What caring for a child who died was like for me: My experience of pediatric patient death as a new graduate nurse

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ABSTRACT

What caring for a child who died was like for me: My experience of pediatric patient death as a new graduate nurse

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I utilized analytical autoethnography to analyze and interpret my own experience of what caring for a child that died was like for me within the academic and institutional culture that I was educated and trained in (Chang, 2008). Themes of lack of preparedness, relationships, loss and emotion, death denial, and lasting impacts and growth were identified. Pediatric death and dying education and training for nurses should encompass nursing responsibilities, communication strategies, holistic assessments, symptom management, cultural awareness, and grief literacy (Bensoussan, 2024; Chew, Ang, & Storey, 2021; Kent, Anderson, & Ownes, 2012; RNAO, 2012). A system to accommodate, acknowledge, and value emotion. A platform to share, learn, and grow from the experience with death and dying. This autoethnographic account provides insights into the personal and professional impacts of pediatric patient death on nurses and the importance of associated education, training, and support to improve care for patients, families, and self.

Keywords: pediatric patient death, nurse, autoethnography, lack of preparedness, relationships, loss, emotion, death denial, lasting impacts, growth, support, education, metabolizing grief, disenfranchised grief, self-transformation, tiered peer support program, mindfulness strategies

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To all of the patients lost, the families left behind, and the nurses that will never forget them.

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Background

A child actively dying while under my care was not at the forefront of my mind as I entered my nursing career in pediatrics. I was so excited to get a nursing job right out of school, to have the opportunity to start working at an esteemed hospital, and to be a part of an amazing team that would support my learning and growth in my career. A team that could do everything to make kids better. I was excited about my role in helping kids get better, to go home, to live out their childhoods as kids should. I never considered what the alternative looked like. I never considered how often that may occur. I never considered how that would affect me or change me as a nurse, as a person.

Nurses feeling inadequately prepared to manage the death of a child has been frequently reported (Chew, Ang, & Storey, 2021). Research dedicated to investigating new nurses' experience with patient death is focused on experiences with adult patients with limited research on nurses' experience with pediatric death (Chew, And, & Storey, 2021). Nurses highlight that much of the end-of-life care education is focused on adult care rather than a focus on pediatrics (Chew, Ang, & Storey, 2021). Furthermore, the literature that is focused on nurses' experiences with pediatric death is predominantly investigated in critical care units, emergency departments, or oncology and palliative care settings. Predominantly, pediatric deaths do occur in critical care settings (Roth et al., 2017). However, there has been a shift, patients and families are making decisions about end-of-life care and wanting it to be provided on the wards in the absence of various life-sustaining measures (Roth et al., 2017). This shift is not matched by research in these areas or increased resources and education for ward nurses to be able to confidently provide end-of-life care to patients on the ward and many report feeling a lack of preparedness (Roth et al., 2017).

I utilized autoethnography to analyze and interpret my own narrated experience of what caring for a child that died on a general medical surgical ward in Ontario was like for me (Chang, 2008). In exploring my own experience as a new graduate nurse within the culture that I was educated and trained in, I sought to discover what is imperative for new nurses to learn about and be supported with through the death and dying of a child. My thesis work allowed me, or rather forced me, to write about the emotions and feelings I had about pediatric patient loss beyond the surface level of it being "sad". I felt overwhelmingly unprepared to care for a dying child patient, their family, and myself. The initial objective of my thesis was to solve this problem that I encountered within the cultures I was immersed in; my university level nursing education and institutional training as a new graduate nurse. Self-transformation was not actually a "conscious goal" of mine as Chang describes and yet, a welcomed benefit of autoethnography (Chang, 2008). An emotional healing (Chang, 2008). This is how I got here; self-transformed through reading, writing, reflecting, and learning.

Methodology

I sought to discover the impact of pediatric patient death on nurses personally and professionally by interrogating what caring for a child who died meant to me as a new nurse and what it revealed about the culture in which I was educated and trained. I sought to explore what is imperative for new nurses to learn about and be supported with through the death and dying of a pediatric patient. The methodology, autoethnography, enabled me to understand my experience within my cultural context. I utilized analytical autoethnography to explore my experience as analysis promoted the identification of connections and relationships amongst the data and interpretation enabled me to draw meaning from the relationships and make sense of this experience in the context in which it was experienced (Chang, 2008). An analytical approach allowed for the incorporation of existing literature at various points in the research process such as during external data collection and thematic analysis. Exploring the existing literature throughout the research process promoted contextualization and validation of my experience and the means to engage and frame my experience with theoretical perspectives (Chang, 2008).

Beginning with my own experience of pediatric patient death and dying, I analyzed the impacts and implications of child death on my personal and professional life, how these were shaped by my institutional contexts, and interpreted how new nurses can be better prepared, trained, and supported throughout the experience of child death (Chang, 2008). The exploration of my experience with pediatric patient death is rooted in a social constructivist perspective as the development of my knowledge about pediatric death and dying was informed and limited by cultural and institutional processes (Greenhaus & Callanan, 2006). My knowledge and understanding of pediatric death and dying was shaped and constructed by the educational and hospital cultures that I was educated and trained in. Cultures more rooted in objectivist science than human science. Therefore, I adopted a social constructivist approach, to understand my experience of a child's death and how this was constructed by my cultural contexts (Aguzzoli et al., 2024). Bochner and Ellis describe autoethnography as exploring the usefulness and meanings rather than facts and the truth of lived experiences which can "heal, change, validate, and engage others" (p.239) (Bochner & Ellis, 2016). Chang's autoethnographic method extends the exploration of lived experience and adds the elucidation of culture that can limit or enable such healing, change, validation and engagement.

Heewon Chang's "Autoethnography as Method" guided me through understanding myself and others within the academic and institutional culture that I was educated and trained in (Chang, 2008). I followed a typical research process, starting with data collection and progressing through to analysis and interpretation (Chang, 2008). I incorporated a combination of internal data collection and external data collection strategies to promote contextualization, increase validity, and promote triangulation (Chang, 2008). I utilized outlined strategies for internal data collection such as chronicling the past, inventorying self, and visualizing self to elicit memories through guided writing exercises (Chang, 2008). External data collection was focused on examining existing literature and policy and conducting interviews (Chang, 2008). A literature review was conducted to examine nurses' experiences with pediatric patient death. Trent University Research and Ethics Board approved unstructured individual interviews which were conducted with two individuals (Protocol number: 29366). Written and verbal informed consent was provided by all participants who were de-identified prior to the transcription of interviews. Utilizing thematic analysis, I identified recurring themes from both internal and external data: lack of preparedness, relationships, loss and emotion, death denial, and lasting impacts and growth. The meaning of these themes was then further interrogated and connected to existing literature such as Rachelle Bensoussan's theory of "metabolizing grief" and Kenneth Doka's "disenfranchised grief".

Data Collection

I utilized Chang's data collection framework whereby I focused on assembling both internal and external data to increase validity and promote triangulation (Chang, 2008). Internal data collection was focused on assembling personal memory data and self-reflection data while external data collection highlighted concepts and ideas from literature and others (Chang, 2008). I utilized outlined strategies for internal data collection such as chronicling the past, inventorying self, and visualizing self to elicit memories through guided writing exercises (Chang, 2008). I began collecting personal memory data by first sharing my self-narrative of what caring for a child that died was like for me within the context of nursing university education, institutional training, and working as a new graduate nurse (Chang, 2008). I chronicled the past with an autobiographical timeline of pediatric patients I had cared for who had died (Chang, 2008). I began 'inventorying self' by creating lists in categorized themes to expand upon values, rituals, and artifacts such as relationships, music, debriefs, and gifts (Chang, 2008). In 'visualizing self', I did a free drawing of the image that sticks in my mind the most when I think about my experience with the death of a child patient. This free drawing led me to explore the existential concepts of subjective human experience of space, time, body, and relationality (Davidov & Russo-Netzer, 2022). To collect self-reflection data, I reflected and explored my identity as a nurse and as a person (Chang, 2008). Inevitably, my memories include other people: the child I cared for, their parents, the medical team: to protect their privacy and confidentiality, identifying data was anonymized.

External data collection was incorporated to validate and triangulate internal data (Chang, 2008). I utilized existing literature, interviews, and relevant policy as a form of external data collection to provide additional context, perspective, and examine my experience in relation to nurses' experiences caring for a dying child (Chang, 2008). A literature review was conducted to examine the existing literature on nurses' experiences caring for a dying child. The Trent University academic search tool "Omni" was utilized to access resources from various university libraries across Ontario utilizing key phrases related to nurses' experiences with death, pediatric death, coping strategies, and grief. Trent University Research and Ethics Board approved unstructured individual interviews which were conducted with two individuals (Protocol number: 29366). The social media platform "Instagram" was used as the sole recruitment strategy where a recruitment ad was posted, and candidates were welcomed to express their interest in participating by emailing the author. The two individuals that met the inclusion and exclusion criteria of being a registered nurse in Ontario that has experienced a pediatric patient death were interviewed. Written and verbal informed consent was provided by all participants which were de-identified prior to the transcription of interviews. The potential for emotional distress was considered, and interviewees were informed of available support services prior to the interview. Both interviews were transcribed with data storage aligning with Trent University Research and Ethics Board specifications. The interview participants were invited to "*share with me what caring for a child who died was like for you"* (Protocol number: 29366).

My Experience

I begin by sharing my self-narrative of what caring for a child that died was like for me within the context of nursing university education, institutional training, and working as a new graduate nurse:

Knowledge acquisition was heavily based on my practical experiences in nursing. Exposure to these practical experiences was largely dependent on the varying practicums that myself and other students were afforded. Nursing education is standardized; however, extreme variability exists in the acquisition of specialized knowledge amongst individual students and nursing university programs based on which practicums universities are able to secure and which practicums individual students are able to experience during their education.

In relation to my experience as a nursing student, my exposure to death and dying in class and practicum was minimal and non-specific. It was non-existent in relation to pediatric death and dying. As a student, I experienced an older adult death in an ICU setting following a heart attack. The nurses did not know the patient well or the family, the nurses acted as if this was simply routine, and the only discussion that I recall having with my preceptor was that they try to give the family uninterrupted time before doing any after death care and let them know we are there if they need anything. That was the extent of my exposure to death and dying as a student. It seemed mundane, unremarkable, a fact of life, a part of the job . There was no debrief after, no discussion; everyone just continued on with their shift, moving on to the needs of their next patient. I assumed this was how it was, how it was supposed to be, how it was expected to be. I never thought much more about it as a student, and I never had any further education dedicated to patient death and dying. During my pediatric practicum, I did not experience a child's death. It was not ever at the forefront of my mind while I was considering my future career and work in pediatrics. The death of a child seems unnatural, not the norm. Maybe naïve for me to not have considered this, but again, it was never a focus of my nursing education and it *was not something that I experienced in my pediatric placement. Furthermore, I had not experienced a death of anyone close in my personal life, either.*

I loved working with kids and found it so inspiring how resilient they were through their journeys with illness. I recognized the importance of developing therapeutic relationships with the patients and families, and how these relationships impacted the quality of care given and received. The unit culture and nurses were very positive, upbeat, and supportive, making an effort to ensure the kids had as good a day as possible and amidst it all were still able to be kids. They got better. They went home. I did not dwell on the possibility of these kids not going home, ever. How would child death and dying affect patients, families, and the nurses caring for them? Focused on developing therapeutic relationships and critical thinking skills, understanding diagnoses and plans of care, memorizing lab values; this was a question I never asked myself as a nursing student.

I met and cared for a teenaged patient as a student nurse in my pediatric practicum. In addition to her care, I helped her with homework for school, we chatted about life and her family, about popular shows to watch on Netflix. It was one of my first experiences where I, too, felt like I was actually making a difference, making her hospitalized days more normal and enjoyable. I did not know at the time. I never could have. She would be a patient that I would continue to care for during my transition from nursing student to new graduate registered nurse, that I would experience many career firsts with her, and that I would continue to think about her often throughout my career.

I had a very extensive and thorough orientation when I started my full-time position as a new graduate nurse. The institution was and is very highly focused on best practice guidelines *and policies to promote safe practice and high levels of quality care. As orientees, we were introduced to the hospital's palliative care team and their role in patient care. However, I do not recall learning about expectations for end-of-life care practices at the hospital, end-of-life and after life care policies, or resources and supports available for patients, families, and staff.*

The first year of my nursing practice was a mix of emotions like it is for many. Rewarding, exhausting, joyful, stressful. It took about a year to become more comfortable in my practice and confident in my knowledge, skills and critical thinking, and my ability to adapt and care for critical patients. I had opportunities to learn how to navigate most experiences that I would continue to encounter within my first year, except a child death.

The teenaged patient that I had met as a student had been in and out throughout this first year. Initially, her readmission was not surprising and she came back in when I had just over a year of experience. With diagnostics and results incoming, it became increasingly obvious that her prognosis was not good.

She had a journal in which she could write her wishes and care preferences. I remember thinking how mature this was of her to be able to have these conversations and conceptualize dying at that age. She was able to choose the nurses to care for her and I cared for her the majority of my shifts for many months as she got increasingly sicker with increased care requirements. She bought coffee mugs for all of the nurses. She gave one to me and another nurse at the same time and we both said how thoughtful a gift it was and that we would think of her every time we drank from it. I knew I would think of her if I had my coffee from that mug, but the thoughts that surrounded that mug were more of her death and remembering a child death everyday with morning coffee felt too heavy and always did. It is a mug that I can not drink from *and it sits in a cabinet untouched. Two things that were important to her were to not be in any pain and to be able to pass on the unit with her family and the nurses that she knew and was comfortable with and to not go down to ICU. When she was ready, the plan was to withdraw care and monitoring but continue comfort measures.*

I was working the weekend this was to occur. I was asked by the charge nurses if I was comfortable caring for her that weekend knowing that the plan was to withdraw care. I appreciated this text and appreciated the option. I had no idea what to expect but did not want to decline and appear that I was not capable or willing to take on challenging assignments. I agreed and went in early for my shift and the start of my weekend stretch.

When I arrived at work, I was not aware of the acuity on the floor that day or the status of any other patient, I was focused on my assignment, and I immediately began to prepare the planned sedation with another nurse. This was something that is not routinely done on the floor and required further support from the medical team. Before entering the room, the palliative care staff doctor spoke to me about the plan. She told me that after I hooked up and set the infusion that she would start the infusion and push the button for the first time so that I did not feel responsible for her death if she passed away with the initial administration. Feel responsible? Was that a feeling I was supposed to even have with a planned and expected death? Another first. I recall getting flushed, feeling flustered, and shaky after that, wondering if I had made the correct decision agreeing to this assignment, if I was experienced and knowledgeable enough. I can picture myself back in that room, in that moment. I can see myself kneeling beside the bed with the doctor sitting on the end of the bed, the patient lying in her family's arms under the fluorescent lighting. I can picture the exact lighting of the room. I can feel my hands shaking *while hooking up the infusion and sensing everyone's eyes on me. I said to the patient "It's okay I'm just hooking up your lines" so that she wasn't shocked by feeling my hands or the flush. I will never forget what she said to me, "It's not okay, nothing is okay". I knew everything was not okay. I did not intend my words to hold that meaning. I often wish I had said something different. The doctor started explaining to the patient and family about starting the sedation and how we would step out after but that I would be seated outside the room at all times. She pushed the button to administer the first dose and we exited the room.*

I felt very supported with providing care throughout that weekend. The nursing team was very supportive and the charge nurse spoke with me about some things that could potentially happen that we would normally respond to differently but in this case would just be providing comfort measures. I recall not knowing what I should be saying to the family, what was appropriate at this time. I tried to be as quiet as possible to promote comfort and peace. The room was dark all night, each night, with only the glow of the infusion pumps. I repeatedly administered pain medications and counted respirations. I had a binder that had a policy on after death care printed in it and was told to read it at some point if I had time but that the charge nurses would be available to help me with this when the time came. I recall not ever seeing or hearing about this policy before, not knowing it even existed, and thinking it odd that it was never discussed. I recall being on edge sitting outside of that room for the whole weekend, feeling nervous about the unexpected, feeling conflicted and thinking I should be doing more but trying to respect the family's time together and letting go of the nursing need to monitor and intervene. I did not sleep well between shifts, ready for something to happen, but it never did on my shift.

