

Engaging with patients who desire death: Interpretation, presence, and constraint

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ABSTRACT

Canadian end-of-life care is changing. Given recent legislative changes concerning assisted death (euthanasia and assisted suicide), it is vital to examine the perspectives of nurses regarding their care of patients who want to die. This qualitative descriptive study reports findings from interviews with 11 oncology nurses about their experiences of engaging with patients who desire death. Findings provide important insights about how oncology nurses interpret patients' desire-for-death and enact therapeutic presence with these patients. Findings further speak to contextual forces that constrain therapeutic engagement. Interviews were conducted before laws changed in Canada, generating insights that are relevant now more than ever, as increasing numbers of patients will contemplate and receive assisted death in the new landscape of Canadian end-of-life care.

Euthanasia involves deliberately ending the life of a patient for compassionate reasons and at that person's explicit request. Assisted suicide involves providing to a patient the means by which they can end their own life, e.g., providing lethal medications for self-administration. Collectively, these

two practices constitute assisted death (Van der Mass, van Delden, Pignenborg, & Looman, 1991). The Canadian province of Quebec legalized euthanasia (referred to as “medical aid in dying”) in June 2014; the law came into effect on December 10, 2015 (Publications Québec, 2016). In June 2016, the Government of Canada—in response to the Supreme Court of Canada decision in *Carter v. Canada* that decriminalized euthanasia and assisted-suicide (*Carter v. Canada*, 2015)—enacted new end-of-life care law (S.C. 2016, c.3). This legislation—which uses the umbrella term “medical assistance in dying” to refer to both euthanasia and assisted suicide—makes euthanasia and assisted suicide legal in all Canadian provinces and territories (Government of Canada, 2016). Therefore, Canadian society is now living dramatic transformations in how we deliver and experience end-of-life care.

In international jurisdictions that have legislation regulating assisted death, laws typically specify that it be physicians, not nurses, who either prescribe (in the case of assisted suicide) or administer (in the case of euthanasia) assisted death. In Canada, however, nurse practitioners are granted legal authority to prescribe and administer life-ending drugs in the context of assisted death (Government of Canada, 2016). This makes Canada the first and only country in the world wherein nurses can independently enact assisted death, as part of their scope of practice in end-of-life care.

Still, even if nurses' authority to provide assisted death is limited to nurse practitioners, other nurses will play an important role in the care of patients who contemplate and receive assisted death as part of end-of-life care. Care of patients at the end of life is a universal aspect of nursing practice (Jacono et al., 2009), including oncology nursing practice (Wright & Pugnaire-Gros, 2012). Nurses develop unique relationships with patients and families in everyday practice, and these relationships become the context within which important insights are generated that are relevant to ethical decision-making (Bergum, 2013; Doane & Varcoe, 2007; Nortvedt, 2001; Wright & Brajtman, 2011). Further, nurses share an emotional proximity to patients and families in end-of-life care (Barnard, Hollingum, & Hartfiel, 2006; Mok & Chiu, 2004; Raus et al., 2014; Roberts & Snowball, 1999) and, as such, may be the first health professional to whom a patient confides his or her desire to die (De Bal, Dierckx de Casterle, De Beer, & Gastmans, 2006; De Beer, Gastmans, & Dierckx de Casterle, 2004).

As noted by the Canadian Nurses Association (CNA) in their brief to the Federal Expert Panel for a Legislative Response to *Carter v. Canada*: “Nurses, because of their critical skills in interpretation, are vital to the assessment process of a patient requesting physician assisted death (PAD) and must be part of the patient's decision-making process... they can assist

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DOI: 10.5737/236880762715664

with exploring patients' feelings and perspectives, discussing available options/alternatives and helping to explain the PAD process" (Canadian Nurses Association, 2015, p. 6). The CNA further highlights that nurses will face a number of risks—psychological, moral, and legal—that need to be acknowledged and mitigated as legislation changes.

