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"I can't be the nurse I want to be": Stories of moral distress in pediatric oncology nurses' caregiving narratives

Monica L. Molinaro, *The University of Western Ontario*

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Abstract

This thesis presents the caregiving narratives of nine pediatric oncology nurses that illustrate the embeddedness of their caregiving and moral distress within institutional contexts that limit their capacity to be the nurses they want to be. Informed by the concepts of moral distress, bearing witness, and narrative repair, a critical narrative methodology was employed to examine the nurses' caregiving experiences in relation to broader discourses and neoliberal, corporatized health care settings. The nurses' stories were marked by ambivalence and moral distress and are presented in four narrative themes, which illustrate: the nurses' struggles to complete their tasks and address multiple and shifting needs of patients and families in under-resourced and chaotic working conditions; institutional constraints on nurses' capacities to maintain physical, narrative, and moral proximity to patients and families; how the nurses form collective resilience through their shared moral distress to survive unsupportive working conditions; how the nurses mobilized narrative knowledge of patients and families to enact their moral responsibilities; and how they narratively repaired their fractured moral identities to restore their identities as the nurses they wanted to be. The findings illustrate how the nurses' counterstories ascribe value and meaning to the relational caregiving that exceeds the physical care associated with treatment and cure, and re-locate the source of moral distress within unsupportive institutions rather than in the emotionally challenging character of pediatric oncology caregiving. By linking individual caregiving narratives to broader contexts, the findings contribute epistemologically grounded narratives to enrich research on the stresses associated with pediatric oncology caregiving, provide narrative depth to enhance theoretical work in nursing on moral distress and bearing witness, and extend the concept of narrative repair to consider how narrative functions to facilitate relational caregiving and restore nurses' damaged moral identities. The creation of narrative spaces is suggested as a way to complicate cultural and professional understandings of pediatric cancer caregiving. Storytelling can inform nursing education, practice and policy to highlight the ambivalences of pediatric oncology caregiving and to bridge nurses' experiences of caregiving with management, other health care providers, and the general public, as well as to stimulate social change.

Keywords

Summary for Lay Audience

Pediatric cancer, or cancer in children and teenagers aged 0-18, is one of the most highly publicized cancers in Canada. Advertising campaigns that feature stories about children with cancer have shaped how society has come to understand what pediatric cancer is like, and what caring for someone with pediatric cancer entails. Pediatric oncology nurses do not typically appear in public representations of pediatric cancer caregiving, yet they spend the most time with patients and families and have a unique range of caregiving tasks that they must complete in their daily work. This study collected and analyzed the caregiving stories of nurses who work in pediatric cancer care settings in order to understand what their caregiving involves and the difficulties associated with their caregiving. The nurses' stories provide evidence of how they experienced moral distress; that is, they felt as though they could not be the nurses they wanted to be because their institutional contexts and working conditions often prevented them from providing the care they found meaningful and important. In their stories, they described their chaotic and relentless schedules, demanding workload conditions and constraints, not being supported by management, bonding together with other nurses to survive working in difficult working conditions, and bearing witness to suffering. Their stories also show the meaning they assign to their relational caregiving, such as getting to know the patients, families, and their stories, and how this knowledge enabled them to enact their moral identities (being a good nurse) and moral responsibilities (doing what they felt was aligned with the interests and needs of their patients). The study findings show how storytelling can be used to connect individual experiences of caregiving with broader institutional contexts, and provide greater understanding of the constraints that shape how nurses provide care to children with cancer and their families. Further, this study has implications for how stories can be used in nursing education, practice, and policy as a way to bridge nurses' views with management, other health care providers, the general public, and to stimulate social change.

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We have all heard the tale of it taking a village to raise a child; it also takes a village to support a graduate student through their PhD. There are two villages – my academic and personal villages – that I would like to acknowledge. Without their help and support, the completion of this dissertation would not be possible.

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1   Introduction

This thesis presents the stories of nine pediatric oncology nurses and examines the embeddedness of their caregiving within institutional contexts and systems that limit their capacity to be the nurses they want to be. Conveying a range of emotions, including joy, pride, devastation, frustration, and despondency, their stories highlight the range of caregiving they perform, and the rewards and difficulties of pediatric oncology caregiving, which focuses on the treatment of cancers and tumours in children aged 0 to 18 years (Bray, 2009; Buka, 2009; Canadian Cancer Society, 2008; Canadian Institutes of Health Research, 2014; National Cancer Institute, 2015; Nolan et al., 2014; Public Health Agency of Canada, 2013; Yi et al., 2014). A thread that weaves across these stories is the frustration and moral distress as the nurses described their lamentable working conditions, their struggles to maintain relationships with patients and families within these conditions, and the ways that they sought to resolve the differences between the nurses they had to be and the nurses they wanted to be.

As I struggled to write the introduction to this thesis, I asked myself a number of questions. How should I begin? How can I make my research sound important and compelling? How do I do justice to my participants' stories? What story do *I* want to tell? As a narrative study of pediatric oncology nurses' caregiving, I started thinking – why don't *I* start with a story? In keeping with the reflexivity that is essential to the narrative approach I used to generate and analyze the nurses' caregiving stories, I decided to begin with my own story of how I came to be interested in researching this topic. This reflection is the first of a number of reflections that I have made throughout the data collection, analysis, and writing of this thesis, including the difficulties I experienced maintaining my critical stance, my positioning in relation to my participants, how I've come into my own understandings of their stories, and how their stories ultimately affected me and steered me in specific analytic directions. This introduction thus serves as the telling of how I began the process of becoming the researcher I want to be.

1.1 My Path to Qualitative Pediatric Oncology Research

I did not have cancer as a child. However, when I was in the eighth grade, I remember my sister and I making a friend at a basketball camp. "Ben" went to school with some of the girls on my representative basketball team and I thought he was hilarious. He was like the human version of Tigger from Winnie the Pooh – always bouncing around and full of energy. After I met him, I told my friends I thought he was really nice, and as we talked about him, the girls told me in hushed tones that "his mom died of breast cancer" and "he used to have cancer". I remember feeling both shocked and sad – sad that his mom had died when he was so young, and shocked that he had cancer. I remember thinking that it was weird for a kid to get cancer, but if his mom had cancer, maybe that's why he had it too, like it was genetic. I imagined him with a bald head lying in a hospital bed, but still acting like himself.

Ben and I kept in touch after that basketball camp (via MSN, as this was before the time of texting), but we eventually lost contact as we went to high school. One night, around grade ten or eleven, my sister and I tuned into a Raptors game. As we were watching the warm-ups, she turned to me and yelled "Oh my god. That's Ben!" I looked at the screen, and in front of me, walking on the court and shooting baskets before the game was not the person I had met at basketball camp – the person I saw was a taller, much skinnier version of Ben, who had no hair, no eyebrows or eyelashes, and was extremely pale. He appeared just as happy as I remembered him from that camp, but the way he looked shocked me - his big, dark brown eyes were jarring against his pale skin. My sister messaged him and confirmed it was him.

Ben told her that he had cancer again. We felt badly for him but didn't think much of it – he would probably be better soon. Months after seeing that game, around Christmastime, I logged into MSN and saw that many of my friends had "RIP Ben" or something similar in their profiles. Confused, I asked a friend what happened, and she told me that he died. I remember feeling sick and shocked – we were only 15! As a naïve teenager, I could not believe that he could have died from this cancer. After his death, I became more aware of pediatric cancer, but my shift into exploring it as a research topic came while I was in my undergraduate studies.

Heading to McMaster University for my undergraduate career exposed me more to pediatric oncology. The university is attached to a children's hospital, and so I would walk through the hospital every day to get to campus because my bus stopped right outside the hospital doors. I saw a lot of families and children there, walking around with IV poles and striped gowns, or getting something to eat at one of the cafés. I also became more aware of popular depictions of pediatric cancer, which showed sad-looking children with bald heads. In particular, Ronald McDonald House had become much more well known to my friends and I through their advertising and fundraising campaigns, and because it was located beside the hospital. I had a friend who volunteered there throughout undergrad, and she told me how rewarding it was – she loved being able to help the families and play with the kids. As she told me how much she enjoyed it I was a little envious – I too wanted to be someone who could get involved and help these families and their children. Maybe I could feel as though I was doing something that made their bad experiences a little bit better. I didn't realize that it would also lead me into my research trajectory.

My interest in pursuing research in pediatric oncology began when I was in my third year, which is when I became a volunteer with Ronald McDonald House and worked in the "Family Room" in the hospital. This room provided respite for families whose children were staying in the hospital; it was stocked with food, drinks, coffee, televisions, toys, and a washer and dryer, and contained multiple quiet nooks where families could spend some time alone. As volunteers, we did various things to help the families, including leaving them alone when they came into the room, making them a fresh pot of coffee, sitting with them, talking and listening to them, and even doing their laundry so that they are met with a bundle of clean clothes when they return to the Family Room. Sometimes, if I was lucky, the kids would come to the room as well, to have some quiet moments of play by themselves or with their siblings. Playing with the kids was always my favourite part of volunteering there.

It was one of these play nights that ultimately steered my research trajectory. I was sitting by myself at our front desk when a little girl came in with her mom. The girl was around five or six years old and bald, with the angry red line of an incision spanning from her

temple to the back of her head. She was wearing a bright pink robe, and had an IV sticking out of her hand, which was attached to an IV pole that she dragged along beside her. Mom quietly said hello to me and told me they wanted to come and watch TV for a little bit by themselves. I directed them to a corner of the room where they could have some privacy and directed mom to the kitchen in case she wanted to make something to eat. Mom walked over to the kitchen while I stayed with her daughter. I said "hi" and asked her what her name was. She said "hi" back and told me her name while struggling to get on to the couch because it was too high for her. I asked her if she wanted me to lift her up, and she said yes, warning me to be gentle with her because her bum was sore. (I learned later that they had taken a skin graft from her behind to patch up her scalp, as she had a large brain tumour removed six weeks prior). I lifted her up onto the seat, got her an oatmeal cookie (with mom's permission), and we began to chat. She told me all about her pink robe, her classmates at school, and what she liked to watch on TV. At this point her mom had come back and was watching us talk, quietly crying to herself, which I did not notice until a couple of minutes had passed. When I turned around and saw her, I instantly panicked – did I hurt her daughter? should I not have given her a snack? did I offend her somehow? I immediately started apologizing and she stopped me. Through tears, she told me that in the six weeks they had been in the hospital, her daughter had refused to speak to anyone who was not a family member – I was the first person she had spoken to.

This experience shaped how I came to the topic of my Master's thesis, in which I explored the long term effects of cancer treatment on young adults (aged 21-28) who had cancer as children as well as on their primary caregivers. In this study – my first experience conducting qualitative research – I found that: the time during their treatment was marked with a rollercoaster of joys and sorrows (Molinaro & Fletcher, 2017a), many of the participants were already experiencing late effects, or living with outcomes from their treatment, such as amputations (Molinaro & Fletcher, 2016, 2019), that they felt compelled to "give back" to cancer charities or by participating in a mentoring program with children who had cancer (Molinaro & Fletcher, 2018), and that the term "survivor" held different meanings to different participants (Molinaro & Fletcher, 2017b).

When I was applying to PhD programs, I knew that I wanted to continue doing pediatric cancer research, but was unsure of what, exactly, I wanted to continue to study. A number of my PhD courses steered me towards conducting narrative research, in particular Dr. Laliberte Rudman's course on qualitative research methodologies, and a directed reading course I took on interdisciplinary perspectives on narrative, health, and medicine with Dr. Polzer and another graduate student in the English department. Throughout this narrative course, we engaged deeply with a number of articles and other forms of narratives (e.g., documentaries, graphic novels) on different topics within health and medicine that slowly shifted how I came to think of and understand pediatric cancer and pediatric oncology.

1.2 Critical Shifts: Questioning Common Conceptions of Pediatric Cancer

The first shift that happened came when I watched Pink Ribbons Inc. (National Film Board of Canada, 2011) by Léa Pool. This documentary brilliantly highlights how corporate philanthropy has shaped public perceptions of breast cancer and notions of breast cancer survivorship by sponsoring annual fundraising events, such as annual runs for breast cancer. This documentary highlighted that these corporate campaigns place emphasis on breast cancer "survivors" who "fight" cancer through their active participation in these runs, thereby excluding a range of women and breast cancer experiences, including women with stage IV breast cancer. The promotional narratives of these events position women who die from cancer as having not "fought" hard enough, thus individualizing their prognosis as a personal failure (Pack, 2020). As well, the documentary reveals how the majority of money earned through these campaigns is used to pay for overhead, staff, and promotional materials, while a very a small proportion of the money that is collected actually goes to research, necessary equipment, and supporting patients and their families. Some of the companies that endorse these fundraisers are also questioned for their role in actively contributing to causing breast cancer, by creating iatrogenic products, such carcinogenic parabens in makeup (breastcancer.org, 2020; Konduracka, Krzemieniecki & Gakos, 2014). This helped me understand how corporate narratives drive public perception by redefining breast cancer

patients as "fighters" who are active agents against their cancer; the stories of others with breast cancer who do not fit this master narrative are purposefully obscured so that those donating money feel as though they are fundraising for a successful cause.

Not long after I watched this documentary, a series of commercials and advertisements came out from the SickKids Foundation (known as the *SickKids VS*. campaign (SickKids, 2017)) that featured children with cancer and other diseases, such as cystic fibrosis and autism, and frustratingly drew on many of the same war metaphors and battle analogies used in breast cancer campaigns. These ads typically frame children similarly to women in breast cancer campaigns: as active fighters who inevitably win their battles against disease and emerge victorious. In the *SickKids VS*. campaign, this victory was depicted with imagery of children standing on top of piles of broken medical equipment, the "weaponry" that enabled them to stand tall and proud after successfully "defeating" their illness.

By emphasizing the glory of survivorship, these representations of cancer overlook the ways in which children are often passive recipients of treatments administered by those caring for them. As well, the iatrogenic nature of pediatric cancer treatments produces multiple physical and often damaging long-term side effects that typically are not represented within these public narratives. Rather, children are presented as coming out unscathed with the exception of chemotherapy-induced alopecia (hair loss), which functions visually in the ads to indicate a child's cancer diagnosis.

While the current survival rate of pediatric cancer is above 80% (Canadian Cancer Statistics Advisory Committee [CCSAC], 2019), many children will still die. In 2016 in Canada, cancer was the leading cause of disease-related death in children under 15 (CCSAC, 2019), and second in all-cause mortality after accidents (CCSAC, 2019; Ellison & Janz, 2015). Overall, the one-year survival rate for all childhood cancers is 93%, and five-year survival is at 84% (CCSAC, 2019). While the incidence of pediatric cancer is low (approximately 943 cases per year in children aged 0-14 in Canada) (CCSAC, 2019), pediatric cancer is one of the most highly publicized cancers (with the exception of breast cancer) and has a large fundraising presence in the media, as evidenced by the

advertisements developed by the SickKids Foundation.

My next shift in my understandings of pediatric cancer happened as I was reading *Teratologies* by Jackie Stacey (1997), who, similar to Pool's analysis in *Pink Ribbons Inc.*, illuminated how adults often face blame for their diagnoses of cancer. Stacey (1997) contrasts the disjuncture between cultural understandings of cancer, and her own experience as a lesbian diagnosed with a teratoma in one of her egg cells. As she describes throughout her book, her questionable morality and decision-making are often suggested as the reasons underlying the development of her cancer. In particular, she highlights how cancer is culturally constructed as a sign of a person's inner weakness, self-destructiveness, and moral decay; cancer is "a disease 'occasioned' by the self" (Stacey, 1997, p.175) and a diagnosis of cancer is therefore a sign of some personal, lifestyle, or moral failing.

In contrast to Stacey's critique of the ways in which adults with cancer are blamed for having cancer, children with cancer tend to be portrayed as blameless victims of their disease (Clarke, 2005). Because cancer is typically considered a disease associated with aging, a pediatric cancer diagnosis disrupts common conceptualizations of cancer and childhood (Dixon-Woods et al., 2001). Cultural perceptions of childhood as the start of life and as a time ripe with potential are incommensurate with cultural perceptions of cancer, which signal moral decay and are strongly associated with decline and death. The threat to the future potential of the child is further emphasized by prevailing discourses on childhood innocence and the societal belief that children should be protected (Clarke, 2005; Dixon-Woods et al., 2001). Pediatric cancer thus disrupts the normative understandings of the developmental trajectory of childhood whereby childhood and adolescence are considered uninterrupted times of growth and development (e.g., physically, emotionally, psychosocially), which cancer delays, hinders, challenges, and, in some cases, stops altogether. While these discourses produce a belief that childhood cancer is greatly unfair (Clarke, 2005), a diagnosis of cancer during adulthood is often framed as a moral and personal failing to properly ward off such a fate, through lifestyle changes, such as diet and exercise (Butts Stahly, 1988; Stacey, 1997; Willig, 2011).

My engagement with Audre Lorde's *The Cancer Journals* (1980) was another critical shift for me. Lorde's writing in her *Journals* speaks powerfully to the ways in which narrative, or storytelling, can function to counter common understandings of cancer, which privilege dominant (white, middle-class) social positions. I became especially attuned to the ways in which she located herself as a "Black, feminist, lesbian, poet" throughout her journal. I wrote a paper on her repeated use of this phrase, to explore what I now understand as Lorde's counterstory about her experience with breast cancer, which is written from her specific social location and purposefully draws attention to the ways in which her experiences do not fit the mold provided by master narratives of breast cancer. The mismatch of her own experience and these master narratives are brought into sharp relief when she was fitted for a breast prosthesis, which only came in shades that matched white skin tones.

As my thinking shifted to consider the broader cultural narratives that shape how cancer is viewed and experienced, I reflected on my research with my Master's study participants, whose stories about their cancer treatment countered common portrayals of children with cancer. For example, they would describe the gruesome side effects they experienced, such as having to be put in a coma and having their limbs develop necrosis and amputated, and the late effects of treatment they experienced as adults, such as developing learning disabilities, needing hip replacements, and going into early menopause or being rendered infertile. They also spoke about their care providers frequently in their stories, and I began to wonder how formal cancer care providers, such as oncologists and nurses who work in pediatric oncology care settings, experience their caregiving for pediatric patients and are influenced by broader discourses and social contexts. My decision to include only nurses was heavily informed by a conversation I had with a friend's sister, a pediatric oncology nurse, who affirmed that pediatric oncology nurses hold a range of caregiving responsibilities and have sustained proximity with families, whereas oncologists' interactions were more limited. She also told me that there are nurses working in a range of pediatric oncology settings, and so there would be a more diverse set of nurses to sample from who would have multiple perspectives. After this conversation and consultation with my thesis committee, I decided to focus my doctoral research on the perspectives of pediatric oncology nurses. As my critical

awareness about public narratives of cancer was growing, I began to wonder how nurses perceived these narratives and worked within them – would they, like the participants in my Master's research, tell me stories that were counter to what we commonly assume about pediatric cancer and pediatric cancer caregiving?

1.3   Pediatric Oncology Nursing in Ontario

Currently, pediatric cancer treatment is available at 17 centers throughout Canada, including five major hospitals within Ontario. According to the Pediatric Oncology Group of Ontario (Childhood Cancer Care Plan, 2018), provincial planning for childhood cancer care and control in Ontario began in the late 1980s and was generated to help create a better integrated, geographically comprehensive provincial system of pediatric cancer care, including seven satellite clinics and eleven Interlink nurses that cover the geographic areas between hospitals and satellite clinics. Within this network of hospitals and satellite centers, a multitude of health care providers are responsible for performing a wide range of physical, emotional, communicative, administrative, social, and relational care (Canadian Cancer Society, 2021; Newman et al., 2019). Within this domain of caregivers, nurses are understood as occupying a unique position in pediatric cancer care. According to the Canadian Cancer Society (2021) webpage for parents with children who have cancer:

> Nurses give daily nursing care in the hospital or at home. They often have the most contact with you and your child. Nurses give medicine, take blood, give chemotherapy and give any other care your child will need while they are being treated. Nurses are often involved with teaching and helping your child and your family. They can answer questions and give emotional support. A nurse helps to admit you into the hospital, performs important monitoring while in hospital and makes sure you are prepared when your child is discharged from the hospital. Many nurses will care for your child, and there are different types of nurses with different specialties.

As suggested above, nurses are understood as being responsible for a wide range of caregiving tasks and as occupying a unique spatiotemporal position; they provide care in the hospital and in a child's home, and they are often the caregivers in the closest physical proximity to pediatric patients and their families and for the duration of a child's cancer experience.

In Ontario, pediatric oncology nurses work within a range of care environments that are dedicated to caring for patients with different types of cancer with varying severities. Inpatient settings focus on both providing treatment and care for children who are acutely ill (Canadian Cancer Society, 2021; Childhood Cancer Care Plan, 2018). Outpatient clinics (or satellite clinics) are care settings where patients whose cancers are manageable from home receive medications, such as chemotherapy, medical procedures, such as blood transfusions, and where they receive additional forms of care, such as education on side effects (Children's Oncology Group, 2011a, 2011b; Childhood Cancer Care Plan, 2018). In Ontario, Interlink nurses travel across designated geographical regions to make home visits with patients and families post-treatment to check if they need help attaining resources. Interlink nurses also provide educational school visits on behalf of children and families with cancer, to help staff and students learn about that child's cancer (Childhood Cancer Care Plan, 2018).

1.4   Framing my Research: Moral distress

Initially, I was compelled by the notion of moral distress as a framing concept for my research because of my understanding that pediatric oncology caregiving would revolve around the suffering and emotional devastation that is commonly associated with pediatric oncology. As I undertook my research, I began to realize how moral distress, or "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (Jameton, 1984, p.6), was a constant presence in my participants' stories; it underpinned their narrations and was at times discussed explicitly. During the analysis process, I came to understand these stories of moral distress as instances of counterstories – that is, in their storytelling, they countered common conceptions that nurses experience moral distress because pediatric oncology is emotionally devastating. Rather, their experiences of moral distress manifested in their stories about: the difficulties they had completing their caregiving tasks; the intensification of their workloads; their struggles to provide care among competing demands; their bearing witness to suffering; their bonding with colleagues to stay resilient through their experiences of trauma; and how they strived to be the nurses they wanted to be.

Through their storytelling, the institutional constraints that shaped their experiences of moral distress became more discernible. Similarly, the stories of health care providers working during the COVID-19 pandemic drew (and still draw) attention to the institutional constraints as the root of moral distress. During the last year and a half, health care providers working in Ontario have been loudly applauded for heroically sacrificing their time, safety, and in some cases, lives, to care for patients during the pandemic. However, the popular framing of health care providers as "heroes" has deflected from the fact that they have been working in a health care system shaped by neoliberal policy and budget cuts, with the effect that "frontline" health care and support workers were not adequately supplied with personal protective equipment (PPE) at the beginning of the pandemic, and have had to frantically develop policies for caring for and triaging COVID-19 positive patients (Amarasinghe et al., 2020; Wu, Stayra, & Gold, 2020). Many of these health care providers did not receive additional compensation for their work or for having to isolate away from their families and loved ones (Bennett, 2021). Many health care workers have since burnt out, left their profession, or experienced moral distress as a result of their harried working conditions (Amarasinghe et al., 2020; Pelley, 2020; Wu, Stayra, & Gold, 2020), and some have voiced their concerns that the source of their moral distress is not COVID-19 itself, or the emotional difficulties associated with their health care work, but rather their lack of support from their institutions and provincial government (Bennett, 2021; Hepburn, 2020; Pelley, 2020).

Watching this unfold during the COVID-19 pandemic made me angry. I would think about the nurses in my study, all of whom were working during the pandemic, and some of whom worked on COVID-19 units. The stories they told me about their overwhelming working conditions, unsupportive management, and understaffing during our interviews were reminiscent of what was unfolding in real time. One night, while I was living at home during the first few months of the pandemic, we received a notice in our mailbox that the neighbourhood was going to bang pots and pans at 7pm to celebrate the "health care heroes" working in the pandemic. I grabbed the notice, looked at my mom, and angrily expressed: "half of this neighbourhood voted for our current government, who are the ones that cut spending to healthcare and won't supply adequate PPE, or compensate

providers for time in isolation. And yet they're going to go out and bang their pots and pans 'in appreciation'?!" I feel that, in the same way that the nurses in my study told counterstories to convey that their distress emanates from their working conditions and not from the emotional difficulties of providing care to kids with cancer, some of the health care providers working during the pandemic suggested that they were not willing "heroes", but rather were sacrificed by governments and institutions because of funding cuts and a lack of support (Mohammed, Peter, Killackey, & Maciver, 2021). The discourse of "healthcare heroes" normalizes the risks and conditions that health care providers must face when working in the COVID-19 pandemic.

Gaining a critical perspective that I revealed to my mom that day took many years to cultivate. When I began writing the proposal for this dissertation, I was very much still engrained in post-positivist ways of thinking. Through many nights crying and concerned that I would never be "critical" enough, and through the reassurance and support of Dr. Polzer, as well as the guidance of Drs. Laliberte Rudman, and Savundranayagam, I present to you this thesis, which has been constructed with a critical lens, and shaped by my perspective and reflexivity throughout the project. This is a story in which I explore the caregiving stories of pediatric oncology nurses and diagnose their moral distress as rooted in their intense workloads and institutional contexts. Their stories made me laugh, cry, and have additional sessions with my therapist, but this work has truly changed my perspective on pediatric cancer, nursing, moral distress, and healthcare, and has been a giant step forward in the direction of becoming the researcher I want to be.

Below, I outline how my dissertation unfolds.

1.5   Chapter overview

In *chapter two*, I present a review of the literature on pediatric oncology nursing, highlighting the need for critically oriented qualitative research in this area. I outline how a significant proportion of the pediatric oncology nursing literature combines the perspectives of nurses with other healthcare providers, thereby conflating nurses' caregiving experiences with those of other members of the health care team. From there, I explore how the limited literature on the experiences of pediatric oncology nurses

provides insight into their caregiving experiences with a specific focus on nurses' experiences of stress, burnout, and grief. I then highlight how a significant proportion of this research uses quantitative methods, and thus reduces understandings of these negative effects of pediatric cancer caregiving as a matter of nurses' personal failure or lack of ability. I present narrative methodologies as having the capacity to address an interpretive gap in this body of literature, and I argue for the need for critically oriented, narrative research to elucidate nurses' conceptualizations of caregiving and situate their caregiving experiences within broader institutional and discursive contexts.

In *chapter three*, I outline the conceptual frames I used to analyze my data, specifically moral distress, bearing witness, and narrative repair. I review the conceptualization of moral distress offered by nursing theorists Peter & Liaschenko (2004, 2013), who situate nurses' individual experiences in larger institutional contexts, such as the increased corporatization of healthcare informed by neoliberal ideologies. I review Peter and Liaschencko's (2013) theorization of moral distress in relation to moral identities, relationships, and responsibilities, and their call for counterstories to repair moral identities. I then proceed to put this conceptualization of moral distress in conversation with nursing scholars' conceptualizations of bearing witness and proximal nursing (Cody, 2007; Malone, 2003; Peter & Liaschenko, 2004), as well as with Frank's (2013) work on narrative repair.

In *chapter four*, I present the critical narrative methodological approach and the specific methods that were used for this study. I begin this section by outlining the central assumptions of narrative inquiry and critical narrative inquiry. From there, I describe the methods used in this study, including the overall design of the study, recruitment of participants, and data collection and analysis techniques. I also include my methodological reflections, with a particular focus on how my narrative analysis allowed me to understand the ambivalences and ambiguities that characterized the study participants' stories and storytelling. Details regarding ethical considerations and quality criteria are addressed at the end of this chapter.

In *chapter five*, I present the participant narratives. These narratives provide an overview of each participant's caregiving background and context. In each participant narrative, I outline and describe the nurse's narration style, and highlight the main contours of their stories, including their motivations for working in pediatric oncology, how they assigned meaning to their caregiving, and how they navigated their institutional contexts.

In *chapter six*, I present the findings of my study in four overarching narrative themes: i) stretched too thin; ii) bearing witness; iii) bonded by trauma; and iv) caregiving and narrative repair. In s*tretched too thin*, I focus on how the nurses felt as though they could not be the nurses they wanted to be while working within the chaotic and relentless conditions that required them to pivot among competing caregiving demands and distance themselves from relational caregiving. In b*earing witness*, I present stories to illustrate how the nurses become entwined in the family's illness narrative and how they engaged in and ascribed meaning to the narrative proximity they had to families and patients. As well, these stories show how the nurses had to bear witness to suffering and how they experienced moral distress because they were limited from being morally proximal to their patients. In *bonded by trauma*, I present the nurses' stories of how they bond together to survive the chronic traumas of their work, which they located in unsupportive management, as well as the sudden, acute traumas, such as when a child suddenly dies. Lastly, in c*aregiving and narrative repair*, I describe how the nurses strived to be the nurses they wanted to be by repairing the families' narratives, as well as their own fractured moral identities, through their caregiving and storytelling.

In *chapter seven*, I discuss my findings in relation to the existing research on pediatric oncology nurses and in relation to the theoretical concepts that frame my analysis. In particular, I describe how the critical narrative methodology employed in this study contributes to our understandings of how neoliberal ideologies and the increased corporatization of health care had bearing on my nurses' experiences of moral distress, and how the nurses told counterstories to draw attention to and make visible the caregiving they ascribed meaning to. I highlight how my nurses' stories illustrate and provide narrative depth to Peter & Liaschenko's (2013) theorization of moral distress in relation to nurses' moral identities, moral relationships, and moral responsibilities. As

well, I outline how my findings expand upon and challenge individualized conceptualizations of bearing witness, and how nurses often felt constrained in their ability to bear witness to their patients. I then illuminate how my study extends Frank's (2013) conceptualization of narrative repair. To conclude this chapter, I highlight the strengths and boundaries of my thesis and discuss the implications of my research findings for further research, policy, and practice.

Chapter 2

2 Literature Review

In this chapter, I situate my study within the research literature on pediatric oncology caregiving. In particular, I identify how literature on pediatric oncology caregiving emerged as a field of research in the 1970s, and how much of this literature includes the perspectives of nurses, but often conflates their experiences with other caregivers, such as oncologists. From there, I describe and discuss the literature that explores nurses' caregiving experiences. I also delve into the pediatric oncology caregiving research that primarily focuses on the experiences of nurses and discuss how this literature focuses on nurses' experiences of stress, burnout, and grief. I conclude this chapter with a discussion of the merits and limitations of this body of literature. In particular, I point to the ways in which existing research tends to present a decontextualized and reductionist view of nurses' abilities to manage their own experiences of stress, burnout, and grief, and to how the perspective taken up in my research adds to this body of scholarship by linking individual caregiving experiences with broader contexts.

2.1 Research on Pediatric Cancer Caregiving

Pediatric cancer began to surge as an important area of research in the 1970s in response to an increasing incidence of pediatric cancer in North America, and advancements in pediatric cancer treatment. Highly cited studies conducted during this time include randomized control trials to determine the best courses of treatment and prognosis for particular cancers, and research on the experience of survivorship and long-term effects of pediatric cancer treatment (examples of some highly cited studies include D'Angio, 1975; D'Angio, Evans, Breslow, et al., 1976; Evans, Gilbert, & Zandstra, 1970; Koocher et al., 1980; Sutow et al., 1970). More recently, this body of research has examined the experiences and needs of the caregivers of pediatric cancer patients (e.g., Manne et al., 1996; Martinson et al., 1999; Wells et al., 2002), where caregivers include parents and other family members (e.g., grandparents, aunts and uncles) and a myriad of health care

providers (HCPs), such as oncologists, nurses, child life specialists, and social workers (CCSAC, 2019).

This research highlights that pediatric oncology nurses occupy a demanding position in the pediatric cancer caregiving context; while they are members of a large team of healthcare providers caring for children with cancer, nurses occupy a unique spatiotemporal position in pediatric oncology caregiving and thus shoulder a significant amount of the care work for both the child and the family (Bond, 1994; CCSAC, 2019; Cohen & Erickson, 2006; Evans Emery, 1993; Hinds et al., 1990; Mukherjee et al., 2009). However, much of the research that addresses the perspectives and experiences of pediatric oncology nurses groups them with other caregivers in pediatric oncology, such as oncologists (e.g., Barnes et al., 2014; Bartholdson et al., 2015; Montgomery et al., 2016) and parents of pediatric cancer patients (e.g., Beykmirza et al., 2019; Mirlashari, Ebrahimpour, & Salisu, 2021). In particular, nurses' perspectives are often combined with other health care providers and studied as one large group, generating a generalized view of caregiving experiences, which are sometimes used to supplement the perspectives of other informal caregivers, such as parents.

For example, in a widely cited qualitative study by Hedström et al. (2003), 50 children, 65 parents, and 118 nurses were asked to discuss distressing events they had experienced during their time in pediatric oncology. Anticipating that the children in this study were too young to communicate and express themselves verbally, the perspectives of mothers and nurses were included to help "achieve an adequate picture of their experiences in relation to disease and treatment" (p.121). However, the primary focus of this study was on the perspectives of the children, and the data collected from the nurses and mothers were used to supplement their perspectives. Thus, the experiences of mothers and nurses were rarely discussed.

As another example, a recent qualitative study by Mirlashari et al. (2021) combined the perspectives of children undergoing cancer treatment, their parents, and their nurses in order to examine the experience of pediatric cancer care during the COVID-19 pandemic in Iran. The results of this study indicated that children and their families felt that they

were afraid of what getting COVID might mean for them, and that they had to spend even more time isolating from friends and family members. Nurses' perspectives were highlighted in the third theme of the results, which focused on how families' and children's needs, particularly their emotional needs, were overlooked in order to prioritize the needs of the health care system, leaving the children and families feeling as though they were not receiving good quality of care.

When considering research that has combined perspectives of nurses and oncologists, Bartholdson et al.'s (2015) survey on the ethical climate of pediatric oncology included physicians, nurses, and nurse assistants. Physicians rated all items on the survey more positively than nurses, suggesting that nurses perceived the ethical climate of their institutions more negatively than physicians. Furthermore, nurses' notable responses on the surveys were highlighted, and included their concerns that: physicians were not listening to nurses and nurse assistants regarding treatment-related decisions; their opinions were not respected by other professions or included in decision-making about was in the best interest of their patients; they did not have access to the necessary resources to solve ethical issues. Nurses also indicated that they trusted each other, as well as their assistants.

Other literature on pediatric oncology caregiving that has examined the perspectives of pediatric oncology nurses in conjunction with other health care providers and informal caregivers, such as parents, includes research exploring oncologist and nurse perspectives on the efficacy of phase I clinical trials (Barnes et al., 2014), health care provider perspectives (e.g., nurse, nurse practitioner, dietician, physician) on nutritional support during pediatric cancer treatment (Montgomery et al., 2016), pediatric and adult oncology nurses' experiences of burnout (Davis, Lind, Sorensen, 2013), and pediatric oncology nurses and mothers' perspectives on nurses' adherence to ethical codes (Beykmirza et al., 2019).

Although research on pediatric oncology caregiving that combines nurses' perspectives, experiences, and understandings in combination with other caregivers is useful for generating knowledge about what may be involved in pediatric cancer caregiving and its

effects on caregivers, they may assume that cancer care providers undergo a similar range of experiences and have similar perspectives on caregiving. Thus, these studies do not provide an in-depth understanding of how nurses specifically experience their caregiving within pediatric oncology caregiving contexts.

2.2   Pediatric Oncology Nursing: Forms and Experiences of Caregiving

Research that focuses on pediatric oncology nurses' caregiving experiences is varied; some research is focused on the highly specific skillsets and tasks that nurses complete within the scope of their caregiving, while other studies have been conducted to explore nurses' experiences of providing care, and how nurses ascribe meaning to this care, which I discuss below.

Quantitative research in this field has enhanced understandings of pediatric oncology nurses' specific skillsets, including research on nurses' nutrition-related clinical decision making (Lulloff et al., 2019), nurses' experiences with prognostic-related information (Newman et al., 2018), gauging nurses' understanding of children's oral health needs (Perry et al., 2015), and understanding nurses' attitudes about fertility preservation for their patients (Clayton et al., 2008). These specific skillsets were described in an article on pediatric oncology nursing by Cantrell (2007) as constituting the "science" of pediatric oncology nursing. Distinguishing between the "art" and a "science" of pediatric oncology nursing, Cantrell (2007) contends that emphasis in the research literature and public understandings is on the "science", which includes the provision of care in relation to administering treatment protocols. Cantrell (2007) further argues that while the tasks involved in this science of nursing practice are necessary, in order for them to "be truly effective, they must be embedded within the *art* of nursing practice" (p.132, emphasis added), which includes "nursing presence" (p.133), and which thus involves physical proximity to the patient and their family. Cantrell argues that the art and the science are connected; even administering medication and treatments, such as chemotherapy, involves nursing presence, knowledge of the patient, creativity, and resourcefulness. She provides an example of the "artful" tasks involved in giving chemotherapy to a patient, that are often taken for granted:

as the pediatric oncology nurse prepares the drugs to administer, she or he also considers several other critical aspects in the plan of care. The nurse considers the manner by which she or he will enter the adolescent's room with the chemotherapy, the timing of when to enter the room, the meaning of this experience for the adolescent and his or her family, the nature of how to approach the patient, and how much interaction to have with the adolescent (how much or how little to say). (p.135)

By pointing to the connection between the art and science of pediatric oncology nursing, Cantrell highlights how the interactions necessary to facilitate treatment will vary by patient, and that these interactions are often dependent on how well the nurse has come to know the patient and their family. She concludes by calling pediatric oncology researchers and nurses alike to "give serious attention to discover its nature before the art of pediatric oncology nursing becomes lost" (p.138). In particular, she suggests that it is important make the art of nursing visible, particularly through qualitative means, as the art of nursing is "challenging to quantify" (p.133).

There is a small body of qualitative research that has elucidated the "art" of pediatric oncology nursing, including nurses' experiences of providing care, and how nurses conceptualize and assign meaning to this care. Specifically, this body of literature has focused on the perspectives of student nurses working in pediatric oncology and their experiences of transitioning from their education to practice (Kostak, Mutlu & Bilsel, 2014; Mirlashari, Warnock & Jahanbani, 2017), nurses' understandings of their perceptions of professional development (Hopia & Heino-Tolonen, 2019), the lived experiences of pediatric oncology nurses who were once pediatric oncology patients (Conte, 2018), and the care practices and meaning of care for nurses working in the bone marrow transplant unit (Morrison & Morris, 2017). As well, qualitative methods have been used to generate knowledge about specific skillsets and caregiving tasks in pediatric oncology nursing, such as communication during palliative and end-of life care (Montgomery, Sawin, & Hendricks-Ferguson, 2017) and distracting children during painful procedures (Olmstead et al., 2014).

Some of the above studies highlight the tumultuous transition that nurses undergo as they transition from their nursing education to pediatric oncology nursing settings (Kostak, Mutlu & Bilsel, 2014; Mirlashari, Warnock & Jahanbani, 2017). Kostak et al. (2014)

found that new nurses experienced difficulties communicating with families and patients, particularly because they were attempting to navigate patients' and patients' parents' feelings, as well as patients' senses of autonomy. Additionally, new nurses experienced fear and anxiety about making caregiving mistakes, and feelings of helplessness about not being able to do anything about patients' prognoses when they are dying. Mirlashari et al.'s (2017) study on nursing students who were completing clinical practica in palliative pediatric oncology generated similar findings using semi-structured interviews and daily self-reflective journals for content analysis. The students described that their first few days in pediatric oncology nursing were ridden with anxiety, as they did not know how to approach the patients and their families or have sufficient knowledge to provide care for them. After their first few days working in pediatric oncology, these students became used to the care environment, often referring to pediatric oncology as "a different world" (Mirlashari et al., 2017, p.12). Students also reported that self-reflective journaling allowed them to express how they were feeling and process their emotions related to caring for dying patients and their families. Both of these studies suggest the ways in which nurses are unprepared for what pediatric oncology caregiving entails, particularly regarding situations of death and dying, as they often felt unsure of what they could do or how they could help and provide care for families during this period.

The literature examining pediatric oncology nurses' caregiving experiences has also examined how nurses provide care for their patients (and patients' families) through palliative care. de Souza et al. (2013) conducted a narrative study to provide insight into "the meaning of dignified death and the interventions employed by nurses in pediatric oncology to promote dignified death for children" (p.1). The authors highlighted how nurses took it upon themselves to promote a dignified death for their patients, which involved: creating emotional bonds with the child and family and offering support to the family by way of physical comfort, being present, alleviating pain, providing holistic care, and learning how to cope with death and dying in order to better help families. Although the presented narratives identified the ways in which institutional demands constrained nurses' abilities to promote dignified death for their patients and how they lacked autonomy in their work and decision-making, the authors' analysis of their perspectives did not explore these constraints in depth or provide insights into how these

constraints could be alleviated or rectified. Instead, the authors offered suggestions for how nurses could better care for dying children individually. As an example, the authors conclude their discussion section by stating that nurses need to be attuned to the ways in which families' behaviours may have bearing on their coping when their child dies: "the nurses need to understand the reactions and behaviors families exhibit before death to assist them in their needs during the end-of-life process" (p. 36).

2.3   Challenges and Effects of Pediatric Oncology Nursing: Stress, Burnout, and Grief

In addition to the above literature, which provides insight into the forms and experiences of pediatric oncology caregiving, a significant amount of research on pediatric oncology caregiving addresses occupational challenges, including the stressors related to pediatric cancer nursing (e.g., Evans Emery, 1993; Lazzarin, Biondi & Di Mauro, 2012; Mukherjee et al., 2009; Wilkinson, 1988). In this section, I provide an overview of the literature that focuses on nurses' experiences of stress, burnout, and grief.

Quantitative and qualitative studies alike point to pediatric oncology nurses' experiences of stress (e.g., Bond, 1994; Hecktman, 2012; Hinds et al., 1990; Hinds et al., 1994; Hinds et al., 1998; Hinds, 2000; Maytum, Heiman, & Garwick, 2004; Skeens et al., 2019). A significant portion of this research has been driven by Dr. Pamela Hinds, a pediatric oncology nursing researcher, who developed the Stressor Scale for Pediatric Oncology Nurses (SSPON). This Stressor Scale quantifies and measures the job-related stressors of nurses working in pediatric oncology (Hinds et al., 1990). These quantitative studies typically aim to delineate and describe specific sources of stress for pediatric oncology nurses, how nurses react to these stressors, and what they (or others) can do to mediate and resolve these stressors (e.g., Hinds et al., 1994, 1998, 2003). These studies also tend to focus on comparing stress responses in newer versus more experienced pediatric oncology nurses (Hinds et al., 1994) and on the further development and refinement of these stressor scales (Hinds, 1998; Hinds et al., 2003) in order to develop interventions to better support pediatric oncology nurses.

This body of research identifies a number of stressors for pediatric oncology nurses, including: a lack of resources and staff to provide quality care; administering highly aggressive treatments, being overburdened with a high patient load, having to witness children in pain, suffering, or dying; hearing of a patient's relapse or death, making treatment mistakes; and having poor relationships with managers (Bond, 1994; Cohen et al., 1994; Evans Emery, 1993; Florio, Donnelly, & Zevon, 1998; Hecktman, 2012; Jameton, 1984; Mukherjee et al., 2009; Solomon et al., 2005). Some of this research has linked these stressors to high levels of staff turnover and burnout, as well as a high incidence of anxiety and depression in pediatric oncology nurses (Davis, Lind, & Sorensen, 2013; Mukherjee et al., 2009; Sadovich, 2005). Further, this literature has reported that pediatric oncology nurses often experience stress, ethical dilemmas, and difficulty in maintaining professional boundaries (Bond, 1994; Cohen et al., 1994; Hinds et al., 1994). Some of the research has attributed this stress to spending prolonged periods of time with children and their families (Stutzer, 1989), while other research has linked nurses' stress with their daily occupations, particularly the variety of caregiving tasks they are responsible for, including post-mortem caregiving, which includes removing equipment, cleaning, and dressing the child after they have died, and providing emotional support to the family (Hecktman, 2012).

Some studies have situated the stressors associated with pediatric oncology caregiving in relation to broader contexts. Morrison and Morris (2017), as an example, conducted focus groups with 24 nurses as "key participants" (p.214), as well as two smaller focus groups with two nurse managers, and seven caregivers of inpatients as "general participants" (p.214) to "better understand care for nurses within the context of their clinical practice on a pediatric BMT [bone marrow transplant] unit" (p. 214). The findings suggest that nurses experienced stress related to their caregiving because of having to complete multiple tasks that impeded their ability to provide emotional support to families, the blurring of professional boundaries with families, and because they felt that management, physicians, and parents did not listen to or appreciate their clinical expertise. Further, nurses identified open and honest communication with families and other members of the care team as necessary in order to provide good care for their patients, and that their relationships with their nursing colleagues were especially strong because they could not

speak about their work or frustrations to family and friends. The nurses appreciated being able to care for families with diverse cultural backgrounds, and "bearing witness to suffering" (p.219) because it helped them understand how to better help patients and their families. Although it was not a primary aim of the study, the authors note in their discussion that the nurses' negative experiences within their institutional contexts were consistent with other literature, pointing to the fact that institutional contexts have bearing on pediatric oncology nurses' caregiving experiences.

One quantitative study, conducted nearly two decades ago by Evans Emery (1993), had similar results as Morrison & Morris (2017), highlighting that working conditions and institutional constraints as sources of stress have been a longstanding issue for pediatric oncology nurses. Evans Emery (1993) used a descriptive, correlational design (the Pediatric Oncology Nurse Stressor Questionnaire, which she developed, with open-ended questions at the end of the survey) to examine the stressors "most commonly experienced by pediatric oncology nurses" (p. 87). Analysis of the responses of 155 pediatric oncology nurses indicated five "stress categories": death and dying concerns, moral and ethical dilemmas, professional communications, management issues, and working conditions. Specifically, the items that were identified by nurses as causing the most stress were: "when a favourite patient relapses or dies suddenly", "when my workload is too great to give quality patient care", "caring for families who are anticipating the death of their child", "lack of adequate staffing", "being a 'middle-man' between doctors and parents", and "when my supervisor does not try to make a situation better" (p.90). The findings of this research also suggested that nurses who worked night shifts had more stress, and nurses with less experience had more stress, especially in relation to providing palliative care. These findings are also similar to those of Mukherjee et al. (2009), who reported that sources of stress for pediatric oncology nurses include: poor support from management, poor relationships with colleagues, long and exhausting working hours, lack of time for socialization, having to witness a child in pain or suffering, and a lack of resources to provide quality care. These studies suggested that while some of these stressors stem from the relationships developed with families through pediatric oncology nurses' caregiving, many of these stressors are rooted in difficult working conditions, unsupportive management, and discord between the nurses and their colleagues.

