

Offering a Concert for Two: An Interpretation of Friendship in Pediatric Oncology Palliative Care Nursing

Katie M. Webber

Abstract

In this paper, written for a hermeneutic research course for my master's graduate work, I discuss how pediatric oncology nursing is an interpretive practice. I explore the subject of the relational complexity of pediatric oncology nursing, conceptualized as friendship. I then discuss the similarities between understandings of hermeneutics and friendship. In the second part of the paper, I provide a narrative and interpretive account of a personal experience of friendship with a palliative patient and his mother, to offer understanding about the complexities of the work of pediatric oncology palliative care nursing.

Keywords

Interpretation, hermeneutics, pediatric oncology nursing, friendship

On an inpatient unit, where patients and their families often spend more time than at the address listed in their chart, it is not uncommon that nurses and the parents of pediatric oncology patients develop relationships. Pediatric oncology nurses bear witness to parents experiencing the diagnosis, treatment, and sometimes palliation of their child. Over time, the relationships between nurses and parents develop and become increasingly complex. An interpretation of this relational complexity is friendship. However, due to a focus in nursing on the creation and maintenance of professional boundaries, it is challenging to understand how friendship could be experienced in a professional

Corresponding Author:

Katie Webber
Master's student, Faculty of Nursing
University of Calgary
Email: Katherine.webber@ucalgary.ca

hospital setting, such as pediatric oncology, as it is rare for *friend* and *nurse* to be held together as equal partners. When I consider, from a hermeneutic perspective, how I might understand the moments of meaningful connection that have contributed to a sense of purpose in my work as a pediatric oncology nurse, an interpretation that seems to aptly describe these experiences is friendship.

Exploring the Complexities of Pediatric Oncology Palliative Care Nursing

In my own experience, the rigidity of personal and professional boundaries, which divides nurses, patients, and their families, becomes more interpretable and more flexible when providing palliative care. Palliative care nursing offers a relational permission that does not always exist when the focus is curative. As the focus shifts towards palliative care, there is a necessary reimagining and reinterpretation of the role of bedside nurse. This shift, from personal experience, can be uncomfortable and requires, as Moules, McCaffrey, Field, and Laing (2015) suggested of Heidegger's understanding of *Dasein*, "a thereness of being" (p. 23), which encourages an absorption into the experience itself, in this case, the experience of caring for a dying child and their family.

In many ways, when caring for a palliative patient, one's perspective of time shifts. No longer are vital signs, assessments, and chemotherapy administration the focus. Instead, an ability to be visibly invisible becomes the priority. In other words, as a pediatric oncology nurse caring for a palliative patient, the focus is to be available and present to the experience, while still offering the space and room needed for the patient and parents to have time alone together. Pediatric oncology nurses become interpreters of how to best support the needs of the patient and family members. There is no manual, guide, or certification that pediatric oncology nurses can follow in doing the work of palliative care. Gadamer (1960/1994) referred to *phronesis* as a "practical knowledge...[which] must grasp the 'circumstances' in their infinite variety" (p. 21). Applied to pediatric oncology, an understanding of phronesis, as the practical wisdom needed to interpret and understand both the universality and infinite variability of the dying process, is helpful in describing the interpretability of the practice of pediatric oncology palliative care nursing. A few years ago, I remember hearing a mother recount the experience of her son's death. She recalled sitting on the parent bed, taking a few minutes to herself in what had been an exhausting week of being at the bedside of her dying son. She shared that her nurse came into the room and softly suggested that she crawl into bed beside her son. Within the hour, her son had passed away. She was so thankful for that nurse's wisdom in that moment. I, too, am so thankful for my colleague, whose practice was profoundly phronetic.

As I endeavor to express how nursing in pediatric oncology is interpretive, I will offer some beginning understandings of the connection between hermeneutics and friendship. To illustrate this connection, I have included a personal experience and interpretation of friendship, as a bedside pediatric oncology nurse, with a palliative patient and his mother. As Gadamer (1960/1994) offered, "understanding begins...when something addresses us" (p. 299). Admittedly, when wrestling with the topic for this paper, I was overwhelmed with emotion. I did not want to confront the topic of the relational complexity of pediatric oncology in the context of palliative care nursing. However, it was undeniable that the topic was addressing me and, having avoided it my entire first

semester as a graduate student, it became clear that the time had come to enter into the topic of friendship in pediatric oncology nursing, from a hermeneutic perspective.

