

Canadian Oncology Nursing Journal

Revue canadienne de soins infirmiers en oncologie

Volume 26, Issue 3 • Summer 2016
ISSN: 1181-912X (print), 2368-8076 (online)



Canadian Association of Nurses in Oncology
Association canadienne des infirmières en oncologie

The price of compassion—Letting go of your ideals to provide better care

by Kim Sadler

Accompanied by his family, Adam, 20, consulted various hospital centres looking for treatment. In Canada, for just under a month, he is admitted directly into palliative care. There is no cure to help him.

My name is Sophie and I am a nurse. I am getting ready to meet him, equipped with all the compassion I can muster. I walk into his room, introduce myself and ask how he's doing. With an aggressive tone, he shoots back, "I am fed up with all you people who come in here so cheerfully and introduce yourselves! And you, don't come in here again with a smile on your face unless you've got a cure for me!" Then, he turned his back on me and covered his head with his covers. His room is always dark and he spends all his time in bed.

A week after he arrived, new metastases compressed his spinal cord, paralyzing him from the waist down. On several occasions since then, he was found on his stomach on the floor, legs twisted under him. If only you could have seen the rage in his eyes each time we worked to get him back into bed. The medical team fired up the arsenal of available resources: musical therapists, art therapists, psychiatrists, psychologists, the chaplain and volunteers to try and reach out to Adam in his suffering. Each time, his reaction was the same: he angrily chased the parade of professionals from his room.

I never doubted his judgment. Every time he tried to get out of bed, he knew very well what would happen. This did not stop him from testing his new reality. For him, there was probably no compromise to be had between life as he had known it before his illness and his current state, which, for him, was the same as death. In the end, our medical team had to leave him alone, telling ourselves—perhaps to protect ourselves from fully admitting our helplessness—that things would surely have been better for Adam had he "at the very least" allowed others to reach out.

Seeing someone suffer is barely tolerable. Another person's cry for help is upsetting. It painfully reminds us that we have little true power. Despite our wish to help, others can suffer in ways that are raw and that we won't ever be able to relieve.

ABOUT THE AUTHOR



Kim Sadler, BScN, PhD(c) Clinical Psychology

Address for correspondence: Kim Sadler, Palliative Care Unit, Jewish General Hospital, 3755 Côte Sainte-Catherine, Montréal, QC, Canada H3T 1E2 Tel.: 514-340-8222, ext. 5422. Email: kim.sadler@hotmail.ca

DOI: 10.5737/23688076263233237

This is very difficult to accept. Nurses often choose their profession out of a desire to help others. This ideal can transcend the professional sphere and even come to define them as individuals. It is difficult to be confronted with the limitations of our compassion, a state that regularly gives rise to major questions. Am I strong enough? Am I good enough? Am I where I belong in life? These questions, combined with the resulting painful effects, can exhaust nurses' compassion, so much so they feel they can no longer care for patients or even for themselves. While this phenomenon of "compassion fatigue" and its harmful effects on caregivers has been extensively described in recent years, the effect of suffering on the care patients receive has been less explored. Caregivers' suffering caused by their contact with patients is certainly not inconsequential. It is a reality that too often goes unrecognized.

We will first analyze the sources of nurses' suffering upon patient contact. Then, we will look at these sources of suffering that cause nurses a variety of self-protective reactions. We will go on to consider how these reactions may influence the care nurses provide their patients and, lastly, will propose avenues for improving nursing care.

SOURCES OF SUFFERING IN NURSES

Suffering is a part of being human. And it affects caregivers and patients similarly: neither wants to feel it (Miller, 2004). It is both a rupture in time and in space, a break with oneself and a rupture with others. Suffering is felt in different relationships, be it the relationship with oneself, with others or with time.

