BRIEF

CANADIAN NURSES ASSOCIATION*

PHYSICIAN-ASSISTED DYING

Brief for the Special Joint Committee on Physician-Assisted Dying (Based on CNA's Brief for the Government of Canada's External Panel on Options for a Legislative Response to *Carter v. Canada*)

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BACKGROUND

This brief was originally prepared by the Canadian Nurses Association (CNA) for consideration by the Government of Canada's external panel, tasked with developing the federal legislative response to the 2015 Supreme Court decision in *Carter v. Canada (Attorney General)* regarding physician-assisted death (PAD). It has since been updated for submission to the special joint committee on PAD.

CNA acknowledges that PAD is an incredibly intricate and emotional topic. However, it is not up to CNA to suggest a position on an issue that the law has already made clear through a unanimous ruling by Canada's highest court. CNA must respect the Court's decision. As the voice for registered nurses in Canada, CNA's priority is to support nurses on this issue and help them provide the best ethical and competent care to patients, including those either at or near the end of life, as per the CNA *Code of Ethics for Registered Nurses*. This work includes collaboration with both provincial/territorial nursing associations and/or colleges and the Canadian Nurses Protective Society (CNPS) to provide input on the implications of PAD, in connection with the code of ethics, and bring forth the nursing perspective.

CNA would like to mention that this submission is informed by comprehensive information collected through a series of in-depth, one-on-one interviews with Canadian and international thought leaders and experts in this field. These include

- international associations involved in developing national and state policies related to PAD
- direct care practitioners with expertise in palliative care and end-of-life care and research
- nurses with expertise on legal and ethical issues or those with a regulatory background who have insight from a jurisdictional perspective as to how PAD may impact nursing practice.

As the most consistent health-care providers for patients, nurses are the ones patients talk to and seek answers from most often. In fact, it is not uncommon for a nurse to be the first person a patient approaches regarding assisted death. It is our hope that the special joint committee on PAD will seriously consider our comments and make use of the insight and specialized knowledge nursing has to offer on this very important issue.

KEY ISSUES

FORMS OF PHYSICIAN-ASSISTED DEATH (PAD)

Current PAD models suggest two possible scenarios for patients wishing to pursue this option:

- Patients themselves may take a lethal dose of medication, which is provided by a physician (as is done in Oregon).
- A physician administers the lethal dose of medication to the patient (as in the Quebec model).

While it is not part of CNA's mandate to comment on the merits of either process, the involvement of an interprofessional team throughout any process is essential (discussed more fully below).

It is also important to consider the language and terminology we use to ensure clarity and care when we talk about a patient receiving assistance to die. Health-care providers have always assisted their patients when dying. However, there is a difference between such a scenario and the one contemplated by the Carter case. For this reason, the term *assisted death* is preferable to the term *assisted dying*.

In addition, the term *physician-assisted death* rather than *euthanasia* or *assisted suicide* may help facilitate rational dialogue. Since the two latter terms can carry a stigma or negative connotation, they may leave the patient who requests assisted death with a feeling of being judged.

Lastly, the discussion on assisted death has been framed around the physician. Yet, when we talk about "physician-assisted death" we overlook the crucial role of the health-care provider team. As a key element of this team, the nursing perspective has not been part of the conversation, even though nurses have expertise to share on this issue.

ELIGIBILITY CRITERIA AND DEFINITION OF KEY TERMS

In its 2015 ruling, the Supreme Court of Canada noted that, to qualify for physician-assisted death, one needs to be "a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is

intolerable" to that person (p. 85). The patient does not have to suffer from a terminal illness.

The competency requirement should apply *both* at the time of request for PAD and at the time the assistance is provided. Being competent throughout the entire process (as opposed to starting off competent and losing competency at some point before death) ensures a degree of safeguard, in terms of narrowing the possibility of coercion and enabling a person to feel they can change their mind at any point and back out of going through with the act.

As part of the therapeutic relationship, health-care providers have a duty to provide persons in their care with the information they need to make informed decisions, related to their health and well-being, and to ensure they have understood the information and implications and have consented to a particular treatment. This duty is most well-known in cases of surgery, but the finality of PAD makes this process much more significant. The CNA code of ethics highlights the importance of informed consent and the need for nurses and others to recognize, respect and promote a person's right to be informed and make decisions. These criteria are crucial to the assessment and eligibility process.

While it is not within CNA's mandate to define phrases such as "a grievous and irremediable medical condition," it is vital to have a clear and common understanding of what these broad terms mean in relation to an illness, disease or disability in order to provide proper guidance for all involved in PAD and for public knowledge.

