

Thought Leadership Unit



A dignified death: Realising the promise of living wills and palliative care

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About this paper

At Aetna International, it's our mission to reshape health care across the globe by developing solutions to improve the quality, affordability and accessibility of care. To this end, we take a two-pronged approach: raising awareness of critical health challenges facing the world and promoting effective, value-based care solutions that could help others combat and prevent the worsening of some of the world's most serious health care problems.

Summary

Death is an inevitable part of life. Yet, there is a pressing need to rethink how it is we die. Record numbers of us are living with chronic conditions and terminal illness into even older age. And far too many people are experiencing unnecessary suffering at the end of life. The argument is often made that if an individual has the right to live with dignity and is expected to take responsibility for the quality of their life, they should also have the right to die with dignity.

We need to create an integrated infrastructure that involves policy makers, health care systems, care givers, communities, payers and education institutions. In this way, we can focus on quality of life to the very end, to the benefit of individuals and their families. In this paper, we examine some essential changes that can be made towards helping individuals realise a death that makes all of us feel more human, connected and dignified.

Introduction

Drs M R Rajagopal and Bob Uslander both treat terminally ill cancer patients, but there the similarity ends. Rajagopal, an Indian anaesthetist, has related the harrowing story of “Mr S,” a lung cancer patient who once travelled two hours to a palliative-care clinic in Kerala, India, only to discover that no morphine was available to ease his agonising, crippling pain. In testimony to the Lancet Commission on Palliative Care and Pain Relief (cited in its report “Alleviating the Access Abyss in Palliative Care and Pain Relief”), Rajagopal described what happened next: “Mr S told us with outward calm, ‘I shall come again next Wednesday. I will bring a piece of rope with me. If the tablets are still not here, I am going to hang myself from that tree.’ He pointed to the window. I believed he meant what he said.”¹

Uslander, who practices in California, tells a far different story about ‘Albert’, a successful businessman who had been fighting an aggressive form of thyroid cancer for a year. The cancer eventually metastasised, and Albert entered hospice care at his home overlooking the Pacific Ocean. A few days before his death, Albert told Uslander he was happy — mouthing the words due to the tracheostomy tube in his throat. “Amazing,” the doctor later wrote. “Yet I wasn’t completely surprised because a few days before that he had scribbled a note to his family telling them that the past several days (days in which he was confined to bed, required around-the-clock nursing care and needed assistance going to the bathroom) had been some of the best days of his life!”²

Everyone dies, but not in the same manner. For every Albert who dies in peace, his family close by and his pain under control, there are many Mr S’s, people for whom the idea of a dignified death is a cruel oxymoron.

1 <http://www.thelancet.com/commissions/palliative-care>

2 <https://www.drbuslander.com/2016/01/15/a-peaceful-end-to-an-amazing-life/>

Chapter I

Today, lifestyle-related diseases are becoming rampant, in part because nearly a quarter of all adults are categorised as either overweight or obese.

Death, dying and a fate worse than death

Modern medicine offers treatments and cures that previous generations could only dream of — and ones that many in low- and middle-income countries still cannot access today. It also allows, even encourages, interventions that extend the lives of people in pain when they should perhaps be allowed to die in peace. What's needed today is a careful balance between the possible and the appropriate, between the compassionate care of previous centuries and the clinical competence of today. As the line between life and death blurs, individuals, families and whole societies must wrestle with the questions of when and how physicians should step aside and let nature take its course.

These questions are taking on increasing urgency as the world's population gets sicker. Today, lifestyle-related diseases are becoming rampant, in part because nearly a quarter of all adults are categorised as either overweight or obese. These conditions put them at heightened risk of developing type 2 diabetes, hypertension, coronary heart disease, stroke, gall bladder disease, osteoarthritis, sleep apnoea and cancer. The prevalence of type 2 diabetes, for example, nearly doubled between 1980 and 2014.^{3,4}

What's more, the population is getting older. In a 2011 report, the World Health Organization (WHO) and the U.S. National Institute on Aging predicted that within five years, for the first time in history, the world will harbour more people age 65 and older than under age 5. That means millions more people will be at heightened risk for life-threatening illnesses and conditions, such as dementia that make it harder for them to be full partners in decisions about their end-of-life care.⁵

And someone must frequently make those decisions, choosing among three basic options: taking so-called heroic measures that extend the quantity, if not the quality, of life; stopping actions that could prolong life (by removing a feeding tube, for example); or taking concrete actions to speed death (by prescribing an overdose of a sedative, for example). (It's important to note that there are significant nuances in each category.)