Burnout is another commonly examined area in pediatric oncology nursing research and is often related to nurses' experiences of stress. Specifically, Leiter and Maslach (1998), who developed the widely used Maslach Burnout Inventory (MBI), conceptualized burnout as an incessant response to job-related stressors characterized by "overwhelming exhaustion, feelings of cynicism and detachment from the job, and a sense of ineffectiveness and failure" (p. 68). Research suggests that many pediatric oncology nurses leave this specialized field of nursing as a result of experiencing severe and prolonged burnout (Mukherjee et al., 2009; Sadovich, 2005), which manifests variously as emotional exhaustion, chronic fatigue, anger, depression, feelings of helplessness and defeat, and in physical symptoms including nausea, gastrointestinal issues, weight loss (or gain), headaches, and insomnia (Italia et al., 2008; Maslach, Schaufeli, & Leiter, 2001; Mukherjee et al., 2009). In addition to these physical manifestations, burnout has been linked to a number of social effects, including relationship difficulties with colleagues and family, indifference towards patients, increased absenteeism, and withdrawal from interactions with patients (Barnard, Street & Love, 2006; Peterson et al., 2008; Quattrin et al., 2006). Burnout is such a frequent and persistent phenomenon in pediatric oncology nursing that there are multiple literature reviews focused solely on examining the experiences of burnout in this professional group (e.g., Boyle & Bush, 2018; De la Fuente-Solana et al., 2020; Mukherjee et al., 2009).

Similar to the literature on pediatric oncology nurses' stress, the literature on their experiences of burnout often focuses on describing their burnout and comparing their experiences with other populations. For example, Liakopoulou et al. (2007), conducted a quantitative study with the goal of understanding the rate of burnout in pediatric oncology caregivers (primarily oncologists and nurses) compared to control groups of caregiving staff in other pediatric disciplines (pediatric orthopedics and general pediatrics). Using the MBI and a number of additional scales, the authors found that there were no statistically significant differences in burnout between the HCPs in pediatric oncology versus the control groups. However, roughly 40% of all the oncology staff reported experiencing emotional exhaustion, and emotional exhaustion was higher for individuals who were newer to pediatric oncology and who had difficulties with role clarity, particularly in regard to what their specific caregiving tasks and duties were. They

also found that depersonalization ("impersonal response toward the recipients of one's care" (p.145)) was higher in caregivers who did not have children and had less experience working in pediatric oncology. While this study did not separate the perspectives of nurses from other staff in pediatric oncology, it concludes that novice caregivers face working conditions and responsibilities that are incongruent with their education and expectations for their caregiving (Liakopoulou et al., 2007). David, Lind, & Sorensen (2013) further illustrate how pediatric oncology nurses' experiences of burnout compare to other nurse populations. In this mixed methods study, questionnaires and an observational, descriptive research design were used in order to understand differences in burnout between pediatric (N=15) and adult (N=59) oncology nurses who worked in inpatient and outpatient settings. The authors reported that adult oncology nurses had notably higher senses of personal accomplishment than pediatric oncology nurses. As well, the coping strategy that was most effective for all nurses was their relationships with their coworkers and their ability to rely on one another for support.

Much of the research on pediatric oncology nurses combines their perspectives with other caregivers and focuses on describing and comparing their accounts of stress and burnout with other caregiver groups. This body of scholarship often fails to address how and why this stress and burnout is experienced, and thus presents decontextualized accounts of stress and burnout and individualized solutions to these problems. This decontextualization is suggested in Evans Emery's (1990) letter to the editor of the *Journal of Pediatric Oncology Nursing*. A former pediatric oncology nurse and parent of a child who died from cancer, Evans Emery responded to an editorial in the journal that expressed concern about pediatric oncology nurses' lack of job satisfaction and burnout. Evans Emery's letter argues that one of the main reasons that pediatric oncology nurses burn out is because of the lack of support they receive from their management. Specifically, Evans Emery refers to the ways in which cost-cutting has resulted in understaffing, thereby requiring nurses to take on more responsibility and limiting them from providing what they believe to be high quality care. As a consequence, pediatric oncology nurses develop burnout, which manifests through their feelings of frustration:

> Frustration is the key – frustration that these nurses cannot possibly find the time to sit and read a story to a child afraid of being alone, or be with a parent when they need an understanding shoulder. Nursing management isn't there in the middle of the night, or on the holidays, or the weekends; but the bedside nurse is, and this feeling of alienation and "them against us" seeds those feelings of frustration. (p.47)

This commentary situates nurses' experiences of frustration within the constraints placed on their time by chronic understaffing. As her writing suggests, decontextualized research that focuses on burnout as an individual experience alone cannot actually resolve the cause of the burnout. Nurses' frustration, as Evans Emery (1990) highlights above, is the expression and effect of a deeper structural problem that leads to difficulties in care provision.

In addition to the literature on stress and burnout, a subset of the pediatric oncology nursing literature focuses specifically on nurses' grief in relation to their caregiving. This predominantly quantitative body of literature focuses on the effectiveness of support programs for nurses experiencing grief (Conte, 2010; Kaplan, 2000; Macpherson, 2008) and highlights that pediatric oncology nurses experience losses that result from unsuccessful treatment and when a patient dies, which compound the difficulty of their work (Conte, 2014; Wenzel et al., 2011).

For example, Papadatou et al. (2002) conducted qualitative interviews with 14 Greek pediatric oncologists and 16 pediatric oncology nurses about their experiences of providing care to children dying of cancer. The findings showed that for over half of all the oncologists and nurses (57%), the process of a child dying, and their eventual death, caused great distress (Papadatou et al., 2002). In particular, the oncologists and nurses were distressed by the fact that, in some cases, they could not ease the suffering of their patients and families, and that they were unsure how to help them (Papadatou et al., 2002). Additionally, the authors report that a substantial proportion of participants (43%) felt distressed when having to communicate the nature of the disease to the children and their families; in particular, participants noted that it was distressing when children asked about their prognoses because, in Greece, children are often shielded from their diagnoses and are unknowing of the fact that they have cancer, or that their condition may be

terminal (Papadatou et al., 2002). As well, when asked about the most stressful aspects of their careers, the majority of the nurses (71.4%) identified caring for a dying child in pain, followed by the unexpected death of a child (50% of nurses). Further, when speaking to the relationships that are developed with children and their families, half of the nurses stated that it caused them great distress to witness the death of a child with whom they had developed a strong relationship (Papadatou et al., 2002).

Similarly, Conte's (2014) qualitative study of the work-related losses experienced by pediatric oncology nurses found that, the longer nurses spend time with patients and their families, the more intense were their feelings of grief if the child died. In this study, nurses reported alienating themselves from loved ones and support networks when they experienced feelings of grief (so as to not burden them) and, as a result, ended up harbouring intense feelings of grief with reduced outlets for support. The nurses in this study also discussed the emotional labour they performed in order to keep working and maintain a sense of control over their caregiving work after a child died, as their work does not afford them the time to process their feelings after a patient died (Conte, 2014). Further, the results of this study indicate that the nurses' workplaces did not have sufficient staff to allow the nurses to take time off in order to process their feelings of grief.

2.4   Merits and Limitations of the Research on Pediatric Oncology Nurses

As I have highlighted above, the literature on pediatric oncology caregiving has generated insight from a range of pediatric cancer caregivers into how to treat particular cancers (e.g., D'Angio et al., 1976; Sutow et al., 1970), and generated knowledge about the specific skills and tasks involved in pediatric oncology nursing (e.g., Lulloff et al., 2019; Newman et al., 2018). As well, this body of literature has produced some insights into how pediatric oncology nurses' perspectives differ from other health care providers in pediatric oncology (e.g., Barnes et al., 2014; Bartholdson et al., 2015) as well as health care providers in other nursing environments (e.g., David, Lind, & Sorensen, 2013).

While the quantitative research on pediatric cancer nursing is well-suited to examine highly specific aspects of the caregiving experience by breaking down specific facets (e.g., stress) into a highly detailed set of responses, participants' responses and caregiving experiences are decontextualized, reduced to and limited by the response options provided in the research data collection procedures (e.g., questionnaires). This renders pediatric oncology nurses unable to provide detail about their caregiving experiences in their own words and from their own perspectives, and thus presents barriers to highlighting and examining the complex nature of pediatric cancer caregiving. More specifically, this body of research tends to describe and measure specific aspects of pediatric cancer caregiving, such as stress, burnout and grief, which remain decontextualized (e.g., Bond, 1994; Hecktman, 2012; Hinds et al., 1990; Hinds, et al., 1994; Hinds et al., 1998; Hinds, 2000; Maytum, Heiman, & Garwick, 2004; Mukherjee et al., 2009; Sadovich, 2005; Skeens et al., 2019).

By allowing participants to elaborate on their caregiving experiences and articulate their perspectives, qualitative studies on pediatric cancer caregiving have addressed many aspects of pediatric cancer caregiving that have been left unanswered by quantitative research approaches. Specifically, research on the experiences of pediatric oncology nurses has elucidated the care practices and meanings that nurses ascribe to their care (e.g., Morrison & Morris, 2017), the range of nurses' caregiving tasks and responsibilities (e.g., de Souza et al., 2013; Morrison & Morris, 2017) and highlighted the institutional contexts that have bearing on nurses' ability to provide care (e.g., Conte, 2014; Evans Emery, 1990). This subset of the literature on pediatric oncology caregiving has highlighted that nurses derive meaning from bearing witness to their patients and caring for patients and families through palliative care (Mirlashari et al. 2017; Morrison & Morris, 2017), that nurses are responsible for bridging patients, families, and other members of the health care team (Montgomery, Sawin, & Hendricks-Ferguson, 2017; Morrison & Morris, 2017), and that institutional contexts, such as understaffing, or lack of supportive management, have bearing on their abilities to provide care (de Souza, 2013; Evans Emery, 1990).

While this qualitative research has produced insight into what being a pediatric oncology nurse entails, many of these studies use qualitative data collection and analysis methods informed by post-positivist assumptions that emphasize researcher objectivity in order to uncover an objective truth that is generalizable, correlational, and comparable across nurse populations and other health care providers in pediatric oncology (e.g., Lazzarin, Biondi & Di Mauro, 2012). This emphasis is suggested in the efforts researchers make to remove their "biases" and to ensure and maintain objectivity and accuracy of the data through specific techniques such as triangulation and member checking (e.g., Nelson et al., 2017). Further, many of the qualitative articles also note limited generalizability and small sample size as limitations of their work (e.g., Conte, 2018; Newman et al., 2019). This could, perhaps, be a reason why much of the pediatric oncology nursing literature focuses on the experiences of nurses combined with other health care providers or caregivers.

Furthermore, many of the qualitative studies use qualitative data collection and analysis methods (e.g., interviews, focus groups, thematic or content analysis) without explicit acknowledgment of a particular epistemological alignment or methodological approach. Papadatou et al.'s (2002) study of pediatric cancer caregivers' experiences of providing care to children dying of cancer provides an example of how qualitative data were collected through qualitative means, and then quantified and reported in percentages, rather than interpreted. In this regard, these studies are epistemologically untethered and tend not to be explicitly informed by an interpretive position. Only one of the studies included in this literature review identified using a narrative methodology (de Souza, 2013), and one other study took an explicitly phenomenological approach (e.g., Conte, 2018). This emphasis placed on qualitative methods over qualitative methodologies, in part, may be an effect of restrictions placed on how research in health science and/or health professional journals is published. This emphasis on qualitative data is consistent with Dahlstrom's (2014) distinction between a narrative communication format, with its emphasis on storytelling, and a "logical-scientific writing" format that claims to be "context-free in that it deals with the understanding of facts that retain their meaning independently from their surrounding units of information" (pg.13614). This scientific writing format aligns with the stated goals of many health sciences journals that are

aimed at clinician audiences and conform to the principles of evidence-based practice. Within these formats, qualitative research is reported in ways that follow suit with the needs of the readers and users (Carpenter & Suto, 2008a). Despite the growth in popularity of critical and interpretive qualitative research methodologies in the health sciences, there is still much emphasis and legitimacy placed on the "hard" sciences and their notions of objectivity, reliability, and validity (Carpenter & Suto, 2008a). While the use of narrative and narrative methodologies within the health sciences has increased, Dahlstrom (2014) suggests that literature within the health sciences attempts to maintain this objectivity and validity by applying post-positivist principles and techniques.

In summary, while the qualitative studies have contributed to developing an understanding of the pediatric cancer caregiving experience, they often stay at a descriptive level and lack interpretive frameworks that enable them to connect personal experiences with broader institutional, political, and social contexts. This stifles critical thought about how personal meanings and experiences of pediatric cancer caregiving are embedded within, influenced by, and potentially reproduce and transform broader discourses and institutional frameworks. Through this decontextualization, the experiences and effects of pediatric oncology caregiving are often individualized as a matter of personal responsibility. This is reflected by some of the studies reviewed above, which allude to institutional constraints on nurses' ability to provide care (e.g., de Souza et al., 2013; Morrison & Morris, 2017), but that ultimately offer individual solutions (e.g., spend more time learning families' reactions and emotional responses during palliative care in order to care for them better) to institutional issues (e.g., a lack of education or training for giving palliative care).

An example of this individualization is provided by Sullivan et al. (2019), whose quantitative study aimed "to develop an evidence-based compassion fatigue program and evaluate its impact on nurse-reported burnout, secondary traumatic stress, and compassion satisfaction, as well as correlated factors of resilience and coping behaviours" (p.338). Prior to the start of the pilot program, the 37 pediatric oncology nurses reported their secondary traumatic stress, burnout, satisfaction, resilience and coping style. During the program, nurses were provided with: self-care and healthy

lifestyle resources; educational materials regarding compassion satisfaction and fatigue; nutrition support from a dietician available for consultations; time every month allotted for remembrance and debriefing about newly passed patients; and a respite room. The program structure framed the participants as active agents who needed to seek change by using these new resources in order to "enhance professional quality of life" (p. 341). There was no mention of the occupational conditions within which the nurses provided care, and how these conditions contributed to their feelings of burnout, stress, and compassion fatigue. This study placed the responsibility of managing compassion fatigue on the nurses' willingness and participation in the program, rather than on the institutional context in which this compassion fatigue was cultivated.

In contrast to the individualizing effects of these decontextualized, post-positivist research approaches, critical interpretive methodological perspectives allow researchers to connect individual experiences and the structural, institutional, and broader contexts that shape these experiences. Critical narrative methodologies use storytelling as the basis for connecting individual experiences to broader institutional and discursive contexts and provide the opportunity to situate nurses' pediatric cancer caregiving experiences within these contexts. This methodology can expand our understanding of the ways in which these contexts and discourses, and the caregiving practices they foster, shape how individuals provide care and how they can hope to provide care.

2.5   Conclusion

Existing research has shown that pediatric oncology nurses' perspectives are often combined with the perspectives of other caregivers within pediatric oncology. The research that focuses on the experiences of pediatric oncology nurses provides some insight into their caregiving experiences, as well as the tasks involved in their caregiving. The majority of the literature on pediatric oncology nurses emphasizes that nurses face occupational challenges that lead to the development of stress, grief, and burnout. A significant proportion of this research uses quantitative methods, and thus reduces understandings of these negative effects of pediatric cancer caregiving as a matter of nurses' personal failure or lack of ability. While some qualitative research elucidates pediatric oncology nurses' experiences of their caregiving, its emphasis on qualitative

data collection techniques over interpretive methodologies is also limited and typically informed by post-positivist assumptions.

In order to link nurses' individual experiences to broader institutional contexts, this thesis presents an analysis of pediatric oncology nurses' caregiving narratives using a critical narrative methodological approach. In so doing, this thesis elucidates how the nurses narrate their experiences of providing care, conceptualize and ascribe meaning to their care and caregiving, and experience moral distress within broader institutional and discursive contexts. In the following chapter, I outline the theoretical concepts that informed my analysis and enabled me to link nurses' caregiving experiences with their broader institutional contexts.

Chapter 3

3   Moral Distress and Pediatric Oncology Nursing

In this chapter, I outline key concepts that informed my data analysis and interpretation, with a particular emphasis on moral distress, as well as the related concepts of bearing witness and narrative repair. I begin by outlining definitions and conceptualizations of moral distress, including the one I align with in this thesis. I then link this notion of moral distress to neoliberalism and discuss how this neoliberal ideology, and the associated corporatization of health care, prioritize cost-cutting and economic efficiencies, which clash with nurses' idealized identities as relational caregivers. I discuss moral distress in relation to nurses' moral identities, relationships, and responsibilities, as conceptualized by Peter & Liaschenko (2013), and put moral relationships into conversation with Malone's (2003) work on proximity, which situates moral proximity within both physical and narrative proximity. I then connect these ideas about proximity to the concept of bearing witness and discuss how bearing witness informed my analysis. Lastly, I expand on Arthur Frank's (2003) concept of narrative repair, which suggests that storytelling can restore and repair the "narrative wreckage" that chronic illness, such as cancer, inflicts upon one's storied identity. In this section, I suggest that moral distress may be mitigated, and compromised moral identities repaired, through counter narratives that draw attention to nurses' experiences of moral distress from their own points of view.

3.1   Conceptualizations of Moral Distress

Moral distress was originally conceptualized in the context of nursing by Jameton (1984), who defined it as "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (p.6). Since then, many definitions expanding upon this original conceptualization have been advanced and moral distress has been researched in many health care contexts, particularly nursing (e.g., Burston & Tuckett, 2013; Epstein & Hamric, 2009; Hamric, Davis, & Childress, 2006; Meltzer & Huckabay, 2004; Peter & Liaschenko, 2004, 2013). Moral distress has become such a frequent and consistent phenomenon experienced by nurses that it is included in

the Canadian Nurses' Association (CNA) Code of Ethics (2002), which states that moral distress occurs in:

> [S]ituations in which nurses cannot fulfil their ethical obligations and commitments (i.e., their moral agency), or they *fail to pursue* what they believe to be the right course of action, or *fail to live up to their own expectations* of ethical practice, for one or more of the following reasons: *error in judgment, insufficient personal resolve or other circumstances truly beyond their control* (Webster & Baylis, 2000). They may feel guilt, concern or distaste as a result. (p.6, emphasis added)

This official definition and understanding conceptualizes moral distress primarily in relation to the nurses' individual failings and incompetence ("error in judgment") and lack of will ("insufficient personal resolve") and renders structural and institutional factors ("circumstances truly beyond their control") that create conditions conducive to moral distress invisible. In addition, it dilutes the seriousness of moral distress and the severity of its effects on nurses by describing these as "guilt, concern or distaste". It does not acknowledge the extent to which moral distress leads to serious psychological and health concerns, including depression, anxiety, and burnout, as well as feelings of helplessness, powerlessness, anger, frustration, and loss of confidence and self-worth (Lazzarin, Biondi, & Di Mauro, 2012; Lievrouw et al., 2016; Wilkinson, 1988).

Conversely, definitions of moral distress forwarded by critically oriented nursing scholars place emphasis on the conditions in which moral distress is fostered. Specifically, researchers have argued that moral distress is experienced in relation to structural and institutional factors and contexts that impose particular constraints that limit nurses' capacities to provide quality care (Pauly, Varcoe, & Storch, 2012; Peter & Liaschenko, 2004, 2013). In this thesis, I align with these framings of moral distress, which provide ways of understanding how individual experiences of distress (e.g., burnout) are produced and shaped by broader institutional conditions and constraints. In particular, moral distress has been conceptualized in the nursing literature as a phenomenon associated with the difficulties nurses experience when attempting to engage in ethical health care practice and uphold professional values and responsibilities while working in and navigating institutional systems that conflict with their values (Epstein & Hamric, 2009; Hardingham, 2004; Kälvemark et al., 2004; Kälvemark Sporrong et al., 2006;

Pauly, Varcoe, & Storch, 2012). The institutional roots of moral distress have been articulated by other health researchers, who have similarly argued that a positive ethical climate is necessary to support nursing practice and alleviate moral distress (McDaniel, 1997, 1998; Olson, 1995, 2002; Olson and Hooke, 1988). This is consistent with arguments for systemic policy changes to mitigate the increasing occurrence of moral distress in healthcare (Hamric, 2010; Kälvemark et al., 2014; Pauly, Varcoe, & Storch, 2012).

Much of the research literature on moral distress has highlighted that health care (particularly in a North American context) has shifted to a corporate model based on neoliberal economic and political priorities, beginning roughly in the 1980s (Hamric, 2010; Kälvemark et al., 2014; McGregor, 2001; Pauly, Varcoe, & Storch, 2012; Peter & Liaschenko, 2004, 2013; Polzer & Power, 2016). Neoliberalism is a political ideology that emphasizes that markets and public services should be deregulated, privatized, and have little governmental regulation and intervention. Now the key approach to governance within Canada, neoliberalism actively advocates for cuts to social services and programs and shifts responsibility for health and health care to the individual, as well as reframes public services in ways that can generate revenue and control public debt (McGregor, 2001; Polzer & Power, 2016; Valle, 2016).

As one of the largest social services in Canada, the Canadian health care system has been restructured and modelled through a neoliberal ideology (Valle, 2016), and as a result, has become highly corporatized. Fried, Deber, & Leatt (1987) define corporatization as an "organizational restructuring in the direction of an organizational form typically found in industrial corporations, characterized by clearly articulated corporate objectives and a division between corporate and operational levels" (pp. 567-568). A corporatized structure typically has a board of executives who are compensated (Brownlee, Hurl, & Walby, 2018; Ewell, 1972) and take on the role of advising and counselling the operational aspects of the organization. In health care, corporate organization is most obvious in the emergence of multi-institutional health care systems and "highly diversified corporate entities" (Fried, Deber, & Leatt, p.568; see also Brownlee, Hurl, & Walby, 2018), which may include both health and non-health divisions.

In keeping with neoliberal political ideologies, Canadian healthcare organizations have come under intense pressure over the last few decades to operate more efficiently, and have borrowed corporate approaches from the private sector to generate these efficiencies (Brownlee, Hurl, & Walby, 2018; Fried, Deber, & Leatt, 1987). The Government of Ontario specifically adopted the Business Oriented New Development (BOND) program in 1982, which was believed to help the public sector benefit from private sector ideologies. This program highlighted many ways in which hospitals could increase their revenues and decrease their costs, as any cost deficits would not be covered by the province. Cost-mitigating measures included contract management to improve managing systems, private fundraising through campaigns, developing hospital foundations, and partnering with corporate entities (Fried, Deber, & Leatt, 1987).

The increased corporatization of pediatric health care in Canada is evident in the corporate fundraising campaigns by the Sick Kids Foundation, established in 1972, to generate revenue for the Hospital for Sick Children (Sick Kids Hospital) in Toronto, which is world-renowned for its pediatric oncology care. Capitalizing on the historical legacy of the hospital as a charitable institution since its creation in 1875 (Wright, 2016), the Foundation raised 190 million dollars in 2020 (Ernst & Young LLP, 2020; Sick Kids Foundation, 2020). Described as essential for the provision of optimal services and facilities upgrades because the hospital's "70-year-old building can't keep up with the rapid pace of medical technology" (Sick Kids Foundation, 2020), such fundraising points to the drive to generate revenue outside of the public funding envelope. As well, the fundraising campaigns developed by the Foundation use powerful imagery to reproduce and proliferate particular cultural understandings and narratives about childhood disease and pediatric health care. For example, the *SickKids VS.* fundraising campaign (Sick Kids, 2017) comprised a series of print and video ads appearing in newspapers, television, and on social media that promote highly technologized visions of health care and heroic imagery of health care providers and child patients who are viewed as victorious in their "fight" against disease (e.g., see SickKids, 2016). In one video, this is communicated with the image of a girl standing on top of a pile of broken medical equipment, staring over the horizon, suggesting that she has won her battle against illness. These advertisements generally depict sick children as those who are successful

in their battles against disease and obscure the stories of children who are not successful – that is, who die. Additionally, when health care providers are shown, they are typically physicians, thus masking the care provided to these children by other caregivers. Recognized with a Canadian Marketing Association award (Lloyd, 2019), this fundraising campaign thus serves as an example of how (pediatric) healthcare has become an opportunity for advertising innovation within corporatized health care environments.

While this increased focus on fundraising generates significant revenue, cuts to healthcare funding persist and have significant and lasting effects on staff. Along with the prioritization of efficiency, cost-cutting, and support for technologically driven approaches to health care (Cody, 2001a, 2001b; Krol & Lavoie, 2013; Naef, 2006; Peter & Liaschenko, 2013), health care systems are increasingly marked by understaffing and a lack of investment in training resources for staff (Corley, 2002; Kälvemark et al., 2004; Raines, 2000). Approaches to caregiving that extend beyond the technical aspects of caregiving, such as the many aspects of relational and psychosocial care, take on little value and meaning within these approaches. Furthermore, nurses in charge of providing care are often excluded from decisions to cut costs and increase efficiencies. These decisions tend to be made by those at a distance from the patients, families, and health care providers (particularly nurses) who ultimately experience the effects of these cost-cutting measures. Davis, Lind, & Sorensen (2013) contend that, as a profession, nursing is "at risk of being affected by burnout because of the growing pressure to do more with less resources" (p.E303). Peter and Liaschenko (2004) note that such decisions have serious moral consequences for nurses who are responsible for patient care:

> Those who remain close, such as bedside nurses, however, experience moral distress when encountering the damaging consequences of inadequate staffing and unavailable services. It may be morally less burdensome to give the orders than to carry them out or to live closely with their consequences (p. 221).

Huffman and Rittenmeyer (2012) argue that hospital settings and management have "institutional culpability" for creating the conditions that cause nurses' moral distress. This longstanding critique of managerialism in health care specifically has also been highlighted by Davis and Aroskar (1978), who argue that the bureaucratic nature of

hospitals has the power to limit nurses' ethical capacity in caring for their patients. Curtin (1980) extends this sentiment by stating:

> ethical problems arise from the usurpation of the legitimate authority of the nurse over *nursing* decisions regarding care. The major ethical dilemma in nursing is that nurses are not free to practice nursing (p.22, original emphasis)

In summary, neoliberal approaches to health governance, with its emphasis on corporatization and managerialism, intensify conditions that constrain nurses' moral identities. In particular, the priorities of the healthcare system, which are often guided by values of cost efficiency, directly conflict with master nursing narratives, which position the nurse as the ideal provider of patient-centered, relational, and holistic care.

3.2   Theorizing Moral Distress: Moral Identities, Relationships, and Responsibilities

More recently, arguments have been made that research and action on moral distress has been held back due to a lack of theoretical and conceptual clarity. These critics suggest that conceptual models of moral distress should move beyond definitional issues to more thoroughly consider and elucidate its various aspects, causes and effects (Peter & Liaschenko, 2013). In alignment with the critical position taken in this thesis, McCarthy and Deady (2008) note that research on moral distress must take a critical stance in order explore moral distress in relation to the ethical dimensions of nursing practice. In this sense, research on moral distress has not been researched in "moral terms", that is, in relation to theories and concepts developed in nursing ethics (Liaschenko & Peter, 2004; Peter & Liaschenko, 2004; Rodney et al., 2002; Weiss et al., 2002). This is reflected in research on pediatric oncology nursing, which has generated descriptive accounts of nurses' experiences of stress, grief, and burnout (see Chapter 2), but which has insufficiently examined moral distress in this practice area.

Similar to McCarthy and Deady (2008), Peter and Liaschenko (2013) contend that moral distress is "an umbrella concept that captures the range of experiences of individuals who are morally constrained" (p.54) and go further to generate theoretical links between the individual experience of moral distress and its associated institutional components. In

particular, they argue that feminist moral theory is useful to explore moral distress, given its commitment "to changing uneven distributions of power and privilege in everyday life, resulting in a blurry boundary between ethics and politics" (Peter & Liaschenko, 2013, pg. 338; see also Liaschenko & Peter, 2006). This perspective reflects the ways in which nurses' care(giving) is embedded in and shaped by systems of power and multiple, complex social networks that include other health care professionals, patients, families, and administrators. They specifically suggest that exploring moral distress through the view of feminist moral theory can allow us to understand three primary facets of moral agency: identities, relationships, and responsibilities. I will discuss each of these facets of moral agency and explicate how they provide meaningful ways of understanding moral distress in the context of my research on pediatric oncology caregiving.

Moral identities are generated by and formed within their respective institutional and professional contexts and, as such, are socially constructed. Nursing training and education are shaped by and tend to reproduce master narratives – that is, "normative discourses" (Bamberg, 2004, p.331) – that frame nurses as individuals with moral values who are professionally responsible for providing high quality, holistic, patient-centered care, and developing close proximal and personal relationships with patients (McCarthy & Deady, 2008; Peter & Liaschenko, 2013). In particular, Storch (2004), a Canadian nursing scholar, highlights how nurses' identities are constructed through their education, which instructs nurses how to engage ethically through their practice. In her chapter on navigating the moral terrain of nursing, which is in her co-authored textbook on nursing ethics, leadership, and practice, Storch (2004) contends that nursing education and identities are shaped by values that include quality of care, respect, and dignity of the patient. In this chapter, the following questions are used to highlight how nurses can engage their moral agency in their nursing practice:

> [N]ursing ethics is about being in relationship to persons in care. The enactment of nursing ethics is a constant readiness to engage one's moral agency. Almost every nursing action and situation involves ethics. To raise questions about ethics is to ask about the good in our practice. Are we doing the right thing for this patient? Are we listening to this person's need for pain relief? Are we respecting a family's grief over their dying child as they struggle to squeeze out a few extra days or hours for the child through alternative therapies? Are we ready to stand up

for what we know to be right when we face a situation requiring us to perform a procedure that we are confident is not appropriate and that violates the dignity of another human being? Are we willing to find time to debrief after complex situations to determine how we could have done better, with a commitment to doing everything in our power to prevent similar situations from occurring in the future? (Storch, 2004, p. 7)

The ways in which nurses' moral identities are formed through this emphasis on the relational ethics of care is challenged when trainees enter the workforce and realize that institutional values and priorities do not support and may directly oppose the nurses in fulfilling their professional responsibilities, including the provision of holistic care and developing close relationships with patients and families. This violates nurses' trust in the moral commitment of the institutions in which they work, as they enter into the workforce with the belief that the institution will support them to act in the best interests of their patients and value high quality patient-centered care over efficiency and technological imperatives aimed at achieving cure (Peter & Liaschenko, 2009). It has been found that nurses are unable to engage with their moral identities because of constraints presented by their work environments and institutions, which include but are not limited to unsupportive management and an intensified focus on cure-oriented and technologically-driven tasks. These constraints have been shown to lead to high turnover, and as a result, understaffing, which can create further moral distress (Krol & Lavoie, 2013; Lazzarin, Biondi, & Di Mauro, 2012; Lievrouw et al., 2016; Rodney, 1997; Rodney and Street, 2004; Rodney et al., 2002; Storch et al., 2002; Varcoe et al., 2004; Wilkinson, 1988). In the context of pediatric oncology nursing, Ventovaara, Sandeberg, Räsänen, & Pergert (2021) found that understaffing and being overburdened with a high workload (to compensate for understaffing) caused great moral distress, which was defined by the authors as experiencing anguish or feeling greatly disturbed by an event or action. Considered alongside Peter & Liaschenko's (2013) conceptualization of moral identities, it can be argued that these nurses felt constrained by their institution and thereby could not enact their moral identities.

Nurses' moral identities are further shaped and constructed through their relationships with others, including other health care providers, health care managers, as well as patients and their families. Through these relationships, storytelling acts as an exchange

of knowledge about one's self and identity. It is through this storytelling that moral identities are enacted, and moral relationships are developed. According to Peter & Liaschenko (2013), these moral relationships must be "based on trust in which we possess and negotiate mutual expectations and call on each other to account for things we do and fail to do" (p.340). To sustain moral relationships, Peter & Liashcenko (2013) argue that shared standards must exist and be upheld, which, in the context of nursing, include wanting the best for patients, as these relationships are necessary for good patient and family care. These relationships are facilitated through stories that communicate expectations and understandings. For Peter & Liaschenko (2013), moral relationships and their associated responsibilities "are understood to us in narrative form as we come to reflect and act on responsibilities in relationships" (p.340). In instances where others (e.g., patients, patients' families, managers) do not understand or share nurses' values and standards of practice, the quality of nurses' moral relationships are weakened in a way that may compromise care, thus causing moral distress.

For example, nurses may experience moral distress when other members of a patient's care team act in ways that nurses believe are not in the best interest of their patients. This conflict in moral relationships is apparent in the relationship between physicians and nurses where they may not be agreement with regard to what the best course of action or treatment should be (Huffman & Rittenmeyer, 2012; Peter & Liaschenko, 2013). These conflicts in professional relationships have been highlighted in the literature on moral distress experienced by pediatric oncology nurses. In particular, Pye (2013) found that pediatric oncology nurses experience moral distress when they have poor relationships with colleagues (particularly physicians), conflicting priorities over best courses of action for treatment of their pediatric patients, and when there is a breakdown in communication between nurses and their colleagues.

In addition to the relationships between nurses and other health care providers, Peter & Liaschenko (2013) also emphasize nurses' relationships with patients and families. In particular, they contend that nurses' caregiving is situated in a particular spatiotemporal "social space" (p. 218) which places nurses in close proximity to patients and families, thus compelling them to act upon their moral responsibilities. Thus, this proximal "social

space" is also a moral space in which nurses are able to "nurse" through the nurse-patient relationship and enact their moral responsibility. As I will demonstrate in Chapter 6, this is particularly relevant to the context and practice of pediatric oncology nursing, as the proximal nature of caregiving and the sustained relationships created with children and their families through life and death shape nurses' caregiving experiences and experiences of moral distress.

3.3   Moral Distress, Proximity and Moral Identities

In the spatiotemporal context of nursing practice, nurses develop their identities and sense of moral agency through their proximity to patients and families (Peter & Liaschenko, 2004). In addition to the master narratives provided by nursing education, nurses' identities are also shaped by their contact with patients and families. This contact allows nurses to develop an identity separate from other healthcare workers because this proximity is unique to their practice and profession (Liaschenko, 1994, 1995; Peter & Liaschenko, 2004, 2013). In her highly cited work on distal nursing, Ruth Malone (2003) outlines that there are three types of proximity nurses have to patients. First, *physical proximity* allows nurses to be physically close to the patient and family. This physical proximity enables nurses to gain *narrative proximity*, that is, an understanding of the patient as a person with a life that the nurse can understand through storytelling. Specifically, Malone (2003) defines *narrative proximity* as a process by which "nurses come to 'know the patient' (Tanner et al., 1993) by hearing and trying to understand (and, in turn, transmit to one another) the patient's 'story' (of the illness for him/her, of his/her particular life)" (p.2318). In turn, understanding the stories of the patient and family allows for *moral proximity*, which helps nurses recognize the vulnerabilities of the patient. It is through this moral proximity that nurses can advocate for patients as they "encounter the patient as the other, recognize that a moral concern to 'be for' exists, and are solicited to act on a patient's behalf" (Malone, 2003, p. 2318).

This moral proximity is enacted, as an example, when pediatric oncology nurses witness suffering, as it elicits an "emotionally laden caring response" (Peter & Liaschenko, 2013, p. 340; also see Peter & Liaschenko, 2004) to act on another's behalf. In cases where this suffering or pain is a result of physician or family decision-making, or denies the

autonomy and defies the wishes of the patient, nurses are restrained in their moral responsibilities to their patients, causing moral distress (Lazzarin, Biondi, & Di Mauro, 2012; Pye, 2014). Lazzarin, Biondi, & Di Mauro (2012) found that pediatric oncology nurses experience moral distress when they witness parents make treatment decisions that prolong their child's death and suffering. In such cases, nurses are required to follow through with orders that conflict with their moral responsibilities and values and their understandings of what is in the best interest or support of their patients and their wishes.

These ideas about proximity also illuminate the ways in which bearing witness enables nurses to act upon their moral responsibilities and enact their moral identities. To bear witness is to acknowledge and testify to another person's experience (Cody, 2001a, 2001b, 2007; Hatley, 2000; Naef, 2013). Bearing witness involves being present with their experience in a manner that is "non-judgmental, non-intrusive, and respectful; it is attentive presence, involving relationships with others, standing in solidarity with others, being in community, and paying utmost attention to what is at hand" (Naef, 2006, p.150; also see Bunkers, 2001 and Cody et al., 2001). Nursing philosophers and scholars have noted that bearing witness is not synonymous with nursing (Naef, 2006); while there are master narratives in nursing that emphasize the centrality of providing holistic, relational, and quality patient-centered care, bearing witness in nursing constitutes a very particular way of caring for patients. In particular, Naef (2006) outlines that bearing witness, in comparison to caring more generally, is:

> being with and relating to others that is based on values and beliefs that give rise to a commitment to attend to, honour, and stay with persons' truths, perspectives, priorities, hopes, and dreams; that is, their lived experience (p.149).

Testifying to another's lived experience also transcends time; it may happen in any moment in the past, present, or future (Naef, 2006). It is important to note that bearing witness is not limited to physical interaction or verbal communication with another. Rather, "bearing witness happens face to face, but also through rituals, testimonies, documentation, literature, story-telling, and art" (Naef, 2006, p. 149; see also Cody, 2001a, 2001b; Rashotte, 2005).

As one of the most important theorists of bearing witness, Emmanuel Levinas (1979, 1984, 1998) proposed the ethics of the face, which posits that witnessing the face of "the Other" (p. 103) invokes an ethical responsibility and eagerness to care for the other by "seeing" their vulnerability. He argued that through the face of the other, we are able to witness their humanity, and our proximity to the other calls us to be ethical and responsible for them. Levinas' conceptualization of bearing witness has been taken up in the nursing philosophy literature to highlight the ethical and moral responsibilities and obligations nurses feel and act upon in relation to their patients. In particular, Cody (2001a, 2001b) and Hatley (2000) highlight that to bear witness is to remain true to patients in one's nursing care. Parse (1998), in her human becoming perspective of bearing witness, highlights that bearing witness involves being attentive to each person's lived experiences, and supporting their choices, because nurses believe that the patient knows themselves the best (Parse, 1998). Building upon these conceptualizations of bearing witness, Naef (2006) argues that bearing witness and recognizing vulnerability in the other does not only occur in the extreme moments of suffering and death, but also happens in the "day-to-day, moment-to-moment being with persons" (Naef, 2006, p.150; Parse, 1998).

The time required to bear witness and build relationships that foster moral proximity with patients is often threatened in health care environments that are increasingly shaped by corporate and neoliberal imperatives that reduce staff and increase workload demands (Peter & Liaschenko, 2004; Rodney et al., 2002; Varcoe & Rodney, 2002). In such environments, the prioritization of "biomedically dictated tasks" (Cody, 2007, p.289) may cause nurses to reorient their caregiving duties, and result in moral distress when they cannot gain proximity and bear witness to their patients and their families.

3.4   Narrative and the Mitigation of Moral Distress

It has been suggested that by bringing conceptual and theoretical clarity to moral distress, its prevalence can be reduced in practice. As Peter & Liaschenko (2013) have argued, moral distress is experienced when nurses' moral identities, responsibilities, and/or relationships have been threatened or constrained. They further suggest that the creation

of counterstories can aid in healing nurses' moral identities, when they become damaged by conflicting values of the institutions in which they provide care:

> Counterstories are needed that portray nurses as skilled caregivers with serious responsibilities that require knowledge, skill, and virtue. They also have the potential to portray nurses as powerful (Peter & Liaschenko, 2013, p. 343).

This is informed by the notion that because nurses' moral identities are created narratively, they can also be repaired narratively (Lindeman, 2006; Peter & Liaschenko, 2013).

This resonates with Arthur Frank's (2013) work on the role of narrative in repairing fractured identities that result from episodes of chronic illness, such as cancer. Frank contends that humans construct a sense of self and stability through their storytelling: "the self is being *formed* in what is told" (p.53). However, when an individual is diagnosed with or experiencing a life-threatening illness, their story, and thereby their identity, becomes irreversibly changed. In the *Wounded Storyteller*, Frank (2013) describes this change as "narrative wreckage", extending Ronald Dworkin's (1993) conceptualization of the "narrative wreck". This "wreck" is the damage inflicted upon one's story; that is, the narrative that informed one's sense of how the future and their future self would unfold. In the face of cancer, the coherence and stability of one's life story, or what was expected of one's future, is no longer conceivable as the illness has thrown an unexpected obstacle into this story that skews the narrative and one's preconceptions about the future self:

> The conventional expectation of any narrative, held alike by listeners and storytellers, is for a past that leads into a present that sets in place for a foreseeable future. The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable. (Frank, 2013, p.55)

In these instances, self-narratives are "shipwrecked by the storm of disease" (p.54) as one's sense of self, identity, and stability become ruptured by illness. Narratives, or storytelling, can be used to navigate this instability in one's story and repair it. Expanding upon the shipwreck metaphor, Frank argues that:

> Stories have to repair the damage that illness has done to the ill person's sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations. (p.53)

Understood as "repair work on the wreck" (p.54), storytelling is positioned here as a way to restore the individual's identity and sense of self. This sense of self is not a return to the former self, however; the telling of these stories is not to fully erase the illness from the narrative, but rather to redirect, or change the future, with the acknowledgement that the illness had a part in how the individual navigates their new biography:

> The illness story faces a dual task. The narrative attempts to restore an order that the interruption fragmented, but it must also tell the truth that interruptions will continue. Part of this truth is that the tidy ends are no longer appropriate to the story. A different kind of end – a different purpose – has to be discovered. (Frank, 2013, p.55)

This work highlights that the telling of one's illness story helps repair one's self-narrative and forges new directions for one's life story and how it might unfold.

In combination with Peter and Liaschenko's (2013) theoretical insights about moral identities and counterstories, Frank's (2013) notion of narrative repair has interesting implications for the ways in which nurses may enact and repair their threatened moral identities (Nelson, 2001; Peter & Liaschenko, 2013). Creating counterstories, or counter narratives, can act as a form of resistance that locates the causes of their moral distress from their own points of view. By creating space for the construction of counterstories, nurses' power can be better used and strategized to combat the sources of their moral distress. In contrast to definitions of moral distress that focus on individual competencies and failures, such counter stories have potential to situate the nurses' moral distress in institutional contexts and ideological frameworks that privilege cost-cutting and efficiency over holistic, relational care, and that effectively limit their capacity to act upon their moral identities and be morally proximal to their patients.

3.5   Conclusion

In this chapter I reviewed the theoretical concepts that informed and framed my analysis, specifically moral distress, as well as bearing witness and narrative repair. Moral distress

has been described as one of the most significant concerns facing health care providers, including nurses, in contemporary health care contexts. Moral distress has been linked to burnout, anxiety, depression, and demotivation in nurses. Neoliberal ideologies have informed the increased corporatization of healthcare, which emphasizes cost-cutting and efficiency as health care priorities. These ideologies directly conflict with nursing identities fostered by nursing education, which emphasizes the centrality of providing proximal relational, holistic, patient-centered care to their patients. This emphasis on efficiency also limits the ways in which nurses can establish and maintain physical, narrative, and moral proximity to their patients, thus affecting their moral identities and ability to bear witness to their patients. Creating counter stories can provide a way to foster narrative repair by enabling nurses to articulate their experiences of moral distress and its effects on their caregiving and by forging a route to reconstructing their identities. Such narratives may contribute to stimulating critical reflection among nurses about the sources of their moral distress and its mitigation and may aid in challenging corporatized paradigms of health care. With these analytic framings in mind, in the next chapter I outline the narrative methodology I used to collect and analyze the caregiving narratives of the nurses in my study and discuss how these framings came to inform my analysis.

Chapter 4

4   Methodology

The purpose of this chapter is to orient the reader to this study's research questions and objectives and to describe the methodology and methods used to explore these questions. In the first part of this chapter, I outline my research questions and objectives, provide an overview of critical narrative inquiry, and discuss my rationale for using this methodological approach. In the second part of this chapter, I outline the specific methods used to conduct this study. I describe the recruitment, sampling, data collection and analysis, and how key ethical concerns and quality criteria were addressed.

4.1   Research Questions and Objectives

The purpose of this study was to use critical narrative inquiry to examine the caregiving experiences of pediatric oncology nurses in relation to broader discourses and other contextual features. Originally, I had hoped to situate nurses' caregiving narratives in relation to discourses on childhood, childhood cancer, and cancer survivorship, in order to understand how their narratives are situated within, informed by, and challenge dominant discourses on pediatric cancer care. The research questions and objectives generated to guide this study were:

1. How do pediatric oncology nurses narrate their experiences of providing care to children with cancer?
2. What complexities and ambiguities about caregiving are revealed in these narratives?
3. How are broader contexts and discourses inflected, reproduced, and challenged by these narratives?

Within this broader set of questions, the specific objectives of this study were:

i. To identify the meanings that pediatric oncology nurses ascribe to care and caring for children with cancer;
ii. To understand how nurses conceptualize care and caregiving;

iii. To situate these meanings and conceptualizations in relation to broader social contexts and discourses;

iv. To understand how they construct and position their identities (e.g., as caregivers) in relation to these discourses, and in relation to personal, professional, cultural, and social contexts.

Before embarking on this research, I acknowledged that moral distress may emerge in my participants' stories. However, as the data collection and analysis unfolded iteratively, moral distress became a central concept that shaped my understanding of the participants' caregiving narratives, which is reflected in the narrative themes presented in Chapter 6. While my research questions did not change substantially, using a critical narrative methodology allowed me to explore the nurses' experiences of moral distress in relation to their narrations of pediatric cancer caregiving, highlight the complexities and ambivalences revealed in their narrations of caregiving, and illuminate the meanings they associate with particular kinds of care. This methodological approach also enabled me to actively interpret these narrations, ambivalences, and meanings in relation to theoretical concepts such as moral distress, bearing witness, and narrative repair, which aided in my understanding of how nurses' experiences of moral distress and experiences of caregiving are embedded within and influenced by broader institutional contexts and discourses.