That last morning, I changed her, washed her face, did her hair, and repositioned her prior to the next nurse coming on shift. It scared me how limp and lifeless she was and it was obvious that the end was near. I said goodbye to her and her family knowing that they would be gone when I returned. I opened my email prior to coming in for my next shift, knowing that she would have passed. I walked on to the unit and for the first time in many shifts, I was not assigned her room. I felt tears starting to well up seeing different room numbers by my name. I never thought that would be something I would get emotional about. I choked back the tears, buried the feelings, and got on with my job. I did not want to appear like I was not capable, like I was not competent, like I couldn't handle it. There were multiple open group debriefs that week on the unit for all nurses to discuss the death. I attended but I didn't talk, I still felt new and not fully comfortable. That was it. I found it upsetting being close to her in age and knowing that she wouldn't be able to experience so many of the things that I have been able to experience in life. Driving your first car, going away to school, meeting new friends, travelling to new places, starting your first career job. I sat with these feelings, reflected on what I could have or should have done differently. I was not aware of any further resources or supports at the time and I did not seek them out and no-one sought me out.

Did I learn from this experience? Did I grow personally and professionally? Of course. Nursing is a job such that you come in every day not knowing what your day will hold. A child's death and dying is one of the worst things that can happen. Knowing that I experienced a child dying gave me some confidence and decreased some stress and anxiety coming to work and a day of unknowns. I knew what a child death could look like for myself, the patient, and the *family. I learned what one of the worst unknowns was like and knew I would now be better prepared for an inevitable next death.*

I felt prepared for the next death and felt I was better able to support the patient, family, and newer staff through the experience. Still, images from the next death stuck with me. I can see myself holding a bowl of putty that the parents submerged their hands into with their child's hand between them, straining to hold the bowl steady to not ruin the hand molds. How many other nurses have these images of death and dying that stick with them, moments that stay with them?

There are standards and expectations in so much of what we do but there are not consistent standards for supporting nurses and especially new nurses through patient death and dying. Do I think that further education, resources, and support should be available to nurses in regards to experiencing patient death and dying? Absolutely. Death and dying is a reality in our work, it should be a priority in nursing university education, institutional orientation education, and employee supportive measures. Or is it simply the expectation that this is part of the job and we are to let go and get back to it with emotions in check?

Internal Data Collection

Internal data collection was focused on assembling personal memory data and self-reflection data (Chang, 2008). Strategies for internal data collection such as chronicling the past, inventorying self, and visualizing self allowed me to elicit memories through guided writing exercises (Chang, 2008).

Chronicling The Past

Chronicling the past guided me in writing and reflecting on all the patients that I have known and cared for that have died since I started as a new graduate nurse. A handful have been on the ward; I was heavily involved in the care of a few of these patients, leading up to their deaths. In focusing on chronicling the past and collecting personal memory data, I wrote:

We think of the kids we care for and have cared for more than some will ever know, more than caregivers might imagine. We are happy for them, we are sad for them, we worry for them. We think of the families, their siblings. How having a sick child or sibling may not define them but will always be a part of their lives. We think of the ones that experienced the worst, the ones that made it through, the ones that didn't, the ones that got left behind. Some of these kids and families fade away with time, some stick with you like glue. Every once in a while a memory is triggered by a diagnosis, a medication, the room, a sound, a smell, a discussion with a nurse that was there with you.

I looked everywhere that I could think of and I have not been able to find the binder. It has been many years, many changes ago. We have new policies, new nurses. Those that reside in the room and go in and out of it are different and ever changing but the room, the room has not changed. For me, that room stays the same. The first place I cared for a dying pediatric patient. A lot of rooms hold no meaning to me but as the years go by and patients come and go, a few rooms hold many memories good and bad behind their heavy doors.

I walk around looking, the typical sounds of the unit that I have become so accustomed to, the sounds that mean we are needed, increasing with each step. I know what every alarm means within seconds of hearing it. De-sensitized to many, the typical, the non-emergent. Call *bells ringing, feeding pumps beeping, IV pumps alarming. The binder was on my mind but I wasn't able to go look there right away, pulled away to attend to the needs, the alarms, the tasks.*

Despite all the noise, I try to maintain a peaceful environment, I always do, especially during the night. I made an exceptional effort to that weekend with her. Quietly opening and closing the door so that it didn't even click. It is a dance in the dark to maintain standards of care, while tip toeing around trying not to wake up the patient or family, a current drawn to shield the light from the hallway, blinds fully down to shut out the city lights, the room illuminated only by the screen of the pump, the computer, my phone. So many minutes I have spent standing silently in front of the IV pump while the patient sleeps beside me. Counting their breaths. Trying to catch and silence the beep so that they do not startle or stir. The main vehicle for us to heal, to provide comfort, to maintain life, can be so disruptive. You can tell the acuity of a patient solely from the number of channels they have on their pumps. Indicative of how ill the patient is. She was very ill, but she did not have many channels. We were withdrawing life prolonging treatments, she only had channels for comfort. I don't think I have ever thought before that one of those beeps or alarms that I jumped to silence and have so many times since was the last that I silenced for her in that room to try and maintain her peace and comfort. I don't remember when or what the last beep or alarm was for her, but I know I silenced it.

I see some books on a unit shelf which is just out of my reach. I pull out a chair and stand up on it bringing this shelf to my eye level. I have never paid much attention to this shelf, I have seen books here, but I have never looked at them. Once hand molds of a patient and family that I helped to make sat here to dry but I have never looked at the books here. I tilt my head to read a *couple of the book titles, "In the face of death", "The next place". I haven't looked at these books before, didn't even know they were here, or why.*

I took a picture of the first page, my phone focuses on the word "peaceful", lining it with a yellow border. That gave me a bit of an eerie feeling. I took a few quick pictures of other pages and sayings and images that stood out to me as I turned the pages. I flip through sunsets, rainbows, moons and stars, clouds. I come to one page that resonates with me the most "I will travel empty-handed. There is not a single thing I have collected in my life that I would ever want to bring except… the love of all those that loved me, and the warmth of those who cared. The happiness and memories and magic that we shared." I set the book back how I found it. I can't really imagine how we would use this, I suppose for a family, or as a way to broach the topic with a child. It is not something I have seen. I see a small, old, written label as I set the book back that says "Bereavement books". No binder though.

I open my email with the intention of searching for the subject line "sad news", to retrieve an email announcing her passing and come to the realization that every such announcement would still be in my inbox from over the years. I have never initiated that search before, it makes my stomach drop. Many emails populate. The first is from many years ago when I started. A patient who went to hospice care, a baby, I cared for only with my preceptor as a new nurse in orientation but the name brings an image of her back to me in her crib…she had been in the same room. Some of the names I don't recognize, patients I never cared for. Recognizing the names, my stomach drops again. I don't need to see the date, I know exactly when it is from. Most of the emails say it happened in ICU. This email is different, mentions passing on the unit peacefully with her family who are very thankful for her nursing family on the unit. I was *expecting it, but this is how I found out she passed. I can remember reading it before going into work that night. Reading this is upsetting, it gets me choked up, and a tear runs down my face as I read the description of what happened. I was the one doing all that and that's one of the parts of it all that sticks with me the most. I forgot about this email, I don't know if I fully even read it at the time since I lived it. One of the emails months later for another baby lists services for support that you can reach out to, one of few that mentions that. Another mentions my name among others for helping care, comfort, and make memories for a patient and family. I have never seen these emails grouped together, back to back like this. I remember all of the names and can picture how each of the kids looked, frozen in time. I count all of children that I knew and had cared for at one point. I have never read some of these emails, being there, and hearing about it at work is enough. I have never quantified it before. I was not present for any of these kid's actual moment of death, but I was there for a portion of their lives before and then the dying that preceded their death.*

Inventorying Self

In continuing to probe into my personal memory data, I began inventorying self by creating lists in categorized themes to expand upon values, rituals, and artifacts (Chang, 2008). In considering what I value both personally and professionally, connections and development were at the top of my list and interactive self-observation occurred naturally with those I have worked with and experienced similar with (Chang, 2008):

The value of friends:

When I first started working as a nurse, I conversed professionally with my colleagues, but I didn't talk very much. I was so focused on the work, doing a good job, paying attention to the details, trying not to make an error, making sure patients and families had everything they needed, ensuring everything was on time. It was a busy and acute unit, staff shortages were common. I didn't feel like there was time to make friends or that it should be my focus, I had lots of friends outside of work, I didn't talk much, I did my job. I didn't realize it at the time but I needed work friends. I needed people that understood what precisely it was like. What it was like caring for the patients that we did, in the environment that we did. Friends with different jobs don't get it. Even friends with the same job don't completely get it.

There is a sort of isolation in caring for kids that die. It isn't something most people would even want to talk about. I remember getting invited to a colleague's house for a gathering one night after she died. I was nervous to go. I hadn't talked much about caring for her with anyone, I thought this was just how the unit was and what happened here and there, and that I shouldn't have feelings about it. One of the more experienced nurses asked me how I was doing and started talking about how upsetting that day was and how she felt torn between the two patients and not being able to help either nurse enough. She was tearing up talking to me. I don't remember many of the details of the conversation but I remember being relieved that someone was talking about it and having the realization that this is hard for everyone, its not what most people have to deal with in their daily work and it is okay to talk about.

I am now closer with these work friends in a lot of ways than a lot of my other friends. Two of them cared for her and were there at some point that weekend. They knew what it was like. We talked about it a lot, the frequency has decreased. I've experienced some of the worst *things in life with them, have worked every hour of the day with them. They have seen me exhausted, stressed, upset, sick, happy, humorous, a student, a new grad, a leader.*

I don't think I would have stayed without them. I learned a lot from them. They have supported me and encouraged me. When I think back to when I became friends with them, I think of that time, with her. She couldn't have known that she would bring us together but we were all on her core nursing list, nurses that she chose, considered friends, and wanted to care for her in the end. Maybe she knew more than we did at the time. Gave us a gift that you can't hold but we all could hold on to. Friends.

Exploring rituals led me to consider music, hospital debriefs, and patient's funerals.

There is a song. It took me randomly hearing a song that brought me back to walking on a sidewalk home from a class in university. It brought me to a time and place. Nothing particular about that memory, other than I liked that song at that time. I was just scrolling on my phone on social media and it plays the song and asks "do you remember when this song came out?". I do. It makes me think, there was a song, from that time. It came up randomly on a playlist some time back that made me think of that time. I click it and start listening.

The first notes I can feel in my chest. 8 seconds in I can picture myself in my room, dark outside, getting ready to go in for a night shift. I pause it. I don't know if it was before that weekend, during, or after. The lighting is vastly different from the time it takes me back to, its bright outside, snow everywhere, further brightening and illuminating outside where I sit in the same room in the sky, floors above the ground. I replay from the beginning. The words "just to get me by", reminds me that it was tough going to work then. I pause it and replay it from the beginning again. I close my eyes and just listen. My hands are cold on my cheeks, holding up my *head. I can picture myself walking to work, cutting through the same parking lots that I do now, the same walk I have done for years. I would have listened to this song on repeat. I often use music to prepare myself, get me in a mindset, ready for a game, to sit in an emotion, to not let my brain wander, to focus. Preparing and focusing for the unpredictability of the shift ahead. "I wish you the best, its going to be a long long ride, you should get some rest". "The pain won't leave me, I don't want to fight it no more". I definitely did not dissect the lyrics to this song at the time but maybe subconsciously felt what they were saying related to me at that time, to the patient. As the song comes to an end I can picture the "repeat 1 song" icon clicked on. I screenshot the lyrics and my eyes focus in on "then the pain". The whole palliative plan for her was based on her not wanting to be in pain in the end. When the pain got too much, we withdrew care, and started her on comfort measures to control the pain, and sedate her until the end.*

The song repeats back to the beginning, the first few notes on the piano is again what I can feel in my chest. That is what brings me back to that time, preparing for something I had never experienced before, focusing on keeping myself calm, trying to keep her comfortable and free of pain. I might have listened to it the whole walk some nights. I think music has the ability to make you feel viscerally how you did in a time and place of your life. The first few piano notes catch me in my chest, slow my breathing, bring me back.

Everyone offers help and not just to say they asked, but to actually help. Can you be helped through a child's death? It is a very supportive environment to learn, to grow, to achieve career goals. I have been here for my entire career, I have learned, I have grown, I have achieved career goals, I have made lifelong friends, and met people from all over the world. I am pleased *with who I have become professionally and personally which both have been immensely influenced by my job, the work I do, and the people I work with.*

We have a lot of long-term patients and families, patients that are in and out of the hospital throughout their life, teenagers that nurses have known since they were babies. We do not have a dedicated palliative care unit. I suppose part of that is that maybe that's not the decision most children or parents make. Most will try anything and everything to try and keep their child alive. Ultimately, most children pass away in the ICU, after all and everything has been tried to save. Those that do go palliative are supported on the unit or in and out of home. Not something that happens often, but something we are not additionally trained for. Case by case we are supported by the palliative care team which goes by a different name that emphasizes promoting quality of life. Parents will often say that regardless they know what that team is for and why they are there. They don't often connect with us the nurses on what they discussed with the patient or family, just that they are involved. I know what this involvement looks like as I saw it first hand but I'm sure many nurses do not.

Hearing that one of our long term patients has died in the ICU is often a scheduled debrief that you may or may not be able to attend, may or may not want to attend. Then return to regular programming, not letting the other parents or patients know or sense the upset, the other patients' care isn't interrupted. We return to working, affected or not. Is this the expectation or the culture of nursing? Surely not everyone can "take the day" after receiving this news. I compartmentalize it. I don't like attending the debriefs, I often choose to not. Debriefs for me make it too upsetting, I feel my emotions and everyone else's. Some nurses are comfortable sharing emotions in group settings, I would prefer to talk to one of two close colleagues. Talking *about mine and everyone's feelings would crack at the layers of steel I have worked to put up around the feelings and upset I have for all of these children and families that I have cared for that have gone through truly awful circumstances.*

A gift that I received from a child that was dying is the artifact that held the most meaning to me.

The cup:

It was not long after I received the coffee mug that she passed away. In the gift bag that I received it in, I took it to my parent's home. I placed it in the very back of their china cabinet and folded up the gift bag behind it. Not visible in daily passing, only the pink of the gift bag could be seen if you looked in. I knew it would be safe there and would not get used, misplaced, or accidentally damaged. I wanted to put it away, maybe even some of the feelings that I had towards the experience away with it. I did not want to be reminded daily before work that sometimes no matter what, we can not save them all.

Before approaching the cabinet to take out the mug, I tried to remember receiving it. Another nurse who had also been taking care of her and had cared for her that day was given the gift at the same time as I was with her close family at the bedside. We exchanged a look, knowing we were not really supposed to accept gifts, however, this seemed different. We thanked them all and said how they did not need to do that but how thoughtful it was and learned after leaving the room that the patient had used some of her money to buy thank you gifts for the nurses that had cared for her. She had not been feeling well at the time so we did not linger. The other nurse and

I went to the nursing lounge and looked at the mugs there, stating how touching and upsetting this was before placing them in our bags to take home.