Relationship with oneself. Suffering is felt by the whole person and arises when someone's whole being feels threatened. It happens when aspects of our life—including values and ideals—are under attack in such ways that we feel incapable of existing as we wish or as we have up until now. Most of the time, nurses project onto their profession the ideal of doing good, from which stems a need to feel that their presence makes a difference to their patients. Studies have shown that while parents tend to over-estimate their child's suffering, caregiving staff systematically under-estimates it (Carnavale, 2009). If nurses acknowledged their incapacity to relieve suffering, they would be in a position of failure. This reality can often be brutal for ideals. Longneaux (2004), a philosopher who was interested in caregivers' suffering, reminds us that we are never strong enough to do only good.

Relationship with others. Levinas suggests that the first meeting we have, as humans, is the one that takes place between our own being and the other (as mentioned in Miller, 2004). As soon as we recognize the other's existence, we feel a sense of responsibility towards them. The exact feeling of suffering is unique to each individual, but there seems to be a universal

feeling that allows us to help another person overcome challenges that are beyond our own experience (Miller, 2004). Compassion is the tool nurses possess to relieve suffering. It simultaneously engages a combination of emotions, thoughts, behaviours and major motivation to open up not only to others' suffering, but also to one's own—this is often forgotten. Compassion requires both distance and closeness between the two parties. Some situations are more difficult for nurses, like when they might perceive either too great a distance between them and their patients, or too great an intimacy.

In the first case, they are unable to connect with the patient. They may “blame” the patient for this, for example, by explaining the failed healing relationship by denial, anger or even certain of the patient's personality traits. The caregiver often has the need to feel her patient's receptivity (Boston & Mount, 2006). Like with Adam in the example above, patient anger is a particularly difficult aspect to manage and it becomes all the more trying when it targets the caregiver. Possible sources for this anger are many. For example, if nurses do not reassess health care objectives with their patients, as the health of these latter evolves, patients will most likely develop unrealistic expectations, which will sometimes provoke aggressive reactions. Particularly, the transition period between curative and palliative care can be cause for upset. If this transition is too abrupt, the patient may even feel rejected or abandoned. For a caregiver who mostly works in therapeutic care, it is difficult to transition from “saviour” with everything to offer to being “blamed” or held responsible for the limitations of science.

On the other hand, when there is too much intimacy between the caregiving personnel and patients, each party's experiences become intertwined. For example, nurses might draw a parallel between their personal experience and their patient's. This could cause them to lose the perspective they need to offer care focussed on patients' unique experience. When nurses become invested in a therapeutic relationship, they are more likely to lose sight of what is best for their patient and begin providing care centred instead on their own needs (Anewalt, 2009).

In a normal lifecycle, death follows life and life follows death. In a palliative care unit, however, deaths come one after another and this quick succession leaves nurses little time to digest their experiences. The demands of providing care and continuing to meet the needs of the sick is ongoing and the time it takes to stop, withdraw from daily life and fully experience these periods of “mini-grieving” is not always possible. This reality is generally and widely left unspoken.

Relationship with time. In suffering, there is a major reference to the notion of time. British writer Graham Greene (1940) expresses in *The Power and the Glory* that no one knows how long a second of suffering truly lasts. Starting at birth, individuals must learn to manage the temporal effect of separation and loss. Awareness of the ephemeral nature of time touches on the sorest point of our experience: recognizing our own mortality. The progress of medicine over the past decades would lead us to believe that this has never been as true. In an elegant

essay entitled “Letting go: What should medicine do when it can't save your life?” (2010), surgeon and author Atul Gawande explains that although death is still certain, the timing of death no longer is. He adds that technology can now keep our organs alive well beyond the point of consciousness. Regardless of where patients are on the care continuum, there is always something that can be suggested: we are reminded of all the cases of patients with terminal conditions being “mistreated” by futile, often invasive medical care just because, as caregivers, we simply don't know where to stop. Caregivers can be tempted to believe themselves almighty and, therefore, think they are able to “stave off” the moment of physiological death. People now live longer and longer, including those with advanced stages of cancer. But do we stop frequently enough to ask ourselves at what price this extended lifespan comes? End-of-life discussions with patients are regularly put off until they are no longer possible—even up until the very moment patients can no longer express their wishes. And when the patient's preferences are not known, we are often left with a fear of “not doing enough,” which leads us to “doing too much.”