4.2 Critical Narrative Inquiry

In order to address my research questions and objectives, a critical narrative inquiry was designed and conducted. Overall, narrative inquiry is an umbrella term for a variety of approaches, methods, and assumptions with a common interest in narratives, or stories (Riessman, 2008; Smith and Sparkes, 2006, 2008). Narratives include verbal conversations, written texts, visual depictions of experience, observations, as well as stories collected through research interviews (Riessman, 2008). In the context of qualitative research, narrative inquiry involves the researcher collecting stories as a form of data for analysis (Emden, 1998). This allows the researcher to scrutinize the language and telling of a participant's story, and thus to examine how the story was narrated, why it was narrated in a particular order, what purpose the narrative serves, and what "cultural resources" (Riessman, 2008, p.25) the narrative draws upon.

Narrative inquiry is founded upon the assumption that humans are storytelling beings who live storied lives, and can use storytelling as a form of social action (Atkinson and Delamont, 2006; MacIntyre, 1981; Sarbin, 1989; Smith and Sparkes, 2008). Additionally, storytelling acts as a way of meaning-making, and of constructing and negotiating our realities and selves (Mishler, 1986, 1995; Smith and Sparkes, 2008). A key assumption of narrative inquiry is that storytelling is central to identity construction (Mishler, 1995). Lieblich et al. (1998) have argued that "one of the clearest channels for learning about the inner world is through verbal accounts and stories presented by individual narrators about their lives and their experienced reality" (p.7). Through storytelling, individuals construct and reconstruct their identities in relation to different events and actions, and identities can change through the telling of stories at different points in a person's life (Mishler, 1995). As stories change, so do identities, and as identities change, so do stories (Corey, 2009).

Bissel et al. (2006) argue that the stories people tell can also be moral stories; one's sense of self is embedded within the ways that they narrate their connections to others. They posit that stories "are often embedded within issues of power and control as we attempt to construct our sense of self" (p.55). When a person's sense of identity is challenged or threatened, stories are a useful tool for making sense of the ambiguities and challenges that characterize the person's relationships with others and with the structures within which they are embedded (Bruner, 1987; Emerson & Frosh, 2004; Riessman, 1993).

Narrative methodologies are particularly well suited to illuminate the ambiguities that characterize complex experiences, such as the experience of providing care to a child with cancer. Further, narrative methodologies provide an avenue for examining and understanding ambivalences (or contradictions and tensions) in one's story, as well as how storytelling can be used as a way to counter master narratives. For example, Polzer, Mancuso, & Laliberte Rudman (2014) used a discursive narrative methodology to understand how young women made decisions about getting the vaccinated against human papillomavirus (HPV). The findings illustrate how these women navigated their identities in relation to discourses on risk and responsible citizenship and highlight the ambivalences that characterized their participants' decision-making narratives. In

particular, the participants drew on different discourses to make sense of doing what they felt was right for them and to construct themselves as responsible citizens.

As a form of critical inquiry, critical narrative approaches locate individual accounts and the meanings ascribed to them within larger power structures (Canella & Lincoln, 2009; Laliberte Rudman & Aldrich, 2017; Mumby, 2014). Critical approaches to methodology are embedded paradigmatically in critical theory, which aims to challenge and disrupt the status quo, with the ultimate goal of transformation (Ponterotto, Kincheloe & McLaren, 2005). The dialogic and transactionist nature of critical theory can allow for a transformation of misunderstandings that historically mediated structures are "immutable" (Lincoln & Guba, 1994, p.110) or "natural or inevitable" (Carpenter & Suto, 2008b, p.24; Kincheloe & McLaren, 2005).

In keeping with the goals of critical approaches more generally, critical narrative methodologies use their work as "a form of cultural or social criticism" (Ponterotto, 2005, p.130). Thus, critical narrative inquiry specifically focuses on situating and analyzing stories in relation to their cultural, social, and political contexts (Hardin, 2003; Laliberte Rudman & Aldrich, 2017). As well, the analysis is not limited to reading the narrative as is. Rather, this methodology questions how narratives are woven into and take shape in relation to systems of power and how narrators negotiate their own positions within these systems, depending on the positions available to them. The analysis considers individual, sociocultural, and historical contexts while understanding how narrators actively construct meanings and identities in the ways that they take up, challenge, and negotiate their realities within these contexts (Allen & Hardin, 2001; Laliberte Rudman & Aldrich, 2017).

Critical narrative inquiry is dialogic and dialectical (Guba & Lincoln, 1994). The transactional nature of critical narrative inquiry requires dialogue between the researcher and participants that must be dialectical in nature. This dialogue and co-construction serves to "uncover and excavate those forms of historical and subjugated knowledges that point to experiences of suffering, conflict, and collective struggle" (Giroux, 1988, p.213). In the case of my research, the dialectical nature of the research-participant relationship

places emphasis on co-construction of the data as data collection transpires (Guba & Lincoln, 1994). What can be known or understood about a particular experience (in this case, being a pediatric oncology nurse) is assumed to be based on the relationship between myself and my participants, and what they find of value to story in the context of the research interview situation. These values come through in our co-constructions, meaning that the results are "value mediated" (Guba & Lincoln, 1994, p.110).

In this regard, a strength of critical narrative inquiry for the present study lies in its capacity to elucidate the ways in which institutional contexts mediate caregiving experiences and constructions of care. Further, the use of a narrative interviewing approach allows participants the freedom to narrate their stories without pre-imposed interpretations or pre-defined questions set by the researcher. A critical narrative approach also required me to be deeply reflexive and honest about my role and experiences in relation to conducting this research and constructing the study findings based on my interpretations. Below, I present my reflexive statement, in which I discuss my experience grappling with conducting a critical narrative study, as someone who comes from a post-positivist academic background.

4.3 Reflexive Statement

As I described in my Introduction, what inspired me to become involved in pediatric oncology research was my volunteering experience during my third year of my undergraduate studies. In particular, the experience I described with that little girl and her mom stuck with me as I completed a fourth-year thesis project in parasitology. I realized that I really enjoyed doing research and wanted to continue, and I came to believe that doing research in pediatric oncology could be something that I would be passionate about. As I mentioned previously, I pursued my Master's thesis research on this topic and it was during my Master's degree in Kinesiology that I first learned about qualitative research methods. These methods departed markedly from my undergraduate degree in Life Sciences, which didn't allow for an understanding of how knowledge could be generated beyond quantitative, objective and scientific methods of inquiry.

The post-positivist attitude shaped by my undergraduate education in the sciences has stayed with me as I've progressed through my graduate degrees. Although I had completed qualitative methods courses and conducted a qualitative thesis for my Master's research, I had not realized until I started my PhD that the way that I learned and conducted these methods was still quite post-positivist in nature. I honestly came into my first PhD qualitative course feeling a bit too confident, like I was going to be ahead of the class. That mindset changed very quickly as I realized that in my Master's program, we had not learned to distinguish between ontologies, epistemologies, paradigmatic considerations or how iterative and interpretive qualitative research could be. Rather, we simply learned a "how-to" approach for different qualitative methodologies. One day in my qualitative methodology class during my PhD, particularly after learning about phenomenology, I walked up to Dr. Laliberte Rudman during a break and told her that I thought I did my Master's thesis wrong, that my phenomenological study was not at all iterative or interpretive, was stepwise and linear in nature, and generated general themes. Not only did this moment highlight how entrenched I was in post-positivism for believing there was one "right" and "wrong" way of doing qualitative research; it also highlighted that my perspective was open to (and slowly) changing.

The next big "a-ha moment" for me was during my candidacy exams when I had what I believed to be an epiphany in response to reading a constructively framed study on pediatric oncology narratives: "the story is about more than just the story". This was a colossal shift for me, because highly structured methodological approaches that took people's words for what they are without interpretation was all that I had known. As time progressed, and within it the writing of my dissertation proposal and initiation of my research, my perspective slowly continued to change. In the years since that class and that epiphany, my perspective has shifted substantially, and I have grown into a much better researcher as a result (or so I would like to think).

Conducting a critical narrative study that examines the caregiving stories of pediatric oncology nurses has been a struggle in multiple ways. While it branched directly from my Master's research, and examines the experiences of the nurses my previous research participants spoke so highly of, actually conducting this research has been a completely

different experience for me. Between the emotional (and sometimes traumatic) content of my participants' interviews and their stories of caring for children with cancer and their families, and my continual struggle with post-positivism, I can very honestly say that conducting this research has been the hardest thing I've ever done.

The easy part was recruitment. The rapidity with which I recruited participants was shocking – in about two weeks, more nurses had contacted me than I could possibly interview. What I soon began to realize as I proceeded with the interviews was that they were eager for the opportunity to tell their stories to somebody who wanted to listen to them. Through our conversations I came to understand that many of these nurses don't have anyone to speak to about their joys, triumphs, sorrows, and traumas at work other than their fellow nurses. So much of our interviews centered around how much they care about the patients and families they care for, and these interviews acted as an opportunity for them to express it without fear of being unprofessional. At the time, I did not know that I was creating a narrative space for my participants to tell stories that helped them engage in narrative repair. I knew immediately that some of my participants were using me as a sounding board, or someone to vent to about their frustrations and experiences of moral distress, but that was the extent of what I believed my role to be at the time.

My interviews with my participants made me laugh, cry, and spend a lot of time thinking. While I entered into this research with the understanding that many of their stories wouldn't necessarily be happy, looking back, I was not emotionally prepared for how their stories would affect me. Some of the stories they shared with me were narrated in vivid detail, laced with frustration and disappointment for how the children they cared for spent their final days and weeks alive. One story, in particular, left me in a daze for the rest of the day. I could not stop thinking about that child and what they had gone through. I had a FaceTime call with some friends that night and told them that I felt really sad and tired by what I had heard that day. I left our phone call early because I was exhausted and went to bed thinking about that story and that child. I had heard traumatic stories like this one before, and had spent time thinking about the stories of my participants; however, I have never had a story leave me imagining the details and feeling tired for days after. I kept thinking about this child and this participant's story so much that, eventually, a few

days later, I told my therapist in an appointment. My therapist, who is a trauma therapist, listened as I repeated the story and told her how I felt. When I finished, she told me that I was experiencing vicarious trauma.

I had heard of and actually written a paper on vicarious trauma before, but I never thought that I could experience it, particularly in the course of a research interview. I wasn't a health care or social service provider, which are professions known to experience vicarious trauma. I wanted to conduct these interviews, and I knew (or thought I knew) what I was getting into. My therapist, however, assured me that I was experiencing vicarious trauma, and as I progressed through the rest of my interviews, I was told to keep track of my feelings and reactions to their stories, ensure I had no meetings or obligations after our interviews, and, after completing an interview, take the rest of the day off. I did all of these things and slowly but surely started to feel better. However, what I did not realize until later was that an unintended effect of experiencing this vicarious trauma was my deepened understanding of my participants' moral distress and their experiences of bearing witness.

Through listening to their stories, I came to understand my role as bearing witness to their narratives of bearing witness. As they provided testimony to the lives and hardships endured by their patients and their patients' families, I understood how they bore witness to suffering and to stories, and how their proximity to their patients and families (both physically and emotionally) enabled them to bear witness and was central to their caregiving. I also understood as time progressed that moral distress was not a discrete experience; it was a constant presence in their interviews, like a dark cloud shading their stories. If I had not experienced this vicarious trauma, I'm not sure if I would have become sensitized to the ways in which the nurses' narratives reflected their experiences of moral distress and incorporated this into my data analysis.

While I understood that my analysis would be interpretive and iterative, I was not prepared for how messy, iterative, and grey it actually was. The interview data are/were so rich that I felt trapped in it, constantly wading, thinking, writing, reflecting, and often crying. I spent hours on the phone and in Zoom with Dr. Polzer making sense of all the

analytic mud that I was stuck in. Eventually, with some help, I was able to climb out of that mud and present what is now presented in Chapter 6. I spent a lot of time worried that I wasn't analyzing my data the "right" way – it was not as structured as I hoped it would be and I was uncomfortable going back to the literature to help my interpretations. I have been grappling with this throughout the writing of my entire dissertation, including in this moment as I write this statement. To this day, I still sometimes think that my interpretations and ideas are "wrong". At this point in time, I do believe that I can approach research critically, but to say that my perspective is always critical would be a lie. I still struggle and continue to experience impostor syndrome for not being "critical enough". However, I also understand that, like my research, I am growing and changing as new information and ideas emerge.

Over these last few years, I have learned and realized a lot about myself. I can do hard things. I can interview participants in a way that makes them feel comfortable telling me their stories, and many of the ebbs and flows they've experienced. I can engage with my data interpretively, creatively, and critically. I can see how the story is about more than just the story. It's hard for me at times to see how much I (and my perspective) have grown. The person that I was before I started my PhD would not have been able to conduct and complete this dissertation as it currently stands. I *am* doing it, and I continue to resist that post-positivist urge in the back of my head to judge what I am doing as either "right" or "wrong".

4.4   Methods

4.4.1   Participant Recruitment

In keeping with the purpose of eliciting detailed narratives of pediatric oncology nurses' caregiving experiences, a purposive sampling strategy was designed (Patton, 1990). To participate in this study, participants had to be: (i) a licensed and practicing pediatric oncology nurse; (ii) residing and practicing in the province of Ontario; (iii) able to read, write, and communicate in English; and (iv) able to provide informed consent.

The recruitment process began in January 2020 after ethics approval was received from the University of Western Ontario Health Sciences Research Ethics Board (HSREB). A

three-pronged recruitment approach involving recruitment by email, a nursing Facebook group, and snowball sampling was developed; however only the first prong of the recruitment plan was needed and used to recruit all participants. In this first prong, an email inviting potential participants for the study was shared with two nurse members of the Pediatric Oncology Group of Ontario (POGO) who agreed to send the study invitation to their nurse contacts within the POGO network. These nurse members were only involved in distributing the study invitation and were not involved in any other aspect of recruitment. This invitation included information about the study, what would be required for those who participated in the study, and my contact information (email and telephone number) for recipients who wanted to express their interest in participating or to ask further questions about the study. In this email, potential participants were invited to contact me directly.

Potential participants, once learning about the study (via their email from POGO), contacted me via email to gain more information about and/or volunteer for the study. At that time, the letter of information (LOI) and consent form was emailed to each potential participant for their review. In the email containing the LOI, potential participants were invited to ask any questions about the study and were informed that I would follow up with them twice if I did not hear from them (after one week and after two weeks). Potential participants were also informed that no further emails would be sent after two weeks following initial contact.

In total, 18 people responded to me by email. Once potential participants indicated willingness to take part in the study, a telephone screening script was used in order to generate a sample of participants who were diverse in terms of their work environments, locations, and years of experience (see Appendix A). Potential participants who worked in caregiving contexts already represented by recruited participants were asked if they were willing to be put on a waiting list. If they were willing to be waitlisted, these potential participants were contacted one month later for an update about their status. They were also contacted and updated one month after the first update. Five nurses were waitlisted and were eventually told that their interest in the study was appreciated but that

their participation would not be needed. Four nurses contacted me with interest in the study but did not respond to follow-up emails at one week or two weeks.

Ultimately, a total of nine participants were recruited to participate in my study. My participants worked in a range of locations, care environments, and had a range of three to thirty-three years of experience being a pediatric oncology nurse. In particular, the nurses in my study worked in pediatric oncology settings in Ontario, specifically in London, Hamilton, Toronto, and Ottawa. Four of the nurses worked in inpatient (or bedside nursing) environments, three of the nurses worked in outpatient/transplant environments, and two were community travel nurses. This information and a brief summary of the main contours of each nurse's narrative is presented in Table 1.

Table 1: Overview of Study Participant Narratives

	Experience & Care Setting	**Summary of Participant Narrative**
P1	12 years Outpatient	P1 always wanted to be a pediatric oncology nurse. After spending roughly five years as an inpatient nurse, P1 transferred to outpatient and is currently occupying a nursing leadership role. Her daily work is heavily administrative and coordination-based and involves emailing, calling, organizing, and bridging the families and the care team. She misses the closeness developed with families at the bedside.
P2	4.5 years Inpatient	P2 originally wanted to become a physiotherapist, but as his undergraduate career progressed he knew he didn't have the marks required for admission. He was first introduced to pediatric oncology during a placement and got a job in pediatric oncology upon graduating. He currently holds a leadership position in an inpatient oncology unit where his role involves bedside care and administrative tasks such as scheduling and teaching newer nurses.
P3	4 years Outpatient	P3 was in grade nine when her baby cousin died from cancer and this inspired her to go into pediatric oncology. She is currently pursuing her Master's in Nursing to one day work with the palliative care team and help facilitate better deaths for children and their families. She began her nursing career on the inpatient unit and quickly found herself burnt out and emotionally exhausted because of institutional demands. At the time of the interview, she worked in the outpatient clinic but misses the relationships built with the kids and families on inpatient.
P4	5 years Inpatient	P4 took the first nursing job she was offered out of nursing school, which was in pediatric oncology. After a few years, she moved to a new city to continue working on inpatient where the children were more acutely ill than on her previous inpatient unit. With 5 years of cumulative pediatric oncology experience, she is one of the more senior nurses on her unit. She has thought about leaving pediatric oncology because of burnout, and to develop new nursing skills in other fields. However, she felt it may be difficult to leave because of her attachment to the families.

P5	3 years Bone Marrow Transplant Outpatient	P5 became a nurse in pediatric oncology after doing a placement in the bone marrow transplant unit and eventually started taking shifts on the inpatient unit as well. After five months, she found herself feeling burnt out – emotionally drained, anxious, and tired. Since then, she has continued in the bone marrow transplant unit, but stopped working in the inpatient unit. She had plans to move to the U.S. to be a pediatric oncology nurse there, but these plans were halted due to the COVID-19 pandemic.
P6	25 years Community travel	Before becoming a community travel nurse, P6 worked in different areas of pediatric oncology, including pediatric ICU. Her role is almost entirely administrative and primarily involves emailing and calling patients and families to check in and answer questions, helping families with paperwork and with travel and accommodations, and mobilizing resources to help them financially. As well, her work involves educational school visits and creating educational materials for families and she has been involved in pediatric oncology research.
P7	3.5 years Inpatient	Originally, P7 had never wanted to work in pediatric oncology, as she perceived it as too sad, but her mom convinced her to try it. At the time of our first interview, she said that she could not imagine working in any other care environment and she had applied for a nurse case manager role in the outpatient unit. While this new role excited her because it would expand her knowledge of different cancers, treatments, and procedures, she was unsure if she wanted it because she would not spend time spent and build relationships with families.
P8	6 years Inpatient	P8 works as both an inpatient bedside nurse and charge nurse (a leadership position) on the same unit. She loves working with children and developing relationships with families, and believes she is incredibly lucky to be supported by her coworkers. She is a nurse who enjoys working with palliative cases and tries to make the death and dying experience as best as it can be for dying children and their families.
P9	33 years Community travel	P9 began her work in pediatric oncology as an inpatient nurse and eventually became a community travel nurse, which has been her position for almost 20 years. She plans on retiring soon but finds this prospect difficult because she is incredibly fond of the children and families she cares for. She positions herself as their advocate, as someone who stands up for them and their care needs in team meetings.

4.4.2   Data Collection as Narrative Elicitation

In order to generate narratives about pediatric cancer caregiving, I conducted two interviews with each participant. Interviews were conducted over a 10-month period, from February 2020 to November 2020. Due to the COVID-19 pandemic, all interviews were conducted via Zoom (N=15) or by telephone (N=3). All interviews were also conducted at a time that was mutually convenient and when neither of us had commitments after the interview to allow for as much time as needed to narrate. For the most part, both the Zoom and telephone interviews seemed to allow for open discussion and ease in their caregiving storytelling with me. Most participants were able to participate in their interviews from a quiet spot in the comfort of their own homes, or in their private office at work, and they had more flexibility in choosing an interview time as they did not need to travel to speak with me. I conducted all the interviews from a quiet space in my home at a spacious desk or table, where I could have all of my materials spread out and I could take lots of notes, while actively listening to my participants without distraction.

4.4.3   Interviewing Approach and Process

4.4.3.1   Interview 1

An assumption of narrative inquiry is that conversations are foundational to human interaction and meaning making, and that conversations are composed of stories. The role of a narrative interviewer is to "activate narrative production" (Holstein and Gubrium, 1995, p.39) by developing a strong interviewer-participant relationship. Mishler (1986), as reported in Riessman (2008), contends that interviewing is a "discursive accomplishment" (p.29) by the researcher and participant, who are viewed as two active participants in conversation, and who mutually construct narratives and meaning (Gubrium & Holstein, 2002; Riessman, 2008).

For the purposes of this study, I followed Bertaux and Kholi (1984), who suggest that narrative interviews consist of two parts. The first interview is an opportunity for the participant to engage in storytelling whereby the interviewer initiates the narration with an open-ended question and probes in response to this narration for the remainder of the

interview. This is in conjunction with the approaches supported by other narrative researchers, who claim that narrative interview formats are unstructured and in-depth (Flick, 1998; Hatch & Wisniewski, 1995; Jovchelovitch & Bauer, 2000; Lamnek, 1989; Riessman, 1993).

In keeping with this approach, in the first interview, my goal was to encourage my participants to tell their stories about providing care to children with cancer. The first interview consisted of five broad narrative questions that prompted my participants' storytelling. The questions also had additional probes to elicit further storytelling (see Appendix B). The prompt that initiated the narrative elicitation was: "Please tell me, in as much detail as you can, your story of what it's like to provide care to children with cancer. Feel free to start wherever you want and end wherever you want – it's completely up to you. I'm here to learn about you. You are more than welcome to take some time to think about it before you begin." The other questions asked about what they found rewarding or challenging about their caregiving, asked them to describe a typical day in their work and about situations where they were unable to do what they wanted in their caregiving.

While participants narrated their stories, I wrote down notes and probes that emerged. This was done so that I did not interrupt their train of thought and could have my probes ready for when they came to a natural pause in their narration. Throughout the interviews, I also used multiple non-directional probes, including: "Can you tell me more about this?" or "What do you mean by that?" (Berteaux & Kohli, 1984) to encourage participants to elaborate on their stories. I also wrote down aspects of their narratives that caught my interest as they emerged, as well as their body language, emotional responses, and tone of voice. When I finished probing, and the participant felt as though they had nothing else to say, I ended the interview and audio recording.

Once each interview was completed, I listened to the audio recording and transcribed the interviews verbatim. In doing so, I was able to immerse myself in the interview data and begin the process of analyzing the data for particular narrative themes. This is consistent with Riessman's (1993) contention that interview transcription acts as the onset of data

analysis, as the transcription process allows the researcher to reflect on what was said, how it was said, and what elements comprised participants' storytelling, such as particular phrases, emotional reactions and body language. I strived to produce transcripts that were as accurate as possible in terms of reflecting each participant's speech, and thus transcribed every "um", "ah", "like", as well as pauses of varying lengths. I ensured that line numbers were included in the transcripts for easy reference during analysis, and I italicized words that I or my participants emphasized during their interviews. Each transcript was checked twice against the audio recording to ensure its accuracy. A deidentified copy of each transcript was saved onto a secured Western University OneDrive, which was accessible only to me and Dr. Polzer.

After their first interview was transcribed and de-identified, my participants were sent a copy of their interview transcript. Participants were sent an email confirming that they were the sole user of their email address and were asked to send me a password for their transcript. When a password was sent, their anonymized transcript was encrypted with their password to ensure confidentiality and emailed to them for review. At the time their transcript was sent to them, we also arranged a time for their second interview. Consistent with narrative approaches, the sharing of interview transcripts with the participants facilitated co-constructions of their descriptive narratives (Mancuso & Polzer, 2010). By reading their interview transcripts, participants were able to reflect on the stories they told and offer further insights, stories, or memories during their second interview.

4.4.3.2   Interview 2

The second interview was approached as "a period of questioning" (Berteaux & Kholi, 1984, p.224) in which the interviewer asks questions both in regard to the original narration, as well as other relevant topics based on the researcher's emerging interpretations. This allows the researcher to probe for more "narrative detail" (Berteaux & Kholi, 1984, p.224) that may have been overlooked or disregarded in the original interview. The intent of the second interview was to further pursue participants' narratives about pediatric cancer caregiving and further discuss and refine narrative themes using three questioning approaches: (i) asking them if they wished to reflect on or further discuss their first interviews; (ii) asking specific questions about topics that

emerged during their first interviews based on my multiple readings of their first interview; and (iii) asking questions based on themes that emerged from my readings across all of the participants' first interviews.

The second interview began with me asking my participants what they thought about their first interview transcript and if there was anything that they wished to discuss or reflect on in further detail. In response, some of my participants noted how sad, angry, or negative they had seemed in their first interview, and discussed why they felt that way, or that they didn't mean to be that way. A few participants responded by clarifying information or discussing something they had forgotten to mention in their first interview. Generally, all of the study participants received their transcripts well and their comments about the content of the first interview were in regard to their perceptions of their speech (e.g., saying "like" or "um" too much).

Once participants had the opportunity to share these thoughts, I continued the interview by asking specific questions based on my readings of their original transcripts. The development of these participant-specific questions was facilitated by the transcription of the first interview, during which I made additional reflexive field notes to document my thoughts, interpretations, and feelings, points for further questioning, and additional observations that I may not have noticed when conducting the interview. These interview questions enabled me to clarify and amplify the stories the participants told me in Interview 1. As an example, a common question format I used to stimulate narrative production in Interview 2 was: "In your first interview you mentioned _____. Can you tell me more about that?" Additionally, seven questions were included at the end of the second interview to further explore narrative threads that I interpreted from reading all of the participants' first interviews. These questions were purposefully asked at the end of the interview in order to ensure that I did not limit how the participants wished to elaborate on their first interviews. Specifically, these questions asked participants to comment further on the following stories and narrative threads that I had deduced from my multiple readings: (i) workload; (ii) caregiving roles and responsibilities, and (iii) perceptions of pediatric oncology (personal and public). The second interview guide,

which includes the questions that were commonly asked of all participants, can be found in Appendix C.

Each of these interviews was also transcribed verbatim, following the same process described above for Interview 1. After each of their interviews were transcribed and deidentified, transcripts were sent to each participant with the same password as their first transcript to ensure confidentiality. If they had additional comments, questions, or edits to their transcript, they were asked to email me back within a two-and-a-half-week period. Participants were also informed that if I did not hear from them by the end of those two and a half weeks, I would assume that they had no edits to propose and no further feedback or commentary on their interview transcript. Three out of the nine nurses responded that they had no feedback on their transcript, and I received no response from the others.

Overall, between the first and second set of interviews, interviews ranged in length from 50 minutes to three hours and fifteen minutes and generated roughly 400 pages of interview data for analysis. Below, I describe how I conducted the analysis of this interview data.

4.5   Data Analysis Process

Critical narrative inquiry does not have one singular, defined analytic approach. Rather, it encompasses many approaches and methods that are tailored to the research questions at hand. In critical narrative research, understanding the context of each narrative and its production (e.g., interviews) is imperative for understanding the narrative itself (Riessman, 1993).

Narrative analysis can take on multiple forms and can be conducted using differing methods. Narrative data can be "analysed along a myriad of dimensions, such as contents; structure; style of speech; affective characteristics; motives, attitudes, and beliefs of the narrator; or his or her cognitive level" (Lieblich et al., 1998). McLeod and Balamoutsou (2001) contend that researchers should create their own methods for analysis of their research. The approach I took to analyze my participants' stories and

generate narrative themes drew upon numerous approaches, including the work of Laliberte Rudman & Aldrich (2017), Lieblich et al (1998), Pitre et al. (2013), and Riessman (2008).

Riessman (2008) contends that "a good narrative analysis prompts readers to think beyond the surface of a text" (p. 13). In particular, when initiating analysis through my close reading of interview transcripts, I asked the question: "What is the storyteller telling me through this story?" (Pitre et al., 2013). This question was particularly useful for analyzing my nurses' stories of caregiving, as this question not only addresses the literal content of their stories, but also their perspectives on caregiving, what meanings they ascribe to their caregiving, how they narrate their experiences of moral distress (which emerged as a central focus through the analytic process), and the broader frameworks and institutional contexts their stories and narrations are embedded within. I also used Lieblich et al.'s (1998) holistic content approach in order to conduct multiple close readings of my participants' interview data, generate narrative themes, and pay close attention to ambivalences, contradictions, and context in my participants' data. To read narratives in a holistic manner, Lieblich proposes five steps: (i) reading the raw data several times until a pattern emerges; (ii) noting any ambivalences or contradictions to the pattern; (iii) deciding on and highlighting key content or themes; (iv) reading separately and repeatedly for each key theme; and (v) keeping track of distinctive features (i.e., contradictions, context, and transitions) of each theme (Lieblich et al., 1998).

Lieblich et al.'s (1998) second and fifth steps share similarities with the critical narrative analysis techniques outlined by Laliberte Rudman & Aldrich (2017), whose critical narrative analysis includes paying attention to instances of conflict, tension, or fragmentation, to understand what these instances suggest about the narrator's identity and context. In particular, taking note of these instances in the telling of a story can generate insights into how narrators position themselves in their stories, how they are positioned in relation to broader contexts, and how they navigate this broader positioning (Laliberte Rudman & Aldrich, 2017; Polzer, Mancuso, & Laliberte Rudman, 2014).

The interview data were analyzed in three general phases, which are described below. Through this process I generated descriptive narratives for each study participant (participant narratives) and narrative themes that addressed my research questions and highlight how each of my participants came to conceptualize pediatric cancer caregiving, their role as a pediatric oncology nurse, and how they ascribed meaning to their caregiving. Although the data analysis process for this study is presented as having occurred in distinct phases, the process was, in reality, non-linear, and iterative. As Denzin and Lincoln (1994) describe: "The process of analysis, evaluation, and interpretation are neither terminal nor mechanical. They are always emergent, unpredictable, and unfinished" (p.479). This became evident, for example, in the midst of my data analysis, as my reading of the participants' narratives allowed me to deepen my understandings of their caregiving and moral distress. At this point, I further focused my analysis to reflect these understandings, and I subsequently became more familiar with the concepts of moral distress, bearing witness and narrative repair, which aided in my readings, re-readings, and re-interpretations of my data. Spending time understanding these concepts and how they were enacted and addressed through my participants' stories and storytelling allowed me to better understand the significance and meaning of the stories that my participants told me.

4.5.1   Analysis Phase One: Open Reading and Identifying Narrative Themes

The goal of this first phase of analysis was to begin understanding the themes stemming from the participants' narratives, and to consider how I would construct the participant narratives. I began this first phase of analysis during transcription of the first set of interviews. I began my reading of each interview transcript asking the question "What is the storyteller telling me through this story?" (Pitre et al., 2013). In order to begin generating narrative themes to probe further in the second interviews, I specifically engaged with Lieblich et al.'s (1998) steps i) reading the raw data several times until a pattern emerges, and ii) noting any ambivalences or contradictions to the pattern, which also overlapped with Laliberte Rudman & Aldrich's (2017) technique of identifying instances of ambivalence, contradiction, or tension.

I developed a list of interpretive questions to help guide the analysis. I referred to these questions while reading the raw data in order to understand how the nurses conceptualized care and caregiving, what meanings they ascribed to the care they provide, and the institutional frameworks they are embedded in, navigate, or challenge and what details they choose to narrate and bring attention to in their stories (Laliberte Rudman & Aldrich, 2017). While reading the transcripts, I asked myself a number of questions, which were framed in regard to *what* they storied about their caregiving, including, for example: who and what was discussed?; what was said about these different people?; what do they speak about when they discuss caregiving?; what meanings about caregiving are generated in their stories?; do they discuss particular concepts (e.g., moral distress)?; were there tensions, ambivalences, or conflicts in their stories?; did they resolve these tensions, and if so, how? Other questions were framed in regard to *how* the participants storied their caregiving, including, for example: where do they begin and conclude their stories?; what do the passages look like (e.g., do they speak in long, uninterrupted monologues or short, succinct vignettes)?; through what metaphors and other narrative devices are these meanings generated?; how do their stories elicit information about the broader contexts and discourses that influence their caregiving?

During this stage I documented broad, overall reflections, initial thoughts, impressions, themes, and notable features of their narratives (e.g., conflicts in their descriptions of being a pediatric oncology nurse) as well as similarities and differences between the participants' narratives in my analytic memos. It was during this stage of analysis where the participants' experiences of moral distress became highly apparent; moral distress was omnipresent in their transcripts both implicitly and explicitly. These interpretations of my first interviews were recorded in an interim analysis document and sent to Dr. Polzer and my advisory committee for discussion and feedback. This interim analysis document included a table providing demographic information about each participant, and main points about them from their interviews, as well as emergent themes that I had generated through my analysis. All members of the research team provided feedback about the plausibility of my emerging interpretations, my application of a critical lens, and the quotes I drew on to support the emerging narrative themes.

4.5.2   Analysis Phase Two: Refining Narrative Themes

This second phase of data analysis began as I transcribed the second interview transcripts. The purpose of this phase of analysis was to further refine my narrative themes and begin constructing the participant narratives. During this second phase, I continued to use the holistic content approach as outlined by Lieblich et al. (1998) by completing multiple open readings of the transcripts. I also applied the guiding questions used when analyzing the first interview transcripts and paid close attention to both what was told and the telling of my participants' stories. Additionally, I continued to make note of conflicts, tensions, ambivalences, and contexts, as suggested by Laliberte Rudman & Aldrich (2017) and Lieblich et al. (1998).

In this phase of analysis, I began to refine my interpretations by taking note of additional facets of my participants narratives. In particular, I noted how my participants' narrations substantiated, related to, or conflicted with what they had narrated in the first interviews, and if there were any new insights generated from these interviews. As well, I started engaging more thoroughly with Lieblich et al.'s (1998) third and fourth steps of analysis: (iii) deciding on and highlighting key content or themes, and (iv) reading separately and repeatedly for each key theme. I also began making notes of patterns within these themes and to document counter stories within these themes and patterns, in order to be wholly representative of my participants' experiences.

In this fourth step of analysis, the iterative nature of my analysis became much more explicitly interpretive. Specifically, I began to notice my participants' stories alluded to the concept of bearing witness, and the reparative aspects of their caregiving narratives. While they did not discuss these concepts explicitly, my interpretations of their stories led me to begin deepening my understanding of bearing witness and narrative repair through the literature. This allowed me to interpret their narratives more thoroughly and with a better understanding of what their narratives were "telling" me.

Specifically, the notion of bearing witness emerged during my analysis of the interviews, particularly when my participants described developing close relationships with the children and their families, how my participants felt distressed when witnessing their

patients suffering, and the distress they felt when they were unable to spend time with and build relationships with families due to their working conditions. I started believing that bearing witness held significant meaning for them, and was often a part of their care that was not facilitated or encouraged by their institutional contexts. My understanding of bearing witness became further developed after an interview I had with P4, who, when discussing how working in an ICU would be "easier" than working in pediatric oncology, noted that "you don't know their stories". This moment was significant for my understandings of bearing witness, and I began to understand my nurses as bearing witness to their patients' and families' stories as well as to their suffering. I also began to understand that I was bearing witness to bearing witness; that is, I was bearing witness to the stories of these children and families, as well as to the struggles and joys experienced by the nurses in my study.

4.5.3   Analysis Phase Three: Interpreting Narrative Themes

The purpose of this third phase was to actively interpret my emerging themes in relation to the theoretical concepts of moral distress, bearing witness, and narrative repair through continued close reads of all of the transcripts. While keeping these concepts in mind, I also engaged closely with Lieblich et al.'s (1998) fourth and fifth steps of analysis: reading separately and repeatedly for each key theme, and keeping track of distinctive features (i.e., contradictions, context, and transitions) of each theme, particularly in order to substantiate my interpretations and creation of the narrative themes. I continued to focus my attention on moments of conflict, ambivalence, tension, and context (Laliberte Rudman & Aldrich, 2017; Lieblich et al., 1998) to substantiate these themes and generate counter stories within some of these themes as well.

Toward the end of this stage of analysis, I prepared a draft of the participant narratives and synopses of the narrative themes that I had interpreted, supported by quotes that exemplified each narrative theme. The participant narratives, presented in the following chapter, include details regarding each participants' style of narration, career trajectories, motivations for being a (pediatric oncology) nurse, meanings that they ascribe to their caregiving (or what they suggested was most important), and the main themes, discussions, and stories that characterized my interviews with each participant.

Throughout the narratives, I've included quoted words and phrases that I've taken verbatim from the interview transcripts. By including direct quotes, I have attempted to remain as close to the raw data as possible. Words that are capitalized are words that the participants emphasized in their interviews. The participant narratives are a co-construction that includes my perceptions of the interviews, particularly how the participant narrated their stories, any specific words or phrases that were notable in the way they narrated, and my interpretations of their stories. When constructing these individual participant narratives, I drew on Kvale's (1996) processes of narrative finding (incorporating specific quotes, words, and phrases within interviews) and narrative creating, whereby I wove together un-storied aspects of the participants' interviews into a narrative. All of my participants' stories, as I will discuss below, were distinguished by particular ambivalences in the context and telling of their stories.

4.6   Methodological Reflections

My participants' stories were often characterized by ambivalence and inconsistency, both in relation to how they narrated their experiences of pediatric oncology nursing, and what they narrated about. These ambivalences emerged with varying juxtaposition: within the same story or paragraph, throughout the same interview, and between the two interviews. In keeping with my transactionist epistemological position, these conflicting accounts were not interpreted as right or wrong, lies or truths. Rather, these seeming contradictions were understood as examples of "strong multiplicity" (Hartman, 2015) by which participants narrate their stories and construct their identities as fluid, ongoing and dynamic. These ambivalences should be treated as open for interpretation, rather than as calls to resolve differences in one's voice and self-construction. Hartman (2015) described strong multiplicity with the metaphor of different kinds of listening: the vocal variance of strong multiplicity (or ambivalence) is not a zero/one dialectic but is rather an entire chorus of different voices. Strong multiplicity is not listening to music in stereo, it is listening in surround sound.

There were two patterns in these multiplicities. The first involved the nurses' ambivalence in *how* they narrated their stories; the way that they narrated often highlighted how they positioned me in their narrations. This narrative pattern flipped

between positioning me as an insider, or confidante, and positioning me as a stranger, and as an outsider to nursing and its contexts. The second pattern pertained to the nurses' ambivalence in *what* they narrated in their stories. In these cases, the nurses would highlight the joys and the sorrows, the triumphs and the disappointments, and the satisfactions and frustrations that are inextricably woven into their caregiving. These narrative patterns in ambivalence are described in further detail below. Sections of their quotations that I emphasize are italicized, and words that the participant emphasized themselves in their interviews are capitalized.

4.6.1   Ambivalence in the Storytelling

My participants' stories, and how they told their stories fluctuated based on how they positioned me. By this, I mean that at times, I was spoken to as an insider. Much of the time, I felt as though I could have been another coworker or confidante who was listening to them vent about a difficult situation at work. In the middle of some of our interviews, however, participants would ask me if I was a nurse, to understand my positioning and orient their storytelling accordingly. When I was analyzing the interview data, I realized that in those moments, my participants were navigating how they were going to tell their story based on their positioning of me as an outsider. Their stories then included additional definitions or details for me to make sense of what they were saying, and I, as an outsider, did not have the professional knowledge and experience to discount, counter, or minimize their stories and feelings. My outsider status was also often shocking to my participants in the sense that they could not conceive why someone who was not a nurse would care about their caregiving experiences. As my analysis of the interviews progressed, I began to make sense of this in relation to their stories about the difficulty they had explaining their work to outsiders like their family and friends, and to their stories about their management ignoring their concerns and complaints.

For example, throughout his first interview, P2 unabashedly told me about the poor working conditions on his unit and his frustration with management at the hospital where he works. At the very end of this interview, he asked me if I was a nurse, admitting that he "should" have asked me at the beginning of his interview:

> I'm actually more curious I didn't ask this at the beginning, *what, are you a nurse are you not are you, like I don't know what your background is in healthcare in general*. And I feel like, I probably should've asked that at the beginning but […] (P2, Inpatient Nurse, Interview 1)

After this, he asked why I was so interested in doing this specific research, as did many of the other participants. All of them expressed curiosity and confusion as to why I would care about their caregiving if I myself wasn't a nurse. These questions suggested that they embodied some of the attitudes of their institution – no one actually cares about your struggles, and the ones who do are the ones struggling with you.

In other interviews, it seemed that my outsider status enabled me to provoke tellings that nurses might not feel are worthwhile stories – such as the work that goes into administrative care. During one of P5's interviews, I probed about her coordination work, which stuck out to me because I had not known that coordinating comprised such a large part of being a pediatric oncology nurse. When I asked, she remembered I was an outsider who had observed something that, if I were a nurse, would be implicit in my understanding of caregiving:

> Um, yeah it's, *I almost like even ffforgot that that was even something worth mentioning because it's just SOOO engrained into like your everyday stuff that I like, totally forgot that it's not necessarily my job. But it is*. 'Cause at the same time like all we want, is we just want the patients to get the care that they need and so if that means that we need to, take on another like role or do something that's maybe not entirely within our scope to get that done like, we'll do it. (P5, Transplant/Outpatient Nurse, Interview 2)

As her interview continued, she discussed how she constantly shapes her stories in relation to the person she tells her stories to. In particular, she noted that she carefully crafts her stories for non-nurse audiences because she does not want to "traumatize" them. Her story highlights the difficulty she has in narrating what it is like to be a pediatric oncology nurse, and that she must manage how she narrates her stories in order to protect outsiders from misunderstandings of pediatric oncology as only being emotionally devastating:

> I mean I get it like, it is such a unique experience and a unique role and a very unique like, privilege to be a pediatric oncology nurse that […] I I don't think you really understand it and, *it's hard to explain too like I don't, 'cause you don't*

> *want to like, [pause] not like oversell it or undersell it* but you don't want to like 'oh it's not that bad and it's always like, you know sunshine and rainbows' when it's not, but you don't want to undersell it where it's like 'yeah it is really sad but, like, but it's not always like really sad' right like it can be very happy and very joyful. *[...] I can't explain it in a way that provides it the justice that it needs but also doesn't like traumatize the person I'm trying to explain it to.* (P5, Transplant/Outpatient Nurse, Interview 1)

Overall, the way my participants narrated their stories was based on their perceptions and positionings of me. My outsider status seemed to prompt their narrating to include stories that they may not have perceived as important, or potentially traumatizing.

4.6.2   Ambivalence in the Stories

In addition to the ambivalence in how they told their stories in relation to their audience (including me as a researcher), ambivalence was also present in the meaning they ascribed to their caregiving. In particular, my participants told stories about their work that seemed to be contradictory; on the one hand they described their work as positive and rewarding, "wonderful", and at times, even fun. In the same breath, they told me their work was emotionally devastating, traumatizing, and embedded in institutional frameworks that limited their ability to provide care that aligned with their values.

The ambivalences that were noted in their stories about their caregiving were conveyed powerfully in P1's concise response to my question about what it is like to be a pediatric oncology nurse: "What is it like it's fuuuun, it's challenging it's rewarding it's, ummmm frustrating sometimes, it's sad sometimes, iiiit's, ummmm [pause] [tongue clicks] it's great!" (P1, Outpatient Nurse Manager, Interview 1). Similarly, the ambivalences that characterized pediatric oncology nursing were described by P8 as requiring a level of emotional resolve in order to move through its ups and downs:

> *I think it takes A LOT more of an emotional backbone to be able to do that.* There's a lot of connections that are developed and, y-you make bonds you meet people and you impact them whether you realize it or not. It's a really big thing that the families and the children go through themselves. *It can be very difficult, but I also think it's a very rewarding and WONDERFUL thing to be able to do.* (P8, Inpatient Nurse, Interview 1)

Similarly, P5 described the wide-ranging emotional bandwidth necessary to be a pediatric oncology nurse, highlighting the "highs and lows" that fluctuate within any given day. Her narration flowed back and forth between the good and the bad, the rewarding and the challenging, the joyful and the traumatizing:

> *now the amounts of like highs and lows that you go through in a day like there's moments when you wanna cry and then the next, hour later the kids are doing something so stupid that like you're crying of laughing* like, it it's very, it's very difficult to, to capture that in a few short sentences. (P5, Transplant/Outpatient Nurse, Interview 2)

P2's ambivalences manifested similarly, in that he described that he has a "love/hate relationship" with being a pediatric oncology nurse. His narrative suggested that the ambivalence he felt was informed by a disconnect between his training and the realities of what the caregiving requires:

> Um, I think I also went into, the profession and the role, very blind. […] *as a student everything is 'oh my god everything's so new and fun and cool, and exciting' and then you get there for a few months and you're like 'wow this SUCKS or like this is not what I expected.'* […] I didn't realize how, impactful or how much a nurse or the nursing role could influence a child's care. I think that's something that was really good. Um, I also think that the, not everything is butterflies and rainbows. I think every – not all of these situations are all good and everything goes well I think there's a lot of politics a lot of bullshit within the role, and in the profession and healthcare in general really. There's a lot of hoops you have to jump through. […] but in general *I think it's very different than what I initially thought I think in a good way overall.* (P2, Inpatient Nurse, Interview 1)

In summary, the narrative methodology used in this study highlighted a number of ambivalences in the nurses' stories about caregiving. These ambivalences were expressed both in relation to how they tailored their tellings to me, as well as how they ascribed meaning to being a pediatric oncology nurse. These ambivalences are apparent in my narrative themes, which are presented in Chapter 6.

4.7   Quality Criteria and Ethical Considerations

Issues of "quality" have been highly contested in the literature on qualitative research (Connelly & Clandinin, 1990; Tracy, 2010). Connelly & Clandinin (1990), Lieblich et al (1998), and Altheide & Johnson (1994) contend that the quality of narrative research

cannot be based on markers of quality used in quantitative research. In particular, "narrative [research] relies on criteria other than validity, reliability, and generalizability" (p.7). Connelly & Clandinin (1990) suggest that narrative researchers should select and defend criteria that best apply to their work. The purpose of my study was not to produce findings that could be generalizable to all pediatric oncology nurses or caregivers. Rather, it was to provide insight into how a group of pediatric oncology nurses with varied levels of types of caregiving experiences and work environments ascribe meaning to their care and caregiving. Because narrative research is interpretive, it is thus open for multiple interpretations that showcase the wealth and depth of the data collected (Lieblich et al., 1998).