There it sat on the second shelf from the top undisturbed and unnoticed for years. I discussed with my advisor about writing a reflection about this gift the next time that I went to visit my parents. At the time, I did not realize what time of year it was. It did not come to me until I saw the pink of the gift bag at the back of the second shelf from the top and think, the same month of her passing, merely a couple weeks away from the date, I look on the second shelf from the top and see the pink folded up bag resting against the back of the cabinet. I know the mug sits in front of that bag, not visible through the window doors, disguised behind rows of souvenirs from around the world and cherished family heirlooms from generations past. I can't remember the months or dates of many patients' deaths since, but this one I do.

I open the cabinet and see the tag of the bag laying on top of the mug, I do not recall what it says, so I pick up the bag first. Written in black ink "Thank you so much for everything, being super sweet:)". The flip side of the tag, rimmed with gold says to and froms. To me, from her. I recall the mug being white and pink with a saying I also do not recall. I reach back in and grab the handle of the mug in my right hand, expecting to find dust left behind on my hand, but the mug and everything else is clean in the cabinet. The white mug is cold in my hand but my first feeling looking at it is warm. There is a light pink flower, rose like, only the bloom, on the front with writing in lowercase cursive underneath that says "everything you need is within you". I look at the inside of the mug which is a lovely light pink, bright, and positive. It makes me smile actually. Honestly, not what I expected. It makes me think of how much I have learned and grown since then. How I am not nervous or anxious going into a shift like I was then. How work *consumed so much of me then and now I have more of a balance. I remember not having time to exercise then and how it is something I prioritize now. I run my thumb over the flower and the saying again, feeling this printed design, reading the saying over a couple times to myself. "everything you need is within you". It makes me smile, it does not bring back flooding memories of what preceded her passing, only that moment of being passed the bag and being so surprised that through everything she was experiencing that she was so resilient and thought of how she could thank others, maybe not even realizing how special and appreciated this would make us feel. It is really a lovely mug. "Everything you need is within you", that is a good saying to start your day with.*

I put it back, exactly how I found it, with the tag sitting on the edge of the mug "Thank you so much for everything, being super sweet :)" visible on top. I wonder what the other nurse did with her mug, does she use it? Or does it sit safely away like mine.

Visualizing Self

In visualizing self, I put pen to paper. I did a free drawing of a place and drew the image that sticks in my mind the most when I think about my experience with the death of a child patient. The moment that stays with me. This free drawing led me to explore the existential concepts of subjective human experience of space, time, body, and relationality through reflective writing and "how" patients stay with us and "where" patients live within us (Davidov & Russo-Netzer, 2022):

My experience of the space in which the child I was caring for, died:

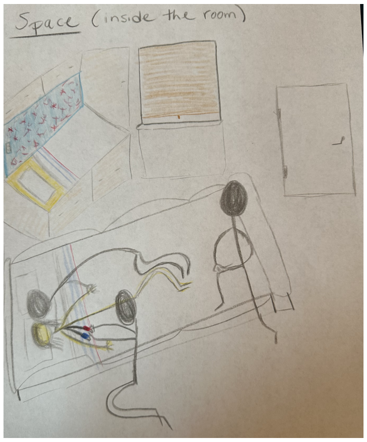

Figure 1: *The space*

All of the rooms from the outside look similar, there is nothing overly special or different about any of them. Gowns in bins sit out front of some, computers and a chair out front others. All have sanitizer, gloves, signage, a room number, a patient name. I stood outside of that room with another nurse double checking our resources and setting up the infusion. I remember not wanting the patient or family to feel nervous or uncomfortable that I was starting a medication I had never administered before. We were trying to not make the space in the room medical or medication focused. That work still had to be done but was planned and done outside of the room. Trying to keep the space inside the room peaceful. I spent a lot of hours sitting there in that chair, waiting for something I had never experienced before. Not really knowing what I was waiting for exactly. Was it going to be traumatic, a seizure, an awful bleed. Would it be peaceful, a last breath, embraced in her family's arms. Something in between? What would my role be at that moment, how was I going to act or respond? For hours sitting in that chair, on edge and at the ready, these thoughts filtered through my mind. Colleagues coming and going past me, in and out of other rooms, checking to see if I needed anything. Bells ringing that I couldn't respond to.

A lot of the time, most of those nights, it was just me, in that space, faintly hearing chit chatting at the nursing station down the hall. My job was to sit there, to stay there, to be ready for something I knew I wasn't ready for. A lot of the meds were ones I wasn't familiar with and hadn't given before, I sat in that chair looking through the resources on the computer to make sure I was prepping and administering everything safely. I spent a lot of time planning my care and making sure I wasn't missing anything in her care plan, I repeatedly would go back and check everything once, twice, three times. I didn't want to make an errors or miss something that she needed to be comfortable. I have sat outside of a lot of rooms since in a similar space and set up. None for the exact purpose of why I was sitting there then. And haven't since felt the same way I felt as I sat there. I was nervous, anxious, tired. Trying to be present for her and her family. Setting aside me and my own life, not being home with my own family on family day weekend. I went in and out of the room at least every hour, then back to my chair, to be there for anything they needed, in case anything happened. Outside of the room I could be stressed, I tried not to bring that into the room, not let the patient or family feel what I was feeling.

Grey and yellow are the colours I choose to draw this space. The rooms are very beige, grey, yellow, white. Neutral colours, not happy, not dark, but neutral. I started with the window, central in the room. It was drawn to not let light in. I see the room from varying perspectives. From varying moments in time. The two moments inside that room that live as images in my mind are when I hooked her up to the infusion and when I saw her for the last time. Standing at the door looking in, I can see the room, set up like the rest, no one in the room. I can also see her sleeping…sedated… flat in the bed, a dark room, me standing at the IV pumps, putting on meds, my hands and the meds illuminated only by the light of the pump. If I think of the moment in time *when I hooked her up to that infusion I can see differing perspectives of that image. I can picture seeing myself in that space as an observer. I can see me in that space, my back to the door, me facing her, my back to "me" observing. Her and her family on the bed, the palliative care doctor sitting on the end, me kneeling at the head of the bed. I can also picture the space in that moment in time when I hooked her up to the infusion from my eyes, looking down at my hands shaky, trying to breathe quietly, aware of the other eyes in the room on me, aware of the heaviness in the air, the heaviness of the situation at hand. Me joggling her central line, IV lines, flush, swab, all in my hands shaking as I try to connect her without touching the end of the lines to anything. It was not just that I thought my hands were shaky, they were physically and noticeably shaking. At that moment, inside that room, I could hear alarms ringing outside in the halls. She groaned as I went to get her line again and that's when I said "it's okay, I'm just hooking up your line", her response being "it's not okay". I knew nothing about that situation was okay, a child knowing she was about to die laying in her family's arms. That wasn't what I meant, I meant I wasn't doing anything annoying or painful, that I was trying not to disturb her. Her response made me more shaky and I had to focus on looking only at the end of her line while I connected it. The doctor said she would push the button the first time so that I didn't feel responsible. Inside that room was the first time I was made to feel like I was responsible for her death. It was not done intentionally, but rather to make me feel the opposite, but hooking her up to it was the beginning of her end and everyone inside that room felt that. I went in and out of that room as quietly as I could all weekend with the sole purpose of making sure she was comfortable, that was her priority, and I made it mine. I was scared to do anything wrong or to disrupt her peace. Other* *nurses weren't allowed inside the room at this point unless asked. It felt isolating and lonely in that room, like I was going through it mostly alone.*

The last moment I saw her in that room, I felt shaky again. Another nurse and I tried to clean her up and make her comfortable for the day. She was lifeless and not responding, only breathing, couldn't hold her own head or limbs up. We changed her and I did her hair, putting a roll under her neck to support her head. A doctor came in to check on her and told her how nice her hair looked. I found it comforting how calm and normal she was when she came in, maybe unlike myself something she had experienced before. It was a drastic difference to how I was feeling, constantly on edge, waiting for it to be the last moment she took a breathe inside that room. I was not there for that but can picture touching her arm and leaning in to say goodbye with the next shift of nurses and doctors standing at the end of the bed. I felt for the nurse I had given report to, knowing it wouldn't be long, and that she now was going to have to take on and feel many of the things that I had all weekend inside that room.

That space has always felt different to me since. Walking into that room, especially on a night shift feels different than the other rooms, like it was her room, and someone else is in it.

Even after all this time, somewhere in me lives all the kids that I have taken care of that have died:

I love the part of my job where they get better, go home after all that we did to them, live a better life than they were when they were sick. That's what I wanted to do. Not see them die, left behind at the hospital without their parents, their siblings. See them live and go home, but somewhere in me lives all the kids that didn't, all the kids that I have taken care of that have died.

Most of them I didn't even care for during their death. Their dying though. Somewhere in me lives their families, their names, their faces, their smiles, their eyes. How they looked the last time I saw them alive. Inert until made active, something unexpected can bring you back to that time, in that space, with that body. A sound, a smell, a picture, an item, a person. Every once in a while, something reminds me of them, I wonder how their families are, if they have had other children. They sit frozen in that age, in that space, in that time, somewhere in us. Sometimes I stop to think how old they would be and what they would be doing but the image of them then, how I knew them right before they died doesn't change. Most people don't have to carry the death of children with them, especially from a job, the memories of kids stuck in time, stuck in that space, stuck in that body and that age they died at.

I like to think we make an impact, a positive one. This had a lasting impact on me that has remained for years. Most of these experiences do. We spend hours and hours of our days with them. When they pass, an email, maybe a debrief, a message to the family, then on to caring for the next patient. Do we get closure, get to say goodbye? Not often, but time moves on and those memories and feelings stick. I don't really agree that "time heals all". I think over time you can feel things less deeply, they impact your daily life less, but there is always a part of you that can feel how you did in that moment in time.

Collecting personal memory data from a time when I felt much different about my work and life than I do now. It is difficult to bring myself back there to remember where I was when I started out, a moment in time. I have sat outside of a lot of rooms since in a similar space and set up. None for the exact purpose of why I was sitting there then. And haven't since felt the same way I felt as I sat there. After this death, I felt less stressed coming to work, less anxious, more *comfortable. I had the feeling that this was one of the worst things that could possibly happen, a child dying that I had taken care of. I experienced it, I knew now what it was like. My hands haven't shook like that again. I attribute it to the magnitude of what I felt like I was doing, hooking up the infusion, a remarkably poignant moment, the start of her death that weekend. Everyone in that room knew that: I did, she did, her mom did, the palliative care doctor did. I still try to leave my stress at the door. I think I am much better at it now but I've maintained that trying to remain calm externally rather than whatever I am feeling internally is how I approach care and stressful situations at work.*

My experience changed me and the direction I wanted to take my career. I had always thought that I would work in ICU. Over time, I changed as a nurse. I often think of the term "steel yourself", and that is what I did. I felt like I got too close, that I was too affected by something that had happened at my job, it was bleeding into my life, I was actually upset by this loss. I changed, I didn't fully open myself up and give all of myself to patients and families. I don't think this was a noticeable change to anyone, it was one that I was actively trying to accomplish though. I shifted my values, shifted my perspective, developed boundaries, and looked at my life outside of the nurse. I remained compassionate and caring and empathetic, still had patient and family centered care in the forefront of my mind, but this was about me and how I had felt, how I didn't want to feel again, I wanted work to be work and to not get too attached. Over time following this experience, I recognized that I did not want to subject myself to children dying frequently. Inevitably it would happen again on the floor, but not to the same extent. I changed my mindset, I didn't want my work to be all consuming, I wanted a life outside of work and to not take work home with me. Maybe that was a gift that I received from this experience, *something that forced me to find balance and look at the bigger picture in life. Over time I changed my focus to be on nursing education, a goal to progress as a leader in nursing, but also to achieve this balance, spend less time at the bedside. This change was not all because of this one experience, but some of it definitely was.*

My embodied experience of witnessing a body dying:

Some illnesses and diseases there are machines that can act in place to continue the body's physiological purpose. Others, there are medications to treat symptoms but ultimately no treatment. As a student, I saw the first person I ever saw dead that was not at a funeral. There was no preparation, my preceptor told me another nurse's patient had died and it would be a good experience for me to go watch the process. I knew people died in the hospital, I naively though never consider what a nurses' role was in that. Caring for those that were dying and had died was not what I thought of when I thought of a nurse and the job I was training for. I thought of caring for someone and helping them get better. School never taught or discussed what it would be like to see someone dead for the first time. My preceptor definitely did not, chalked it up to a good experience to learn from. Is it something that should and can be taught early on in a nursing curriculum? Or is it just that, an experience that you need to learn from in the moment.

I walked in and stood at the door, two other nurses were in the room and had started to wash the yellow body and remove jewelry. I had never seen someone that yellow before in my life, so yellow and yet grey at the same time. That hue I have seen many times since, but that yellow body, seemed to be the most yellow. That yellow body was all that I knew of that patient, I had no connection to them, I didn't even know her name. The body was all that I knew. It was a *bit unnerving seeing a dead body, I was shocked by the colour, and I can picture the body laying there if I think back and me standing at the door. I had no relationship with her though, no emotions associated with it, other than having empathy for her family. Just the body. Having a relationship beyond the body, knowing the person, that is what I have come to realize elicits emotions for me.*

A body in liver failure bleeds. Can bleed from anywhere and everywhere. A body in liver failure can not maintain its blood sugar. A body in liver failure gets confused and lethargic. As a student, I had this knowledge from a text book, over the years, I know what it looks like, I know how to assess it on the body of a baby, of a teenager. Typing that stirs up emotion in me…I think liver failure is the worst organ failure, it is awful seeing children and their families go through it. Objective and subjective data and assessments collated to determine the clinical status of a patient. We use all of our senses to assess the body. Listen, look, feel, smell. Is their body breathing laboured, does it sound in pain, does it look alert, comfortable, can I feel its strong pulses, does it feel warm or cold, do I smell blood. This can be done without the development of a relationship. Many things we assess, parents may not be able to interpret if it is good or bad. Liver failure is more obvious, parents know that being that yellow and bleeding and lethargic or confused is not good. They know that when we don't leave the bedside and keep having multiple other people come in to help that it is not good, that we too are worried. I still care for the body, try to ensure the body is well. Over time, I have become better and faster at identifying when and why something is wrong with body and how to proceed. When should I become concerned is a question that I have learned how to answer over time.

It's amazing how fast the colour of the body, eyes, changes after a successful transplant. Though if this was a deceased donor, that means that some other family has just gone through one of the worst experiences of their life losing a loved one, in some cases losing their child. I don't think that is at the forefront of mind on this side of things. Hoping and wishing for an organ so that the patient, their child, themself, can get better. For a deceased donor organ, ultimately equates to hoping someone else is getting taken off of life support or is passing away. I consider the bigger picture now, the other side of transplant. I didn't think of that part when I first started, I thought of all of the positives of transplant. One of my friend's mothers recently reminded me of this candidly in chatting to me about my job. She knew I was a nurse, I knew that she lost a child many years ago before my friend was born. I didn't know that they had donated her son's organs after his passing. Through tears, she said that she had called the hospital, just wanting to know that the kids that received her son's organs were okay. They gave his body to save so many others, to give someone else's child more time in their body.

