that inside place of connection with patients and families in PICUs.

The entirety of the *Inside* section reflects engagement, but the theme of *Silent Presence* could also be termed “engagement,” however it focused on enacting that engagement in a more specific way - remaining present when there was nothing else to be said or done. There is abundant literature describing the harm of loneliness (Trzeciak & Mazzarelli, 2019) and being present with a person who is suffering can be beneficial even, perhaps especially, when nothing tangible is done or said. In many articles, the benefit of silent presence is described as facilitating listening which is consistent with much of the research on compassion (Baguley et al., 2022; Buffington et al., 2016; Kemerer, 2016; Nagano et al., 2022; van der Cingel, 2014). The way participants in this study spoke of silent presence, though, is more than facilitating listening; rather it was reflective of a deep connection between people, which is consistent with other literature (Bartels et al., 2016; Malenfant et al., 2022; Sinclair et al., 2016). As others have reported, the act of being present helps show patients and families that one is not only there to perform a task, but also there *for* and *with* them - that the patient and family are not alone, which is an essential part of helping people endure suffering (Trzeciak & Mazzarelli, 2019).

Many of the other actions described in the *Inside* chapter in this study are consistent with broader literature regarding how compassion is expressed through word and action by healthcare providers. There are extensive bodies of literature from a variety of disciplinary backgrounds describing emotional nourishment and physical touch as expressions of compassion. Both have been shown to measurably alleviate suffering. One specific example is that physical touch has been shown to decrease pain and improve health outcomes when that touch comes from a trusted individual (Goldstein et al., 2016; Trzeciak & Mazzarelli, 2019). Emotional support has also long been known to help improve patient outcomes (Mumford et al., 1982). Placing these actions in the inside domain is consistent with the broader literature because trust is required for both for a patient or family to disclose their vulnerable emotions and for physical touch to help alleviate suffering.

The theme of *Being the Calm in their Storm* is somewhat less common in the literature about compassion. Much of the existing healthcare literature about being calm focuses on personal practices of meditation among healthcare providers and of developing calm in oneself, with most references to compassion being to self-compassion. This study, in contrast, focused on creating a calm environment *for* the suffering patient and family and is primarily other-focused instead of self-focused. While participants did mention some practices like taking a deep breath, this way of enacting compassion was primarily concerned with managing one's own emotions and the physical environment in order to help the patient and family. Reciprocally, focusing on helping others has also been shown to produce a calming response in the one who is helping (Luks, 1988; Trzeciak & Mazzarelli, 2019). Existing literature does suggest that the presence of a calm person can cause physiological changes that help a person who is anxious become more calm in part through the response of mirror neurons (Kemper & Shaltout, 2011; Shaltout et al., 2012; Trzeciak & Mazzarelli, 2019). This study also added perspective that attending to the physical space inside the physical room - ensuring that it is neat and tidy - is another way of enacting compassion that helps patients and families be calm. Interestingly, this

echoes very early nursing theory in the writings of Florence Nightingale that instructed nurses to provide a calm environment to facilitate patient healing (Nightingale, 1860). As the nurse is inside both the physical and metaphorical room, bringing calm through one's own way of being as well as the arrangement of the physical space are ways of enacting compassion that may be uniquely important in the storms patients and families experience in the PICU.

Guiding was another prominent theme in this study that is not prominently featured in the broader research on compassion. In some healthcare literature, there is significant resistance to direction being given by healthcare professionals (Bamm & Rosenbaum, 2008), but participants in this study reflected on how lost and disoriented they felt patients and family members were at times. This may reflect to some extent the unique environment of the PICU. Dealing with the unexpected death of a child, unless out of hospital, typically happens in a PICU. If a child has had a long course of illness that concludes with death, this could be considered an expected death and is therefore a different context. Often, if a child is unwell enough to be near death, they are in a PICU. As a result, sudden unexpected death and emergent interventions to preserve a child's life may be much more common PICUs than other settings. It is immensely difficult to watch one's child teeter on the edge of life and death – one that is often heart-breaking or devastating, but also unanticipated and disorienting for families. In the midst of an experience that was seen to be novel and disorienting for parents, participants gave examples of guiding that were based on being engaged with patients and families inside their journey with them and responsive to their unique needs. These examples included being responsive to an emotional mother confiding her fear that she was losing it, responsive to the family who was losing their child and needed to hear "now is the time" to know when they could go get something to eat without being afraid their child would die while they were gone, and responsive to a child's need for her father who also needed to be given a role.

