Economist Intelligence Unit

The Economist

The quality of death

Ranking end-of-life care across the world

A report from the Economist Intelligence Unit

Commissioned by

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This report and more information on the Quality of Death Index can be found at:

www.eiu.com/sponsor/lienfoundation/qualityofdeath

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Acknowledgments

During research for this white paper the Economist Intelligence Unit interviewed a number of experts from across the world—including palliative care specialists, physicians, healthcare economists and sociologists. Their time and insights are greatly appreciated. The following list includes only those experts interviewed for the white paper and does not include all those consulted while constructing the Quality of Death Index. Nor does it necessarily imply that the persons listed were involved in the construction of the Index, or the findings of this report, for which the Economist Intelligence Unit takes full responsibility.

For her time and advice throughout this project, we would like to extend our special thanks to Dr Cynthia Goh, Centre Director, Lien Centre for Palliative Care; Co-chair, Worldwide Palliative Care Alliance; and Chair, Asia Pacific Hospice Palliative Care Network.

Sarah Murray was the author of the report and David Line was the editor. Anna Morris assisted with the research. Gaddi Tam was responsible for design. The Index was devised and constructed by an Economist Intelligence Unit research team led by Tony Nash, Hirofumi Sano and Manoj Vohra.

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Executive summary

"Quality of life" is a common phrase. The majority of human endeavours are ostensibly aimed at improving quality of life, whether for the individual or the community, and the concept ultimately informs most aspects of public policy and private enterprise. Advancements in healthcare have been responsible for the most significant quality-of-life gains in the recent past: that humans are (on average) living longer, and more healthily than ever, is well established. But "quality of death" is another matter. Death, although inevitable, is distressing to contemplate and in many cultures is taboo. Even where the issue can be openly discussed, the obligations implied by the Hippocratic oath—rightly the starting point for all curative medicine—do not fit easily with the demands of end-of-life palliative care, where the patient's recovery is unlikely and instead the task falls to the physician (or, more often, caregiver) to minimise suffering as death approaches. Too often such care is simply not available: according to the Worldwide Palliative Care Alliance, while more than 100m people would benefit from hospice and palliative care annually (including family and carers who need help and assistance in caring), less than 8% of those in need access it.

Few nations, including rich ones with cutting-edge healthcare systems, incorporate palliative care strategies into their overall healthcare policy—despite the fact that in many of these countries, increasing longevity and ageing populations mean demand for end-of-life care is likely to rise sharply. Globally, training for palliative care is rarely included in healthcare education curricula. Institutions

Note on definitions

The definition of terms used to describe the process of caring for terminally ill patients varies. In this report, "palliative care" is used with reference to the World Health Organisation (WHO) definition, which is as follows:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."[1]

"End-of-life care" in this report includes palliative care but also refers to broader social, legal and spiritual elements of care relevant to quality of death.

"Hospice care" in this report refers to care in specialist institutions, except where noted. (NB: in North America, "hospice care" is generally interpreted to mean end-of-life care and may refer to care within the home.)

[1] Available at http://www.who.int/cancer/palliative/definition/en/. The WHO provides an additional definition of paediatric palliative care, which is not considered in the Quality of Death Index or this white paper.

that specialise in giving palliative and end-of-life care are often not part of national healthcare systems, and many rely on volunteer or charitable status. Added to this, the availability of painkilling drugs—the most basic issue in the minimisation of suffering—is woefully inadequate across much of the world, often because of concerns about illicit use and trafficking. The result of this state of affairs is an incalculable surfeit of suffering, not just for those about to die, but also for their loved ones. Clearly, the deeper inclusion of palliative care into broader health policy, and the improvement of standards of end-of-life care—raising the "quality of death"—will also yield significant gains for humanity's quality of life.

With this in mind, the Economist Intelligence Unit was commissioned by the Lien Foundation, a Singaporean philanthropic organisation, to devise a "Quality of Death" Index to rank countries according to their provision of end-of-life care. Overall rankings and the Index methodology are summarised in the first chapter of this report (see p11 for a table of the final scores and the appendix for a full explanation of the Index methodology). A detailed examination of the Index findings and country scores is also possible on the following website: www.qualityofdeath.org.

To accompany the Index, the Economist Intelligence Unit interviewed experts around the world and reviewed existing research on the topic of end-of-life care for this white paper, which addresses issues relating to the Quality of Death as quantified by the Index rankings. Not all of the complex cultural, ethical and sociological issues connected to dying could be included in the Index, but many of these are examined qualitatively in the chapters below. (The Index, and this paper, do not address violent or accidental deaths, which are undoubtedly a great cause of end-of-life suffering globally, but for which remedies are rarely related to standards of healthcare.) This paper also puts the Index findings into context and attempts to define the issues that must be considered when policymakers seek to improve the quality of death faced in their countries by those with incurable illness. Its key findings are as follows:

- **The UK leads the world in quality of death; many developed nations must work to catch up.** The UK has led the way in terms of its hospice care network and statutory involvement in end-of-life care, and ranks top of 40 countries measured in the Index. This is despite having a far-from-perfect healthcare system (indeed, it ranks 28th on the Basic End-of Life Healthcare Environment sub-category, which accounts for 20% of the overall score). But the UK is top in the Quality of End-of-Life Care sub-category, which includes indicators such as public awareness, training availability, access to pain killers and doctor-patient transparency (and accounts for 40% of the overall score). However, in the overall score, many rich nations lag a long way behind: these include Denmark (22nd), Italy (24th), Finland (28th) and South Korea (32nd). In these cases the quality and availability of care is often poor and policy co-ordination lacking.

- **Combating perceptions of death, and cultural taboos, is crucial to improving palliative care.** Death and dying are stigmatised in some cultures to the point where they are taboo—as in Chinese culture. In Western societies death has become medicalised and curative procedures are often prioritised ahead of palliative care. In the US, discussion of end-of-life care often inflames religious sentiment that holds the sanctity of life paramount. The issue is complicated by the perception that "hospice care" is often associated with "giving up".

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- **Public debates about euthanasia and physician-assisted suicide may raise awareness, but relate to only a small minority of deaths.** While debates about these issues gain the most media attention, they affect only a tiny proportion of the terminally ill. (Consequently, policies on these issues are not included in the Index, although the legal status of "do not resuscitate" orders is included.) Nonetheless, pressure brought on policymakers over these issues can be a catalyst for the improvement of palliative care services—as in Australia, where the federal overturning of a Northern Territory euthanasia law in 1996 led to increased national funding for end-of-life care.

- **Drug availability is the most important practical issue.** Pain control is the point from which all palliative care stems, and the availability of opioids (morphine and its equivalents) is fundamental to quality of end-of-life care. But across the world an estimated 5bn people lack access to opioids, principally due to concerns about illicit drug use and trafficking. A lack of training is also a problem, with many doctors and nurses ignorant of how to administer them.

- **State funding of end-of-life care is limited and often prioritises conventional treatment.** In many countries—even where palliative care treatment is available through national healthcare systems or insurance—end-of-life care bodies rely on charitable donations and philanthropic activity to support them. In the US, while palliative care is available through public medical insurance, patients must relinquish curative treatments to be eligible for reimbursements (unlike in the UK, for example, where both courses of treatment may be pursued).

- **More palliative care may mean less health spending.** By increasing the proportion of community and homecare, palliative care can reduce costs associated with hospital stays and emergency admissions. In the US in particular, with the recent passing of a major healthcare reform bill, this is likely to become a focus of debate. In Spain, one study found that in 2006 a shift away from the use of conventional hospital treatment towards palliative care, an increase in homecare and lower use of emergency rooms generated savings of 61% compared with expenditure recorded in a 1992 study. However, the costs associated with non-cancer palliative care are higher than for cancer-related care. And as the population ages, more end-of-life care will be needed overall.

- **High-level policy recognition and support is crucial.** Pioneering areas in developing countries—such as Uganda, and the state of Kerala in India—show the importance of receiving high-level backing for palliative care strategies. Yet only seven countries in the Index have a national policy in place (another four are developing them). In other countries, awareness at a national level has not led to coherent national policies: high-level statements of support for a general position (such as that articulated by the Council of Europe) aren't enough. End-of-life care must "get into the bloodstream of policy", in the words of one interviewee. Deeper integration of palliative care into national healthcare systems is also vital.

- **Palliative care need not mean institutional care, but more training is needed.** Much palliative care can be—and is—given at home; indeed more than 75% of those receiving such care in the US die at

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home. This is often representative of the patient's wishes, which may be ignored in conventional curative medicine. However, capacity building, particularly training of caregivers, is necessary to enable homecare with suitably high standards. Technology will be of increasing importance in the provision of end-of-life care at home, whether to put those in developing countries in touch with doctors via mobile phones, or to enable remote monitoring of medical devices through advanced systems.

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Introduction: new challenges in managing the end of life

For the first time in the history of humanity, people over the age of 65 will soon outnumber children under the age of five. This will happen some time during the next few years. By 2030, the number of people aged 65 and older is projected to reach 1bn (or one in eight of the global population), rising even more sharply (by 140%) in developing countries.[2] Compounding the effects of an ageing population are falling birth rates, particularly in the developed world. And while they vary country-by-country, such rapid demographic shifts have dramatic implications for governments around the world.

For a start, the ratio of working people to dependants is shrinking rapidly, particularly in China, where the one-child policy will leave parents with fewer offspring to care for them in old age. While developing countries such as India still have a very large young population, particularly in rural areas, their parents and grandparents are ageing and those in between them are often moving out in search of a better life.