For these reasons, there is a pressing need to better understand the nursing perspective about desire for death among terminally ill patients. Yet, in jurisdictions where assisted death is legal, the body of empirical and ethical literature that articulates the nursing experience of this practice remains small (Denier, Dierckx de Casterle, De Bal, & Gastmans, 2009, 2010; Denier, Gastmans, De Bal, & Dierckx de Casterle, 2010; Dierckx de Casterle, Denier, De Bal, & Gastmans, 2010; van de Scheur & van der Arend, 1998). Furthermore, in jurisdictions where assisted death is illegal but actively debated, there is a relative lack of a discernible nursing voice informing these debates (Woods & Ascher, 2015).

Nursing perspectives about the diverse ways in which people die and how we ought to respond are guided by "convictions of what is morally good" (Cronqvist, Theorell, Burns & Lutzen, 2004, p. 68). While deontological and utilitarian frameworks, borrowed from moral philosophy, can assist nurses in their ethical deliberations about end-of-life care, equally important are frameworks that focus attention on the interpersonal relationships that constitute such care (Wright, Brajtman & Bitzas, 2009). Relational ethics is one such framework that considers "the kind of relationships that allow for the flourishing of good" (Bergum, 2004, p. 487). Beginning from the premise that relational space is the location in which morality itself is enacted, Bergum (2013) argues that ethical considerations are ubiquitous in nursing practice; they occur "in every situation, every encounter, and with every patient" (p. 127). According to Austin (2011), research in relational ethics has repeatedly demonstrated the importance of authentic engagement and connection within such encounters. Qualifying ethical relational encounters as authentic is, for Austin, a helpful way of resisting the customer-service mentality that has resulted from the corporatization of healthcare culture. Austin laments the drift toward inauthenticity in healthcare relationships as an evolutionary threat to our discipline, calling on us to reaffirm what is real in nursing practice. For Austin, "Real nurses engage those in their care in a sincere way, seeing patients and families as real persons, being with them in a real way, and acknowledging the real range of human possibilities" (p. 163, emphasis added). We take this normative emphasis on authentic engagement in nursing relationships as our starting point for a study about how nurses create 'real' therapeutic relationships with patients who may desire death in end-of-life cancer care.

The research question that guided this study is: How do oncology nurses describe their engagement with patients for whom a desire to die may be a concern? Our purpose was to explore how oncology nurses understand and respond to their patients with advanced cancer who may desire death, and to better understand nurses' own perspectives about their therapeutic relationships in this context.

METHODS

Eleven nurses were interviewed for this qualitative study, between September 2012 and January 2013 (i.e., before Canadian end-of-life laws changed). Participants were recruited from various care settings within the same institution, which was a large university-affiliated teaching hospital with a well-recognized oncology program in an urban area of Quebec. This oncology program contains a specialist palliative care division. Nurses were purposively targeted for participation based on whether or not they worked within the specialist palliative care department, as we wanted to ensure that the perspectives of both nurses with and without specific expertise in palliative care would be represented. Six of the nurses (55%) worked within the specialist palliative care division, in various roles including direct-care nursing of inpatients and consult service. The remaining five oncology nurses (45%) cared for patients in the acute stream of the oncology program, including on two inpatient floors and an outpatient clinic. Though years of experience varied, most nurses in this study had between five and 10 years of nursing experience. Eight of the nurses interviewed (72%) held university degrees, four (36%) at the graduate level.

Interviews were conducted by two authors, and ranged in duration from 30 to 60 minutes. Interviews were transcribed verbatim for analysis. Data collection and analysis took place concurrently, and initial interviews informed the development of additional questions for later interviews. Specifically, participants were asked about the way(s) they see desire for death manifest, as a concern for their patients with advanced cancer, what challenges they face, how they respond when they suspect a patient may desire death (what does the participant think, feel, prioritize, worry about, say, and do), their thoughts on what might underlie patients' desire for death in advanced cancer, and to relay at length their experiences of caring for these patients who expressed a desire for death.

Interview content was analyzed systematically to identify prominent themes and patterns among the data (Lincoln & Guba, 1985). Two authors read and reread each transcript with the goal of becoming immersed in the participants' narratives. Procedures of open and then focused coding enabled the development of a category list that represented the main ideas contained within the interview texts. After a first round of analysis and generation of preliminary findings, two additional authors reread the interview transcripts and checked the accuracy of interpretations against the original data, leading to validation of preliminary analyses and the creation of new insights. Throughout the analytic process, all authors met regularly to discuss the interview content and to develop, challenge, and refine ongoing interpretations.