This theme of *Guiding* also strongly echoes the work of Patricia Benner on the development of expert nursing practice (Benner, 1982). In her influential work on becoming an

expert nurse, Benner described that nurses who have seen many families through illness and loss are able guide patients and families along a journey that, “for the patient, is a foreign, uncharted experience” (Benner, 1982, p. 406). Participants in this study described this action of guiding as something deeper than telling people what to do. This action is situated in the inside space, built on a deep understanding of the patient and family’s context – where they specifically are on their journey. This, again, echoes Benner’s description of this as an expert practice that involves incorporating nursing knowledge learned from other situations into the particulars of a specific situation. In PICUs, this action is particularly relevant as patients and families learn to find their way forward in their healthcare journey, in grief, and perhaps in life without their child.

Application of Findings to Education and Practice

Each narrative shared by a participant offered an example of ways compassion was enacted in practice. Interpretive description explicitly aims to answer questions of relevance to practice. This research does not provide a prescriptive list of ways to enact compassion, but repeatedly illustrates what compassion looks like in practice. Participants not only gave examples of their actions, but also shared their reflections of how they came to these ways of enacting compassion through their own experiences and their understanding of each individual patient situation. As such, while there are certain behaviours that convey compassion that this study revealed, the ways compassion was enacted were also dependent on the unique context in which those actions were taken including the patients, clinical situation, and the nurse.

This study can serve to inform education programs for new PICU nurses. The themes identified along with their examples can help new nurses understand what enacting compassion in the PICU looks like. As family-centred care is becoming more prevalent, nurses have described experiencing difficulty mentoring new nurses specifically in regard to allowing new nurses to observe interactions experienced nurses have with patients and families (Coats et al., 2018). This study can help PICU nurses at diverse stages of clinical experience and expertise

consider how they enact compassion in their own practice. The examples shared in this study of nurses enacting compassion can also serve as illustrations of compassion between nurses and patients that are often private because of their intimacy. The examples of being inside with families in the midst of their suffering might help nurses have a better idea of how to step into these vulnerable places and inspire them to have the courage to do so.

Limitations and Future Research

There are a number of limitations of this study. First, it only includes the perspectives of nurses, not patients or families. Since compassion involves both parties, the perspectives of both are important. Although participants did share reflections on experiencing compassion as patients themselves, in most cases those examples were not in the PICU setting and may not be reflective of patient and family experiences in PICUs. Including perspectives of patients and families was not feasible for this study, but would be very important for future research, especially to verify with patients and families that the effects participants perceived compassion to have, such as calmness, were indeed experienced by patients and families. Second, the majority of participants identified as Caucasian and women which limits an understanding of ways of enacting compassion that might vary between genders or cultures. Future research should seek to include a wider variety of perspectives on the research question.

Third, this study was conducted in multiple hospitals in the province of Alberta, Canada. Although multiple hospitals were included, the scope of practice of nurses as well as norms may vary significantly in other provinces and other countries which may shape how compassion is enacted. For example, in Canada there is a public healthcare system so unaffordability of treatment is not a concern for families, but there may be ways nurses in other countries enact compassion that address the significant financial burden of care in PICUs.

Within the methodology of interpretive description, the researcher does not aspire to generalizability (Thorne, 2016), but instead to describe and interpret the views of these participants. Since many of the ways of enacting compassion in this study are consistent with

the broader literature, it is likely that there may be some relevance to other PICUs and perhaps other pediatric settings. In terms of navigating emergent situations, there may be applicability in adult intensive care settings, but it may be quite limited because of how much care in the PICU is shaped by the presence of families and various developmental considerations. Future research could further explore the themes of *Being the Calm in their Storm* and *Guiding* as these are under-represented in the nursing literature about compassion. Additionally, future research could more deeply explore the end-of-life situations in PICUs and how nurses navigate those situations in ways that are compassionately *with* patients and families.