While Europe's population has been among the fastest to age, Americans are catching up. According to the Pew Research Center, 13% of the population is now over the age of 65, up from 4% in 1900. By 2050, about one-in-five Americans will be over the age of 65, with about 5% reaching 85 and older (up from 2% today). This will put the US roughly on par with the current age demographics of Japan, Italy and Germany.[3]

People are certainly living longer, healthier lives, with smaller numbers dying of communicable or infectious diseases, particularly in developed countries. By 2030, non-communicable conditions are projected to account for more than three-quarters of all deaths, according to the World Health Organisation (WHO).[4] However, with longevity comes more complex diseases of ageing that are harder and more costly to manage. Growing numbers of people live with heart disease, for example, rather than dying of a heart attack. And while more and more people are living into their 90s and even 100s, the proportion of them who are free of health problems is shrinking.

For the end-of-life care community, this presents a new and complex set of problems. For while cancer—the catalyst for the creation of many hospice and palliative care services—has a fairly well established prognosis, conditions such as cardiovascular disease, dementia and Alzheimer's disease, arthritis, and diabetes are less predictable. These chronic illnesses bring about a slow decline, with a number of incidents, most of which are managed but any one of which might result in death.

As a result, demand for end-of-life care services is likely to rise sharply. While the hospice movement has made much progress, huge gaps remain—often in developing countries, where the demographic challenges of ageing are likely to be most pronounced. Too often such care is simply not available: according to the Worldwide Palliative Care Alliance (WPCA), while more than 100m people would benefit from hospice and palliative care annually (including family and carers who need help and assistance in caring), less than 8% of those in need access it.

Some countries have well-developed services for dealing with the end of life. The UK, for example, is well ahead, having led the world in establishing a dedicated hospice movement, spearheaded by Dame

[2] *Why Population Aging Matters: A Global Perspective*, National Institute on Aging, National Institutes of Health, US Department of Health and Human Services, and the US Department of State, 2007.

[3] *Growing Old in America: Expectations vs. Reality*, Pew Research Center, June 2009.

[4] *The Global Burden of Disease: 2004 Update*, World Health Organisation, 2008.

Cicely Saunders, who founded St Christopher's Hospice in 1967. The US followed suit in the 1970s. In 1988, palliative care was enshrined in the Australian healthcare agreements, through which the federal government funds expenditures by the country's states and territories. In 2006, according to a study by the International Observatory on End of Life Care (IOELC, a research body at the UK's Lancaster University), more than 150 countries were actively engaged in delivering hospice and palliative care services. Yet the IOELC also found many instances where services were localised and inaccessible to much of the population. And of the 234 countries it reviewed, only 35 had achieved any notable level of integration with mainstream healthcare providers.[5]

In many parts of the world, hospice and palliative care is either non-existent or in its infancy, with about 5bn people living in countries with insufficient or no access to medications to control severe or moderate pain, according to the WHO.[6] Meanwhile, in developed countries, medical services have all too often focused on preventing death rather than helping people meet death without suffering pain, discomfort and stress.

As the world ages, the task for national governments and health services will be to provide care for citizens that are living longer but doing so in fragile health. In light of this increasingly challenging demographic and healthcare-hungry environment, this report aims to highlight the parts of the world and areas of practice where most progress is being made and to assess where more work still needs to be done when it comes to improving the accessibility to and quality of end-of-life care globally.

This report is based on two areas of research: the first is the Economist Intelligence Unit's "Quality of Death Index", which ranks 40 countries in terms of the quality and availability of end-of-life care (see box on p11 for a summary of the methodology used in constructing the Index, which is also explained in more detail in the appendix). For this paper, the author also conducted in-depth interviews with over 20 experts on the subject from across the world—including palliative care specialists, physicians, healthcare economists and sociologists—and reviewed existing research on the topic.

[5] *Mapping levels of palliative care development: a global view*, International Observatory on End of Life Care, Lancaster University, 2006.

[6] "Access to Controlled Medications Programme", World Health Organisation Briefing Note, February 2009.

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1. The Quality of Death Index

Index methodology

The Quality of Death Index measures the current environment for end-of-life care services across 40 countries: 30 OECD nations and 10 select others for which data was available. The Economist Intelligence Unit's research team devised the Index, collated data and built the model from a wide range of indicators. They interviewed a variety of doctors, specialists and other experts to compile and verify the data.

The Index scores countries across four categories: Basic End-of-Life Healthcare Environment; Availability of End-of-Life Care; Cost of End-of-Life Care; and Quality of End-of-Life Care. Twenty-four individual indicators fall into three broad categories:

Quantitative indicators: Eleven of the Index's 24 indicators are based on quantitative data, such as life expectancy and healthcare spending as a percentage of GDP.

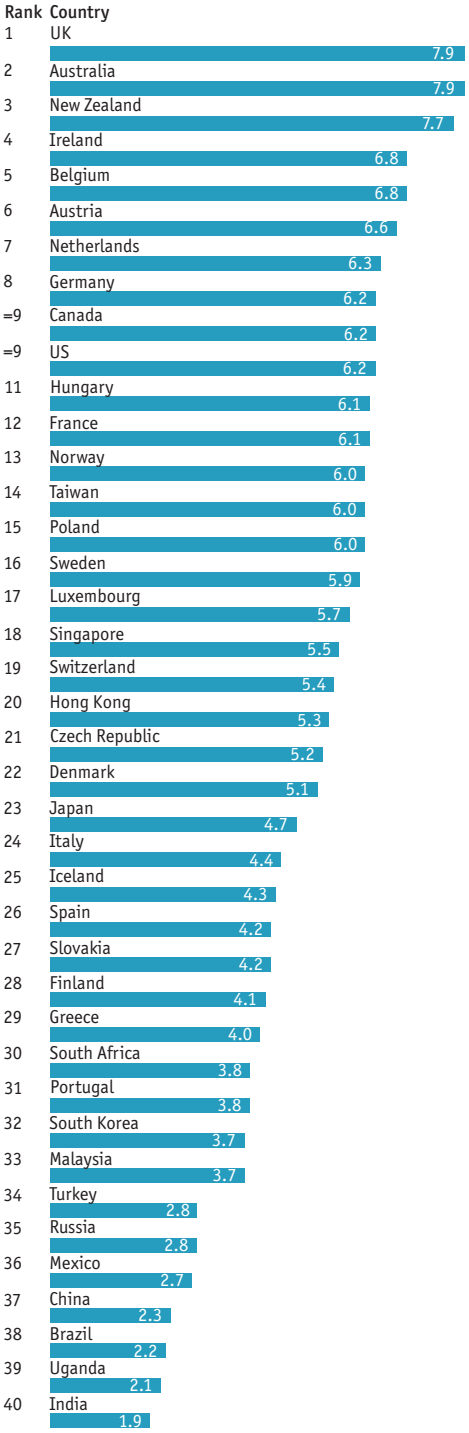
Qualitative indicators: Ten of the indicators are qualitative assessments of end-of-life care in individual countries, for example "Public awareness of end-of-life care", which is assessed on a scale of 1-5 where 1=little or no awareness and 5=high awareness.

Status indicators: Three of the indicators describe whether something is or is not the case, for example, "Existence of a government-led national palliative care strategy", for which the available answers are Yes, No and In Progress.

The Index is an aggregate score of all of the underlying indicators, normalised to make the data comparable. Data is first aggregated by category and then overall, based on the composite of the underlying category scores. To create the category scores, each underlying indicator was aggregated according to an assigned weighting, determined by the EIU's research team following consultation with experts interviewed for the research. Each category is also accorded a weighting within the overall score. Quality is given the largest weighting, accounting for 40% of the overall score; Availability accounts for 25%, Basic End-of-Life Healthcare Environment 20% and Cost 15%.

Although the index scores were calculated to two decimal places, they have been rounded to one decimal place in the charts in this white paper. For this reason, countries with different rankings may nonetheless display the same score.

Figure 1
Overall score



Source: Economist Intelligence Unit.

A high quality of death

It is no surprise to find countries such as the UK, Australia and New Zealand high in the overall ranking, given their relative wealth, advanced

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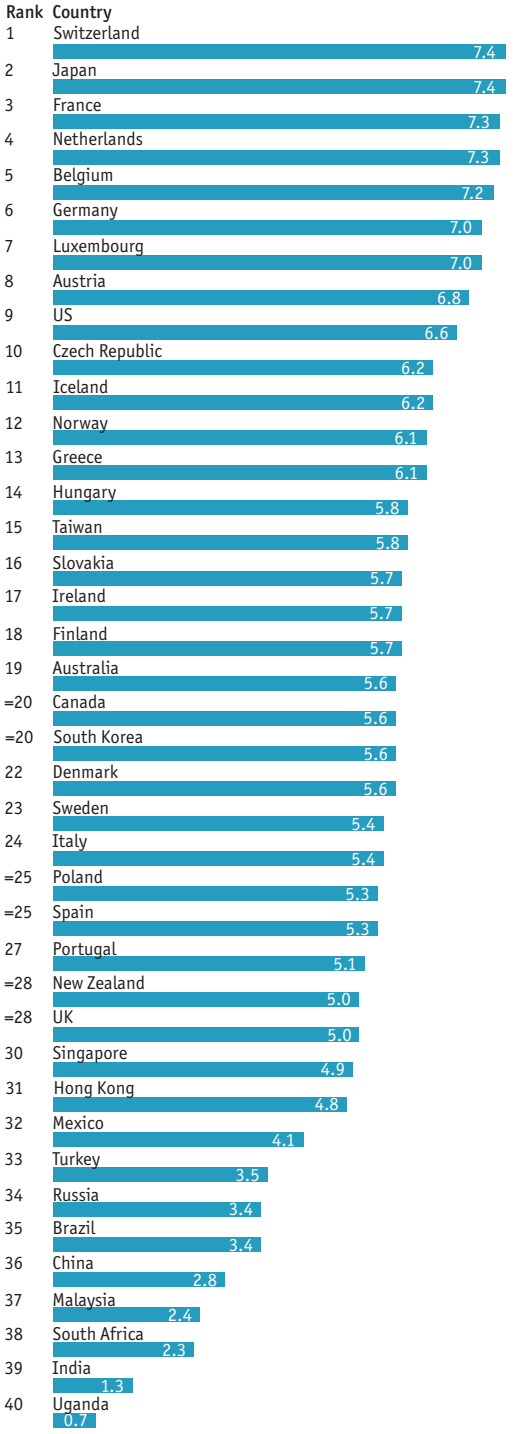
Figure 2
Basic end-of-life healthcare environment (20% weighting)