Hermeneutics and Friendship

Much like hermeneutics, which defies a clear, methodical definition (Moules et al., 2015), friendship finds itself in a similar situation. As Moules et al. offered, hermeneutic interpretive work is best understood through practice, rather than by the careful examination and execution of a specific method. Understanding or interpreting friendship seems to be much the same. It is not a step-by-step guide that one follows in friendship, but a human connection that transcends the traditional nurse-patient relationship, which seems to happen “over and above our wanting and doing” (Gadamer, 1960/1994, p. xxviii). As a pediatric oncology nurse, my experiences of friendship, with patients and their parents, are not the results of an ability to skillfully complete a central line dressing change or to effectively teach a parent about fever and infection. Of course, the technical skills of nursing contribute to building trust and understanding, but my experiences of friendship seem to have happened, over and above what was done or what ought to have been done (Gadamer, 1960/1994).

As Moules et al. (2015) offered “the art of interpretation, that is often only learned through experience and is difficult to teach, involves the process of moving past the initial descriptive themes into the depth and richness of interpretation” (p. 119). In the same way, the art of friendship between nurses, patients, and their families, in the work of pediatric oncology nursing, is also difficult to teach. It requires a moving past the tasks and skills, policies and procedures, and rules and regulations of the work of nursing to experience the depth and richness of friendship. Of course, not every patient or family member becomes a friend, but it seems remiss to not acknowledge that patients and family members may become friends somewhere along the cancer trajectory, particularly, in my own experiences, when the treatment shifts in focus towards palliative care.

Sir Francis Bacon (1612) offered a poignant and practical attribute of friendship as it relates to understanding. “For friendship maketh indeed a fair day in the affections, from storm and tempests; but it maketh daylight in the understanding, out of darkness, and confusion of thoughts” (para. 6). I cannot help but draw a connection to the complex relational work of pediatric oncology palliative care nursing. Perhaps one of the darkest storms, a tempest in life, is the experience of being present during the death of a child. How could any daylight be experienced in this storm? How could the confusion of the experience be made clearer, even just for a moment? Perhaps, in the confusing experience of the death of a child, an experience of friendship between a nurse and a parent offers an opportunity for a new perspective, similar to the work of hermeneutics (Moules et al., 2015). These friendships that develop, between nurses and parents who have experienced the loss of a child, is perhaps why many parents, even after the passing of their child, return to the unit to visit the nurses; to tangibly experience *aletheia*, a working “against what was dead bringing it to life” (Moules et al., 2015, p. 3).

As a pediatric oncology nurse, it has been my experience that friendship, true human connection, offers an opportunity for understanding to begin. The memories that I draw on from my nursing practice about friendship are the moments where authentic human connections, which defy the traditional nurse-patient boundary, have taken place. In the moments where I, as a nurse, no longer

hold a position of power, but a position equal to or perhaps even lesser than that of the patient or their parent. I must be clear, though, that it is not always a comfortable or easy place to sit. As a nurse, I have been employed to know, to advise, to educate. I am there to meet the needs of the other, the patient and their family, not the for the other to meet my needs. However, when given the space to consider the meaningful moments in my career as a nurse, the moments that have grasped a hold of me, they are often the quieter moments of sitting with, listening to, and sometimes even sharing something personal about myself. These moments give way to an opportunity that transcends the traditional nurse-patient boundary, and enters into one that allows for a greater, more human understanding and appreciation of one another.