CAREGIVERS' REACTIONS

Confronted with their limited ability to relieve suffering and heal patients, caregivers can watch their ideals crumble. In reaction, nurses may isolate themselves, hide their distress or become divorced from their emotions (Longneaux, 2004). Some become disaffected from their work, while others throw themselves into it (Longneaux, 2004). These reactions do not all occur consciously. When the anguish is too great, people protect themselves in various ways. In psychoanalysis, these are called “defence mechanisms” (processes in which a painful emotion becomes detached from its source in the real experience). While beneficial when used temporarily (since they protect people), they can be silently damaging when used regularly. And, indeed, these mechanisms are a way of putting distance between oneself and suffering. Nurses use this distance to protect themselves from feelings of failure and helplessness to relieve the other's suffering, and from their own anguish. This distancing does not lead professionals to recognize and verbalize patients' painful emotions, which is, indeed, often the first step to relieving suffering. Let us take a closer look at a few defence mechanisms.

Denial. Only one thing is sure in life: the end. To protect ourselves from the anguish of annihilation and allow ourselves to function through our daily lives, the mechanism of denial keeps our consciousness from accessing our fear of death. Freud said that all doubts about our immortality persist up until the very end (Freud, 1915). We must only think of all the patients in the terminal phase who continue going about their lives “as if.” Psychoanalyst Michel De M'Uzan (1977) noticed a paradox in his work with the dying. Even when the end was very near, many of his patients showed a regain of life and a desire for intimacy. There are also the numerous patients who go through with “aggressive” treatments despite the absence of positive results as to their efficacy, who turn to experimental treatments still in the very first stages of development or who

almost obsessively research miracle remedies. Caregivers even find themselves offering all these “options,” even if they know very well how unlikely they are to help. Some studies have revealed that more than 40% of oncologists prescribe treatments they know have improbable efficacy (Gawande, 2010). As Gawande pointed out, it is somewhat easier to feed fantasy than address end-of-life issues.

In modern Western society, many people hold death at arm’s length over their lifetimes. If aging and suffering are barely touched upon in nursing school, death is entirely absent from the curriculum. Several hypotheses can be put forth to explain this conspicuous absence. First, the underlying notion that medicine exists first and foremost to save lives persists. Second, death is invisible, as it has become a painful trial, frequently taking place alone in a hospital room (Zimmerman & Rodin, 2004).

Caring for patients with terminal illness can stir caregivers’ awareness of their own losses and vulnerabilities (Sherman, 2004). Despite nurses’ desire to get closer to the patient through compassion, a gap often forms between caregiver and patient. It is as if the caregiver surrounds their dying patients with an aura to keep him or her at a safe distance (Sadler, 2014). This “aura” is denial, as caregivers refuse to believe their patients’ reality could one day be their own. This situation is peculiar in palliative care given that death is not just a possibility, but a daily reality. Nurses’ defences are constantly solicited in this context, leading us to wonder about the effects on their psychological health and the care they are able to provide to their patients. It is easy to imagine that, occasionally caught in their own issues, nurses are not always focused on patient needs.

Rationalization. Nurses regularly rationalize to explain what they see and participate in. Rationalization is the development of a logical justification to explain a difficult-to-accept behaviour. For example, nurses are regularly called upon for tasks that cause physical pain (e.g., punctures, changing wound dressings). If it is difficult to watch someone suffer, it is all the more difficult to cause suffering. To be able to carry through with these acts, nurses must cultivate their detachment. Here are a couple examples of this defence mechanism at work: “I don’t get to decide; I’m just doing my job,” “It’s normal to suffer a little when you’ve got metastasized cancer,” “He’s unconscious, so he must hurt less.” Notice once again how they are distancing themselves from the suffering taking place.