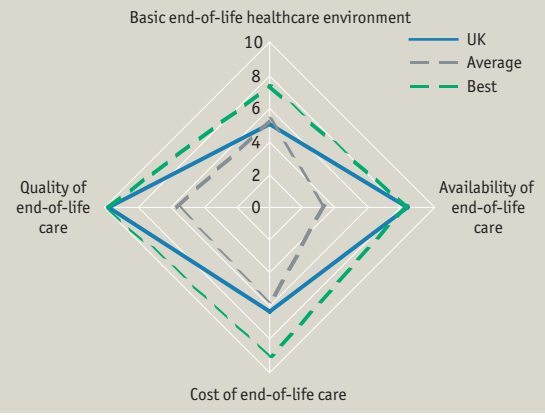
Source: Economist Intelligence Unit.

infrastructure and long recognition of the importance of developing national end-of-life healthcare strategies. The UK's position at the top of the Quality of Death ranking is explained in part by the head start it has had in the field. "The UK has perhaps had longest period of sustained charitable development of hospices and, more recently, limited statutory involvement and investment," says Sheila Payne, director of the IOELC at Lancaster University in England. Moreover, the UK ranks top of the Quality of End-of-Life Care category, which includes indicators such as public awareness, training availability, access to pain killers and doctor-patient transparency. This is the most important category in the Index and accounts for 40% of the overall score.

While the appearance in the top ten of some other western European nations with good healthcare systems may be expected, it is perhaps more surprising to find Hungary ranking as high as position 11. Hungary scores very well (at position 4) when it comes to Quality of End-of-Life Care, the most heavily weighted category. "Some countries in Eastern Europe have built up astonishing programmes in the past few years," says Lukas Radbruch, president of the European Association for Palliative Care (EAPC). "And, because these countries are younger and smaller, some advocates for palliative care have even managed to reach their governments in a way that they wouldn't be able to in other countries." Stephen Connor, senior executive at the WPCA, agrees. "Poland along with Romania have been leaders in palliative care development in Eastern Europe," he says. Poland scores among the top 15 overall and comes in at position 10 on Availability of End-of-Life Care. (Romania is not included in the

Figure 3

UK	Score/10	Rank/40
Overall score	**7.9**	**1**
Basic end-of-life healthcare environment	5.0	28
Availability of end-of-life care	8.4	1
Cost of end-of-life care	6.3	18
Quality of end-of-life care	9.8	1



Source: Economist Intelligence Unit.

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Index but its rapid progress is examined in a box on page 22.)

Taiwan is also noteworthy among the top 15 overall in the Index at position 14 (it scores very well on Quality but not so well on Availability). Its strong position in the Index can be ascribed to a relatively early recognition of the need for end-of-life care. Moreover, it shares top position with Luxembourg, Singapore and Switzerland when it comes to the percentage of the population covered by a national pension insurance scheme (an indicator in the Basic End-of-Life Healthcare Environment category). It also ranks third in terms of the number of hospital beds for every 1,000 non-accidental deaths. "Taiwan has a very strong commitment to palliative care," says Mr Connor.

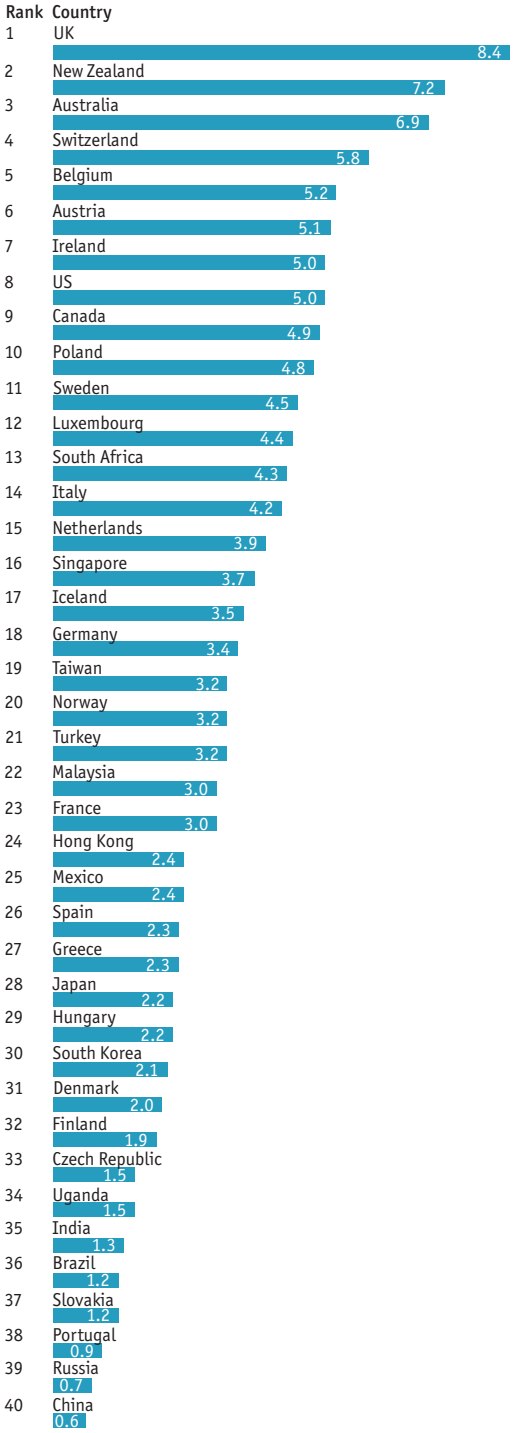
Meanwhile, the US stands no higher than number 9 in the overall ranking principally because of the financial burden of end-of-life care. This reflects the high overall cost of healthcare in the US, where expenditure has risen sharply in recent years, now accounting for one dollar in every six spent. The US ranks better in terms of infrastructure—at positions 7 and 8 for Quality and Availability of End-of-Life Care respectively (and top of the list when it comes to healthcare spending as a percentage of gross domestic product). However, this is offset when considering the financial burden to patients, driven up by the low availability of public funding and social security spending on healthcare. These factors collectively push the US to a lowly 31st in the Cost category. (See also Chapter 3, below.)

Similarly, despite placing in the top five countries for Quality of End-of-Life Care, Canada also suffers in the overall ranking as a result of the cost of end-of-life care. While the Canadian government has shown a heightened interest in recent years in improving access to palliative care, and hospitalisation is 100% funded by the state, homecare may still be a considerable burden. A recent study in the journal *Palliative Medicine* found that Canadian families frequently shoulder 25% of the total cost of palliative care. [7]

A low quality of death

The bottom-ranked countries in the Quality of Death Index include, unsurprisingly, developing and BRIC countries, such as China, Mexico, Brazil, India and Uganda, where despite notable exceptions of excellence—such as the Indian state of Kerala, and services delivered through Hospice Africa Uganda—progress on providing end-of-life care is slow. (It should also be noted that the Index covers only a limited number of nations, of which three quarters are OECD members: these developing countries might be expected

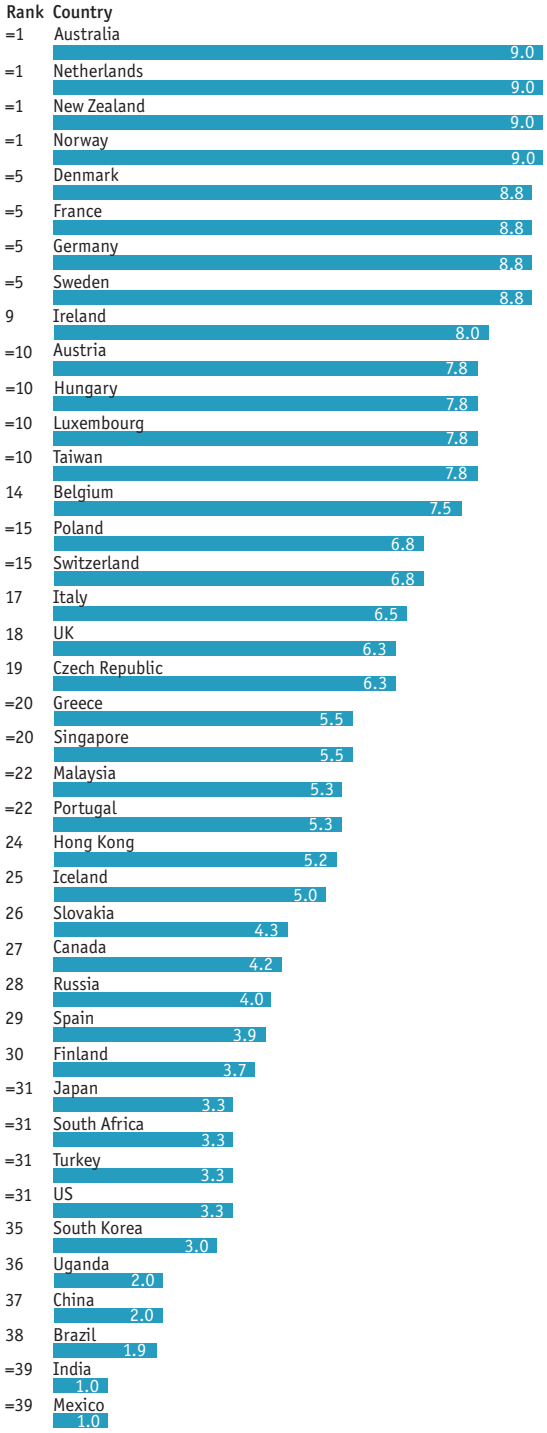
Figure 4
Availability of end-of-life care (25% weighting)



Source: Economist Intelligence Unit.

