

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?⁵ 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 difficult⁷; it is ripe for innovation, such as the use of advance consent⁸ 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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ties is crucial. The Art of Dying programme in London (www.kcl.ac.uk/depsta/humanities/art_of_dying/) and the Seeing the Difference project in California (<http://seeingthedifference.berkeley.edu/>) brought together artists, humanists, and medical professionals to deconstruct the representations and realities of death, literally opening up new “ways of seeing” death and dying. The medical view, for example, takes the body as literal: an entity on which to implement physical and psychological change. The humanist’s view sees the body as a site of multiple layers of meaning to be explored and interpreted. The artist’s creation of the body gives form to the space between the physical and the metaphysical, the “unknowable.” Together these frameworks of dying help us to imagine and conceptualise the care and empathy that are needed to ensure a good death for our patients.

What we have thus far failed to do, however, is to combine these innovative frameworks with research that draws explicitly on patients’ perspectives. Worse, we have failed to do so with sensitivity to the differences across patients’ cultures, religions, and social circumstances. Death and dying deserve much better research, and this is research from which all of us

can benefit. Perhaps a major research programme into death that uses many different methods and focuses on the patient would be a way to bring us back to the lost realisation that death is central to life.

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Reforming the coroner’s service

Major necessary reforms would mean an integrated service and more medical input

A review of the coroner’s service in England and Wales and Northern Ireland was published in June 2003.¹ This was followed on 14 July by the Shipman inquiry report of Dame Janet Smith, which dealt with the role of coroners.² Dame Janet Smith also commented on the review. The coroner is central to death investigation in the English legal system, and implementation of these proposals will result in major changes. The current system is fragmented, legalistic, and inadequately funded. The coroner was exported to many Commonwealth countries. In the United States and Canada, many states and provinces have abolished the coroner’s system, replacing it with a medical examiner’s system. Other systems have been modernised, notably in Ontario, Canada, and Victoria, Australia.

Both the review and the judicial inquiry recommend a full time service. The review recommends that all coroners should be legally qualified (some are currently medically qualified) with a reduction to 60 full time jurisdictions. Overall responsibility for the coroner’s system will be vested in a national “coronial council.” Medical input into the coroner’s system is currently lacking, and such input is proposed by the creation of a statutory medical assessor, with a post in each coronial jurisdiction. The statutory medical assessor will have responsibility for the supervision of the death certification system and audit of the death certification process.

The Shipman inquiry proposes greater medical input. The inquiry rightly recognises that many of the decisions taken by the coroner, or frequently the coroner’s officer, are medical. The inquiry therefore

proposes 60 medical coroners in district offices, along with regional medical coroners and a chief medical coroner. There would only be legally qualified judicial coroners in 10 regional offices with a chief judicial coroner. The medical coroner would have the responsibility for the medical investigation. Where there is a need for a wider investigation the judicial coroner would supervise and would conduct inquests where appropriate. Properly trained coroner’s investigators, headed by a chief investigator, would replace the current system of coroner’s officers.

Both the review and inquiry recommend replacing the current system of death certification and cremation certificates with one unified process. The review gives the statutory medical assessor responsibility for organising a second, independent doctor to review a death. The inquiry proposes that the coroner’s system should conduct the second review of all death certificates, with the coroner’s investigator initially providing this role and the medical coroner supervising the process. The inquiry proposes random and targeted checks with fuller investigation of selected deaths.

Public inquests have been criticised, often being considered intrusive or perfunctory. However, the public inquest does provide a public review of controversial deaths. This is particularly important where the death involved law enforcement agencies or where someone has been deprived of their liberty. Both the review and inquiry see a reduction in mandatory inquests, with other inquests being discretionary.

Postmortem rates would fall under both the newly proposed systems. The review recommends more