Isolation. This process could be defined as the elimination of emotion caused by a conscious representation (e.g., memory, idea, thought). During a trying experience, cognitive and affective elements are separated, and caregivers display emotionally detached behaviour. Nurses emotionally withdraw when their patient’s death becomes imminent (Kain, 2006). A very frequent example of this would be a nurse listing in a monotonous voice—with no perceptible affect—the difficult details of a patient’s medical history during her reporting to a colleague. Detachment sometimes has us lose sight of the fact that, for certain patients, every interaction has become a form of aggression, including that “little” capillary glycaemia, blood pressure reading or mobilization.

While some defence mechanisms, like those listed above, stem from “unconscious” mechanisms, others operate on a more “conscious” level. We will take a look at a few of these strategies that sometimes become habits.

Hiding behind false limitations. We tend to believe that dealing with suffering absolutely requires time, while we are short of time. It is too easy to resort to external explanations, like being short on staff, insufficient training, tight schedules, inadequate pay, administrative or legal limitations to ignore feelings of suffering. My position is that we should revisit our priorities, and that all forms of relieving suffering should be seen AS A PRIORITY. Despite the importance of relieving physical pain to avoid its many harmful effects on all the bodily systems, it is still a challenge to systematically assess this pain in health care settings. In recent years, although some have tried to make pain the “fifth vital sign” caregivers should systematically check, this objective is hardly reached. And if the reflex to evaluate pain level is not in place, treating it is even less so. How many patients wait hours in the ER before they are given an analgesic? This occurs even while their vital signs are taken regularly, their ingesta and excreta measured and their medical history scrutinized. And we are just talking here about physical pain! The more global and complex, vague and less objective suffering goes greatly untreated.

Avoidance behaviours. Sometimes avoidance of a situation is clear, but other times it can be so subtle that it becomes habit—the effect of which is no longer questioned. Maguire and Weiner (2009) catalogued many avoidance behaviours in patient communications: normalizing, premature reassurance, subject changing and selective attention. In normalizing, the caregiver perceives the distress but, instead of exploring it, sends patients the message that their suffering is legitimate and will diminish with time. When reassuring, caregivers offer advice and information too quickly. Caregivers may also change the subject when their patients talk about painful aspects. When caregivers pay selective attention, they listen, but are only sensitive to the physical symptoms patients report and they ignore their psychological, social or spiritual causes of suffering. According to Maguire and Weiner (2009), caregivers report using these distance-taking strategies so as not to cause their patients further distress, because they lack training or emotional support from their team. But what about caregivers’ discomfort in addressing suffering as another probable reason?

CONSEQUENCES ON CARE OF CAREGIVERS’ REACTIONS

Faced with a patient they are unable to help, nurses may begin feeling distress themselves. This unpleasant feeling leads them most often to try harder and practise more “interventions,” as they say in the profession. By being active, nurses feel they aren’t sitting by while their patients suffer, but this may prove to be a trap. In the context of care characterized by major technological and pharmacological progress, we must be vigilant that “symptom control” does not replace “palliative care,” which should be global by definition. This is a true risk since it is almost instinctive to fall back on what can be

“controlled,” and symptoms (e.g., physical pain, vomiting, difficulty breathing) are perfect for that since they are objective. They can be sized up and dealt with. While relieving symptoms is crucial, relieving suffering is much more than just that. To illustrate the slippage that can occur, Vasse (1983) stated that “the multiplicity of care [...] that the nurses provide to their patients who complain can become a kind of alibi that is organized scientifically and socially instituted” (p. 30). He wondered if nursing care did not, in fact, wish to silence the cry of help. The danger is that this cry for help no longer has the time to be verbalized and it is “the most cruel blockage when the patient’s voice is no longer heard and his cry for help no longer made out from the symptom” (p. 31).

