

## Discourse

# Needless Suffering

**Kimberley Widger**

*We cannot keep them from suffering but we can keep them from suffering for the wrong reasons.*

– Anonymous

I found this quote while completing my master’s degree in nursing. I had been in practice only about 3 years and had provided care primarily to children with cancer. While the vast majority of children with cancer survive their disease, I provided care to many who had experienced a great deal of suffering throughout their treatments and to several who later died. Nothing in my undergraduate program prepared me for feeling completely overwhelmed and helpless while watching the suffering of the parents or the children who experienced uncontrolled symptoms or ultimately died from their disease. I went back to school to learn how to “fix” or take away all that suffering. Instead, I learned that unless I could wave a magic wand and tell parents, “This has all been a bad dream — go home with your healthy child and forget this ever happened!” there was absolutely nothing I could do to take away the pain that surrounded the death of a child. What I could do was make sure that nothing I said or did, or did not say or do, added needlessly to that suffering.

My practice, and, later on, my research, became focused on identifying causes of “needless” suffering for families and finding ways to prevent or address them. I practised with this idea of bearing witness to the suffering that I cannot fix, and doing my best to prevent or alleviate the rest. It served me well. However, in recent months, following the Supreme Court of Canada’s decision on physician-assisted death (*Carter v. Canada*, 2015), I have spent considerable time revisiting my ideas of what constitutes needless suffering. While my clinical practice has all been in pediatrics and the new ruling does not apply to children under 18, in some jurisdictions euthanasia is allowed for people as young as 16 as well as for infants (Verhagen & Sauer, 2005). What follows are some of my musings on the subject, in particular on the very important role I see for nurses

in ensuring that needless suffering is addressed in the midst of imminent changes to the way we practise and the options available to our patients.

The Supreme Court ruling (*Carter v. Canada*, 2015) identifies two options for adults “who are grievously and irremediably ill . . . : she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes.” The first option seems to be that adults can choose to end their life prematurely in a more humane way, through ingestion of medications prescribed by a physician. However, if they do not take that option they are left with suffering until death from natural causes. Statistics from jurisdictions where access to physician-assisted death has been in place for a number of years show that only 0.21% of the population choose this option (Oregon Public Health Division, 2013). Interestingly, however, more people request physician-assisted death and receive a prescription for the medications than actually ingest them to end their life (Oregon Public Health Division, 2013). Maybe simply having the option available reduces some suffering due to fears about life and death and affords a measure of control, giving people the means to end their life on their own terms. For some, perhaps, the end-of-life experience is not as bad as they had imagined and death is dignified and peaceful without the need to exercise their right to physician-assisted death. Regardless, the fact remains that the vast majority of the population, even when they have the right to choose physician-assisted death, do not. So what are the options beyond “suffer until death”?

Under the Supreme Court ruling (*Carter v. Canada*, 2015), the informed consent process for physician-assisted death must include a description of all reasonable palliative care interventions. The assumption seems to be that all Canadians have access to all reasonable palliative care interventions, when in fact they do not. Recent estimates indicate that 16% to 30% of the adult Canadian population has access to high-quality palliative care (Canadian Institute for Health Information, 2007). In 2002 we estimated that only 5% of children in Canada accessed specialized pediatric palliative care services (Widger et al., 2007), though an update of that study, currently underway, finds that the proportion has increased to 17%. While significant improvements have been made, the vast majority of Canadians still do not have access to high-quality palliative care. In Canada, geography is a strong barrier to palliative care; specialized services are simply not available in many rural and remote areas. And even where palliative care *is* available, not everyone who might benefit is actually referred. Whatever the reason, lack of access results in needless suffering for our patients.

What can nurses do? Advocacy is one avenue for addressing needless suffering on a broad scale. Nurses can get involved both locally and

nationally to support initiatives to improve provision of palliative and end-of-life services. The Canadian Hospice Palliative Care Association (CHPCA) and the Quality End-of-Life Care Coalition of Canada have led the development of a national framework for an integrated palliative approach to care. This framework is supported in a Joint Position Statement by the Canadian Nurses Association (CNA), CHPCA, and the Canadian Hospice Palliative Care Nurses Group (2015):

The integrated palliative approach to care focuses on meeting a person's and family's full range of needs — physical, psychosocial and spiritual — at all stages of a chronic illness. It reinforces the person's autonomy and right to be actively involved in his or her own care, and strives to give individuals and families a greater sense of control. It changes the understanding of hospice palliative care from a service offered to dying persons when treatment is no longer effective to an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging. (CHPCA, 2014, p. 14)

Contrary to what most people think, palliative care is about living rather than dying. The palliative approach to care is also not about specialized services but about all health professionals providing this approach to care in all settings. Every health professional can and should be able to talk with patients about their goals of care and ensure that treatment is aligned with these goals, as well as to provide basic symptom management and care that support the person's autonomy. Specialized services and health professionals with additional training and expertise can support this “frontline” palliative approach and become more involved when symptoms are particularly difficult to manage or when there are other challenging issues that need to be addressed. The Canadian Association of Schools of Nursing (2011) recently published entry-to-practice competencies to ensure greater integration of knowledge about palliative and end-of-life care into undergraduate curricula. Thus, new graduate nurses will be better prepared to provide a palliative approach wherever they practise. Also, specialty certification in Hospice Palliative Care Nursing is available through CNA to ensure that there are nurses with the knowledge to provide this specialized care when it is needed (CNA, 2015).