[7] *Costs associated with resource utilization during the palliative phase of care: a Canadian perspective,* Palliative Medicine, Dec 2009.

Figure 5
Cost of end-of-life care (15% weighting; top = lowest cost to patient)



Source: Economist Intelligence Unit.

to rank more favourably among their peers.) In the case of China and India, further problems are vast populations for whom end-of-life coverage extends to only a fraction of those in need.

Unsurprisingly, developing countries also score badly in the Basic End-of-Life Healthcare Environment and Availability of End-of-Life Care categories. "This is due to lack of finance and lack of recognition in these countries in government healthcare policy of palliative care," says Professor Payne. "And poverty means there is little chance to raise money for hospices."

David Clark, director of the University of Glasgow's Dumfries Campus and founder of the IOELC, cites specific problems in low-scoring countries. "Turkey has some signs of palliative care development but it's only very localised," he says. "Russia has some longstanding hospice services—for example, in St Petersburg—but faces great challenges in scaling up."

Some OECD and developed countries also rank unexpectedly low in the overall scoring. These include Denmark at 22, Japan at 23, Italy at 24, Finland at 28 and South Korea at 32. "Denmark seems to have had some problems of coverage," says Professor Clark. "Italy has had a patchy history of palliative care development with a lack of coordination and also until recently, poor access to opioid medications." Finland, notably, scores badly in the Availability of End-of-Life Care category, which includes factors such as an ageing population, number of volunteer workers and number of hospice and palliative care services.

Professor Payne offers an alternative explanation for the low scoring of some of these countries—that they have "strong hospital medical-care programmes that see little value in hospices" and instead value the services of oncologists and "the power of medicine".

This may explain, for example, South Korea's relatively low position: it scores poorly on a number of indicators relating to training, accreditation and end-of-life care strategy. Cultural factors (examined in more detail in Chapter 2) may also affect the availability of—or willingness to supply—palliative rather than curative medicine.

Japan also scores relatively poorly, at 23 in the overall Index and at 28 in the Availability of End-of-Life Care category. This may be because, with one of the world's oldest populations, it has many more elderly to care for. The country also scores poorly when it comes to the indicator on average weekly patient payments for hospice and palliative care services.

Nevertheless, Japan scores relatively well on the government attitude towards end-of-life care indicator. "Hospice and palliative care is one of the most important political issues," says Tetsuo Kashiwagi, president of the

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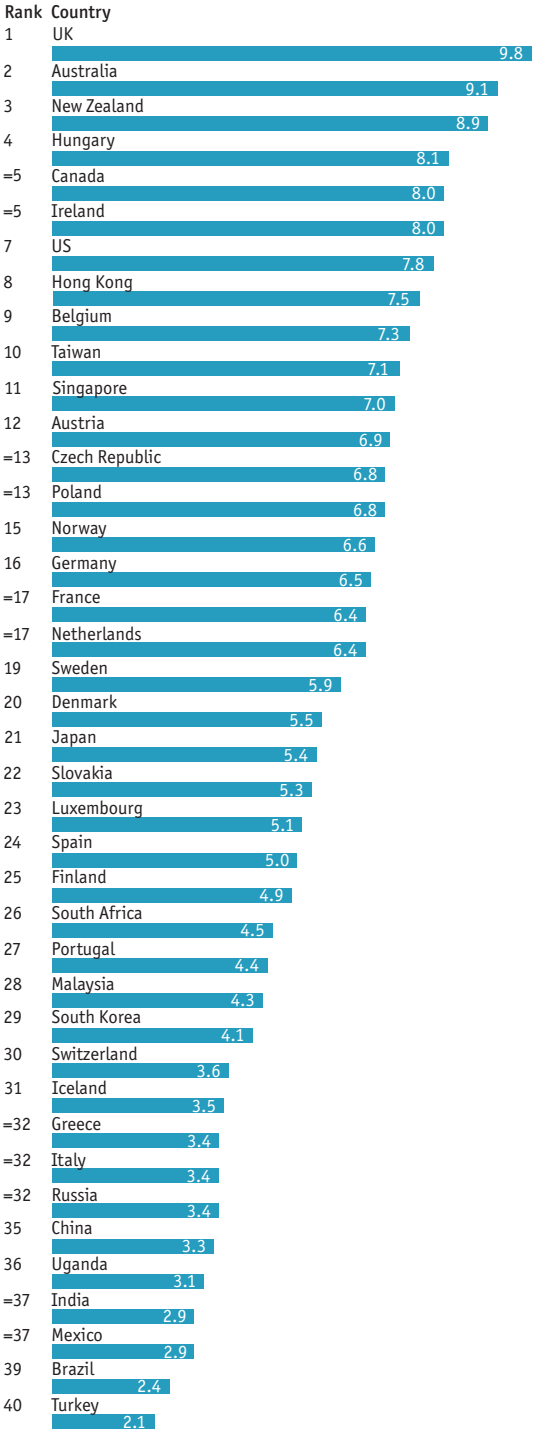
Japan Hospice Palliative Care Foundation. But he adds that the country lacks sufficient numbers of specialists. "Shortage of palliative care specialists is one of the biggest problems," he says, adding that there is also a need for more non-professional caregivers, particularly volunteers.

When it comes to the Basic End-of-Life Healthcare category, there are some notable absences from the top of the list. The UK, for example, falls down in this category principally because it scores relatively badly on life expectancy, on the number of hospital beds per 1,000 non-accidental deaths, on the number of doctors and on national spending on healthcare. And Australia, while ranking highly in most indicators and second in the overall score, falls to position 19 on the Basic End-of-Life Healthcare category. However, there are also strong correlations between this indicator and overall scoring when it comes to the poor performers. Countries such as China and India are near the bottom of the list both in the overall scoring and in the Basic End-of-Life Healthcare category.

Figure 6
Quality of end-of-life care (40% weighting)



Source: Economist Intelligence Unit.

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2. Cultural issues in end-of-life care

Attitudes to death and dying

"The weariest and most loathed worldly life that age, ache, penury and imprisonment can lay on nature," cries Claudio in Shakespeare's *Measure for Measure*, "is a paradise to what we fear of death." Mortality salience, as it is sometimes known, shapes discussions about death and dying—or lack of such discussions. However, variations in religion, education and the media mean that national attitudes to death and dying are far from uniform.

Strong taboos against talking about death exist in countries such as Japan and China, for example. This is even the case in India, where death is discussed more openly and the Hindu philosophy of reincarnation should, in theory, mitigate fears about death. "Despite possibly a greater acceptance of the inevitable consequence of life and our philosophical attitude, when it actually happens to somebody in your family, you deny it and don't want to talk about it," says MR Rajagopal, chairman of Pallium India, a clinic based in the southern Indian state of Kerala.

Even so, in India, a bigger barrier more often is the protective attitude of the family. While relatives are often available to care for dying parents, Dr Rajagopal says that they are reluctant to disclose their condition. "They don't want the patient to be told that they're dying," he says, "so they prevent open communication with the patient."

In the UK, the attitudes of some ethnic communities mean care must be delivered in a different way. David Praill, of Help the Hospices, the UK's leading charity supporting hospice care, cites a project in the East End of London that is working with the Somali community. "They made it very clear they don't want to know they're dying," he explains. "So they've had to redesign the whole way the community engages with the hospice to provide care in such a way that it doesn't send a signal that they're on death's door."

When it comes to children, taboos around death and dying are stronger in rich countries. "In the developing world, where people see so many children die, it's more accepted," says Joan Marston, chair of the International Children's Palliative Care Network, WPCA (South Africa). "But in the developed world, there's still this feeling that children shouldn't die and we don't like to talk about children dying, so we shut it off and turn a blind eye."

In the US, appropriate end-of-life care is often trumped by the "cure at all cost" attitude of doctors, along with the strong religious views many families hold on the sanctity of life. "We're the epicentre for the technologies that allow us to keep people alive for 60 additional days with no improvement in outcome but with substantial increase in costs," says Paul Keckley, executive director of the Deloitte Center for Health Solutions, the health services research arm of Deloitte, an international consulting and accounting firm. "And the more fundamentalist, evangelical or conservative, the less likely people are to challenge a physician's opinion or to want anything done that's not recommended by the doctor."

Meanwhile, recent healthcare reform debates in the US—provoking talk of "death panels" and with references in some quarters to a "euthanasia bill"—have forced the issue of end-of-life care into the

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background. "Everyone has been terrified about talking about palliative care until health reform passed," says Diane Meier, director of the US-based Center to Advance Palliative Care.

The inflammatory nature of the US debates has highlighted the biggest cultural barrier to delivering palliative and hospice care—the fact people associate it with dying rather than providing quality of life when suffering terminal illness. Dr Meier views this as a social marketing challenge. "The problem with hospice is that it's firmly linked in everyone's minds with giving up." The irony, she says, is that to promote higher-quality and better access to palliative care, the services need to go by another name. "We force people to wear the scarlet letter in order to get the care," she says.