With respect to the psychological component of pain that can be inferred in the Supreme Court's criteria of "enduring suffering that is intolerable," it is important to ask how this pain is assessed in comparison to physical pain and suffering. What if a person's request is driven by depression, loss of hope and perceived loss of value as a human being? The CNA code of ethics instructs nurses that "care [be] directed first and foremost toward the health and well-being of the person" (p. 10) while acknowledging the need to "recognize, respect and promote a person's right to be informed and make decisions" (p. 11). Respecting a competent adult's right to make informed decisions should not stop the physician or others involved from offering assistance, such as helping the patient connect with support or counselling resources before deciding to go forth with the request for assisted death.

A patient's eligibility for PAD will rest on the assessment process. Here, the collective experience and expertise of an interprofessional team is key, as we explore in more detail below.

RISKS

A number of risks become possible with the allowance of PAD. Most significant are concerns about vulnerability and coercion in relation to the patient and the apprehension that, over time, society may become cavalier about the issue. Safeguards are therefore important for ensuring that PAD is dealt with carefully, competently and ethically (discussed more fully in the safeguards section below).

In addition, the legal and psychological risks for health-care providers, including physicians, nurses and others involved in caring for patients who request PAD, are crucial areas to address. Finally, it is noteworthy that increased access to palliative care would be a success and could potentially reduce the demand for PAD.

Legal risks

The Carter case provides legal protection to physicians involved in PAD, so they can practise without risk of criminal prosecution. Nurses require this protection, too.

Although nurses do not deliver physician-assisted death, they care for these patients. In a sense, PAD is another treatment option (what is needed is more clarity regarding a nurse's role at the hour of death).[1]

Nurses, because of their critical skills in interpretation, are vital to the assessment process of a patient requesting PAD and must be part of the patient's decision-making process. They are also an important and reliable source of information. They can assist with exploring patients' feeling and perspectives, discussing available options/alternatives and helping to explain the PAD process.

Accordingly, when nurses are asked a question they must feel at ease to speak with the patient. In responding, nurses must have proper protections through amendments to the Criminal Code, so they can do what they have always done (i.e., discuss, listen, educate, assess, evaluate, document, and support patients and families) without fear or risk of criminal prosecution.

Nurses (registered nurses and nurse practitioners) are independent professionals within a self-regulating profession. This standing assures the public they are receiving safe and

[1] "Nursing regulatory organizations in Canada have yet to adopt standards and guidelines as a result of the *Carter* decisions. It is expected that such guidelines will be adopted once the legislative framework is in place. Each provincial and territorial regulatory body can, within that specific legislative framework and the existing regulatory framework, adopt guidelines and standards applicable to specific circumstances that it deems most appropriate in order to satisfy the ethics of the profession, the needs of the health care system and the protection of the public" (Canadian Nurses Protective Society, 2015, p. 8).

ethical care from competent and qualified caregivers. It is the reason nursing keeps its place as one of the most trusted professions. The nurse is part of an interprofessional team and is integral to providing a comprehensive assessment of a person making a PAD request, rather than simply being a doer under the direction of the physician. Patients receive the best care when there is a lateral relationship among health-care team members, when physicians and nurses work side by side (as they currently do), no matter what the issue is. Because of this working relationship, nurses also need proper protections through amendments to the Criminal Code. The quality of patient care is at risk of decline if this protection is not given to nurses.

CNA's colleagues from the Canadian Nurses Protective Society (CNPS) addressed this issue in more detail in their submission to the external panel. CNPS offers legal advice, risk management services, legal assistance and professional liability protection related to nursing practice for eligible registered nurses.

Psychological risks

Risk of burnout: While assisted death is a new issue, it is being rolled out within a challenging context: the pressures and stresses health-care providers face today. Staffing shortages, time constraints, and being pulled in several directions at once will all have an effect on a health-care provider's ability to deliver proper care with patients considering PAD. Such conditions, for example, can restrain a nurse's ability to fully engage in the necessary therapeutic conversation with a patient and may leave the nurse feeling a sense of failure or distress. Thus, there is a need to provide extra care for nurses and other health-care providers within the PAD environment.

Risk of increased moral distress: Moral distress is a very significant issue in end-of-life care, generally, and assisted death only adds to this moral complexity. Thus, to avoid burnout among health-care providers, it is important to ensure they are supported, emotionally and psychologically as well as ethically, via clinical ethicists and experts. The nursing clinicians CNA interviewed drew attention to grief/burnout studies that suggest health-care providers leave the profession faster when they are not supported. One can imagine that this risk would be even greater when cases of assisted death are included.

Risk of trauma: One of the nursing experts CNA spoke with made the point that assisted death will radically transform the moment of death, changing what health-care providers are used to regarding what a good death looks like. A nurse or physician is generally accustomed to seeing a patient deteriorate over time, eventually becoming less alert, more sleepy, etc. Assisted death will change this. At one moment a patient

may look well and be eating breakfast and then, after the administration of the medication, they will stop breathing, change colour, and their death will be sudden. It is a different way of dying, which health-care providers are not yet familiar with. Another possibility to consider is if something goes wrong during the procedure that results in the patient being harmed. Here, there is a risk that nurses and doctors may feel traumatized in ways not yet experienced. Thus, health-care providers need support and the necessary skills to provide care in a competent and ethical manner when requests for PAD are made.

