

Quality of death

The importance of discussing end-of-life options.

Case 1: A 77-year-old man

A 77-year-old man with diabetes, cardiac disease, and an implantable cardioverter defibrillator (ICD) develops a bleeding colorectal cancer. He is high risk for surgery and decides to forgo it. He requires several hospitalizations and spends the last month of his life bedbound at home with his family struggling to care for him without any community support. He is awoken from sleep by his ICD discharging and has eight shocks on the way to the hospital. He declines further treatment at the hospital and dies the next day.

Case 2: A 94-year-old woman

A 94-year-old woman, living in a facility, has moderate dementia due to Parkinson disease and chronic heart failure, but good quality of life. She presents with a perforated duodenal ulcer and is taken to the OR (her DNR is changed to CPR) and after surgery and fluid resuscitation she is still in shock. Because she is now a full code, she goes to the ICU and is treated for 5 days. She is able to be extubated and sent to the ward with no return planned. She is clearly not recovering and has ongoing problems with delirium. Other systems are failing and the family requests no further treatment. She dies more than a week later after a prolonged period of unresponsiveness.

We all work hard to provide patients and their families with the best medical treatments possible based on medical evidence and the patient's clinical

situation. And often it is very difficult to predict the outcome.

In the case of the 77-year-old man, the various medical teams dutifully attended to their specialty areas while his family encouraged him to have all the treatment he could, which may have led physicians to be silent on the issue of his impending end of life and options for comfort. As a result, the patient and his family missed out in receiving home nursing care and support while he was dying, as well as the chance of a peaceful death in his sleep.

In the case of the 94-year-old woman there is no doubt that if her perforated viscus was not treated she would have died, but the risk of death was likely high even with surgery. Was the option of active treatment of symptoms without surgery considered? Was the option of surgery with no intubation or defibrillation considered as a compromise if she did not respond to the surgical intervention?

The quality and safety agenda for health care looks to reduce errors in the provision of care. Error is defined as "failed processes that are clearly linked to outcome."¹ Typically we think of death as the worst possible outcome, but in advanced disease death is natural and expected.

Errors in the management of advanced disease can be easy to miss, as they are likely errors of omission rather than commission. Moreover, if we wish to consider that there is such a thing as the quality of dying² then there are adverse outcomes that can be defined by the quality of death. Only the patients in the above case examples could tell us whether the manner of their death was consistent with their preferences, but neither of these patients or their substitute decision-

makers was given the opportunity to discuss all possible options.

It is entirely possible that the patients and families would not have changed their consent for intervention, resulting in the same outcome. However, they would have had truly informed consent and could have accessed palliative care services such as pain and symptom management, psychosocial and spiritual support, and home services or hospice for the first patient.

There are many reasons for physician reluctance to discuss end of life and possibilities of withholding or withdrawing therapies:

- Lack of training in having the conversation.
- Lack of awareness of what palliative therapies and services can do and how to access them.
- Lack of expertise in other comorbidities and their prognosis.
- Perception that they are consulting on one aspect of the patient's care and that someone else is considering the overall situation with a good understanding of the patient's values and preferences.

With the increase in discussion about euthanasia, there has also been confusion around the ethical principles of withholding and withdrawing care.

Any treatment that we offer should be medically indicated and based on the clinical situation and knowledge of the patient's values and preferences. A treatment may be withheld or not initiated if it is not medically indicated. While we are not obliged to offer treatments, it is always helpful for the family to understand why that treatment is not being offered. If the treatment is medically indicated the patient or substitute decision-maker

This article is the opinion of the Council on Health Promotion and has not been peer reviewed by the BCMJ Editorial Board.

who has an understanding of the benefits and risks of this and other options can make an informed decision.

A treatment can be withdrawn or stopped if it is no longer medically indicated, is causing excessive burden to the patient, or is no longer consistent with a patient's preference for care, providing the patient or the substitute decision-maker is aware of the consequences of the decision. Here it is most important for family to understand that if treatment is withdrawn and the patient dies it is because of the underlying disease and not because the family made the decision to end the patient's life.

Both withholding and withdrawing care are ethically acceptable because the intention is to no longer intervene with a burdensome treatment that is unlikely to improve length or quality of life, or is no longer in keeping with patient preference. Palliative care can help patients to live as well as they can for as long as they can and, if death from disease is imminent, to control symptoms until death occurs.

Euthanasia is "knowingly and intentionally performing an act that is explicitly intended to end another person's life."³ The intention is always to cause immediate death. In contrast, dying from an incurable disease can take days, weeks, or months.

Many patients and substitute decision-makers may not be aware of their right to refuse or withdraw from treatment.⁴ If we physicians find this confusing, then we can be sure that patients and their families—who are usually dealing with these issues for the first time—will find it particularly challenging. The whole process of being sick and approaching end of life is bewildering and frightening, and more than ever patients and families need us to communicate with them about their future and ensure that they have enough information to make decisions.

Another concern of physicians may be the perception of "doing nothing"

in the face of a life-threatening illness. This is where palliative care therapies and skills can provide active care resulting in a good quality of death according to the patient and his or her family.

In situations where there is a high risk of death from all treatment options, where the family is conflicted or ambivalent, or where the patient has complex multiple comorbidities, discussing palliative care and ethics should occur early in the disease trajectory and not after a protracted course of interventions.

Part of patient assessment should involve asking how much patients want to know about their illness and how they wish to make decisions about their care. If substitute decision-makers are involved, doctors need to help them understand their role in the process so that they can effectively help us understand the values and preferences of their loved one and not feel that they were solely responsible for decision making.

If we are to truly offer patients and their decision-makers the best care our system has to offer, we need to consider the reality of quality of dying, patient preferences, and values as much as imaging, lab work, or operative risk. And, if patients or substitute decision-makers are aware of all possible options, patients are far more likely to die in a manner that matches their preferences. This is also quality and safety at its best.

—**Romayne Gallagher, MD**
Chair, Geriatrics and
Palliative Care Committee

References

1. Sibbald RW, Chidwick P, Handelman M, et al. Checklist to meet ethical and legal obligations to critically ill patients at the end of life. *Healthc Q* 2011;14:60-66.
2. Mack JW, Weeks JC, Wright AA, et al. End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol*

2010;28:1203-1208.

3. Canadian Medical Association. Canadian Medical Association policy. Euthanasia and assisted suicide. Revised 2007. Accessed 12 June 2012. <http://policy-base.cma.ca/dbtw-wpd/Policypdf/PD07-01.pdf>.
4. Silveira MJ, DiPiero A, Gerrity MS, et al. Patients' knowledge of options at the end of life: Ignorance in the face of death. *JAMA* 2000;284:2483-2488.

Welcome home

Welcome to **bcmj.org**,
the online home of
BC physicians.

Come home to

- Get advance access to upcoming articles
- Watch video interviews with your colleagues
- Download patient information sheets
- Comment on articles instantly
- Learn what's new in medicine in BC (and beyond)
- Find back issues containing the articles you need

With fresh articles and information updated all the time, you'll want to drop by regularly.

bcmj.org

The online home of BC physicians

www.twitter.com/BCMedicalJrnl
www.facebook.com/BCMedicalJournal