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“The best places to die”

Improving end of life care requires better population level data

Although the oldest health statistics are based on death certificates, one of the weakest areas of health information is how we die. For example, in Canada 220 000 deaths occur each year. We know how many people died, and whether it was from cancer, heart disease, or other causes. But we have no idea how many of these people died in pain, hooked up to life support they didn’t want, or alone. In the absence of systematic information and monitoring of end of life care and comparisons across health regions (or health care organisations) there is no possibility of learning what is possible (those regions with the highest ratings), nor of tracking whether improvements are occurring.

Twenty years ago, the challenge was to engage healthcare workers in the care of the dying. Ten years ago, the challenge was to engage healthcare organisations in quality improvement efforts on end of life care. Today, the challenge is to develop systematic and comprehensive information on the quality of end of life care at the population level.

Canada, like many countries, has a well developed health information structure—organisations such as Statistics Canada and the Canadian Institute for Health Information, which systematically collect a range of data and turn it into credible and widely available information on the health of the population and characteristics of health care. Additionally, a popular weekly, *Macleans*, publishes regular reports with league tables on “the best” regions for health care or the healthiest cities. Although these rankings have statistical problems, they are popular with the public. What if there were annual rankings of “the best places to die?” On what data would these be based?

Predicting who is within six months (say) of dying, in order to have a sample frame, is impossible. A feasible alternative is to work backward from death certificates, drawing on routinely collected data that are already available for administrative purposes. In Canada, this could start with linking them to the discharge abstract records of admissions to hospital in the preceding six or 12 months—giving some ideas of the extent to which individuals spent their last days in hospital settings and the patterns of treatment they received—for example, how aggressive the various procedures were. Statistics Canada has recently initiated a project on health related, person oriented information under which this could be undertaken. One example of such linkages was a comparison of one year survival after acute myocardial infarction across health regions in relation to the rate of revascularisation.[1]

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Still, these data will be limited because they tell us nothing about the kinds of care individuals receive outside hospital. In future, given plans for electronic health records, routinely collected data could also cover people in nursing homes and those receiving home care.

This approach of working back from death certificates has an important advantage over collecting standardised data from institutions formally offering palliative care.[2] The reason is that some (unknown, but probably substantial) number of individuals die without any contact with a palliative care institution. Indeed, one objective of a population based assessment is to determine just what an individual’s chances are of dying with access to high quality end of life care services.

But even working back from death certificates and linking to routinely collected administrative data will not be adequate because these records typically capture nothing about how patients felt in terms of their health and the kinds of care they were receiving.

Ideally, such data would be augmented with more subjective information on the quality of end of life care—either from self report or from close relatives.

While these strategies are feasible they may not be efficient. Self report of patients would not be efficient because most of the data collected would not be used (only a small proportion of patients—and identified only through hindsight—would be receiving end of life care). Tracking back to loved ones would not be efficient because a whole new survey would need to be conducted and one could not rely on data already collected for other purposes.

An alternative would be to start with close relatives and loved ones and ask them if they had any gravely ill or recently deceased close relatives. This would certainly be a sensitive kind of survey and would need to be handled with compassion and tact. It is not clear whether the public is ready for such questioning, even from a highly respected national statistical agency. But several major recent reports and policy statements in Canada and elsewhere have drawn attention to the need for much improved end of life care.[3–5]

From a sampling point of view, if each dying person had on average three close relatives or loved ones (such as spouse, children), with a crude death rate of about

0.7%, Canada's new community health survey, with a sample size well over 100 000, would "find" over 2000 deaths per year (although this sample would be biased toward dying individuals who were married and had children). Of course, loved ones might offer a slightly different window on the dying person's experience compared with the person themselves.

These are among the notable statistical challenges in establishing an ongoing surveillance system for end of life care. But there are feasible starting points. The statistical task will become easier as many developed countries move toward electronic health or patients' records. These initiatives are being driven by expectations of improved care for patients and better management of systems. One of their objectives should be to enable monitoring of the quality of end of life care. In turn, the regular publication of comparable results should provide continuing pressures for improvements.

Ultimately, international comparisons—for example, the *World Health Report*—could be made to give greater attention to the silent 85% of 56 million deaths in the world which occur in developing countries.[6]

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Patient centred death

We need better, more innovative research on patients' views on dying

A good death has always been important in all cultures. To achieve your chosen afterlife you died either well (euthanatos) or nobly (kalosthanein). But what is a good death in a world that for many is post-religious and medicalised? We know something from research on patients and their families—but not nearly enough. We need much better research that uses innovative and different methods.

We don't have good data on how people die (as opposed to what they die of), but there is a strong impression that many die badly.[1] People do not die in the places they wish or with the peace they desire. Probably too many die alone, in pain, terrified, mentally unaware, without dignity, or feeling alienated. People who are poor, from ethnic minorities, or marginalised may have even worse deaths.

Modern dying involves a struggle for control. Some doctors fear failure when they cannot keep their patients living. Families, filled with grief and sometimes guilt, often have their own strong views on how and where patients should die. This can lead to struggles with doctors, who may see such assertions as an affront to their authority. The "needs" of the dying patient are defined and thus filtered through the views of family and healthcare professionals.

So while debates about a good death are hardly new, what has largely been a professional and expert driven exercise now needs to incorporate patients' views. The authority over dying must now be invested in patients.[2] Patients' concepts of a good death should guide our efforts to make deaths better.

We know that patients wish for their financial, emotional, and spiritual needs to be addressed, and for a chance to say goodbye[3,4]—hardly the stuff of fancy medical technology. What troubles patients is a lack of autonomy over the circumstances of their dying—and, in particular, powerlessness in decisions over medical treatments, including those that prolong life. Indeed, it seems the fear of death is being replaced by the fear of dying.

But this research base is slim, derived mostly from people with cancer and patients in hospice settings and from studies that used quantitative designs. We know little about the needs and desires of people from non-Western cultures, patients with dementias and non-malignant conditions, and dying children. Research with relatively healthy people has produced expectations for a good death, but whether these forecasts are realised or change (and why) still raises several questions. What does it "mean" for patients to say they wish to die with dignity, or quietly, or suddenly?[3] What is the meaning of the desire for death?[5,6] Does suffering have any meaning? How do these notions vary across cultures, time, and space?

And how do we access dying patients' perspectives? Research in palliative care settings is notoriously difficult[7]; it is ripe for innovation, such as the use of advance consent[8] and novel qualitative methods. Ethnography, phenomenology, and textual analysis—once the province of anthropologists and sociologists—can provide ample insights. Glaser and Strauss's classic hospital ethnography in the 1960s transformed modern understandings of dying. Their study revealed how the doctor's diagnosis of dying shaped the interactions and decisions of staff, family, and the patient, resulting in either closed, denied, or open communication about dying. These different awareness contexts produce different experiences of dying for the patient.[9]

But the search for meaning cannot be located in medical settings alone,[10] so drawing from the humani-

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