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Caring for the Terminally Ill: An Interpretation of Time, Existence, and Mortality

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Abstract

In this paper, the first author explores the complexity of caring for palliative care patients approaching end of life in response to the statement *nursing is an interpretive practice*. A real-life scenario is used to unravel the exploration of time, existence, and mortality. The author proclaims that the question of death remains unanswered, and the call to palliative care nursing requires an extensive examination of one's own temporality to cultivate an understanding of patients experiences of grief, legacy, and meaning making in the context of terminal illness.

Keywords

philosophical hermeneutics, death, grief, legacy, palliative care, end of life

When I (Dhaliwal) first grappled with the question of how palliative care nursing exemplifies interpretive practice, I was reminded of Niall Keane's (2021) exploration of time as giving and time as taking away. This dichotomy of time established by Keane (2021) draws attention to the relentless exploration of death as an adventure that involves coming face-to-face with the question of what it means to have lived. Time, which gives the opportunity for love, celebration, and hope is also an expert in loss, heartache, and tragedy. Palliative care nurses are bestowed the responsibility of living in this delicate *in-between*, constantly moving between life and death. In this work, I will explore how caring for patients diagnosed with a terminal illness is an inherently interpretive venture that reminds us of death's inevitability. I will begin the paper by providing an example of a real-life scenario in which I cared for a terminally ill palliative care patient. I

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will then examine the ways in which interpretation made space for understanding this experience. Finally, I will explore the complexity of time, existence, and mortality in shaping the care of patients approaching death.

The Call to Palliative Care

I began my career four years ago working as a registered nurse on an inpatient cardiology and overflow general medicine unit. Patients requiring palliative care were frequently admitted to the unit, often with a diagnosis of congestive heart failure or cancer. As a nurse that regularly engaged with patients diagnosed with a terminal illness, I became acclimated to the grief that unwelcomingly housed itself in the room of dying patients. Specifically, it was following my initial experience caring for Patricia,[1] a patient at end of life, that I first recognized the pervasiveness of death that seamlessly bypassed the sterility of medical science and accentuated nursing as an artistic venture.

When Patricia first visited the emergency department, it was for standard treatment. She was experiencing symptoms of a pulmonary embolism and required anticoagulation treatment. Although a pulmonary embolism can be life-threatening, it is highly resolvable with treatment. Upon examination, diagnostic testing during Patricia's visit would reveal a higher-than-normal count of lymphocytes and monocytes. Over the next four weeks, Patricia would be informed by oncologists of her grim prognosis. She would then proceed to experience a stroke three days prior to her death. A room that was once filled with laughter and Patricia's frequent quips, would now be filled with silence.

Interpreting Taking and Giving

Palliative care nursing is an interpretive practice. As Gadamer (1960/1989) declared, "understanding begins when something addresses us" (p. 298) and I was moved by the 71-year-old woman, once described as "the life of the party" by her husband of 40 years, who was unable to verbally communicate in the final days prior to her death. Many years later I can still recall the ethereality of being in the same room as Patricia and witnessing her resilience in the face of life-altering news that followed numerous diagnostic tests and visits to the cancer centre.

One morning after Patricia returned from an ultrasound, her hair was disheveled, she was evidently exhausted, and she complained of having to wear a patient gown that stripped her of her personality. Rather than asking Patricia how the ultrasound went, we exchanged numerous jokes. I turned to her husband and said, "she's a funny one, I see why you picked her." He then informed me that he moved to Calgary for Patricia, and they had two children. He proceeded to disclose that their daughter died of cancer three years prior. Following the realization that Patricia had experienced immense grief following the death of her daughter under similar circumstances, I recognized that this is where palliative care nursing lives. It is being present and *right there* (Dhaliwal et al., 2020) with our patients as they navigate death and dying. As we interpret what they need from moment to moment, a portal to new understanding reveals itself (Moules et al., 2015). As nurses, our jobs extend beyond interpreting blood tests and vital signs. In my interactions with Patricia and her family, there was a delicate balance that needed to be

maintained between knowing when to provide medical information, knowing when to make room for witty remarks, and knowing when to listen.