FINDINGS

In the sections that follow, we answer our research question about nurses' engagement in the context of desire for death by describing three themes that emerged from these interviews. Our first two themes describe oncology nurses' engagement as a process of interpretation (Theme 1) and enactment of therapeutic presence (Theme 2). We then highlight forces apparent

in the nurses' narrations that appear to constrain their abilities to engage with patients who may desire death (Theme 3).

Theme 1: Interpreting the patient's desire for death

I think we have to be careful with how we hear the word; that they may not always mean death by saying that they want to die.

We found that for our participants, the first aspect of engaging with patients who may desire death is one of interpretation. Specifically, nurses describe striving to understand what is meaningful to the patient, through paying attention to verbal, non-verbal, and behavioral cues. Nurses appear to attune themselves to the lived experience that surrounds a patient's apparent desire for death, seeking to better understand what such a desire might actually mean for the patient concerned. In the following quote, a nurse describes hearing an expressed desire for death as an invitation, described as an "opening", for further dialogue and exploration between nurse and patient.

...patients express it, you have the opening for asking and talking about anything and whatever because he has just told you something that is so important. It's the last part of their life... they tell you what they want, and then you have open doors to go and explore... so, when that happens you just put your stuff down, you sit down, and you have free opening...

By taking advantage of the "opening" that patients provide—an invitation to better understand their lived experience of dying—nurses described a nuanced understanding of the various meanings they might attribute to a patient's desire for death. It may reflect a loss of enthusiasm for continued life, a desire for better nursing care, a desire to regain control, or a frustration with a situation that is perceived to be hopeless. Nurses further emphasized that the nature of a patient's desire for death can fluctuate over time. Thus, there is no uniform meaning of desire for death that nurses can draw on to support them in their practice, because careful interpretation of the patient's desire for death might reveal a host of potentially overlapping or contradictory 'desires'.

Well, it [desire for death] can have several meanings, and I think that's what makes it a tricky concept... I think sometimes people, they want to end their suffering, or they want to prevent further suffering, or they want to prevent potential loss of dignity, or loss of independence, so it's teasing apart what that means to the patient. I guess depending on the patient, it can have different meanings.

For some participants in our study, there was an overall tendency to interpret their patients' expressions of desire for death as reflective of some other underlying and hidden meaning(s), as opposed to signaling a genuine desire to be dead.

...a couple of years ago I treated a gentleman in his early 50s who had gastric cancer... in the last two to four months of his life he was just skin and bone... he could not play hockey anymore, he had many losses... I guess his sense of self was really gone. He did not look like himself anymore and he was always uncomfortable, he did not want to eat anymore, but he was afraid to not eat anymore because he was afraid of starving to death... he was afraid of not being there for his

family... he was just like, 'I am burdening everyone and I do not feel like myself anymore and I do not know if I can do this anymore. I am just starving to death and I just want to die.' He was not expressing that he wanted to actually do it, or have us do it, but he was going through that difficult period of like, 'What is the point? What do I do to make this better?'

For this nurse, the meaning of her patient's desire for death is best understood not as an interest in hastened death, i.e., euthanasia or assisted suicide but, rather, as a reaction to living through various losses in advanced illness. In fact, this patient is described as experiencing distressing emotions that are somewhat typical of the end-of-life experience, including a perception of losing a sense of self and burdening others. Later in this same interview, this nurse continued her reflection about this patient, stating:

...it is tricky, he did not say 'I want to die'... 'I am going to end this' kind of thing, but he talked around it. Like, 'I do not know if I can live like this anymore.' 'I do not know how much longer I can do this.' That kind of thing.

This nurse chose to tell us about this particular patient for a reason. This was not a patient she had cared for recently, and he did not appear (to her) to explicitly convey a clear and consistent message that he desired death. The contradictions in her narration (...I just want to die/...he did not say 'I want to die') demonstrate how nurses' impressions of their patients' experiences are the product of an interpretive process. In the passage below, a nurse draws a distinction between caring for someone who is seeking "assistance" in hastening death, and caring for someone who is seeking someone to which to confide their emotional experience.

...they have alluded to it without being so direct by, you know, saying things like, "I've had enough" or "I'm tired" or "I just want to go", you know, or whatever. And in those situations, it hasn't been, I haven't felt that they were asking for my assistance, or for anything other than just expressing how they were feeling.