Doctors and medical ethicists often use the terms *active euthanasia* and *passive euthanasia* to describe the latter two options, but those terms aren't universally accepted. For example, the International Association for Hospice and Palliative

3 <http://www.who.int/mediacentre/factsheets/fs311/en/>,

4 http://apps.who.int/iris/bitstream/handle/10665/204871/9789241565257_eng.pdf

5 http://www.who.int/ageing/publications/global_health.pdf

“You’re asking people to make a whole series of rational choices at the most stressful, potentially most painful time of their life ...”

Care argues that “withholding or withdrawing ineffective, futile, burdensome and unnecessary life-prolonging procedures or treatments does not constitute euthanasia or PAS [physician-assisted suicide] because it is not intended to hasten death, but rather indicates the acceptance of death as a natural consequence of the underlying disease progression.” As Dr Dan Knecht, Head of Clinical Strategy and Policy for Aetna, explains, “Palliative care involves maximising quality of life and minimising suffering. There is a difference between that and actively facilitating death.”⁶

Complicating the situation is often the decision-making capacity of the person who is near death. As the *Journal of Medical Ethics* has noted, “Cutting across this active-passive distinction is a distinction between voluntary, non-voluntary and involuntary euthanasia, depending on whether patients autonomously request their death, are unable competently to give consent or are competent but have their views on the matter disregarded (or overruled).”⁷

Moreover, life-altering decisions must often be taken at the most inopportune time. “You’re asking people to make a whole series of rational choices at the most stressful, potentially most painful time of their life,” says Susan Garfield, Principal, Commercial Lead, Advisory Life Sciences Sector for Ernst & Young. Rather than provide an infinite array of options, she adds, “it’s up to us as leaders and stakeholders in this industry to give them a handful of well-qualified support choices that fit in with their circumstances.” And, says Aetna’s Dr Dan Knecht, “it’s critically important to engage with the patient, the caregiver and the family much earlier than the time when the patient’s clinical condition is deteriorating.”⁸

Arguments for and against the right to die

Few people outside the medical community like to think about either active or passive euthanasia, but they’re forced to do so when individual cases occasionally command public attention. In the United Kingdom, for example, retired lecturer and amyotrophic lateral sclerosis (ALS) sufferer Noel Conway has made headlines in his attempt to have assisted suicide legalised, arguing that the current ban interferes with his right under the European Convention on Human Rights to respect for his privacy and family life. In the United States, Michael Schiavo fought for 15 years to win permission to withdraw life support for his wife, Terri, who was in a persistent vegetative state due to cardiac arrest. Both the Florida Legislature and the U.S. Congress intervened in the highly

⁶ <https://www.liebertpub.com/doi/pdf/10.1089/jpm.2016.0290>

⁷ <http://jme.bmj.com/content/31/2/64>

⁸ Aetna International interview with Susan Garfield

“... more and more people in the U.S. are starting to understand that there is a trade-off, that we can't just endlessly spend resources ...”

politicised case, as did several courts, before Schiavo prevailed and his wife was allowed to die in 2005.^{9,10,11,12,13}

Noel Conway offers one powerful argument for the right to die: that a person should have the right to control his own destiny. As he said in a January 2018 statement, “I have accepted that my illness will rob me of my life, but how it ends should be up to me. Why should I have to endure unbearable suffering and the possibility of a traumatic, drawn out death when there is an alternative that has been proven to work elsewhere?”

The Terri Schiavo case offers another powerful argument: that existing in a persistent vegetative state kept alive solely by machines, or suffering with unbearable pain, is a cruel parody of living. In fact, the fear of such a life was demonstrated in a review of the medical charts of terminally ill cancer patients in Korea between October 2012 and September 2013. According to researchers, just 1.3 percent requested life-sustaining treatments, while 89.5 percent requested palliative sedation. As Dr Prashant K R Dash, Medical Director for Indian Health Organisation by Aetna, notes, “The young are afraid of death, but the elderly are afraid of dying.”¹⁴

A third argument for the right to die involves cost. According to published reports, Terri Schiavo's care cost \$80,000 U.S. per year, much of it paid for by taxpayers. When taxpayers and insurers don't pay the bills, the cost of care can indeed be devastating. A study published in the *Indian Journal of Community Medicine* in 2010 found that cancer diagnoses drive 25 percent of Indian patients' families into poverty, while cardiovascular disease does the same thing for 10 percent of families.¹⁵