Safeguards to address risks and procedures when assessing requests for PAD

Instituting safeguards are vital to mitigating PAD-related risks in Canada and are key to upholding the integrity of the entire process. Below is a summary of important safeguards to have in place.

Ensuring that requests for PAD are addressed through a comprehensive assessment process by an interprofessional team

In terms of confirming a patient's eligibility for PAD, CNA has heard a range of experts in end-of-life care and nursing say that having an interprofessional team to undertake this very comprehensive assessment is an important safeguard. Indeed, it is not something one individual practitioner can do on his or her own. The idea of simply having a physician who checks competence, which is then verified by another physician, is a highly reductive perspective on what health care should be.

To date, the discussion about assisted death has been framed around physicians. The role of the collaborative and interprofessional health team, such as nurses, pharmacists, psychologists and social workers has been left out. Yet, the reality is that health teams are present in a variety of care settings and are integral to providing good care. While the nursing perspective has not been part of the PAD conversation, it has much to contribute to the issue.

Part of the assessment process to confirm that the patient requesting PAD is competent is ensuring that the consent to PAD is voluntary. Once a person makes a request for PAD, a critical element is having continuous and meaningful opportunities for communication with the patient. Having an interprofessional team that undertakes this very important process is essential. Nurses need to be part of this team. Their independent assessment is vital.

It is important to note that assisted death is not just an act. It is a care process. It begins right from the time the patient says they are considering such a request, and it continues until death or until the patient changes their mind. Thus, it is a relational process that occurs over time. Nurses play a crucial role in this relational process. They play an important part in verifying the authenticity of the patient's request (i.e., that a person's request is really a desire for assisted death and no coercion is involved) by virtue of their consistent presence with patients and families in general and, more specifically, their experience during end-of-life care and their clinical skill of interpretation.

Nurses have a great deal of experience with these requests, with putting them into context and with understanding what they really mean. Nurses are adept at understanding what brings a patient to this point, what their story is and what the dynamics of the family are. They have the expertise to see a request motivated by fear of pain, abandonment or some other concern, such as lack of financial resources or the worry of being a burden to loved ones.

This level of understanding comes through skilful questioning of the patient — for example, through the use of different words to see if one gets the same answer (while documenting this process) or going back to see if the answer is consistent and does not waver the next day(s) to ensure the patient was not in a temporary phase of wanting death. It is also important to have more than one health-care provider hear the answers and to have health-care providers across disciplines asking the questions (such as physicians, nurses, social workers, psychologists, psychiatrists, pastors) while using different lines of inquiry. This process serves to provide important checks and balances.

The process should also involve team members who are in frequent communication with their colleagues (e.g., asking "How does this resonate with what you heard?"). It's a group process of engagement and collective interpretation, and it may include challenges to one other (e.g., "She said X to you, but that is not what I heard."). This way of approaching requests for PAD allows the team to get the best sense of how to proceed.

Ensuring that nurses receive legal protection when caring for patients who have requested PAD

As noted above, the Carter case provides legal protection to physicians involved in PAD, so they can practise without risk of criminal prosecution. The role of the nurse and nurse practitioner also needs to be recognized, articulated and protected in law. This will safeguard the quality of care a patient receives.

Indeed, it is important to note that some settings are not physician-led (other health-care providers have the primary role). In the case of nurse practitioners, careful consideration is warranted. Nurse practitioners have additional educational preparation and expertise. They carry their own caseload of patients and sometimes are the health-care provider with the most contact with patients. Many nurse practitioners work in areas where they are the sole practitioners.

As a means of ensuring access in some communities, there may be a potential role for the nurse practitioner to prescribe medications for PAD. As CNPS noted in their submission, "Should one or more nursing regulatory body eventually determine that the nurse practitioner could, acting within her scope of practice, provide medical assistance in dying, such a nurse would also be vulnerable to criminal prosecution (p. 9)."

