

Thoughts occasioned by the dying of my mother-in-law

Much of our preventive care and therapeutic work is designed to enable people to live fulfilling lives for longer. This practice fails to acknowledge that the quality of death should be given due consideration.

William David Robertson, MBCh

Joan was an active, independent 80-year-old until the spring of 2013. She underwent bowel resection for stage I colonic cancer in 2011 and recovered fully. She had a history of essential hypertension and had smoked tobacco in the past. In April 2013 she developed a flu-like illness. Initially she did not seek care for this as it was clearly viral, and she was able to manage the fever and remain hydrated. The illness progressed to pneumonia after a few days, and she was admitted to hospital 6 days after the onset of the original illness. Over the first 24 hours in hospital she suffered an MI with some congestive failure. She was also somewhat confused. Thanks to prompt treatment she recovered from both the pneumonia and the MI to the point where she was discharged to go home 10 days after admission. She was booked to have a MIBI after discharge, and the

plan was to see how that went and get her back to as much of her normal life as possible.

Shortly after discharge she called us at home (my wife and I live nearby and acted as her principal support) and advised us she wished to have nothing to do with a MIBI. From discussions that followed it became clear that she understood the nature and purpose of a MIBI but that she was not interested in whether she had any predictable chance of having another MI.

She told us that while she was recovering in hospital she spent time walking up and down the corridor in the nursing unit. As in most medical inpatient units in Canadian hospitals, this one was about 50% occupied by people awaiting placement in long-term care facilities. The prospect of becoming one of those people horrified her. As she put it, “that is not living, and they would be much better off dead.” In her mind, having another heart attack would be a blessing, and we were instructed not to take her to hospital if she developed another case of pneumonia.

She agreed to preventive treatment with an oral statin, ACE inhibitor, and beta-blocker. She made a moderate recovery over the next few

months, but she never returned to being well.

In September 2013 she started to develop symptoms suggestive of intermittent partial colonic obstruction. An abdominal CT in early October showed a cancer in the head of the pancreas that was unresectable, thickening in the descending colon at the anastomosis site from her previous resection, and thickening of the colonic wall in the ascending colon. Either colonic lesion may have been another cancer. She understood the implications of this diagnosis—her mother had died of pancreatic cancer.

She immediately stopped taking antihypertensives, statins, and aspirin. She made it clear she would refuse chemotherapy and radiation—in her mind they were nothing more than attempts to buy more misery when dealing with pancreatic cancer. She asked for details about what stents and celiac plexus blocks would involve, and said she would consider them if necessary.

Over the weeks that followed she became jaundiced and developed celiac plexus invasion discomfort and pain. During this time, and occasionally after, she came home to recover from pneumonia, and we talked a lot

Dr Robertson is a staff anesthesiologist at the Cowichan District Hospital and former medical director for community hospitals for VIHA. He worked in Nova Scotia for many years before moving to Vancouver Island in 2006.

This article has been peer reviewed.

about her impressions of health care. She was firmly of the opinion that death was preferable to being demented in a facility. She would rather have died while she had pneumonia than deal with what she was now facing.

While these are one individual's views and cannot be ascribed to everyone, they prompted me to think about some of the consequences of our work. Much of our preventive care and therapeutic work is designed to enable people to live fulfilling lives for longer. We strive to give our patients both quantity and quality of life, though we tend to emphasize quantity over quality—assuming that almost all states of life are better than no life at all. Individually, each of us treats the conditions we specialize in without necessarily looking at the bigger picture—some treatable conditions come with more pleasant ways of dying than the untreatable conditions that may follow. As a profession, we treat everything we can, the consequence of which is enabling our patients to live to the point of developing something untreatable. Probably the most common of these treatable conditions is community-acquired pneumonia. As a result of competent and prompt medical care my mother-in-law recovered from pneumonia and had to die in a manner she would rather have avoided.

I was one of her advocates during her illnesses and played my part in getting her to the hospital. At each step, the system cared for her in the way she wanted in that instant. Initially she wanted no care for a flu-like illness. When she became short of breath and weak she agreed to go to hospital. On admission, she agreed to treatment of the pneumonia. After that, she was too confused for a number of days to understand and consent fully to each step of her management. However, her care followed a standard path. At each step the medical system acted in accordance with her immediate wishes. But the cumula-

tive effect was not what she desired. In her mind, the medical system did not do her any favors.

My mother-in-law's experience raises three questions for me: Could this outcome have been avoided? Can her wishes and experiences be extrapolated to apply to the general population? Do we have a responsibility to inform patients that preventive treatment increases the likelihood that they will develop an untreatable condition that they may not want?

**As a profession,
we treat everything
we can, the consequence
of which is enabling our
patients to live to the point
of developing something
untreatable.**

The outcome (a painful and unpleasant death from pancreatic cancer on 16 March 2014) could only have been avoided in Joan's case by not treating her pneumonia and subsequent heart attack through hospital admission. She would have died, relatively peacefully and in no pain, in bed at home within a day or so. She later told us, vehemently, that with the benefit of hindsight she regretted going to hospital at all. And she told us this just after she got home because she recognized that the result of successful preventive medical care is often dementia in an institution. She did not need pancreatic cancer to develop this opinion, though when she received the diagnosis it reinforced her beliefs.

Her opinions regarding the treatment of her pneumonia/MI cannot be ascribed to others, though many people likely think the way she did; however, her experience is far from unique. We no longer allow pneumonia to be the "old man's friend,"

as the saying goes, and many who would have died of pneumonia end their lives with less pleasant deaths, the most common of which involves some degree of dementia or facility-based dependence.

My mother-in-law's case also illustrates to me that we do not have a legal responsibility to inform. The legal requirements of consent require us to describe the risks and benefits of treatment, along with treatment alternatives. Undefined rates of increased risk of developing an untreatable condition cannot be considered a risk of treatment in the context of fulfilling consent requirements. I cannot imagine there being any legal obligation on physicians to warn patients of such possible consequences. However, her case does illustrate to me that we have a moral obligation to educate patients about these consequences. I am sure she would have refused hospital admission for pneumonia if she had been aware that by receiving treatment she was increasing her chances of facing something more unpleasant, such as dementia and institutionalization.

We are educators for our patients. We focus on clearly defined health benefits (treating high blood pressure will help avoid a heart attack), and we are good at describing long-term threats to the quality of life (losing weight will help avoid diabetes, arthritis, and hypertension). However, we are not good at describing long-term threats to the quality of death. We do not tell elderly patients that getting a flu vaccination, taking a statin, or taking antihypertensives may increase their chances of an unpleasant death. Neither I nor anyone else advised my mother-in-law of this. It is not part of the common currency of health care decision making. And as a result we ensure that more people, as Joan said, "die a death I would not wish on a dog."

In this I think we do a disservice to our patients. **BCMJ**