With this in mind, I considered the following criteria for this study: (i) Lieblich et al.'s (1998) criterion of coherence; (ii) Lincoln & Guba's (1985) criterion of fairness; (iii) Tracy's (2010) criterion of sincerity; and (iv) Mishler's (1990) criterion of trustworthiness. Each of these criteria is considered further below.

4.7.1   Coherence

According to Lieblich et al. (1998), coherence represents "the way different parts of the interpretation create a complete and meaningful picture" (p.173). Coherence can be evaluated both internally and externally. Internally, coherence refers to how "the parts fit together" (p.173). Externally, coherence represents how well this research engages in conversation with existing theories and previous research.

In this dissertation, internal coherence was achieved by using narrative in "narrative terms" – that is, this study was epistemologically tethered in that the data collection and analysis techniques were informed by and consistent with a narrative methodology throughout the conduct of the study. Further, external coherence was optimized through an explicit articulation of the theoretical concepts that informed my interpretations of the narrative data.

With regard to my research, I strived for internal and external coherence by soliciting feedback from Dr. Polzer and my advisory committee in regard to the structure and

content of my participants' narratives. I also sought their feedback about my interpretations of the data, and how I had constructed and structured my findings into narrative themes. In terms of evaluating the coherence of the data externally, that is, in relation to existing theories and previous research, I completed multiple steps. I first conducted an extensive literature review in which literature on pediatric oncology nursing and caregiving was examined. Additionally, I approached this research with the lens of moral distress, which, as I noted earlier, oriented the interpretation of the narrative themes more centrally as my analysis progressed. Lastly, as my narrative themes started to take shape, I purposefully deepened my knowledge of additional sensitizing concepts, particularly bearing witness and narrative repair, in order to strengthen my interpretations. Through this process, I was able to articulate more clearly how my narrative methodological approach enabled me to yield new insights about moral distress and have been previously discussed in the nursing literature. I elaborate further on these insights in the Discussion chapter.

4.7.2   Fairness

Lincoln & Guba (1985)'s criterion of fairness refers to: "A balanced view that presents all constructions and the values that undergird them" (p.79). They contend that if one's research is value-bound, and a topic that holds multiple meanings is discussed, it makes sense that "different constructions will emerge from persons and groups with differing value systems" (p.79). This aligns well with a critical narrative methodology, where the intent is not to produce generalizable findings, but is rather to present the different, value-mediated stories of the participants, and highlight how their stories are constructed by and within (and sometimes challenge) particular contexts and institutions. They argue that exploring these conflicting values should be a significant part of the data collection and analysis processes (Lincoln & Guba, 1985). Therefore, the goal of the researcher is to ensure that all different constructions, including conflicting constructions and value structures, are highlighted and discussed (Lincoln & Guba, 1985; Shannon & Hambacher, 2014). In order to have the depth of understanding required to present these perspectives, many have argued that a prolonged engagement with the data, persistent reflexivity, and

having participants verify and discuss the transcripts are all considered critical processes for ensuring fairness (Mays & Pope, 2000; Reason, 1981; Sands, 2004).

In my research, I spent many months (February 2020 to January 2021) immersed in my data, analyzing and interpreting my participants' stories. Throughout the conduct of this study, I remained reflexive and honest with myself, Dr. Polzer, and my advisory committee about my decision-making and feelings in regard to research (which I describe in more detail below). I also ensured that my participants had the opportunity to comment and discuss both of their interview transcripts in as much or little detail as they liked.

In the presentation of the narrative themes, I strived for fairness by presenting the stories of more than one of my participants and attended to the ways in which the stories took shape in relation to the particularity of their nursing experiences and care contexts. Also, through the development of the participant narratives (see Chapter 5), I was able to keep my participants' accounts situated within their respective perspectives, and to maintain an awareness of how my narrative themes took shape relative to each participant's context. I also attended to the conflicts within the nurses' narratives, which emerged in diverse ways. First, as discussed in my methodological reflection above, my participants would often narrate multiple conflicts and tensions within their narratives, highlighting the ambivalences they ascribe to being a pediatric oncology nurse. By drawing attention to these ambivalences, I paid attention to the different perspectives on pediatric oncology nursing expressed by the participants and highlighted how each nurse experiences conflict in their own conceptualizations and perceptions of pediatric oncology nursing. As well, by recruiting pediatric oncology nurses who had worked varying lengths of time and in differing care environments in pediatric oncology, I was able to understand and present differing and, at times, conflicting meanings ascribed to their caregiving and the kind of caregiving they perform. Further, I was also able to understand how the values they assign to caregiving differ from the values of their institutions through their stories of moral distress. Lastly, in the presentation of the narrative themes in Chapter 6, I paid attention to the ways in which their stories expressed values that counter dominant narratives. Often, these stories were used as rhetorical devices to counter master

narratives about nursing and establish the nurses as individuals embedded within systems that limit their capacity to provide quality care.

4.7.3   Sincerity

Lieblich et al. (1998) argue that being open and honest about the research process and the decisions made through the progression of the research "is of the highest significance in narrative inquiry" (p.173). A key aspect of sincerity is transparency, which "refers to honesty about the research process" (Tracy, 2010, p.842). Sincerity involves transparent acknowledgement of assumptions, goals, and mishaps in the research and how these may have influenced the research throughout the progression of the study (Tracy, 2010). Self-reflexivity, a component of sincerity and one of the "most celebrated practices" (Tracy, 2010, p. 842) of qualitative research, allows the researcher to acknowledge the assumptions and motivations that guide their work. Self-reflexivity is "considered to be honesty and authenticity with one's self, one's research, and one's audience" (Tracy, 2010, p.842). To engage in self-reflexivity means to be aware of one's own assumptions and perspectives prior to, during, and after engaging in the research. Throughout the progression of my study, I took reflexive notes, often writing about my perspectives and assumptions about pediatric oncology caregiving. I was also reflexive about my growing comfort and expertise with critically oriented research and narrative methodologies, the ambiguity and messiness of narrative analysis, and how I engaged with my data differently and with more comfort as time progressed. Further, I made sure to acknowledge my impact on the research, the decisions that I made, and my role in the co-construction of my participants' narratives. I was also honest in my notes, and with my advisory committee, about how my participants affected my emotions, assumptions, and life outside of our interviews and throughout the progression of my study. Further, my work is written from a first-person perspective, to highlight my presence and influence on the research.

4.7.4   Trustworthiness

Mishler's (1990) criteria of trustworthiness is "the task of articulating and clarifying the features and methods of our studies, of showing how the work is done and what problems

become accessible to study" (p. 423). Maintaining trustworthiness can include creating an "audit trail" that provides documentation of any research decisions and processes throughout the progression of the study. Research that is trustworthy explicitly acknowledges how the researcher is involved in the work, how fieldnotes are created, and the level of detail of transcription involved.

Lieblich et al. (1998) argue that narrative researchers are responsible for providing a comprehensive rationale and account for the processes and methods used for their research. In addition to field notes I made before and after the interviews that included my initial interpretations of each interview, and notes regarding significant events that each of the nurses highlighted in their narratives, I also kept track of methodological decisions and data analysis procedures by noting my own reflections regarding the research process and how I came to decisions and analytic conclusions. All of the interviews were transcribed verbatim by me, and all of my participants were given a copy of their de-identified transcript. All of the nurses were able to comment on both of their interview transcripts and provide additional detail if they felt that they had more to discuss.

Additionally, trustworthiness was illustrated in my study by substantiating my interpretations with my participants' quotations. In doing so, I grounded my interpretations in the data, and displayed how my interpretations were generated through my understandings of the participants stories. These interpretations and their plausibility were further substantiated through meetings with my advisory committee as I progressed through my phases of analysis. At each stage of analysis, I presented my committee with provisional themes that were substantiated with quotations from interviews, to receive feedback on the plausibility of my interpretations and their groundedness in the data. Through this process, we refined some of my interpretations, which included collapsing some provisional themes into broader themes that were agreed upon as more aptly capturing the participants' stories.

4.8   Ethical Considerations

4.8.1   Institutional Ethics

Separating the ethics of a study from the study's quality is difficult; a well-done research study is one in which the researchers constantly weave ethics into its composition. Smythe and Murray (2000) contend that narrative research has specific ethical considerations that span key ethical issues of obtaining free and informed consent, obtaining process consent, ensuring privacy and confidentiality, and ensuring open co-construction of narratives.

All study materials and procedures were sent to the Western Research Ethics Board (WREB) for approval prior to the initiation of the study (see Appendix D). After receiving ethics approval, I abided by the guidelines related to issues of informed consent and confidentiality. All participants were asked to read a letter of information with all pertinent information regarding the study and were encouraged to ask questions about the study if they had any prior to signing the informed consent form. Participants were also reminded of their rights prior to their second interview and given the opportunity to ask any questions that might have emerged since completing their first interviews. Participants were also encouraged to contact me via email if they ever had questions regarding the study outside of our interviews.

4.8.2   Narrative Ethics

While the above issues are important, they pertain primarily to institutional requirements for the ethical treatment of human subjects. Alongside these institutional concerns to protect privacy, particular ethical issues and demands emerge in the context of narrative research. Specifically, narrative interviewing and storytelling in a research context can raise issues of narrative ownership and the multiplicity of narrative meaning (Smythe & Murray, 2000). In particular, concerns may arise regarding how participants' stories are interpreted by the researcher; there may be instances in which the researcher interprets their stories in a way that may or may not be consistent with the meanings ascribed to the story by the participant. This can become problematic, as the voice of the researcher is often perceived as the voice with the most authority (Smythe & Murray, 2000). To

address this, I have committed to ensuring that all presentations of my participant narratives are described as co-constructions between me and my participants, and my role in the co-construction of the narratives will be explicitly acknowledged. I have also committed to ensuring that my findings, particularly my narrative themes, are described as my narratively and theoretically informed interpretations of the study participants' interviews.

As with other qualitative methods, narrative research also raises ethical issues when stories involve patients or other individuals within the participants' stories. As this study examined the caregiving experiences of pediatric oncology nurses, I expected that the nurses might narrate their experiences with reference to their patients, their patients' families, their coworkers and the institutions where they worked, information that may identify them and others who did not directly consent to take part in the study. To protect participants' identities, their names, as well as the names of other persons and places, were assigned pseudonyms and replaced with generic descriptors (e.g., hospital). If my participants discussed details in their stories that could potentially identify their patients, these were details were removed and replaced with generic descriptors.

Lastly, as the topic under study was about caregiving for children with cancer, I anticipated that my participants may become emotional, or have difficulty speaking about some of their experiences. I ensured that all my participants were given the time they needed to narrate their stories, take pauses or breaks if they needed to, and were aware that I could stop the recording and interview at any time if they requested. I also ensured that I debriefed with my participants after their interviews to gauge how they were feeling. I also had resources available to direct participants to if needed at the end of the interviews.

4.9   Conclusion

In this chapter, I outlined my methodological approach and the specific methods I used in the collection and analysis of my participants' stories about caregiving. Using a critical narrative methodological approach, I conducted eighteen interviews with nine pediatric oncology nurses who had varying years of experience and worked in different locations

and care environments. Narrative analysis of the nurses' stories allowed me to understand how they conceptualize care and caregiving, and the meanings they ascribe to their care provision and to being a pediatric oncology nurse. This approach also allowed me to connect their stories of pediatric oncology caregiving to broader contexts by analyzing their narratives through the lens of moral distress. As well, I outlined the iterative and reflexive character of the analytic process, and how I deepened my understandings of moral distress, bearing witness, and narrative repair, and acknowledged my presence and changing perspective as the study progressed.

In the following chapters, I present the descriptive participant narratives (Chapter 5) followed by the narrative themes (Chapter 6) that were generated by the data collection and analysis procedures outlined in this chapter.

Chapter 5

5   Participant Narratives

In this chapter, I present the first analytic product generated from my analysis: descriptive narratives for each of my participants. The descriptive narratives were constructed from my analysis of each participant's interviews, and aim to draw the reader's attention to how the nurses in my study narrated their stories, assigned meaning to their caregiving, and negotiated their identities within their institutional contexts. Additionally, these narrative summaries include details regarding each participant's career trajectories, motivations for being a (pediatric oncology) nurse, and the main themes and stories that characterized the interviews with each participant. The participant narratives also illustrate how my participants felt about their working conditions and their motivations for participating in my study.

As co-constructions, the participant narratives include both my interpretive voice and the voices of my research participants. Throughout the narratives, I've included quoted words and phrases to remain as close to the raw data as possible. Additionally, the narratives incorporate my interpretations of the participant's stories and their styles of narration.

5.1   P1

P1 has been a pediatric oncology nurse for eleven years – ever since she graduated from nursing school in 2008. She has "always wanted to do this work", but she could not articulate why. Her pediatric oncology nursing career began in a small center where all pediatric patients (including pediatric oncology, surgery, and general medicine) were on one large unit. Her nursing role at that time included many forms of caregiving, including administering chemotherapy, accompanying patients and families to procedures, and educating families about medications. When she described the technical skills and tasks she did, she would preface them with the word "just". At one point, I asked her to describe what accessing a port was like, and she outlined a very technical set of steps (which, to me, seemed complicated). When she finished outlining what to do to me, she

said, "It's JUST a way to facilitate um, the chemotherapy administration". Her use of "just" in a noticeably frequent manner to describe the technical caregiving she performed suggested that she acknowledged its importance, but she deprioritized it in relation to what gives her caregiving meaning. As her interview was my first interview for data collection, her use of "just" also alerted me to this style of narration in the other interviews.

P1's narration strongly conveyed that the care that makes her feel fulfilled is relationship building with children and families. When she spoke about her relationships with families, it was often in relation to why she loved her former role as an inpatient nurse, as being a bedside nurse meant getting to know and spend time with each patient and family. The importance she placed on relationships with patients and families was also noticeable in a story she told about when she cared for a child who died, which she described as having "a big impact on [her] life". This impact involved thinking about and emotionally processing the deaths of children outside of work; as she put it, it would be "impossible to just like go home and not think about, the fact that a six-year-old just died". To this day, she maintains that the most difficult part of the work is caring for "these families where you feel a strong connection you have a good relationship with, and then you have to watch, [pause] um, [pause] their child die and watch the, sadness and the pain and the physical and emotional pain".

She highlighted that pediatric oncology was both rewarding and difficult. Although she described how her caregiving affects her emotionally, and outside of work, she was very clear that she loves her job and mentioned "finding the joy" on multiple occasions. It seemed as though, for her, joy is something in her work that actively needs to be sought out or found because it's difficult. She mentioned many times that she loves her job and does not want to leave it. This ambivalence was interesting and alerted me to this dynamic in the other interviews. This ambivalence was discussed in Chapter 4, and is discussed further in Chapters 6 and 7. She currently works as a clinical program coordinator on an outpatient unit, where she is "one step removed" from her inpatient role. At the time of our first interview, she had been in this role for over five years and prefers it to her bedside nursing experience. When I asked her why she preferred this role

over her inpatient role, she described how supportive her team is, which included other nurses, nurse practitioners, and staff physicians, and emphasized the respectful and trusting qualities of their relationships: "…the level of respect is very high. The level of trust is very high". This comment made me wonder what motivated her to change positions and whether she felt unappreciated in her former inpatient role, which many of the other study participants who worked in inpatient settings spoke about while describing their experiences of moral distress.

In her current role, her work focuses more on coordinating care, support and education: *"I do all of the education or a large part of the education, and supporting care and organizing and making sure it all happens when it needs to happen"*. Her days are split between working in the clinic and in her office, which she calls "office days". While working in the clinic, her caregiving includes building relationships with families, educating families about different treatments, procedures, and test results, and managing uncertainty by helping families understand what the following months might look like. On her "office days", she works by herself and does a lot of administrative work, such as emailing and calling the families. Even though she no longer works at the bedside, she is still able to build relationships with families; she is often present at their disclosures (i.e., when families are told their child has cancer), and follows families through treatment, remission, relapse, palliative care, and death.

P1's style of narration aligned with the requirements of her current caregiving role and duties. Her narrations were shorter than most of the nurses I interviewed and were succinct but still rich. This concise and efficient style of narration likely reflects the time constraints, multi-tasking and workload that shaped her communication style.

5.2 P2

P2, who consistently narrated in long, descriptive passages, began our first interview by telling me his story of becoming a pediatric oncology nurse: he completed an undergraduate degree in Kinesiology with the hopes of going into pediatric physiotherapy, but as time progressed, he realized his grades were not high enough to get into physiotherapy programs. Wanting to stay in healthcare and knowing that he had

family members in nursing (i.e., his mom), he decided to complete a two-year advanced nursing degree. For his final placement, he worked in inpatient pediatric oncology, and he was hired onto the unit when he finished his schooling. At the time of our interviews, he still worked on this unit and was working in a clinical support nurse role, meaning that he assists with care for the most complex cases and is in direct contact with the unit manager.

He did not recall having expectations for what pediatric oncology nursing was going to be like, but he had a preceptor that helped him through "the really good to the really bad and everywhere in between". He started out caring for patients in less acute states and their families to get used to the inpatient environment, but because of high rates of nurse turnover on his unit, he was very quickly "thrown in" to oversee the children who were severely acutely ill, medically complex, and palliative. In this short period of time, he learned that pediatric oncology is a "general mess" where you must expect the unexpected. In his interviews, he often cracked jokes about this mess, and the nurses' (poor) working conditions.

In his narrations about his caregiving, P2 would often use analogies. For example, to help me understand the multiple roles and expectations placed upon him, he explained that nurses are part "doctor pharmacist social worker, psychologist, um, nutritionist like dietician" and "palliative Sherpa". He feels that this variability can be exciting, an aspect of the job he likes because he is someone "who cannot sit at a desk for, like, forty hours a week just typing on a computer".

As one of the only male nurses on his unit, P2 explicitly addressed the ways in which his experience of being a nurse is gendered, drawing on examples of how he is sometimes treated differently than his female-identifying colleagues. Specifically, he suggested that parents are less likely to be aggressive or intimidating towards him and that he often gets mistaken for a physician. He also described instances when families requested a "different" (i.e., female-identifying) nurse because of their religious or cultural practices and beliefs. His manager, who is also male-identifying, was described as singling the two of them out, saying things like "it's different for us [because we're men]". However, P2

felt as though he didn't relate to his manager as well as he did to his female-identifying colleagues because he felt that their "personalities" and "emotional intelligence" are more similar.

Overall, he believed that pediatric oncology nursing is very "fun" and "rewarding", with a ratio of "70/30, good to bad [caregiving experiences]. Maybe 80/20". This assessment contrasted greatly with the stories he shared during our first interview, which felt like a platform for him to express how frustrated he was feeling with his management on the unit, and the decision-making that had happened on behalf of the patients (by the care team) he was caring for before our interview. Most of his stories were about the "moral distress" he and his nursing colleagues experienced, which he mentioned explicitly and without prompting. He outlined that turnover rates on his unit are at 100% over a five-year period, nurses are burnt out, and management does a poor job of listening to and protecting the nurses. Specifically, many of the nurses' concerns, when brought forward, are briefly acknowledged by management, but then quickly ignored and never addressed. The nurses, in turn, feel as though they cannot provide good care: "one of the most annoying parts of our job [is] that we can't do a good job, we know what we're supposed to do but we can't do it the way we want to."

In his second interview, he told me that his first transcript was reflective of how he felt at the time; before his first interview, he had worked a set of difficult and frustrating shifts, which came through in his interview. In his second interview, he mentioned that preceding shifts were better, and that he felt less frustrated. The way he acknowledged how he felt in his first interview, and how his moods contrasted between his first and second interview seemed to be reflective of the emotional rollercoaster that is pediatric oncology.

At the end of his second interview, once I had shut off the audio recorder, we stayed online (as his interview was conducted on Zoom) for a bit to talk. During this time, he gave me more context to his frustration in his first interview. At the time he and his colleagues received the recruitment email for my study, there was a great sense of dissatisfaction with their management on his unit, and many of the nurses felt as though

they were constrained from providing what they believed was good care for their patients. When they received the recruitment email, P2 told me that he and many of the nurses on his unit openly discussed my study. The nurses were excited about the potential of participating in my study and having someone to talk to about their work and experiences. Shortly after this discussion, he found my recruitment email, and reached out to me to indicate his willingness to participate.

5.3   P3

P3's interviews were full of pages-long monologues, which began with her story of how she became a pediatric oncology nurse. When she was in grade nine, her cousin died during infancy from acute lymphoblastic leukemia, which motivated her to go into pediatric oncology. After completing nursing school, she was immediately hired on the same inpatient unit where her cousin was treated. In this story, she told me that she uses the same stethoscope her aunt and uncle had purchased to care for her cousin, thus revealing the personal significance of her decision to become a pediatric oncology nurse. She described working in pediatric oncology as "an honour" and often described how she felt like a member of her patients' families, referring to her patients her "little brothers and sisters". The relationships that she makes with children and her families as part of her nursing work brings her meaning and joy.

While P3 currently works in the outpatient unit at her hospital, her nursing career began in inpatient oncology, and, like P2, she had to acclimatize to providing care for very sick children very early on in her career. She was warned by many people when she first started her nursing career that "this [inpatient pediatric oncology] is not a forever home" and that she was "going to love it, and then [she] was going to leave". At first, she was led to believe that she would leave because of the emotionally demanding nature of the work. However, she soon learned that people left because of the demanding workload and caregiving responsibilities thrust upon the nurses, even when the nurses were not fully ready to take on these complex responsibilities. She "began to feel anxious coming into work" because she was still relatively new, had limited experience, and was taking on patients who had complex and difficult cancers and side effects from treatment. Oftentimes, she would leave her shifts internalizing what she was not able to do because

of her working conditions, thinking that she "could have done better", or "done more", or "done" things "differently".

P3's narrative revolved primarily around a particular event with the death of a child that changed the trajectory of her career. It seemed as though telling this story during our interviews was a way for her to process emotions and trauma that she had been holding on to for an extended period of time. She brought up this story in her first interview, and prefaced her story by telling me that this was the first time she had told anyone about this particular event. This story tragically highlights the ways in which the demands of pediatric oncology caregiving conflicted with her own nursing priorities of building relationships, and with patient and family expectations of nurses' caregiving. Her story was about her experience with an 11-year-old girl who had just started treatment and was incredibly "anxious". P3 spent "hours" trying to get this patient to take her medications and had to leave the room multiple times during this ordeal to care for and give medications to other patients. Feeling stretched between all of these caregiving responsibilities, P3 experienced a great deal of frustration in trying to get this patient to take their medication. After asking the patient's mother for help, the mother responded that "she [patient/daughter] thinks you hate her" because she overheard P3 say that she "did not have time" to keep trying to get this patient to medicate and P3 was continually leaving the room. Several days later, P3 found out that the patient had become septic and died in the ICU. This caused P3 an enormous amount of distress because she "was unable to fix [her] relationship with [the patient]". The night that the patient died, P3 applied for a secondment through a children's cancer camp because she "just needed to go, like I just needed, a break". She spent a year working at camp, but ultimately returned to the hospital because she felt that she was not being treated or compensated fairly at camp.

However, in her time at camp, in an instance that she described as "meant to be", she and the mom of the deceased child were enrolled in the same palliative course. As introductions were happening, P3 heard a woman introduce herself. P3 told me that when she recognized the voice "I just leaned over and I saw her face and I was like [whispers] 'oh my god.' [returns to normal voice] Went to the bathroom, had a, absolute meltdown". She went back in the room and re-introduced herself to the mom, and began a

conversation, which provided her with an opportunity to apologize to the mother, provide her with context of what happened when P3 was with her daughter, and process their grief together. She told me that this interaction was "meant to happen as like a, full circle, for me".

After finishing her position at camp, she returned to the inpatient unit, where she barely knew any of the staff because of such high staff turnover. She transferred to the outpatient unit where she still works, and while she is still able to form connections with families, she lamented that it's not the same as inpatient. She often finds herself "romanticizing inpatient" because of the bonds created there. Her hope, as she finishes up a Master's degree in Nursing, is to specialize in palliative care. Her stories suggested that making death and dying meaningful for children and their families is what brought her the most meaning when working in inpatient, describing her role in palliative care as her being "a puppeteer for magic." Her hope is to one day be one of the head nurses on this team and to do palliative care full time.

5.4 P4

P4 narrated her stories in shorter vignettes than P2 or P3, and continually changed course as she narrated. She was much more comfortable responding to specific questions instead of open-ended questions because answering open-ended questions made her think she "answered [the question] wrong". Her story began with her describing her lack of experience caring for children prior to working in pediatric oncology; she had spent her training and the beginning of her nursing career caring for adults. When she started to nurse in pediatric oncology, she quickly became aware of how pediatric oncology nurses care for the entire family: "each family member was a patient themselves like in an oncology unit for kids it's almost like, the WHOLE family is your patient so that's a big challenge". Her narrative suggested that caring for families encompassed "the hard parts" of pediatric oncology, particularly through the emotional, mental, and relational care that she provides to them. For her, to hang an IV bag, or check vitals is "the easiest part of my job" – the hard part is when she walks into the room, and "the family's really distraught, the like the sibling's crying there's families crying everyone's really upset like, dealing with, the, the aftermath of those [highly emotional] situations I think is really hard". She

went on to highlight that it's not necessarily the skills of emotionally comforting and caring for the family, but rather "being able to compose yourself sometimes in the room when you're doing them is hard". The complexity of caring for the family was a significant part of both of her interviews, which could potentially be due to her limited experience in pediatrics before beginning her work in pediatric oncology.

During our interviews, P4 shared that she had contemplated leaving pediatric oncology, but that it was a difficult decision. On the one hand, she wanted to leave because she had experienced feelings of burnout, and also felt as though pediatric oncology requires a specific set of skills that are not necessarily marketable in other nursing contexts. However, she highlighted that the attachment formed with families during treatment compounds the difficulty of leaving because of guilt: "a couple nurses have left and they even feel like – you almost feel a sense of guilt from leaving, the families and their, the kids".

When P4 discussed her feelings of burnout, she highlighted that she and her colleagues had experienced moral distress in their work. Specifically, P4's stories about moral distress included stories about the difficulties of balancing multiple caregiving demands, working with unsupportive management, and providing care in end-of-life situations. In these stories, she described the intensity of workload, which involved handling difficult parents, attempting to balance all of her caregiving demands, and skipping breaks in order to perform essential caregiving duties. She would briefly mention her frustrations with management when discussing how, at times, families treated the nurses poorly and management did not give support to the nurses. Often, she would contextualize these experiences with justification for why parents sometimes behave poorly, or rationalizations of poor working conditions and unresponsive management, as though she did not want to present herself as speaking badly about anyone or anything.

In our second interview, she shared that she was not leaving pediatric oncology fully, but that she had recently has taken on a job share which involved spending half of her time working in the pediatric ICU and the other half in inpatient pediatric oncology. Her narrative suggested that working in the pediatric ICU will not be as difficult as in

pediatric oncology because "you don't know people's stories". While she described the care in the pediatric ICU as technically and medically difficult, and difficult to witness, she highlighted that "you don't know the patients, at baseline". She suggested that working in the pediatric ICU may act as a reprieve from pediatric oncology because of its looser attachment with patients and families. She also seemed excited to start this new position because she would be able to work one-on-one with patients as opposed to the three-to-one nursing ratio she has in pediatric oncology, and learn nursing skills associated with more acute, critical cases, which she would be able to transfer to other nursing contexts, including the inpatient floor.

5.5 P5

In our first interview, P5 told me stories that were often pages long, which she herself admitted was surprising at the beginning of our second interview: "it kinda made me laugh like you know your one question like, pretty simple then it's like three pages of a response for me". Like some of my other interviews, her interviews felt, at times, as though I was a person to whom she could vent about her frustrations related to nursing. In particular, she often discussed complex patients and difficult families, as well as the lack of support provided to her and her colleagues by management. She told me that she was someone who often held back from sharing the details of her work with family and friends out of her concern that this might traumatize them. Our interviews thus provided her with the opportunity to share her experiences, feelings and opinions with someone who expressed interest in hearing her stories.

Her first interview began with her story of how she became a paediatric oncology nurse. Her final placement in nursing school was in a bone marrow transplant unit and was particularly informative for her decision to become a paediatric oncology nurse. In particular, this placement challenged her preconceived knowledge of pediatric oncology as emotionally difficult, and allowed her to understand what working in pediatric oncology was like when working with less complex or emotionally demanding patient cases: "I didn't, really know what it is, what it was and, it probably would have just like scared me away that like, pediatric oncology itself".

Within her first week of working in pediatric oncology, however, she was thrust into providing post-mortem care for a child who had died, even though palliative care was typically reserved for nurses with at least one year of experience. This experience left her "traumatized", and her narrative suggested that this was the first of many experiences in a year that was characterized by feelings of "burnout". In her first year of practice, she started to feel "burnt out" because she "had, a lot of really, difficult families to work with" that "put us [the nurses] on edge or kind of made us, feel like we would have our backs against the wall." In addition to dealing with difficult families, they were also treating very sick children who were candidates for clinical trials: "kids that, had like less than a five percent survival um mainly because we had these clinical trials opening up". Her burnout manifested through becoming "disengaged" at work because she had "a really difficult time from separating, like my work life from my home life". After this first year, she joined a "nursing resource group" to help mitigate her feelings of burnout. Her experiences of burnout motivated her interest in the study, which she shared with me during her screening phone call. This burnout, as well as her dissatisfaction with management were significant themes in her narratives.

P5's descriptions of her frustration with management highlighted how management often compounded the difficulties she experienced. Like some of the other participants, P5's stories highlighted how management was unsupportive, misleading, and ignored her and her colleagues' concerns. In one example of these stories, P5 revealed how she was covertly directed by management to "lie" to inspectors about treatments that she had been giving to patients on her unit, as she found out at that time, was not fully certified to perform. Ultimately, her frustration with management resulted in her accepting a position in a pediatric bone marrow transplant unit in a children's hospital in the United Status. Originally, she was planning on moving in the spring of 2020, but the COVID-19 pandemic abruptly halted those plans.

Her work experiences during COVID have compounded her frustrations with her working conditions and with management's unresponsiveness: "the leadership team, you know, would always say that they're very like open to suggestions and then we would suggest things and like, you know, they'd be like 'oh that's a great idea' and then nothing

will be sort of implemented". As well, she ended up working on the COVID-19 unit, which meant that she had to live in an AirBnB away from her parents – a cost that was not reimbursed by her employer. Given the lack of clear guidance and direction from management during COVID, she and her nursing colleagues developed their own care guidelines that were based on their clinical knowledge and experiences of caring for COVID-19 positive patients. In doing so, the nurses were brought together in solidarity for their patients and against management. At the time of our final interview, her plans to move to the US had been postponed indefinitely.

5.6   P6

At the time of our interviews, P6 had been a pediatric oncology nurse for about 30 years, and her career involved many roles (inpatient nursing, research and education) in many hospitals and settings, including pediatric ICU, and pediatric oncology inpatient and outpatient units. At the time of our first interview, P6 had been a community travel nurse for about 15 years, and it seemed as though she will not leave this role until she retires.

She began her narration by describing what it means to be a community travel nurse. She emphasized that she focused "more, with the psychosocial aspect" of care compared to the hands-on curative care completed by inpatient and outpatient nurses. This psychosocial support work included linking families with organizations, agencies, and charities (e.g., financial aid), assisting the families with filling out the forms and paperwork required by these organizations, finding equipment that the family may need (e.g., wheelchairs, thermometers), assisting with travel accommodations if families needed to travel for treatment, and connecting the family with other members of the child's medical team to assist them with questions or concerns about specific treatments and procedures. As well, her caregiving role regularly involved doing "home visits" to assess the patient and family's needs after the patient was released from the hospital as well as "school visits" where she would teach classmates, teachers, and staff who were connected to the patient and the family about the cancer and what to expect. The aim of these school visits was to help prepare students and staff for the return of the child with cancer to school, educate them about the type of cancer and what it means for that child

to have that cancer, and ultimately to support the patient to have a more seamless transition back to school after their diagnosis.

P6's style of narration was often very short, sweet, and to the point. At times, I felt quite intimidated by her and as though I wasn't doing a good job of interviewing because her narrations were much more succinct than the other nurses. However, I soon came to wonder if, similarly to P1, her narration style mimicked her communications in her role as a community travel nurse. By this, I mean that she divides her time and care (which is highly administrative and predominantly involves coordinating and education) amongst at least 20 patients. Like P1, it seemed as though her position required her to be able to address questions and help others quickly and succinctly in order to provide care to all of her patients and their families. Her experiences of workload were also narrated differently than many of the other nurses in my study. In particular, she highlighted that her work is "autonomous" in the sense that she has control over her schedule in a way that inpatient and outpatient nurses do not. In particular, she has some ability to schedule when she completes her caregiving tasks. She admitted that this control allows her to be the nurse she wants to be, and acknowledged that her colleagues in inpatient nursing were often experiencing distress because of their demanding caregiving tasks and lack of time or control in their schedules.

P6's narrations highlighted that what she enjoys most about her community travel role is that she can tailor some of her work to her interests, particularly conducting research and creating educational materials, while still working closely with families. She had taken on research and education roles prior to her community travel nurse role, which she enjoyed, but in those roles she missed being able to develop relationships with families. In her current position, she has conducted research involving siblings of children with cancer and on the development of a mentorship program for medical students. She also started an interdisciplinary oncology education and support committee with her colleague, which meets every month to discuss educational needs and create educational materials for staff and families. She and her colleagues have also written books for the families that explain medical procedures.

At the time of our second interview, which was in the summer of 2020 (during the COVID-19 pandemic), she was no longer able to do home or school visits with and for the families. She was hoping that as case numbers went down, she would be able to travel to see her patients and families again, because she missed being able to see them in person at home or school.

5.7 P7

P7 started her narration by telling me that, while she has always worked with kids in some capacity, she never thought her nursing career would involve working with them as well. She had some trepidation about working in pediatric oncology when she first found out she had a pediatric placement in nursing school because she perceived it to be emotionally demanding, but was convinced by her mother to give it a try.

She specifically enjoyed her placement because of the amount of time she was able to spend with patients: "we did a lot more, like, playing games with kids we had a lot more TIME on our hands [as nursing students] than we do, as a nurse and I, became very attached to the population of oncology". As she highlights, her position as an inpatient nurse does not afford her the opportunity to spend the same amount of time with patients and their families, and she connected this to her multiple caregiving responsibilities and heavy workload. She also implied that their working conditions could be improved and that the nurses can be better supported by management. In particular, her unit is understaffed and only a fraction of the nurses are certified to give chemotherapy, so the nurses are constantly pulled between multiple caregiving responsibilities to help one another.

Similar to some of the other nurses in my study, she would often use the word "just" before describing some of her caregiving work, particularly the cure-oriented, technologically based care she provides for patients. To me, it seemed as though she believed this care was important, but not the kind of care that she assigns the most meaning to. Like many of the other study participants, she made a point in her interviews to note the importance of developing relationships with patients and families she cares for. In particular, she finds meaning in being able to see a child through "their journey".

However, she also acknowledged that, for her and "the girls" (the other nurses on her unit), it's important to set boundaries when developing relationships with families, because it can become difficult when nurses get attached to families. She illustrated this particular point by telling me a story that was significant to her, which we discussed at length in both of her interviews. This story illustrated how boundary-setting became especially salient in her approach to caregiving when, one day, she came into work and saw her friend's child's name on the patient list. When it was confirmed that the patient was, in fact, her friend's son, P7 immediately told her charge nurse that she "never" wanted to be charged with the care of this patient. To P7, it was important to separate her role as a nurse from her role as a friend to the mother of this child who would be on the unit frequently. While she spent time with the family after her shifts, and would get updates directly from them, there were times when her nursing colleagues would break the boundary she had set by giving her updates on his medical condition before the family could. She reaffirmed this boundary for the length of the patient's two year stay on the unit, which ended in his death. Although she was not assigned as this child's nurse, her stories about him suggested that this altered how she approaches and considers her care as a nurse. In particular, she discussed how this situation helped "back me up, from even getting attached" to patients, and now she has a bit of "a wall up" when it comes to getting close to families so that she doesn't experience burnout. Although her relationships with the families are what she ascribes the most meaning to, she also highlighted an ambivalence about her relationships with them in order to create boundaries between her work and personal life. She's learned to "leave it [her relationships and care for families] at work*"*, because she doesn't "want to go home sad all the time, or go home thinking about these kids every single day."

At the time of our second interview, P7 was considering taking on the role of nurse case manager in her outpatient unit. To assist her decision-making, she picked up some shifts in the outpatient unit, to help her further develop her skills and get an understanding of how the unit worked. She posited that working in outpatient enabled her to understand that not all children with cancer had incredibly acute, or complex side effects, and allowed her to see "how well" some kids with cancer can be. Working these outpatient shifts also allowed her to experience a new way of interacting with the families because,

compared to inpatient, where "the family doesn't want to be, as, engaging or as they they just want their kid to get better and that is what we're focused on", on outpatient "they want to tell you, about their week and what tr – family trip they went on, or things like that". However, she noted that, if she were to be offered and accept this new leadership role, her responsibilities would involve a lot of administrative work, which would involve coordinating patients and families, being the point person for the different teams and staff, and working directly with physicians. For P7, getting this job would mean that she would no longer directly caring for the family, which is important to her. To her, the loss of not being able to spend time and build relationships with families had her seriously considering whether or not she wanted the job.

5.8   P8

P8 began her story by explaining that she never wanted to be a nurse; she wanted to be an obstetrician. Her mindset changed when she had a stay in the hospital when she was seventeen years old, and it was then that she realized that nurses "are the people that are there for you." She didn't have any expectations for what nursing would be like because she is the first person in her family to become a nurse and is "the only person in the medical field" in her family.

Her interviews, like the other inpatient and outpatient nurse interviews, felt as though they were an avenue to help her process feelings that she had been harboring about certain patients, their families, and her working conditions for quite a long time. In the same way that P5 acknowledged feeling unable to talk about her work experiences to her family and friends, P8 shared that she doesn't "always want to burden them" with her stories because:

> "my family might have their own problems right now or with this whole coronavirus bit [as an example]. They don't want to know about the ch- the dying child in the hospital. 'Cause they're struggling, dealing with being stuck at home all the time and not being able to go out and do the things they normally like to do to help them cope with their lives".

Inpatient pediatric oncology was her last placement in nursing school, and ultimately the field in which she began her nursing career. She believes it takes an "emotional

backbone" to be able to work in pediatric oncology nursing, specifically because of the connections and long-term relationships created with families. Like some of the other nurses interviewed in this study, these relationships are her favourite part of being a pediatric oncology nurse, and where she derives the most meaning from her work. Many of the stories she shared during her interviews were about the children she has cared for and highlighted how deeply she becomes entwined within their families. There were many times where small details about her patients were easily recalled – she remembered their birthdays, death days, and the special anniversaries they had while staying on the unit. She found each of these children "hard to forget" for different reasons. For example, while P8 recalled many stories of patients and families during her interviews, there was one particular patient who she mentioned on a recurring basis, and who she described as "the cutest, chunkiest little thing that said hi to everyone". This one-and-a-half-year-old girl was mentioned throughout both the first and second interviews and highlighted how important relationships with the patients and their families are to P8. During our first interview, P8 highlighted that the anniversary of this child's death was upcoming and that it was an important date for her, as was the child's birthday; having borne witness to the entire life of this child, she and her coworkers planned to celebrate this patient's life on her birthday.

For P8, the most challenging part of being a pediatric oncology nurse was "when they die". Many of the stories she told about children she cared for who had died were told with despondency, sadness, and frustration with how they died. Specifically, when telling these stories, she suggested that there were times where she couldn't provide them the care that she believed would be most meaningful, and that they suffered before they died.

5.9   P9

Like my interview with P6, P9's interview left me feeling intimidated because of her years of experience (almost 40) and the extremely succinct nature of her narratives. I found myself once again feeling as though I was a poor interviewer because of how quickly and concisely she answered my questions, which were predominantly open-ended. However, in a similar vein to P6, I began to think that her narration style resembled her communications in her role as a community travel nurse. Dividing her time

and (highly administrative) care amongst at least 20 patients, P9's position required her to be able to address questions quickly and succinctly in order to provide care to all of her patients and their families.

P9 spent the first five years of her career working in adult care, which she felt gave her a strong grounding for nursing. However, even then, she knew her "gut" and in her "heart" that she "wanted to work with kids". She started working in pediatrics in the late 1980s and has spent the majority of her nursing career in various roles within pediatric oncology. Ultimately, in 2006, she settled into a community travel nurse position (after being a community travel nurse for a year previously) and has been in this role ever since.

P9 described her current role as a community travel nurse as made up of "a really interesting mix of being, in hospital but also being a community nurse as well". In particular, P9 described her role as a "liaison" between the family and the care team, and she is happy to act in this bridging position. She sees these families throughout their cancer trajectory – just like P6, she often meets them immediately after a diagnosis and helps them with financial, community, equipment, or travel resources as they are needed. She also enjoys spending time doing home visits, because in those visits (which are normally a few hours long) she really gets to know the family, and in a way that the team at the hospital may not, which is a sentiment that was similarly noted by P6. Her role in connecting families with resources extended to palliative care, particularly in helping them to "link up with" hospices or community resources. She has also done bereavement visits with families after a child has died, where she can check in on the family and support them in ways that they find meaningful. For example, for one family, this involved showing her their child's gravesite after they had died, as it provided them with a sense of comfort.

 P9 reflected on a number of changes in nursing she has witnessed over the course of her lengthy career. As she reflected on these changes, she noted that she has seen a lot of changes in the way that families are cared for and how they receive treatment. As an example, she noted that "we don't have many children die in the hospital anymore and

that's because we can now get them home". To do this, she has accompanied nurse practitioners to palliative home visits, and coordinated with local community care teams to set up equipment and resources for the child to die at home or in hospice. Another difference she has witnessed during her time as a pediatric oncology nurse concerns parents' willingness to use alternative therapies. Her discussion of alternative therapies suggested that she was concerned that families spend a significant amount of money and resources on these therapies; she's "seen families go bankrupt" paying for alternative therapies to help their children. She understands why parents may try them though – when your child is sick, you want "grab onto anything" to make them better.

Another comparison she noted was that inpatient nurses today spend a lot less time with the kids and families than she did when she was an inpatient nurse, and that "the relationship [between the nurses and patients and families] has changed" even though current patient loads (2 to 3 patients) are smaller than what hers used to be (7 to 9 patients). Specifically, she noted that "the job has become very task driven" and takes time away from the patients and their families, and as a result, her inpatient colleagues are unable to provide the same relational care as she once did. Through her comparisons, she acknowledged that spending time with the children is compromised by multiple competing caregiving demands, such as taking on the role of coordinator, or helping less experienced nurses set up equipment and give their patients medications and treatments.

In her interviews, she wondered out loud about what retirement would look like for her. Knowing that she would likely retire within a year of our last interview, she admitted that retiring was going to be difficult for her because she would miss her "bald-headed beauties". However, she knows that when she retires, she needs to "fully separate" herself from pediatric oncology – no volunteering, no coming back to the hospital, and no visits. What she has enjoyed the most about her time in pediatric oncology is "how much you learn".

5.10 Conclusion

This chapter presented descriptive narratives for each study participant, which helped situate their particular experiences and perspectives within their specific pediatric care

contexts. In each participant narrative, I outlined and described the nurse's narration style, and highlighted the main contours of their stories, including their how they assigned meaning to their caregiving, and how they navigated their institutional contexts. In the following chapter, I present the narrative themes, which resulted from my analysis across the interviews, and in relation to the concepts of moral distress, bearing witness, and narrative repair.

Chapter 6

6   Narrative Themes

In this chapter, I present four narrative themes that I constructed from the analysis of my participants' interview data.

I begin this chapter with the theme Stretched Too Thin. In this theme, I first provide context for the daily chaos and relentlessness that characterizes pediatric oncology nursing. From there, I highlight how the nurses' narratives attend to the institutional constraints that exacerbate this chaos and load them with multiple caregiving demands, leaving the nurses feeling that they cannot "be the nurse" they "want to be", an expression of their moral distress. I then go on to describe how within these chaotic working conditions and institutional constraints, the nurses assume multiple caregiving responsibilities and roles for their patients and families in their respective caregiving environments, and how their caregiving spans from the moment a child is diagnosed with cancer to after the child has entered remission or died.

In Bearing Witness, I highlight how the proximal and relational nature of pediatric oncology nursing generates close relationships between the nurses, patients, and patients' families. Through their sustained physical proximity, the nurses also gain narrative proximity as they come to understand and know the stories of their patients and patients' families, as well as their needs, wants, hopes, and dreams. This narrative proximity enables the nurses to testify to the experiences of their patients and to be morally proximal to their patients. However, the nurses also bear witness to suffering that they believe is unnecessary by virtue of their narrative proximity to their patients, particularly when the care team and family are at odds with the nurses, patients, or each other about the treatment the patient should receive. This is distressing for the nurses because they are unable to enact their moral responsibilities to their patients in ways that they perceived was in the best interest of their pediatric patients and their families.

In the third theme, Bonded by Trauma, I present narratives to illustrate how the nurses bonded together through their shared experiences of moral distress. The stories in this

theme highlight how the more experienced nurses mentor and assist less experienced nurses who are thrown into complex care earlier than expected and how nurses support each other through collective approaches to care that emphasize interdependence and teamwork. The acute traumas associated with witnessing suffering, as well as the chronic trauma associated with their working conditions, lack of support from management, and treatment by abusive families, drives the nurses together as a united front to survive pediatric oncology nursing.