Most of the time, nurses offer quality care for their patients, particularly by taking stock of their emotions, working as a multidisciplinary team and making sure to take care of themselves, as well. Nonetheless, there are times when their own emotional reactions keep them from giving optimum care. In extreme cases, they can try to lose themselves in action—what is commonly called futile medical care—or perhaps they disengage and lose themselves in inaction. In both situations, there is denial of the other person’s suffering and the care becomes dehumanized. Even if they are surrounded by all these “specialists” and machines, patients find themselves increasingly alone. Some ask to die—a request stemming occasionally from this institutionally enforced loneliness. When the “heavy artillery” of euthanasia or palliative sedation are used to relieve existential suffering, to what extent is it about our powerlessness, as caregivers and family members, when faced with the unknown and death, over which we have no control, in addition to our immense desire to relieve people’s suffering? Death has gone from a natural extinction of the soul to a highly technological event (Zimmerman & Rodin, 2004). Gawande (2014) pointed out that science has turned aging and death into medical experiences and our discomfort at looking closely at these processes any differently increases the violence that is waged against patients, particularly by denying them what they need most: care focused on their well-being.

AVENUES FOR IMPROVING NURSING

Acknowledging our own suffering. We must begin by addressing nurses’ suffering if we are to help them perform their complex role. Longneaux (2004) says it is the caregiver’s dreams and ideals that cause suffering, and that the solution is to let them go. However, this is a slow and tortuous process. Above, we developed a conceptualization of caregivers’ suffering based on three relationships, namely, with oneself, with others and with time. As regards the relationship with oneself, it is important to accept one’s limits and be satisfied to do and be the best we can, even if that regularly is not enough. Nurses can begin by disclosing to the patient that they will probably not be able to meet all their needs (Anewalt, 2009). Relative to others, it is necessary to accept that it will never be possible to totally reach others in their suffering because we all always live in separate realities. We can and we must accompany patients along their path, but we can never carry their suffering for them. With regard to time, the future is a luxury that no

longer exists at the end of life. Hope for a cure fades into hope focused on the sick person’s desires for their remaining days. Only acceptance can be the key to releasing one’s ideals: acceptance of not always having the solution (so as not to escape to action or inaction), acceptance of feeling pain and acceptance of sometimes being slowed down by the flood of uncommon experiences that a succession of deaths represents. When this is the case, the difficult experiences are only being suppressed until the moment they can no longer be contained. And that is when it becomes difficult to take care, be it of others or of oneself. It is also important to break nurses’ isolation. This implies that institutions must be open-minded. Regretfully, the subject of caregivers’ mental health remains taboo and, as a result, many keep quiet about how they are really doing, fearing the judgment of colleagues or supervisors, not wanting to let down their patients, or believing that speaking up might limit their potential for career advancement.

Acknowledging the inevitability of suffering. It is essential to accept that a patient’s suffering cannot be grasped. Suffering belongs only to the person experiencing it, enduring it, carrying it. Therefore, the third-party assessment of a patient (by loved ones, nurses, etc.) will always be nothing more than speculation, a reconstruction based on the third party’s frame of reference. Some interventions say more about the third party’s discomfort than the patient’s suffering per se. Caregivers must have a solid sense of self (De Graeff & Dean, 2007). They must familiarize themselves with their own ideas about illness, suffering, vulnerability, and death, as well as shame and guilt (Ohlen, 2002). This will allow them to be at their patient’s service. It is also important to let go of the idea that there is ONE single trajectory, ending in an acceptance of death, that all patients must follow at the end of life and that it is the caregiver’s role to accompany them toward this predetermined outcome. The reality is that each patient has their own journey, which reflects their philosophy on the role that determinism plays in life. But this never means abandoning patients to their terminal fate. The priority must always be to relieve suffering in all its forms, and this demands active care until the final breath. It is essential to know how to change courses when the time comes. In curative care, it is appropriate to sacrifice the patient’s quality of life today for the possibility of gaining time in the future. But in palliative care, the focus is on providing the best possible quality of life here and now, regardless of the impact on survival time (Gawande, 2014).

Improving training. The recommendation to improve nurse training cannot be overlooked, especially with regard to their communication skills. Dr. Susan Block, an important figure in palliative care development in the United States, stresses the importance of communication for talking about a patient’s suffering and her recommendations are simple: take time to sit down and listen (Gawande, 2010). According to Dr. Block, if the caregiver is talking more than half the time, it is too much. Let’s keep in mind that communication is a process, and that the goal is not to have a “good talk” once and for all: given the constant changes in a patient’s physical and psychological state, his or her priorities must be reviewed regularly.