Levels of debate across the globe

Although cultural attitudes are difficult to quantify, the Quality of Death Index does measure public awareness end-of-life care (an indicator within the "Quality" category, based on responses from national-level palliative care organisations and governmental bodies). As the discussion above illustrates, this varies across the globe: Belgium, Ireland and the UK rank highest when it comes to evidence of public discussions about end-of-life care. China ranks last on this indicator.

In China, there is little knowledge of the existence of hospice care or understanding of what it provides, says Dr Ma Ke, director of the Third People's Hospital of Kunming Hospice Department. "Most family members of the patients can't fully understand it," he says, adding that even in medical circles, many doctors and other healthcare providers remain unaware of what palliative care entails.

In the Index, the US ranks relatively poorly in this respect, reflecting lack of awareness among Americans of hospice services and end-of-life care in general (much of which takes place in the home).

Figure 7: Public awareness of end-of-life care

Highest ranking (excellent)				Lowest ranking (poor)
5	4	3	2	1
Belgium	Australia	Canada	Brazil	China
Ireland	Austria	Czech Republic	Finland	
UK	France	Denmark	Greece	
	Hungary	Germany	India	
	Japan	Hong Kong	Italy	
	South Korea	Iceland	Luxembourg	
	Netherlands	Malaysia	Mexico	
	New Zealand	Poland	Portugal	
	Norway	Singapore	Russia	
	Sweden	Slovakia	Switzerland	
	Taiwan	South Africa	Turkey	
	Uganda	Spain		
		US		

Source: Economist Intelligence Unit ranking, based on input from Ministries of Health, country palliative care advocacy organisations.

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The law and the decision to die

The recent unveiling of a new UK policy for prosecutors dealing with cases of assisted suicide has put the question of a right to choose when to die back in the headlines. Debates around euthanasia (in which one party takes action to end the life of a second party, at the request of the second party) and assisted suicide (where physicians, or others, provide the means for patients to end their own lives) often overlap with those about palliative care. However, hospice and palliative care professionals see what they do as quite distinct from assisted suicide or euthanasia.

Euthanasia is now possible in three European countries. In 2002, the Netherlands passed a law allowing patients suffering unbearably to request euthanasia and protecting the doctors carrying out those requests from prosecution, as long as they follow a set of strict guidelines. Belgium followed suit the same year and Luxembourg did so in 2009.

In Switzerland assisted suicide—but not euthanasia—has been legal since 1941, provided assistance is given for altruistic motives. Stricter legislation is currently under discussion. (The Netherlands and Luxembourg also permit assisted suicide, although Belgium does not.) Meanwhile, in the US state of Oregon, the Death With Dignity Act, passed in 1997, allows terminally ill, adult residents of the state to take self-administered lethal medications prescribed by a doctor. Take up of the option is relatively limited, with the 60 people that died under the terms of the law in 2008 corresponding to fewer than 20 per 10,000 deaths.[8] About 400 people have died this way since the law was passed. A similar law was passed in the st ate of Washington in 2008.

Most recently attention has focused on the UK, where prominent campaigners such as author Sir Terry Pratchett, who has Alzheimer's disease, and Debbie Purdy, a multiple sclerosis sufferer, are pushing legalisation of assisted suicide. Sir Terry has called for tribunals to review cases of individuals wanting to end their lives.[9] However, such demands are coming largely from the public, rather than the palliative and hospice care profession. "If you look at the percentage of palliative care doctors who are opposed to assisted suicide in the UK, it's over 90%," says David Praill of Help the Hospices. "This is a publicly driven debate and definitely not a hospice and palliative care driven one."

In fact, in many places, the medical professionals promoting end-of-life care do not support euthanasia or assisted suicide. In 2003, the Ethics Task Force of the European Association for Palliative Care (EAPC) produced a paper concluding that, among other things, "provision of euthanasia and physician-assisted suicide should not be part of the responsibility of palliative care". It argued that a distinction should be made between terminal or palliative sedation—the purpose of which is to relieve the dying person of intolerable suffering and distress—and the administration of lethal drugs to a patient with the intention of killing them.[10]

"Palliative care is about trust in the relationship between patient and carers and it's not possible to have that kind of relationship when killing the patient is one of the options," says Lukas Radbruch, president of the EAPC. The constitution of the Asia Pacific Hospice Palliative Care Network is also explicit in this regard, stating: "The Association values every moment of life and does not support any action that has the intention of shortening a person's life."

Meanwhile, it was the 1996 enactment of pro-euthanasia legislation in Australia's Northern Territory—legislation subsequently overturned by the federal government—that prompted the creation of a national strategy and the allotment of new funding for end-of-life care. "Clearly the pro-euthanasia lobby was a huge catalyst for government—that was not keen on euthanasia—responding with genuine new money to look at service development," says David Currow of Cancer Australia, a national government agency.

When it comes to living wills and do not resuscitate (DNR) policies, more than half the countries in the Index score highly on the question of whether or not DNR policies have a legal status. For some this has been a relatively recent development. In Taiwan, for example, legislation passed in 2000—the Natural Death Act—allows patients over the age of 20 with terminal diseases (diagnosed by at least two physicians) to express in writing their wish to discontinue medical treatment and does not prosecute doctors who allow such deaths.[11]

In the US, most states recognise living wills, but how they are regulated varies from state to state. However, whether doctors adhere to them or not is another matter. The difficulty for doctors is whether to meet the wishes of a document that may have been written several years ago when the patient was in a very different mental and physical state.

"It's another complex existential problem," says Diane Meier of the Center to Advance Palliative Care. "Who is the person with jurisdiction? Is it the cognitively impaired person in front of us right now or is it the cognitively intact person of five years ago? And that's really complicated, particularly if the cognitively impaired person in front of us right now looks very happy and comfortable."

[8] *Death With Dignity Act Annual Report 2008*, Oregon Department of Human Services, 2009.
[9] "Terry Pratchett: my case for a euthanasia tribunal", guardian.co.uk, Feb 2nd, 2010.
[10] *Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force*, Palliative Medicine, 2003.
[11] *End-of-life decision making: a cross-national study*, The MIT Press, 2005.

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Jennie Chin Hansen, president of the AARP, a membership organisation representing the interests of Americans over 50, believes discussions should focus on the opportunity for the process of dying to be more dignified. "There needs to be an aggregation of stories about people who have had more positive end-of-life experiences," she says. "When there gets to be a more visible set of stories, that will change attitudes."

However, Professor Clark argues that in some ways, public debate in the US has been pushed higher by high-profile cases such as that of Jack Kervorkian, the right-to-die activist doctor, and the decision in 2005 to disconnect Terri Schiavo—diagnosed as being in a persistent vegetative state—from life support.

The British media have also recently engaged in spirited public debates about the right to choose to die. However, despite having well-established hospice facilities, Britain's population generally has a poor understanding of end-of-life issues, argues Professor Clark. "In the UK, very few studies have looked at public perceptions of palliative care and hospice care," he says. "A lot of energy has gone into service development and specialist recognition, and one of the things that has been lost is wider public debate."

Public education and information campaigns are considered critical to changing public attitudes. In Hong Kong, which sits in the middle of the Index when it comes to awareness of end-of-life care, efforts are under way to reduce fear of death and encourage individuals to be more proactive when it comes to planning for it. Cecilia Chan, a health and social specialist at the University of Hong Kong, is developing educational materials using artwork, music, songs and documentary footage showing positive real life stories about people who have prepared for death. "We're trying to detoxify death," she says.

Hospice professionals see their task as similar to that of organisations battling cancer and HIV-AIDS, which have tried to battle the stigma surrounding the diseases. "It's about educating the population as a whole to think about death, dying and loss in another way," says Allan Kellehear, professor of sociology at Bath University. "And also getting people used to the idea that there are professionals who work in death, dying and palliative care—and they're not scary and they can be useful."

Dr Meier agrees. "Until we can get across to the public and health professionals that palliative care is about living as well as possible for as long as possible with a serious illness," she says, "patients will continue to suffer unnecessarily."

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Three contrasting attitudes to death

In Chinese society, denial of death is extremely strong. Even language related to death is avoided. Many buildings in Hong Kong and other parts of Asia, for example, do not count the fourth floor in the storey numbering system because the Chinese word for "four" sounds like the word for "death". This horror of death means many refuse to accept its inevitability. "There's a huge negative taboo about talking about and contemplating death," says Hong Kong University's Professor Cecilia Chan. "People believe that even thinking about it can bring bad luck."

While more progressive attitudes are emerging, particularly on the part of the younger generation, the reluctance to talk about death can have painful consequences for all concerned. Families often try to prevent their relative from finding out what the prognosis is, while individuals may ask doctors not to let family members know they are dying. This can make it hard to select an appropriate treatment plan. "People are reluctant to prepare for death so when they die, there are a lot of regrets on the part of the dying person and family members," says Professor Chan.

This comes in contrast to some African countries, where death—particularly since HIV-AIDS swept across the continent—is never far away. "The majority of people have seen people dying since they were children," says Anne Merriman, founder of Hospice Africa. "So they're much better at bereavement than we are."

Africans also have strong community care networks, through family and friends. "If someone is living alone, the neighbours will come and help because they're part of the community," she says. This is reflected in the Quality of Death Index, in which South Africa scores highly when it comes to the availability of volunteer workers for end-of-life care. Uganda, while scoring lower on this indicator, still ranks alongside countries such as the US and Switzerland.

"African culture is particularly community oriented with a lot of shared care," says Elizabeth Gwyther, chief executive of the Hospice Palliative Care Association of South Africa (HPCA). "So where we have developed a model of care that relies on community care workers, that's very well accepted."

As is the case in other developed regions such as the US and Europe, the "medicalisation" of death in Canada has engendered a culture where many people are afraid to raise the topic of death. Consequently, when several years ago Canada started to launch public awareness campaigns to combat these attitudes, it focused on the need for advance planning. "We decided to take another angle, which is talking about how you want to live your life," says Sharon Baxter, executive director of the Canadian Hospice Palliative Care Association.