Lastly, in the final theme of Caregiving and Narrative Repair, I illustrate how the nurses engage in narrative repair in two ways. First, through their narrative proximity to patients and families, the nurses come to know and understand the cancer stories of the families they care for. The stories presented in this theme demonstrate how the nurses mobilize this narrative knowledge in order to assist families in repairing their biographies after a child has died, for example, by creating hand molds or tangible keepsakes. Second, the nurses engage in narrative repair in order to repair the damage done to their moral identities as nurses when they are unable to enact their moral responsibilities; that is, to provide care that they believe is in the best interest of their patients and families, care that aims to reduce unnecessary suffering and assists in repairing the fractured narratives brought on by the child's cancer. I suggest that narrative repair is reparative for both nurses and families, and that when narrative repair cannot be fulfilled, the nurses are left experiencing moral distress, and feeling as though they cannot be the nurse they want to be.

In the themes that follow, and in keeping with the co-constructed character of narrative analysis, I have woven my interpretations with quotations taken directly from interviews with my participants. In the quotations, I have used italicized text to draw attention to words or phrases that I am emphasizing in relation to the theme under discussion; words and phrases that my participants emphasized during the interviews are capitalized. Readers should note that some of the stories presented in this chapter include graphic and possibly upsetting details about caring for children who died from cancer and who were suffering at the end of their cancer treatment.

6.1   Stretched Too Thin

A common thread that emerged in the nurses' narratives pertained to the ways in which nurses are stretched incredibly thin among a number of competing tasks and priorities, resulting in feelings that they cannot be the nurse they want to be. In reading the narratives, I came to visualize these stories of competing caregiving demands as multiple hands, each grabbing the nurses and pulling them in different directions: a patient who needed a new dressing, a family who needed a pack of diapers, the clerk paging overhead to take a call, another nurse asking for someone to watch their patient temporarily while they hang an IV for a different patient. While the stories of being stretched too thin were most prominent in the stories about nursing in inpatient settings, those who worked in more administrative settings also noted that they had witnessed this pull among their colleagues and how the competing demands they experienced in their largely administrative roles differed than those experienced by nurses in inpatient roles. Overall, the nurses' narratives highlighted that they were overwhelmed by the competing and constant demands they are expected to fulfil. Their narratives also suggested that these multiple responsibilities often pulled them away from their own caregiving priorities. As a result, these pulls left the nurses often feeling as though they could not be the nurses they wanted to be.

6.1.1   All in a Day's Work: Pediatric Oncology Nursing as Predictably Relentless and Unpredictable

The nurses' narratives conveyed that there is nothing "typical" about pediatric oncology nursing, and that the variability of each day provided new challenges in every kind of nursing setting. Overall, P2 referred to working in pediatric oncology as a "mess" because "there's no consistency within a lot of the things we do" (P2, Inpatient Nurse, Interview 1). Similarly, P1 shared her "tagline" with me: "the only predictable thing is that it's not predictable at all" (P1, Outpatient Nurse Manager, Interview 1). Simply put, the nurses often worked in "chaos" (P6, Community Travel Nurse, Interview 1).

In my first set of interviews, I asked all of my participants what a "typical day" in pediatric oncology looked like to garner an understanding of what was commonly

involved in their caregiving. Responses to this question usually involved jokes about how relentless and chaotic it is, mentions of never getting everything done that they wanted to do, highlighting the pull they feel between the needs of their patients, and commentary about using their personal time to care for their patients, including skipping breaks, staying late, and not having the opportunity to go to the washroom. A sense of chaos was also apparent in how the nurses narrated their typical days; often their stories were narrated at length and highlighted the multiple and constantly shifting responsibilities they must attend to. This led to feelings of frustration with being unable to complete all of one's caregiving tasks. This was expressed by P4, who clearly articulated that sometimes providing the care she wants comes at her own expense:

> I do try to, be mindful that I need to take care of myself but I'm kind of bad for that like I get, you know people will be like 'you have take your break' but it's like I don't, like, *I feel bad taking a break if I don't- haven't done what I want to do for that day* (P4, Inpatient Nurse, Interview 2).

Even with using personal breaks and working after their shift, the nurses felt that there still was not enough time to provide the care they want to. This is illustrated by P3's story below, which highlights the "hectic" nature of inpatient nursing and the range of care that nurses are responsible for on a typical day. Her narration style was reflective of this – she narrated very quickly, listing off responsibilities and darting from one to the next, leaving me feeling overwhelmed by the end of her narration. Her narration (which I have edited for clarity and readability) was incredibly long, emphasizing the number of responsibilities she is torn between on a daily basis:

> Show up at, seven – 6:45, um, shift officially starts at 7:15 but we spend some time to read up on our kids care plans […] write out the times of meds, oh do they have chemo today what time is that? Do they have x-ray like, we have to change a dressing like just kind of write out a-all of the things that are to be done that day. Seven o'clock – or 7:15 we'll take the report from like theee outgoing nurse, um so they just tell us about like the, how the night went, um, going over like fluid balances going over if the kid had a feeever what antibiotics we started like, just kind of updating, that. Talk about the plan for the day with them like 'oh they had mentioned yesterday they want to walk, like, go for a walk or physio is coming today make sure you call physio' like that kind of stuff just highlighting, that. Um, then 7:30 like they leave you take over um, you do, vitals at 8:00, 12:00, 4:00. Um, fluid balances around then […] and then you make sure you have a bath, give them their chemo try and get them up to walk change their bedsheets

sometimes parents will help you with that. Um, um, *sometimes, we get breaks sometimes we don't on inpatient like, you're supposed to technically get a break [laughs] um so you're supposed to technically get a break, in the morning um, for a half hour and then an hour break, at some point for lunch. Um sometimes we don't get a break, that morning break like, sometimes it just never happens or sometimes the evening break doesn't happen like, I can't tell you how many times, um, I would work a FULL 12 hours without even peeing um, without drinking, a glass of water [laughs]* like, literally, just because you're just running, the entire time trying to get all your work done like do the best that you can like be there for rounds, take this kid to the procedure like, whatever. Um, so you just don't really have time to like take care of yourself […] *So I'll chart on my lunch um, sometimes lunch breaks on inpatient* […] uuuum *on the inpatient side as you can tell it's a very hectic day*. (P3, Outpatient Nurse, Interview 1)

In addition to the relentless work schedules and multiple caregiving demands that the nurses' stories revealed, many of the nurses' stories described that their typical days also involved having to respond quickly to unexpected occurrences, such as attending to side effects experienced by patients, which required them to adjust their priorities and schedules accordingly. However, the caregiving agility that this reorganizing required was difficult as they were already overburdened. These unpredictable moments were elaborated by P2, who described days where the "shit hits the fan" during an already busy shift:

Ummm so say we're going by our day *everything's going fine everything's quiet and then, a child, starts coughing vomiting blood. And you're like 'where the hell did that come from?'* And then you have to rush and, do call the code and get the physicians and, or they deteriorate to the point where you have to like, run a code and you run like you have to like do compressions on them and you're intubating like, all these things where that wasn't supposed to happen. Like y-you have no plan of that happening. Um, or, there's a situation where a child's getting a routine scan or routine, um, test, and everything's supposed to be fine whatever and then the results come back and it's like oh they've actually relapsed. Or, become refractory [does not respond to treatment]. Mid-day, when they're just supposed to be cruising. *And then, changing your whole plan and getting the physicians here involved. Then meeting with the family and saying, 'oh by the way you came in for a routine chemotherapy, fun fact, your disease is worse and we have to change our whole plan.' And saying 'well I was supposed to have a three patient assignment because, everyone was supposed to be calm and relaxed and, logical', but then saying, 'oh I actually have to do an emergent chemotherapy right now. And I have to be there with the family for, an hour and a half straight. How am I gunna manage all of this?' So those types of, things like kind of just change very quickly on a dime. Um, always seem to, that's what I mean by shit hits the fan.* Not the predictive things where it's like, oh, this child is probably

gunna react to this medication and, they react. That one's fine. That one's easy. (P2, Inpatient Nurse, Interview 1)

The unexpected, as narrated here, can cascade into multiple other responsibilities, which further complicates the days of the already overwhelmed nurses. P2's narrative conveyed feelings that many of the nurses expressed in their interviews.

However, not all of the nurses in my study experienced chaotic days and feelings of overwhelm in their current caregiving contexts. In their roles as community travel nurses, P6 and P9, at the time of our interviews, did not experience being pulled in their current positions and responsibilities to the same extent, but they expressed empathy for the nurses in other settings. For example, P6, acknowledged that in her role, she has time that other nurses do not; she has her "to do lists or things that I feel that I need to get done", but she doesn't have "like a short, timeline" (P6, Community Travel Nurse, Interview 2). It seemed to me that the autonomy the nurses associated with their roles as community nurses may provide them more control over their schedules and responsibilities. As an example, P6 told me that, when she was an inpatient nurse, she may have "10 antibiotics to give in the next hour or so", whereas in her role as a community travel nurse: "I always have admin work to do, but I'll just, work it into my, work it into my day" (P6, Community Travel Nurse, Interview 2).

Overall, the nurses' narratives suggested that a typical day left many of the nurses feeling stretched very thin, and atypical days that did not go as planned are even worse. It was apparent that the majority of the nurses in my study were constantly reorienting their priorities and caregiving to account for the expected relentlessness and unexpected twists associated with their caregiving.

6.1.2   Institutional Constraints and Idealized Identities

Many of the nurses' narratives suggested that, as a result of being pulled in multiple directions, they were experiencing moral distress. The nurses' experiences of moral distress were identified explicitly by some of the participants (e.g., P2, P4) and were expressed by some of the other nurses as not being able to be the nurse they wanted to be. Being embedded within institutional constraints that inhibited them from providing the

care they wanted and having to pivot between caregiving demands was already overwhelming for many of the nurses. These feelings of overwhelm were exacerbated by the intensification of their workloads as they had to compensate for the burnout and high turnover rates in some of their units. P2 told me that "On average we lose a nurse every, two and a half weeks", and that the nurses felt trapped between their workload demands and unsupportive management. When nurses tried to voice their concerns to management, they were ignored, or nothing was done, leaving the nurses feeling more distressed and demoralized. This, to P2, was "why a lot of people leave." He described the frustration that accompanied these situations, where the nurses felt as though:

> My voice isn't being heard. Why would I stay in a situation that, compromises both my, like emotional, states as well as my, just frustration level at least like it's, yeah it's terrible. That is, one of the most annoying parts of our job that *we can't do a good job, we KNOW what we're supposed to do but we can't do it the way we want to*. (P2, Inpatient Nurse, Interview 1)

The nurses' narratives also conveyed that high turnover rates produced situations where inexperienced nurses had to assume responsibilities for which they were insufficiently prepared. In these situations, nurses expressed moral distress related to their concerns that their inexperience could lead to mistakes and compromise the quality of care they were able to provide. This trend in staffing turnover and having to assume responsibilities early in one's career as a pediatric oncology nurse was described by P5 as "the blind leading the blind". She further suggested that the pressure to do well and appear competent actually leads to mistakes that could have serious implications for patients:

> *I think it's hard when, you know your charge nurse has two years of experience and they're managing a floor of, you know, 10, 15 nurses that have less than a year and a half of experience and it's almost like the blind leading the blind* where, you know, no one really, not to say that they don't know what they're doing 'cause a lot of them are like very competent nurses but, ummm just, everyone is still just trying to like figure it out, and *I think that, pressure and that stress to them like it really* adds up and *there's been a LOT of BIG mistakes, on that unit of issues where, you know, kids got, like, when they were supposed to get just a little bit of an opioid ended up getting the entire syringe and like going into an over – like, there's been a LOT OF big issues on, that unit um, and I think, a lot of that has to come from some of these nurses just not knowing any better or not knowing, to speak up and say like 'this is unsafe' or like, I guess having that awareness to, be like 'I d- I don't know how to do this' or 'I don't, know what to*

do in this situation' and then when they go to their colleagues because their colleagues are at a similar stage as they are or even less, they also don't know and then, *the turnover starts happening and so then they can't, can't retain staff to then, have those competent, like expert nurses who have been there for 10 15 years and be like 'oh when this happens like, this is what we do.'* (P5, Transplant/Outpatient Nurse, Interview 1)

P5's narration points to the institutional power relations within which experiences of moral distress emerge by illuminating the ways in which inexperienced nurses, shouldered with caregiving responsibilities too soon, may feel insecure voicing their concerns about their workload demands to management. This was also highlighted by P3, who disclosed how she attempted to resist promotion by management early on when she had only been working as a pediatric oncology nurse for one year: "I was the most senior one on night shifts other than the charge nurse and I had the sickest kids consistently *I was asked to precept far too early*" (P3, Outpatient Nurse, Interview 1). Although she declined the promotion, and said she needed more time and experience, she was eventually told that she had to precept six months later. P3 further went on to suggest that management took advantage of many inexperienced nurses to compensate for understaffing, promoting them to mentoring positions and charging them with the care of medically complex children. These additional responsibilities led P3 to her realization that she was being stretched too thin:

Um [pause] uuuh there was one night shift that, there was, this patient who was, going septic and *the nurse who was caring for her was my hire group but didn't know what [laughs] to do like didn't know how to like bolus secure [fitting a feeding tube securely to avoid gastric leakage] or anything like that* so, [sniffles] so this kid's blood pressure was super low and I was like 'do you want me to check it for you' and she's like 'oh no like someone else is' and she's charting, prepping meds for her other kid and *I'm like, blousing [feeding through a tube] this kid and calling the critical care team like, I had three kids of my own and it just like she ended up going to ICU this kid that night and, I was at that point of like, 'holy crap' like, 'I am the senior person that's responsible for like, not only, you know carrying the slack of my three VERY VERY sick children, but also picking up other people's slack' and I got to a point where I'm feeling really [sniffles] like anxious um, coming into work knowing like,* I'm gunna have, a crappy day pardon my [laughs] language but I know I'm gunna have like a really bad day 'cause I know I'm gunna get the sickest kids I'm gunna have to help everybody else like, I know that I'm, I know what I'm walking into at that point. *And then I guess I was like getting a bit frustrated with that, like consistently just,*

> *you know it was HARD, every day was getting harder.* (P3, Outpatient, Interview 1)

Management's perceived unwillingness to manage staffing or workloads was described by some as leading to breaking points. For example, P6 described how she was "witnessing" feelings of overwhelm, frustration, and exhaustion among "inpatient nurses" at her hospital, noting that: "*they feel that they don't have the support of their manager.* And, who are, people who are supposed to be supporting them so, um, so *it just makes everything worse everybody's angry upset they don't want to come to work*" (P6, Community Travel Nurse, Interview 2). These feelings of being unsupported illustrate the conflict that the nurses experience when trust is broken in their moral relationships with managers. This can be understood in relation to Peter & Liaschenko's (2013) conceptualization of moral identities and relationships: the moral identities of the nurses conflicted with the lack of support by management, and upon realizing this, the nurses understood that management broke trust in their moral relationship. The anger the nurses expressed feeling is suggestive of the moral distress that resulted from the conflict in the nurse-management relationship.

Many of my participants' narratives also suggested that management used the emotionally challenging character of pediatric oncology nursing to deflect from their intense workload demands: "management liked to, kind of pick up on that and say like, "oh people are leaving because like, it's emotionally difficult and it's HARD to watch kids die and it's HARD to watch them not do well" (P3, Outpatient Nurse, Interview 1). To challenge this assertion, P3 provided a counterstory of how she ultimately left inpatient pediatric oncology because of the pull she constantly felt between caregiving responsibilities:

> it was the workload like for me. That, was a huge thing like *the amount of work that you just DO and you coordinate care for so like these kids are SICK and they need a lot of care and you feel like you're just being pulled in so many directions because staffing is not good* (P3, Outpatient Nurse, Interview 2).

In addition to feeling unsupported by management, the nurses' stories revealed that the way they had to constantly pivot between priorities and patients made them feel as though they were neglecting their patients and not providing the care that they should be

providing. As discussed earlier, nursing education frames nurses as individuals providing care through building relationships with families through sustained physical and narrative proximity (Malone, 2003; Storch, 2004). However, upon entering the workforce, and compensating for institutional demands and understaffing, the nurses in my study were often left feeling distress and that they could not be the nurses they wanted to be. Although constructions of the ideal nursing identity were not identified specifically by the nurses, ideas about the ideal nurse were invoked in their narrations of how their working conditions limited their ability to assume this identity, as P3 does below:

> [you] have three kids when you should only have two and, or you have two kids when you should only have one and because you, can't divide your time appropriately you're kind of neglecting one, um, and *you just, feel, like that sense of like, 'I could've done better. If I had more time I could've done better. Or I could have done more and I could've done it differently'* (P3, Outpatient Nurse, Interview 1)

In addition, these narratives demonstrated the ambivalence the nurses held regarding their inability to provide the care they wanted. This is suggested by the way that P3 individualizes her inability to provide the care she wanted – she references not dividing *her* time appropriately, and that *she neglected* her patients, while simultaneously acknowledging that she was unable to do so because of the institutional constraints she was embedded within. This understaffing, increased patient loads, and assuming multiple responsibilities to compensate for turnover left the nurses in my study feeling defeated, and internalizing narratives of being a nurse who "could've done better".

Contrary to the narratives from inpatient and outpatient nurses, who felt that the demands of workload and understaffing and the constraints imposed by unsupportive management prevented them from constructing their identities as nurses they aspired to be, the nurses who worked in more administrative or managerial settings described having more control and autonomy over their caregiving. This was the case for P6, who clearly articulated that she was the nurse she wants to be. However, she also made a point of commenting that many of her inpatient colleagues often do not have the time they need to provide the care they want because of staffing: "Double the staffing. Yeah. I mean in pediatrics we, often nurses will have you know up to four patients […] Um but uh yeah if if a nurse, you

could have like, two, two patients, right and and their families that would, it would be much better" (P6, Community Travel Nurse, Interview 2). This point about staffing was discussed widely in my participants' narratives, which acknowledged the conditions necessary to foster nurses' moral identities so that they could be the nurses they wanted to be. These conditions included having more time to provide the care they wanted (and the care they had been taught to provide) for their patients, which meant having more staff to ease their workload demands. P2 mentioned that "in a perfect world we'd have one patient, one nurse for every single situation […] to provide that kind of care that you need" (P2, Inpatient Nurse, Interview 2).

6.1.3   Navigating Caregiving Responsibilities Among Diverse Care Needs of Patients and Their Families

In addition to the ways in which workload and understaffing led to competing care demands and nurses feeling stretched too thin, the nurses in my study also expressed difficulty in navigating competing caregiving priorities among the patient, the patient's family, and the care team.

For all of the nurses in my study, attending to the diverse needs of their patients was layered with complexity; their caregiving must be carefully tailored in relation to the unique characteristics of each patient's cancer, age, and degree of autonomy. Pediatric patients, whose ages range from 0 to 18 years, present a wide range of care needs and have varying levels of autonomy, and nurses must adapt their caregiving in ways that is suitable to these factors. This was highlighted by P4 who told me about the stark contrast in caring for an adolescent versus a toddler, reflecting Cantrell's (2011) assertion that pediatric oncology nursing is both an art and a science: "like when you're doing vitals on a fifteen-year-old, if a fifteen-year-old says 'I don't want you to touch me right now' you kind of have to be like, 'okay I will not, do your vitals I will come back'" (P4, Inpatient Nurse, Interview 2). She went on to compare these points to caring for a toddler, where "they really don't have a CHOICE on whether I'm doing their, their vitals you kind of have to go between, the different levels of autonomy between patients it's just hard" (P4, Inpatient Nurse, Interview 2). In addition, the nurses expressed that they had to navigate an additional layer of ambiguity about patient autonomy for their patients who are in the

"in between" ages (the pre-teens): "that really hard age group between I dunno, school age I guess like eight year I -I can't even say the age group but, an eight- to twelve-year-old. Like if a ten-year-old doesn't want something to happen to them like y-you kind of have to make a decision on like, what, what am I allowed to do here?" (P4, Inpatient Nurse, Interview 2).

In addition to assessing their patients' autonomy and adjusting their care accordingly, the nurses also emphasized that their caregiving involved navigating whose voice (the child's or the family's) should be given priority when it comes to the patient's care. The presence of families was consistently evident in the nurses' caregiving stories and included close and more distant family members (e.g., parents, grandparents, stepparents, cousins, aunts, uncles) as well as friends of the family. The nurses often told stories of navigating the complexities and dynamics of the families, revealing how a significant amount of care they provide is relational care (Beckett, Gilbertson, & Greenwood, 2007; Hartick Doane & Varcoe, 2007). This relational care for the family members involved, for example, checking in with them emotionally and providing them with respite time:

> *I always tell like new nurses that our job is about 80% pediatric oncology 20% adult mental health. Um, if we had to JUST deal with children with cancer our job would be exponentially easier. […] so we have one, one patient who's the child, but at least at [hospital] we consider the family unit, our patient as well. So, instead of having one patient we have about five, because we have parents, and then, obviously there's the grandparents or the uncle or the cousin who's a doctor and this person who does that. And everyone together and you have to try and, please everyone.* Or, I had this situation actually, what day is it today, Wednesday night I had a patient who is First Nations so their, like pretty much their entire, family unit was their entire, clan their whole, group together. And, we had to try and talk and convince 19 people of a plan, when you normally would just be like, 'okay, I have to do this, I have to do it to the child', done. Quick and easy. *So, I think, working with the family makes it, extremely difficult. I also acknowledge the fact that if we didn't have family members there our jobs would be a lot easier – or a lot harder sorry. Like providing the kind of ADL care like the activities of daily living, bathing, feeding, just, being there with the child like, children need to be entertained. We can't be that, those people, so we rely on family members to do that. So, I think, A LOT of it is dealing with families. I think the, some of the hardest parts, are dealing with the families.* Children are easy children like, no offence to children, they're kind of stupid in a good way. Like they're oblivious to a lot of things, they are easily entertained they're easily satisfied with answers as opposed to kind of these more, deep moral and

philosophical, debates and questions that we have to have with family members, on like an hourly basis. (P2, Inpatient Nurse, Interview 1).

This rich passage highlights a number of points. First, it clearly highlights a tension reflected in many of the nurses' commentaries that caring for the entire family was often rewarding but was simultaneously one of the most difficult aspects of being a pediatric oncology nurse. Additionally, P2 illustrates that nurses often rely on family members for particular caregiving tasks, such as bathing their child, which is suggestive of how families may also help nurses compensate for understaffing. Further, his narrative highlights how nurses' relational caregiving with families must adapt to recognize families with diverse sizes, structures, and cultural backgrounds. Here, he highlighted how caring for an Indigenous child included negotiating with extended family and members of their clan. Lastly, his narration suggested that, at times, family members themselves require attention and psychosocial care and that this care can be difficult. As I will discuss further in Bearing Witness, the complexities of caring for the family was consistently narrated in many of the nurses' stories, and often was a source of distress.

P1, P6, and P9, who described having more autonomy over their caregiving, also remembered times when they worked as inpatient or outpatient nurses and had similar experiences. While these three nurses felt generally satisfied that they could be the nurses they wanted to be, they also highlighted that they must navigate the distinct needs and priorities of different families in their work, and that this can be complicated by "time constraints, in the healthcare system" (P1, Outpatient Nurse Manager, Interview 1). P1 told me that, in her role, there are "certain families that, either require more attention and more, care, that you, end up, spending on them and spending more time, with, what may be called like, higher needs families for whatever reason" (P1, Outpatient Nurse Manager, Interview 1). Her narrative suggested that these higher needs families may not get the care they need on account of nurses having insufficient time to help them and that when they do, it takes nurses' time away from other families who also need care, making her coordinating difficult.

Caring for patients and their families with distinct needs requires the nurses to oscillate their mental and emotional states (sometimes between extremes) while caring for them.

Many of the stories highlighted the emotional labour (Hochschild, 1983) that was involved in caring for patients and families with different needs. P3, for instance, told me a story about caring for two patients: one in the palliative stages of care, and one who had a new leukemia diagnosis – one patient at the end of their cancer trajectory, and one at the beginning. Her narrative conveyed how she must modulate her emotions to effectively care for patients, and that doing so subsequently affected her. Though the situation shared in her story is extreme, it is suggestive of the intensity of this emotional dynamic and the vigilant emotional regulation that is required when providing care to multiple patients and families with vastly different care needs:

> …sometimes, um, they put you with like a new leukemia diagnosis and that is terrible to be with [laughs] like, a dying child trying to like provide that kind of support, and then, to switch [snaps fingers] in your head to like 'ooh, now let's, go back to hopeful and happy, hopefulness' like 'let's do that' and then, try and go back to your new leukemia patient and try and like, you know give the family hope and teaching and about like, but you're it's just two opposite ends of the spectrum and that is impossible and *I think like for my mental space like, you know maybe I can provide physical care that I want to but mentally I'm not there and mentally I'm not really in it because it's just too hard to take on to wear those, two hats simultaneously it's just too much*. (P3, Outpatient Nurse, Interview 1)

My participants' narratives suggested that this emotional labour was engrained in their work; shifting their emotional state was narrated as happening frequently because the needs and emotional states of the families dictated how the nurses needed to present themselves when caring for them. For instance, P8's engagement in emotional labour was evident in a story about a patient with whom she developed a close relationship. In her narration, she described how she had to put her "nurse face on" in order to communicate with the little girl's parents. She described her engagement in this emotional labour as an active and deliberate learning process: "in the beginning, I would have to take the extra time, and before I go in take some breaths, those moments, and focus so that I could put it on without breaking my face" (P8, Inpatient Nurse, Interview 1). As she has progressed in her career, this emotional labour has become a more implicit and internalized part of her caregiving: "now in my career it happens a lot more instinctively and I don't have to think about it as much" (P8, Inpatient Nurse, Interview 1). Her narrative conveyed that this emotional labour is an essential part of being a pediatric oncology nurse, and is

required to perform other forms of caregiving, including communicating and caring for the parents' emotional needs: "putting that nurse face on makes it easier because then I can relay the information I need to or put in care and effort that I need to […] And it makes that easier for the parents as well" (P8, Inpatient Nurse, Interview 1). Many of the nurses expressed similar sentiments. Their narratives revealed that engaging in this emotional labour and switching emotional states between patients and families, while necessary, can be exhausting.

6.1.4 Assuming Multiple Caregiver Roles and Identities and Assigning Meaning to Caregiving

The nurses' caregiving narratives illustrated the multiple roles and identities they assume as they performed a wide range of caregiving tasks for their patients and families that spanned a child's diagnosis, remission, relapse, and, in some instances, during and after a child's death. The nurses used counterstories to ascribe value and meaning to certain forms of caregiving, particularly relational and emotional care, and to counter institutionally shaped priorities of cure-oriented, technologically driven, aspects of care. Navigating this wide array of caregiving responsibilities, and having to reorient their priorities due to time constraints often left the nurses experiencing moral distress

The multiple caregiving roles played by the nurses were clearly identified by P2, who described that "the role of a nurse is a combination of, doctor, pharmacist, social worker, psychologist, um, nutritionist like dietician whatev – like all these together. So we take pieces of everything to try and provide holistic care I think that's, really the backbone of nursing is, kind of holistic medical care" (P2, Inpatient Nurse, Interview 1). Through his narration and the descriptions provided by the other nurses, it became evident to me that providing "holistic" care involved attending to a diverse range of demands and assuming a number of caregiving responsibilities. P2's narration also suggested that holistic care is "good" care, and that in order to be a good nurse (or caregiver), one must engage in multiple forms of care for their patients.

For the inpatient and outpatient nurses, attending to the physical needs of the patients required a broad range of skills, techniques, and treatments. By attending to physical

needs, I mean performing technologically based, cure-oriented care, which the nurses' stories suggested was considered the highest priority care in their pediatric oncology nursing institutions. Interestingly, the nurses rarely described these cure-oriented caregiving tasks in their interviews, but rather emphasized and made visible the other forms of care that they provided. Often, the nurses elaborated on technologically driven caregiving only when I probed further about specific terms or jargon that I did not understand, or when I sought clarification about certain procedures or treatments. In this regard, their caregiving that was oriented to curative medicine (e.g., chemotherapy) was often trivialized in relation to the meaning it held for the nurses. For instance, in P7's first interview, descriptions of administering medications – which are necessary to treat and cure any child's cancer – were often prefaced with "just":

> [You have] one patient getting chemo, let's say a new diagnosis, and one doing count recovery, then your tasks are a lot different like, um, *your kid getting count recovery [bringing their white blood cell numbers back up] if they have, if they've already have their fever and started their antibiotics, you're really just, hanging antibiotics and making sure they're comfortable for the day.* They're not necessarily SICK. A new diagnosis as long as it's not the first day, you're, there's lots of times in that first week where they're they don't have anything going on that day so you do have the time to, *just give them their oral meds and just sit and chat with them.* (P7, Inpatient Nurse, Interview 2)

When I probed about what caregiving meant and looked like, P2 affirmed that the technologically driven, cure-oriented care is considered a minor part of the caregiving by nurses. He suggested that their caregiving would be much easier if they only had to provide care in relation to curative medicine. Again, his use of the phrase "all you do" is suggestive of how he minimizes the difficulty and complexity of this kind of caregiving work:

> Yeah so if you actually think about how you cure cancer, *all you do is you – so for instance, standard leukemia. You have let's say the the start of their treatment their induction therapy. It's a four-drug induction therapy so you get, uh oral medications twice a day, you need to do, um, two IV medications that take about, between five and fifteen minutes to administer, and theeeen, on in two times during the month cycle you get this, this infusion that goes in over an hour. That's pretty much it* yes there's a little bit of bloodwork yes there's some other like supportive medications but *the actual, work that needs to be done, is extremely minimal. In terms of curing their cancer.* (P2, Inpatient Nurse, Interview 2)

He elaborated on this minimizing later in his narrative, when he told me that the "heavy workload" of being a pediatric oncology nurse comes from providing other forms of care, such as providing support to the family by teaching them about medications and treatments and what to expect in the months following their child's diagnosis, coordinating other members of the team to come and speak to the family, and helping families feel confident in caring for their child if/when they go home:

> *making sure the parents are comfortable with the information, making sure they're doing okay, making sure they are able to support the child at home. Making sure that all the team members that need to speak to the family or need to kind of touch base with them kind of have that opportunity to.* Pretty much just like building capacity for those families at the beginning. *And that's, kind of the heavy workload.* In terms of the pure, technical side of it, there really isn't a lot and truthfully as a nurse yes we administer medications but if it's a kid who, can swallow pills, it's even less. (P2, Inpatient Nurse, Interview 2)

While the nurses downplayed the caregiving work they did in relation to curative medicine, either explicitly or by not narrating these aspects of care, they discussed at great length the caregiving work they did in relation to coordination, education, advocacy, relational and emotional care, and end-of-life/post-mortem care. In these stories, the nurses assumed multiple caregiving identities and actively assigned value and meaning to a number of their caregiving activities.

The work involved in coordinating care was highlighted in all of the nurses' narratives. This coordination positioned the nurses as necessary links between patients and families, the medial care team, and other organizations. According to P2, nurses are "*the bridging point* from the medical team – or from like from the healthcare team, to the family" (P2, Inpatient Nurse, Interview 2). For nurses who were in primarily administrative roles, this coordination work was a significant part of the care they provided. P1, for example, likened her work to a "constant communication stream" and her position to a central node in a complex network of providers, resources, and organizations:

> *information is constantly flowing through me, from team members, to families, from team to family, from family to satellite centers, from one department to the next department, from doctor to doctor, you name it I talk to them. Or I email with them or, text with them on a regular basis* to make sure that the care is efficiently coordinated as best as possible. (P1, Outpatient Nurse Manager, Interview 1)

Similarly, P6, described her role as bridging the medical and psychosocial teams and the family, to make sure that "our child life specialist, our psychologist our – the rest of the psychosocial team, is aware and then theyyy, like they plug in whatever help that the patients need" (P6, Community Travel Nurse, Interview 2). The linking and coordinating aspect of pediatric oncology nursing was also evident in the inpatient and outpatient nurses' stories:

> The *nurses are literally the point person for – yeah, they coordinate all the consult teams they coordinate all the appointments they coordinate like, families' preferences for course and they do the physical care* let's say they need it – a port needle change they coordinate that with the family and make sure, all the appointments fit around when you're gunna do the needle change like, *it's ALL the nurse*. (P3, Outpatient Nurse, Interview 2)

These stories also drew attention to the ways in which the nurses' coordination work was informed by the understaffing of administrative support. The extent of the coordination involved in being a pediatric oncology nurse, and how much of their care work is based on compensating for nurse and clerk understaffing, was evident in P4's story where she described how coordinating was one of the largest parts of being a nurse. While there are clerks that are supposed to help facilitate and coordinate patient care, P4 told me that "there's only one of them. For everybody". As the nurses take on this labour because it is necessary for their patients' care, this takes even more time away from tending to other patients' needs:

> *But, a lot in that coordination piece like, the the calling and, um, sending you know getting transport to send people to appointments and to their, you know an x-ray or a CT scan. Like that's still part of your role. We do have clerks that help facilitate that. But you're still responsible, for all those different pieces* [….] I think the coordination piece could be taken over more. By another person like *we have a clerk, but they're so busy they can't always, coordinate all these phone calls, and set up all these appointments because, then they would, you know there's 24 patients on the floor. So then you sometimes act as a clerk in a way. But I try to avoid that, as much as possible because it does really, take away from the time that you're supposed to be spending with your patients.* Like if you're spending like an hour, trying to get a hold of someone in MRI like that's, quite some time and or you're distracted from doing another task. (P4, Inpatient Nurse, Interview 2)

In addition to their roles in coordinating caregiving, providing educational support for families comprised a large part of their caregiving. This educative aspect of pediatric oncology caregiving encompassed the majority of the work for those nurses who were in more administrative roles. This was the case for P1, whose description of her education work highlights how her role as one that consists primarily of support and coordination, compared to the in/outpatient nurses whose caregiving also includes physical care. In her managerial role, P1 explains that her work involves answering questions specific to each patient's/family's experience, which are questions that can be about: "literally anything. Their pump malfunctions or, they have new pain, or, they don't know when their appointment is or they had a fever last night and but they didn't call anybody, is nice, uh - the, the possibilities are pretty much endless" (P1, Outpatient Nurse Manager, Interview 1).

For some of the nurses who worked in outpatient settings, like P3, it was this educational part of nursing in inpatient that they missed the most. In the outpatient clinic, patients and families come to the clinic for appointments, treatments, or procedures that may last a few hours, but go home the same day. Because of the condensed periods of time spent with families on the outpatient units, not as much teaching can be done. However, P3 has adapted her role in outpatient so that she can continue teaching, by doing "a little bit of it when I can", like "when the kid is like, recovering and *I LOVE that part like just even like, talking about their first lumbar puncture and what to expect* when the kid wakes up and things to monitor like*, any teaching moment that I can do and hold on to, I do*" (P3, Outpatient Nurse, Interview 2).

These nurses' narrations highlighted that teaching patients and families was an aspect of caregiving that provided them with a sense of meaning and was part of their caregiving that they take on alongside the provision of technical, cure-driven care. However, their narrations also highlighted that this teaching was time-consuming, and at times, they were unable to engage in this type of care due to their competing caregiving demands.

The nurses' narratives also suggested that they assume the identity of advocate through the significant amount of time they spend in close proximity to families. Reflecting

Malone's (2003) insights about the nesting of physical and narrative proximity, the nurses considered themselves as the primary channel for communication and coordination on the family's behalf, exemplifying their narrative proximity to the families they cared for. This emerged in the nurses' descriptions of communicating with the medical team on behalf of the family, coordinating appointments, or tailoring their education to what worked best with the family, and relaying information between the family and care team regarding tasks, tests, check-ins, and medical procedures that needed to be done. The nurses' narratives suggested that they assign meaning to the proximity they have to families and the kind of care it enables. This was evident in P8's narration, which conveys that, while families have little choice but to trust the nurses with their child's care, this trust is fostered by their sustained proximity to the families, and the relationships they build with families as a result, which the nurses find meaningful:

> […] the nurse goes and talks to the doctor and all the other, uh team members such as physiotherapy, the diet team, social work, occupational therapy, whoever else is involved in the patient's care. Um, and we go over everything that's happened in the past 24 hours the plan for the next 24 plus hours, and anything big that's happening. So sometimes in those meetings I'll go and talk to those families and be like 'hey! So this is what's going on' and at times they'll be like '*whoa, this is news, what's going on*?' […] *so we become that person especially because us as nursing staff we are there 24/7. We are always there and even though there's always a doctor in the hospital they're not always on the floor.* […] *Um, so we develop that rapport where we're able to, say 'hey this is the plan this is what's going on' and they trust us. In what we're saying. Part of it I think is they trust us 'cause they have to, they don't have a choice.* […] *The kids need to get that specific care and they need that specific test to be able to determine if their heart is safe enough to start chemo or if they need any supportive meds in terms of that. So, yes, I would saaaay, we communicate A LOT from what goes on.* (P8, Inpatient Nurse, Interview 2)

Through their physical and narrative proximity to families, the nurses were further able to engage their moral proximity to the families by advocating on the family's behalf. This moral proximity was exemplified in a narration by P9, who told me that her relationship with the family positions her as: "not a very popular person at rounds because I will, push the, the comfort level or I will ask a difficult question. But that's, I see that as, that's my part of advocating for families" (P9, Community Travel Nurse, Interview 2). P5's story below suggests that nurses advocate for, and thereby act upon their moral proximity, by

blocking or refusing certain kinds of care for their patients. This allows the nurses, who see themselves in a protective role, to prioritize the care they judge as most important for their patient:

> Yeah like *we are, whether you want to say like, the gatekeepers to the patient I kind of feel like we're more like the bodyguards to the patient where it's like, you know we put signs on the door saying 'check with my nurse before you enter my room!'* Like things like that because maybe they're sleeping maybe they're taking a bath like before you even go in there we want to know who you are and what you're gunna do 'cause *if I just spent, the last two hours trying to put an irritable colicky baby to sleep, and some consult service comes in and completely unbundles my baby to like, look at their chest, I'm gunna be upset* because what they're gunna do is they're then gunna leave the room, with the unbundled baby and come to the nurses' station and say 'oh the baby's crying.' 'Yeah well what did you do? To make them cry? Like I could've told you to come back in an hour after they had a nap but, no.' *Um so now they put more work on me 'cause now I need to go fix, the kerfuffle that they have just done.* (P5, Transplant/Outpatient Nurse, Interview 2)

P5 also suggests that this protective blocking helps her manage her time because these additional services can interrupt the goals of her caregiving – letting the baby sleep, in this case – and cause more work for her on top of her already demanding caregiving tasks.

In addition to the physical care, educational care, coordination, and advocacy caregiving the nurses performed, many of the nurses' stories also often highlighted the relational care they engage in. Relational care, or relational practice, is characterized as "a humanely involved process of respectful, compassionate, and authentically interested inquiry into another's (and one's own) experiences" (Doane, 2002, p.401). This relational care was often "woven within" "the regular conversations" that the nurses were having with patients and families. The nurses frequently mentioned that they "love talking to people" and "making those relationships" (P8, Inpatient Nurse, Interview 1) with families, because in pediatric oncology, the nurses find it "very easy to get close and to, develop that relationship with people" (P8, Inpatient Nurse, Interview 1). This closeness was illustrated in the ways that some of the study participants described their patients as extensions of their own families. For example, P3 described how she "treat[s] [the patients and families] all *like they're my little brothers and sisters* I just care for them,

with all my heart" (P3, Outpatient Nurse, Interview 1). P7's sentiments were similar, stating that she loves "being able to do that relationship bit and, having those long-term goals with families and helping them out long term" (P7, Inpatient Nurse, Interview 1). P1 described how, for her, relational care is thoroughly entwined with her check-ins with the family: "at the same time that I'm like 'have you pooped yesterday?' I also say like 'how have you, have you seen your friends? Have youuu, gone out in public? What, what does living in isolation mean to you?' so it's, it's really just kind of woven within it" (P1, Outpatient Nurse Manager, Interview 1).

Many of the nurses' narratives suggested that they believed the relational care to be the most important aspect of their work, but it was also the care that they were often unable to accomplish because of other competing workload demands. P4 told me that it's the relational care:

> that gets missed. That's, that's the big like *I feel like there's, families that need needed emotional support or psychosocial support that day and didn't get it. Because you physically couldn't be in the room* and to support them in that way (P4, Inpatient Nurse, Interview 2)

P5 told me how, on her shifts on the outpatient and transplant units she works on, she can't provide the care she wants to on a daily basis because she's "overburdened or overtaxed" by other caregiving demands that take precedence, which are often the cure-oriented, technologically driven physical care tasks: "one family who's really struggling with something like psychosocial […] but then you know your other patient is, struggling with something very, you know, clinical and they need all these like vitals or assessments or meds" (P5, Transplant/Outpatient Nurse, Interview 1). She expressed concern that when the needs of some families get pushed back to tend to other more pressing needs (of other patients, families, or management), these families may perceive the nurses as forgetful and uncaring – that is, as bad nurses. She resisted this idea with the following counterstory that nurses are trying their best to help, but are constantly being stretched too thin and "pulled" and reoriented towards more pressing responsibilities:

> *people, forget like especially, nursing like the amount of times where, families have had to ask me for a pack of diapers like three times in a row* and like I know you literally asked me this and I go into the supply room being like I know I'm

supposed to grab you something but I forget. Like and it's, *a lot of it's because I get pulled 'oh so and so's on the phone on hold for you can you come and talk to them' and I'm like 'okay' [laughs] like you just get very like, sidetracked*. (P5, Transplant/Outpatient Nurse, Interview 2)

The nurses' stories illustrated that the caregiving they found most meaningful did not end when cure was no longer possible. In these instances, the nurses' relational caregiving became oriented towards normalizing death for families and providing post-mortem care. Many of the nurses spoke about how their coordinating work extended into palliative situations. For example, P1 described that she is often the "nurse in the room with the physician as they, tell the patient bad news" and often continues as the family's point person throughout the palliative process. Similarly, the community travel nurses, whose roles were centrally concerned with coordinating care, made sure that "things are properly set up the way they should be" (P9, Community Travel Nurse, Interview 1) during end-of-life care. This included finding specialized hospital beds so the child can be at home and connecting the family with hospice care. In her community-based role, P6 highlighted how her proximity to the families throughout their child's cancer trajectory enabled her to act as their advocate and engage in moral proximity when the child is palliative. As well, her bridging work involved her connecting the family to the palliative care team and collaborating with other support workers, such as social workers, to provide care to the child and the family:

> Yeah so I mean our role description does say that we follow families from diagnosis to, to end of treatment or bereavement and I mean palliative, death and and bereavement […] all of *the [community travel] nurses I think we're, you know we take on that role definitely 'cause sometimes, we're the only ones who will advocate for what this family needs at end of life* […] *Ummm, but there, even, so again I link between the two sooo, so the palliative care team um they welcome families at the hospice for end of life or for respite um but I'm the one who knows the family from the beginning so, so I help, I help that process. And then I, I on many occasions I would go over, the family would call me at at end of life and if they were at, the hospice, then I would go over just to be that familiar face.* Um for them or there was once instance where, um, the social worker and I would tag team with this one family the son and the mother, whereee the social worker was the prime, primary support for the son, and theeeen, and then and I would often be that support for the mother. *And then um, and so we were both um, invited to go, meet with this family at end of life and it was uh, it was, it's um, rewarding.* (P6, Community Travel Nurse, interview 2)

This proximity to a child's death and dying is also highlighted by P8, who describes the range of care that inpatient nurses do to coordinate different care providers and administer medications for comfort. In addition, her narrative conveys that the nurses use their medical knowledge to emotionally support the family and the child, by providing them with the knowledge they need to comfort them through the dying process. In this regard, a substantial amount of their palliative care, as her narrative suggests, focuses on normalizing death for families:

> So, our, involvement in the palliative care process, is *a lot of what you said about coordinating between the different people, and we're the ones that are there like sometimes families aren't comfortable with the kids being alone all the time*. And, if a family member can't be there they ask us to go in there. And so we're in there we're sitting with this dying child that is rasping and gasping for breaths, which by the way, this – the child, they have no idea that they're having such a hard time breathing. *We, as outside people, are distressed by hearing it, but they themselves don't know. Just so you know I thought that was really interesting when I first heard that, 'cause usually they're so heavily sedated and so med-medicated that it just, it is what it is. And a big part of dying is, l- is, your body doesn't know how to process all the fluids as your kidneys are shutting down so the fluids go into your lungs. That is one of the first places fluids will go. So it's a lot of, trying to you know tell the families 'hey, this is normal. This happens all the time. The kid doesn't feel it, they're comfortable.'* Or, if it's like a kid that's like, on a like, things are happening very quickly you have to be in the room all the time. Because their fever's getting higher and even though they're dying, you want to keep them comfortable so you're still giving them Tylenol you're giving them antibiotics so you're constantly in and out of the room performing that care. (P8, Inpatient Nurse, Interview 2)

This passage also reflects the ways in which care is provided by the nurses to comfort both the dying child and their families. For the child, comfort is provided by being physically proximal and administering medications. For the family, comfort is provided by providing insight into what is happening and reassurance of the child's comfort during the process of dying. Because there are few cultural narratives available about children who die from cancer, these "tellings" provided by the nurses constitute an important part of their relational caregiving in order to make death and dying as "normal" as possible for families. Her narrative also highlights that palliative caregiving requires being attentive and adaptable to changes that emerge in the situation. At times, the conditions or state of the child can change so quickly that the nurses need to be prepared to provide them

medical care, coordinate with others, and keep parents emotionally supported as things change.

P8 also suggested that caring for the child and family does not end once the child has died. Rather, the nurses often engage in post-mortem care, which begins with contacting "the Gift of Life Trillium Foundation. Even though they can't donate any organs, you still need to get a Trillium number to register them for a death certificate" (P8, Inpatient Nurse, Interview 2). Once that is done, nurses often consult with the family to understand:

> what does the family want? Do they want the *patient to go to the morgue, do they want their kid to go to a funeral home, do they have a special outside service they'd like involved.* So you have to connect that part as well (P8, Inpatient Nurse, Interview 2)

As evidenced in P8's quotation above, many of the nurses acted as bridging points and coordinators for the family, even after their child had died. For instance, P4 described "even that's just helping them set up like if they were, going to donate their cornea maybe I'll make sure the doctors have the forms".