Ensuring health-care providers involved in PAD have the proper skills and access to information, resources and support

An important safeguard is ensuring that health-care providers who are involved in PAD practise competently and ethically. Providing the proper educational resources, information and supports are key. For example:

- Educational materials to ensure health-care providers have the information they need to understand what the law means, what the options are for a patient and what the process is for PAD. In this way, they can provide proper information to patients who ask questions. A hotline that offers health-care providers information about what the law/regulations mean would be helpful.
- Educational materials and courses that foster strong communication and interview skills, so a health-care provider can understand and verify the motives of a person who requests PAD and ascertain if there are gaps where support is needed during the assessment process.
- Education that fosters expertise in pain/symptom management so nurses and other health-care providers can assess, articulate and advocate for a patient whose symptoms are not being addressed.
- Education that cultivates a strong foundation in ethical principles and moral guidance, so health-care providers have a good knowledge of issues/implications and access to guidance in specific situations. In addition, it would be important for nurses and other health-care providers to have access to ethical support, via clinical ethicists and experts, to help them navigate difficult issues.
- Psychological support for health-care providers, so burnout does not occur, is key. For example, in hospice care models, psychologists sit with the nursing team and

debrief with them about any experiences they found to be traumatic. This process helps to sustain them in their practice. Supports are especially needed for those working in rural and remote areas.

- A process that enables health-care providers to follow their conscience is essential, should they feel PAD conflicts with their moral/religious beliefs. The CNA code of ethics (2008) emphasizes that "employers and co-workers are responsible for ensuring that nurses and other co-workers who declare a conflict of conscience receive fair treatment and do not experience discrimination" (p. 46). At the same time, health-care providers cannot abandon a patient and must arrange for alternative care, which is also in keeping with the CNA code:

  > the nurse provides safe, compassionate, competent and ethical care until alternative care arrangements are in place to meet the person's needs or desires. . . . When a moral objection is made, the nurse provides for the safety of the person receiving care until there is assurance that other sources of nursing care are available. (pp. 44-45)

  We have heard that the concrete guidelines outlined in our code are highly useful to nurses and employers (see pp. 44-46, https://www.cna-aiic.ca/~/media/cna/page-content/pdf-fr/code-of-ethics-for-registered-nurses.pdf?la=en).
- Teachings on PAD should be part of nursing and medical students' curriculums and part of health- care providers' ongoing professional development.

Ensuring patients who request PAD, and their families, have access to information, resources and support

Another important safeguard is ensuring that patients who request PAD, along with their families, are fully informed and supported during the process. For example:

- Patients have the right to be fully informed about their health condition, to know what to expect and to have reliable and unbiased information, so they have a good understanding of the options/alternatives available to them (e.g., comfort care, palliative and hospice care, pain and symptom control) aside from PAD.
- Counselling and/or spiritual support is an important additional resource that should be offered to a patient (and his/her family) contemplating such a momentous decision as PAD.
- A waiting/cooling-off period is important to allow time and space for patients to think about their options and discuss them with their family. It is important that this process not be rushed. Time is also crucial to allow for modifications in treatment (e.g., for counselling or adjustments of medication to decrease pain and suffering)

that may assist with a patient's situation and affect their perspective. In cases of terminal illness, where time is of the essence, a shorter timeline might be considered. Here, given potential system constraints, advocacy efforts are needed to ensure equity and timely access for patients requesting PAD.

- For patients that pursue PAD, it is important that they always feel they can opt out at any time. They need to be told, even during the actual process, that it is not too late to change their mind (this should also be documented).

Ensuring a pan-Canadian approach regarding end-of-life care and PAD

Instituting a pan-Canadian approach to end-of-life care and PAD is valuable and a critical safeguard. For example:

- A pan-Canadian approach that helps patients be clear about and have access to all the options/alternatives to PAD, while enabling them to receive consistent and accurate information about the process of PAD, would be enormously beneficial.
- A national oversight body for PAD to promote a uniform standard of care and practice and ensure consistency of data monitoring and reporting is also essential. In this way, trends (including adverse events) can be tracked and analyzed and provide a solid picture of what is happening in Canada with respect to PAD. Further, such an approach would allow PAD to be evaluated and ensure it is being provided in a safe, competent and ethical manner.
- A pan-Canadian approach that would ensure equal access to PAD for all eligible Canadians is key. Patients should be able to access PAD without having to leave their home community, since most people wish to die at or close to home. Unique implementation issues with respect to accessing PAD in certain communities will need to be thought through. Furthermore, it will be important to strengthen home care, as there is currently no standardized approach. The uneven level of services across the provinces/territories may challenge our efforts to implement PAD at home.

CONCLUSION

Nurses are intimately involved in end-of-life care processes, including decision-making, and are therefore in a favourable position to develop therapeutic relationships with patients and their families and to work collaboratively with all members of the health-care team. Our comments reflect this specialized knowledge and experience and offer an assessment through the lens of CNA's code of ethics. CNA's consultation with experts in the field highlight the importance of recognizing nurses and other members of the interprofessional health-care team who are involved in PAD.

We thank the special joint committee on physician-assisted dying for the opportunity to provide input on this important issue and hope our comments will inform its work.

REFERENCES

Canadian Nurses Association. (2008). *Code of ethics for registered nurses.* Ottawa: Author.

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