Ernst & Young's Susan Garfield says people in high-income countries are generally more willing to invest in potentially futile end-of-life interventions, but even in those countries she sees attitudes beginning to change. “I think more and more in the U.S., people are starting to understand that there is a trade-off, that we can't just endlessly spend resources,” she says. “And that's not just from a payer or government standpoint; that's from an individual and family point of view. There's a lot of evidence that people and individuals are starting to make choices. They're not only asking ‘What are the side effects of

9 <https://www.independent.co.uk/news/uk/home-news/noel-conway-latest-terminally-ill-right-to-die-court-challenge-ruling-motor-neurone-suicide-a8165606.html>

10 <https://www.theguardian.com/society/2018/jan/18/terminally-ill-noel-conway-appeal-right-to-die-ruling>

11 https://www.echr.coe.int/Documents/Convention_ENG.pdf

12 <http://www.nejm.org/doi/full/10.1056/NEJMp058062>

13 <http://abcnews.go.com/Health/Schiavo/story?id=531632>

14 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4310940/>

15 <https://www.ncbi.nlm.nih.gov/pubmed/22628905>

“Our research points to having to do a better job taking care of people who have multiple chronic conditions in a way that maintains or improves the quality of care they receive, but with cost in mind ...”

this treatment?’ and ‘How is it going to impact my health?’ but ‘What are the costs?’ and ‘What is the burden going to be to my family once I’m gone?’”¹⁶

On the other side of the issue, of course, many would argue that cost should not be a factor, and that people shouldn’t be faced with death just because their money has run out. Moreover, early intervention could go a long way toward reducing both spending and suffering. After studying the cost of end-of-life care, one University of Michigan researcher concluded, “Our research points to having to do a better job taking care of people who have multiple chronic conditions in a way that maintains or improves the quality of care they receive, but with cost in mind. This also suggests that if we focus purely on care for those with a poor prognosis, we won’t be able to contain the growth of health costs that you might anticipate.” (In this regard, Aetna International focuses on getting upstream of diseases and conditions through health and wellness services that help members achieve their health goals. Examples of how this is achieved include text reminders of the need for immunisations, group coaching programmes for smoking cessation, and proactive outreach based on algorithms that identify individuals who may be at risk.)¹⁷

A second argument against an expanded right to die is the danger of people gaming the system, either to opt out of life themselves or to hasten the death of a loved one for questionable reasons. The Terri Schiavo case lasted so long in part because her parents, Robert and Mary Schindler, accused her husband, Michael, of giving up prematurely both because of the costs and because he was already living with another woman.¹⁸

Another argument — or at least a hope — is that there’s always a chance that a cure might be just around the corner or that doctors could be wrong about a person’s prognosis. In 2017, French researchers made headlines when they used vagus nerve stimulation to awaken a man who had been in a persistent vegetative state for 15 years (ironically the same amount of time as Terri Schiavo). Breathless headlines aside, however, the cause offered relatively little hope. As a *National Geographic* story explained, “It wasn’t a scene from a daytime soap opera, but his progress was surprising. In medical terms, his condition shifted from a vegetative state to a minimally conscious one. After a month of vagal nerve stimulation, the man was newly able to respond to simple commands, such as slowly turning his head from left to right.”¹⁹

People on both sides of the issue draw lessons from the Netherlands, which legalised euthanasia and assisted suicide in 2002 for those with ‘unbearable

¹⁶ Aetna International interview with Susan Garfield

¹⁷ <https://labblog.uofmhealth.org/industry-dx/of-four-paths-to-end-of-life-one-far-pricier-than-others>

¹⁸ http://www.libertytothecaptives.net/petitiontoremoveguardian_amended.html

¹⁹ <https://news.nationalgeographic.com/2017/09/vegetative-state-vagus-nerve-stimulation-health-science/>

In an ideal world, people would think through their options long before facing a life-threatening illness and would make their wishes known ahead of time.