After arranging with outside organizations and agencies, nurses described the caregiving tasks they undertook "out of respect for the patient and their body" (P8, Inpatient Nurse, Interview 2). This involved giving the child a bed bath, changing the sheets on the bed, and putting the child in an outfit of the family's choosing. After, the nurses may also be involved in bringing the child to the morgue as their final caregiving task. The response of the family to these post-mortem caregiving struck P2, who told me how uncanny it is to be "bringing children, putting them in a freezer in the morgue" and then have the families be grateful for it: "this child passed we brought them down, and then the family just HUGGED us on the way out and THANKED US for what, we did like, that's so weird" (P2, Inpatient Nurse, Interview 2).

In conclusion, the nurses' narratives highlighted that they often felt stretched too thin. The generally chaotic climate of pediatric oncology nursing described by the nurses was exacerbated when unexpected side effects or medical complexity arose throughout their shifts, which intensified the relentlessness of their workloads. The nurses' stories linked

their experiences of frustration and burnout to the ways in which they had to compensate for high turnover and understaffing on top of their already demanding caregiving responsibilities. The nurses' stories prioritized the educative, relational aspects of their caregiving and downplayed the meaning of the technologized care. The caregiving narratives conveyed how this range of responsibilities was tailored to meet the needs of patients and families across the cancer trajectory. Navigating these care responsibilities, patients, families, and institutional demands, the nurses were often left feeling as though they could not be the nurses they wanted to be.

6.2   Bearing Witness

In the previous theme, I highlighted how the nurses felt stretched too thin between institutional constraints and competing workload demands, differing needs of patients and families, and multiple caregiving roles and responsibilities. In this theme, I explore the ways in which the nurses' caregiving narratives reveal different forms of bearing witness. As I reviewed in Chapter 3, to bear witness is to acknowledge, testify to, and be present with another person's experience, in order to remain true to that person and their experience and honour to their perspectives, priorities, hopes, and dreams (Cody, 2001; Hatley, 2000; Naef, 2013). In reading these narratives, I came to understand that bearing witness is fostered by the close proximity nurses have to families, and the relational and emotional attachments that this proximity fosters between nurses and families.

In this section, I begin by highlighting how bearing witness is rooted in the proximity nurses have to patients and their families. From this, I discuss how the nurses bore witness to suffering and to families' stories, noting the ambivalence that characterized the nurses' accounts of bearing witness. In particular, I highlight how the nurses' stories conveyed that bearing witness was meaningful to them, and something they wanted to actively engage in, but simultaneously was emotionally difficult. Further, their narratives highlighted that spending time with the family is integral to bearing witness, but on any given shift, the nurses often feel as though they have not spent enough time with the families. In addition to bearing witness to suffering, and in keeping with physical and narrative proximity (Malone, 2003), the nurses also bore witness to families' stories of

sorrow and triumph, joy and devastation, and at times became active characters in these stories.

6.2.1   Ambivalence and Proximal Care

The nurses acknowledged they inevitably form strong relationships, or "partnerships", as a result of the proximity they have to families, the time they spend getting to know and listen to the families, and through the relational and emotional care they give to families. P9, who had over 25 years of experience in pediatric nursing care contexts, highlighted that the proximity that pediatric oncology nurses have to patients and families distinguishes their caregiving from other members of the medical team, which allowed them to better "look" at the child and family, understand their context, and ensure that their care remained true to their needs.

Some of the nurses noted that, through this necessary and sustained proximity to the family, they became like family members or friends. In particular, the nurses, through their physical proximity, also gain narrative proximity, which enables them to understand the family and their contexts through sharing stories (Malone, 2003). In her caregiving narrative, P5 suggests that the child's cancer disrupts normal social patterns and relationships, and the nurses become the family and friends because of their sustained proximity:

> …we had this one kid umm, on our unit for a while he came for a transplant stayed on the unit for like three months and then he relapsed shortly after came back for a second one. And, it was always mum mum her, husband haaad um, MS and, she had, another daughter and, so *mum was like the primary caregiver at the hospital. And when, he was discharged and started coming to the clinic um [clears throat] I kept taking care of her in the clinic and she had said to me she was like 'this is gunna sound weird' but she was like 'for the last two years like you nurses like you guys have been my best friends because, like when I'm here, I'm like with you for twelve hours of the day like you're the only person I talk to 'cause I don't see any of my friends I don't see, some of my family' and like it, it's true because, now I've even said it to some of my own family like there's very few people [laughs] in this world that I will spend a full undivided twelve hours [laughs] with. Four days a week.* (P5, Transplant/Outpatient Nurse, Interview 1)

Many of the nurses' narratives included similar stories about feeling like members of the family, and that they witness the growth and change of a patient and their family during

the time they spent caring for them. The nurses also described different ways of having proximity to the family, based on their specific roles. For the community travel nurses, proximity to the family happened through their home visits, which uniquely positions them to bear witness to the family's living situation and dynamics:

> So part of my role um as the community travel nurse is I go into the homes. Um *I work between the hospital and the community so, uuuum, I have the advantage oooof, um, going into their home setting, and sitting down at the kitchen table and getting a really good feel for what's going on with that family. And it never ceases to amaze me what comes out from times in the home that haven't necessarily come out at – in the hospital at the bedside.* Uh either with the social worker or the NP [nurse practitioner] or the physician. *So it's a very valuable part of um, looking after these families and figuring out what's working and what's not working* (P9, Community Travel Nurse, Interview 1)

For all of the nurses, regardless of specialty, the long-term nature of pediatric oncology establishes *"a strong, partnership with the families"* (P9, Community Travel Nurse, Interview 1), allowing the nurses to witness the growth of the child and family through the progression of their cancer. P2 explained that, because of these close relationships, the nurses become thoroughly entwined in the family's dynamic and story. As he put it: "Their victories their celebrations are your victories and celebrations. Their bad times are your bad times". He further explained that bearing witness to a family's life and growth made the struggles encountered as pediatric oncology nurses worthwhile, despite its challenges:

> *So you really get, very close with the families. Um, which I think is why, I've been able to stay where I am for as long as I am, or have been um, as well as why people are drawn to it.* You kind of have this, *like they're a part of your family and you become a part of theirs to an extent.* I think it's really good, *and something that, makes it easier to provide care and easier to do your job.* But also it's, *I think one of the strongest reasons why there's burnout why there's this, uh, aggressive, negative side to the pediatric oncology world* because, you're kind of constantly exposed to that, um, that heaviness, within, their situations instead of one family going through ONE cancer journey, you are one person going through many families cancers journeys and it's very, uh, additive in that way. (P2, Inpatient Nurse, Interview 2)

P2's narration further highlights that proximal care that lends itself to bearing witness is accompanied by ambivalence. To bear witness to a family's growth and triumphs is

meaningful, and can be rewarding, but it can also be emotionally devastating and lead to moral distress, especially when nurses must bear witness to multiple families at once who are experiencing hardship and difficulty. This ambivalence was noticeable in other stories from the nurses, who described the difficulties of maintain professional boundaries in their sustained relationships with families:

> The longer stay kids for suuuure it, depends on the kid for sure but we, myself and other nurses we definitely develop relationships with them. Right? So they're not just, they're not just a patient anymore *they become more of s-someone we think about outside of work, someone we're excited to take care of for y-your duration of your shifts.* Uuuuum, obviously *we, all do our best to maintain professional boundaries, that's part of being a nurse but I would definitely say sometimes those get blurred when the patients have been there for so long. As well, the families, we become their family too. We're who they see every day and, um, and if it does, should something happen to that child they relapse, they pass away it is, you can definitely see the kids that are there for a long time weigh a lot harder on myself and other staff members.* (P7, Inpatient Nurse, Interview 2)

Other nurses took it upon themselves to set boundaries in order to mitigate the potential for experiencing moral distress. P1, for instance, highlighted that it is important to her to maintain boundaries to manage her connections with families, yet also admitted that setting boundaries was difficult:

> *I try really hard not to become part of the family*. But it FEELS like, it feels like because you see these families, um, most of our treatments are between like 6 and 9 months, and you just see them on a weekly or bi-weekly or sometimes a daily basis for *that entire 8-to-9-month period so it's a very intense thing and, intense experience, um, so you get very connected to families.* (P1, Outpatient Nurse Manager, Interview 2)

In addition to these ambivalences, where moral distress was experienced through sustained proximity to patients and families, other nurses narrated their distress regarding their inability to be proximal to patients and families. Many of the nurses highlighted instances of being unable to bear witness due to time and work constraints. As an example, P3 recalled how her work in the outpatient clinic does not afford her the time "in the trenches"; she is only able to have "superficial conversations" with families. Getting "in the trenches" or doing "deep dives" to her meant engaging in narrative

proximity: hearing their stories, understanding their contexts, and integrating herself in their narrative:

> *the nature of the flow of the work in general just doesn't allow for you to sit down and really just like talk, and, see 'how-how are you doing' like, 'is there anything that youuuu, you know want to talk about today that I can help support you' just even open-ended questions like that I just, don't have, time. And conversations end up being quite superficial.* Which is okay you can still build really great relationships with patients but they don't, you don't have time to like, do a deep dive in - maybe it's the outpatient setting, maybe it's because of workload maybe it's because of the flow of where I work but um *you don't have time to do those deep dives and kind of, see how, you can support them on levels that you wouldn't, know, if you're just kind of, talking about them and on a superficial level so. Yeah that's something I still definitely feel is that I don't, I feel like I can't be the nurse that I want to be and I've learned that that's the kind of nurse that I wanna be over my years of experience and that's what gives me, a lot of fulfillment is being able to really, feel like I'm there for them or the patients and families like feeling like I'm just I'm really there for them when they're in the trenches that's, when I feel like I can do my best work* (P3, Outpatient Nurse, Interview 1)

The conclusion of P3's narration clearly suggests that being unable to sustain proximity to her patients prevents her from being the nurse she wants to be.

I learned from my interviews with the nurses that their bearing witness did not only happen during the time in which they were actively caring for their patients and patients' families. In this sense, the nurses did not forget or stop to care about the family after their formal caregiving ended, on a shift or permanently. On the contrary, the nurses' narratives suggested that their bearing witness to the families through proximity has effects that stay with nurses long after a child's treatment, and their formal caregiving relationship, has ended. P5 suggests in the following passage that, while institutions have tried to prevent nurses from getting too close to patients via emphasis on discourses of "professionalism", the narrative proximity that is inherent in nurses' caregiving results in nurses become enmeshed in the social network of families:

> I just think it's because it's just something that's not often talked about and, you know like y-*you can't as a nurse, always say to your patients like, [laughs] 'I like I think about you when I go home at night' or like you know, and I mean sometimes we do I mean there's definitely some kids where I like, come in a week later and I was like 'oh my god I thought about you on Tuesday 'cause I went to the grocery store and I saw that stupid aloe vera drink that you always drink and*

I decided to get it and it tastes like crap. I don't understand how you drink that.' Right like, sometimes there there are those moments, um, but, you know sometimes *you can't always say like 'I literally, did not sleep last night because I could not stop thinking, about you.'* And, we don't say that and we don't talk about that (P5, Transplant/Outpatient Nurse, Interview 2)

This unspoken aspect of the effects of their caregiving also highlights how deeply the nurses' assign meaning to the caregiving they do for families. Her narration continued, and through her story below, she counters professional constructions that require distance between parents and families by stating what she remembers about the families she has cared for:

I just think that sometimes, parents perceive um themselves as like just another patient to us and, we remember *so* much about these kids. Like *so* much. *And sometimes we might forget like, their names, but we'll remember what room they were in, we'll remember remember the names of the PARENTS, or we'll remember the names of their DOG. Like we'll remember really obscure things like I have some patients where, I don't remember their last name but I know when their birthday is. Or, you know just like random little things of, you know they're never really just another patient to us they, they do impact our lives as much as, you know they feel we impact theirs* (P5, Transplant/Outpatient Nurse, Interview 2)

Throughout this passage, the repetition of the word "remember" suggests that even after her patients and families have finished treatment, she is still able to provide testimony to their lives and stories. This illustrates how proximal care and bearing witness transcend time: one does not only provide testimony in the present as a witness. Rather, nurses bear witness to their patients through the telling of their patients' stories, even after they are no longer caring for that patient, as they did in their interviews with me. Bearing witness to these patients and families was so powerful and meaningful that the patients become embedded in their lives, leaving a mark that forever stays with the nurses, and that further informs their caregiving for other patients and families.

6.2.2 Bearing Witness to Suffering

Bearing witness to suffering was a frequent experience storied by my nurses. These stories of bearing witness to suffering were often in relation to children experiencing complications from treatment or receiving palliative care. These stories illustrated how

bearing witness to suffering was particularly fraught when there were instances of disagreement between the family and the child, or between the nurses and physicians.

The nurses' narratives often suggested that bearing witness to suffering becomes especially difficult in situations where the family's needs and wishes were different than the child's, or when the family's wishes were not, according to the nurses, in the best interest of the child. In palliative situations, the deaths that were most distressing to the nurses were those that occurred when parents were unwilling to admit that their child was dying and wanted to continue chemotherapy or other cure-oriented treatments which ultimately caused their children more pain.

This kind of story of bearing witness to suffering was told to me by many of the nurses, and the moral distress they experienced arose when there was incommensurability of the patient's desires and family's wishes. For example, P4 told me how one of her patients had told her (and other nurses) what she wanted for her treatment. However, as her disease progressed and her condition got worse, she was no longer lucid. Her parents' wishes, which were enacted by the medical team, opposed what the patient wanted for her death. P4's narrative shows the difficult position that nurses are put in when they are aware of their patient's wishes, by virtue of their narrative proximity, but must provide care that conflicts with these wishes and in a way that supports medical directives and the family wishes:

> *So it like in those situations where you are feeling moral distress* it's usuallyyy, what, if you've had this patient a couple times […] *like a, older patient who, she was at one point lucid and able to express her concerns to nurses.* But the family – *it was a different kind of family dynamic a different kind of cultural background um. So ultimately, her wishes may have fallen on deaf ears at the end of her life but.* A doctor in order to make that decision would have to have her lucid, at that point. *So the family was able to make those decisions for her which, we didn't really agree upon, because you've had that relationship with the par- uh patients where you're kind of, you feel like you know what they want.* (P4, Inpatient Nurse, Interview 2)

P4's narration highlighted the narrative proximity she and her colleagues had to this patient, and the moral distress they experienced as a result of their inability to be morally proximal to the patient by being unable to act upon her wishes. This distress was

compounded by the fact that the nurses were the ones actively administering lifesaving measures to the patient. P4 conveyed that she and many of her colleagues experience significant distress in their daily lives outside of the hospital as a result of fulfilling the wishes of the families instead of the children:

> it's SO much more straightforward, in adult care in some situations not when they're delirious or have dementia or anything like that but, where somebody can say 'hey. When it comes down to this I don't want this chemotherapy. And I want you to, I don't want you to like you know intubate me like please don't do that to me' whatever and, the situation's like the family's like 'I want you to do everything for my child.' Um, and then *a nurse will maybe, when taking care of that patient seeing them suffer and like, to what end right? Um, you're you're going home and thinking [pauses] about, the like 'I know I provided care for this patient, but I don't feel like I did the right thing for them today.' Or like you went through a whole day of caring for a patient but you're like 'ahh I don't think I did, I don't feel like I provided the kind of care that I wanted to.' So. And just being not able to do it, because there's the people you can't, you know, you can't bypass the families' decisions in this situation.* And if a team's, if you have the discussion and the team still says 'we have to go by what the family wants' you have to, you have to go by what the family wants so that's always hard. (P4, Inpatient Nurse, Interview 2)

These kinds of deaths were often traumatic to witness for the nurses, who acknowledged that you "learn more from the traumatic deaths" (P8, Inpatient Nurse, Interview 2) and that the bad deaths are the ones most remembered. In our interviews, a "bad death" took on various forms, including deaths where: the child died in pain; the child died suddenly; the child died when the family was unprepared for the death, was unaccepting that the child was palliative, or was abusive; or when there was discord regarding the best course of treatment or action between the medical team and family, between the medical team (particularly physicians) and nurses, or between the nurses and family.

In their stories of these difficult situations, the nurses were sometimes able to rationalize these circumstances by reminding themselves that they do not have to live with the death of the child the same way the family does. However, in many cases, the nurses also had great difficulty processing the patient's death, and experienced moral distress as a result. This was the case for P5, who told me a story where the father of a dying child demanded that his son be free of pain medication so that he could remain awake with the family for as long as possible. She felt torn between the child and his family; she wanted the family

to be able to spend time with their child before he died but did not want the child to suffer because of it. Witnessing the suffering brought on by her narrative proximity to the needs of both the child and the family, and knowing that they were in conflict, was a source of great moral "struggle":

> *My struggle comes from, with some families and some patients and when I feel like, I can't DO what I should be doing, because of the limitations that that parent has now set on me*. So when I think about um, like some of those days where I just like, felt awful I remember we had, umm, one patient who, and this is the one that I was mentioning earlier that had been like, dying on the unit for months he, started like just bleeding out of, like his GI system so he was like stooling a bunch of blood vomiting a bunch of blood. And soooo, we obviously like needed to give blood. Aaaand, when we give like blood products we have to do a number a set of vitals just to make sure that they're not reacting to it and all these things and, you know I would go in to do vitals and dad would be like *'he's asleep' like 'don't do vitals don't bother him this and that' and so then, like dad's refusing and if you would even try to argue with dad he would just like yell at you tell you to get out of the room that you're murdering his child like, all of these things* and, it would just, like you would just leaaaave the – like you would leave the room a) because you're well I would because I was scared. I DON'T want to be in a fight with a parent and I'm like 'if this is what he wants to do then fine that's the care that he's gunna get' but then like, realizing like, what if he's having an anaphylactic reaction and dad's asleep and like no one's there to like, see that or, you know if there would be times where he would be *in sooooo much pain like I remember, when dad wasn't there he like grabbed me by the hands and was like 'NURSE' like [voice becomes urgent] 'do something can't you see I'm SUFFERING.' [returns to normal voice] And like when he said that to me I was like, okay yeah like I need to do something. Aaand I remember I gave him [clears throat] some pain meds when dad came back he was soooo upset because he was like 'no!' Like 'now he's sleeping he's sleeping so much and I don't want him to spend the whole day sleeping! I'd rather him be in pain but be awake so he could be present with us!'* (P5, Transplant/Outpatient Nurse, Interview 1)

In her narration above, P5 emphasizes how the patient demands her to bear witness to his suffering, reflecting Levinas' conceptualization of witnessing "the face of the other". The patient's called to recognize his suffering invoked P5's moral response, which meant going against what his family had ordered. By giving him pain medication, she was able to engage in her moral proximity and act upon her moral responsibilities to the patient, even though it defied the parents' wishes of keeping him awake.

6.2.3   Bearing Witness to Stories

The nurses' stories also suggested that they bear witness to the family's stories, which was facilitated by the narrative proximity they gained through the relationships they built with patients and families over time. During this time, they learned many stories about their patients and patient's families, which were mentioned at various points during the interviews: stories of what the patient was like before they had cancer, stories of what the patient hopes to be when they grow up, and what the family hopes and dreams their child to be when they no longer have cancer, stories about the patient's or family's personal experiences, quirks, or embarrassing instances, stories about other family members or friends, and stories of grief, sadness, and loss.

The narrative proximity that nurses have to patients and families was described by some of the study participants as something that is unique to pediatric oncology, in comparison to nursing in other pediatric environments, such as the ICU. P4 suggested this in her second interview, when she explains that nurses in the ICU, on account of not having narrative proximity, are ultimately not as affected by difficulties with the patients and their families as the pediatric oncology nurses:

> […] *they [ICU nurses] don't know the patients at baseline. Like they, they didn't like you don't know them in the same way. So I I don't think you have that same connection.* To them, when you're doing all this care like you're still doing your job and it, it is very sad and the whole you know any situation could be sad when someone comes in that sick from the community but, it's it also not all cancer kids, and yeah you don't**,** *you don't know people's stories, which, I dunno if it makes it I guess it does make it better. For some of those nurses 'cause they're able to do their job without being clouded by all of that emotional attachment.* (P4, Inpatient Nurse, Interview 2)

This enmeshment of the nurses in the families' stories was highlighted by P8. In one of her caregiving stories, she told me about a five-year-old boy whom she had cared for since he was first diagnosed with cancer at age two. Her narrative conveyed how the nurses' narrative proximity to their patients and families could result in them becoming engrained into the family's stories. In this case, the nurse affectionately described the boy as her first "work boyfriend" after the child articulated his love for her. Her story about

this boy and his family suggested how she became enmeshed in the family's story, and how this this gave meaning to her bearing witness to his cancer experience:

> Sooooo, I've taken care of him since he was diagnosed. He, he was actually my first 'work boyfriend' 'cause he told me one day, [baby voice] 'I wuv you.' [M laughs, P returns to normal voice] And theeen, mum was, his mum was like 'do you love her 'cause she's your girlfriend?' And he said yes. So he was my first work boyfriend. Um, at two years old. He's been a little player [M laughs] he's always been a little player [M laughs] (P8, Inpatient Nurse, Interview 1)

However, this narrative proximity and enmeshment with the family also meant bearing witness to the changes in his personality and physical condition as his cancer progressed. Her narration provided testimony of his life during our interview and conveyed how she bore witness and saw the majority of his life unfold, including the changes to his personality and demeanor as his cancer slowly took over his body. At the time of our interview, there was an article in the local newspaper about a parade that passed by his house with messages of love and support as he was dying. "Seeing him" turn into a completely different person was heartbreaking for her:

> Aaaand, it's hard, not tooooo, feel. 'Cause I've been there I've been there the first time he beat cancer. I've been there the second time, and now, you know he's not beating it. *It's- it's taking over his body and, seeing the pictures of him, in the article, I can see how it's affecting him. He does not look like the same boy. I do not see the same spirit. He was, he was a little firecracker he was always talking and running and playing and jumping and yelling. He never stopped. So seeing him in those pictures, immobilized, stuck in a bed, stuck in a chair, his eyes all droopy 'cause the tumours have spread to his brain and are affecting his, his nerves and everything, it breaks my heart.* (P8, Inpatient Nurse, Interview 1)

In "seeing" the pictures of him in the newspaper, she registers the difficulty of witnessing how his cancer has taken over his body and affected him physically and emotionally. Further, she highlights the ambivalence of this witnessing. After having developed narrative proximity over time, "seeing" him dying with the cancer taking over his body is difficult for her as she is unable to recognize him ("He does not look like he same boy"). Levinas' conceptualization of bearing witness notes that "seeing the face" calls the observer of the face to respond; in this case, however, there is nothing that P8 is able to do for this child, and it "breaks [her] heart". He died less than a month after our interview.

Oftentimes the nurses' narratives, such as P8's above, revealed that the long term and proximal nature of pediatric cancer care encourages narrative reciprocity. Originally, this starts as "getting to know" the families. As time progresses, storytelling becomes more of an exchange between nurses and families:

> Um, based on what you're taught in nursing school like, *you're supposed to maintain boundaries and keep like your professional and like work life very separate. And I just think in pediatrics peopleeeee are not very good at that? And I think like, this, you know maybe not just pediatrics but long-term care, that's really difficult just because you know you do get to know them on a very personal basis and, just the way that conversations flow is like you do end up sharing, um, kind of like personal things about them and, y-you know, I have boundaries in terms of what I tell them but they do all know I have a boyfriend from England, like, they they know a lot about, um, my familyyyy and like, how long I've been at [hospital] and, that kind of stuff.* So there's things I don't tell them obviously but, that boundary is, kind of, I would say blurred in with those patients and I think, um, I wonder what you'll kind of gather from talking to my colleagues also 'cause I I see it in a lot of my colleagues as well and that's something we're not THAT good at is like keeping those professional and personal boundaries. (P3, Outpatient Nurse, Interview 1)

In this counterstory to the distance required by master narratives of nursing professionalism, P3 emphasizes that sustained physical proximity with patients lends itself not only to narrative proximity, but also narrative reciprocity.

Similar to P3, and as discussed earlier, some of the nurses' narratives suggested that nurses become integral characters in the social support network of the families, as their lives are disrupted by and must adapt to their child's cancer and its treatment. In this context, both nurses and families share stories that convey who they are and what their lives are like. This storytelling promotes narrative proximity and allows nurses to make their caregiving more meaningful as they come to better understand the family's routines, contexts, and needs. As time progresses, as suggested by P3's narrative below, the nurses become actors in the family's story, and assume the role of extended family as they help families raise their children outside of cancer treatment:

> Um, you're there for like when the kids like take their first steps there's this like one kid she's, I think she's done treatment now because I haven't seen her in a while but she, *we, met her when she was eight months old and like she was just learning to like, s-s-sit up, and then we saw her like walking and her hair's now*

back and she's like running and like blowing us kisses like, you can really like, you see these kids grow up right in front of your eyes and, you feel like you were there. Like, you helped raised them you were like a very big part in that and, like kind of like their big sister. (P3, Outpatient Nurse, Interview 1)

P7's story highlights how intricately nurses become entwined in a family's dynamic while providing care, and how the family's stories not only become known and understood, but further influence the care they receive. Her story suggested that bearing witness to her patient's struggles and story as a transitioning transgender teenager undergoing chemotherapy helped her realize that he was not getting the specialized support and care he needed. Her narrative conveys that her proximity provided her with a perspective that the other health care providers on the care team may not have had and helped her understand that she was insufficiently prepared to provide the specific supports he needed:

> I guess it would just beeee, um more recently *we had a teenager whoooo, is transgender. Um, and he needed,* much more psych – I mean he was sick and he needed oncology support we needed to give him his chemo and everything like that but, he - there was a much bigger psych aspect to providing care to him that, I just, never really underrrrsssstood? I would, I would I mean they gave us all the resources in the world to, try and support him and, I would just say, I continuously kept saying 'we're failing him.' The support he needed, was not the support we could provide. We, we didn't have the training to do it. Um, we definitely asked for, resources and help and support, the group of girls that took care of him, took care of HIM all the time. Um, *there was also issues with dad not accepting the transgender, and what do you say to the parent, whooo, their kid now has cancer and is transgender. Um, and the kid is, not happy, with the response right like, for example the dad had said 'oh I had took care' – he's a PSW he was like 'I took care of, um a girl, in her twenties with the same diagnosis as you and her name is the same as yours, [Molly]' and, the patient just looked at dad like, 'that's not my name anymore.' Like, and you just want to say to dad, 'SHUT. UP.' Like that's not what, this kid needs to hear right now this kid needs to hear that we're going to get HIM better, and get him on the right track of things.* Um, definitely, we, used our art therapy and, everything like that but, his mental health was *so poor* and, you worry about him at home you worry about, everything that's happening because, are you providing, like, you would leave work 'did I even do anything for him today' and I, I know we ALL, all the girls who did take care of him felt that way. Because we never felt that we were, yes maybe we got him up for a walk but he didn't want to do it like, he, needed someone who was actually going to talk to him about what he was feeling *and, yeah so I would say, just not knowing, how to, do that.* (P7, Inpatient Nurse, Interview 1)

This nurse's narrative highlights that she was able to bear witness to this patient's struggle with gender transitioning, but was unable to enact her moral responsibilities to him, evidenced by her saying that she was "failing him". P7's narrative suggests that she was able to be physically and narratively proximal to this patient, however this led her to realize that she could not be morally proximal to him as she was not trained in the kind of care that he needed. Furthermore, through her proximity to the patient and family she was able to understand that her patient was not only dealing with a transition and a cancer diagnosis, but a parent who was having difficulties accepting his transition, which made the patient's experience of his cancer treatment more complex and difficult.

In this narrative theme, I have drawn attention to bearing witness as intricately embedded in and resulting from the proximity pediatric oncology nurses have to their patients and families. Specifically, I have addressed how bearing witness is fostered through physical, narrative, and moral proximity and relational care that nurses provide to families, and that bearing witness takes on multiple forms. Specifically, I have highlighted that the nurses in my study not only bear witness to suffering, but also bear witness to stories, and for some nurses, they narrate themselves as integral and active characters in the families' illness stories. As well, I have highlighted that proximity poses an interesting ambivalence, particularly that bearing witness is meaningful and rewarding, but can simultaneously be a source of moral distress when nurses are unable to be morally proximal to their patients and uphold their moral responsibilities.

6.3   Bonded by Trauma

Thus far, I have presented narrative themes that explore how the nurses expressed being stretched too thin by competing workload demands and compensating for turnover, limiting their capacity be the nurse they want to be. Their stories of relentless workloads and wide-ranging caregiving roles and tasks, being unsupported by their institutions, and of being thrown into caregiving responsibilities with little experience, revealed that pediatric oncology caregiving was often distressing for the nurses. I then outlined the nurses' narratives of bearing witness to the suffering and stories of their patients and their patients' families through the proximity of their caregiving, and how their stories suggested that, in instances where nurses were unable to be morally proximal and enact

their moral responsibilities to their patients, they experienced moral distress. In this narrative theme, "Bonded by Trauma", I highlight aspects of the caregiving narratives that emphasize the ways in which the nurses depend on each other for survival in pediatric oncology caregiving context. In this theme, I explore how the nurses spoke about bonding to withstand their shared experiences of trauma and mistreatment. Their stories revealed that their dependence on one other through their working conditions and unsupportive management also fostered close friendships, both inside and outside of work.

In this section, I begin by presenting the nurses' stories of how they bonded in order to remain resilient in the context of their continual interactions with unsupportive management and their intense and multiple, competing workload demands. I conceptualize these narrations as the nurses being bonded by the chronic trauma imposed by unsupportive management and difficult working conditions. I then illustrate how the nurses described being bonded through their shared experiences of more acute forms of trauma, such as witnessing a child's death.

6.3.1   Bonded by Chronic Trauma: Unsupportive Management, Overwork, and Being Stretched Too Thin

The nurses' stories often highlighted that they had incredibly close relationships with their nursing colleagues and that they often relied on one another for support, both professionally and personally. Many of the nurses in my study related stories of bonding and establishing close relationships with one another. These can be considered as counterstories to the idea that "nurses eat their young", which is something that three of the nurses in this study mentioned they had heard in nursing school. According to these nurses, and as evidenced by P4, below, the expression that "nurses eat their young" refers to situations where senior nurses would often bully younger nurses into doing more difficult tasks that they may not be trained or ready to do, and as a way to initiate them into the profession. In contrast to this idea, the nurses in my study described pediatric oncology nursing as collaborative profession where the nurses work together and support each other through collective problem-solving as evidenced by P4's narrative below:

when we were in nursing school, there were some experiences in nursing school. But they, would say 'oh. Senior – like nurses eat their young, in some situations' and that just, I think what, it just means that, in some situations if you're brand new, people are gunna make, are gunna give you things that, a task that you don't need to do, an ul – ultimately, kind of treat you like very unequal to them. But I'm gunna say I've never had that experience in, innn, both jobs that I've had. And it's very collaborative I also work with people in the same age group as m- as me, so, when, even if I'm doing something I've done like a thousand times and I'm like 'hey! Do I have to use this filter' I'm gunna research anyways but they'll be like 'yeah yeah you have to use this filter' [….] *It's like no one would ever, make you feel stupid for, you know overthinking something and I kind of try to do that when I'm working as well. 'Cause people make mistakes and it's, usually the mistakes you make are sooo, small, but you've you give yourself, a really hard time for them that's what I'm realizing. Um so just, trying to treat, the new nurses with some, kind of [pauses] you know give them a benefit of the doubt [laughs] 'cause I still ask a lot of questions and, I've been working there for, four years so.* (P4, Inpatient Nurse, Interview 1)

P4's narration also highlights that to be a pediatric oncology nurse means that you have to rely on the other nurses to be able to provide care through the uncertainty that characterizes their caregiving, and that much of the learning in pediatric oncology often happens on the job.

In order to withstand the chronic trauma of pediatric oncology nursing, more experienced nurses often supported newer nurses in their caregiving, and their own experiences of chronic trauma informed their willingness to help. Many of the nurses in the study shared that they take the time to answer questions, show each other different techniques, and encourage other nurses to ask questions without fear of looking unknowledgeable or incompetent. This support and mentorship helped the newer and less experienced nurses to feel more comfortable and competent with their care, especially when being stretched between multiple caregiving demands. This was expressed by P8, who understood well how new nurses are often thrown into new situations with very little training:

I really don't mind I, *I'm always asking my coworkers if they need a hand or something I could help them with. And I try to encourage them to ask questions when they want because, they're they're not. This like, you learn by doing in nursing.* You don't know how to put a port needle in until you put a port needle in. You don't know how to doooo peripheral blood work until you do peripheral blood work. So I'm always trying to encourage them to ask questions and to seek out the help when they need it and vol - I volunteer whenever I'm able to. *Um, it's*

what we have to do. We have to help each other. We don't let each other sink. We help each other float. (P8, Inpatient Nurse, Interview 1)

P8's metaphorical description of helping her colleagues suggests that, without the support of more experienced nurses, less experienced nurses would "sink" or drown in their responsibilities and emotional burden of the work. To support one another, or "help each other float", is necessary to survive pediatric oncology nursing.

These stories of the necessity of mentorship and support suggest that the nurses developed a collective resilience in order to withstand the chronic uncertainty and trauma that they experienced in their work. The collective character and goals of this resilience were signalled by the ways in which these stories were framed in "we" language, such as that P8 invoked repeatedly at the end of the above quotation: "it's what *we* have to do. *We* have to help each other. *We* don't let each other sink. *We* help each other float."

This sentiment was concisely described by P7, who highlighted that to rely on each other as nurses is necessary to protect against burnout in pediatric oncology:

> I feel like it's, just part of us as pediatric oncology nurses we just, *we know we have to work together as a team 'cause I think if we did it one on one or we, didn't ask for help or didn't do those things, I don't think we would succeed at our job and we could burn out, 'cause we would take on, too much.* (P7, Inpatient Nurse, Interview 1)

Furthermore, pediatric oncology was frequently referred to as its "own world" by the nurses, as the stresses associated with being a pediatric oncology nurse are difficult to understand from an outsider's perspective. Many of my participants highlighted that they sustain their friendships with their nursing colleagues after leaving pediatric oncology because of the specific workload demands and stresses they experienced together, as evidenced by P1:

> I do think it's fairly, at least it's been my experience seeing nurses kind of come up through the, years at [hospital] you see different groups, kind of, evolving and sometimes just on social media like oh that's so cute they're still friends and, I think that being an *oncology nurse is a very bonding experience because of the stressful situation that we work in*. Um, and I think it's really great that, *no one really understands it like, people going through it and, and doing the work, so. It's nice!* (P1, Outpatient Nurse Manager, Interview 1)

In particular, she references that the bonding between pediatric oncology nurses happens through their withstanding difficult conditions together over time, which helps them weather those conditions. Also, by highlighting that pediatric oncology is a unique context that "no one really understands", she further suggests that their shared experiences of working in the field are particularly strong bonding points.

Many of the nurses' stories furthered P1's point that pediatric oncology is an environment where nurses bond through their collective trauma and resilience. P3 conveys that the ambivalences associated with their caregiving – the joys as well as the sorrows, the triumphs as well as the traumas - would be difficult to comprehend from an outsider's perspective:

> they're [my fellow nurses] some of my closest friends I've ever had in my life and they just, they really understand, me and the work that we do and my feelings that, like I think that's why you're going to get a lot of similarities in terms of their responsibilities is just – we get it. *We just really understand like the work and the nitty gritty but the magic at the same time and all of that intertwined like, we just understand it and I don't have to, explain my feelings the same way that, um, I would have to my non-nursing friends and it's just a really special environment to just have yourself surrounded by people who just are so like-minded and just really get it.* Um, so I don't know where that fits in to your study but that's um, just from the, working environment is like it's just such a supportive like, generally really good place to work in terms of your, your coworkers and just, you have a good, a really good team. (P3, Outpatient Nurse, Interview 2)

Her narrative also highlights that members of the nurses' support networks outside of work, like family and friends, may try to understand and listen to the nurses' experiences and stories, but they can never have the level of understanding that coworkers do. The unique range of emotions and situations experienced in the profession are difficult and exhausting to contextualize and explain to people outside of the profession.

The nurses' stories also suggested that they were bound together by and united in their thoughts and feelings about not being sufficiently supported by management. The nurses' stories revealed many examples where they would often ask for resources that would never show up, request emotional or mental support but never receive it, and be left to face abusive parents and other family members on their own with little or no protection.

For instance, P5's frustration with management and the futility she felt was apparent in a story she told me about her venting her frustrations to her coworkers during their carpool:

> I was feeling like really burnt out and just like, kind of tired of it all, at the time I had been carpooling with five other nurses one of them being, um one of my supervisors and *I had had like SUCH a bad day and I, like, TOTALLYY let loose in the car forgetting that she [supervisor] was sitting in the back because my best friend was sitting in the passenger seat. And you know I was just saying like, [raises voice, becomes stern] 'there's NO support whatsoever we've had like four deaths on the unit in the last, like three weeks no one's come to do any debriefs to see if we're okay' I was like 'this is bullshit like, yadda yadda yadda yadda' [returns to normal voice] and you know my like, friend's sitting the passenger she was like 'I just looked in the review mirror and I saw like our supervisor's face like, DROP.'* And 'cause I just totally forgot that she was there and, literally the next week we got an email saying like, 'oh we're having like peer support come byyyy' and like this and that and, it wasn't really until like she*, I guess, saw me in that moment where I'm like driving on the highway like crying like so upset, um, did I think she realize that, people were actually, STRUGGLING with a lot of things. And, it wasn't like it hadn't been brought up before it was something that was always like 'oh yeah' like, 'we should do that' or 'we'll look into it this and that' but then nothing like would, sort of come about it.* (P5, Transplant/Outpatient Nurse, Interview 1)

P5's narrative highlights that the only reason why she and her coworkers were able to get support was because a manager was in her car and "saw" her the day she got extremely upset – it was by accident that the manager was called to respond, and the nurses ultimately got the debrief that they had wanted. In other examples, such as another narration by P5, below, the nurses ultimately had to take matters into their own hands because of management's lack of action about nurses' concerns. Her story highlights how frustrations with management were exacerbated by the COVID-19 pandemic, and how the lack of support from management led the nurses to form their own policies and procedures for caring for patients who were diagnosed with COVID-19:

> *It was very frustrating aaand, you know theeey, on these calls like the leadership team you know would always that they're very like open to suggestions and then we would suggest things and like, you know they'd be like 'oh that's a great idea' and then nothing will be sort of implemented.* Uuum, so THAT was very frustrating and, it almost seemed like a lot of these like town halls and different meetings that we were having were more so, spaces where nurses were able to just kind of vent and voice their concerns without really having a lot of, of action being taken, after that? Um, aaand, *it kind of got to a point to where we, were sort*

> *of even like kyboshing what the leadership team was saying and we were just kind of doing what we FELT was the safest.* (P5, Transplant/Outpatient Nurse, Interview 2)

It was also evident in this quote that the nurses unite through their concerns for their patients. Specifically, her quote suggests that the nurses, with their clinical expertise, came together to create care plans for their COVID-19 positive patients, and to help stop transmission to their non-positive patients.

Another example of the nurses bonding in response to the lack of supportive management was narrated by P2. In this narration, P2 described experiences in which the nurses are treated abusively by the families of their patients. Typically, this abuse was described as verbal, though it was also physical in some instances, for example when a nurse described being physically blocked from providing patient care. In these stories, the nurses described feeling unsupported when they reported instances of family abuse to management, who would often justify the family's actions by stating that they were under a great deal of stress. In response, P2 told me that the nurses must rely on and protect each other in these situations:

> We're not [protected]. Not really. *We're protected by each other.* [pause] Yeah. That's really how we do it we put ourselves in situations where we try to avoid these conflict issues or *if we are, in a situation we go in two nurses into a room at a time.* Again, taking away resources but we'll, protect ourselves that way. *We will, we continue to advocate try to say well, you HAVE to look out for us. We're actually in the process of meeting with, one of the senior VPs about kind of handling these situations better. Um, but, we do the best we can. Yeah. We rely on each other.* (P2, Inpatient Nurse, Interview 1)

This narrative highlights that this protection requires nurses to come together to "advocate" so that they can document instances of abuse and influence management. In addition to this advocacy, this passage clearly highlights that the nurses must rely on each other because they cannot rely on their management to protect or help them. Further, P2 outlined that in having to support each other in instances of potential abuse by having two nurses in a room, the nurses spread the already limited resources they have even more thinly. This is suggestive of how unsupportive management contributes to exacerbating precarious working conditions for nurses who are already stretched too thin.

6.3.2   Bonded by Acute Trauma: Volatility and Bearing Witness to Suffering

In addition to being bonded by the chronic traumas associated with unsupportive management and of being stretched too thin, the nurses also bonded through the acute traumas they experienced in relation to their proximal caregiving and bearing witness to suffering as they nursed patients and families during dying and after death. A child's death often united the nurses in their shared experiences of trauma, grief, and in their shared palliative and post-mortem caregiving experiences. The nurses' narratives suggested that they were never truly prepared for their "first death". In this respect, the nurses described that they felt like "a deer caught in the headlights" (P7, Inpatient Nurse, Interview 2) with their first palliative case, and that "you don't know what to do. And you don't know what to expect" (P7, Inpatient Nurse, Interview 2). P5 illustrated this in a story she told about having to care for a patient who died unexpectedly in the first week she started her job. She explained that, typically, units try to wait at least a year before a new nurse is involved in a palliative case. Because the patient died unexpectedly and quickly, she was charged with the responsibility of helping the family and performing the post-mortem care. Overall, the experience was difficult and overwhelming for her: it was her first death, she had to prepare the body, and she had to comfort the family and attend to their specific needs. This early caregiving experience left her emotionally fragile for months:

> I remember my case, um, like the patient had died on the nightshift and then when I came in the morning like I was assigned to like the body, and I didn't really understand aaaand it was partly because, the patient like *there was a lot of like social stuff going on and like they were on welfare so they needed OW to like, receive the death certificate before we could move the body to the mosque and but like essentially the patient's body was at room temperature for like 14 hours because mum would not be able to – like mum was not able to let go of her, and I was the one that was like a nurse literally one week on the job being like 'your daughter's body is starting to decompose and we need to get her like into like, the freezer. Or else like it's going to start to smell really bad and you will not even be able to have any sort of like, burial or like funeral or anything.' And like, I felt, SUPER insensitive saying that and being like the last person to like, peel this mom's body off of her dead daughter is like, a horrible experience of like that's like, the last, like like I'm the last person to like remove her from her? Um, but [pauses] it was mainly because of like these other factors it wasn't like I didn't*

want her to grieve the loss of her daughter and to have you know, those last few hours or moments with her but because science, is gunna do what science does and bodies are gunna decompose at you know, 24 degrees Celsius like, they, they need to be prepared and so, you know I kind of held my stuff fine enough and I remember, preparing the body with the other nurse and I moved the bed in some weird way and there was um, [laughs] there was a Frozen, like Anna or Elsa like balloon, kind of a helium balloon that had deflated behind the bed and when I moved the bed the balloon popped and like went around the room and that sound, literally made me scream as loud as I probably have ever screamed in my life and then immediately from that I started crying like afterwards 'cause I was like 'oh my god' like, like just like the shock of it and then like this emotional release and then we were crying and then we were laughing at like the balloon it was just a very weird, weird moment. (P5, Transplant/Outpatient Nurse, Interview 2)

This story suggests how the particular social circumstances of this family added an additional layer of difficulty onto an already overwhelming caregiving task, and highlights how the nurses must cater their caregiving and be knowledgeable of the social circumstances of each family they care for. In this case, P5 had to balance comforting the mother, tending to the body, waiting for the death certificate to be received through their social services, and help coordinate moving the body to their mosque in accordance with their religious beliefs. Her story also highlights the difficulty of balancing the science and art of providing postmortem care, which requires attending to the physical body (and its state of decomposition) and helping the parents cope with the death, grieve, and make arrangements. P5 went on to tell me that during the preparation of the body, she felt fine. However, after processing what had happened, she realized that she had been traumatized by the experience: "I was not fine for like weeks and months after. And it took me a while to like, come to terms with everything that sort of happened and, you know like I definitely needed some therapy for that". It was evident that being thrown into providing postmortem care with no experience, training, or preparation was incredibly distressing and had enduring effects.

Many of the other nurses' stories about providing palliative and post-mortem care similarly acknowledged that they felt unsupported, or that they had heard stories about other nurses who were not sufficiently prepared or trained to provide care for a palliative child. Many of the nurses identified that nursing education and training organizations do not "do enough teaching and support for new nurses" (P4, Inpatient Nurse, Interview 2)

with regard to death and dying. The nurses conveyed that they didn't learn how to provide care for palliative patients until they were thrown into caring for palliative patients with no experience. Their narratives also suggested that they rely on the help and mentorship of older nurses who supported them through caring for these dying patients, because the older nurses remembered what it was like to care for their first dying patient with little knowledge and experience.

The stories also revealed how the nurses bonded together in moments of nursing a child through dying and after death. To illustrate this, P8 told me how after a child she and her coworkers had cared for died, they sat together, talking about their experiences with this child. In doing so, they were able to share their stories about the patient and support each other through their grief:

> My coworkers are really good. Um, there was one night that, the four of us were there when this one girl died the girl that I pronounced. We sat afterwards after they had taken her body away and we all just talked. We just talked for like three hours. *We told stories about her we t- we talked how this night WENT, we talked about the first time we had each met her and all our experiences with her and the families. Like I've mentioned before my coworkers are AN AMAZING support group. I'm VERY fortunate and thankful to have them.* (P8, Inpatient Nurse, Interview 1)

She went on to explain that it was difficult at first to come to terms with a child dying. But, over time, it became easier, largely in part because of the support she felt from her fellow nurses. Many of them, on account of forming close working relationships, become good friends in life, and were able to continue to support each other beyond the walls of the hospital and in other aspects of their lives:

> Yeah so it's – again that's taken some learning and I've gotten better with it over time. *But being able to get together with my coworkers talking with my coworkers, getting drunk, eating a whole pizza, having, a bowl of ice cream, g-going for a run doing yoga whatever it is that's needed in the moment, whether it IS going toooo um, a pub or going out with my coworkers and we talk a bunch um, we just have a good time and let loose and let everything go.* That might be what we need to help, get over this, patient this period of time that's, been difficult for us and move on to the next one. (P8, Inpatient Nurse, Interview 1)

Overall, the nurses' narratives suggested that their relationships with one another are influenced by their being bonded by trauma. The narratives of being united in their experiences of chronic and acute trauma shows how nurses manage to develop and maintain resilience to withstand difficult working conditions and trying emotional situations in the absence of support and training. Bonding through acute and chronic traumas sometimes resulted in the transformation of their close professional relationships into friendships that extended beyond their work contexts. These professional and personal relationships helped the nurses stay afloat by mediating support from colleagues with insider understandings of the institutionally constraining and emotionally taxing nature of pediatric oncology caregiving.