My Last Day with Ryan

I remember walking into the report room. I was going away for the weekend, and so I had elected to take the last four hours of that Friday's shift as vacation. I knew that there was a palliative patient on the unit, but, in general, palliative patients are assigned to nurses who are working full twelve-hour shifts and several shifts in a row, in order provide consistency for families. Somehow, though, I had known driving to work that I would be assigned to him. I felt anxious as I listened to the report from the night shift nurse. My heart was beating, and I was frustrated. I had hoped to have a weekend away that did not involve any baggage from work. I had hoped for a stress-free, eight-hour shift. I had hoped not to care for a dying child that Friday. I was wrong, though. Caring for Ryan that day was exactly what I needed. Ryan and his mother, unknowingly, taught me something about friendship that continues to influence my nursing practice today. The nurse, who walked into his room at 8 a.m., heart-pounding, worried that his mother might ask something hard that she would not know the answer to, was a different nurse, who walked out 3:30 p.m.

Throughout the morning, doctors, nurses, and family members filtered in and out of the room. There was a certain thickness in the air that only rooms with dying people seem to have in them. However, when Michael, the mandolin-strumming spiritual care worker, came in, whistling a happy tune, he breathed a freshness into the room with his music. Ryan was unconscious, heavily sedated by the intravenous analgesics being given to him, but his mother smiled so graciously as the music played. After the mandolin-playing finished, she thanked Michael because she knew Ryan, as a violin player himself, had been listening and appreciating the music.

Almost before I realized what I was potentially offering to do, the words came tumbling out of my mouth "I play the violin, too." In wanting to find a connection with his mother, perhaps even to attempt to expose myself, if only in a small way, as I watched her be so exposed by the experience of watching her son die, I had disclosed something that, at the time, I held quite quietly to myself. She looked at me, with soft, pleading eyes, and asked if I would play my violin for him. I paused. It was my general practice to avoid any public appearances with my violin, but I could not help but promise that, when I returned to work on Monday night, I would bring my violin.

While the hours of my shift progressed, I continued to mull on this willingness in me to play the violin for Ryan and his mother. Something had shifted between Ryan, his mother, and me. By extending a piece of myself that I generally kept quite private, the distance between myself as a nurse and Ryan's mother had closed ever so slightly, moving towards a fine balance of friendship in pediatric oncology palliative care nursing. I moved in and out of the room for the next hours,

propping Ryan up when he slipped down, listening to Ryan's mother's fears about what it would be like to watch him die, and trying my best to be present to their needs. As the hours went by, I felt myself relax into the role of palliative care nurse.

In the last hour of my shift, Ryan's mother asked if I would sit with him while she went for a long walk. She told me that it was her birthday, and she said that she wanted to mark the day, even in the midst of sorrow, by walking to the pond near the hospital. I wanted to be brave for her. I wanted to acknowledge the trust and friendship she was extending to me to sit with her son on one of his last days. However, I must admit that I was terrified that Ryan would take his last breath with only me by his side. As she left, I sat down beside him and held his hand. I do not remember what I said to him, but I remember softly chatting, humming a little bit, and then long moments of quiet. An hour or so later, she returned from her walk. Her face held a settled despair that only the mothers of dying children must know all too well. As my shift ended, I said my goodbyes to her and Ryan, and I thanked her for the time I had spent with them that day. I was grateful, calm, and deeply moved by the opportunity she had given me to hold the hand of her boy on one of his last days. Of course, that would be the last time I ever saw Ryan and his mother.

As is the practice of our unit to notify nurses of patient deaths, my phone rang the following day. I did not answer but waited for the message to be left to let me know that Ryan had passed away. I was somewhat at a loss of how to respond to the news, which was surprising because I knew that Ryan was going to die. I do not write in a journal very often, in fact, it is the only time that I have written about a patient, but, the experience of friendship and human connection that transcended the traditional nurse-patient boundary, compelled me to respond in writing to what I was feeling. I wanted to capture the moments of that day. The following is what I wrote, which I share as my own interpretation of the experience of caring for Ryan that day.