While involvement in advocacy and system-wide improvements, including the education of new and specialist nurses, is important and will reduce needless suffering in the future, these initiatives may not help the current patient. I still hear and read many more horror stories than positive stories about people's experiences with health care. Part of the problem, I sometimes think, is that we don't know what we don't know. I experienced this lack of knowledge firsthand when I went to work

with a renowned pediatric palliative care physician, Dr. Gerri Frager, in Halifax. I came to the job a few years after receiving my master's degree, armed with a great deal of learning and what I thought was a great deal of experience in delivering good palliative care. What I quickly learned was how very little I actually knew. I had not seen uncontrolled pain treated as an emergency that included staying with the patient until medications were appropriately titrated with physical and psychological interventions fully incorporated, to ensure that the pain was truly under control. I had not learned how to take the time to really connect with patients or families, to find out who they were and what "little wishes" they might have to make a horrible situation a little brighter — having a favourite pet brought to the intensive care unit, taking a newborn transferred to the hospital at night out to see the sun and feel the breeze before discontinuing a ventilator, or taking a bed-bound teenager up an incredibly narrow flight of stairs so she could spend her last days at home in her own bedroom surrounded by friends and family. The more I learned, the more I thought of different patients I had cared for, and realized how much I may have contributed needlessly to their suffering because of my lack of knowledge. At the time, there was no specialist palliative care team to whom I could have referred my patients, but even if there had been I likely would not have done so, as I thought I was doing a pretty good job on my own. I encourage all nurses to increase their knowledge about the basics of palliative care and, where specialized services exist, find out more about what is offered so that they recognize when the situation is beyond their skills and specialists need to be added in order to ensure that the suffering of the patient and the family is minimized.

While lack of knowledge on the part of health professionals can cause needless suffering for patients, even more fundamentally, I think, a lack of connection is at the heart of patient suffering. Maybe it is self-preservation on the part of health professionals to not connect with patients and families who are suffering, but I would argue that the opposite is true. I remember a particular day on a pediatric oncology unit when I ran the entire shift trying to get everything done. I had a long list of chemotherapies, medications, and blood products to administer, several patients needed frequent monitoring of vital signs and were located at opposite ends of the unit, and one child had a reaction to something. By the end of the day my legs were so tired I wasn't sure how I would even walk to my car. A patient's father stopped me in the hallway on my way out and asked if I was okay. He said, "I didn't see you smile once today." I went home physically exhausted. I had ticked off every last task on my "to do list" yet I felt horrible, burned out and ready to quit nursing. This kind of task-oriented nursing with no time to even smile at my patients

was not what I had signed up for. But there were other days. I remember sitting with an incredibly angry young teenager who had just been diagnosed with osteosarcoma. He had a large tumour on his femur and more than 25 small tumours in his lungs. Up to that point he had allowed us to do only very basic care and had kicked anyone out of his room who even tried to talk to him about his diagnosis or treatment. I had looked after him nearly every day since his admission. Now I had to give him his first dose of chemotherapy. I told him he could be angry all he wanted but I needed to stay in the room to monitor him for a couple of hours. As the chemotherapy finished running and I was packing up to leave, he quietly asked what kind of cancer he had. His mom and I talked with him about his cancer and answered all his questions about the type and number of tumours, about the treatments he would be getting, and about dying. We cried together. I went home that day emotionally exhausted and worried that this boy would never want to see me again because I had given him such horrible news. As it turned out, he became much less angry and I remained one of his primary nurses. There were many more emotionally exhausting days caring for this patient and others, where there was so much suffering related to what they were facing, but after those days I never felt that I wanted to quit nursing; I felt I was making a difference. I developed strong connections to these patients and their families, which allowed me to bear witness to their suffering and understand what they did or did not want, to ensure that I was not adding to their misery.