When Patricia's diagnostic test results first indicated incurable cancer, the oncologists delayed visitation. Patricia's husband, a former physician at the same hospital, pleaded for staff to communicate the results of her test. He said, "I know you've gotten the test results back for the ultrasound and I know you're not supposed to tell me, but I need to know. We need to know." I knew that disclosing the test results was not within my scope of practice and as Patricia's husband awaited my response, I fell silent. I said nothing at all, and yet, it was this silence that gave him the confirmation he needed. Albeit unintentional, Patricia's husband and I had a profound interaction without the exchange of verbal dialogue. He was interpreting my silence for what it was – tragedy. He returned to Patricia's room, and from his silence, I knew that he understood that time had come to take (Keane, 2021). His focus shifted from pleading with staff about the results of the test to confirming Patricia's end-of-life wishes.

When Patricia died, I was in San Francisco on vacation. I returned to the unit to find her room occupied by a newly admitted patient. I was consumed with sadness, but I knew that I had a job to do – I needed to care for the next dying patient. Keane (2021) wrote, "the first silence we experience in time appears to be the silence of loss. It is the silence of the other who no longer responds" (p. 2). Patricia's death was a stark reminder that silence also has something to say. As nurses, we develop a secret language with our patients. When we are present with our patients during their most vulnerable moments, conversation naturally ensues. It is the time we spend *with* them, caring *for* them, that allows this special language to develop. As we get to know our patients, we begin to move in response to them, maintaining a fluidity of to-and-fro movements that occur in reciprocation to one another. Perhaps the most difficult aspect of caring for the terminally ill is knowing that eventually, that language will never be spoken again. Although immediately following Patricia's death I felt a relentless anger towards time for its unapologetic nature as it continued to take, I also experienced gratitude. I felt thankful for the moments that I got to know Patricia and her family, and it was the first time I understood that time also gives (Keane, 2021).

What Interpretation Has to Teach Us About Death

Heidegger explored death as a concept tangled up with the idea of existence (Shariatinia, 2015). He believed that the only certainty of existence is death. Existence is derived from the Latin term *existentia*, which means to "come into being" (Lexico, n.d.). After caring for Patricia, I began to question the conceptualization of death as the end of being. My colleagues informed me that following Patricia's death, her husband continued to share his favourite stories of her. It was his recollection of her that cemented Patricia's existence. Despite her death, she continued to be right here, in the stories that her loved ones shared of her. I realized that existence does not have to end with death. Instead, death is simply a reframing of being.

In 2021, when I lost a loved one tragically to suicide, I remembered Patricia. I felt immersed in a sense of knowing that would change the lens from which I viewed the world. With nursing, interpretation does not end when the patient interaction does. We are in the business of remembering and re-remembering (Moules et al., 2015) until understanding shakes us to our

very core. At the time of our interaction, I did not want to fully understand what Patricia and her family were experiencing because it meant coming to terms with my own temporality and the temporality of those that I loved most. When I remembered Patricia and her family following my own loss, I recalled the stories that her husband told of her. I experienced *Erfahrung*, meaning to travel or journey with (Moules et al., 2015). It was caring for Patricia and interpreting her family's response to her death that taught me how to make sense of my own loss many years later. I knew that if I continued to say Jay's[2] name in conversation, he would not cease existing. As poet Thomas Campbell (1825/n.d.) once wrote, "to live in hearts we leave behind is not to die" (para. 1). With each mention of Jay's name following his death, I was not only inviting others into my own experience of loss, but also Patricia and her family's experience. The two were intertwined, and they could not be uncoupled or deconstructed from one another. Ultimately, Jay's and Patricia's deaths collided and coexisted in such a way that they could no longer be seen as independent entities.