In the above reflection, it is not clear how or why the participant "felt" (i.e., interpreted) that the patient's desire was for relational accompaniment (i.e., a listening ear) and not for direct "assistance".

Theme 2: Enacting therapeutic presence

...they kind of pull you in, but not in a negative sort of way... It's almost like, don't leave me alone with this.

We found that the idea of therapeutic presence appeared as a core value at stake for the nurses in our study. Our participants repeatedly described themselves as needing to be "available" for patients and understood their role as one of "gentle accompaniment." What it is to be present, however, was not easy for nurses to explain. In this section, we describe those elements of participants' reflections that speak directly to their interactions with patients, with the aim of further illuminating the meaning of engagement in the context of caring for patients who may desire death.

Nurses reflected upon the difficulties inherent in being “just present” in those cases where there are no clear solutions or easy answers. Nurses’ own hesitations and insecurities in having difficult conversations—about desire for death and about end of life more generally—could interfere with engagement, particularly where they feared such conversations might inadvertently harm the patient.

I feel bad bringing it up. Like, what if they don't desire to die, what are they going to think of me asking them that question? You know, you're afraid of their reaction, they might interpret it as, 'Does that mean that she thinks I'm going to die?' So, it's a touchy subject. I have to be honest, I'm not the most comfortable approaching the subject.

Nurses also wrestled with accepting the limits of their own abilities to control, fix, or offer something concrete and tangible toward alleviating their patients’ suffering.

I guess you feel, I always feel torn... because we're always trying to fix things, as nurses. We're always trying to make things better, and you can't make this better, you can't make the patient better, and you can't really enable them to die, so it's hard.

Though presence was widely viewed as an essential part of caring for patients at the end of life, many nurses described questioning the efficacy of their presence in the face of intense suffering, and even second guessed their own skills and abilities, as a nurse. Interestingly, while some participants second guessed themselves in the context of desire for death, others did so in the context of a broader discussion about the transition from curative to palliative care. The content of these reflections, in either case, was remarkably similar. As an example, consider the following two reflections from different participants; the first is about desire for death, and the second about palliative care:

...that sense of failure when they ask you to die, is it because you could not manage their comfort properly, because you could not do more for them, or could not attend their expectations of care?... Is that why they are now asking you to die?

...I think a lot of physicians and nurses I work with, when it comes time to thinking about palliative care, sometimes you feel like you have failed... You feel like you have not provided all you could and you did not do the best that you could...

In both of these cases, the risk of feeling like a failure is evident. Therefore, it appears as though desire for death represents, for these nurses, one context in which a more basic challenge of end-of-life care nursing is manifest: that of coming to terms with the limits of one’s own power to fix the suffering of another. In the following passages, we see evidence of a nurse working through this challenge.

...even the most experienced nurse can feel in over her head in that kind of situation... I found that talking to my colleagues [was] very normalizing for me... It's good and reassuring that it's not that I don't know what to do, but that it's a legitimately difficult situation, and that everybody, well first of all most advanced practice oncology nurses, have been in that situation, and second that it's difficult for everybody, even if they have tons of experience...

By using the words “legitimately difficult situation” and likening her experience to that of “most advanced practice oncology nurses”, this participant appears to be validating for herself that the difficulties she faces—including not having answers to solve another’s suffering—are inherent to the care situation, and are not a result of her own inexperience or incompetence. It is against this background of letting go of a fix-it approach to end-of-life care that the relevance of “just being present” emerges.

I have been learning over the years... sometimes you just have to put that desire away [to “do something”]. It is learning in those moments of being there for someone, through the toughest moments and just being present... just learning how to be quiet and comfortable, being quiet and listening versus just wanting to occupy yourself with doing something you (emphasis) feel comfortable with.

One nurse, at the end of her interview, was asked how working with patients who desire death has been beneficial to her practice. She responded that she believes her practice has become “more genuine” because she has “let go of the sense that it’s my responsibility to fix anything for them”. We also found in our data the idea of desire for death as prompting increased relational engagement by the nurse in the patient’s end-of-life experience:

“...it promotes a trusting relationship. To me, the patient is being honest about how they feel, and so there is value in that... when somebody tells you that they desire death, that might be a clue that they need more of something. More psychosocial support, more symptom management, you know, what have you. But I think if somebody expresses to you such a significant feeling, then your level of engagement goes up, because you want to help them through that.”