6.4   Caregiving and Narrative Repair

In the previous themes, I explored how the nurses, through their sustained physical and narrative proximity to patients and families, come to bear witness to their patient's and families' suffering and to their stories. As a result, the nurses become integrated into the family's cancer story. In this theme, I explore the ways in which the nurses conduct narrative repair as part of their caregiving for patients and families. As I reviewed earlier, narrative repair, as conceptualized by Arthur Frank (2013), is a way in which individuals who have experienced chronic or life-threatening illness repair the "wreckage" that is left behind by the ruptures to their identities and biographies through storytelling and narrative means. In this theme, I extend this notion of narrative repair in three ways. First, I outline how the nurses resolved their caregiving narratives when their narrative proximity to their patients and families ends abruptly, or without the nurses resolving their own caregiving narrative. Second, I describe how the nurses' caregiving facilitates narrative repair for the family in situations when their child dies. Third, I discuss how the nurses engaged in narrative repair of their fractured moral identities resulting from their moral distress.

6.4.1   Resolving Caregiving Narratives

As I described in Bearing Witness, when a family's biography has been disrupted by their child's cancer, the nurses become entwined in the family's story and may even become

characters in the family's story. Eventually, the nurses' roles as characters in the families' cancer stories waned or ended, as their patients went into remission, or when treatment was unsuccessful and their patients died. The nurses' narratives highlighted that successful treatment with families was their goal and brought them tremendous joy; this was the hoped-for happy ending to their caregiving story. For example, P1's narration highlighted that seeing the families come in for follow-ups allowed the nurses to bear witness to the resolution of the family's cancer story, which was facilitated, in part, by her caregiving:

> Ummmm the MOST rewarding part is dealing, uh with the families! So you, meet families on like, pretty much the worst day of their entire lives. And then you see them go through, the most, CHALLENGING experience and then a LOT of the time you get to see them, literally grow up in front of you. And you see them, rise, and you see, um, families seem very resilient and, get through an experience that, really no one should have to go through. *Um, ye-yeah you get to meet a really, you get to, experience a part of their lives, that's so challenging but hopefully, I can be a positive, um support person, throughout that experience to make that transition a little easier for them. Um, and then when you get to see them after, when they're, when all that experience is done and they come back and they see you on follow-up visits, it's just, it's SO NICE to see those families.* (P1, Outpatient Nurse Manager, Interview 1)

Many of the nurses, however, mentioned that they could not be present for follow-up visits or see the families when they returned for check-ups, thus leaving their caregiving narratives without resolve. In these instances, the nurses' narratives suggested that they find alternate ways to resolve their caregiving stories.

For example, several nurses described how they volunteered at children's cancer camps in an attempt to resolve their caregiving stories. These camps were designed for children who no longer have cancer, or children who have an easily manageable cancer to have a "normal" camp experience without their diagnoses having bearing on their abilities. P7's narration below highlights how she was able to find a resolution to her caregiving narrative by volunteering at camp during a week when many of her past patients were attending:

> It's so great like, and I went and [coordinator] is so great she sent me on a week where she knew there was a lot of [city] kids going so obviously those [city] kids

know me attached to me but *it was just so, nice to be able to actually like, watch them get ready for the musical [...]* (P7, Inpatient Nurse, Interview 2)

In this example, P7 was able to see an end to the cancer stories of many of her patients. Watching them get ready for the musical and participate in activities unbound by their cancer allowed her to feel good about how her patients' cancer stories had ended. Additionally, watching her past patients participate in something like the musical allowed her to see the result of her caregiving, which assisted her in resolving her own caregiving narrative.

These stories further conveyed that attending camp required the use of their vacation days. The use of their vacation days also highlights the ways in which the nurses take it upon themselves to resolve their caregiving stories. At time same time, the nurses who spoke about camp said this was "worth it" to revitalize their dedication to their work. P3 explained that her use of her vacation days to go to camp was worth it because it motivated her to continue working in pediatric oncology at a time when she was feeling burnt out because of her being stretched too thin among various institutional demands and constraints:

> So you put in a vacation request, you use your, [laughs] your paid vacation time and THEN go to camp to do work so. It's very difficult, from like a, like, balance like work life balance perspective like, how are you supposed to get enough TIME, um, to like care for yourself and take vacation for yourself when you're using vacation to go do work at camp. *Like camp is something that every nurse should be participating in because you see the kids like, on the other side you see them well you see them happy you see them playing. And that really helps with like, I came back from camp every time feeling like refreshed and rejuvenated and seeing like, all the hard work that I did in the hospital was helpful to get the kids to this point.* (P3, Outpatient Nurse, Interview)

Her recommendation that all nurses should go to camp also suggested that the nurses rarely get to engage in forms of narrative repair that provides a resolution to their caregiving stories. Her encouragement of others to attend highlighted that she understood how restorative the experience was for her and her caregiving, and she believed that many nurses would also feel similarly.

The restorative aspects of volunteering at the children's camp was also signaled by other nurses, who described it as "magical" (P5, Outpatient/Transplant Nurse, Interview 2) and who said that they "fell in love with camp [because] it's so nice to see the kids look well" (P7, Inpatient Nurse, Interview 2). Through these descriptions, the nurses suggested that they derive meaning from seeing these children outside of the context of their cancer and are willing to give up their personal time to do so. This was also narrated by P3, who described her feelings of overwhelm from the contrast of witnessing the children severely ill in the hospital, to seeing them living with hair, and the willingness, energy, and ability to dance, swim, play, and act as if they had never had cancer:

> *And I was blown away I was in tears the whole time 'cause I was literally just, like, this place is magic like, I see these kids, so so so so so so sick, in the hospital and then I see them like, wearing their jammies, singing songs at the campfire.* Like closing ceremonies and I'm like losing my mind I see these kids like dancing, um, like doing – we call them FBCs they're full body commitments that's what we call them and there's like, choreographed dances. I'm sure you've heard about this already from, yeah so, they're like choreographed dances to like Bulletproof and *I'm like, there dancing with these kids that were like, very very ill in the hospital and I'm like, crying crying crying like literally like ask my coworkers I was crying all weekend 'cause I just, could not wrap my head around like how special it was.* (P3, Outpatient Nurse, Interview 2)

In another instance, both P5 and the mother of a former teenaged patient were overwhelmed by the "magic" and reparative function of camp. In this case, her care for the teenager at camp allowed her to witness and facilitate the resolution of her caregiving narrative, as well as elements of his story that were believed to have been stripped away by his cancer:

> *I remember we had one kid who got his leg amputated, and his mum did not allow him to swim at all because she just genuinely didn't think that he would be able to swim and she was so worried that he was gunna drown.* And he was a teenager so he kind of knew that, but I remember I was out with him, um, in the canoe one day, and I was like, *I asked him what he really wanted to do and he's like 'ah I really want to like go in the water and go swimming.' He was wearing a life jacket so I was like, 'well why don't you' and he was like 'my mom doesn't want me to' and I was like 'well, that's really unfortunate' and he was like 'yeah.' But he's like, 'but what if the canoe accidentally tipped into the water?' And I was like 'I dunno' so then we just tipped the canoe, and he was in the water swimming having the best time the next day we went out on the water ski boats and we got photos of him like jumping off the boat into the middle of the lake, and his mum*

was just like crying and like freaking out because he just looked so happy. Doing that aaand when he went back home like he ended up doing swimming lessons again and just, was constantly being in the water and that's a lot of things where, I think, parents let their own fears for their children hold them back from kind of experiencing things that just, normal kids should be able to experience. Um, and so [pauses] *to kind of be a part of that and to see these kids outside of the hospital is very special and it's one of those things that like, always fills up my cup and I like, cannot stop smiling when I talk about camp because of that.* (P5, Outpatient/ Transplant Nurse, Interview 1)

Collectively, these stories illustrate how their participation in the children's camps provided them with unique opportunities to witness the children beyond their cancer and resolve their caregiving narratives. These stories also suggest how participation in these camps keeps the nurses engaged with families, which "refreshes" them and keeps them motivated to stay in pediatric oncology, despite their demanding working conditions and lack of support from management.

6.4.2 Narrative Repair During Death and Dying: Facilitating Meaningful Death

While in the examples above, the narrative repair was predominantly oriented towards resolving the nurses' caregiving narratives, the nurses also told stories about how they actively engaged in narrative repair for the families through their caregiving. This was especially evident when a child died or was dying, in which narrative repair involved caregiving tasks that focused on creating meaningful memories and creating tangible items for the family to bring home. In particular, the nurses' descriptions of "legacy building" and "post-mortem care" suggested that these were ways to bring some semblance of repair to a story that was culturally incomprehensible and ended in a way that nobody wanted.

All of the nurses' narratives conveyed their ideas about what constituted a meaningful death for the children they cared for. Their narratives highlighted how they believed that, after bearing witness to the lives of each of their patients and their families through the proximity of their caregiving, they were often able to tell what would make for a good and meaningful death for each patient and family unit. To the nurses, narrative repair for the patients' and families' stories was possible when the family was able to acknowledge

that their child was dying. Under these conditions, the nurses were able to engage in narrative repair by helping to create a meaningful environment for the family. In these cases, nurses acted as "palliative Sherpas" (P2, Inpatient Nurse, Interview 1) who assist the family in traversing an unfamiliar and painful journey. Many of the nurses highlighted that, in order to engage in narrative repair during palliation, time is needed to build relationships with the families and engender trust in the nurses and their abilities, which emerges through the proximal characteristics of their caregiving:

> [a meaningful death is] something that can, give closure and, support to the family. It's, *if someone dies very quickly you don't have that time to kind of build that relationship build that, um, that comfort within the process* it's kind of just dropped on you like, hit by a car. *This is something where the family is able to take more time to kind of rationalize it ACCEPT the fact that their child is going to die.* (P2, Inpatient Nurse, Interview 2)

As discussed previously in Bearing Witness, caring for a child with cancer and their family involves an "evolution of conversations" (P6, Community Travel Nurse, Interview 2). This narrative proximity to, and narrative reciprocity with, families unfolds over time and in relation to the child's prognosis: "First you're just talking about cure, conversations focus to, hope, and then the conversations focus to hope, but now we're, we know there's no cure possible. And you, those – those conversations naturally evolve" (P1, Outpatient Nurse Manager, Interview 2). In this regard, caregiving includes narrative exchanges facilitated by nurses' physical and narrative proximity. In palliative situations, the nurses continue this narrative proximity and literally help the families story their experience of suffering and loss by mobilizing their knowledge of the families and the patient in order to ensure a "good death" for their child. Some of the nurses suggested that, if possible, involving the children in the process was an important feature of facilitating a meaningful death. This included getting the children to "help plan what they want at their funerals or, talk about really amazing things what heaven or whatever the afterlife looks like to them" (P1, Outpatient Nurse Manager, Interview 2). By having the children speak to what they would prefer and imagine their deaths look like, the nurses could mobilize their narratives to make these possibilities a reality and facilitate narrative repair in a way that the child had a hand in constructing.

Engaging in narrative repair for both the child and the family also involved what the nurses referred to as "legacy building". Their narratives about their engagement in legacy building suggested that to do these activities is to provide witness for a life lived, however brief it was. In many of the nurses' stories, legacy building involved creating keepsakes for the family, which provide physical testimony of the child's life after the child has died. These included:

> hand molds and hand prints and, um, families like that is – kind of thing 'cause then they have, *a hand mold of them holding their daughter's hand or of their daughter's foot or, a footprint like you know like baby feet that you put together to make into a heart. That kind of thing. Memories to take home.* (P8, Inpatient Nurse, Interview 2)

This quote powerfully conveys how these memorial objects facilitate ongoing relationships between the family and child and are suggestive of how the nurses' work facilitates these relationships. P5 particularly remembers one family that she helped create hand molds for, and to this day, that hand mold serves as a positive memory for the family. Her narrative highlights how she played a part in facilitating an ongoing playful relationship between her former patient and his sister after he died:

> I jokingly said to him like, 'when your hand's in the mold, you're doing whatever you want you could be making a fist or giving us the middle finger like, we don't know.' And, whatever he did his hand mold right? Aaand, after he had died and, we were preparing like the mold, and funny enough um, he didn't give us the finger *but, when we were doing the molds his middle finger fell off, which like [laughs] was [M laughs] really funny and when [laughs] when we [laughs] told the parents when the parents came to pick it up, like, everyone was laughing hysterically they were like, 'oh my gosh that's so typical of him like, like that is for sure like a joke that he played from like up above because, hhhhhe for like he would've loved for his middle finger to fall off'* like. And, it was just, yeah it was just a funny thing and like, um, and I think *the last time like anyone had any communication with the family like his sister was saying that like any time she has to go and do something that's like, kind of hard or like she needs to be really brave like she takes her brother's middle finger and like puts it in her pocket [laughs] so it's like [laughs] it's just something that's like really funny but really unique to like that family.* (P5, Outpatient/Transplant Nurse, Interview 2)

As part of their narrative repair work, the construction of these physical items sustain the family's narrative of their child after death. This continued narrative is further suggested by other keepsakes such as teddy bears where "patients can record little messages and

like the audio things and, you can then take it to build a bear and like, put it inside a bear" (P5, Outpatient/Transplant Nurse, Interview 2). Constructing the audio recordings for these teddy bears would often become a game for the kids and the nurses – when the nurses were giving the parents some relief, they were "getting the kids involved being like [whispers] 'let's record your parents like a secret message or like a surprise message'" (P5, Outpatient/Transplant Nurse, Interview 2).

Another example of legacy building was memory-making for the child so that they have happy memories of their family and life before they died, and so families can remember their child experiencing happiness and joy before their child died. For one teenage patient, this involved creating "memory boards or vision boards" and "videos and dances and pictures" (P7, Inpatient Nurse, Interview 2). For other families, legacy building focused on sharing stories or memories of their child. The nurses engaged in narrative proximity by encouraging the family to tell their stories about their child: "'Tell me about them. What were they like as a kid? What were they like as a baby what was your pregnancy like with them?' They LOOOOVE, looove talking about their child" (P8, Inpatient Nurse, Interview 2).

P3, in particular, told me a story that highlighted how her understanding of her patient's wishes and the family's narrative made their child's death meaningful. Her story highlights the lengths that nurses go to in order to provide a good death for a child, and the ways in which nurses mobilize their narrative knowledge of the family to do so. For her, it was an example of a "perfect" death, which was "all you could ever hope for":

> *they [parents] wanted to take her to the aquarium and it wasn't gunna happen, and there's this wonderful window between [bone marrow transplant unit] and [other unit]. Huge, huge window. And they decorated it like an aquarium they like drew on like jellyfish and stuff and we were singing like, underwater songs and, oh my god it was amazing.* Um, and then the next day I had her again. And they were all just like sitting in their room we have room [number] which is like our palliative room it's like a, a room with like a family room attached with like couches and stuff so, if they have more family then we they can stay there but um, anyway they were just sitting in the room and I was like 'do you guys want to do something today?' Like, 'let's do something. What do you want to do.' And they were like 'is there like a nice room that we can sit in' I was like 'yes I've got a great idea.' So there's a starlight lounge on the [number] floor. And it's like, it

was like newly renovated at the time – or the [corporate brand] space whatever it's called now. And like, big bright windows, like there's like, um games in there and like PlayStations and like just, toys and toy kitchens whatever huge space. We went up there, and her [laughs] ENTIRE family came too. *You're not supposed to have food and drinks in there but like, I turned a blind eye quite frankly I was like ''kay, sure' like if that's what, no problem like. So they brought like sushi burritos they bought me one like that was my first time eating a sushi burrito and they were laughing at me because I couldn't chew through the, seaweed properly. Um, anyway we had like the music therapist up there [kids cancer camp] came like all the doctors like I called her doctors and I said 'come play up here like we're just having a celebration of life'* she was on like, Midaz [a sedative medication to help with anxiety], and, something else I can't remember but I just remember the, like whenever [patient] she was asleep most of the day but whenever she would wake up, like, the mum would look at me and, be like [whispers] 'is she okay is she okay' and I was like 'yes. Just enjoy' like I just tried to get them to focus on her and the fun and singing the songs and like, I had pressed her Midaz bolus [given her more medication] like every now and again but, most of the time was just like them playing. *Anyway [corporate brand] space closes at 4PM normally so I was like, like I'm not kidding there was like 30 people in this room at this point. I called security and I was like 'can we keep this space open for a little bit longer' they're like 'nope, nope nope we close at 4' and I was like 'listen. This kid is gunna die today or tomorrow like, this is their family's like request. Please make this happen for me.' I fer [laughs] – I was like kind of pushy. Anyway, he's like ''kay I'll call you back' called me back, and he's like 'yupp they can keep it as long as they want'. So they stayed, until, 12:30. They just stayed in the room like singing songs, playing, whatever just having a GREAT great great time like it was literally a celebration of her life. And then at 12:30 they decided they were tired so mum and dad, took her downstairs and mum and dad got into bed and put [patient] between them and, parents fell asleep and she died while they were asleep. And I was like, that is, perfect. Like, that is like, all you can ever hope for*. (P3, Inpatient Nurse, Interview 1)

In addition to creating keepsakes and facilitating a meaningful death, the nurses' narratives suggested that they continued to engage in narrative repair after a child had died. For nurses like P9, a form of narrative repair looked like going to "gravesites with families because they've wanted to show me where their, you know their child is buried now". For inpatient and/or outpatient nurses, hand molds and teddy bears were created while the child was alive and were prepared for families to take home to remember their child. Through their narrative proximity, the nurses facilitated these memorial acts as part of their caregiving and in effort to repair the family's narrative.

6.4.3 Narrative Repair and Moral Distress: Restoring Moral Identities

In comparison to stories above, where I focus on the ways in which the nurses' caregiving sought to repair the family's narrative through legacy building and facilitating meaningful death, the nurses' narratives also showed how they restored their own identities in response to situations that compromised their moral identities when they were unable to uphold their moral responsibilities to patients and families. Instances when families were unaccepting of child's death brought this into sharp relief because nurses were not able to act on a patient's behalf, which left them feeling as though they could not fulfill their moral identities and enact their moral responsibilities.

In these cases, the nurses felt unable to provide care in a way that would facilitate a meaningful death and assist in repairing the family's narrative, which furthered their feelings of moral distress. The nurses' narratives suggested that their distress stemmed from their inability to maintain moral proximity to the patient and family, mobilize their narrative knowledge of patient and family, and contribute to the family's narrative in a way they felt was meaningful. In addition, there were times when the nurses were forced to provide care and life sustaining measures in way that fractured their moral identities, and therefore deepened their feelings of distress.

In the interviews, many stories were shared about patients who had Do Not Resuscitate (DNR) forms signed for them, but when their heart stopped, their parents changed their minds and demanded cardiopulmonary resuscitation (CPR). For example, P5 highlights how this puts nurses in situations where they are unable to be morally proximal to their patients and facilitate a meaningful and peaceful death:

> *we plan to have this like super peaceful you know death, when the patient dies the parents are immediately like 'do CPR do this do that' grandma's on the floor like crying in a ball* like there's like, they're like immediately withdrawing like all of the things that they've consented to and *now they're asking you to do CPR so now you're performing CPR for like, 45 minutes to an hour* (P5, Outpatient/Transplant Nurse, Interview 2)

In these instances, the nurses' narratives suggested that their moral identities were affected by being unable to be morally proximal to the child. They described feeling as

though they were bringing the children back to life to be in pain, which was inconsistent with their ideal nursing identity and goals for care. While these stories were distressing to hear, the story that was the most striking was P8's story of a girl who had cancer for eight out of the ten years of her life, who had been palliative for a long time, and whose father could not accept that she was dying. This father forced the nurses to perform CPR when his daughter's heart stopped. P8 had provided care to this girl for the majority of the girl's life, and witnessing her colleagues attempt to bring her back to life was not the way in which P8 believed the patient's story should have ended. While her narrative reflected many of the sentiments shared by other participants, as an outsider, I found this story shocking. I spent the rest of the day thinking about this patient and the end of her life, realizing that if simply hearing this story made me this upset, I could not imagine how distressed the nurses who cared for this patient until her end must have felt. Through hearing this narrative, I could feel P8's despondency about how this girl was treated at the end of her life, how her colleagues' insertion into the family's illness narrative was distressing and misaligned with their goals and intent, and how their involvement in the end of this family's illness narrative left lasting marks – both on the girl's body, and on the nurses' perceptions of the care they provided:

> Dad did not want to give up [….] She had been battling cancer for eight and a half years she was diagnosed when she was two she was ten and a half when she died. So, her whole life has been cancer. It was very sad. Very very sad. She constantly looked sick. And we knew she was gunna die. It was passed on to family, everyone knew she was gunna die but the dad never wanted to let go. So instead of giving her the pain medication that would've made her comfortable and letting her go to sleep and never wake up, she, died while she was on the toilet. We thrust her back in bed, we did, a FULL ROUND of everything so we're like breaking her ribs 'cause we're doing CPR. We're giving her the meds that she needs to get her heart beating even though it's not beating on its own, because dad couldn't find closure. *I didn't agree with that but, it's not my place to say it's not my choice. I would've, because I think, we can make death such a beautiful thing, as as twisted and weird as that sounds. We can make them comfortable where, their last memory is being h-held by their parents and, and singing their favourite songs or watching their favourite show cuddling in bed with mom and dad. Having, their dog come and sit on their lap. We can make that their last memories before they go, or the families' last memories of them. Not their body bruised and broken, because of, us trying. That's what family wanted so that's what we did, but I just didn't agree.* (P8, Inpatient Nurse, Interview 1)

Through her telling of this story, I suggest that P8 was engaging in a form of narrative repair to her own nursing identity, which was damaged by having to provide lifesaving measures that she felt were harmful to the patient and that conflicted with her moral responsibilities and ideas of good caregiving. In this sense, the interview situation provided a narrative space for P8 to describe the conditions surrounding this patient's death, how the parents' desires conflicted with what she and her colleagues thought was best for this girl, and how this girl's death affected her and her colleagues. The moral distress experienced by P8 is contrasted with an alternative narrative in which the nurses could have enacted their moral responsibilities by facilitating a peaceful passing. In asserting this alternative vision, P8 restores her caregiving identity and defines a meaningful death as one where the child may be medicated, but is free of pain, able to spend time with their family, and feels comfortable as they die. P8 went on to disclose that this case was very difficult for the nurses to cope with, even after the child had died. She noted that many of them went to the visitation and could still see the bruises that were left on her body from them performing CPR – a distressing reminder of their last morally conflicted caregiving interaction with this child.

One of the nurse's stories also illustrated how she engaged in narrative repair to address the moral distress she experienced in relation to a patient's sudden death, which left her with little time to address the difficult relationship she had with this patient. In this lengthy story shared by P3, the patient died on another nurse's shift, which meant that P3 was unable to address difficulties she experienced with the patient, leaving her with a fractured moral identity. P3 shared an emotional, "full circle" story which detailed how she was unable to give the patient the care she needed because of competing workload demands. These various caregiving responsibilities meant that she had insufficient time to spend with her patient, who perceived this as P3 not caring about her. Ultimately, P3 had to reorient her attention to other more urgent needs, and before she could reconcile with that patient on a different day, the patient died. As this lengthy and emotionally fraught passage suggests, being unable to "fix" her relationship with this patient was the source of incredible moral distress for P3 who left her position in inpatient oncology shortly after the patient's death:

I had this one patient in induction she was like, obviously brand new very anxious. Um, trying to get her to take steroids was just a nightmareeee like, it was just, get like her meds, she was like throwing them just, not cooperative I was trying to do her blood pressure and just, you know taking vitals took her like a half an hour and I was just like 'I have two other kids like I don't have time for this.' Like I literally said like, 'okay like, like, why don't you call me when you're ready because I don't have time for this' like I literally said that [sniffles]. And sheeee, and anyway I like pulled her mom out of the room and I was like 'I'm really sorry I'm really frustrated can can you help me like help me, you know find a way to connect with her easier like I just this is not like working well and I want to have a good day with her and I want you know', and she's like 'she thinks that you don't care about her.' That's what the mum said 'she thinks you don't care about her she thinks that you're rushing her she thinks you don't care about her.' And I was like 'I do, I like I so do but I'm I'm just, tied. Like I'm just tight for time and I have two other kids' and, you know if I had [pause] more time then I could've been more patient and I could've done things a little bit differently and I could've like changed the way I approached it and not been so pushy but I just, I didn't have time. Um, and my meds were late for the other kids like I just, I knew that I had, you have a set amount of time that you can be with these kids. Anyway [pause] I didn't have her again like that was like the second day I had had her in a row or something I didn't have her again but, I think it was day 17 or day, under day 20 basically sheeee um *I was coming out of day shift and at 6:30am she called out [pauses] for a nurse saying she couldn't see. Um [pause] and they tried to like do her blood pressure and couldn't get a blood pressure couldn't feel peripheral pulses, she was in DIC she um, like ended up having fasciitis and, um, she went septic from [pause] her bowels leaking and, she died. They did CPR down in ICU for fifteen minutes and she died. And I, couldn't fix my relationship with her. Um [pauses, becomes emotional] I was so upset, like [starts crying] for so long about that [cries].* Anyway that was the night I applied to [kids cancer camp] and I took um [pauses] like a secondment through [hospital] so I'm still gunna be on inpatient oncology unit um, once like, a week or once every two weeks but I just needed to go like *I just needed, a break and I felt like [sniffles] I was at the point where I couldn't be the nurse that I wanted to be 'cause I just I was so [sniffles] like frustrated with the timing and like the workload and I just like I couldn't be the nurse that I wanted to be and I couldn't fix it with [sniffles] [patient].* (P3, Outpatient Nurse, Interview 1)

Through her repeated mentioning of "not being the nurse she wanted to be", P3 suggested that she experienced moral distress constantly in her caregiving, and that this extreme situation pushed her to a breaking point. Over time, her identity as the nurse she wanted to be was becoming fractured, and this scenario, in which she was unable to repair her relationship with the patient, was the catalyst for leaving inpatient pediatric oncology and changing her work environment to outpatient pediatric oncology nursing.

At the end of this narration, P3 mentioned working at a children's cancer camp to get away from her unit. In a "serendipitous" interaction, P3 was able to speak to the mother of this girl who died and share the lessons she learned from caring for her daughter. As this passage suggests, sharing her story with the mother was reparative in the sense that it enabled her to restore her caregiver identity by making amends for the damage that she was unable to address while her daughter was alive:

> *Um, anyway this is kind of like serendipitous but when I was at [kids cancer camp], [sniffles] I decided I wanted to do a palliative [....] so I took a palliative course when I was [kids cancer camp]* I was, one of the nurse coordinators, um there for a year and [sniffles] um, the palliative course is children's grief and bereavement course. It was a five-day, certificate course. On day three, you – people can come and go like you don't have to do the whole um [clicks tongue] the whole week but I chose to and on day three uuuum the room was kind of set up like a U. And, *I heard this mum talking, um, saying you know, 'hi my name's [mom] I'm [pauses, sniffles] here because I'm trying to like, find ways to work with my son to help him deal with our you know my daughter's death better. She was eleven years old. Died of leukemia in induction' and I just leaned over and I saw her face and I was like [whispers] 'oh my god.' [returns to normal voice]* Went to the bathroom, had a, absolute meltdown [pauses] and um, she's like she was my trigger to leave [inpatient unit] like that was for me, when I realized I needed to, take a step back and [sniffles]. Anyway I spoke to her at the end of the day I – the whole day I was I couldn't focus on the course I was like, like 'oh my god oh my god like what do I do?' [sniffles] Anyway *at the end of the day I went to her and I was like '[name] I don't know if you remember me but I was [patient]'s nurse' and she was like 'yeah of course I remember you [daughter/patient] didn't like you'. That's what she said [laughs] right away. [sniffles] I was like 'yeah I know' and like anyway I cried to [mom] and I was like 'I just need to tell you that like I really learned a lot from your daughter and [pauses] I really um, took what you said to heart and I really, um, am trying to be more patient with anxious children because you don't know, you know when, what will happen you don't know if you can fix it and I just I never want a kid to feel that I never, I didn't care about them'.* Um, soooo, anyway she was like 'I'm so happy [patient] could give that to you like that's a gift that she was able to give to you' and, she said like 'this is meant to be it was meant to be' that we like, met up in this way so that you know, we could talk, and like, kind of like rehash and she was asking me about, stuff, about [patient] and like you know 'what did this mean when they said this and this and this' but it was so I think therapeutic for both of us in that, um, I really think that that was like, meant to happen as like a, full circle, for me. (P3, Outpatient Nurse, Interview 1)

By sharing her story and the lessons she learned from her conversation with this parent, P3 finally had an opportunity to narratively repair ruptures in her nursing identity and in

her relationship with the deceased child's mother, which were influenced by being stretched too thin and which resulted in a morally distressing and unresolved situation. As with the previous example, I suggest that our interview also acted as a narrative space for P3 to engage in narrative repair of her identity and her caregiving story. Before beginning her narration, she told me that she had never told anyone this story before. In having the opportunity to tell me this story, she was able to revisit her caregiving story in order to repair the significant rupture in her moral identity that occurred during her time in inpatient oncology.

In conclusion, the stories in this theme illustrate how, after a prolonged period of sustained proximity and bearing witness to a family's illness narrative, nurses can become active characters in the family's cancer story who attempt to resolve and repair the family's narrative, as well as their own caregiving narratives and caregiver identities. When the children they cared for entered remission and their involvement with the families ended, some of the nurses sought to resolve their caregiving stories by attending a children's cancer camp. In instances where the child was palliative, nurses strove to engage in narrative repair for the family by actively mobilizing the families' narratives to make their child's death as meaningful as possible. However, in instances where nurses were prevented from facilitating meaningful death, contributing meaningfully to the family's narrative during and after the child's death, and thus from maintaining moral proximity to patients and families, the nurses experienced ruptures in their caregiving stories and fractures to their moral identities, and experienced great moral distress as a result. Through the telling of their stories in the interviews these nurses engage in narrative repair to restore their identities as the nurse they want to be.

6.5   Conclusion

In this chapter, I have presented four narrative themes that describe what it is like and means to be a pediatric oncology nurse, and how these experiences were shaped within particular institutional contexts and in relation to idealized constructions of being a "good nurse". These narrative themes illustrate the ways in which these nurses experience moral distress as a result of being stretched too thin by competing caregiving demands and constraints, and in corporatized institutional contexts that place little value on the

relational aspects of their caregiving. These themes suggest that the physical, narrative, and moral proximity of their caregiving made their work meaningful, yet it could also heighten their experiences of moral distress as witnesses of suffering, particularly when they were pulled in many directions and were unable to enact their moral responsibilities to their patients. In bearing witness to the patients' and families' stories, and by taking part in narrative proximity and reciprocity, the nurses were able to help the families engage in narrative repair. Finally, the nurses' caregiving stories also showed how they engaged in narrative repair to heal the fractures made to their moral identities in instances where they could not be the nurse they wanted to be.

Chapter 7

7   Discussion

The purpose of this study was to use critical narrative methodology to examine how nine pediatric oncology nurses narrated their experiences of pediatric cancer caregiving. Using this methodology, I analyzed the content of their stories of caregiving, identified the complexities and ambivalences revealed in their storytelling about caregiving, and illuminated the meanings they associate with particular kinds of care. By drawing on the concepts of moral distress, bearing witness and narrative repair, I identified themes and counterstories across and within the participants' narratives in order to interpret how pediatric oncology nurses' experiences of caregiving are situated within and influenced by their work environments, how they construct their moral identities in relation to idealized nursing identities, and how they struggle to perform a variety of caregiving tasks and attend to the diverse needs of patients and their families within their hectic work environments. These themes and counterstories illuminate how the study participants strived to be the nurses they want to be by helping their patients and families restore their damaged narratives, and how they assign meaning to caregiving that is rendered invisible by their institutional contexts, which are shaped by the broader contexts of health care corporatization and neoliberal ideologies. The narrative themes and counterstories provide insight into how these broader institutional contexts prevented them from "being the nurse" they "want to be" and the ways in which they restored their fractured moral identities and relationships and enact their moral responsibilities.

In this chapter, I continue to analyze the research findings in relation to the broader contexts of health care corporatization and neoliberal ideologies, in order to gain a deeper understanding of how the nurses narratives reproduced, challenged, and/or otherwise navigated these broader contexts. As well, I consider how the study findings contribute to research on pediatric oncology nurses' caregiving experiences (Chapter 2) and how they extend theoretical insights provided by conceptualizations of moral distress, bearing witness, and narrative repair (Chapter 3). I begin by discussing how the critical narrative methodology employed in this study contributes to our understanding of how neoliberal

ideologies and the increased corporatization of health care had bearing on the nurses'
experiences of moral distress, and how the participants' stories draw attention and
ascribed meaning to forms of caregiving that are often rendered invisible by their
institutions. I then discuss how the stories generated by my critical narrative methodology
contribute to scholarship on moral distress, with a particular focus on how they provide
narrative depth to Peter & Liaschenko's (2013) theorization of moral distress in relation
to nurses' moral identities, moral relationships, and moral responsibilities. From there, I
outline how my findings challenge individualized conceptualizations of bearing witness
and how the nurses in my study often felt constrained in their ability to be morally
proximal and enact their moral responsibilities to their patients. Lastly, I illuminate how
my study extends Frank's (2013) conceptualization of narrative repair to illustrate how it
can be a fruitful way of thinking about caregiving for chronic illness and caregiver
identities. In particular, I focus on narrative repair as engrained within caregiving and as a
way of restor(y)ing identities through counterstories.

7.1 Neoliberal Ideologies and Health Care Corporatization: Invisible Care, Counterstories, and Compensating Within an Under-Resourced System

The narratives generated by this study provide rich examples of the moral conflicts that
nurses experience in pediatric oncology nursing as they navigate their caregiving
responsibilities within broader institutional contexts that are shaped by neoliberal
ideologies and corporatized health care priorities. While the nurses in my study did not
address "corporatization" or "neoliberalism" explicitly in their narratives, their stories
consistently highlighted how their increased accountability to their institutional priorities
of cost-efficiency (reflected in understaffing), and technologically-driven, curative care
fractured their moral identities.

The nurses' stories of being stretched too thin revealed the ways in which they had to
constantly reorient their caregiving priorities in relation to understaffed work
environments in order to attend to patients' immediate needs, as well as to apply and
maintain particular technologies for their patients. This reflects Krol and Lavoie's (2013)
observation that nurses spend a significant amount of their time "checking on devices,

watching monitors, and charting vital signs. They regularly interrupt care to respond to numerous alarms or to adjust the parameters of the instruments" (Krol & Lavoie, 2013, p.115; see also Sandelowski, 2002). In contrast to this emphasis on technologized, cure-oriented care, the nurses' narrative descriptions of their caregiving in my study consistently drew attention to aspects of their caregiving that are rendered invisible by their institutions. In particular, their counterstories illuminated the care that institutional discourses render invisible, including "practices such as listening, touching, taking the time to talk with a patient, instilling trust, fostering self-expression and the expression of emotions" (Krol & Lavoie, 2013, p.115). These relational forms of care are what often characterize nursing practice (Nyström et al., 2003, Wang et al., 2009). As my findings suggest, having the time to be physically and narratively proximal to a patient, and thus to bear witness to a patient, becomes increasingly difficult to do because these tasks are unrecognizable as valuable within a system that prioritizes efficiency and accountability for performing technological tasks over relational care:

> The current health care rhetoric of efficiency and scarcity, in relation to considerations of justice and resource allocation, undermines nurses' ability to engage in meaningful relationships with persons they care for (Naef, 2006, p.153)

My position as an outsider researcher with no training in nursing drew my attention to the ways in which the nurses who participated in this study downplayed this technologized form of caregiving, such as giving chemotherapy or other treatments. The downplaying and relative invisibility of technological tasks in the participants' narratives may reflect their assumptions that outsiders, like me, are assumed to be already familiar with, and thus place value on, care that is cure-oriented and technologically driven. This is suggestive of the ways that master narratives (i.e., "normative discourses" (Bamberg, 2004, p.331)), such as those that emphasize health care heroes who use technology to cure their patients, shape public perceptions of pediatric cancer. As I reviewed earlier, these master narratives circulate broadly in public discourse through corporate-driven fundraising campaigns, including the *Sick Kids VS*. campaign sponsored by the Sick Kids Foundation (Sick Kids, 2017; Szigeti & Hamr, 2018).

To counter these master narratives on technologized, curative care, most of the nurses spent almost the entirety of their interviews highlighting the relational care that they provide to both their patients and families. These stories made visible the ways in which their caregiving involves relational care and emotional support for the family, for example in their stories about taking time to learn dances with the patients, learn and celebrate important dates to the families such as birthdays and anniversaries, do arts and crafts, or sit and eat ice cream with the patients, and emotionally support the parents. By focusing on the care they ascribe meaning to and forms of care undervalued by their institutions, these counterstories resist the ways in which public narratives on sick children almost exclusively focus on the survival and "happy endings" to children's cancer stories, as well as technological success in achieving survival and the heroism of the health care providers using technology to cure their patients. These caregiving counterstories highlight the relational, patient- and family-centered forms of care that are foundational to upholding their moral responsibilities to their patients and maintaining the integrity of their moral identities. While these forms of care may be noted in institutional mission and vision statements that emphasize patient-centeredness, the nurses' stories suggest that these are often not supported at the level of practice. As Cantrell (2011) notes, it is this art of pediatric oncology nursing that is often overlooked, and that is necessary to facilitate the science of administering treatment protocols and medical procedures. Through their engagement in the narrative space of their interviews with me, the nurses spent hours describing the caregiving responsibilities that bring them a sense of meaning and reward and even joy on some occasions, but which are often disregarded and taken for granted by their institutions.

The nurses' stories and storytelling were often characterized by ambivalence and ambiguity, which provides further insight into their moral distress and the ways in which they experienced burnout. In particular, many of the nurses commented on their poor working conditions, having to constantly reorient caregiving tasks, and the lack of support by their management, but simultaneously highlighted their love of providing relational care and how meaningful and rewarding it was to them to provide care. Their experiences and stories of burnout are consistent with the findings of Davis, Lind, & Sorensen (2013), who argue that, for oncology nurses, "the effects of workplace social

context have a significant impact on […] burnout syndrome" (p. E304; see also Lee & Akhtar, 2011). This societal context includes undervaluing of nurses by management, conflicts with other staff and management, and a negative social space in which to provide nursing care, which all contribute to burnout (Bartholdson et al., 2016; Davis, Lind, & Sorensen, 2013; Leiter & Maslach, 1988). My findings further suggest the ways in which distress and burnout is informed by the experience of how nurses must constantly pivot between caregiving tasks and other responsibilities that suddenly become urgent, such as a child becoming septic. The nurses' care that is foundational to their moral identities is undervalued, without recognition, and regularly interrupted in order to respond to more pressing caregiving tasks that may have immediate consequences (Alasad, 2002; Almerud et al., 2009; Bennett, 2010; Krol & Lavoie, 2013).

There were several occasions in which the participants' stories suggested that their moral distress is informed by the ways in which they must compensate for chronic understaffing and high turnover in their units. In their discussions of their caregiving responsibilities, including the coordination work they do, the nurses drew attention to the ways in which their caregiving responsibilities further expand with a lack of administrative support. In particular, their stories of relying on parents for caregiving tasks, or spending hours working between patients, families, and different members of the care team to get appointments or consults scheduled, are indicative of how the nurses compensate for shortages in nursing and support staff. Further, it became evident that this compensation for understaffing had become an engrained feature of their caregiving work. This was reflected by P4, who acknowledged that if it were not for the nurses, "nothing would get done". Compensating for this understaffing seemed to become internalized by the nurses, which in turn left their poor working conditions unquestioned. Even though the nurses' stories of distress drew attention to their poor working conditions and unsurmountable caregiving demands, they simultaneously internalized the blame for not being able to compensate for system shortages and blind spots because they were driven by idealized moral identities. This was evident in the story shared by P3, who discussed always feeling as though she "could've done better" when finishing her shifts in inpatient, even though she knew that her caregiving demands were overwhelming. Through this internalization of blame, the nurses inadvertently maintain the idea that the management

and resolution of their moral distress is an individual responsibility, thereby reinforcing neoliberal individualization of responsibility for the provision of "good care".

The study findings complicate, contextualize, and challenge individualized understandings of moral distress reported in the pediatric oncology literature. Many of the specific features of moral distress noted in the nurses' stories have been reported in this body of literature. In contrast to studies that focus on nurses' experiences of stress, moral distress links individual experiences with broader contexts, including: inadequate time with patients (e.g., Lazzarin, Biondi, & Di Mauro, 2012; Ventovaara et al., 2021; Pergert et al., 2018); witnessing patients suffer or not being included in decision-making and caregiving at the end of a patient's life (e.g., Lazzarin, Biondi, & Di Mauro, 2012; Pye, 2014); being unsupported by management (e.g., Pye, 2014; Ventovaara et al., 2021); and conflict with colleagues or families (e.g., Pergert et al., 2018; Pye, 2014). As I suggested in Chapter 2, research on pediatric oncology caregiving tends to view occupational challenges, particularly stress, burnout, and grief, as an individualized and decontextualized experience through its reliance on quantitative and uncritical qualitative methodologies (e.g., Hinds et al., 1990; Lee & Akhtar, 2011). In this body of research, the individualized framing of these occupational challenges is reflected in the individualized approaches that researchers recommend to resolve stress, such as seeking resources or asking for help (e.g., Sullivan et al., 2019). The narrative findings presented in this thesis align with research that identifies the institutional roots of moral distress (Liaschenko & Peter, 2004; McDaniel, 1997, 1998; Olson, 1995, 2002; Olson and Hooke, 1988; Peter & Liaschenko, 2004, 2013; Rodney et al., 2002; Varcoe et al., 2004; Weiss et al., 2002), and provides rich stories of how nurses experience their moral conflicts and strive to revalue relational care. In particular, the caregiving narratives generated by the critical narrative approach used in this study "diagnose" the cause of pediatric oncology nurses' moral distress as a manifestation of chronic shortages and faults in the health care system and unresponsive management, which is compounded by the acute traumas of the specific stresses of pediatric oncology nursing.

The nurses' counterstories and narrative themes also challenge individualized definitions of moral distress advanced by professional organizations. For example, in their document

Ethics in Practice for Registered Nurses, the Canadian Nurses' Association (2002) outlines steps to mitigate moral distress, which includes asking nurses to "recognize" their moral distress, "refer" to the Canadian Nurses' Association Code of Ethics, and "request" help for themselves (Canadian Nurses' Association, 2003). The nurses' stories of moral distress directly counter these individualized approaches by locating nurse's distress, in part, in their working conditions and with management who do not respond to their requests for assistance. This was evident in the nurses' stories of asking for help from management to protect against abusive parents, or for additional resources and debriefs after their traumatic experiences.

7.2 Ambivalence and Fractured Moral Identities: Idealized Identities Versus Workplace Realities

The narrative findings lend further insight into how moral distress is experienced by pediatric oncology nurses and provide empirical depth to theoretical conceptualizations of moral distress. In particular, the narratives of moral distress generated by the current study situate individual experiences in broader contexts and provide rich narrative illustrations of Peter & Liaschenko's (2013) theorization of moral distress in "moral terms", that is, in relation to moral identities, relationships, and responsibilities.

The critical narrative approach used in this study also allowed for participants to narrate the many ambivalences and ambiguities that characterized their caregiving. The centrality of these ambivalences in their narratives challenges the idea of a coherent self and speaks to the ways in which the idealized moral identity they strove for was not attainable (Borland, 1991; Gergen & Gergen, 1983; Hartman, 2015; Ochberg, 2003). Drawing on Hartman's (2015) conceptualization of "strong multiplicities", which is rooted in postmodern assumptions that there is no one singular identity, I interpreted the ambiguities and ambivalences in the nurses' stories as instances of multiple expressions of the self. Hartman also argues that in the context of an interview (or in my case, multiple interviews), the relationship between the narrator and the researcher evolves, allowing the participants to share "a broader range of emotions and/or perspectives than they had been aware of before the interview began" (Hartman, 2015, p.26). This helped me understand that what I originally viewed as conflicts and tensions in the nurses'

stories were, in fact, ambivalences that were central to their experiences of caregiving and moral distress. In particular, the tensions and ambivalences that I analyzed were expressions that reflected inconsistences between the nurse they aspired to be and the nurse they were required to be given their institutional constraints.

The nurses' caregiving narratives illustrate how their moral identities were often fractured and incommensurate with their idealized nursing identities as a result of their institutional demands and the difficulty of attending to all of their caregiving tasks. As discussed throughout my findings, many of the nurses felt as though they could not be "the nurse" they "wanted to be", suggesting that they had an idealized moral identity that they were unable to attain. The stories collected in this study provide numerous examples of the ideal pediatric oncology nurse – a nurse that was "a kind caregiver […] and a virtuous healer" (Peter & Liaschenko, 2013, p.339) who has a "holistic, caring approach" (Kelly, 1992, p.10). As I explored in Chapter 6, the ideal nurse is narrated as someone who provides care by spending significant amounts of time with their patients, who gets to know their patients and families through their narrative proximity, who bears witness to their suffering and stories, who mobilizes their narrative knowledge to support patients and families with diverse care needs throughout the cancer care trajectory, and who remains morally proximal to the patient in order to advocate for them.

The study findings suggest that nurses, driven by their fractured moral identities and moral responsibilities to their patients, will use their unpaid work time, as well as personal time and resources (e.g., by working during lunch or past shift) to ensure that they provide quality care and enact their moral identities as the nurses they want to be. The nurses' stories conveyed that in their day-to-day caregiving, they are compensating for an under-resourced system designed for technology, cure, and efficiency, but they are not well supported in the work they do to engage in the caregiving responsibilities they see as foundational to their moral identities. As well, these stories speak to the ways in which the nurses' caregiving tasks are always left incomplete, as they never have enough time to fully engage in these forms of relational caregiving.