suffering with no prospect of improvement'. In 2015, there were 5,516 cases of euthanasia in a country of 16.8 million people. Proponent Paulan Stärcke argues that "euthanasia is a good death by the wish of the person who dies and no one else." Others express alarm that without careful policy protections, people with treatable mental disorders can too easily choose to die. A study in *JAMA Psychiatry* found that patients in half of approved cases could have received effective treatment but declined it. As Dr Paul S Appelbaum, who teaches psychiatry, medicine and law at Columbia University, told *The New York Times*, "The criteria in the Netherlands essentially require that the person's disorder be intractable and untreatable, and this study shows that evaluating each of those elements turns out to be problematic."^{20,21}

Clearly, wherever either active or passive euthanasia is a legal option, robust safeguards must be in place to prevent abuse. Ideally, the decision to pursue euthanasia should not be left to the patient alone but should include input from family members, the attending physician and an objective third party. As Aetna's Dr Dan Knecht notes, "The patients are at a very vulnerable point in their lives and may not be thinking completely clearly — or coherently with their earlier stated goals."

Imagining the unthinkable

The Conway and Schiavo cases illustrate the fraught nature of any discussions involving death. Of course, those discussions became even more fraught when they involve ourselves or our loved ones, not people in distant places.

In an ideal world, people would think through their options long before facing a life-threatening illness and would make their wishes known ahead of time. Most people agree that that's advisable. According to a 2012 survey in California, 90 percent of people say talking with their loved ones about end-of-life care is a good idea, and 80 percent say they would want their doctors to know their wishes. Yet only 27 percent have actually broached the subject with their loved ones, and just 7 percent have talked with their doctors about end-of-life care.²²

And those numbers are from a state that enacted a living-will statute in 1976 — the first in the United States to do so. First proposed in a 1969 law journal article, a living will (also known as an advance directive or advance decision) specifies a person's wishes for end-of-life care. It is analogous to how a traditional will specifies how a person's property and other assets should be handled after death. A living will describes in detail what measures should or

²⁰ <https://www.telegraph.co.uk/news/2016/05/11/netherlands-sees-sharp-increase-in-people-choosing-euthanasia-du/>

²¹ <https://www.nytimes.com/2016/02/11/health/assisted-suicide-mental-disorders.html>

²² <https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf>

... one study found that just 26 percent of U.S. adults have a living will — even though nearly 68 percent of survey respondents expressed concerns about end-of-life care.

should not be taken to keep the person alive, including resuscitation, mechanical ventilation, tube feeding and dialysis. Since no planning document can take into account all potential situations, a living will is typically paired with (or incorporates) a second document known as a health care power of attorney or durable power of attorney. This document designates a proxy or surrogate to make health care decisions on a person's behalf if he or she is incapacitated. (Without such a document, the person's spouse normally has the ability to make health care decisions; beyond that, next-of-kin status doesn't necessarily guarantee the ability to make any decisions. A living will states the identity of the proxy, or proxies.)^{23, 24, 25, 26}

Today, every U.S. state recognises the legality of living wills. The federal Patient Self-Determination Act, which went into effect in 1991, requires most hospitals, long-term care facilities and home health agencies to both abide by and provide educational materials about living wills. Yet one study found that just 26 percent of U.S. adults have a living will — even though nearly 68 percent of survey respondents expressed concerns about end-of-life care.^{27, 28}

And the United States actually leads the world in living will uptake. Just 13 percent of Canadians had completed advance-care plans as of 2013, while acceptance in most Western European countries ranges from 10 to 20 percent, according to a 2016 report by the Public Policy Institute for Wales. Far behind their European peers are England at 4 percent and Wales at 2 percent (as of 2013) — even though the United Kingdom's 2005 Mental Capacity Act gave statutory support to advance-care decisions. But even Wales, with the lowest uptake of any country in Europe, shines in comparison with India, where virtually no one had a living will before they were legalised in March 2018.^{29, 30, 31, 32}

23 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2980344/>

24 <https://www.repository.law.indiana.edu/cgi/viewcontent.cgi?article=2525&context=ilj>

25 <https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303>

26 <https://www.psychologytoday.com/us/blog/love-and-gratitude/201505/next-kin-healthcare-dilemma-is-stressful-any-age>

27 <https://www.gapna.org/patient-self-determination-act-psda>

28 [http://www.ajpmonline.org/article/S0749-3797\(13\)00521-7/pdf](http://www.ajpmonline.org/article/S0749-3797(13)00521-7/pdf)

29 [http://www.hpcintegration.ca/media/50750/TWF-infographic-poster-eng-1.5%20\(1\).pdf](http://www.hpcintegration.ca/media/50750/TWF-infographic-poster-eng-1.5%20(1).pdf)

30 <http://ppi.wales.gov.uk/files/2016/02/PPIW-Report-Increasing-the-awareness-and-uptake-of-Advance-Decisions.pdf>

31 <http://ijme.in/articles/the-urgent-need-for-advance-directives-in-india/?galley=html>

32 <http://www.bbc.com/news/world-asia-india-43341155>

Palliative care aims at relieving physical, psychological or spiritual pain without addressing the underlying medical problem, although palliative and curative care can work in concert.