In the passage above, the participant describes hearing a stated desire for death as a “clue” about what the patient needs. This description is consistent with the idea of engagement as an interpretive challenge, described above. In this reflection, however, the nurse’s description moves beyond interpretation, to interaction. She positions herself as someone who capitalizes on the chance to earn and deepen the patient’s trust, by consciously increasing her “level of engagement”. Also apparent in this nurse’s reflection is a sensitivity to the moral implications of such engagement; she respects the magnitude of what is being shared with her, and feels compelled to act in response.

Theme 3: Forces that constrain engagement

...there are days where you just feel like you were not meeting up to what you should be doing

In the preceding sections, we have shown that nursing engagement with patients who may desire death is a process of interpretation and presence. Interpretation is characterized by the nurses’ openness to a host of possible meanings that constitute desire for death, the elucidation of which involves a careful reading of sometimes very subtle cues. Presence is enacted when nurses recognize and act on the opportunity that desire for death creates, to enhance the level of their therapeutic connection to their patients.

Engaging with patients who may desire death in the manners described above, however, is not without its challenges. In this section, we elaborate on forces that appear to interfere with the enactment of relational engagement when patients desire death. The first of these forces is temporal. All nurses pointed to the lack of time, as a factor that impedes their ability to engage with patients and provide the close care that an apparent desire for death requires, as illustrated in the following two reflections.

...we have a patient on the floor right now who is very agitated, he has said to me "please kill me". And he wants you to stay there and hold his hand, which, it's an easy thing to do, but you've got four other patients, or three other patients, or whatever and you can't... Does he want to die because he wants to die? Or does he want to die because no one will sit there and hold his hand?

Because for sure a patient who's desiring death, unfortunately the reality of nursing isn't going to give us as much time and attention to them as you will someone who's currently actively critically ill and has the desire to live... You just don't have the time, it's not because you don't want to, it's just that you don't have the time to address it in the same way.

The second force is legislative. At the time of this study, euthanasia and assisted suicide were illegal in Canada and Quebec, and were not a part of nursing practice. In discussing their care of patients who may desire death, nurses appeared to favour discussion of patients whose desire for death represented a general feeling of distress, as opposed to a specific request for a deliberately hastened death. For one participant, the idea of desiring a hastened death was not something she had ever encountered, and she cast this idea as "outside of the scope" of her practice. Throughout her interview, desiring death was never considered as desiring a deliberately hastened death.

...But we have not had a case where someone has desired hastened death. There have been people that desired death or are exhausted and express like, 'Ah I just want to die already'... But not people who are saying, 'Please end my life', not people who are saying, 'I am going to end my life'. Because when that is occurring, it is a very different situation. It is outside of the scope of our team... So, I am talking more about the people who have lost their desire to live.

For other participants, however, it was a reality of their everyday practice to care for patients whose desire for death did appear (to the nurse), to refer to a deliberately hastened death.

...patients who really want you to kill them, and that's obviously unethical, and they'll constantly be asking for more morphine, or some of these patients have subcutaneous drips for pain and they'll try to adjust the dosage of the pump, so that's a difficulty.

The evaluation of acquiescing to a request to deliberately hasten death as "obviously unethical" is noteworthy, and points to the way in which the legislative context served to limit the focus and content of our participants' narrations. Indeed, our

participants offered very few insights about the complexities of engaging with patients for whom a desire for death really does mean a desire for deliberately hastened death. It is possible that for these nurses, ideas of euthanasia and assisted suicide were so foreign to their practice that they were unable and/or uninterested in discussing these practices in detail. What is apparent in the data, however, are descriptions of constrained engagement. There were clear limits to nurses' abilities to enact therapeutic presence when patients desired hastened death; in such cases, the nurses were being asked to do something that was, quite simply, not possible.

How to respond to them, how to make them understand how much you can do, and how much you care... they just want you to do one thing, and it's to end their life, so that's a challenge.