Her body was yellow and yet grey, more noticeably in the fluorescent lights. Her body took breathes in and out slowly. Her body was warm when I hooked her up in the beginning of that weekend. At that point we stopped everything but looking and listening to see if she was breathing. I felt like I wasn't caring for her body anymore. Only making her body comfortable, so I couldn't hear or see pain. The last time I saw her, her body was lifeless, limp, cool. I cared for her leading up to her death but I never saw her body take that last breath. I don't know if that was a good or bad thing for me.

My relationship with the child who died and what that meant to me:

She trusted me, she liked me, she chose me to be one of her nurses when she was dying. I liked her, her mother, her sister. I was a part of her life and she mine, not just a fleeting moment in time. I knew her for years, she maybe didn't realize it but she saw me grow from a student and into a novice nurse. I didn't realize it at the time but what I experienced with her has stayed with me, changed me.

She was a teenager, her family didn't often stay overnight, sometimes not during the day if they were working, unless she wasn't feeling well, and towards the end. She spent a lot of days and nights with us, we came and went, but that was her life, she was too unwell to go home this time. When she was getting sicker sometimes as a nurse I would only have her. I sat and watched movies, chatted about shows she liked, tried to be a support, a friend. She was a teenager and this was her life here in that space, in that room, on that floor. Not hanging out with friends, going to school, having an after school job, playing sports. I often felt bad about that and tried to make time and make an effort to spend some "non-medical" time with her. Her mom had once told us that we were her friends, her family. Caring for kids, I think boundaries get blurred. I think we sometimes get too close, not for them, but for us. We are taught in school about holistic care, we are good at this, we are good at developing relationships that benefit the health of the children and families that we care for. I just never thought how developing those relationships would affect me, now it is something I think about often.

My relationship with her consisted of a lot of career firsts for me. She was one of the more acute patients I had ever cared for. The first child patient I had cared for that had died. Actually, my first realization that transplant is not a cure, it is a treatment, and even though they *are kids and so so many of them are so resilient and just bounce back, a realization that they can't all be saved no matter how hard we try.*

I can picture her in that room, sitting in front of the window, writing in this booklet, writing about her preferences and values that should be taken into consideration for her death. What I felt was most hard was the heart wrenching realization that as a kid, she knew she was going to die. She sat and wrote in this book about how she wanted to die. She knew that by me connecting her to that infusion was the pivotal moment, the point of no return, the beginning of the end. That is the moment that I think of most, that I hooked her up to die. Reminding myself that that was her wish to be comfortable and not in pain, something that I was so desperately trying to accomplish for her. I cannot imagine what it would feel like to know that this is the point where your death begins. At the time, it was a task I was supposed to do, the tasks overwhelming my ability to feel the impact. I never thought at the time how I would react in her situation if I knew that I was going to die. I don't know what I would write in that booklet. She prioritized comfort and family. She was mature, calm, gracious, respectful, reasonable, rational. She was strong for her family, for us.

The last moment in time that I saw her. I touched her arm, leaned in closer to her ear and said bye. I knew that would be the last time I saw her, the end of our relationship. She died that night. A lot of times we get invited to funerals or celebrations of life, I was scheduled to work on hers. The decision was made for me to not go. Some nurses went, some nurses do go to them every time. I never have. Going to me always felt a bit like I was crossing a boundary, that the relationship was meant to end in the hospital and not extend beyond those walls. Going, I know I would have felt a lot of emotions and I think that is what I avoid by not going. Avoiding opening *a box of emotions that I work to keep closed so that I can continue to do the work that I do. Creating a boundary so that work does not spill into my personal life and consume me, so that there is an end to the relationship in the hospital.*

Self-Reflection

In reflecting on my self, I explored my identity as a nurse and as a person. As a person, I am Canadian, born and raised in Ontario, a white female of middle class. As a nurse, I was educated and trained in Ontario through an accelerated nursing program following a previous biological sciences degree.

Does the nurse go to work every day or does the person? Can they really be separated? Are we valued as a nurse or a person by the patients, families, organizations? My experiences have shaped who I am and influenced how I act, react, and reflect on any situation. I have experienced things at work that have changed the nurse I am and the person I am. I will carry some of these experiences with me for my entire life. If I were to quit tomorrow, I would be easily replaced, as a nurse, likely forgotten as a person fairly quickly at work. But still I would carry with me some of the images, conversations, feelings, memories, that are burned into my mind, forever changing some parts of me and the path I took.

As a person entering into the world of nursing, I had not yet experienced the passing of an immediate family member in my own life. I had all of my grandparents, both of my parents, my siblings, aunts and uncles, cousins. I recognize now after years of working in healthcare, how blessed I am and how blessed I was. My grandmother died following the patient's death. My grandmother was my first close family member to die. She had been a nurse herself, she didn't *want to be in the hospital, she wanted to pass at home. I think about that sometimes and wonder what her experiences were, what changed her as a nurse, as a person, that made her not want to die there. Her decision to stay at home necessitated family members helping and staying. I worked and came home when I was off to help. I had 3 days off for her death and then returned to work. I can picture myself sitting at a computer writing out my care plans for my patients, thinking why was I there, and how was I supposed to do this without getting upset. I was trying so hard to push down the person and just be a nurse. Push down the person to be present for other people, total strangers. All I could think about and wanted to be doing was be present for my people, my family, my person, that just went through equal and worse.*

As a nurse, I did experience death before her as a student in two instances. Neither case did I know the patient for more than a shift. I recall one of the nurses who was not my preceptor telling me to just go in this room and see how to prep a dead body. Thinking this was a learning experience and something I needed to do, I walked in, stood at the door, and watched. It seemed emotionless, as a yellow lady was washed, stripped of jewelry, tagged, bagged, and zipped up. I can easily picture the yellow lady in the bed in that hospital room. As a person, this was the first death I saw. I thought it was sad that she had no family there but I didn't carry much with me from that. I could picture the yellow lady, but I had no emotion attached to it, as a person, I didn't know her.

As a person, I got to know her, since I was a student. It is not a nurses' role to sit and do homework with a patient, to chat about their favourite shows. Is getting to know a patient crossing a boundary or considered a therapeutic relationship and holistic care? The person *worries about that patient and family when they walk out of those hospital doors and go home. When they wake up in the night wondering if they are okay. The nurse isn't required to worry.*

As a nursing student and new staff, I always thought that I would go on to be an ICU nurse. I was medically knowledgeable, motivated, thought I would thrive in the acute, face paced, challenging environment. I never attached emotions to this plan, never thought of how I would feel being surrounded by death and dying monthly, weekly, daily. Why would anyone want to willingly do things like this repeatedly? Were they better at not feeling it than me? Could they separate the person and the nurse? Not until I connected her to that sedation, when the staff doctor told me she didn't want me to feel responsible if she died when we started it. This was a point of no return, the beginning of her death for me, and when I changed my mind about where I would take my career. Changed my mind about the nurse I had thought I would become. The nurse and person now realize that children die and there is sometimes nothing that we can do to stop it. As a person, I don't know what it is like to lose a child, but I have watched it more than once. It affected me beyond the nurse to my person, ever changing both.

I changed how attached I got to patients as a person after that. I liked when a patient and family liked me and wanted me to be their nurse. I thought it meant I was doing a good job, that I was doing meaningful work. I got away from that. I needed some separation of the person from the nurse. I learned how to not give all of myself, how to keep my own cup full. How to not take on all of their feelings and how to not take that home with me. How exactly is hard to explain. Spending a little less time in their rooms just talking, asking patients and families a few less questions about themselves, sharing a little less about myself when asked. Did I become less empathetic? Did I become a better nurse, a worse nurse? Did it matter to the nurse at all? Did *anyone notice a difference but me? I knew it mattered to the person. I knew I could have empathy without being an empath. I started to "steel myself" to stay in the work, to stay at the job.*

External Data Collection

Existing literature, interviews, and relevant policy were utilized as external data to provide additional context, perspective, and examine my experience in relation to nurses' experiences caring for a dying child (Chang, 2008).

Documents: The Policy

The binder had the policy in it for after death care. These policies are all online and have been for years, they were also at the time, but I am sure that is why the binder is gone, deemed redundant and unnecessary. I sit down on the chair I was just standing on and access the policy on the computer. I didn't look at it, just printed it and folded it up. I have only seen this policy a few times, I have never actually been the one to search it, many policies I have committed to memory that entail day-to-day standards of care. I really don't know much about the after death policy.

Before I read it, I try to remember what I know of the policy, I know we never went through this policy in orientation like we do so many others. What I know is from the one time I skimmed it, the version that was printed out in the binder, sitting outside that room. I remember thinking that this is what I was going to have to do at any moment. I needed to try and remember the steps so that I could tell her mom what I had to do and to be able to ask her if she wanted to help me or not. I don't really remember much of what it says, the moment never came on my *shifts that I had to do any of it. What I know of it was from that one night. Remove the tubes and lines, ask the family if they want to be involved, wash the patient, bag and tag them, accompany them to the morgue. The policy is a lot more detailed than that. Looking at it now I feel like I can actually retain what it says, it seems helpful and informative, information we should all know, information I definitely did not. It is very organized with a whole package of required forms and the tags. I did not look at this that in-depth at the time. This is not how I felt when I first read it and realized all the nursing responsibilities that accompany a patient death. I was nervous, anxious, scared sitting outside of that room, constantly on edge, trying to anticipate when it was going to happen and what I was going to do, what I was going to say. I was not in a mindset to learn about a new policy for the first time and all of expectations of me as the nurse.*

Literature: Nurses' experience with pediatric death

The literature was consulted to collect external data and to further examine nurses' experience caring for dying children and to increase validity and promote triangulation (Chang, 2008). Shimoinaba, McKenna, and Copnell (2021) explored the phenomena from the perspective of emergency department nurses while Chew, Ang, and Storey (2021) explored new nurses' experiences in tertiary public hospitals in Singapore. The literature highlighted many similarities between my experience with patient death and that of other nurses.

The death of a child is a significant stressor

The death of a child has been rated as a significant stressor and nurses express being personally and professionally affected by the death of a child initially and beyond (Shimoinaba, McKenna, & Copnell, 2021). Nurses reported becoming personally affected due to developing relationships and rapport with the patient and family and ultimately mutually experiencing grief with the loss (Chew, Ang, & Shorey, 2021; Shimoinaba, McKenna, & Copnell, 2021). Death is often seen as a failure and nurses questioned their competency (Chew, Ang, & Shorey, 2021). Nurses described a difficult transition from focusing on life preservation to supporting death and that not every nurse is exposed to death in the same manner (Chew, Ang, & Shorey, 2021; Shimoinaba, McKenna, & Copnell, 2021). This transition was noted to be more difficult for nurses outside of palliative and oncology care settings, highlighting a need for more support beyond these areas (Shimoinaba, McKenna, & Copnell, 2021).

Caring for children who die is a deeply emotional and embodied experience

Nurses described the various emotions and feelings they experienced along with memories that stayed with them. A child dying is often seen as unnatural and elicits feelings of sadness, anxiety, stress, frustration, overwhelmed, numbness, helplessness, demoralized, anger, and guilt were common emotions expressed by nurses recalling their experiences with child death while one described sleepless nights initially following (Chew, Ang, & Shorey, 2021; Shimoinaba, McKenna, & Copnell, 2021). Nurses discussed how these experiences stayed with them, recalling memories such as the sound of a mother’s despair that has stayed with them for over 10 years (Shimoinaba, McKenna, & Copnell, 2021). Nurses expressed that their first experience with death had the most impact (Chew, Ang, & Storey, 2021). The lasting impressions of nurses’ experience with child death can impact their view of the nursing profession and be emotionally scarring (Chew, Ang, & Storey, 2021). Many nurses noted reflecting personally and professionally on these experiences and that each experience was an opportunity for growth and to better manage a subsequent death and improve patient care in the future (Chew, Ang, & Storey, 2021).

How nurses cope

Nurses described both internal and external coping mechanisms including reflecting and talking about experiences with colleagues and receiving their support as the most highly used strategy due to a mutual understanding and commonality allowing for an openness of emotion (Shimoinaba, McKenna, & Copnell, 2021). Internal strategies highlighted included emotions and acceptance (Shimoinaba, McKenna, & Copnell, 2021). Some nurses emphasized the importance of showing and sharing emotion with families as it aided them in finding meaning in the death and was received well by parents (Shimoinaba, McKenna, & Copnell, 2021). Alternatively, others favoured internalizing, compartmentalizing, or suppressing their emotions, due to personal choice or the societal expectation and need to move on to care for another patient (Chew, Ang, & Storey, 2021; Shimoinaba, McKenna, & Copnell, 2021). Kent, Anderson, and Owens describe suppressing emotions, being avoidant, and distancing yourself as coping mechanisms when nurses are inadequately prepared and finding the death to be very difficult (Kent, Anderson, & Owen, 2012). Some nurses elaborated that talking about emotions with colleagues was felt to be seen as weakness and that emotions needed to be kept together in order to support families experiencing some of the worst days of their lives (Shimoinaba, McKenna, & Copnell, 2021). One of the nurses describes pediatric nurses as having to be both soft and tough to be able to be open and develop meaningful relationships with children and be able to handle if the child does not survive (Shimoinaba, McKenna, & Copnell, 2021). Chew, Ang, and Storey highlight that compassion fatigue can result from a failure to address emotional needs (Chew, Ang, & Storey, 2021). Support from colleagues on the same unit was highly valued as they were aware of the context and could relate (Chew, Ang, & Storey, 2021). Senior nurses were identified as useful resources and supports capable of providing both emotional and clinical support to new nurses experiencing child death as they were knowledgeable about the affects a patient death can have on a nurse and were able to validate their feelings (Shimoinaba, McKenna, & Copnell, 2021; Chew, Ang, & Storey, 2021). Additionally, their past personal and professional experiences with death fostered a more accepting attitude and recognition that despite all efforts some children will die and that they can support the family without it being their sadness to hold (Shimoinaba, McKenna, & Copnell, 2021). Coping strategies were recognized to be very individualistic and also included self-care and religion (Shimoinaba, McKenna, & Copnell, 2021).

Nurses felt unprepared

In order to effectively provide a high level of care, support patients and families, and manage their own grief associated with caring for a dying child, nurses identified a need for increased formal support and death related education and training instead of voluntary options (Shimoinaba, McKenna, & Copnell, 2021). Feeling inadequately prepared to care for patients during end-of-life was commonly expressed amongst new nurses with specific concerns related to inability to effectively communicate with grieving patients and families (Chew, Ang, & Storey, 2021). Nurses recalled that during their training patient death was only mentioned vaguely (Chew, Ang, & Storey, 2021). Additionally, nurses were concerned about offending patients and families while supporting them through grief if they were not familiar with their cultural practices around death (Chew, Ang, & Storey, 2021). Nurses also explained that their expectations entering into the profession did not match the reality of nursing and they did not expect having to perform some of the tasks required of their role during a death such as the withdrawal of care (Chew, Ang, & Storey, 2021). Nurses expressed the impact this had on them and how withdrawing care felt as if they were ending the child's life (Chew, Ang, & Storey, 2021).

Neither nursing education nor hospital culture adequately prepare or support nurses for death or grief:

Nurses recognized the importance of being able to prepare a patient and family for death but highlighted that although this was an expectation in the profession, it was not taught in school (Chew, Ang, & Storey, 2021). Suggested topics for death related education included loss and grief, communication skills, and coping strategies as most nurses identified receiving minimal education in these areas (Shimoinaba, McKenna, & Copnell, 2021). Nurses identified that training on what can be done or offered to families at this time and communication around withdrawing care would be beneficial to nurses (Chew, Ang, & Storey, 2021). One nurse elaborated on how beneficial taking a nursing palliative care course was for her to improve her care for patients and families during death as well as her self-care (Chew, Ang, & Storey, 2021). Others commented that end-of-life care education that was offered was focused on adult care rather than a focus on pediatrics (Chew, Ang, & Storey, 2021). It was suggested that education or training include realistic challenging scenarios to learn from and develop skills to manage these situations (Chew, Ang, & Storey, 2021).