George (2017) explored grieving in the context of limit situations (Jaspers, 1969), in which our lives are defined by moments of existential challenges. Death and the inevitable suffering that accompanies the loss of a loved one is a reminder of our own cosmic insignificance and impermanence. Becker (1973/2020) insisted that it is death that has the ability to push us to the edge of the human condition. He argued that we retaliate our own temporality with a defiant creation of meaning (Becker, 1973/2020) and in many ways, George (2017) echoed this sentiment in his exploration of grieving as a limit situation of memory. In the presence of death, we immerse ourselves in establishing unshakeable perpetuity. Whether it is creating an archive of documents, such as paintings, poetry, or photographs, or reappearing in the memory, thoughts, or conversations of our loved ones, we have an inexhaustible desire to affirm that our existence extends beyond our limited presence as physical beings on this blue dot circulating somewhere in the cosmos. In his publication, George (2017) explored a passage written by Paul Celan, which reads "the world is gone, I must carry you" (Celan, as cited by Derrida, 2005, p. 141). The work is referenced by Jacques Derrida (2005) in response to the loss of a friend and validates the responsibility we have to remember those that we have lost. As our lives, circumstances, and understanding of the world changes, the task of "grieving remains unending" (George, 2017, p. 3). We acknowledge that forgetting would be a disservice to our patients and our loved ones, and so we carry the burden of grief and all that it encompasses as a radical act of legacy.

Death: A Question the Natural Sciences Cannot Definitively Answer

Gadamer (1960/1989) explored the conceptualization of certainty in the medical sciences and its reduction of human lives as something that can be measured. As the natural sciences take precedence over that which cannot be proven to be objectively true, nursing falters to the trap of quantification. When Patricia's ultrasound results indicated incurable cancer, interpretation was at play and the results were not seen in isolation but instead as a life-altering diagnosis that would undoubtedly change the course of Patricia's life. The results meant that a daughter would lose her mother and a husband his wife; it meant that Patricia would continue to experience agonizing, unresolvable pain. There was no method of quantifying the gravity of what the test result meant for Patricia and those who loved her most. The size, proportions, and objective description of the metastatic cancer did not matter, nor did it occur to me to delve into this information.

Heidegger described dwelling as safety and security (Shariatinia, 2015). Ultimately, it is death that destabilizes our dwelling. It asks to be heard, acknowledged, and remembered. Hermeneutics is an exercise of vulnerability. It calls on us to recognize that, despite the advancements in technology and the natural sciences, the question of death is one that cannot be definitively answered. There is a humility in allowing ourselves to be transformed by the experiences of our patients despite the discomfort that might come with addressing our own mortality in the process. Philosophical hermeneutics is a natural fit for palliative care nursing, as the focus always lies in *phronesis*, that is, practical knowledge (Moules et al., 2015). Nurses are situated "i*n medias res*, in the middle of things" (Caputo, 2018, p. 223). We recognize that there is no "correct" way of caring for each terminally ill patient. There is a constant fluidity required to address the patient, the illness, and the context in which these two things coincide.

Conclusion

Gadamer (1960/1989) maintained that "hermeneutic work is based on a polarity of familiarity and strangeness" (p. 295). I was called to the profession of palliative care nursing because of my Sikh mother, who embedded *seva* (i.e., selfless service) in every aspect of my life and taught me that the most important thing we can do in service of others is to be there *with* them (Khalsa, 2019). There is a familiarity for me when it comes to palliative care nursing and this conceptualization of seva. Yet, caring for the terminally ill also maintains a sense of strangeness, unfamiliarity, and innocence. We serve others without any particular goal of answering the question of death, because we acknowledge it is simply not within the realm of possibility. Although the question of death can never be definitively answered, learning and relearning occurs with each patient interaction. Whether palliative care nurses are obtaining a heart rate and identifying the appropriate course of action in conjunction with patient symptoms or consoling a patient and family following a terminal diagnosis, the opportunity to learn is always abundant and endless. Alongside the privilege of being present with our patients and their families in the face of these incalculable moments is the responsibility to question the mundane, taken-for-granted norms of everydayness, and the responsibility to understand.

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[1] Patricia is a pseudonym used to maintain patient confidentiality.
[2] Jay is a pseudonym used to maintain the confidentiality of the individual that the writer lost to suicide.