I had a very strong sense of aversion when he would ask for, when he would ask me to talk about this.... It was just, I really didn't want to talk to him more than just to acknowledge, yes, I've heard you, yes, you're in a difficult situation, I don't have an answer for you. He cried. You know I was able to provide some comfort. But then after that he would try to sort of re-engage and it felt very negative for me.

While few participants reflected on explicit requests for euthanasia or assisted suicide, discussion of patients who choose to withdraw from life-prolonging treatment was a common point of reflection when nurses were asked about their experiences of patients who desire death. For many nurses, voluntary withdrawal from treatment was understood to be the natural outcome of an individual's desire for death, and was uniformly viewed as an acceptable end-of-life choice. Nurses' reflections about treatment withdrawal in the context of desire for death focused very pointedly on family conflicts, and nurses described struggling to balance respect for patient autonomy with the wishes of the family. In these circumstances, the nurses described that support for the patient could constrain their ability to be fully present for the family.

I think the family appreciated my presence, but they had a really hard time accepting that we were supporting him in his decision to die. And so, I think their view of us, as health care professionals, was that we're supposed to do everything we can to save someone, so they had difficulty understanding why we were letting their father go.

DISCUSSION

Given that medical assistance in dying has just been legalized across Canada, nurses everywhere need to reflect about how their previous experience in working with patients who may have desired death can now be applied to the care of patients who will be requesting and receiving assisted death. According to statistics collected in countries where assisted dying is legally practised, most requests for hastened death arise in the context of serious and terminal cancer diagnoses (Onwuteaka-Philipsen et al., 2012; Oregon Public Health Division, 2013). Therefore, although our findings are relevant for any nurse who cares for patients in an end-of-life context,

they are particularly relevant to oncology nurses. In this section, we identify certain implications from our findings to trigger reflection amongst oncology nurses about their therapeutic engagement with patients who may desire death, and who are cared for within the new legislative landscape of Canadian end-of-life care.

Although our focus in these interviews was the care of patients who may desire death, participants often veered away from this specific topic, and spoke about end-of-life care more broadly. We therefore found, somewhat surprisingly, that an invitation to nurses to tell us stories about desire for death did not predominantly result in conversations about receiving requests for euthanasia or assisted suicide. Instead, our participants spoke more generally about the complexities, challenges, and opportunities at stake in caring for patients who are nearing the end of life. They very often situated their perspectives about desire for death within wider end-of-life discourses, such as the withholding or withdrawal of life-prolonging treatment, and the tension between curative and palliative approaches. For these participants, the very idea of desire for death was not exceptional, controversial, or shocking. Indeed, many participants appeared to normalize the idea of desiring death within the terminal illness context.

Clinical and legal definitions of assisted death are fairly uniform across international contexts. In an effort to avoid terminological ambiguity, such definitions painstakingly reduce euthanasia to its constituent elements. Standard definitions attempt to demarcate clear conceptual boundaries and prevent assisted death from confusion with other end-of-life medical practices. Here is one example: "In the Netherlands, euthanasia has been defined since 1985, as *the administration of drugs with the explicit intention to end life at the explicit request of a patient*" (Rietjens, van der Maas, Onwuteaka-Philipsen, van Delden, & van der Heide, 2009, p. 272, emphasis added). The risk with definitions such as these is that they describe assisted death as a discrete act, circumscribed by a relatively narrow frame of space and time, i.e., the moment in which drugs are administered and in which the euthanasia death occurs. Contemporary anthropological understandings of assisted death, however, problematize the simplistic interpretation of this practice as a discrete act. For example, in an ethnographic study of euthanasia in the Netherlands, Norwood (2007) found that euthanasia is a communicative process, a series of back-and-forth interactions between patients and physicians, that may be stopped and re-initiated multiple times. Understood as a relational care process that occurs over time, 'euthanasia' does not even necessarily result in the deaths of patients, who might withdraw their requests or die before being able to fulfill them. A broader conceptualization of assisted death then, as a relational care process, is inclusive of the many moments that occur between patients, family members, and healthcare providers; from the moment that patients suggest that euthanasia is something they are considering, right through to the moment that they die (whether by euthanasia or not), or alternatively to the moment that they decide definitively that euthanasia is not for them. These

moments include responding to patients' uncertainties and fears, helping them to understand and explore their options, and facilitating dialogue between them and their significant others. Conceptualizing assisted death in this broader sense, as a dialogical care process that occurs within a therapeutic relationship, means that specific steps, as specified by relevant legislation (e.g., competency assessment, consultation with a second physician, drug administration) are not at all sufficient for describing the complexity and nuance inherent in the lived reality and lived enactment of assisted death, as a therapeutic practice.