"It's really critical for people to be having these conversations with their spouses, with their families, with their kids, so that their wishes can be respected," says Ernst & Young's Susan Garfield. "Palliative care can make the end-of-life period more comfortable from a pain standpoint, and advance planning can make it more comfortable from a stress standpoint. Then, the question becomes not 'How can I die faster?' but 'How can I die better?'"³³

Garfield recommends people have a conversation that involves more than just their spouse or next of kin. "You need to make sure you're not only having it with one person, because that person might not be there to make those critical decisions on your behalf," she says. "Put your wishes in writing, and make sure your living will is in a place that's easy to get to." Aetna's Dr Dan Knecht recommends involving the family doctor as well. "Bringing this up gives the physician the invitation to engage in the conversation," he says. "And maybe the physician will feel empowered to have that conversation with another patient."

³³ Aetna International interview with Susan Garfield

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Chapter 2

The need for palliative and hospice care

Whilst every living will may be unique, all of them reflect a desire for a good death — the literal meaning of the word euthanasia. In 1997, the Institute of Medicine put forth a useful definition: “[A] *decent* or *good* death is one that is: free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards.” When the dying process lasts for months instead of minutes, palliative care can offer that sort of outcome.³⁴

Palliative care aims at relieving physical, psychological or spiritual pain without addressing the underlying medical problem, although palliative and curative care can work in concert. It also acknowledges death as a normal process, offers support to patients and families alike, and uses a team approach to ensure both medical and nonmedical needs are met. Hospice care is another term for palliative care and can be provided during chronic illness treatment or at the end of life.

The need for palliative care is great, according to the World Health Organization (WHO). Its January 2014 Global Atlas of Palliative Care at the End of Life report estimates that 20 million people need end-of-life care annually, and another 20 million need palliative care more than a year before their deaths. The Lancet Commission on Palliative Care and Pain Relief paints an even starker picture. It notes that 25.5 million people who died in 2015 — 45 percent of total worldwide deaths — experienced serious health-related suffering and were thus candidates for palliative care. The commission also estimates that nearly 2.5 million children need palliative care each year, while the WHO pegs the number at about 1.2 million.^{35,36}

These figures demonstrate that the need for palliative care isn’t limited to elderly nursing-home residents dying of cancer or middle-aged people dying of HIV/AIDS. In fact, half of the adults who need such care have cardiovascular disease or chronic obstructive pulmonary disease (COPD). Among children, the leading contributors are congenital abnormalities, neonatal conditions, malnutrition and meningitis. (Among Aetna International members, COPD is by far the leading end-of-life condition, with 10 times as many members living with COPD needing end-of-life care in 2017 as members with breast cancer. It’s worth noting, however, that Aetna International’s membership of expatriates

34 [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(98\)90329-4/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(98)90329-4/fulltext)

35 http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

36 <http://www.thelancet.com/commissions/palliative-care>

... palliative care can improve one's quality of life, even as the quantity of life shrinks. In large part, it does so by relieving pain.

and globally mobile individuals isn't necessarily comparable with the larger population.)³⁷

Palliative care is also not limited to those who face imminent death. It can be just as valuable to those facing life-limiting, but not life-threatening, illnesses. In 2016, UK resident Lucy Watts was recognised for her service to young people with disabilities by being named a Member of the Most Excellent Order of the British Empire (MBE). What made the 22-year-old's achievement remarkable was that she had been told in 2012 not to expect to live another five years due to a degenerative neuromuscular disease. In a 2017 essay, she reflected on her MBE honours, charity work, writings and media appearances. "This is all despite a life-limiting, degenerative condition," she wrote. "Despite being hooked up to intravenous drips at least 21 hours a day, despite having a drainage tube and two stoma bags. Despite surgeries, 12 battles with sepsis, despite hospital stays, despite fighting for my life. Despite knowing that my time on earth will be far shorter than it should. Despite knowing that I've outlived the prognosis I was given."^{38,39}