However, while attitudes to death and dying may mirror those of the US and Europe, Canada has a characteristic that sets it apart from these countries—geographical size. With the second-largest landmass in the world and a population of fewer than 34m, hospice and palliative care services reflect the size of the population, yet cannot cover the entire country.

In Yukon, which is about twice the size of the UK, the population is just 34,000, with only one acute care hospital in the territory and limited long-term care facilities. Some parts of Canada facing similar situations have taken a community-based primary care approach to looking after the dying, relying more heavily on volunteers, family and friends than in other developed countries. "It's not unlike what happens in some parts of Africa," says Ms Baxter. "Everything is interspersed in the community outside the main cities."

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3. The economics of end-of-life care

A variety of funding models

One region often cited as having a successful state-funded programme is Spain's Catalonia, where palliative care services are available to all through the regional public healthcare system. However, when it comes to the financing of end-of-life care, governments are not always the main sources of funding. A range of funding models exists from church support, philanthropic funds and international aid to patients and families having to pay for the services themselves—or in some cases, hybrid models relying on a mixed range of funding sources.

In the UK, a well-established network of non-profit hospices plays an important role in cutting National Health Service expenditure. While adult hospices receive about 30% of their funding from the government, according to Help the Hospices, with children's hospices getting about half that, the bulk comes from charitable donations. Together, local independent charitable hospices in the UK spend more than £509m (US$763m) a year.[12] The UK government recently stepped up its financial support for end-of-life care, with £286m (US$434m) pledged for 2009-11 to help those who want to die at home, rather than in a hospital (although some claim the funds have not reached frontline services).[13]

Charitable funds also support palliative care in Ireland. "Ireland has benefited from a programme of major charitable investment from The Atlantic Philanthropies [a private US foundation] which has sought to improve end-of-life care," says Professor Payne of the IOELC.

In Europe, too, hospices tend to be partly financed privately or charitably. And in the case of Eastern Europe, many of the donations are from nations such as the UK, which funds programmes in countries such as Romania, Serbia and Moldova. Professor Radbruch of the EAPC cites the example of Casa Sperantei in Romania, started by a UK philanthropist . "[W]ithout that [funding] they wouldn't have been able to get off the ground," he says.

Some Eastern European hospices, while founded with charitable donations, have succeeded in gaining government support and funding for end-of-life care, as in the case of Romania, where the government now funds several palliative care services. "Though they may still get a funding stream from the UK, they've done a good job at getting the government to take on responsibility," says Mr Praill of Help the Hospices.

In Europe, reliance on government and charitable funding—coupled with a widespread cultural belief that governments should provide and pay for healthcare services—have hampered private sector provision of end-of-life care services. "You have to find some way of being reimbursed by the healthcare system before you can set up [private] services, but almost no one is paying their own way and in many countries, there are national health systems," says Professor Radbruch.

In Africa, the story is different. Because HIV-AIDS is such a severe problem and affects more driving demand for end-of-life care, international aid has been pumped into the continent from organisations such as PEPFAR (the US President's Emergency Plan for AIDS Relief) and the Global Fund to Fight AIDS,

[12] *Hospice accounts: Analysis of the accounts of UK independent voluntary hospices 2005-2008,* Help the Hospices, June 2009.

[13] "The End of Life Care Strategy one year on: extra investment must get through", Help the Hospices, July 2009.

Romania: from last to leader

During the time of the Ceaucescu regime in Romania, end-of-life care in the country was non-existent. Most deaths occurred at home with the dying suffering great pain. As the result of a heavily regulated system, gaining access to opioids was extremely difficult, with Romania's annual morphine consumption among the lowest in eastern Europe.[14]

Since then, a number of developments have turned Romania into a regional leader in end-of-life care. Among the most important was the founding of the Casa Sperantei hospice by UK philanthropist Graham Perolls in 1992, following a conference held in Brasov to raise awareness of the need for palliative care. Training needs were met with the founding of the Princess Diana Hospice Education Centre in 1997—an institution that has now provided more than 4,000 doctors and nurses with palliative and hospice care skills.

In February 2002, Romania—because of its severe restrictions on access to opioids—was selected as a pilot for follow-up of a workshop run by the University of Wisconsin Pain and Policy Studies Group, the World Health Organisation's European office and the Open Society Institute. By 2006, new regulations easing access to painkillers were in force.

Casa Sperantei has become a model institution, now replicated in other parts of eastern Europe, while its funder, now known as the Hospices of Hope, has helped establish partner organisations and hospice care programmes across Romania and in neighbouring countries.

[14] "Reform of drug control policy for palliative care in Romania", The Lancet, June 24th 2006.

Tuberculosis and Malaria. However, Dr Merriman of Hospice Africa argues that the focus of international funding on HIV-AIDS means palliative care for cancer sufferers is often neglected. "If there's less than 6% HIV in a country then the cancer burden is higher than that of HIV-AIDS," she says. "So we need to let the international community know that they must look around and find funding for people with cancer in Africa."

In many places, hospice and palliative care movements that started on a charitable basis have become fully or partly government-funded programmes. Singapore's Hospice Care Association, originally launched in 1989 as a volunteer organisation, was initially funded by charitable donations but since 1996 has received funding from the government for its homecare services. In addition, the Central Provident Fund, a compulsory national savings scheme, has been made available for in-patient hospice care since 1994 and for homecare since 2009. Palliative care is now available in most government-funded hospitals, and is subsidised like other hospital services.

Also in 2009, Taiwan extended hospice coverage through its National Health Insurance scheme to cover a broader range of illnesses, with providers reimbursed through a fixed daily rate. "It's completely covered by the government, so patients don't need to pay anything, even in the hospice," says Tzuchi University's Yingwei Wang. "In the past this was only for cancer patients but from 2009, the new programme gives coverage for most end-of-life diseases."

In 1983, the US initiated government-funded reimbursement for hospice care through Medicare, the federal programme providing health insurance coverage to individuals over 65. Those eligible are the terminally ill with a life expectancy of six months or less (extended from 90-day coverage initially) and patients who opt for palliative care rather than curative treatments. For low-income Americans under the age of 65, Medicaid, another federal programme, covers hospice care—although not in all 50 states.

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However, those not yet eligible for Medicare and not sufficiently poor to qualify for Medicaid must rely on private health insurance, convert their life insurance policies to help pay for hospice treatment or find other sources of funding. In the Index the US ranks poorly in terms of the financial burden for users of end-of-life care and American patients have the highest average weekly costs for their care.

Another important point, raised by Professor Payne of the IOELC, is that to get reimbursements, US patients must relinquish curative treatment. "That's completely different from the UK, where people can continue to have cancer treatment alongside palliative care. So in the US, hospice care typically really is about end-of-life care."

In Australia, the model is quite different from that of the US or the UK. Since 1988, palliative care has been a specific part of the Australian healthcare agreements—the contracts between the federal government and the states and territories. The federal government—which endorsed the country's first national palliative care strategy in 2000—provides no direct support but taxes collected at a national level are devolved through five-yearly agreements to states and territories. This explains why Australia ranks highly in general on the Index, coming near the top of the list in many indicators and ranking first when it comes to the Cost category.

"Palliative care is one of the few areas that has been separately identified in each of the quinquennial agreements," says Dr Currow of Cancer Australia. "So it's expected that states and territories will provide in-patient services that are funded essentially through the same mechanisms as any other acute bed within the system."

At the other end of the scale are countries such as China and India, where government support and funding is thin on the ground for healthcare provision in general, let alone for end-of-life care. In China, some philanthropic funding is available through the Li Ka Shing Foundation. The foundation provides free hospice care services through the Heart of Gold programme, which established China's first free hospice care unit at the First Affiliated Hospital of the Shantou University Medical College. The foundation now funds around 30 hospice units throughout China.[15]

In general, however, funds for end-of-life care in China are hard to find. "There is some money from government but very little, so families pay for their own care," says Luo Ji-Lan of the Chinese Association for Life Care, adding that charitable donations are still very limited. This is reflected in the Index, in which China ranks lower than many countries on indicators relating to the cost of care.

A lack of government funding is a significant issue in Africa as well. South Africa and Uganda both rank 33rd on the indicator relating to available public funding for end-of-life care, and Uganda ranks among the worst, at position 31, on the financial burden to patients for available end-of-life care. Despite the model care offered by Hospice Africa Uganda (see box on p30) and the Ugandan government's recognition of palliative care as a policy priority, such care nonetheless remains out-of-reach to the majority of Ugandans in need.

With the exception of the state of Kerala, India also has little government funding for end-of-life care. "In India less than 1% is spent on healthcare so it's not only palliative care that suffers," says Pallium India's Dr Rajagopal. "There is no public funding, there is no socialised medicine and the same holds true for palliative care."

[15] "Palliative Care Symposium for Health Care Workers in Chinese Population", Chinese University of Hong Kong press release, December 12th 2009.

Kerala: the community model

Amid the lamentably poor access to palliative care across India, the southern state of Kerala stands out as a beacon of hope. While India ranks at the bottom of the Index in overall score, and performs badly on many indicators, Kerala, if measured on the same points, would buck the trend. With only 3% of India's population, the tiny state provides two-thirds of India's palliative care services.[16] Moreover, the state has a formal palliative care policy in place (it is the only Indian state with such a policy) and its government provides funding for community-based care programmes. It was also one of the first of India's states to relax narcotics regulations to permit use of morphine by palliative care providers.[17] Kerala has also extended the definition of palliative care to include the long-term chronically ill and even the mentally incapacitated.

