



Difficult conversations

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It is impossible that anything so natural, so necessary, and so universal as death, should ever have been designed by Providence as an evil to mankind.

Jonathan Swift

A few weeks ago a 65-year-old woman in my practice told me about the challenges of looking after her 89-year-old mother. Although she has a sibling nearby, she has been the primary caregiver for her mother over the past several years. In the past 3 months her mother had been hospitalized 3 times, and she was in hospital when my patient came to see me. The mother has an indolent and slowly progressive type of cancer, but also kidney disease and congestive heart failure; she requires oxygen at home to breathe. Just before the most recent hospitalization, the mother finally accepted some home care, relieving my patient of some of the growing burden. Her mother wants to go home after this hospital stay, but my patient is burning out, and each time she goes home her mother is frailer. "Your mom is getting frailer," I say. "Have the two of you talked about the kind of care she would like as she gets nearer the end of life?" Not for the first time in this situation the answer is no. Equally distressing to me was that her mother's family physician had not had this conversation with them.

In Western society the notion of the *aware death* is very powerful and something to be strived for thanks to the influential work of Dr Elizabeth Kübler-Ross. But this concept of death as a process that involves first denial, then anger, next rationalization, and finally acceptance emerged from work with often younger, aware patients usually dying of cancer. In the elderly the trajectory is often very different. In a recent paper Van den Block et al showed that most old people in Belgium still die in hospital and they usually have at least 1 admission in the 3 months before death. Of those who do get admitted, 72% will die in hospital.¹ The situation is likely similar in Canada.

Lunney and colleagues' description of the 4 "trajectories" of death includes the aware death and sudden death, but also 2 others: long-term disability with periodic exacerbations and unpredictable timing of death that characterizes dying with chronic organ or system failures; or self-care deficits and a slowly dwindling course to death from frailty or dementia.^{2,3} In our aging society it is likely that many people will experience 1 of the latter 2 trajectories.

The challenges of having a good death under such circumstances will be made more difficult by the fact that many patients will not have discussed their wishes for

end-of-life care with family members, and even fewer will have had such discussions with their physicians. In the Framingham Heart Study⁴ of 220 community-dwelling respondents with a mean age of 88 years, 70% said they had discussed their wishes for end-of-life care with someone, but only 17% had discussed them with a physician or other health care provider. Two-thirds said they had health care proxies and 55% said they had living wills, somewhat higher than I suspect is the case among people in most family practices. One of the troubling findings in this study was that while most participants (80%) said they preferred to receive comfort measures at the end of life, more than half said they were willing to endure life-prolonging interventions and distressing health states to avoid death.⁴

Many barriers have been identified that prevent Canadians from having these difficult conversations,⁵ but there is strong evidence that discussions about advance directives for care improve patients' satisfaction with their primary care providers⁶ and that advanced care planning itself improves end-of-life care and patient and family satisfaction, and reduces stress, anxiety, and depression in surviving relatives.⁷ In their study of do-not-resuscitate orders, Robinson and colleagues found that patients identified their family physicians as among the people they most preferred to discuss such decisions with.⁸

While the ways that old people will die present many challenges to the people themselves, the families, the health care providers, and the health care system, there is an opportunity to at least start a conversation about end-of-life care and perhaps avoid ultimately futile "life-prolonging interventions and distressing health states" before death. This is a conversation that we as family physicians are well-positioned to begin and to continue with both our patients and their families. 🌻

Competing interests

None declared

References

1. Van den Block L, Deschepper R, Drieskens K, Bauwens S, Bilsen J, Bossuyt N, et al. Hospitalisations at the end of life: using a sentinel surveillance network to study hospital use and associated patient, disease and healthcare factors. *BMC Health Serv Res* 2007;7:69.
2. Lunney JR, Lynn J, Hogan C. Profiles of older medicare decedents. *J Am Geriatr Soc* 2002;50(6):1108-12.
3. Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. *JAMA* 2003;289(18):2387-92.
4. McCarthy EP, Pencina MJ, Kelly-Hayes M, Evans JC, Oberacker EJ, D'Agostino RB, et al. Advance care planning and health care preferences of community-dwelling elders: the Framingham Heart Study. *J Gerontol A Biol Sci Med Sci* 2008;63(9):951-9.
5. Vogel L. Advance directives: obstacles in preparing for the worst. *CMAJ* 2011;183(1):E39-40.
6. Tierney WM, Dexter PR, Gramelspacher GP, Perkins AJ, Xiao-Hua Z, Wolinsky FD. The effects of discussions about advance directives on patient's satisfaction with primary care. *J Gen Intern Med* 2001;16(1):32-40.
7. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomized controlled trial. *BMJ* 2010;340:c1345.
8. Robinson C, Kolesar S, Boyko M, Berkowitz J, Calam B, Collins M. Awareness of do-not-resuscitate orders. What do patients know and want? *Can Fam Physician* 2012;58:e229-33. Available from: www.cfp.ca/content/58/4/e229.full.pdf.html. Accessed 2012 Apr 20.

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