It is exposing, asks me to be even more vulnerable than I already feel. Barriers are my judgments of others reflected back onto myself. I am emotionally exhausted by yesterday. All I have, all that fills my mind are his breaths, the progression from sixty, to forty, to thirty-eight...to none, as if I could count down his last minutes. The invitation, I am sure, is to let myself feel this, but, the temptation is to try to forget it. Or, perhaps, the temptation is to hold on too tightly? Quite honestly, I do not know. I am afraid to be too affected and I am afraid of forgetting. I am afraid of whatever is left in the middle. The mandolin strums, my foot taps, his eyes are closed. The tube that draws air to his lungs has also taken it away. Who am I in this? I am a healer, but today, a pallbearer. Today, is a sad day. I will not need my violin on Monday night, will I ever need it in that way again? As I write, I notice how I feel. I feel that I do not deserve the grief. But, admittedly, I do. A smile rolls onto my face as I see how alive he was in his death. "Kids have a way of choosing their time," she [the doctor] said. She was right. Not yesterday, but today. So, cheers to you, beautiful, intelligent, young, and experienced Ryan. May you rest in peace.

Unpacking and Concluding

My relationship with my violin has always been complex. I am usually quite shy about playing it for others. As a child, I was embarrassed because it made me different than many of my peers. I remember standing up alone at the front of many stages, feeling so vulnerable, hoping that the

shaking of my hands was being communicated to the audience as vibrato, and desperately hoping that I would remember the pages of sheet music I had memorized. When I finally quit taking lessons late into my teenage years, I questioned whether I would ever want to play my violin again.

This relationship, over time, began to heal, and as an adult I have realized that being able to violin is not such a terrible thing. Although I have become more willing to share this part of myself, largely thanks to Ryan and his mother, I am still, and was certainly at the time, very closed about playing the violin. So why would I disclose this part of myself, let alone share something personal in a professional setting? As Gadamer (1960/1994) suggested, my offer of connection and extension of friendship, was “over and above my wanting and doing” (p. xxviii). Ryan’s mother was going through an experience that I could only begin to imagine. Although her request was to play for Ryan, I was not really going to be playing for Ryan, I was going to be playing for her. What I saw in front of me was a mother, so vulnerable, simply wanting to hear the sound of a violin, to remind her of her son. In my own desire for connection with her and to honour her vulnerability, I wanted to play for her. Unfortunately, I never had the opportunity. I can only imagine how nervous I would have been and how uncomfortable it would have made me to have my coworkers overhear me playing in his room. However, to this day I wish more than anything that I had had the chance to play my violin at a concert for two.

In a pediatric oncology setting, the friendships that develop, between nurses, patients, and family members, can erode barriers that sometimes prevent nurses from truly understanding their patients. From a perspective that nurses and parents of palliative patients do experience friendship, as an equalizing human connection, the anxiety of being the most technically skilled nurse starts to dispel and can soften into a more phronetic experience of nursing. Gadamer (1996) wrote that there is an “unmistakable evidence of a connection between the conscious and self-conscious awareness of our own life and the very ungraspability of death” (p. 63). My experiences of friendship, with parents of palliative patients, due to the nature of working so close to death, have affected my conscious and unconscious ways of being a nurse.

To close, through the process of articulating my own understandings and interpretations of friendship as a nurse in pediatric oncology, I can see the similarity of the challenge that hermeneutics and friendship both face: “hermeneutic questions are hard questions; hermeneutic understanding is hard understanding” (Moules et al., 2015, p. 202). However, I have also begun to see how, going forward, my continued desire to pursue an understanding of the topic of friendship in pediatric oncology nursing, responds to what Moules et al. concluded with about hermeneutics, “at the heart of it is the capacity to know and live differently – to find language that works” (p. 202). It is my sincere hope to continue to find language that works to articulate how we might understand the complex, meaningful experiences of friendship in pediatric oncology settings.

References

Bacon, F. (1612). *Of friendship*. Retrieved from <http://www.authorama.com/essays-of-francis-bacon-27.html>

Gadamer, H-G. (1996). *The enigma of health*. (J. Gaiger & N. Walker, Trans.). Stanford, CA: Stanford University Press.

Gadamer, H-G. (1960/1994). *Truth and method*. (2nd rev. ed.; J. Weinsheimer & D.G. Marshall, Trans.). New York, NY: Continuum.

Moules, N.J., McCaffrey, G., Field, J.C., & Laing, C.M. (2015). *Conducting hermeneutic research: From philosophy to practice*. New York, NY: Peter Lang.