One of the driving forces in promoting palliative care has been MR Rajagopal, chairman of Pallium India, a charitable trust. While Dr Rajagopal laments the lack of funding in India for end-of-life-care services, he argues that money is not the only answer to relieving suffering and improving quality of life for those in the last stages of their lives. Other important factors, he believes, are government policy support, community involvement and the awareness of doctors of not only pain control but also of what palliative care provides more generally.

Kerala's unique system proves the importance of these points, embodied in the Neighbourhood Network in Palliative Care (NNPC) project. Since 2001 this project, which grew from a more traditional, institutional-based palliative care experiment, has employed an army of volunteers that deliver services to patients who largely remain in their own homes. The system is community run and operated and is funded largely through local micro-donations of as little as Rs10 (21 US cents) per month—although in recent years local and regional governments have becoming increasingly involved as the project has gained prominence.

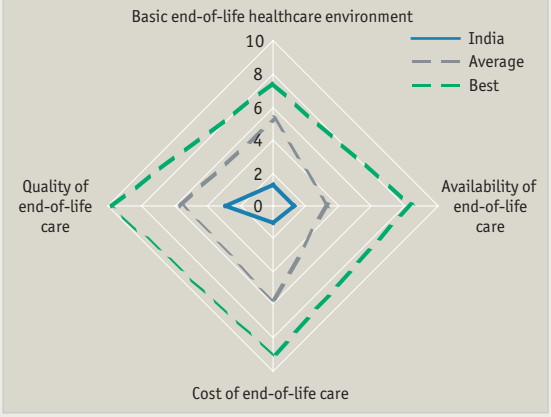
The NNPC's volunteers do not provide medical services, but identify those in their community who need care and supplement the work of healthcare professionals linked to the state's 230 local palliative care units. Importantly, after a few days' theoretical and practical training, the volunteers can provide psychological, social and spiritual support. It is this that marks the NNPC out from more medical-oriented—and expensive—systems in use elsewhere. Suresh Kumar, co-founder of the NNPC, stresses that the aim is to improve both accessibility and quality of end-of-life care, and the principles of community involvement make this feasible on a large scale. "There are a lot of medical problems, but there are also a lot of social, spiritual and financial issues—so anybody who has time to spare can, if properly trained, take care of these people," Dr Kumar says.

Consequently, palliative care advocates not only in developing countries but also across the world are studying Kerala's potent combination of government support and civic involvement in end-of-life care. Dr Kumar thinks that while it may not be possible simply to copy the system elsewhere, its basic principles—particularly community involvement—can be replicated. A number of similar models have been established, including in Ethiopia, Bangladesh and the Seychelles. An experimental model along the same lines is also being tried in Switzerland.

David Praill of Help the Hospices is one who believes Kerala provides a useful lesson for other countries, particularly as ageing populations put increasing pressure on existing services. "Student volunteers in Kerala see it as giving value and meaning to their life

Figure 8

India	Score/10	Rank/40
Overall score	**1.9**	**40**
Basic end-of-life healthcare environment	1.3	39
Availability of end-of-life care	1.3	35
Cost of end-of-life care	1.0	39
Quality of end-of-life care	2.9	37



Source: Economist Intelligence Unit.

Figure 9
Funding of NNPC, 2008-2009

Source	Rs	US$
Local donations	67m (56%)	1.38m
Local governments	30m (25%)	0.62m
Government of Kerala	20m (17%)	0.41m
International agencies	3m (2.5%)	0.06m
Total income	120m	2.47m

Source: Sallnow et al, "Home-based palliative care in Kerala, India: The Neighbourhood Network in Palliative Care", Progress in Palliative Care, Vol 18 No 1, 2010. US$ conversion by EIU at 2009 average exchange rate.

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and they're incredibly passionate about it," he says. "We've got to somehow re-ignite this passion in our own communities, because if we don't empower communities to take more ownership and see dying not just as a medical problem but as a human problem, it doesn't bode well for the future."

[16] *The evolution of palliative care programmes in North Kerala*, Indian Journal of Palliative Care, 2005.
[17] *Unbearable Pain: India's Obligation to Ensure Palliative Care*, Human Rights Watch, October 2009.

Long-stay patients shift the balance

Advocates of end-of-life care often point to evidence that palliative care can be cheaper than traditional medical treatment for patients at the end of their lives. Certainly, by increasing the proportion of community and homecare, end-of-life care can reduce costs associated with hospital stays and emergency admissions. In the US in particular, with the recent passing of a major healthcare reform bill, this is likely to become a focus of debate, as cutting healthcare costs rises up the agenda. "There are enormous opportunities," says Dr Meier of the Center to Advance Palliative Care. "The issues specifically have to do with improving quality and controlling costs, and palliative care has demonstrably done both."

In Spain, evidence has been found of the financial benefits of end-of-life care. One study found that a shift away from the use of conventional hospital treatment towards palliative care, an increase in homecare and lower use of emergency rooms in 2006 generated savings of 61% compared with expenditure recorded in a 1992 study.[18] Dr Meier says that research conducted around the world has yielded similar results. "All studies in a range of settings have shown very substantial reductions in costs when like patients receive palliative care and they're compared to a control group that does not," she says.

[18] *Resource consumption and costs of palliative care services in Spain: a multicenter prospective study*, Journal of Pain and Symptom Management, 2006.

However, while end-of-life care itself may be cheaper both in terms of treatments and lower in-patient costs per day than hospital treatment, as people live longer and are more likely to spend several years with the conditions that will eventually kill them, the cost of end-of-life care as a percentage of overall healthcare spending is likely to rise sharply. Moreover, the cost of caring for cancer patients is very different from that of caring for individuals with diseases other than cancer—patients who tend to need care for far longer. In England, while the cost of providing care in the last year of life to cancer patients is about £14,000 (US$21,200) per patient, this rises to almost £19,000 (US$28,800) for those with organ failure, according to a Rand Corporation study.[19]

[19] *The potential cost savings of greater use of home- and hospice-based end of life care in England*, Rand Corporation, 2008.

"There are clearly cost implications," says Mr Praill of Help the Hospices. "It's more difficult to provide palliative care outside of cancer because the prognosis with cancer is more of a science." For people with other diseases, he explains, the prognosis is less easy to make. "There's likely to be a longer engagement with people in a non-curative phase of life, so it's going to be more expensive."

In the case of the US, the number of people using hospice care services—whether in-patient or homecare—has soared from 300,000 in the late 1990s to 1m today, according to Pedro Gozalo, an econometrician and health economist at the Center for Gerontology and Healthcare Research at Brown University. And the bulk of the increase has come from patients with diseases other than cancer. "Let's say it's 20% [with non-cancer diagnoses]," says Mr Gozalo. "That might not sound like too much but when

you've got 20% out of a million people living three to four months longer than the cancer equivalent, then the dollars begin to climb at a significant rate."

In the US, Medicare reimburses hospice providers at a flat daily rate, based on four levels of home and in-patient care, assuming patients have a terminal illness and an estimated six months or fewer to live. The Medicare Payment Advisory Commission (MedPAC) recently reviewed this payment method, recommending amendments to the system from 2013 to give relatively lower payments the longer the treatment lasts. In a 2009 report to Congress, the agency even suggested that the present system provides incentives for hospice providers to admit long-stay patients "which may have led to inappropriate utilization of the benefit among some hospices".[20] The recently passed healthcare reform may also affect funding for long-term palliative care.

[20] *Report to the Congress: Medicare Payment Policy*, MedPac, March 10th, 2009.

While there may be national differences, as patterns of dying continue to change, a rise in demand for hospice care from non-cancer patients will increase pressure for healthcare economists and funders to find new models of payment.

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4. Policy issues in end-of-life care

Government recognition

As we have seen, pockets of forward-thinking policy that recognise the importance of palliative care have emerged in unlikely quarters, such as the Indian state of Kerala, which has a formal state-wide policy in place, and Uganda, where palliative care is a policy priority. However, policy gaps still exist, even in the developed world.

Only a minority of countries across the world recognise end-of-life care in their healthcare and medical education policies. In the Index, one indicator in the "Availability" category is "Existence of a government-led national palliative care strategy", registering whether the country has a formal strategy specific to such care. Of the 40 countries in the Index, 29 have no such strategy, with only seven—Australia, Mexico, New Zealand, Poland, Switzerland, Turkey and the United Kingdom—having a national policy in place, and four—Austria, Canada, Ireland and Italy—in the process of developing this kind of policy.

The UK put in place a national strategy when the Department of Health published the End-Of-Life Care Strategy for England in 2008. New Zealand and Australia have also put in place strong policy support for end-of-life care, with New Zealand's Ministry of Health publishing its first palliative care strategy in 2001 and Australia's National Palliative Care Strategy endorsed in 2000. "And the most important thing is that since 1988, palliative care has been a specific part of the Australian healthcare agreements," says Dr Currow of Cancer Australia.

Meanwhile, outside government, other efforts have been made to coalesce opinion on the best way to define palliative care and achieve better quality and access to end-of-life care. In the US, for example, the National Consensus Project for Quality Palliative Care has brought together various organisations to create two editions of Clinical Practice Guidelines for Quality Palliative Care (2004 and 2009). These provided the foundation for the National Quality Forum Preferred Practices guidelines for practitioners, policymakers and consumers.

In Canada, the Quality End-of-Life Care Coalition of Canada, which in 2000 developed the Blueprint for Action on end-of-life care in Canada, has recently released the next version, a report measuring progress over the past 10 years.[21]

In Europe, the European Union leaves policymaking in this area up to the national governments of member states. In 2003, the Council of Europe approved a recommendation on palliative care that was adopted by health ministers in all 45 of the member countries of the council.[22] "It's a good document that includes a lot of recommendations, requests and statements that are very valuable," says Professor Radbruch of EAPC. "It's been given to national governments and so they should consider this—but actually only a few did."