Shimoinaba, McKenna, and Copnell (2021) acknowledge that following the death of a child, nurses may experience grief for a long period of time and require institutional support throughout. Immediate supports were identified as being available to nurses but there was a lack of continuing strategies (Shimoinaba, McKenna, & Copnell, 2021). The nurses discussed the shortcomings of the current support of organizational Employee Assistance Programs and debriefs. Nurses highlighted that everyone manages their experience with child death differently although it is difficult for all (Shimoinaba, McKenna, & Copnell, 2021). They identified these supports as poorly structured and under-utilized with debriefs being ineffective and failing to address the emotions and feelings of nurses and instead focus on clinical case specifics (Shimoinaba, McKenna, & Copnell, 2021). Nurses highly valued collegial support and appreciated discussing good memories of the patient with colleagues (Chew, Ang, & Storey, 2021). Another suggestion from nurses for improved support and wellbeing was to have frequent focus groups as suppressed emotions can resurface (Chew, Ang, & Storey, 2021). Focus groups with experienced nurses and interprofessional team members such as social workers could be utilized to share experiences with patient death beyond initial debriefs and promote learning and confidence building and ultimately improve care (Chew, Ang, & Storey, 2021).

Furthermore, shift worker schedules were identified as not allowing for adequate access to supports in a timely manner and an expectation or social norm to not show emotion and move on to caring for the next patient and get back to normal (Shimoinaba, McKenna, & Copnell, 2021). Effective debrief sessions and reflective practices can facilitate building resiliency and create meaning (Chew, Ang, & Storey, 2021).

Interviews: Nurses' experience with pediatric death

Interviewees were first invited to "*share with me what caring for a child who died was like for you":*

Participant 1: *"I think I was very focused on my task at hand and trying not to think too much about what this all meant. The actions that were taking place such as turning off infusions, I think it more hit me after the fact and not necessarily even the couple days after as I was still working and very focused on getting through. It was definitely more of an after effect that was noticed. In hindsight, I felt supported during the shift, but definitely not prepared. I had been prepared in the sense that I had been asked to do this (care for a dying child) the night before. So I knew what I was walking into the next morning and I knew what my shift might entail. In retrospect, I didn't know the questions to maybe ask at the time, because it's not something often discussed and something my unit does not see too, too often. Definitely in retrospect, didn't feel prepared. In school, death was discussed more in theory, not tangibly of what is actually involved in caring for a dying patient. It would have been beneficial to learn this, maybe not in school, I don't know if that would have been the time for me to absorb it, maybe once in my career. I think it would have been beneficial to have had a discussion with the palliative care team to know what signs I was looking for or what to expect. What to expect would happen to the patient clinically, the decline, explaining the certain kind go breathing to see in the end. I don't think it ultimately would have changed anything but I would have benefitted from knowing this from those that are specialized in that area.*

When I was turning off things and withdrawing care, that discussion of what to expect did not happen or from the medical team. Turning off the pumps is a simple task but the impact of it is not. I think I was all very focused on just doing the task and knowing ultimately what the consequences of those actions might be. I think it was less the actual task, but I think it was more recognizing how those actions would impact me. I didn't take into consideration in the moment the impact later I suppose. Things that stuck with me a bit were things like turning off the infusions, knowing my actions had a direct consequence. While the plan had been discussed and everyone was all in agreement, realizing I was the person doing that. Remembering the parents' words. So those are things that I didn't really think would maybe sit with me. Whereas in the moment I just focused on doing it. Those are the two things that I think back on. I felt very supported. The charge nurses that day were very supportive, kind of at my beck and call if I needed them. The managers as well. So I felt people were checking in with me. I don't think I necessarily took that support as maybe I should have those days. Definitely felt the support from colleagues on that day. I've definitely learned some things and things I wish had occurred differently. I learned more of what I would do in this situation again or if I was to support somebody in this situation. I learned what this situation looks like and what is all involved, which was something I didn't. I knew maybe a bit in theory before, but not practically. More what I have taken out of it is a bit more of the emotional side, like supports the nurse may need and people that should be involved. I didn't utilize any other supports. What I think would be beneficial in the future is maybe more support after the fact. That's what I struggled with after is it was more emotions that came after, that's where I found a bit lacking and a bit lonely. That is a feeling that if I were supporting someone in the future I would like to help them avoid. Maybe I *needed to know how to seek that support out more. I could have sought supports for myself after but I think there was just a big attempt on my part as well to move on from it. I kind of pushed off some advice and support from people willing to give it to me unintentionally not realizing the impact the actions would have on me after. I think I didn't take the time to acknowledge what had happened. I understand that the role of the palliative care team is for the patient but I think it would have been appreciated and beneficial to have spoken to me and prepared me and told me a few things of what to expect. That would have been appreciated.*

This experience did put into perspective that pediatric nurses deal with sick kids and unfortunately this (death) can happen. I do think ultimately this experience will benefit me and I would hope that I could support if it's not myself with a bit more insight than I had otherwise."

Participant 2: *"Caring for a child who's died. I mean there's a lot of emotions involved as the nurse. I want to just say it's very sad and upsetting overall. Before, leading up to it, and afterwards. I think there's a lot of deeper emotions, a big range of emotions because it's a child. Because you kind of get to know the whole family dynamic when you get to know the child. You feel the loss with the family. I don't think even after experiencing quite a few deaths I was prepared for that. As a nurse, I still don't feel overly prepared to deal with it. In any regard, physically in the moment when it is actually happening or like emotionally the aftermath of it. I wasn't prepared. It's kind of always in the back of your head when you're a nurses that something bad can happen. You always hope for the best but need to prepare for the worst. I think just generally talking about it more would be extremely helpful amongst the team, the nursing team especially. Hearing from other people, other nurses who have experienced it and* *what they felt before, during, and after. This would be helpful. Talking through the process and responsibilities, but also how they felt. Not even just days after but months after you've experienced this loss. You don't really ever talk about it again. Personally, perhaps it's a defence mechanism, but I do feel like I've tried to become less emotionally attached to patients and their families. When I was less experienced, I on the periphery experienced the death of a child and it really affected me and I was very sad and I thought about it for long periods of time afterwards. I do feel like I've removed myself a little bit more from you know becoming super attached with families. I feel like it's so that I don't feel such intense sadness and loss. Maybe not the most healthy approach. I do think there could always be more discussion and more preparation for the nursing team. Continued discussion about the risk that we work in an environment that is risky for us and our patients. More talking about difficult subjects. Even if nurses were not involved directly, they take emotion away from the experience, and everyone needs to be checked in on. But I would say I felt supported, most supported by my nursing colleagues. My leadership team does a great job at acknowledging that this is emotionally taxing and do their best to provide space and time for us to debrief. I think looking back, I would have taken more time to kind of review the supports in my hospital that are available. When I first started as a nurse, we had a bereavement support nurse, two nurses from our floor that kind of managed our bereavement process for our nurses. It doesn't exist anymore but chatting with them and having them available to walk through things with me and everyone like the process and what it means for a child to die. I really saw the value in that."*

Analysis

Data was first managed and refined through labelling and classifying (Chang, 2008). I categorized my data into experiences, reflections, and conclusions. I did not collect external data until I had completed analysis on my own data sets to maintain my own subjectivity and not be influenced by others. At times, data collection and analysis appeared cyclical and triggered thoughts to write more such as my perspective now, what has changed, and what I would tell my new graduate self. Data analysis and interpretation was accomplished by utilizing Heewon Chang's strategies as a guide for thematic analysis. Heewon Chang's analytic and interpretive strategies included "searching for recurring topics, themes, and patterns; look for cultural themes; identify exceptional occurrences; analyze inclusion and omission; connect the present with the past; analyze relationships between self and others; and frame with theories" (p.131). I did holistic readings of the entire data set as well as segmental readings (Chang, 2008).

I began by reading, rereading, and dissecting my own data, keeping lists and memos as I progressed through the data on recurring topics, general impressions, patterns, emerging themes, cultural themes, exceptional occurrences, and omissions (Chang, 2008). I created a lengthy list that included career firsts, visceral feelings, emotions, avoidance, lasting impacts, lack of preparedness, therapeutic relationships, friendships, expectations, boundaries, death denial, policies, absence of education and training, absence of palliative care units, legacies, honouring wishes, values, gifts, change, experiential learning, emotional knowing, coping strategies, loss, suppression, debriefs, connectedness, life preservation focused, after death care, moral distress, empathy, collegial support, humanity, and depersonalization. I further explored connections between the present and past within my own experiences and examined my personal and professional development and the change and growth that I progressed through. I analyzed my relationships between myself and others. My relationships with patients and families, my relationship with colleagues, and my development of friendships. I compared myself to others through the literature and interviews to provide additional context, perspective, and examine my experience in relation to other nurses' experiences caring for a dying child (Chang, 2008). I repeated the initial analysis strategies with the literature and interviews of searching for recurring topics and revealing emerging themes (Chang, 2008). Creating a list with many similarities of lasting impacts, lack of preparedness, coping strategies, emotions, relationships, life preservation focused, suppression, debriefs, collegial support, moral distress, loss, and death denial.

Initially, extracted from my own data set, I highlighted eight prominent themes. These themes consisted of a lack of preparedness, relationships, lasting impacts, emotions and feelings, death denial, boundaries and expectations, values, and change and growth. I refined these into five main themes and incorporated external data such as interviews prior to contextualizing broadly, comparing with social science constructs, and framing with theories (Chang, 2008). Contextualization, comparison, and framing was achieved by returning to the existing literature and examining the themes as they are present in current literature. The five themes consisted of lack of preparedness, relationships, loss and emotion, death denial, and lasting impacts and growth.

Lack of preparedness

My own experience led me to identify gaps in myself. Gaps in my preparedness, gaps in my expectations of the job and profession, gaps in my education and training. My perception of a lack of preparedness was directly related to an absence of a comprehensive death curriculum during my education and hospital orientation.

I have only seen this death policy a few times, I have never actually been the one to search it, many policies I have committed to memory that entail day-to-day standards of care. I really don't know much about the "Deaths" policy."

Kent, Anderson, and Owens (2012) explain that nurses are highly dissatisfied with the preparation for patient death from the undergraduate nursing education level and they continually feel under prepared. Utilizing a preparedness scoring system, a large number of nurses identified being ill-prepared in the death-related concepts including knowledge of what death is like, communicating with patients and family, providing end-of-life care and grief care, and managing personal reactions (Kent, Anderson, & Owens, 2012).

I said to the patient "It's okay I'm just hooking up your lines" so that she wasn't shocked by feeling my hands or the flush. I will never forget what she said to me "It's not okay, nothing is okay". I knew everything was not okay. I did not intend my words to hold that meaning. I often wish I had said something different.

I did not feel prepared to support a patient and family through death. I did not know what to say. I have learned since that sometimes as the nurse you do not always have to say something. You can just be there and actively listen which can be more powerful at times than saying anything at all. I did not know what death looked like, how the body changes in colour, in breathing, in lifelessness.

Her body was yellow and yet grey, more noticeably in the fluorescent lights. Her body took breaths in and out slowly. Her body was warm when I hooked her up atthe beginning of that weekend. At that point we stopped everything but looking and listening to see if she was breathing. I felt like I wasn't caring for her body anymore. Only making her body comfortable, so I couldn't hear or see pain. The last time I saw her, her body was lifeless, limp, cool. I cared for her leading up to her death but I never saw her body take that last breath. I don't know if that was a good or bad thing for me.

I did not know what I would have to do as a nurse. I did not know what that would feel like. Feeling inadequately prepared to care for patients during end-of-life was commonly expressed amongst nurses with specific concerns related to inability to effectively communicate (Chew, Ang, & Storey, 2021; RNAO, 2012).

My relationship with her consisted of a lot of career firsts for me. She was one of the more acute patients I had ever cared for. The first child patient I had cared for that had died. Actually, my first realization that transplant is not a cure, it is a treatment, and even though they are kids and so so many of them are so resilient and just bounce back, a realization that they can't all be saved no matter how hard we try.

The interviewed nurses also highlighted the commonality of not feeling prepared to care for a child that is dying.

Participant 1: "In retrospect, I didn't know the questions to maybe ask at the time, because it's not something often discussed and something my unit does not see too, too often. Definitely in retrospect, I didn't feel prepared. In school, death was discussed more in theory, not *tangibly of what is actually involved in caring for a dying patient. It would have been beneficial to learn this, maybe not in school, I don't know if that would have been the time for me to absorb it, maybe once in my career. I think it would have been beneficial to have had a discussion with the palliative care team to know what signs I was looking for or what to expect. What to expect would happen to the patient clinically, the decline, explaining the certain kind of breathing to see in the end. I don't think it ultimately would have changed anything but I would have benefitted from knowing this from those that are specialized in that area."*

Participant 2: "I don't think even after experiencing quite a few deaths I was prepared for that. As a nurse, I still don't feel overly prepared to deal with it. In any regard, physically in the moment when it is actually happening or like emotionally the aftermath of it. I wasn't prepared. Hearing from other people, other nurses who have experienced it and what they felt before, during, and after. This would be helpful. Talking through the process and responsibilities, but also how they felt."

Nurses feel unprepared to clinically care for dying children

Nurses express that they are not prepared to clinically care for the needs of a dying child and their family in the moment or to manage their emotions afterwards. The interview participants expanded upon practical knowledge gaps such as nursing responsibilities and clinical assessments of a dying patient and what specifically to expect in regards to the patients breathing pattern changes and other signs of clinical decline. Bensoussan (2024) describes observing nurses, among other healthcare providers, providing grief support in the absence of any formal education or training focused on grief and loss (Bensoussan, 2024). In Canada, Bensoussan highlights that there are not any graduate level programs in nursing that mandate education in grief and loss, rather it is elective or loosely embedded in other courses (Bensoussan, 2024). When grief and loss are mentioned in nursing curriculum, Bensoussan notes it to be outdated and a misrepresentation of grief that focusses on the stages of grief (Bensoussan, 2024). Bensoussan continually emphasizes that grief is not a linear process and it does not follow the same trajectory for each individual (Bensoussan, 2024). She emphasizes the importance of being informed and literate about what to expect from our responses to grief and loss in order to navigate and mitigate some of the associated emotions (Bensoussan, 2024).

Participant 2: "Personally, perhaps it's a defense mechanism, but I do feel like I've tried to become less emotionally attached to patients and their families. When I was less experienced, I on the periphery experienced the death of a child and it really affected me, and I was very sad and I thought about it for long periods of time afterwards. I do feel like I've removed myself a little bit more from you know becoming super attached with families. I feel like it's so that I don't feel such intense sadness and loss. Maybe not the most healthy approach. I do think there could always be more discussion and more preparation for the nursing team. Continued discussion about the risk that we work in an environment that is risky for us and our patients. More talking about difficult subjects."