Benefits of palliative care

As Watts's story illustrates, palliative care can improve one's quality of life, even as the quantity of life shrinks. In large part, it does so by relieving pain — an important factor since in a 1995 study it was estimated that approximately 40 percent of patients dying in hospital experience moderate to severe pain in their last three days of life. But palliative care can also address a host of other symptoms, including breathing difficulty, persistent cough, dry mouth, nausea, vomiting, constipation, fever, delirium, anxiety and insomnia.⁴⁰

It can also, to a limited extent, prolong a patient's life. In a small study of patients with metastatic lung cancer, median survival was nearly 12 months for patients receiving early palliative care, compared with about nine months for patients receiving standard oncology care. At the same time, the palliative-care group showed fewer symptoms of depression and reported a better quality of life. As Scottish GP Dr Margaret McCartney wrote, "The conclusion must be that some of the treatments that had been routinely administered in the past were doing more harm than good. Rather than palliative care being 'last ditch', it extended life and improved its quality."^{41,42}

³⁷ Aetna International claims data

³⁸ <http://www.lucy-watts.co.uk/>

³⁹ https://www.huffingtonpost.co.uk/lucy-watts-mbe/planning-end-of-life_b_18098280.html

⁴⁰ <http://www.nejm.org/doi/full/10.1056/NEJMr1411746>

⁴¹ <http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>

⁴² <https://www.theguardian.com/science/blog/2014/nov/25/palliative-care-can-provide-a-better-death-and-even-a-longer-life>

... an analysis of data from eight U.S. hospitals with palliative-care units found significant cost savings.

It's no surprise that palliative care can also be less expensive than curative care. In fact, an analysis of data from eight U.S. hospitals with palliative-care units found significant cost savings. For patients discharged alive, hospitals saw an average net savings of \$1,696 U.S. per admission (\$279 U.S. per day). For patients who died in hospital, the average net savings were \$4,908 U.S. per admission (\$374 U.S. per day). What accounted for these savings? "Our data suggest that palliative care consultation fundamentally shifts the course of care off the usual hospital pathway and in doing so significantly reduces costs," the researchers wrote. "This shift is likely accomplished by establishing clear treatment goals, reviewing current treatments to establish their concordance with these goals and recommending and legitimising discontinuation of treatments or tests that do not meet established goals."⁴³

Barriers to palliative care

In reflecting on how palliative care can actually extend life, Dr Margaret McCartney wrote, "Metastatic lung cancer is hard to treat. So if there were a treatment for people with the disease that had minimal side effects [and] could extend not just the quantity of life but also its quality, we'd expect it to be a blockbuster."

So why isn't palliative care a blockbuster? Why don't cancer patients seek palliative care as quickly as they seek chemotherapy and radiation? Why don't physicians acknowledge the need to shift from heroic but futile measures to comfort care? It's not as if palliative care is a new idea. The first modern hospice, St. Christopher's in London, opened in 1967 (two years before living wills were first proposed), and palliative care was recognised as a specialty in the United Kingdom in 1987 and the United States in 2006.^{44,45,46,47}

But significant barriers remain, even in countries with relatively extensive palliative-care histories. The (U.S.) National Cancer Institute includes an exhaustive list of reasons in its publication *Planning the Transition to End-of-Life Care in Advanced Cancer – Health Professional Version*. Among them: patients' misunderstanding of their prognoses, language barriers between patients and oncologists, oncologists' reticence to level with their patients, oncologists' mistaken belief that end-of-life discussions are psychologically harmful, and even a fear of lost income among health professionals. (The impact of financial incentives on care decisions was illustrated in one U.S. study. In it, urologists who acquired ownership in a technology called intensity-modulated radiation therapy (IMRT) increased

43 <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/414449>

44 <http://www.stchristophers.org.uk/about/history>

45 <https://www.repository.law.indiana.edu/ilj/vol44/iss4/2/>

46 <http://endoflifestudies.academicblogs.co.uk/palliative-medicine-as-a-specialty/>

47 <https://harvardmagazine.com/2015/03/from-specialty-to-shortage>

their IMRT usage from 13 to 32 percent over a five-year period; usage by their peers without such technology only ticked up slightly.)^{48,49}

Another issue is a lack of palliative-care specialists. One study found an estimated shortage in the United States alone of 6,000 to 18,000 clinicians. In England, a survey of health care professionals found that barely half thought staffing levels were sufficient to meet the pain-management needs of those dying at home.^{50,51}

