

ONLY CONNECT **Nicholas A Christakis**

# Too quietly into the night

As dying people aren't able to make more noise about the poor state of end of life care, it is up to doctors to improve prognosis in this highly vulnerable group

From time to time an intense flurry of media attention is given to an extraordinary case of a particular dying patient: someone in a persistent vegetative state; a family torn apart by disagreement about withdrawal of life support; a shocking case of a poor person dying neglected on the street or, worse, on the floor of an emergency room.

What these cases really should do is highlight a much more thoroughgoing and worrisome reality. For every heartbreaking end of life story like these, there are more than two million others every year (in the United States) that should be just as much a matter for concern. The fact is that the everyday reality of death in the US—and elsewhere in the developed, let alone developing, world—is abysmal.

Our best estimate is that 40% to 70% of Americans die in pain. A large minority of these have other symptoms, such as shortness of breath, nausea, or depression, that are often even more distressing to patients than pain. More than 80% of Americans die in institutions. And roughly 25% to 55% of Americans place a significant burden on family caregivers in the course of their death. For example, about 35% of Americans use up all or most of their life savings in the course of their terminal illness, leaving no money for other family members who go on living and who will themselves need resources for care at the end of their own life.

This reality contrasts sharply with what Americans say they want at the end of their lives and with what the healthcare system should plausibly be able to deliver. Not surprisingly, more than 90% of Americans consider a good death to include such basic elements as being free of pain and other worrisome symptoms, having the opportunity to die at

home or another venue of their own choosing, being kept clean, having loved ones nearby so as not to die alone, and not burdening family members unduly.

There are many reasons for this mismatch between reality and expectations. Explanations include the poor (albeit improving) training in medical schools and in hospitals regarding end of life care; suboptimal decision making by patients and families near the end of life; lack of knowledge about, or restrictive access to, opioids and other drugs in the healthcare system; incomplete use of hospice and palliative care services; and a failure to anticipate the imminence of death in the case of most patients.

Yet one of the most compelling explanations for this sorry state of affairs is that those in our society who are dying constitute a particularly disempowered, even if numerous, group. It may be fashionable in medicine to think about “vulnerable populations,” but it is hard to imagine a more vulnerable population than the dying, nor one that is more neglected or more invisible.

Although extraordinary cases garner tremendous attention, the quiet bad deaths that occur everywhere every day are unnoticed except by shocked family members who are caught off guard by the indignity of death and who may not even realise that a better way to die is possible. There are no court cases, no media spotlight, no candlelight vigils, and certainly no emergency local interventions to affect the terminal care of the hundreds of thousands of patients who die in pain, in hospital rooms, every year.

And the dying people themselves, obviously preoccupied as they are, are not able to band together to advocate effectively for their interests to improve this state of affairs. We



PAUL SCHMITTACHER

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do not see marches of terminally ill people demanding recognition of their rights to more resources and more attention. This may help to explain why Americans do not get better care at the end of life.

But another part of the problem is that seriously ill people often do not know that they are in the vulnerable group at risk of having a bad death, and neither do their families. In fact, their doctors often do not know. To be able to deliver better care to people who are dying we have to be able to identify them. This is fundamentally a problem of prognosis in medicine. The recent development of new statistical and clinical tools that help predict when the end is near should help improve care at the end of life.

In short, one of the reasons that terminal care is so poor is that most Americans never see the end coming, never have a chance to prepare, never have a chance to make decisions about which kind of medical care they would like to receive when they die, and never have doctors who are able to formulate, let alone communicate, a reliable prognosis to them.

The poor quality of dying should concern all of us because we spend vast sums every year caring for people in the last year of their lives (in the US alone, the sum is roughly \$100bn (£50bn; €64bn) dollars a year), and we may not be getting the best value for our money. But, more importantly, it should concern all of us because we will all eventually die, and therefore we all have a stake in improving the state of affairs.

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