Participant 1: "More what I have taken out of it is a bit more of the emotional side, like supports the nurse may need and people that should be involved. I didn't utilize any other supports. What I think would be beneficial in the future is maybe more support after the fact. That's what I struggled with after is it was more emotions that came after, that's where I found a bit lacking and a bit lonely. That is a feeling that if I were supporting someone in the future I would like to help them avoid. Maybe I needed to know how to seek that support out more. I *could have sought supports for myself after but I think there was just a big attempt on my part as well to move on from it. I kind of pushed off some advice and support from people willing to give it to me unintentionally not realizing the impact the actions would have on me after. I think I didn't take the time to acknowledge what had happened."*

Kent, Anderson, and Owens (2012) describe suppressing emotions, being avoidant, and distancing yourself as coping mechanisms when nurses are inadequately prepared and finding the death to be very difficult.

I felt tears starting to well up seeing different room numbers by my name. I never thought that would be something I would get emotional about. I choked back the tears, buried the feelings, and got on with my job. I did not want to appear like I was not capable, like I was not competent, like I couldn't handle it. There were multiple open group debriefs that week on the unit for all nurses to discuss any of the patients that had passed that weekend. I attended but I didn't talk, I still felt new and not fully comfortable. That was it. I found it upsetting being close to her in age and knowing that she wouldn't be able to experience so many of the things that I have been able to experience in life. Driving your first car, going away to school, meeting new friends, travelling to new places, starting your first career job. I sat with these feelings, reflected on what I could have or should have done differently. I was not aware of any further resources or supports at the time and I did not seek them out and no-one sought me out.

Nurses question their competency when they are inadequately prepared

Nurses described a difficult shift from focusing on life preservation to supporting death and that not every nurse is exposed to death in the same manner (Shimoinaba, McKenna, & Copnell, 2021). Death is often seen as a failure and nurses questioned their competency (Chew, Ang, & Shorey, 2021). Additionally, nurses were concerned about offending patients and families while supporting them through grief if they were not familiar with their cultural practices around death (Chew, Ang, & Storey, 2021). I admittedly was not culturally prepared or culturally aware of the different beliefs and practices among various cultures and religions participate in during death.

Encountering child death was unexpected, an existential crisis for many nurses

Nurses also explained that their expectations entering into the profession did not match the reality of nursing and they did not expect having to perform some of the tasks required of their role during a death such as the withdrawal of care (Chew, Ang, & Storey, 2021).

A child actively dying while under my care was not at the forefront of my mind as I entered my nursing career in pediatrics. I was so excited to get a nursing job right out of school, to have the opportunity to start working at an esteemed hospital, and to be a part of an amazing team that would support my learning and growth in my career. A team that could do everything to make kids better. I was excited about my role in helping kids get better, to go home, to live out their childhoods as kids should. I never considered what the alternative looked like. I never considered how often that may occur. I never considered how that would affect me or change me as a nurse, as a person.

Scant research regarding child death, thus scant evidence to inform practice

Much of the research dedicated to investigating new nurses' experience with patient death is focused on experiences with adult patients with limited research on nurses' experience with pediatric death (Chew, And, & Storey, 2021). Some nurses commented that end-of-life care education that was offered was focused on adult care rather than a focus on pediatrics (Chew, Ang, & Storey, 2021). The literature that is focused on nurses' experiences with pediatric death is predominantly investigated in a critical cares, emergency departments, or oncology settings. Many healthcare workers have limited exposure caring for a dying child as compared to adults as the occurrence accounts for less than 4% of all deaths in the emergency department (Shimoinaba, McKenna, & Copnell, 2021). This contributes to having less experiential knowledge and opportunity for learning and growth in relation to child death. Predominantly, pediatric deaths do occur in critical care settings (Roth et al., 2017). However, there has been a shift and increase in patients and families making decisions about end-of-life care and for it to occur on the wards in the absence of various life-sustaining measures (Roth et al., 2017). This shift is not matched by research in these areas or increased resources and education for ward nurses to be able to confidently provide end-of-life care to patients on the ward and many report feeling a lack of preparedness (Roth et al., 2017).

Nursing educational curricula do not adequately address death

My nursing education and institutional orientation did not delve into how to care for a dying child and their family. In reviewing Ontario university nursing-based curriculae pediatric death and dying is not a large focus. Rather, there is a focus on health and healing, wellness, growth and development, health-promotion, and family-centred care approaches (Ontario Tech University, 2025). If death and dying is a topic of the curriculum, it is highly variable in regards to content, style, quality, and credentials of the educator (Kent, Anderson, & Owens, 2012). Nurses recognized the importance of being able to prepare a patient and family for death but highlighted that although this was an expectation in the profession, it was not taught in school and they desire more education (Chew, Ang, & Storey, 2021; Kent, Anderson, and Owens, 2012). Insufficient training and preparation have additionally been reported in relation to caring for dying children and their families and effectively supporting them through death, treat symptoms, or managing ethical concerns (Widger et al., 2009).

A disconnect between evidence-based principles, knowledge acquisition, and practice

Nurses identified that training on what can be done or offered to families at this time and communication around withdrawing care would be beneficial to nurses (Chew, Ang, & Storey, 2021). One nurse elaborated on how beneficial taking a nursing palliative care course was for her to improve her care for patients and families during death as well as her self-care (Chew, Ang, & Storey, 2021). The Registered Nurses' Association of Ontario (RNAO) outlines a comprehensive guideline for end-of-life care that could be utilized and tailored for the development of enhanced pediatric death and dying educational program development (RNAO, 2012). This document outlines evidence-based nursing practice guidelines, some of which were identified as knowledge and practice gaps by myself, interview participants, and in the literature. This document provides a guideline to address knowledge and practice gaps identified and implement solutions systematically such as educational programs (RNAO, 2012). Aligned with gaps identified by myself, interview participants, and the literatures, the guideline provides evidence-based practice recommendations on end-of-life assessments, care and management, decision support, communication, grief, and self-care (RNAO, 2012). End-of-life assessments included signs and symptoms of dying and ultimately death such as lethargy, delirium, dysphagia, decreased appetite and output, breathing changes in pattern, secretion, and noise, and perfusion changes such as mottling and coolness (RNAO, 2012). End-of-life care and management focused on patient and family values and preferences, patient and family education, communication and advocacy, and pain and symptom management (RNAO, 2012). Kent, Anderson, and Owens (2012) highlight that even palliative care focused education would need to be tailored in order to be transferred to nurses that are not working in palliative care units and in cure and treatment focused acute care areas.

Grief literacy in nursing

In addition to clinical and practical knowledge of death and dying, Bensoussan emphasizes the importance of grief literacy for healthcare providers. Being informed and understanding grief can aid nurses in supporting themselves and others through loss (Bensoussan, 2024). Bensoussan discusses that a shared vocabulary and understanding of what grief, loss, and mourning are is the necessary foundation for grief literacy (Bensoussan, 2024). Grief is our involuntary response to loss, loss is the severing of an attachment to someone, and mourning refers to the tools we utilize to navigate and “metabolize” grief (Bensoussan, 2024).

In order to effectively provide a high level of care, support patients and families, and manage their own grief associated with caring for a dying child, nurses identified a need for increased formal support and death related education and training (Shimoinaba, McKenna, & Copnell, 2021). Suggested topics for death related education include loss and grief, ethical concerns, cultural awareness, symptom management, nursing responsibilities in death, communication skills, and coping strategies as most nurses identified receiving minimal education in these areas (Widger et al., 2009; Shimoinaba, McKenna, & Copnell, 2021). This was certainly my experience. Exploring these topics could provide nurses with a greater understanding of how to communicate with grieving patients and families and how to support them through acute grief (Shimoinaba, McKenna, & Copnell, 2021).

Relationships

The concept of relationships for me was encompassed by the ending of a relationship being a new beginning for the development of many of my nursing friendships.

She trusted me, she liked me, she chose me to be one of her nurses for when she was dying. I liked her, her mother, her sister. I was a part of her life and she mine, not just a fleeting moment in time. I knew her for years, she maybe didn't realize it but she saw me grow from a student and into a novice nurse. I didn't realize it at the time but what I experienced with her has stayed with me, changed me.

She was a teenager, her family didn't often stay overnight, sometimes not during the day if they were working, unless she wasn't feeling well, and towards the end. She spent a lot of days and nights with us, we came and went, but that was her life, she was too unwell to go home this time. When she was getting sicker sometimes as a nurse I would only have her. I sat and watched movies, chatted about shows she liked, tried to be a support, a friend. She was a teenager and this was her life here in that space, in that room, on that floor. Not hanging out with friends, going to school, having an after school job, playing sports. I often felt bad about that and tried to make time and make an effort to spend some "non-medical" time with her. Her mom had once told us that we were her friends, her family. Caring for kids, I think boundaries get blurred. I think we sometimes get too close, not for them, but for us. We are taught in school about holistic *care, we are good at this, we are good at developing relationships that benefit the health of the children and families that we care for. I just never thought how developing those relationships would affect me, now it is something I think about often.*

When I first started working as a nurse, I conversed professionally with my colleagues, but I didn't talk very much. I was so focused on the work, doing a good job, paying attention to the details, trying not to make an error, making sure patients and families had everything they needed, ensuring everything was on time. It was a busy and acute unit, staff shortages were common. I didn't feel like there was time to make friends or that it should be my focus, I had lots of friends outside of work, I didn't talk much, I did my job. I didn't realize it at the time but I needed work friends. I needed people that understood what precisely it was like. What it was like caring for the patients that we did, in the environment that we did. Friends with different jobs don't get it.

I am now closer with these work friends in a lot of ways than a lot of my other friends. Two of them cared for her and were there at some point that weekend. They knew what it was like. I've experienced some of the worst things in life with them, have worked every hour of the day with them. They have seen me exhausted, stressed, upset, sick, happy, humorous, a student, a new grad, a leader. I don't think I would have stayed without them. I learned a lot from them. They have supported me and encouraged me. When I think back to when I became friends with them, I think of that time, with her. She couldn't have known that she would bring us together but we were all on her core nursing list, nurses that she chose, considered friends, and wanted to care for her in the end. Maybe she knew more than us at the time. Gave us a gift that you can't hold but we all could hold on to. Friends.

Boundaries can be blurred with kids and teenagers in trying to make their lives more normative and less hospitalized, trying to help kids be kids. Having a holistic care approach with patients and families contributed to a deeper connection for me. I enjoyed working with kids and helping them get better, that was my expectation of the career I chose. I never expected to have as deep a connection with patients, that their loss could affect me, beyond the work day, beyond the hospital walls. My coping strategy was to give less of myself, have less of a connection. There are policies for everything, there is not a policy for letting go. You have to let go, to move on to the next patient, to come in the next day, that is expected.

That the patients that I have met and cared for and developed strong therapeutic relationships with stay with me, live within me somewhere and in some capacity. That the relationship is mutual, they have cared about me too, and expressed this with gifts, cards, and heartfelt words. Nurses develop relationships and connections with patients and families and feel and grieve their loss.

Participant 2: "Because you kind of get to know the whole family dynamic when you get to know the child. You feel the loss with the family."

From my experience, a nurses' loss of a patient is not acknowledged as a significant loss to grieve and is not often acknowledged which Doka refers to as "disenfranchised" (Doka, 1999). Bensoussan discusses that our Western culture perpetuates this narrative that we are not worthy of grieving, feeling upset, or being emotional if it was not one of our immediate family members that has died (Bensoussan, 2024). She elaborates that our culture teaches and embodies the notion that grief is linear, stepwise, time-limited, temporary, and with no lasting impact

(Bensoussan, 2024). Institutional bereavement policies define what relationships are worthy of time off and the length of time individuals are allowed to grieve (Bensoussan, 2024; Doka, 1999). Following a patient death, nurses are expected to start caring for another patient or return the next day unaffected. Nurses highly valued collegial support and appreciated discussing good memories of the patient with colleagues (Chew, Ang, & Storey, 2021). An emphasis on connectedness. Widger, Steele, Oberle, and Davies' model for supportive care highlights that six dimensions contribute to high quality pediatric palliative care (Widger et al., 2009). Creating human connection with patients and families throughout their journey with illness and death is one of the fundamental dimensions that contributed to the achievement of a high level of care (Widger et al., 2009). In addition to connectedness, other contributing dimensions included valuing patient and family's opinions and uniqueness, empowering them by providing information to make informed decisions, meaning finding, and preservation of integrity and the parental role (Widger et al., 2009). Finally, the sixth dimension contributing to high quality pediatric palliative care and the development of strong therapeutic relationships during death and dying is the healthcare professional caring and managing symptoms effectively for the patient and family such as pain (Widger et al., 2009).

Loss and Emotions

Emotions and feelings are both implicitly and explicitly prominent throughout my data set. I explore an avoidance of emotions in order to return to work, visceral feelings, sensory connections, expressions of empathy, and collegial support.

I was nervous, anxious, scared sitting outside of that room, constantly on edge, trying to anticipate when it was going to happen and what I was going to do, what I was going to say. I was not in a mindset to learn about a new policy for the first time and all of expectations of me as the nurse.

Reading this is upsetting, it gets me choked up, and a tear runs down my face as I read "palliative sedation started Friday was difficult to initiate". I came in early to start that, I initiated it, that's one of the parts of it all that sticks with me the most. I forgot about this email, I don't know if I fully even read it at the time since I lived it. "There is a book to leave notes for the family". There were a lot of books that week, I don't remember if I signed any of them, it was awful just looking at 3 of them sitting there.

There is a sort of isolation in caring for kids that die. It isn't something most people wouldn't even want to talk about.

I remember getting invited to a colleagues house for a gathering one night after she died. I was nervous to go. I hadn't talked much about caring for her with anyone, I thought this was just how the unit was and what happened here and there, and that I shouldn't have feelings about it. One of the more experienced nurses asked me how I was doing and started talking about how upsetting that day was and how she felt torn between the two patients and not being able to help either nurse enough. She was tearing up talking to me. I don't remember many of the details of the conversation but I remember being relieved that someone was talking about it and having the realization that this is hard for everyone, its not what most people have to deal with in their daily work and it is okay to talk about.

Participant 1: "More what I have taken out of it is a bit more of the emotional side, like supports the nurse may need and people that should be involved. That's what I struggled with after is it was more emotions that came after, that's where I found a bit lacking and a bit lonely. That is a feeling that if I were supporting someone in the future I would like to help them avoid."

As expressed personally, in the literature, and through interviews with pediatric nurses, many emotions are experienced by nurses caring for a child that is dying. Nurses described the various emotions and feelings they experienced along with memories that stayed with them. A child dying is often seen as unnatural and elicits feelings of sadness, anxiety, stress, inadequacy, frustration, overwhelmed, numbness, helplessness, distress, demoralized, anger, and guilt were common emotions expressed by nurses recalling their experiences with child death while one described sleepless nights initially following (Chew, Ang, & Shorey, 2021; Kent, Anderson, & Owens, 2012; Shimoinaba, McKenna, & Copnell, 2021). Additionally, isolation and loneliness emerged from my experience and the interview participants. My experience and those of the interview participants elicited similar feelings and emotions to the pediatric emergency department nurses in Shimoinaba, McKenna, and Copnell's research as well as Chew's. I internalized emotions in a fear it made me seem incompetent or unprofessional.

Participant 1: "More what I have taken out of it is a bit more of the emotional side, like supports the nurse may need and people that should be involved. I didn't utilize any other supports. What I think would be beneficial in the future is maybe more support after the fact. That's what I struggled with after is it was more emotions that came after, that's where I found a bit lacking and a bit lonely. That is a feeling that if I were supporting someone in the future I *would like to help them avoid. Maybe I needed to know how to seek that support out more. I could have sought supports for myself after but I think there was just a big attempt on my part as well to move on from it. I kind of pushed off some advice and support from people willing to give it to me unintentionally not realizing the impact the actions would have on me after. I think I didn't take the time to acknowledge what had happened."*

However, I see the extreme value in talking about the experiences and having a safe space to do so with peers that have experienced similar. This was also emphasized by the interview participants. I agree that working with children, we let them in, but then we also grief them as a personal loss by doing so.