The French writer Georges Bernanos is cited by Young-Mason (2002) as saying that the act of compassion is heavy, making us painfully aware of the agony surrounding us. Compassion reveals itself to be a double-edged sword: It is a tool that, at times, helps relieve others' pain, but it also has the ability to hurt the person wielding it. Levinas (cited in Oreopoulos, 2001) conceived of compassion as a way of being present to others. Escaping the centripetal force of our own identity, needs, interests and values allows us to launch ourselves along a new trajectory—one that leads to the Other (Oreopoulos, 2001).

REFERENCES

- Anewalt, P. (2009). Fired up or burned down: Understanding the importance of professional boundaries in home health care and hospice. *Home Healthcare Nurse*, 27(10).
- Boston, P.H., & Mount, B.M. (2006). The caregivers' perspective on existential and spiritual distress in palliative care. *Journal of Pain Symptom Management*, 32(1).
- Carnvale, F.A. (2009). A conceptual and moral analysis of suffering. *Nursing Ethics*, 16(2).
- De Graeff, A., & Dean, M. (2007). Palliative sedation therapy in the last weeks of life: A literature review and recommendations for standards. *Journal of Palliative Medicine*, 10(1).
- De M'Uzan, M. (1977). *De l'art à la mort : Itinéraire psychanalytique*. Paris: Gallimard.
- Freud, S. (1915, 2013). *L'Inconscient* (translated into French by Olivier Mannoni from the German). Paris: Édition Payot.
- Gawande, A. (2014). *Being Mortal: Medicine and What Matters in the End*. Doubleday Canada.
- Gawande, A. (2010). Letting go: What should medicine do when it can't save your life? *The New Yorker*, August 2.
- Greene, G. (1940). *The Power and the Glory*. London: Heinemann.
- Kain, V.J. (2006). Palliative care delivery in the NICU: What barriers do neonatal nurses face? *Neonatal Network*, 25(6).

ACKNOWLEDGEMENTS

The author would like to thank Dominique Scarfone, MD; Marie-Laurence Fortin, MScN, CHPCN(C); Ginette Deschesnes, BA; the palliative care team at the Jewish General Hospital in Montréal; and the patients I've had the privilege to meet. Thank you all for sharing your experiences, discussing ideas and providing support, which allowed me to write this text.

NOTE

Text segments from: Sadler, K. (2015). "Le poids de la compassion : Faire le deuil de ses idéaux pour mieux soigner." *Cahiers francophones de soins palliatifs*, 15(1).

- Longneaux, J.M. (2004). La souffrance des médecins et des soignants. *Ethica Clinica*, 35.
- Maguire, P., & Weiner, J.S. (2009). Communication with terminally ill patients and their families. In H.M. Chochinov, & W. Breitbart (Eds.), *Handbook of Psychiatry in Palliative Medicine* (2nd edition). NY: Oxford University Press.
- Miller, R.B. (2004). *Facing Human Suffering*. Washington, DC: APA.
- Ohlen, J. (2002). Practical wisdom: Competencies required in alleviating suffering in palliative care. *Journal of Palliative Care*, 18(4).
- Oreopoulos, D.G. (2001). Compassion and mercy in the practice of medicine. *Peritoneal Dialysis Intl*, 21.
- Sadler, K. (2014). Comment soigner en étant soi-même touché par la douleur de l'autre? *Médecine palliative*, 13.
- Sherman, D.W. (2004). Nurses' stress and burnout. *The American Journal of Nursing*, 104(5).
- Vasse, D. (1983). *Le poids du réel, la souffrance*. Paris: Éditions du Seuil.
- Young-Mason, J. (2002). Transmuting anger into compassion. *Clinical Nurse Specialist*, 16(5).
- Zimmerman, C., & Rodin, G. (2004). The denial-of-death thesis: Sociological critique and implications for palliative care. *Palliative Medicine*, 18.