The ambivalences that were central to the nurses' storytelling further illustrate how corporatized health care settings capitalize on nurses' fractured moral identities. The nurses' stories often conveyed that while their working conditions were not good, the relationships they built with the patients and their families are what kept them working within pediatric oncology; they felt guilty for wanting to leave pediatric oncology because of the relationships they had built with patients and families through their caregiving. This ambivalence is beneficial for institutions because nurses will remain tethered to families and fulfill these additional, undervalued responsibilities without recognition, which maintains the status quo. The findings suggest the ways in which the idealized identities promoted by nursing education function to encourage nurses to strive to fulfill their caregiving tasks without recognition and to withstand unsupportive working conditions.

The present and persistent findings regarding the incommensurability of nurses' idealized identities with the realities of nursing practice have been identified previously in the nursing literature and highlights that this is a consistent (yet still unmitigated) issue in many nursing contexts (e.g., Buckham & McGrath, 1983; Cohen, 1981; Kelly, 1992, 1998; Meha, 1988; Peter & Liaschenko, 2013). In particular, the present findings are reflective of Kelly's (1992, 1998) research on nursing students' ethical identities from training to practice. Kelly (1998) found that nurses were unable to live up to the "respectful" and "caring" nursing identity they had learned about in training and aspired to be due to the harried working conditions they were attempting to provide care within. She highlighted that the nurses in her study were often facing:

> the stresses of trying to be good nurses under frightening conditions, inadequate staffing, 'finish their work on time' despite their inexperience, care for 'too many' acutely ill patients, and perceived a lack of support from both coworkers and nursing management (p.1138).

Similar to the moral dilemma highlighted by Kelly (1998), the nurses in my study provided narrative evidence of how they were torn between their desires to be the nurse they "wanted to be" and having to attend to numerous competing tasks and institutional demands, which rendered them unable to enact their moral responsibilities, thus fracturing their moral identities and causing moral distress. The findings further suggest

that moral distress was particularly pronounced for junior nurses. The stories presented in Chapter 6 provide examples of the ways in which chronic staff shortages lead to situations where inexperienced nurses must shoulder a great deal of responsibility before they are sufficiently prepared and trained. Their lack of experience and relationships early on in their pediatric oncology nursing careers, coupled with expectations of idealized nursing identities forged through nursing education, means that junior nurses are likely to internalize blame for situations that are produced by structural constraints. In addition to causing moral distress, some of the stories were suggestive of how these situations may compromise patient safety, a finding supported by other studies (Kostak, Mutlu & Bilsel, 2014; Mirlashari, Warnock & Jahanbani, 2017).

7.3 Broken Trust and Moral Relationships: Shared Moral Responsibilities Through Collective Resilience

My findings also contribute to understanding the role of moral relationships in moral distress, where moral relationships refer to relationships established with shared moral standards and responsibilities (Peter & Liaschenko, 2013). In particular, the study findings provide narrative examples of how standards for care and trust are misaligned and broken between nurses and management. The misalignment of priorities between nurses and unsupportive management has been acknowledged in the nursing literature (e.g., Davis, Lind, & Sorensen, 2013; Kelly, 1998; Peter & Liaschenko, 2013; Pye, 2014). My findings further contribute to this by elaborating how nurses felt that management had failed "to meet trust, either through incompetence, negligence, or ill will" (Baier, 1986, p. 238), as the nurses' calls for more support were frequently left disregarded. Walker (2006) has highlighted that indignation and resentment are experienced when moral relationships are not upheld, and Peter & Liaschenko (2013) contend that these feelings of anger and frustration, and similarly indignation and resentment, are consistent with the feelings of moral distress (see also Huffman & Rittenmeyer, 2012; Varcoe et al., 2012). In response to this violation of trust and their compromised moral relationships with management, the nurses' narratives illuminated how they became bonded by their experiences of moral distress, strengthened their moral

relationships with one another as a survival strategy, and generated collective resilience to withstand their difficult working conditions.

My study provides evidence of how nurses, in response to moral distress, bond through their shared set of standards for patient care (i.e., solidified their moral relationships), and united to care for their patients to attempt to maintain their moral identities for survival within their challenging working conditions. Further, some of the nurses described confiding in other another and developing close friendships that were strengthened by their inability to share stories or feelings about work to their families and friends, which is consistent with findings from Morrison & Morris (2017). These stories of how the nurses were bonded by trauma challenge Kelly's (1998) contention that nurses may not work well as a team because their education emphasizes individual performance, a position that seems reflective of the narrative that "nurses eat their young" described by some of the nurses in my study. I argue that many of the nurses in my study very clearly articulated that problem-solving with their nursing colleagues was necessary for their survival in pediatric oncology nursing, and that through this collective resilience, the nurses developed close relationships and friendships. As an example, their stories of interdependence for survival conveyed the tacit recognition that nurses are often thrown into new and complex caregiving responsibilities early because of understaffing. The nurses united together in their moral relationships with one another to learn how to provide care, support one another through these institutional constraints, and provide care in alignment with their moral identities. This resilience was also highlighted in their stories of how they advocated for and protected one another, for example by ensuring that there were always two nurses in a room when working with abusive families. Although this made further demands on their time, this provides an example of how the nurses would help each other and advocate for one another to resist further trauma, and in the absence of management support.

The study findings further suggest that fractures in moral relationships are influenced by the undervaluing of the nurses' expertise by their management, as well as the families' disregard of nurses' narrative proximity to their child when making treatment decisions. In this regard, my findings extend Peter & Liaschenko's (2013) contention that:

> nurses' lower place in the hierarchy relative to physicians is thought to be underlying many of these problems notable when nurses believe they have little influence over treatment decisions with which they disagree and when they believe their expertise is devalued" (p.341).

While the nurses' caregiving narratives identified some conflicts with physicians within the care team regarding treatment options for their patients, many of the nurses felt as though their skillset and clinical expertise was generally devalued by management, and described how management often would disregard their concerns or recommendations to help their patients. This is consistent with the findings mentioned previously from Davis, Lind, & Sorensen (2013), who suggest supportive management is necessary for a positive social context for nurses to fulfill their caregiving duties; if management is unsupportive, undervalues or has poor relationships with nurses, nurses are more likely to experience burnout (Davis, Lind, & Sorensen, 2013; see also Evans Emery, 1990; Leiter & Maslach, 1988). United by their confidence in their clinical expertise and their lack of response from management, many of the nurses in my study took matters into their own hands in order to care for their patients. An example of this was P5's story of how she and her colleagues on the COVID-19 unit, after many unproductive sessions with management, created their own set of care standards and practices to halt further outbreaks and ensure that their patients were well taken care of. Bonded by their trauma, the nurses engaged in this collective problem-solving, strengthened moral relationships with each other, and were thus able to uphold their moral responsibilities to their patients. Often, their moral relationships with other nurses are what kept them from drowning in their responsibilities and institutional constraints.

7.4   Institutional Constraints and the Paradox of Proximity

The findings of this study directly challenge the assertions of those who suggest that bearing witness is an individual responsibility and choice (Cody, 2007; Naef, 2006). As the stories within Bearing Witness suggest, the nurses in my study were often constrained in their ability to bear witness to their patients and families, which they found distressing. In the context of this study, the nurses described bearing witness to many things during the period of time that they provide care for their patients and patients' families: to suffering, to family dynamics, to discord between families and the medical team, and to

growth and change in their patients. My study expands upon current conceptualizations of bearing witness through the critical narrative methodology used in this study; in particular, my findings highlight that nurses, through their narrative proximity to families, also bear witness to stories.

My findings extend Cody (2007) and Naef's (2006) conceptualizations of bearing witness by providing rich empirical evidence of the ways that nurses' distress is informed by their bearing witness, situating the act of bearing witness within an institutional context. Cody (2007) acknowledges that nurses, as a result of working within corporatized healthcare environments, often struggle to bear witness to their patients on account of reorienting their caregiving duties:

> Nurses in contemporary North American acute care environments commonly describe harried working conditions that, from their perspectives, do not permit them to listen to persons for any length of time, or try to understand the depth of experiences and values of the persons they serve, or to use valuable time (that must be devoted to biomedically dictated tasks) to perform small kindnesses or to provide elementary comfort measures (p.289)

Relational caregiving having little value in the corporatized healthcare environment was evident in many of the nurses' stories about how they were unable to bear witness to their patients due to competing demands, tasks, and priorities, which caused them to feel distressed.

While these nursing scholars (Cody, 2007; Naef, 2006) view bearing witness as an integral moral responsibility for nurses that is often undervalued, to Cody, nurses are constrained by their institutions, but still hold responsibility for "turning toward" or "turning away" from the other. Thus, to Cody, to not bear witness is an active choice to "turn away" that can "change lives irreversibly, it can eliminate (or create) possibilities, and it can diminish (or enhance) quality of life" (Cody, 2007, p.289). However, the narratives generated by my study suggest that the nurses' inability to bear witness was an outcome of the demands imposed by their working conditions. The participants' stories illustrate their awareness of their inability to gain proximity to their patients and to bear witness, which causes them moral distress. Thus, rather than an isolated "turning away" from the patient (or other), the nurses are being turned away from their moral

responsibility and obligation to the patient (other) by having to pivot to more urgent caregiving demands.

These insights about moral distress in relation to bearing witness are further elucidated through engagement with Malone's (2003) conceptualization of the embeddedness of physical, narrative, and moral proximity. While bearing witness to suffering has been acknowledged in some of the pediatric oncology nursing literature (e.g., Lazzarin, Biondi, & Di Mauro 2013), my findings further highlight the ambivalence associated with bearing witness through proximal care. Peter & Liaschenko (2004) have similarly conceptualized the moral ambiguity of proximity, which refers to the difficulty nurses have setting boundaries on their proximity. Specifically, because nurses' roles are often characterized by their proximity to patients, and nurses are often morally compelled to act on behalf of their patients even when it is not their responsibility in some cases (such as when a certain action is the responsibility of another health care provider), a moral ambiguity exists as the boundaries and limits of their role become blurred. This moral ambiguity thus begs the question of where proximity begins and ends. The nurses in my study similarly suggested that they often compensated for a lack of staffing, which influenced their capacities to engage in proximal care. However, the difficulties they registered in relation to proximal caregiving were not registered as ambiguity over boundaries, and rather concerned their capacities to enact their moral responsibilities. In this regard, their caregiving narratives registered a clear ambivalence. On the one hand, moral distress arose when they were prevented from being physically proximal to their patients, because this limits their narrative and moral proximity, and thus their capacity to do right by and advocate for (or enact their moral responsibilities to) their patients. On the other hand, sustained proximity was distressing in situations where they were unable to enact moral responsibilities that were consistent with their narrative knowledge of patients and families. As I explored in Bearing Witness, the pediatric oncology nurses in my study experienced great moral distress when, after having sustained physical and narrative proximity to both the child and their family, they were restrained in their ability to gain moral proximity to the child. In some of the palliative cases in particular, the nurses were aware of the conflicting wishes of the child and family and were unable to act on what they perceived as being in the best interest of the child when the family's

wishes ultimately took precedence. Being restrained in doing what is best for the child has been highlighted by Pye (2014), who found that pediatric oncology nurses experienced moral distress when a child with whom they were close did not have defined resuscitation orders (and ultimately was resuscitated when they should have died), as well as when they were caring for a family who was expecting the death of their child and had opted to continue treatment instead of engaging in comfort care. In these morally conflicted situations, the nurses in my study often bore witness to the child's pain and were at times charged with the responsibility of administering life-saving treatments that they felt prolonged the child's suffering.

My findings also provide narrative illustrations of how nurses bear witness to patients' and families' stories through the narrative proximity they gain in their caregiving. The value and meaning that the nurses placed on gaining narrative proximity to their patients through their sustained proximal caring relationship suggests the ways in which pediatric oncology caregiving, at times, involves becoming entwined in the illness narratives of their patients and families. As noted above, some of the nurses come to know the patients for an extended period of their childhoods before they are discharged or succumb to their cancer. Further, the nurses' stories suggest that they engage in narrative reciprocity during their relationships with families. In this way, their sustained physical and narrative proximity allows for narrative production, construction, and sharing. Providing evidence of Malone's (2003) idea of narrative proximity, the nurses in my study elaborated on how their narrative knowledge informed their caregiving for each patient and family. This narrative proximity first gave nurses the opportunity to bear witness to the stories of their patients and families. From there, the nurses were able to take what they knew of the patients' and the families' stories and mobilize this narrative knowledge to provide what they perceived as good nursing care. This was particularly noticeable in the stories when they spoke of their experiences nursing during a child's death, which I consider further in next section.

7.5 Extending Understandings of Narrative Repair and a Call for Counterstories

The narrative findings of this study build on and extend Frank's (2013) notion of narrative repair, which focuses on the ways in which individuals narratively restore their identities, and thus re-story themselves, after their biographies have been disrupted by chronic illness and in ways that assist them in navigating a future that has been called into question. In this study, narrative repair emerged in the *content* of the nurses' stories in two ways: first, some of the stories provided examples of how they were able to engage in narrative repair with families; second, it emerged in the nurses' counterstories, which served to diagnose the source of their moral distress not in their individual failings, but in the system that stretched them too thin. In a different way, narrative repair emerged in the research interviews in the *telling* of the stories. In this sense, the interviews provided narrative space in which the nurses were able to restore their caregiving narratives and heal the fractures in their moral identities.

The findings of my research suggest that narrative repair can be relational, that is, that one can engage in repair with and/or for the child, the family, or the other. When a child is diagnosed with an illness like cancer, it is not just an individual's sense of self that has been shipwrecked; the narrative of the entire family has been thrown off course, and subsequently it is the entire family whose narrative must be redirected. My findings suggest that nurses mobilize their knowledge of the patients' and families' narratives to steer their illness stories onto new terrain.

This has implications for our assumptions about how narratives are produced, shared, and repaired. Many authors describing narrative methodology and modes for storytelling in a Western context often situate these narratives as individual accounts or "personal narratives" (Riessman, 2005). Narrative repair, as conceptualized by Frank (2013) implicitly acknowledges that personal illness narratives are constructed in relational to broader contexts; however, his articulation of narrative repair is primarily focused on how individuals engage in "self-repair" after a diagnosis of chronic illness.

Narrative repair was particularly pronounced in the nurses' stories about providing care before, during, and after a child's death. These narratives actively counter presumptions that the difficulties of pediatric oncology nursing are rooted in the emotional difficulties and "sadness" of caring for chronically ill children. These assumptions about the emotional difficulties of pediatric oncology were countered in the nurses' stories when they discussed their willingness to help facilitate a meaningful death for their patients. Through their narrative proximity, the nurses were able to mobilize their narrative knowledge to help the families heal from the "wreckage" left by their child's cancer by engaging in legacy building and creating memories with their child before they died. When the nurses were unable to engage in this narrative repair for the family, for example in situations where the child died suddenly or the family was not accepting of their child's death, the nurses experienced moral distress.

In addition to the ways in which narrative repair functioned as a form of caregiving, the nurses' stories also revealed the ways in which they repair their damaged moral identities through narrative means. My findings illustrate that the nurses in my study restor(i)ed their moral identities by locating their moral distress in their dis-ease of working in a system where they cannot sustain moral proximity with patients, and where their opportunities to narratively repair what has been fractured in their own moral identities and relationships have been seriously constrained. In addition to pointing to their daily struggles of being stretched too thin and striving to be the nurses they wanted to be, the nurses' stories also revealed how they addressed unresolved caregiving narratives when their relationships with patients and families ended suddenly (e.g., because of a child's remission or death).

The ways in which the nurses' engaged in narrative repair to restore their moral identities occurred in two ways. First, some of the nurses in my study shared stories of the efforts they went to in order to witness the lives of their former patients after their treatment had ended. These stories focused on the restorative effects of attending a children's cancer camp, which enabled them to witness the "magical" transformation of children who were extremely sick into children who were reaching "normal" developmental milestones, such as swimming. In some instances, attending camp also enabled the nurses to maintain

some semblance of a relationship with the families they cared for post-treatment. While attending camp was evidently beneficial and restorative, these stories also reveal how nurses salvage their moral identities on their own time; thus, the work the nurses engage in to stay passionate about their caregiving work is a private affair.

The other way in which the nurses engaged in narrative repair was through their stories and tellings to me in the context of the research interview. In particular, my interviews with the nurses functioned as a narrative space in which they could story their experiences to help heal the wounds inflicted upon their moral identities through their work. In this regard, many of the nurses engaged in narrative repair by telling their rich counterstories. As previously discussed, the nurses' counterstories about what constitutes caregiving drew attention to the range of caregiving they do and actively ascribed meaning to. Furthermore, their counterstories pointed to the ways in which management capitalized from the common conceptualization that the emotionally demanding nature of pediatric oncology nursing is justification for high turnover and why so many nurses leave the field. Institutional imperatives to keep workloads high and staff numbers low are supported by appeals to the emotionally demanding character of pediatric oncology nursing. The participants' stories dispute these assertions by making visible their harried and unsupportive working conditions, their highly demanding workloads, and their chronic understaffing. As P3 explicitly suggested, by framing the continued cycle of burnout and turnover as an outcome of the emotional nature of the work, the status quo is maintained by shielding management from having to reflect on and implement changes to the nurses' working conditions. This discourse on the emotional nature of pediatric oncology nursing also serves to uphold the idea that nurses must manage their emotions in order to survive. As a result, the effects of moral distress are individualized. The importance of counterstories as a way to identify and process moral distress was also suggested by P5's description of the silence that nurses maintain in order to ensure they are considered "professional" after their relationships with their patients and patients' families end. These counterstories, therefore, served the function of aiding the participants in restoring their moral identities by providing them with an opportunity to move away from self-blame and locate their experiences within their institutional contexts. In this way, the space provided by the research interviews enabled the nurses to

engage in narrative repair in order to voice their frustrations and identify the conditions necessary for them to be the nurses they wanted to be.

7.6 Strengths and Boundaries

This study makes important contributions to the literature examining the caregiving experiences of pediatric oncology nurses through its use of a critically informed narrative methodology. The critical narrative methodology I used to address my research questions allowed me to collect and analyze empirically rich narratives of pediatric oncology nurses, which have yet to be explored in the pediatric oncology nursing literature. As well, this methodology enabled me to go beyond personal narratives by situating them within broader institutional and discursive contexts. Furthermore, this methodology demonstrates the value of using narrative methodologies in "narrative terms"– that is, to use a narrative methodological approach that moves beyond a focus on narrative understood as qualitative data (i.e., words) and that is informed by an understanding of concepts in narrative theory, and that thus strives for a narrative analysis that focuses on both the content of the stories and the style of the telling. In this regard, a major strength of this study is the consistency in its focus on narrative, from the conceptualization of the research and framing of the research questions, to the interviewing approach, which was designed with the purpose of eliciting stories, to the process of analysis, which involved reading the stories for both the content of the stories and how they were told and in order to acknowledge conflicts, contradictions, and tensions, and presenting participant narratives as reflexive co-constructions. This highly immersive, in-depth, multi-stage interpretive process ensured rich data and substantial depth to the analysis. In addition, the critical orientation of this study situates and links stories of pediatric oncology caregiving to institutional contexts in order to generate new stories and insights regarding nurses' experiences of moral distress, bearing witness, and narrative repair. Specifically, the critical orientation of this study allowed for a nuanced understanding of how the nurses' experiences of moral distress are embedded within their caregiving and how these are influenced by neoliberal ideologies and corporatized institutional contexts.

As well, the interviews I conducted created a narrative space for the participants, which provided a platform for nurses to articulate and share their counterstories about pediatric

oncology caregiving. This narrative space was one that they seemingly did not have, which was evidenced by my observation that many of the study participants came to their interviews prepared with what they wanted to discuss. To the best of my knowledge, counterstories, at this point in time, have not been collected or presented in pediatric oncology nursing research as a way of locating nurses' moral distress within their institutional contexts. By responding to Peter & Liaschenko's (2013) call for the use of counterstories in nursing, the present study also provided a space for nurses to redefine and relocate the sources of their moral distress. In the case of this study, the nurses' narratives illuminated what more popularized narratives on pediatric oncology often (attempt to) mask, including the effects of neoliberalism and corporatization on the nurses' ability to provide care and their resulting experiences of moral distress (Mohammed, Peter, Killackey, & Maciver, 2021).

Another strength of this study is that the nurses who participated had a wide range of experience in different pediatric oncology care settings, which enabled me to identify similarities and differences across job type and by experience level. Their stories provide a broad understanding of what pediatric oncology nursing entails, particularly the range and indispensability of their caregiving activities, which has the capacity to complicate master narratives that tend to highlight medical heroism and technological progress, and glorify particular health care providers (namely, physicians) in an effort to fundraise.

The findings of this research are also bounded by the historical and geographical contexts in which it was conducted. For example, eight of the nine nurses recruited for this study worked in caregiving settings located in southern Ontario. The perspectives of nurses working in rural contexts and in northern Ontario were not included in this study, and thus their experiences may not have been fully addressed or represented within the scope of this thesis. While the generalizability of specific findings is not a goal of qualitative research, the interpretations and conceptualizations offered in the study findings may not resonate fully with nurses who work in other professional and geographical nursing contexts.

This study is also bound by the concepts that I used to inform my data analysis. My interpretational boundaries were informed by the concepts I drew on to make sense of the nurses' caregiving narratives, including moral distress, bearing witness, and narrative repair. However, as suggested by Lincoln & Guba (1985) and Riessman (2008), researchers from other theoretical and disciplinary backgrounds may come to analyze the data through different interpretational lenses and thus have differing interpretations of the data. Lastly, due to time constraints, I was unable to interview all of the individuals who expressed interest in participating in this study. As a result, the perspectives of nurses who occupied different positions or worked in different environments, locations, or institutional contexts may have not been included.

7.7   Implications for Research, Policy, and Practice

Future research should use narrative methodologies to examine how nurses in rural and Northern settings and those who work in adult oncology settings story their experiences of caregiving and moral distress in ways that are informed by their specific geographical and institutional contexts and constraints, and idealized constructions of the good nurse. This research could also enable identification of similarities and differences across oncology caregiving narratives, and illuminate and identify counterstories that broaden and deepen our understandings of nurses' caregiving and moral distress.

Additionally, critical narrative inquiry would be a fruitful approach to examine how other health care providers in pediatric oncology story their experiences of providing care (e.g., oncologists). This may shed light on the realities of their practice and caregiving responsibilities, including their experiences with administering clinical trials, communicating diagnostic and prognostic information, and the nuances concerning their proximity to their patients and patients' families'. In addition, examining their stories may elucidate understandings of how they understand and enact their moral identities and responsibilities, and how they experience moral conflicts and relationships with other providers, including nurses. It would be of interest how oncologists' stories may act as counterstories to popular understandings of their positioning as heroes and champions of highly technologized curative care.

As well, generating narratives with family members of child patients, particularly of those who have died, may provide counterstories to culturally dominant narratives that frame sick children as brave, active fighters who will survive their cancer. The generation and inclusion of these stories in understandings of pediatric cancer may help shape expectations about cancer caregiving and allow for a sense of comfort for families whose stories are often obscured from public view and understanding.

This study has implications for fully embracing narrative inquiry, as opposed to a tendency in health sciences to use narrative as a descriptive term for qualitative data (Dahlstrom, 2014). The current findings challenge notions of the stable coherent self that tends to inform much of narrative research in the health sciences. Whether aimed at exploring illness experiences or caregiving experiences, narrative methodologies allow for illuminating and understanding the ambiguities, ambivalences, and tensions that characterize these experiences. Through the telling of their stories, participants are able to ascribe meaning to particular aspects of their experience, generate counterstories to master narratives that challenge what may commonly be understood about their illness or caregiving experience, and locate their stories in broader institutional or sociopolitical contexts. My research suggests that future research should consider paying attention to ambiguities and ambivalences in participants' stories and identify how participants narrate and narratively treat the fractures and ruptures in their identities.

The current research also has implications for how narrative methodologies can be used in trauma-informed health research methods (Smeaton, 2019). The narrative interviews were a narrative space in which I bore witness to the study participants' stories of bearing witness to suffering, which led to my own experiences of vicarious trauma. However, the difficulty of bearing witness to repeated stories of trauma and suffering necessitates the development of methods for "being with" and continuing to attend to participants' stories, while helping researchers prepare for and manage their own experiences of vicarious trauma. van der Merwe and Hunt (2018) have suggested a number of recommendations for institutions to help mitigate against vicarious trauma, including providing trauma care and trauma-informed training for researchers. Their suggestions for individuals included debriefing about interviews, journaling or narrating feelings, and

spending time away from research-related work (van der Merwe & Hunt, 2018). All of these suggestions would be beneficial for researchers who often bear witness to trauma through their narrative interviews.

This study supports how narrative methodologies can be informed by critical analytical frameworks and concepts, such as moral distress, that enable the bridging of individual experiences and structural contexts. Critical narrative inquiry can aid in understanding how power is reproduced, negotiated, navigated and resisted by personal, professional, and cultural narratives that may sustain and challenge broader discourses and institutional contexts (Carpenter, 2010; Lamiani, Borghi, & Argentero, 2017). Further, in examining stories through the analytic framework of moral distress, future research has the power to elucidate how counterstories illuminate the experiences and struggles of individuals embedded within these larger systems (Peter & Liaschenko, 2013). With the COVID-19 pandemic as a current and relevant example, narrative research informed by moral distress has great potential to uncover how health care providers, positioned as heroes in popular discourse, expose the institutional constraints, political ideologies, and experiences of moral distress that these popular discourses conceal.

In writing the following section on the implications for policy and practice, I am fully cognizant of my status as an outsider with no experience as a health care provider and with no insider knowledge of working within the health care system. Knowing this, I humbly suggest these implications through my narrative lens.

This study demonstrates the potential for proliferating diverse narratives about what it means to be a pediatric oncology nurse. The counterstories revealed by this research are scarce within the pediatric oncology literature as well as in popularized understandings of pediatric oncology. Diversifying public narratives about pediatric oncology nursing may encourage critical reflection on popular narratives, such as those promoted by fundraising campaigns, that obscure the realities of pediatric cancer caregiving. In turn, this diversification of narratives may act as a form of collective support and resistance for practicing nurses, reduce the distance between other health care providers, management

and nurses, and catalyze changes in nursing education about how to best prepare nurses for the realities of practice.

My research supports contentions that nurses' idealized moral identities fostered in their education are incommensurate with the realities of pediatric oncology nursing practice (Canadian Nurses' Association, 2003; Kelly, 1992, 1998). Through the proliferation of narratives within nursing education, via guest lectures, or the development of narrative spaces for sharing advice and insights from practice, nurses currently working in pediatric oncology may be able to narrate what their nursing actually entails to nurses hoping to work within pediatric oncology. Previous nursing literature has highlighted that the development of media materials such as videos or podcasts can aid in learning, particularly in nursing education (Smith & McDonald, 2013). Creating these materials with the stories of current pediatric oncology nurses and integrating them into nursing curriculum may better prepare nurses entering the workforce and mitigate the effects of fractured moral identities. While the values that shape one's moral identity as a health care provider are important, particularly for guiding how one wants to practice and enact their moral responsibilities to their patients, it is also important that nurses are prepared for what nursing practice (and the conditions that shape that practice) actually entails. I further suggest that by integrating these accounts into formal nursing education, the work that the nurses ascribe meaning to, but that is undervalued, can become officially recognized by their institutions.

Because stories are accessible in a variety of audio and visual formats, including social media (e.g., podcasts), film methods (e.g., visual storytelling, documentaries), and performance art (e.g., plays), multiple opportunities are available to create a more critical consciousness about pediatric cancer caregiving, and about caregiving more generally, through the proliferation of diverse narratives that counter common conceptualizations of medical heroism and nuance optimistic visions of unimpeded technological progress. The use of podcasting to complicate public understandings of health care has been used previously. For instance, the podcast "The Doctor Paradox", was created to address "why despite having incredibly meaningful jobs, doctors are increasingly unhappy in their work" (Barrett, 2016). This podcast shared counterstories to glorified understandings of

health care providers (particularly physicians) and highlighted the underlying institutional constraints that these physicians worked within. Similarly, making nurses' counterstories more accessible can allow public audiences (including other nurses and health care providers) to gain narrative proximity to nurses' accounts of moral distress and thus to gain a greater understanding of how their distress is influenced by broader institutional and ideological contexts.

These findings further suggest a need for institutionally recognized narrative spaces where practicing nurses (in pediatric oncology and other nursing/healthcare contexts) can share their stories of moral distress and articulate counterstories in order to repair their compromised moral identities. The benefits of spaces created for pediatric oncology nurses to share stories of grief have previously been studied (Macpherson, 2008), and, as I described in Chapter 2, narrative spaces for the self, through reflective journaling, have also been found to be beneficial for nursing students working in pediatric oncology (Mirlashari et al., 2017). I suggest that narrative spaces can aid in assisting nurses to restory their moral identities as the nurses that they want to be, relocate the sources of their distress in institutional structures, and resist the tendency to engage in self-attribution and self-blame. Sharing counterstories can further illuminate that professional boundaries and discourses of professionalism are not aligned with experiences of caregiving. Through narrative spaces to share counterstories, perhaps this discourse can be reconsidered in light of the caregiving narratives generated by this research that illuminate the centrality of relational care to nurses' ability to enact their moral identities. Narrative repair through sharing counterstories can be viewed as a collective re- and co-construction, or a collective act of repair. In this sense, the relational aspects of narrative sharing, reciprocity, and repair can be viewed as collective experiences, highlighting the ways in which narratives mediate collective experiences and collective action (e.g., to advocate for institutional change to prioritize the wellbeing of staff who can uphold their moral responsibilities to patients).

In a similar vein, through publishing nurses' counterstories in more creative formats, such as those mentioned above, such materials can be used to promote communication between management, policymakers and nurses. The use of digital storytelling has been

used previously to help children with cancer story their experiences, and bridge communication with their parents (Foster Akard et al., 2015). Likewise, documenting stories of moral and political conflict through film and social media has been used towards social change. For example, based on the Fogo Island filmmaking process (National Film Board of Canada [NFB], 1968), St. Michael's Hospital created a filmmaker-in-residence program, sponsored by the NFB, which was designed to use social media in order to bridge gaps between health care providers and their patients (McDonald, 2010). In the same way that these videos have been used to facilitate discussion across patient and provider perspectives and produce social change at institutional and policy levels, recording and sharing nurses' narratives may be a way of generating narrative proximity to their concerns and working realities, obtaining more support from management, and instigating change in institutional policies. Such changes at institutional levels may include access to counselling services to help nurses process trauma, formally recognized narrative spaces, paid opportunities to engage in restorative caregiving with families (e.g., attend cancer camp, providing meaningful death) and to allow nurses to restore (and restory) their caregiving narratives and moral identities without doing so using their own income and limited vacation time.

These strategies could build on the idea of narrative medicine rounds to make a space for nurses to share their narrative proximity to their patients, and further share their counterstories with one another. The nurses' stories attest to the range of patients and families they provide care for, and how their proximity to patients and patients' families positions them ideally to make informed recommendations about their specific care needs, due to their cultural, religious, gender and other forms of diversity. While current practices use narrative rounds for health care teams (Charon, 2001) narrative rounds in the context of pediatric oncology nurses may involve carving out a specific time for nurses to share what they have gleaned in their narrative proximity to the family with one another. As well, similar to the way that narrative medicine rounds are used in public lectures (Columbia University, 2021), narrative rounds in pediatric oncology nursing may also span beyond the walls of their institutions and further allow nurses to ascribe value to the range and diversity of the caregiving they provide, enabling them to educate nurses in training, other members of the health care team, and the public.

7.8 Return to Reflexivity and Conclusion

As I sit here and reflect upon this research, I'm a bit emotional. I remember when I was finishing my undergraduate education, I came across the word finifugal, which very aptly describes my current feelings: "hating endings; of someone who tries to avoid or prolong the final moment of a story, relationship, or some other journey". I thought that when I finished writing my PhD I would be ecstatic – instead, I feel as though this moment is far more bittersweet.

I've learned and grown a lot in the time since this dissertation was originally conceptualized. I'm incredibly proud of the dissertation I've written – illuminating the nurses' stories of being stretched too thin, bearing witness, being bonded by trauma, and engaging in narrative repair. At the beginning of embarking on this research I am not fully sure that I would have considered myself capable of generating and developing these insights. Ending this particular story now makes me realize how far I've actually come.

This story – my research story – has been in the works for the last five years. In those five years, it is no secret that I struggled with my post-positivist assumptions. I still, after conducting a critical dissertation, continue to resist the post-positivist urge to generalize or state my interpretations as facts. Throughout writing the final chapters of this thesis, I was constantly going back in my revisions to ensure that what I was saying was grounded in my interpretations and was not phrased as a general statement. But simultaneously, the urge to state my points as general facts is much less strong than what it once was. I feel as though I've started to own, and have confidence in my critical voice, which I never thought I would actually be able to say or feel. I also noticed that as I was writing my discussion it was so much easier for me to put different authors, scholars, and philosophers in conversation with each other – not only could I connect the dots between their work and my own, but I was able to feel as though I too was engaging in conversation with them. I now had a seat at the table to explore my perspectives and interpretations in relation to their work, without fear of being wrong – rather, I had a different way of looking at things.

I'm especially proud of how I was able to use a narrative methodology in "narrative terms" and explore my topic critically. While at first I felt very much out of my comfort zone with less structured methods, my ease and comfort grew over time. I loved asking participants about their stories, probing about different details, and being able to laugh and cry with them within our narrative space. I also came to deeply appreciate the power of approaching these stories through a critical lens of moral distress – as someone who, at the beginning of this research, had a lot of difficulty putting the micro in conversation with the macro, analyzing this research through moral distress helped me make those connections, understand how the broader context affects individual experience, and how the individual is located within and shaped by the broader context.

Between engaging in critical research and completing the most intense parts of my research during a global pandemic, I feel as though I've undergone a distinct shift in my perspective. The nurses' stories, shared with me in the midst of the COVID-19 pandemic, have helped me understand that we live in a world where certain stories are privileged and that these stories mask and obscure other stories. In having this new perspective, I am happy to say that I will be supported by a Banting Postdoctoral Fellowship at McMaster University, in the Department of Family Medicine, to explore the stories of moral distress of primary care providers caring for individuals who experience social inequities and barriers to health care.

While this opportunity is exciting, it also makes me nervous. The next two years will require me to examine how *my* institutional context has bearing on my individual experiences and perspective. I just spent the last five years working incredibly hard to cultivate a critical perspective and will now be joining a department that has a large number of clinicians and clinical researchers, which may present challenges to maintaining that perspective. As someone who will be new to this department and one of the more junior members, it may be difficult for me to assert myself and have confidence in my critical perspective. One thing I learned from conducting my dissertation, however, was that being an outsider has its benefits: I was able to remain reflexive, open and honest about my position and develop and deepen my critical voice. And so, perhaps

being an outsider will be an asset to this department and will allow me to continue growing into the researcher I want to be.

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Appendices

Appendix A: Telephone Screening Script

E-mail Process:

If potential participants choose to contact me via e-mail, I will respond and thank them for their interest and attach the participant letter of information and consent form. I will request that they contact me via telephone if they have any further questions and/or if they are interested in participating in the study. As described below, the phone conversation will be used to determine the person's eligibility and to potentially arrange an interview time.

General Script:

Caller:	"Hi, I am calling about the pediatric oncology nurse study"
Researcher:	"Hi. Thanks for calling- my name is Monica. I'm doing my PhD dissertation and this project is part my research. Would you like some more information on the study?"
Caller:	"Yes"
Researcher:	"The purpose of this study is to learn more about what it's like to provide care to children with cancer, and understand the factors that influence your caregiving. We'd like to talk to nurses who work in a variety of different settings, like inpatient, outpatient, or Interlink. We'd also like to talk to nurses with differing credentials, like an RN, RPN, or NP. If you decide you would like to participate, you will be asked to take part in two interviews that will be audio-recorded and transcribed word-for-word to ensure accuracy. Because we are interested in learning about pediatric oncology nurses' experiences, these interviews will be open-ended which means that the questions are worded in way that will allow you to answer in your own words. Before any data is collected, you will read a detailed letter of information that reviews your rights as a research participant and the potential harms and benefits of taking part in the study, and you will be asked to sign a consent form indicating that you agree to participate in the study. You can refuse to answer any interview questions and you can withdraw from the study at any time. Do you have any questions?"
Caller:	[caller will ask any questions they have about the study]
Researcher:	[researcher will respond clearly and openly] "Does that answer your question?"
Caller:	"Yes."
Researcher:	"Great. Are you interested in participating in the study?"
Caller:	"Yes." see "Interested"

Screening Question to Determine Eligibility for those Interested in Study

Researcher:	"Ok great. I first have to confirm that you are eligible to participate. Are you a currently practicing pediatric oncology nurse in Ontario?"

Rejection Script (if caller responds 'no' to eligibility question, above):

Researcher:	"I'm sorry but you are not eligible to participate in the study. Thank you for your interest in this research".

Screening Questions to Maximize Variability in Study Sample for those Interested in Study (if caller responds 'yes' to eligibility question, above)

Researcher:	"To ensure your eligibility in the study at this time, I'd also like to ask you a few more questions. This is because I'm interested in speaking with nurses who work in a variety of caregiving contexts (city, inpatient/outpatient, etc.) and with different levels of nursing experience and professional backgrounds (RNs, NPs)." "Which city do you currently practice in?"
Caller:	[potential participant will respond accordingly]
Researcher:	"What kind of care environment do you practice in? As examples - inpatient, outpatient, Interlink."
Caller:	[potential participant will respond accordingly]
Researcher:	"What nursing credentials do you hold? As examples, are you an RN, RPN, NP?"
Caller:	[potential participant will respond accordingly]
Researcher:	"How many years of experience do you have as a pediatric oncology nurse?"
Caller:	[potential participant will respond accordingly]

Acceptance Script:

Researcher:	"You are eligible to participate in the study. Now we can go ahead and decide on our first interview time. What day/time is best for you? I have access to a private space on campus, but I am also able to meet somewhere else if that is more convenient for you"
Participant:	[date/time/location is negotiated with the researcher]
Researcher:	"Excellent. I will see you at [Location] on [Month/Day] at _____(Time). Before I let you go, I need to get your name and some contact information- either a phone number or an e-mail address where I can reach you"
Participant:	[provides name and contact information]
Researcher:	Ok great I will see you on _____(date)!

Waiting List Script:

Researcher:	"Unfortunately, you are not eligible to participate in this study at this time. This is because I am trying to recruit participants who work in different places and caregiving environments and with different backgrounds and levels of experience. I already have

individuals in my sample who have a similar caregiving profile as you. Would you be okay with being placed on a waiting list? I will keep your contact information on file and contact you in a month to let you know if participation is a possibility at that point. This information will be kept confidential, can only be accessed by me, and will be destroyed after recruitment is completed. You are also welcome to follow up with me at any time. Would this be alright with you?"

(If caller agrees to being wait-listed)

"Thank you. I will keep your contact information on file for now and follow up with you in one month to let you know if participation in the study is still possible and to reassess your interest in the study at that time. You are also welcome to contact me any time during this time. Your contact information will be kept until the recruitment period is complete or until you decide that you are no longer interested in participating in the study. At that time, your personal information will be destroyed."

(If caller does not agree to be wait-listed)

"Thank you for your interest in this study. Your personal information will be destroyed."

Appendix B: Interview #1 Guide

Thank you for agreeing to participate in this study. As you know, the purpose of this study is to learn more about your experiences providing care to children with cancer. To do this, I will ask you some open-ended questions and you are welcome to answer any way you like. In order to ensure accuracy for the data analysis, I will be audio-recording this interview. I will let you know when we start recording. As you answer, I will be taking notes of things you mention that I may want to probe further. There are no right or wrong answers and you are free to refuse to answer any questions that you don't feel comfortable with. You decide how much you want to share. Transcripts of this interview will be de-identified for confidentiality purposes. Please also know that you can take a break, or stop the interview at any time. Do you understand? Do you have any questions before we begin?

I am now going to start the recorder and begin the interview.

1. Please tell me, in as much detail as you can, your story of what it's like to provide care to children with cancer. Feel free to start wherever you want and end wherever you want – it's completely up to you. I'm here to learn about you. You are more than welcome to take some time to think about it before you begin.
2. Can you tell me about a time when you were unable to provide care in the way you wanted? You may repeat things you've already said.
   a. What happened? Who was involved? How was the situation resolved?
3. Can you tell me about a time when you were unsure about how to provide care to your patients?
   a. What happened? Who was involved? How was the situation resolved?
4. What is it like to be a pediatric oncology nurse?
   a. What is the most rewarding part? The most difficult part?
   b. What would a typical day as a pediatric oncology nurse like to you?
5. Is pediatric oncology caregiving what you expected it to be?

Non-Directional Probes
That's interesting. Can you say more about that? What do you mean by that?

Thank you for taking the time to participate in this interview. I am going to turn off the recorder now.

Appendix C: Interview #2 Guide

Thank you again for agreeing to participate in this study. As a reminder, the purpose of this study is to learn more about your experiences with care provision as a pediatric oncology nurse. As in the first interview, this interview will be audio-recorded. I would like to remind you that may skip any interview questions that you do not wish to answer, take a break, or stop the interview at any time. Do you understand? Do you have any questions before we begin?

I am now going to start the recorder and begin the interview. Is that ok?

1. To start, I'd like to ask some questions about your first interview.

Did you have a chance to read it over? (If yes, ask follow up questions that elicits their thoughts and follows their storylines)
- What did you think when you read it over?
- Is there anything you wanted to add or reflect on further?
- How have things changed, if at all?

2. Specific follow-up probes from interview 1 (to achieve further clarification and detail)

In your first interview, you mentioned…
- Can you tell me more about that?
- What did you mean when you discussed…?
- What is significant about this?

Example of probe for participant [pseudonym]:
1. You mentioned/talked about Camp Ooch in your last interview. Can you tell me about your experience with Camp Ooch? What was it like? What does this camp mean to you?

3. Follow up questions based on emerging storylines (across interviews)

Now, I'd like to talk about some of the stories that have come up across many of the interviews and get your further thoughts and reflections about these. Again, please feel free to respond any way you like.
1. A consistent story I've been hearing in the interviews is that, at times, nurses feel that they **cannot be the nurse they want to be**. Does this resonate with your experience? If yes:
   a. How so?
   b. Ideally, what would need to change to help you be the nurse you want to be?
2. I've been hearing consistent stories about workload, including stories about **understaffing**, **turnover**, and **heavy workload**. Do these resonate with you?
   a. If so, can you tell me more about workload-related issues?
   b. How do these affect you?
3. The nurses I've spoken with shared many stories about the work they do with patient's / children's **families**. Can you tell me more about the work you do with families?

      a. Related to this, another consistent story I've heard is that nurses often do a lot of the communicating with families. Does this resonate with your experience? If yes:
         i. Can you tell me more about your experience in communicating with families?

4. As well, there have been a number of stories about how pediatric oncology nurses must interact with a number of actors as part of the care they provide, including **families**, other **health care providers**, and other **organizations**. Can you tell me more about what this looks like for you?
      a. Can you tell me about what it's like to work between the family, medical staff, and other individuals or systems?
      b. A consistent story I've heard is that nurses often do a lot of coordinating and coordination. Does this resonate with your experience? If yes:
         i. Can you tell me more about your experience with coordinating/coordination?

5. One thing that was surprising to me were stories about the **various kinds and amounts of administrative and non-medical work that pediatric oncology nurses do**. For example, logging hours and paperwork. Can you tell me about this?
      a. Is there other work you do in your role that isn't directly related to physical care?

6. An important story I've been hearing has to do with the **nurses' involvement with children who are dying and post-mortem.** Does this resonate with you? If yes:
      a. Can you say more about that?
      b. Some nurses mentioned that they want children to have a "good death". Does this resonate with you? If yes:
         i. Can you tell me about your experience with this?
      c. What needs to be done to make death and dying more meaningful for patients and their families?

7. One common story has to do with the **perceptions that others have about pediatric oncology nursing**. For example, the idea that others think that that it must be "so sad" or that they "don't know how you could do" this kind of work. What do you think about these perceptions?
      a. What is it like to confront these perceptions?
      b. What else would you like people to know about the work you do?

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4. Closing Questions

6. Is there anything else you'd like to talk about that you think would be important to this study?
7. What has it been like for you to take part in the study?
8. What are you hoping will come from the results of this study?

Thank you for taking the time to participate in this interview. I am going to turn off the recorder now.

Appendix D: Institutional Ethics Approval Notice

Date: 18 December 2020

To: Dr. Jessica Polzer

Project ID: 114901

Study Title: A critical examination of pediatric oncology nurses' caregiving narratives

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

REB Meeting Date: 12/Jan/2021

Date Approval Issued: 18/Dec/2020

REB Approval Expiry Date: 06/Jan/2022

Dear Dr. Jessica Polzer,

The Western University Research Ethics Board has reviewed the application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

Western University REB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The REB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

The Office of Human Research Ethics

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Curriculum Vitae

Name:	Monica Lynn Molinaro
Post-secondary Education and Degrees:	McMaster University Hamilton, Ontario, Canada 2010-2014 BSc. (Hons) Wilfrid Laurier University Waterloo, Ontario, Canada 2014-2016 M.Sc. The University of Western Ontario London, Ontario, Canada 2016-2021 Ph.D. (c)
Honours and Awards:	Banting Postdoctoral Fellowship (SSHRC) 2021-2023 Social Science and Humanities Research Council (SSHRC) Joseph-Armand Bombardier CGS Doctoral Scholarship 2018-2021 Ontario Graduate Scholarship 2018
Related Work Experience	Research Assistant Centre for Education Research and Innovation, Schulich School of Medicine and Dentistry 2018-2021 Research Assistant The University of Western Ontario 2017-2021

Publications:

Molinaro, M.L., Cheng, A., Cristancho, S., & LaDonna, K. Drawing on experience: Exploring the pedagogical possibilities of using rich pictures in health professions education. *Advances in Health Sciences Education*. https://doi.org/10.1007/s10459-021-10056-9

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