Conclusion

This research project set out to answer the question: how do nurses enact compassion in their clinical practice in Pediatric Intensive Care? Participants enacted compassion as they opened the door through introductions, making offers, and attending to their own attitudes - inviting patients and families to open up, to trust, and to allow the nurse into their experience. Regardless of the response of patients and families, nurses were able to alleviate some suffering in these ways, even if that was simply remembering their name or speaking to them like a human. When patients and families did open the door, nurses had the privilege of entering into the vulnerable sacred space of their experience - of their suffering. Nurses aspired to meet patients and families inside the difficult places where they were. From that place of being with patients and families where they were and walking with them, nurses sought to make the journey just a little easier by being the calm in their storm, guiding, providing emotional nourishment, comforting through physical touch, and being present. Instead of a list of actions telling nurses exactly how to enact compassion, this research depicts a more dynamic and nuanced practice of walking with patients and families so that they do not have to face their experience alone, of being attentive to their unique journey, and of taking action to alleviate their suffering - of enacting compassion.

It requires understanding childhood development, yes, and grief, and other such ways in which we understand people's experiences that are not our own. It also requires understanding what is unique to that person, and meeting needs which are unique to their own situation and to the way in which a particular patient and family is experiencing what is happening. To be sure, that still does not mean always giving people exactly what they ask for. Sometimes it means recognizing what is possibly underneath a particular request. Sometimes it means walking with them into the conversation they are scared of and do not know how to have - and perhaps the nurse is also scared of and does not quite know how to have that conversation, but leans in anyway. In the words of one participant, compassion "is ten times more powerful than fear." Instead of a check-list of actions that dictate exactly how to enact compassion, this research *offers* ideas and examples that invite nurses to the door; to choose an attitude that looks at patients and families and sees their humanity; to bring one's whole self, offering genuine interest and willingness to courageously step into their suffering even when it is painful so that they are no longer alone.

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Appendix A

Consent Form

INFORMATION LETTER and CONSENT FORM

Study Title: Exploring How Nurses Enact Compassion in Pediatric Intensive Care

Research Investigator:
Amy Neufeldt
Faculty of Nursing
3-141 Edmonton Clinic Health Academy
University of Alberta
Edmonton AB
T6G 1C9
alneufel@ualberta.ca
780-977-8161

Supervisor:
Dr. Dianne Tapp
Faculty of Nursing
3-141 Edmonton Clinic Health Academy
University of Alberta
Edmonton AB
T6G 1C9
tapp@ualberta.ca
780-492-4338

Background
You are being asked to participate in the study because you are a nurse in a pediatric intensive care unit (PICU). This study will be exploring compassion in the PICU context from the perspective of nurses. Before the interview begins, the researcher will go over this consent form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will also be sent an electronic copy of this form for your records.

Purpose
The purpose of this research is to explore and share the wisdom PICU nurses have about what compassion looks like in the unique context of PICU for the purpose of promoting professional development.

Study Procedures
This study involves interviews with bedside nurses from the three PICU units in Alberta, Canada. Interviews may be conducted in person or online depending on the preference of the participant. If the interview is happening on zoom, one may choose to keep the camera off if so desired. Interviews are expected to last one to two hours but may be shorter or longer depending on the participant.

A recording of the interview will be stored on an encrypted and password-protected computer until it is uploaded to the University of Alberta's secure research environment using a private internet connection. Once the recording is uploaded, the local files on the computer will be deleted. The researcher, supervisor, and advisory committee will have access to the raw data. The Research Ethics Board and University Auditor will also have access for monitoring purposes. Following transcription, any identifying information will be removed from the transcript and stored as a separate file. Anonymized transcripts will be used for data analysis.

Possible Benefits
- You will not benefit from being in this study in any identifiable way, but you may find the opportunity to talk about your work in PICU to be helpful.

- We hope that the information from this study will help to better understand compassion in PICU, so that knowledge can improve nursing practice.