Participant 2: "I mean there's a lot of emotions involved as the nurse. I want to just say it's very sad and upsetting overall. Before, leading up to it, and afterwards. I think there's a lot of deeper emotions, a big range of emotions because it's a child. Because you kind of get to know the whole family dynamic when you get to know the child. You feel the loss with the family."

Shimoinaba, McKenna, and Copnell (202) emphasize the need for grief education and training to assist nurses in managing their own grief and bring awareness to the fact that showing emotion is not a sign of weakness and experiencing grief can have emotional implications as well as physical and social. Moyle Wright and Hogan discuss how valuable discussing grief theories with nurses is to provide a framework to explore their experiences and care as well as to create a deeper understanding (Moyle Wright & Hogan, 2008). Bensoussan discusses the various tools of mourning that can be utilized to “metabolize” grief (Bensoussan, 2024). She highlights journalling, music, and memorials as some tools of mourning (Bensoussan, 2024).

This is highlighted as education that most nurses have not received formally (Moyle Wright & Hogan, 2008). Finding meaning is another dimension of Widger, Steele, Oberle, and Davies’ model for supportive care to increase the quality of pediatric palliative care (Widger et al., 2009).

The RNAO emphasizes that education on end-of-life care also needs to address the emotional needs of nurses (RNAO, 2012). This could be accomplished through increased discuss and response to nurses experiencing a patient loss, normalizing grief, and creating unit-based support groups (RNAO, 2012). Peer support programs have been highlighted as an another important strategy to mitigate issues with burnout and retention as they provide a platform for emotional reflection, validation, and an increased sense of confidence among nurses (Forster & Hafiz, 2015). Many hospitals have peer support programs, including my employer. However, Wahl et al. explores a three-tiered peer support structure that encompasses unit level peer supporters, a trained team, and clinical experts to increase compassion satisfaction and overall staff wellbeing (Wahl et al., 2018). They emphasized that how to care for yourself is not commonly discussed and there is a need for self-care discussions (Shimoinaba, McKenna, & Copnell, 2021).

This illuminates the concept of mindfulness. Nursing is a stressful profession, and it is not realistic to assume that it can be stress free, however, effective coping skills should be promoted in attempts to mitigate the effects of moral distress that contribute to attrition (Bong, 2019). Chew, Ang, and Storey highlight that compassion fatigue can result from a failure to address emotional needs (Chew, Ang, & Storey, 2021). Vaclavik, Staffileno, and Carlson introduced the notion of a combination of mindfulness approaches bundled in attempts to decrease stress and the perception of distress amongst nurses that could be customizable (Vaclavik, Staffileno, & Carlson, 2018). The "Mindfulness Bundle" consisted of mindfulness sessions, a committee to promote work-life balance, yoga classes on unit, a gift bag, and a dedicated memorial wall for patients that have died (Vaclavik, Staffileno, & Carlson, 2018). I. An additional nurse proposed strategy includes journalling about each child you cared for that has died (Shimoinaba, McKenna, & Copnell, 2021). I can appreciate the value of this to reflect on the child as a person, positive memories, all the things that you did to ensure that they were comfortable, and your care aligned with the patient and family's values. Nurses highly valued collegial support and appreciated discussing good memories of the patient with colleagues (Chew, Ang, & Storey, 2021).

I've experienced some of the worst things in life with my colleagues, have worked every hour of the day with them. They have seen me exhausted, stressed, upset, sick, happy, humorous, a student, a new grad, a leader. I don't think I would have stayed without them. I learned a lot from them. They have supported me and encouraged me.

Another suggestion from nurses for improved support was to have focus groups with interprofessional team members such as social workers to discuss experiences with patient death beyond initial debriefs (Chew, Ang, & Storey, 2021). In my opinion, these mindfulness approaches speak to much of what nurses desire to be offered and support them in addressing their emotions. They promote the development of effective coping strategies, enhanced collegial support, acknowledgement and recognition of the stress challenging situations can cause, and provided a safe voicing space. They mitigate some of the expectation to immediately return to work and move on to the next patient after a distressing event

Death Denial

In formulating my next sentence, I even found myself writing “passing” instead of “death”. “Death” and “died” seems heavier, more final. Acknowledging death is upsetting, uncomfortable. Following the passing of my grandfather, in the face of life-limiting illness and anticipated mortality, my 92-year-old grandmother has said many times “We just thought we would live forever together”. Is it hope, is it death denying, both?

In relation to my experience as a nursing student, my exposure to death and dying in class and practicum was minimal and non-specific. It was non-existent in relation to pediatric death and dying.

I was excited about my role in helping kids get better, to go home, to live out their childhoods as kids should. I never considered what the alternative looked like. I never considered how often that may occur. I never considered how that would affect me or change me as a nurse, as a person.

Death is not the goal. We are not taught how to accomplish death. We are taught to help and to heal. Curative approaches are the focus of healthcare systems which leave nurses unfamiliar and unskilled in providing end-of-life care, especially those not on dedicated palliative care units (RNAO, 2012). Nurses described a difficult shift from focusing on life preservation to supporting death (Shimoinaba, McKenna, & Copnell, 2021). This is the focus of many Ontario nursing curriculae and hospital orientations. Bensoussan emphasizes our culture's relationship with grief as being pathology driven (Bensoussan, 2024). Willer et al. discuss the components of the critical grief pedagogy which highlights a focus on "demedicalizing" grief and refuting the cultural notion of lasting impacts and long-term grieving being abnormal (Willer et al., 2021). This complements Bensoussan's stance that grief is universal and simultaneously unique for all, not abnormal (Bensoussan, 2024). The reality is, death is a part of life, everyone will die. It is a large part of many nurses' jobs and yet not a focus of our education. The absence of dedicated palliative care units and only palliative care consult teams for inpatient units places the palliative care of dying patients on the bedside nurse. The bedside nurse who has not received any additional pediatric palliative care training. Not every hospital has a dedicated palliative care unit, especially pediatric hospitals. I had to experience it firsthand before I truly realized that they can't all be saved.

My relationship with her consisted of a lot of career firsts for me. She was one of the more acute patients I had ever cared for. The first child patient I had cared for that had died. Actually, my first realization that transplant is not a cure, it is a treatment, and even though they are kids and so so many of them are so resilient and just bounce back, a realization that they can't all be saved no matter how hard we try.

Nurses expressed the need and desire to have more discussions about death and dying and to have the occurrence and risk of this acknowledged even if it is not frequent. As a student, it was modelled to me that death is routine and nurses are not affected by it and that the expectation is to move on to care for the next patient, emotions in check.

Participant 1: "In retrospect, I didn't know the questions to maybe ask at the time, because it's not something often discussed and something my unit does not see too, too often."

Participant 2: "Talking through the process and responsibilities, but also how they felt. Not even just days after but months after you've experienced this loss. You don't really ever talk about it again. Continued discussion about the risk that we work in an environment that is risky for us and our patients."

Katz and Lament describe the experience of a pediatrician caring for a dying child and explore some of the unique ethical dilemmas present in the care of children. The parent in this instance wanted the child to be protected from prognosis and medical discussions and any associated feelings to maintain the child's attitude and hope (Katz & Lament, 2020). Medical discussions were had outside of the patient's room (Katz & Lament, 2020). Katz and Lament mentioned that the child's mother forbid any discussion about the child's potential death (Katz & Lament, 2020). Withholding information from a patient at the parent's discretion creates an ethical dilemma for those caring for the patient (Katz & Lament, 2020). I have encountered this many times in my own career as a pediatric nurse. As a nurse, I have often felt conflicted between caring for my patient and what I feel is right and what I am being directed to do by the parent or caregiver. The family of the dying child coped differently (Katz & Lament, 2020). The mother was described as in denial and desperation while the father and siblings were overwhelmed and avoidant of the reality of the child's death (Katz & Lament, 2020). The mother limited visits due to how ill the child was which decreased the child's interaction to immediate family, doctors, and nurses (Katz & Lament, 2020). From my experience, this is a reality for many children when they are patients, their friends do not often come and visit them, and their interactions and relationships become centered around their medical team. Are the friends' parents also protecting their children from discussions around death and denying that is occurring to one of their friends? Katz and Lament state that despite parents' efforts to filter conversations surrounding death, children that are dying often know more than expected (Katz & Lament, 2020). Katz and Lament describes that a child experiences many losses while dying that they need to be supported with such as a loss of future, relationships, control, integrity and identity, and at times trust (Katz & Lament, 2020). Not acknowledging this and denying its possibility made it increasingly challenging for the child to discuss their illness and ultimately death (Katz & Lament, 2020). Families may be heavily impacted by how their child dies, relationships with the medical team, what conversations were had or not, and what resources they received or not (Katz & Lament, 2020).

Death denying is larger than nursing. As a society, challenging situations are often avoided or denied rather than combatted with effective coping strategies (Kiraly & Koves, 2023). The thought of death alone is often avoided due to the anxiety it provokes (Kiraly & Koves, 2023). Kiraly and Koves describe that being human encompasses vulnerability and ultimately finitude which are parts of ourselves that we often hide from society (Kiraly & Koves, 2023). Nurses are often expected to immediately return to work following a patient death and are not given the space and time to reflect.

I sat with these feelings, reflected on what I could have or should have done differently. I was not aware of any further resources or supports at the time and I did not seek them out and no-one sought me out.

Participant 1: "The actions that were taking place such as turning off infusions, I think it more hit me after the fact and not necessarily even the couple days after as I was still working and very focused on getting through. It was definitely more of an after effect that was noticed."

Facing this vulnerability and being more reflective of death can trigger emotional responses, deep reflection, and an alteration of our worldview that increases valuing of relationships and growth (Kiraly & Koves, 2023).

Lasting Impacts and Growth

It does not have to be a traumatic death to be affected by it, a death alone is impactful. Lasting impacts, the impetus of why I wanted to share my experience and to explore a vulnerable and sensitive subject. The moments that when I close my eyes, I can picture and relive. The moments that I have reflected on and tried to learn from. How I remember them, frozen in time, in their room. The moments that stay with me from experiencing a child dying infront of me. The moments that impacted what I wanted to do with my career.

Those that reside in the room and go in and out of it are different and ever changing but the room, the room has not changed. For me, that room stays the same. The first place I cared for *a dying pediatric patient. A lot of rooms hold no meaning to me but as the years go by and patients come and go, a few rooms hold many memories good and bad behind their heavy doors.*

Even after all this time, somewhere in me lives all the kids that I have taken care of that have died. I love the part of my job where they get better, go home after all that we did to them, live a better life than they were when they were sick. That's what I wanted to do. Not see them die, left behind at the hospital without their parents, their siblings. See them live and go home, but somewhere in me lives all the kids that didn't, all the kids that I have taken care of that have died. Most of them I didn't even care for during their death. Their dying though. Somewhere in me lives their families, their names, their faces, their smiles, their eyes. How they looked the last time I saw them alive. Inert until made active, something unexpected can bring you back to that time, in that space, with that body. A sound, a smell, a picture, an item, a person. Every once in a while something reminds me of them, I wonder how their families are, if they have had other children. They sit frozen in that age, in that space, in that time, somewhere in us. Sometimes I stop to think how old they would be and what they would be doing but the image of them then, how I knew them right before they died doesn't change. Most people don't have to carry the death of children with them, especially from a job, the memories of kids stuck in time, stuck in that space, stuck in that body and that age they died at.

I like to think we make an impact, a positive one. This had a lasting impact on me that has remained for years.

Nurses expressed that their first experience with death had the most impact in addition to those involving a child, being unexpected, or traumatic (Chew, Ang, & Storey, 2021; Kent, Anderson, & Owens, 2012). My first experience with child death was the most impactful on me. The death of a child has been rated as a significant stressor and nurses express being personally and professionally affected by the death of a child initially and beyond (Kent, Anderson, & Owens, 2012; Shimoinaba, McKenna, & Copnell, 2021). Nurses report feeling ill-prepared educationally, emotionally, and socially for patient death recognizing that there may be long lasting effects of this such as impacting future career decisions negatively (Kent, Anderson, & Owens, 2012). Nurses discussed how these experiences stayed with them, recalling memories such as the sound of a mother's despair that has stayed with them for over 10 years (Shimoinaba, McKenna, & Copnell, 2021). Bensoussan explains that grief is not only a fleeting emotion or feeling and that our culture reduces grief by describing it as such (Bensoussan, 2024). She elucidates grief as an experience (Bensoussan, 2024). An experience that is transformational, lifelong, has lasting impacts, and changes us physically, cognitively, and emotionally to make space for more meaningful attachments in life (Bensoussan, 2024). Bensoussan expresses the importance of acknowledging, exploring, and learning how we best mourn (Bensoussan, 2024).

Participant 1: "Turning off the pumps is a simple task but the impact of it is not. I think I was all very focused on just doing the task and knowing ultimately what the consequences of those actions might be. I think it was less the actual task, but I think it was more recognizing how those actions would impact me. I didn't take into consideration in the moment the impact later I suppose. Things that stuck with me a bit were things like turning off the infusions, knowing my actions had a direct consequence. While the plan had been discussed and everyone was all in agreement, realizing I was the person doing that. Remembering the parents' words. So those are *things that I didn't really think would maybe sit with me. Whereas in the moment I just focused on doing it. Those are the two things that I think back on."*

Nurses expressed the impact that withdrawing care had on them and how it felt as if they were ending the child's life (Chew, Ang, & Storey, 2021). In congruence with the literature and participant's experience, even though I knew the intended plan, turning off infusions and initiating sedation made me feel as if I connected the child to their death and that is what stayed with me and impacted me the most. What patients and families say in those moments preceding death impact nurses and stay with us. Accumulated grief can contribute to significant burnout (Shimoinaba, McKenna, & Copnell, 2021). Patients live within us and can be evoked and arise unexpectedly. The lasting impressions of nurses' experience with child death can impact their view of the nursing profession and be emotionally scarring (Chew, Ang, & Storey, 2021).

I learned from my experience. For me looking back, it is the point in my career where I can see my transition from novice to experienced. I gained perspective. I reaffirmed my values. I grew and developed as a nurse, as a person. I changed. I started to develop a new career direction that was sustainable, that I was excited about.

Participant 1: "This experience did put into perspective that pediatric nurses deal with sick kids and unfortunately this (death) can happen. I do think ultimately this experience will benefit me and I would hope that I could support if it's not myself with a bit more insight than I had otherwise."

Heewon Chang states that “autoethnographic writings bring this self-development process to light” (p.141) and “after life-changing experiences, people rarely go back to their old selves, but rather move on to a new direction” (p. 133).

The white mug is cold in my hand but my first feeling looking at it is warm. There is a light pink flower, rose like, only the bloom, on the front with writing in lowercase cursive underneath that says “everything you need is within you”. I look at the inside of the mug which is a lovely light pink, bright, and positive. It makes me smile actually. Honestly, not what I expected. It makes me think of how much I have learned and grown since then. How I am not nervous or anxious going into a shift like I was then. How work consumed so much of me then and now I have more of a balance. I remember not having time to exercise then and how it is something I prioritize now. I run my thumb over the flower and the saying again, feeling this printed design, reading the saying over a couple times to myself. “everything you need is within you”. It makes me smile, it does not bring back flooding memories of what preceded her passing, only that moment of being passed the bag and being so surprised that through everything she was experiencing that she was so resilient and thought of how she could thank others, maybe not even realizing how special and appreciated this would make us feel. It is really a lovely mug. “everything you need is within you”, that is a good saying to start your day with. I put it back, exactly how I found it, with the tag sitting on the edge of the mug “Thank you so much for everything, being super sweet :)” visible on top. I wonder what the other nurse did with her mug, does she use it? Or does it sit safely away like mine.

