CNA Webinar Series: Progress in Practice

Strengthen your ethical practice: Care at end of life

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The information and views in this webinar are those of the presenter(s) and do not necessarily reflect the official opinion of the Canadian Nurses Association.
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The purpose of this webinar is to help you

• Understand nursing care at the end of life under different circumstances
• Consider the related ethical and legal aspects that come into play
• Reflect on your own end of life and your wishes
“The generations alive today are the first to live in an era of advanced medical technology, like ventilators, cardiopulmonary resuscitation (CPR), and tube feedings that can prolong life and delay death. Patients and families face difficult choices and nurses are often at the center of these difficult situations.” (Norlander, 2014, p.156)
Refusal of treatment

• In Canadian law, every person who is competent has a right to decline or discontinue treatment (including renal dialysis, medications, etc.)
Individual autonomy: The right of self-determination

“It should not be forgotten that every patient has a right to bodily integrity. This encompasses the right to determine what medical procedures will be accepted and the extent to which they will be accepted. Everyone has the right to decide what is to be done with one’s own body.”

(Ciarlariello v. Schacter, 1993)
Consent

• There is a legal and professional obligation to obtain consent prior to providing treatment

• For consent to be valid, it must be related to the treatment, informed, given voluntarily and not obtained through misrepresentation or fraud
The Criminal Code

• A section of this Canadian federal law prohibits anyone from “aiding and abetting” someone to commit suicide
• Even advising someone about their wish to commit suicide to relieve suffering risks criminal prosecution
• Nurses and other health professionals need to know this
A recent change in law

- In February 2015, the Supreme Court of Canada struck down the prohibition against physician-assisted death in *Carter v. Canada*
- Applies only to competent adults (able to make a choice about their time of death) within specific parameters
- The court set a one-year time limit before this law would take effect
How does this change impact nurses?

- Physician-assisted death will not be legal until June 2016
- Until that time, the current law still applies
- Nurses need to understand the new law and how it will apply to them
5 scenarios for consideration in end of life

• To better understand where and when these legal commitments apply, we will examine five scenarios, based in part on real situations

• Many of these situations were reported in the public press in the past few years

• Although the focus of news reports is mainly on physicians, there are important issues for nurses in all cases
The scenarios in brief

• Amalia – a natural but supported death
• Abdul – providing life support measures
• Monika – wishing to decline food/fluids
• Maurice – challenging the status quo
• Rashida – inquiring about assisted death
Amalia

Autonomy and right of self-determination

• Elderly, competent
• Wishing to die (i.e., she was ready to let nature take its course)
• Amalia’s family knew her wishes
• Her care home knew what she wanted and what help she needed to die comfortably

• “Nurses ensure that nursing care is provided with the person’s informed consent. Nurses recognize and support a capable person’s right to refuse or withdraw consent for care or treatment at any time.”

• “Nurses are sensitive to the power differentials between care providers and those receiving care. They do not misuse that power to influence decision-making.”

(Code of Ethics, p.11)
Abdul

• Comatose following brain surgery; on life support with no advance directive
• Doctors believed he would not recover and recommended stopping life support
• Family (wife) was adamant that he be kept on life support
• Doctors and nurses felt morally comprised by providing his care
Guidance in the Code of Ethics

• To work with families and “take into account their unique values, customs and spiritual beliefs, as well as their social and economic circumstances” (Code of Ethics, p.13)

• To also “advocate for persons in their care if they believe that the health of those persons is compromised by … the decision-making of others” (Code of Ethics, p.11)
Other guidance in the code

• Nurses who experience moral distress and conflict of conscience in a situation like this can declare a conflict of conscience (Code of Ethics, p.19 & p.43)
Need for mechanisms beyond courts of law

• In the real case, the wife sought an injunction to stop the doctors from ending life support
• The court determined that substitute decision-makers must have a say and that similar cases in Ontario are best decided by the Consent and Capacity Board, which is a unique mechanism to have a case heard
Monika

- Resident of a nursing home
- Exists in near-vegetative state
- Had cared for patients with Alzheimer’s disease
- Had an advance directive that she be allowed to die and not be given food or fluids that would extend life
- Her directive was not followed
Advance directives

“A person’s written wishes about how and what decisions should be made if they become incapable of making decisions for themselves. In decisions about life-sustaining treatment, advance directives are meant to assist with decisions about withholding or withdrawing treatment. Also called living wills or personal directives.”

(Code of Ethics, p. 22)
Need for advance directives

• Abdul did not have an advance directive
• Monika’s directive was not clear enough
• Have you personally helped someone to create their advance directive?
• Have you thought about what your directive might look like?
Maurice

• In final weeks of terminal brain cancer
• Paralyzed and struggling to breathe
• Failing vision and hearing
• Loss of control of bodily functions
• Makes a videotape with a public plea for legalization of assisted death
• Calls on physicians to understand his suffering and support “hastened death”
Guidance in the Code of Ethics

“When a person receiving care is terminally ill or dying, nurses foster comfort, alleviate suffering, advocate for adequate relief of discomfort and pain and support a dignified and peaceful death. This includes support for the family during and following the death, and care of the person’s body after death.”

(Code of Ethics, p.14)
When palliative care is not enough

• There is some pain or discomfort for some people that cannot be adequately managed through palliative care
• People experiencing dehumanizing suffering (e.g., Maurice) need another option
• *Carter v. Canada* provisions
Carter v. Canada criteria

• Competent adult person
• Clear consent to terminate life
• Has grievous and irremediable medical condition
• Condition causes enduring suffering that is intolerable for the individual
Carter v. Canada: the persons named

- Gloria Taylor (ALS)
- Kay Carter (severe spinal stenosis)

The people that helped pave the way

- Sue Rodriguez (ALS) challenged the constitutionality of the Criminal Code at the Supreme Court of Canada (1993)
- Nancy B. (Guillain-Barré Syndrome) refused treatment (1992)
Rashida

• Diagnosed with ALS
• Knows she will soon experience locked-in syndrome
• Has expressed a wish that someone could help her die when this locked-in condition occurs, since she will not be able to help herself
Dilemma for her home care nurse

- Rashida frequently asks her home care nurse what options are available to help her die when she is ready to do so.
- Her home care nurse is uncertain what to say and how to support her, but knows he needs to tread carefully. He opens up the conversation about her fears, hopes, anxieties, and speaks to her physician about how to assist her.
Current status of the law based on the court’s decision

• The court’s ruling in *Carter* was to take effect February 6, 2016
• However, the government asked for an extension and received a 4-month extension
A shift is needed

• Gwande (2014) says our culture needs to shift from one that views death as a medical event to one that accepts death as a part of life

• Nurses have a unique role to play in helping make that shift, since they are intimately involved with persons at the end of their life
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Thank you!