The issue of which nurses will or will not be the agents of administration in assisted death, as described at the outset of this paper, somewhat misses the point concerning nurses' involvement in the care processes associated with assisted death. A recently completed analysis of the international literature about nurses and assisted death shows that the experience of nurses engaged in euthanasia or assisted suicide is defined by a strong sense of moral responsibility (Elmore, Wright & Paradis, 2016). As a result of their close interactions with patients, nurses are often the first healthcare professionals to hear requests for assisted death. Nurses experience these requests as challenging on ethical and emotional levels, and work to ensure that patients making such requests are provided with the very best care. This might mean assessing underlying meanings behind the request, searching for palliative solutions, or advocating on behalf of the patient to have his or her request taken seriously by the physician. Contextual factors, such as the time available to create therapeutic relationships with patients and the quality of inter-professional collaboration are important influences on whether nurses realize their perceived responsibilities toward patients in end-of-life care (De Bal et al., 2006; Denier et al., 2009; Denier, Dierckx de Casterle et al., 2010; Denier, Gastmans et al., 2010; Dierckx de Casterle et al., 2010; Dierckx de Casterle, Verpoort, De Bal, & Gastmans, 2006; Harvath et al., 2006; Matzo & Schwarz, 2001; Schwarz, 2003, 2004; Volker, 2001, 2003). Thus, nursing experiences of assisted death are moral experiences, whereby nurses' engagement in assisted death has repercussions for values they deem important (Beagan & Ells, 2009; Hunt & Carnevale, 2011).

In this study, which was conducted with nurses before laws in Canada changed to allow euthanasia and assisted suicide as legitimate end-of-life care practices, oncology nurses spoke to the ways that they engage with patients at the end of life who may desire death. These are the patients who, under new and forthcoming legislative regimes, will potentially be accessing care pathways involving euthanasia and assisted suicide and, so, it is imperative to look closely at the meaning of therapeutic engagement with these patients in oncology nursing practice. First, our findings speak to the importance of honouring the complex nature of a request for hastened death in clinical nursing practice. According to Mak and Elwyn (2005): "The desire for euthanasia cannot be interpreted at face value. Its meaning is not confined to the reality of physical disintegration or suffering from the effects of cancer, but includes fears and existential concerns

with desires for connectedness, care and respect, understood within the context of the patients' whole lived experience." (p. 348, emphasis added). The challenge for nurses in caring for patients who may desire death is to be open to hearing the myriad meanings that may underlie this desire and to use their knowledge of these meanings to inform their response (Gudat, 2015; Houtepen & Hendriks, 2003; Müller-Busch, 2015; Ohnsorge, Gudat Keller, Widdershoven, & Rehmann-Sutter, 2012).

According to the notable nurse ethicist Ann Gallagher: "exemplary nursing practice is not only exquisite, but also fragile, as relationships are negotiated and sustained in contexts of uncertainty" (Gallagher, 2012, p. 712). In the context of assisted death, nurses need to acknowledge the uncertainty inherent in engaging with a patient who manifests a desire for death. Relational ethics for nursing is a perspective that guides us to consider the quality of human relationships as a key focus of nursing inquiry, acknowledging that engagement between nurse and patient is a core element of what it means to deliver and experience quality end-of-life nursing care (Davies & Oberle, 1990; Mok & Chiu, 2004; Wright et al., 2009). Engagement in this context means that nurses "discover and respond to the moral commitment of the relationship" (Bergum, 2013, pp. 135–136), which in end-of-life cancer care includes a commitment to being present for patients and families (Barnard et al., 2006; Wright & Pugnair Gros, 2012). As Cramer (2002) observed: "Sometimes just 'being there' is the most important thing we can do. We call it 'the power of presence.' You don't have to have any 'right words' or 'things' you can do for your patients—just being there to witness, to hold a hand, to show that you care—can be as powerful as any high-tech intervention we can offer" (p. 55).