Some may worry that really connecting with patients takes too much time. I agree that, while sometimes connections are made very quickly and naturally, other times they take a lot of time and work, as with the teenager described above. However, I would argue that it may not take as long as expected, and we may not be taking advantage of the time and opportunity to connect when it can really make a difference in the lives of our patients and their families. One mother who participated in some of my research described an interaction with health professionals when she took her daughter, who had cancer, across the country:

I took [my daughter] on a trip and we ended up in emergency with a fever and I was trying to get her to a hockey game because she was a fanatic . . . And they were so amazing there. They gave her some fluids, they hired a taxi . . . they had her go to the game and brought her right back. And they kept her room and they said “We’re so excited for her!” and joking with her. They made it such a special day. (Widger, 2012, p. 54–55)

The interaction with these health professionals lasted only a few hours, but there was a wonderful connection. They took time in a very busy

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emergency room to find out what was going on with this family and what needed to be done, and then they did it in a warm and supportive way. Contrast this experience with the same family's experience in an intensive care unit where they spent several days:

It was two days before [she] died and [the doctor] came to do rounds . . . they were just outside the door; the door was open . . . she said to everybody, "Well, this one is circling the drain." And then she just carried on a conversation and I thought, [my daughter] doesn't even have a name. I don't even have a name. [The doctor] was so disconnected from my daughter. And all of a sudden my daughter's life was in her hands. (Widger, 2012, p. 54)

This health professional had plenty of time to connect with the family, but instead of alleviating suffering she inflicted it. I spoke with the mother a couple of years after her daughter's death and it was evident that both experiences had a significant long-term impact on her. I wish she had had more experiences like the first one and more health professionals had taken the time to get to know them as a family and find out what they wanted and needed. Health professionals may be afraid to ask what a family needs in case it is something that cannot be provided. However, in my experience families generally ask for little things that are very easy to do or just need some guidance on what to expect or what might be possible. It would help for health professionals to have some sense of the common things that people facing a terminal illness might want in order to be ready to offer suggestions and guidance when needed.

There are many resources and research studies addressing the needs of people facing death and their families, but I particularly like a book written by Dr. David Kuhl (2002) titled *What Dying People Want*. The author shares the stories and wisdom of his co-researchers — people who had been told they had a terminal illness and agreed to talk to him over multiple sessions about their experience. He certainly found commonalities in people's experiences and needs as they faced the end of their lives: the changing perceptions of time, the importance of effective communication with health professionals, physical pain, the importance of touch, the need to review one's life, the importance of being truthful, the need to belong, and the need to understand who one is as a person and to experience a sense of meaning in one's life. But Dr. Kuhl also found that each person was different in terms his or her story and the particulars of what was wanted — hence the need to really connect and to more fully understand who the person sitting in front of you *is*. Some patients might want a hug, some might just want a squeeze of the hand, and some might not want any physical touching at all. If we do not take

the time to ask patients and their families what they want, we risk touching too much or too little and adding needlessly to their suffering. On the other hand, asking what people want can backfire, as described by a mother in my research who experienced the death of her infant daughter after a sudden illness:

They're saying what do you want to do? Like I deal with [my child's death] everyday. Why don't you tell me what I'm allowed, give me some options. I don't think it should be up to me as a distraught, bereaved parent, to be trying to figure out what is okay and what's not; or what's available and what's not. (Widger, 2012, p. 57)

I am quite sure that the nurses caring for this family were trying to do their best in asking the mother what she needed. However, they kept repeating the question and caused more suffering, because the mother had no answer and was given no guidance in finding an answer that might be a fit for her. As nurses increase their knowledge about what might be helpful in such a situation — for example, by reading a book like the one cited above — and gain more experience with families in these situations, they will learn how to ask a family what might be wanted or needed. After allowing time for a response, they can move on to providing suggestions or examples in a tentative way: “Some families find it helpful to . . . I wonder if that is something that might interest you.” A strong connection with and understanding of the family can help the nurse to narrow the list of options or suggestions to those that might be the best fit for that particular family.

Soon, one of the options for patients may be physician-assisted death. It is likely that nurses will have a role in responding to questions that families raise about this possibility as well as in ensuring that patients are aware of it. But this option will be a fit for only a very small segment of the population. The majority — even those who seek physician-assisted death — will benefit from a palliative approach to care and all the options that it can offer. As nurses, we must ensure that, from the time of diagnosis with a life-threatening illness, the physical, psychosocial, and spiritual needs of patients and families are met to the best of our ability. For those with needs beyond our ability, we must advocate for ready access to specialized services and expertise to meet those needs. We must respect and advocate for the autonomy of our patients and their right to be actively involved — to the degree that they want to be — in their own care. Nurses are in a position to identify, early on, those patients who may wish to explore the option of physician-assisted death. However, nurses must ensure that patients are aware of the other options and that patients receive the care they need to prevent them from feeling they have no alternative but to end their life.

Are we causing needless suffering when we fail to offer people the option of choosing the timing of their own death when faced with a life-threatening illness? Probably — but only for a very small proportion of our society. Far worse needless suffering is caused when people do not have access to other options, such as a palliative approach to care and specialized services when needed. Death is certainly one option for the relief of patient suffering, but it is not the only one.

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