Senior nurses were identified as useful resources and supports capable of providing both emotional and clinical support to new nurses experiencing child death as they were knowledgeable about the affects a patient death can have on a nurse (Shimoinaba, McKenna, & Copnell, 2021). Additionally, their past personal and professional experiences with death fostered a more accepting attitude and recognition that despite all efforts some children will die and that they can support the family without it being their sadness to hold (Shimoinaba, McKenna, & Copnell, 2021). Talk about it. Personally, in the literature, and the interviews, nurses expressed that they felt emotional after a patient death for days to months following, however, did not seek out or utilize available resources.

Participant 2: "I think just generally talking about it more would be extremely helpful amongst the team, the nursing team especially. Hearing from other people, other nurses who have experienced it and what they felt before, during, and after. This would be helpful. Talking through the process and responsibilities, but also how they felt. Not even just days after but months after you've experienced this loss. You don't really ever talk about it again. More talking about difficult subjects. Even if nurses were not involved directly, they take emotion away from the experience, and everyone needs to be checked in on. But I would say I felt supported, most supported by my nursing colleagues. My leadership team does a great job at acknowledging that this is emotionally taxing and do their best to provide space and time for us to debrief. I think looking back, I would have taken more time to kind of review the supports in my hospital that are available. When I first started as a nurse, we had a bereavement support nurse, two nurses from our floor that kind of managed our bereavement process for our nurses. It doesn't exist anymore but chatting with them and having them available to walk through things with me and everyone like the process and what it means for a child to die. I really saw the value in that."

Talking about it is one strategy, however, Bensoussan describes three different types of grievers that mourn and “metabolize” grief primarily in varying ways which include cognitive, emotional, and physical (Bensoussan, 2024). Cognitive grievers “metabolize” grief best through reading, writing, thinking, and research to inform themselves and understand their experience (Bensoussan, 2024). Alternatively, grievers that are primarily emotional benefit most from expressing emotions and sharing their experience (Bensoussan, 2024). Physical grievers “metabolize” through activity, exercise, cleaning, and organizing (Bensoussan, 2024). Bensoussan further classifies grievers as intuitive which are primarily emotional and instrumental which are a combination of cognitive and physical (Bensoussan, 2024). She emphasizes that it is imperative to our “metabolization” of grief to recognize our preferred method of grieving (Bensoussan, 2024). Nurses should be sought out following these experiences to support them in “metabolizing” their grieve through their preferred method and not only initially and not only when the death is traumatic. Reflecting on my experience, I was offered space to share my experience in the format of debriefs, however, I did not find these to be overly helpful, not recognizing at the time that this could be attributed to the fact that emotional or intuitive grieving was not my preferred method (Bensoussan, 2024). Periodic check ins by management teams or dedicated nursing bereavement teams over the months following could benefit nurses that have experienced child death and support their utilization of available supports and their learning and growth from the experience. If nurses were informed and aware of their individual grieving method, they could more effectively utilize appropriate supports offered (Bensoussan, 2024). Offering debriefs is well intentioned and beneficial for some such as intuitive grievers, however, may not be most effective for instrumental grievers to “metabolize” their grief (Bensoussan, 2024). Many nurses noted reflecting personally and professionally on these experiences and that each experience was an opportunity for growth and to better manage a subsequent death (Chew, Ang, & Storey, 2021). Bensoussan states that experiences such as death and dying alter us permanently and allow us to learn lessons we would not have otherwise learned (Bensoussan, 2024).

What I would tell my new grad self: Sometimes despite everyone's best efforts, despite our patient's resiliency, sometimes despite all and after trying everything, they still die. Ask and listen and learn from others' experiences, others' learnings, others' coping strategies, others' emotions. You do not need to have had them when they died or immediately before to be upset. You might have had them a week ago, a month ago, popped in and briefly helped, knew their name and face. It is upsetting, you can be upset. You can't anticipate what is going to happen, but if you anticipate that these children do not ever die then you will never be prepared for it. Death and dying might be new to you in both your personal and professional life. The death of a child may be something you never imagined. But it does happen, and it is awful. Awful for the parents, siblings, family left behind, awful for the nurses that bear witness to it. A child dying isn't normal for most. It is devastating, it is heartbreaking seeing the parent's and family's responses. Sometimes you are not going to know what to say. That is okay, sometimes you just need to listen and be there for them. Be aware that this can happen. It is the reality of nursing in many settings. You will never be able to forget some of it, it will stay with you forever. You will be able to picture yourself and everyone else in that room in those moments and relive parts of it on repeat. Random things will remind you and bring you back to those moments. Talk to a colleague about it and how you are feeling. Talk to your leadership team about it, reach out to them even if *they do not come to you. Do not pretend it does not happen and nobody is affected by it. Share your experience so others can learn from it and support you simultaneously. Help others experiencing similar that you have gone through. It is nice to hear and be validated that someone feels the same and that it is normal how you are feeling. Don't be afraid to show emotion. Prioritize self-care. Take time off if you need to. Try to give yourself time to not think about it, decompress and reflect on your walk home and then try to be present in your own life. Go to a workout class, go for a walk with music or call home, see friends, do something with colleagues outside of work. Utilize the resources available. Your perspective will change, you will grow. You will fear things happening that some people never even think of happening to their children. You might fear having kids as you see the rarest disease and all the situations where things go wrong in medicine. You will see the world a bit differently. You will develop more grace and patience and empathy and compassion and kindness for strangers. You will learn to recognize your health is a privilege and to not take some things for granted. You can learn from every patient and family. You are capable and competent, you need to be confident in yourself and your abilities. You have a lot to offer and you can make someone's day better or help them through some of the worst times of their life and maybe make it a little easier for them. Sometimes the smallest gesture can have a big impact. Put yourself in their shoes. It will consume you if you let it. Take your vacation. Call in sick when you need to. You are valued but not irreplaceable. These experiences will affect you lifelong. You have more of an impact on patients and families than you think, you have the ability to support them through this.*

Interpretation

Utilizing thematic analysis, I identified recurring themes of lack of preparedness, relationships, loss and emotion, death denial, and lasting impacts and growth. The meaning of these themes was further interrogated and connected with Rachelle Bensoussan's theory of "metabolizing grief" and Kenneth Doka's "disenfranchised grief". It took me reading Rachelle Bensoussan's "Human(e)" to collate some of the conclusions I had made about my experience with patient loss. I now recognize that I had no knowledge of loss and grief as a new graduate nurse entering into a career that is filled with loss and grief. In exploring my thesis topic, I "metabolized my grief" associated with my first major patient loss and those that followed (Bensoussan, 2024). I did not realize it at the beginning of my thesis. However, this is what I needed to do to "metabolize" the multiple losses and grief I experienced with the first loss of a pediatric patient. The interpretation of my experience and others illuminated for me what is imperative for nurses to learn about and be supported with through the death and dying of a child. Elucidated from my experience, others' similar experiences, and the literature were common themes of a lack of preparedness, emotions and loss, relationships, and lasting impacts and growth. Throughout my data sets, I refer to the terms loss, emotion, or lasting impacts. I do not ever label it as grief. I did not know that I could. Grief was a term I had reserved for the loss of a significant family or friend. I had very minimal knowledge and understanding of grief, especially in relation to losses in my career. Grief as it stood for me did not apply to the loss of patients. I did not think that it was appropriate or that I could or should be grieving a patient. The loss of a patient could be seen as "disenfranchised", not acknowledged as a significant loss for a nurse to grieve (Doka, 1999). This can contribute to not receiving appropriate support, internalizing emotions, and ultimately the exacerbation of grief (Doka, 1999). Our culture pathologizes grief and treats it as abnormal, this cultural notion needs to be refuted and grief "demedicalized" and accepted as a unique experience that occurs to all humans (Bensoussan, 2024; Willer et al., 2021). "Demedicalizing" grief can start with sharing stories of loss and acting on them, especially those that are "disenfranchised" and violate the societal norms of grief and loss (Bensoussan, 2024; Doka, 1999; Willer et al., 2021).

I am seeking to share and act. Seeking to empower nursing students, new graduate nurses, and experienced nurses to learn from my experience and the meaning that I have drawn from it. Seeking to change the culture that denies death and the effect it has upon the nurse. Seeking to improve nurses' ability to support patients, families, and themselves through pediatric death and dying. Pediatric death does occur, and it does occur outside of critical care, palliative care, and oncology units and it does impact the nurses experiencing these deaths. My experience transformed me both personally and professionally. It opened my eyes to the reality of pediatric death and the feelings and emotion associated with it. It led me to refute the culture of nursing in which I was trained to accept the non-affected, unemotional professional persona. It impacted my future career plans and influenced my decision to seek out nursing education opportunities to support other nurses through similar experiences as opposed to pursuing critical care nursing. It is imperative to consider more effective strategies to support and prepare nurses for the inevitability of child death and dying in their career for both themselves and their patients and families. Nurses feeling inadequately prepared to manage the death of a child has been frequently reported (Chew, Ang, & Storey, 2021). The death of a child is not a focus of education or training. So much of medicine is focused on being proactive instead of reactive and yet that is not transferred to nurses' wellbeing and preparedness in caring for dying children. Simply learning from the experience to do better next time is a disservice to the child, family, and nurse. Families may be heavily impacted by how their child dies, relationships with the medical team, what conversations were had or not, and what resources they received or not (Katz & Lament, 2020). Child death and dying needs to be talked about and not avoided.

The interviewed nurses highlighted that they want more discussion about clinical assessments and nursing responsibilities during the death of a patient and more support following a patient death. Education and training should discuss what death looks like. I was not prepared for how the body changes in death, the colour, the breathing, the lifelessness. They emphasized feeling a loss and deep emotions that they tried to suppress in attempts to move on instead of seeking out available resources. They highlighted that death and dying is not commonly discussed but should be as it is a reality of the nursing profession. They valued collegial support and a space to discuss and acknowledge these difficult topics and hear others' experiences not only initially after a death but months following. It was suggested to introduce nursing roles such as a bereavement nurse on units that could actively and periodically check in on nurses and provide more collegial support following a patient death and not only those directly affected. Experiencing a child dying allowed nurses to gain insight and perspective and how to better support colleagues experiencing similar in the future. Nurses want to be more prepared to communicate and care for patients and families during death and dying. What I would have wanted to know looking back is echoed in nurses' accounts in the literature and interviews.

Nurses identified that training on what can be done or offered to families at this time and communication around withdrawing care would be beneficial to nurses (Chew, Ang, & Storey, 2021). Nursing academia and healthcare institutions should develop or enhance end-of-life and bereavement training for nurses to encompass nursing responsibilities, communication strategies, holistic assessments, symptom management, and cultural awareness (Chew, Ang, & Storey, 2021; Kent, Anderson, & Ownes, 2012; RNAO, 2012). In addition to clinical and practical knowledge of death and dying, Bensoussan emphasizes the importance of grief literacy for healthcare providers. Being informed and understanding grief can aid nurses in supporting themselves and others through loss (Bensoussan, 2024). Education on each type of method of grieving could support effective "metabolizing" of grief in order to make space for new attachments and more life and inevitably loss (Bensoussan, 2024). Supportive resources such as a tiered peer support program, self-care and mindfulness strategies, and debriefs and focus groups should be readily available and offer a variety of strategies to support grief "metabolization" (Bensoussan, 2024; Chew, Ang, & Storey, 2021; Shimoinaba, McKenna, & Copnell, 2021; Vaclavik, Staffileno, & Carlson, 2018; Wahl et al., 2018). A system to accommodate emotion. A platform to share, learn, and grow from the experience with death and dying beyond initial debriefs. Nurses need and want support in varying ways prior to, during, afterwards, and beyond the death of a patient. Nursing leadership teams should also receive training in order to effectively acknowledge and support their nursing staff and aid them in navigating and "metabolizing" their grief. Combining these topics and strategies into a thoughtfully curated course recommended for nurses to take between 6 months and 1 year from starting their nursing career could potentially address the gaps and concerns identified by myself, interviewed nurses, and the literature.

Almost 6 years later, I find myself on a night shift with the nurse who was with her when she passed, a nurse who was my support when I eventually started to talk about it, a nurse that I *now call a good friend. Us two now being the most senior nurses on this particular shift. Despite everyone's efforts, a child again came to the point where the best option and the option the patient and family wanted was to withdraw care. A couple of the new nurses said that they could not sleep after the shift of this child passing. The other senior nurse says to them "let's talk about it". We gathered all of the nurses on that night, we took the time, the space to connect, to talk, to acknowledge and reflect on the loss that it was, to express emotion, to share our relationships and good memories, and to share pieces of advice from our experiences and how it impacted us personally and professionally. Not denying that death happens, talking about it.*

It wasn't shattering, but it impacted me. Bensoussan emphasizes that it is not possible to not be impacted in the presence of grief and loss whether experienced in personal or professional life (Bensoussan, 2024). It was not congruent with what I naively thought my job as a pediatric nurse would be. Not wanting to talk about it in a group did not mean I was not impacted or that I did not care or that I was not feeling the loss but was made by our culture and society to feel that the only way people "get over it" is to talk about it. I wanted to know everything. That is what I thought would help everyone through it. I did not and do not need to "get over it". It was a deeply meaningful experience that I learned so much from, and it was an experience that changed and shaped me personally and professionally. I have learned that my way of "metabolizing grief" may only be helpful to those that are cognitive grievers (Bensoussan, 2024). Emotional grievers may need and find value in debriefs (Bensoussan, 2024). I have increased my awareness and knowledge of grief and individual responses to loss and recognize that there are multiple ways of experiencing it and multiple ways of processing it (Bensoussan, 2024). Being impacted and having an emotional attachment is often attributed to poor work-life balance and boundaries in certain professions (Bensoussan, 2024). Our culture denies death and fails at acknowledging grief and loss implicitly and explicitly (Bensoussan, 2024). This is evident by the lack of grief literacy education in Canadian nursing curriculums (Bensoussan, 2024). This should, however, be a focus in a profession where grief and loss are present. This should be a focus of mandated education for nurses entering into a field riddled with loss (Bensoussan, 2024). This awareness and knowledge could have benefitted me earlier in my career. I hope that in sharing this, it will help others earlier in their careers that are filled with grief and loss in addition to the days that are happy and hopeful (Chang, 2008). This autoethnographic account provides insights into the personal and professional impacts of pediatric patient death on nurses and the importance of associated education, training, and support to improve care for patients, families, and self. Experiencing pediatric patient death changed me both personally and professionally. I did not expect to be changed by my research. Self-transformation was not actually a "conscious goal" of mine as Chang describes and yet, a welcomed benefit of autoethnography that I experienced throughout my research journey (Chang, 2008).

I found the binder. Not the one I was looking, but the one I needed. *"Everything you need is within you".* This is what I needed. This is how I finally addressed the loss and the many losses after. I have learned that I am primarily a cognitive griever (Bensoussan, 2024). In writing, researching, and thinking about my thesis and how I could help others, I actually helped myself. Bensoussan describes storytelling as a means to understand and bring meaning to our experiences, "a window into the lives and experiences of others" (Bensoussan, 2024 p.79). This is my story and how I brought meaning to my experience of what caring for a child who died was like for me.

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