Of course, therapeutic presence in end-of-life care, including in care of patients desiring death, is not a trivial activity. It requires focus, commitment, and skill (Strang, Henoch, Danielson, Browall, & Melin-Johansson, 2014). While our participants spoke eloquently of the myriad meanings that underlie desire for death and the sophisticated processes of presence required to engage properly with those meanings, they also spoke of contextual forces that constrain their perceived abilities to properly enact their engagement. According to Dierckx de Casterle (2015), the skilled companionship role of nursing is at risk in "highly technical, rational, fragmented, and rather chaotic" (p. 3332) care environments that undervalue the relational engagement skills of nurses as essential to ethical practice, and by nurses themselves who adopt a conformist ethical practice in response. A conformist ethical practice is one in which nurses follow conventions (e.g., medical prescriptions, rules and norms of a care unit, procedures and guidelines) without reflecting critically and creatively about what is right. Conventions "need to be critically evaluated in context and in terms of their contribution to patient well-being" (Dierckx de Casterle, Izumi, Godfrey, & Denhaerynck, 2008, p. 547). When patients contemplate, or request assisted death, a thoughtful and deeply reflective practice from all healthcare professionals, including nurses, is required. The ways in which nurses interpret and respond to their patients, and the ways in which their

relational practice is facilitated or constrained by the contexts in which they work, will strongly influence our ability to provide ethical care under the new legislative landscape of end-of-life care in Canada.

LIMITATIONS AND NEXT STEPS

This was a qualitative study of 11 nurses working in different areas of a single oncology program, located within an academic and well-resourced hospital in an urban area. In other care settings, such as the community, the ways in which nurses describe their engagement with patients who desire death may be influenced in ways we were not able to identify in this study. For this reason, future studies with nurses working in myriad contexts in which Canadians receive end-of-life care would be valuable. Further, although we purposively sampled from within and outside of the specialist palliative care division (all within a single oncology program), we were not able to identify consistent patterns of difference in nurses' descriptions according to whether or not they had palliative care expertise. Further, we did not ask participants to disclose their religious orientation or other sources of cultural influence on their attitudes toward assisted death. It may be interesting to conduct future research on the ways in which religiosity or other sources of cultural influence impact the ways in which nurses engage with patients who desire death. Finally, while this interview study provides insight into the ways in which nurses talk about and think through their therapeutic engagement with patients who desire death, it would be valuable in future research to use participant observation as a method to illuminate how nurses enact therapeutic presence in a context of desire for death. Ethnographic studies of nurses' practice under the new Canadian legislative framework for end-of-life care, for example, would be well-suited to identify challenges and opportunities in the ethical care of patients seeking assisted death and to clarify and elaborate the nursing role in this process.

CONCLUSION

This study, which was conducted prior to legislative change, demonstrates how a legislative context where assisted death is prohibited can constrain therapeutic engagement. Indeed, nurses were at a loss when they felt their patients were asking them impossible questions for which they did not have answers. These results mirror the feeling of powerlessness that Belgian researchers described in their study of nurses' experiences prior to legalization of euthanasia in that country (De Bal et al., 2006). Now that assisted death is legal across Canada, oncology nurses will conceivably no longer feel constrained by a restrictive legislative context. They should now be able to openly and honestly discuss a fuller spectrum of end-of-life choices with their patients. At the same time, nurses must continue to resist a 'fix it' approach to the suffering of their patients, which our findings reveal is a constant struggle for oncology nurses who care for patients at the end of life. Nursing skills of interpretation and presence are relevant now more than ever, and patients who express

a desire for death in the new legislative regime will require a high level of therapeutic engagement. An apparent desire for death in a patient with advanced cancer should signal a need for critical and reflective analysis about what underlies that patient's suffering, what might be done to help them, and how care delivery systems can be optimized to ensure that nurses are best positioned to deliver the care that the patient requires.

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FUNDING

David Kenneth Wright is supported by a New-Investigator Award (2014–2017) from the St-Mary's Hospital Foundation in Montreal. Funding for this research study was also supported by a research grant from the Nursing Science Axis of the Quebec Suicide Research Network, funded by the Fonds de Recherche du Québec - Santé (PIs Wright & Bitzas).

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