Those concerns, while valid, might be dismissed as so-called first-world problems by people in low- and middle-income countries where palliative care services barely exist — and where 78 percent of adults and 98 percent of children in need of such services live (as of January 2014). According to the January 2014 WHO Global Atlas of Palliative Care at the End of Life report, only 58 percent of countries have one or more palliative services established, and in just 8 percent of countries is palliative care fully integrated with the broader health system. Even where care is integrated, availability varies widely. For example, the Netherlands has one palliative care provider for every 56,000 residents, while China has one provider for every 8.5 million residents.⁵²

Indian Health Organisation's Dr Prashant K R Dash notes that palliative care isn't a recognised discipline in India. "There is no process, path or protocols," he says. "We lack doctors and specialists [for this type of care]. Psychological counselling isn't available for these patients. The majority [of patients] live in rural areas without access to care."

What providers can actually provide in many countries is often constrained by law and custom. In China, for example, laws are contradictory. As researchers reported in the journal *Supportive Care in Cancer*, "One law states that patients have a right to know about their condition. A second law states that it is inappropriate for the health care provider to inform the patient if it would cause adverse events. A third law grants doctors the right to withhold information with good intent." What's more, some physicians fear for their safety if they share negative information with a patient instead of with his or her family. One oncologist said he checks with a patient's family before telling the patient his prognosis. "Because if I tell him right there, the family [member] will probably throw his fist at me," the doctor said. "So I must first

48 https://www.cancer.gov/about-cancer/advanced-cancer/planning/end-of-life-hp-pdq#link/_111

49 <https://www.ncbi.nlm.nih.gov/pubmed/24152262?dopt=Abstract>

50 <https://www.medscape.com/viewarticle/862213>

51 <https://www.hospiceuk.org/media-centre/press-releases/details/2017/05/12/staff-shortages-and-increased-caseloads-prevent-effective-pain-management-at-home-for-dying-people>

52 http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

protect myself. Then after the patient goes out, I will talk to the family," leaving to them the task of informing the patient.⁵³

A similar situation exists in many developing countries, according to Indian Health Organisation's Dr Prashant K R Dash. "The way the patient is seen in India is different from in the U.S.," he says. "Almost always, when it comes to serious decision-making, the family is involved. For example, with cancer or HIV the most common practice is to let the family know."

Families also play a role not just in what care is provided but in where it is provided. "In the United States, as people get sicker and sicker, they end up farther and farther away from home," says Ernst & Young's Susan Garfield. "In other cultures, the family tends to take care of its own. So when people get sick, they may have a limited interaction with a hospital setting but then come home to die."⁵⁴

Other cultural factors must also be taken into account. "For example, in sub-Saharan Africa, the role of the traditional healer is still quite strong," says Aetna's Dr Dan Knecht. "How do you layer that on with concepts of palliative care?"

And then there's the problem of access to drugs like morphine that can manage pain. According to the Lancet Commission's "Alleviating the Access Abyss" report, nearly 300 metric tonnes of morphine-equivalent opioids are distributed each year, but just 0.1 metric tonne goes to low-income countries. Haiti receives 5 mg per patient in need of palliative care, while the distribution in Canada is 68,000 mg per patient in need.⁵⁵

⁵³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5266771/>

⁵⁴ Aetna International interview with Susan Garfield, Principal, Commercial Lead, Advisory Life Sciences Sector Ernst & Young

⁵⁵ <http://www.thelancet.com/commissions/palliative-care>

Beyond health care

While much of the discussion around palliative care relates to medicine, Ernst & Young's Susan Garfield thinks a broader, more holistic approach is required.

"When you think about what a patient needs, it can't be provided by one company or one service provider — or even by one sector," she says. Instead, health insurers, doctors, nutritionists, transportation providers and even financial institutions need to be involved, requiring the creation of new data-interchange models. "Ernst & Young is working really hard to say what needs to happen and how we can harness some of the new technologies to create platforms of interoperability and leverage tools like blockchain to make data exchange safer and create opportunities to share data in a meaningful way," she says.⁵⁹

The Aetna Compassionate Care Program, which began in the United States in 2011, offers a glimpse of what is possible in holistic end-of-life care. When Aetna identifies a member as terminally ill, a specially trained nurse case manager steps in to provide support. Case managers promote coordination among doctors and help members manage benefits. They also provide support to family members and caregivers, connect members to social

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Conclusion

Mapping a way forward

How can we ensure that people around the world — from African children with congenital abnormalities to American senior citizens with multiple comorbidities — receive the end-of-life care they deserve? So much needs to be done that a better future can seem unattainable.