Risks
Talking about your experiences in PICU might be difficult for you and could cause you emotional or mental distress. You are in no way required to share anything you do not wish to share.

If you find that you have negative emotional or mental repercussions following the interview, please contact the researcher or supervisor. Counseling services are available to you through the Employee Family Assistance Program as an Alberta Health Services employee. This program is free and confidential. They can be reached at: **1-800-268-5211**.

If you choose to participate in an in-person interview there may be an increased risk of acquiring a communicable disease such as COVID-19, Influenza, or Adenovirus. In order to mitigate these risks, all provincial and municipal regulations will be followed.

Cost of Participation (if applicable)
Costs of participating include: your time and if participating by online video conference (Zoom), you will need access to electronic resources including a computer or cell phone and the internet.

Voluntary Participation
You are under no obligation to participate in this study. Participation is completely voluntary. If you agree to participate in the study, you can decline to answer any question during the interview or change your response at any point before or during the interview.

If you wish to withdraw your participation after the interview, you may do so up to 48 hours after the interview by contacting the interviewer. If you do change your mind after the interview, your interview will be deleted and excluded from analysis, but the information you shared in the interview may still have some unintended influence on data analysis.

Confidentiality & Anonymity
- This research will be part of my Master of Nursing thesis project. Results may be published in academic journals and presented at conferences. Excerpts from your interview will be used but only after information that could clearly identify you or your unit has been removed.
- Raw data will be kept confidential as indicated above, accessed only by those directly participating in data analysis. Quotations may be shared in the research products described above but only once identifying information has been removed.
- In order to ensure anonymity, pseudonyms will be used in any sharing of the results and the hospital where you work will not be included. The only information about location that will be shared will be the number of people who participated from each site.
- Once the study is finished, written transcripts of the interviews will be stored in a secure research database. Basic demographic information will be included, but your name and contact information will not be included. Transcripts may be used in future research, but only if such use is approved by a Research Ethics Board.

Contact Information
If you have any further questions, please do not hesitate to contact:
Amy Neufeldt: 780-977-8161 or alneufel@ualberta.ca, or
Dr. Dianne Tapp: tapp@ualberta.ca

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can contact the Research Ethics office at: reoffice@ualberta.ca . This office is independent of the researchers.

Consent Statement
I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form.

____ ______________
Participant's Name (printed) and Signature Date

____ ______________
Name (printed) and Signature of Person Obtaining Consent Date

Appendix B

Interview Guide

1. Tell me a little bit about yourself - why are you interested in talking with me about compassion in PICU?
2. In your own words, can you tell me what “compassion” means to you?
3. Can you tell me about a time where you or someone else you witnessed was particularly compassionate with a patient? Can you break that down for me step-by-step?
4. What about that example do you think demonstrated compassion?
5. Could you tell me a bit about why you think compassion may or may not be important in PICU?
6. Would you be willing to share a story of a time when you felt compassion was lacking either in your own practice or a situation you observed?
7. Can you think of any situations away from the bedside (ex. Informal conversations, break room, etc.) where you felt like the way you or others were speaking about patients or families may not have been consistent with the compassion shown in bedside interactions?
8. Are there any life experiences you have had that you think affect how you show compassion? Are there cultural or spiritual influences?
9. Based on your experience, what role do you think compassion has in alleviating suffering among children in PICU?
10. Is there anything else you would like to say about compassion or PICU that hasn’t been covered?

Appendix C

Intake Form

Are you a Registered Nurse?
☐Yes ☐No

Which unit(s) do you work on?
☐ Stollery Children's Hospital PICU
☐ Stollery Children's Hospital PCICU
☐ Alberta Children's Hospital PICU

How long have you been a nurse?
____

How long have you worked in PICU?
____

What is your age?
☐ 20-29 ☐ 30-39 ☐ 40-49 ☐ > 50

What is your gender?
____

What is your race?
____

What is your ethnicity?
____

Would you prefer for the interview to be in person or online using a secure video call?
☐ Online ☐ In person

How would you like us to contact you?
☐ Email ☐ Text Message ☐ Phone call

Please enter your name and contact information below
____

Is there anything else you would like to add?
____