

Out of Hours

Death's worsening taboo:

is hampering the provision of high quality palliative care

A reasonable mission statement for any health professional is that we strive to improve the quality and length of our patients' lives; nonetheless, death remains the inevitable end of that journey. In an age of unprecedented openness and access to information, where everything from sex to mental illness is discussed with candour unthinkable to our forbears, my personal experience is that the societal taboo around death has worsened. Furthermore, the medical profession has colluded with this, with the end result being a disservice to the dying and their families.

The Liverpool Care Pathway was introduced with the hope of bringing hospice-level palliative care to all clinical settings. Following a recent independent review,¹ it was brusquely dropped, yet the review itself encapsulated the reluctance to accept death.² An ethos that equates the reasonable switch to palliation in negative, even pejorative terms, such as not trying, giving up, or 'allowing people to die' puts unreasonable pressure on the medical profession and may damage relationships with patients, relatives, and other healthcare colleagues, but is rife. Nursing homes have the highest concentration of ill people outside acute hospital settings, yet in the face of precipitous physical and cognitive decline I rarely hear relatives acknowledge this, and the discourse invariably centres on cure. One consequence of this is extraordinarily high calls not only on primary care but on hospitals, often from nursing staff under duress from relatives demanding that 'something be done'.

Our profession is, however, culpable in its own way by appearing omnipotent, and our lexicon reflects this. Screening, early detection, and disease prevention is the language of absolutes in an occupation dominated by marginal, considered decisions. Nothing rings more curative than having radical surgery, yet we have all seen men die from prostate cancer after radical prostatectomy, only later than if they had no treatment. Similarly, revascularisation may give people years, possibly decades of additional life before eventual death from heart failure or other vascular disease ensues — surely a success story. Exactly four decades ago, however, Ivan Illich argued in his book *Medical Nemesis*³ that our profession faced a reputational fall if admirable scientific progress was not

matched by honesty about limitations, and I fear his prophesy is correct. I aver that we mislead not through malice, but by an institutional reticence about poor prognosis diagnoses, as well as about when the end is nigh. How often do we receive a clinic discharge concluding with a review date wildly optimistic for the patient's likely life expectancy?

I believe that we need a cultural change to more open discussion about death and, crucially, the experience of dying, beginning with the undergraduate curriculum where death is scarcely mentioned beyond cold mortality statistics. Our much-touted patient-centredness must embrace the notion that death can be our friend, the ultimate relief from the suffering and disability frequently borne, with the ageing population, for many years.⁴ Supporting patients in end-of-life care is just as much our duty: indeed, an unintended consequence of a culture that always seeks cure, and fears discussion and planning of death, is that far too few deaths occur at home, instead taking place in hospital with interventions that are both expensive and futile.⁵ GPs, supported by our district and Macmillan nurse colleagues, could reasonably help more people to die the good death at home, surrounded by loved ones. To do so means utilising our educational role to chip away at one of the few remaining taboos, encouraging, by example, openness and honesty about what will eventually happen to all of us.

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