Fortunately, two recent reports offer at least a starting point. The first, from the British Medical Association (BMA), provides a helpful roadmap for countries where palliative-care programmes are already established. As the outcome of the BMA's End-of-life Care and Physician-assisted Dying Project, the report offers 25 concrete recommendations for governments, doctors, medical educators and health systems. For example, the report recommends that governments should initiate high-profile media campaigns, while medical educators should ensure that doctors receive training on the inevitability of death and the basics of pain control.⁵⁶

For those countries with non-existent or embryonic palliative-care systems, the Lancet Commission on Palliative Care and Pain Relief proposes implementation of what it calls the Essential Package of Palliative Care and Pain Relief Health Services. The package lists the medicines, medical equipment and human resources required to alleviate most serious health-related suffering. According to the commission, implementing such a package would cost \$2.16 U.S. per capita per year in low-income countries and \$0.78 U.S. per capita per year in lower middle-income countries — both a mere pittance when one considers the suffering that palliative care can prevent.⁵⁷

In telling the story of 'Mr S' to the Lancet Commission, Dr M R Rajagopal said that drug shortages are no longer a problem in Kerala, although they still are in most of the rest of India. In fact, the WHO's Global Atlas singles out Kerala's Neighbourhood Network in Palliative Care, which Rajagopal helped found, as a success story. The community-based programme operates out of 230 clinics and relies on 10,000 volunteers, along with 60 doctors and 350 medical staff.⁵⁸

⁵⁶ <https://www.bma.org.uk/collective-voice/policy-and-research/ethics/end-of-life-care>

⁵⁷ <http://www.thelancet.com/commissions/palliative-care>

⁵⁸ <http://innovatedevelopment.org/2014/12/01/a-community-driven-palliative-care-solution-in-india>

⁵⁹ Aetna International interview with Susan Garfield, Principal, Commercial Lead, Advisory Life Sciences Sector Ernst & Young

workers and hospice agencies, provide information on living wills, and facilitate transitions to and from acute and long-term care facilities. In 2017, Aetna expanded Compassionate Care by collaborating with Meals on Wheels America, a meal-delivery charity. This integrates delivery of daily meals to older adults with social support and critical safety checks. "Our work with Meals on Wheels America will help us make better connections with seniors in their homes and communities and enable us to establish truly meaningful relationships that can improve the lives of this vulnerable population," says Aetna Chairman and CEO Mark T. Bertolini.^{61,62}

Some would argue that such heavy reliance on volunteers makes the model difficult to replicate, but Dr Raj, as he is known, strongly disagrees. "Is Kerala the only part of the world where there are compassionate people?" he asked in an *Atlantic* article. "Is Kerala the only place where people who may have gained material success then want to do something meaningful with their lives?"⁶⁰

The world is dying to hear answers to those questions. Although the conversation about end-of-life care is not new, it's far from being resolved. As millions need palliative care each year, it's imperative that health systems and societies as a whole address the need for people to have the best possible odds of experiencing a dignified death.

⁶⁰ <https://www.theatlantic.com/health/archive/2017/02/india-palliative-care/517995/>

⁶¹ <https://www.aetna.com/individuals-families/member-rights-resources/compassionate-care-program/compassionate-care-description.html>

⁶² <https://news.aetna.com/news-releases/meals-on-wheels-america-and-aetna-form-innovative-collaboration-to-improve-senior-care/>



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About Aetna International

Aetna International is committed to helping create a healthier global community. We offer large employers, health care systems and government entities customised technological and health management solutions to help improve health, enhance quality of care and contain costs.

We provide international and national health benefits and services to more than 800,000 people worldwide, and our customers include expatriates, local nationals, the globally mobile and business travellers. We offer comprehensive health care benefits, including medical, dental, vision and emergency medical assistance amongst others, along with preventative and condition management care programs.

Aetna International's parent company, Aetna, is one of the leading health care benefits and services companies in the U.S., serving 46.5 million people with information and resources to help make better informed decisions about their health and wellness.

For more information, see aetnainternational.com and aetna.com, and discover how we are delivering the promise of healthy ... anytime, anywhere.

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