Still, some argue that policy statements and other documents do not necessarily guarantee quality and availability of end-of-life care. For example, Turkey has a national strategy in place yet ranks poorly overall in the Index across all categories. Professor Clark from the University of Glasgow also cites the example of Hungary, where palliative care was enshrined as a legal right in 1997. "Hungary has benefited

[21] *10 Years Later: A Progress Report on the Blueprint for Action*, Quality End-of-Life Care Coalition of Canada, January 2010.

[22] Recommendation REC 24 (2003) of the Committee of Ministers to member states on the organisation of Palliative Care, Council of Europe, 2003. The Council now has 47 members.

The availability and use of opioids

"Pain management opens the gate to bringing in all the rest that we know—the social, spiritual, cultural issues that are there," says Anne Merriman, founder of Hospice Africa. "With pain control, people can start to think again." But while most experts would agree with Dr Merriman, access to pain control medications varies widely across the world.

In the Index, eight countries share the top score on this measure—Australia, Canada, Denmark, Luxembourg, the Netherlands, New Zealand, Portugal and Sweden (see Figure 10). However, across much of the world, patients in pain are facing woefully poor drug availability, with about 5bn people living in countries with insufficient or no access to medications controlling severe or moderate pain, according to the World Health Organisation (WHO).[23]

Part of the reason for this lies in complex narcotics laws restricting the sale of morphine. "One of the biggest problems is that governments are so concerned about illicit drug use that many countries make it almost impossible to access opioids," says Sheila Payne of the International Observatory on End of Life Care.

The rules are particularly restrictive in India, which ranks last in the Index when it comes to availability of painkillers. Less than 1% of the population has access to opioids, according to Pallium India's MR Rajagopal. "Legally any doctor can prescribe it, but pharmacies do not stock it because the licensing system is so complex and the penalties for errors are so stringent," he says.

Dr Rajagopal points to other barriers, such as the fact that few nurses or doctors know how to administer morphine. "Even if it were made available, the physicians need to be educated on how to use it," he says. Human Rights Watch found that even large cancer hospitals in India did not have staff trained to administer morphine and other painkillers.[24]

Some countries are starting to address the problem, at least on the legislative side. In 1992, for example, China—which ranks relatively highly in the indicator on this measure—adopted a national cancer pain relief policy, easing restrictions on morphine and other opioids, increasing the manufacture, sale and distribution of new opioid analgesics and making it easier for hospitals to obtain the painkillers.[25] "Compared to before, it's much easer to get treatment for pain," says Luo Ji-Lan, secretary-general for the Chinese Association for Life Care.

In 2005, Romania—working with the WHO and the University of Wisconsin's Pain & Policies Studies Group—revised national drug policies limiting access to pain control medicines. Meanwhile, in Taiwan, where access to painkillers is generally unrestricted, the medical community is pushing the government for broader access to an additional drug, methadone, which is used for heroin replacement therapy. "A good hospice should have three strong narcotics, and we only have two," says Yingwei Wang, associate professor and a doctor at Tzuchi University's Heart Lotus Hospice. "But even with two, that's better than most countries."

Despite such progress, a 2009 Human

Figure 10: Availability of pain killers (morphine and morphine equivalents)

Highest ranking (excellent)				Lowest ranking (poor)
5	4	3	2	1
Australia	China	Austria	Czech Republic	India
Canada	Germany	Belgium	Greece	
Denmark	Hong Kong	Brazil	Mexico	
Luxembourg	Hungary	Finland	Russia	
Netherlands	Ireland	France	Slovakia	
New Zealand	Japan	Iceland	South Korea	
Portugal	Poland	Italy	Turkey	
Sweden	Spain	Malaysia	Uganda	
	Taiwan	Norway		
	UK	Singapore		
	US	South Africa		
		Switzerland		

Source: Economist Intelligence Unit ranking based on: Pain Policy Center's comparisons of consumption vs. need, interviews, European Atlas of Palliative Care.

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Rights Watch report found that few governments had put in place effective systems or policies for the supply and distribution of morphine or guidelines and training for health workers. In many places, it found excessively strict drug control regulations limited access to morphine. "There are many reasons for the enormity of the gap between pain treatment needs and what is delivered," wrote the report's authors, "but chief among them is a shocking willingness by many governments around the world to passively stand by as people suffer."[26]

[23] "Access to Controlled Medications Programme", World Health Organization Briefing Note, February 2009.
[24] *Unbearable Pain*, op. cit.
[25] *People's Republic of China: Status of Cancer Pain and Palliative Care*, Journal of Pain and Symptom Management, 1996.
[26] "Please, do not make us suffer any more", Human Rights Watch, 2009.

from legal recognition of the right to palliative care," he says, but he points to problems with coverage. This is reflected in the Index: although Hungary scores relatively well overall, it ranks 29th in the Availability category. Notably, even though Hungary has taken the unusual step of giving palliative care legal recognition, it has no national end-of-life care strategy.

Professor Clark believes that while policy statements are important, they are only valuable if backed up by the development of services. "There's a lot of interest in the symbolic language of getting palliative care into these high-level statements of policy," he says. "But it also has to get into the bloodstream of policy, and into the funding and reimbursement programmes—and most countries are struggling to move forward from high-level statements to real action and investment on the ground."

Integration of care into mainstream services

A few years ago, the Australian state of Western Australia decided to close its last purpose-built, freestanding hospice and devolve the beds to a number of district hospitals in order to better integrate its services. Elsewhere, however, evidence of the integration of end-of-life care into mainstream healthcare provision is more mixed. In its 2006 study the IOELC found that, of the 234 countries it reviewed, only 35 of them (or 15%) had achieved any notable level of integration with wider mainstream healthcare providers.[27] And while the UK is admired for its pioneer role and its extensive provision of end-of-life care, charitable hospices still provide a large proportion of the nation's hospice and palliative care through facilities that are owned and managed separately from the National Health Service (NHS).

[27] IOELC, op. cit.

NHS hospices can be separate facilities located on NHS hospital trust sites, while charitably funded non-NHS hospices remain separate entities. "The other NHS hospices have not been part of acute hospitals but are part of community services," says Mr Praill of Help the Hospices. "And some of those have been asked to adopt charitable status, such as the hospice on the Isle of Wight."

In South Africa, palliative care has long been seen as a non-governmental function, although the HIV-AIDS epidemic has prompted health ministers to re-examine models of palliative care. "The people we talk to at the level of national health and social services are very supportive of palliative care," says Dr Gwyther of the HPCA. "But being in a relatively resource-constrained setting, the government has looked at primary care in general and the primary form of palliative care as being a community-based service."

Dr Gwyther adds that efforts are now being made for greater integration, however. "What we're trying to do is ensure that palliative care is also part of the formal healthcare system in hospitals and clinics so people can access it without needing referral to a hospice.

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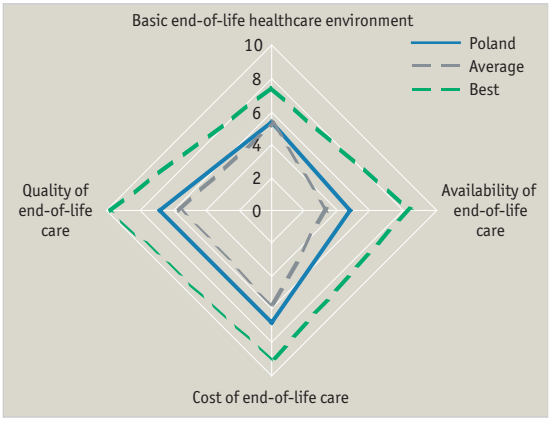
Figure 11

Poland	Score/10	Rank/40
Overall score	**6.0**	**15**
Basic end-of-life healthcare environment	5.3	25
Availability of end-of-life care	4.8	10
Cost of end-of-life care	6.8	15
Quality of end-of-life care	6.8	13



Source: Economist Intelligence Unit.

As end-of-life care develops in other parts of the world, these kinds of models are not necessarily the ones being followed. This is particularly true in Europe, according to University of Glasgow's Professor Clark. "Across most of Europe palliative care is developing, where it's developing at all, as part of the healthcare system rather than as a social movement," he says.

Some examples stand out. Professor Clark believes that Poland's position in the top 15 countries in the Index is partly due to the integration of end-of-life care services. "Since the collapse of communism, Poland has had an integrated approach to service development, policy and education," he says. "It has rolled out service across the country, accredited palliative medicine and developed robust training programmes."

In Australia, meanwhile, most has been done to integrate end-of-life care more fully into acute care services provision. "There's been a diminution of freestanding hospice beds in general," says Dr Currow of Cancer Australia. "And the co-location of services at least on the same campus is seen as important." He adds almost 90% of Australian teaching hospitals have onsite palliative care facilities, far higher than the US or UK.

Professor Kellehear of Bath University argues that the hospice movement needs to think even more broadly about integration and the kinds of alliances it needs to establish, such as those with professionals such as grief

Uganda: a beacon in Africa

With the rapid spread of HIV-AIDS throughout sub-Saharan Africa, the gap between demand and supply for palliative care on the continent remains wide. However, a model developed in Uganda has shown what is possible, given the right funding and policy support.

Hospice Africa Uganda was founded in 1993, and originally operated from a two-bedroom house loaned to the organisation by Nsambya Hospital in Kampala. It is now seen as one of Africa's best examples of end-of-life care. Largely as a result of the work of Hospice Africa Uganda, the government has included pain relief and palliative care in its homecare package.[28]

And while little funding is available from the Ugandan government (Hospice Africa Uganda is supported through charitable donations, many of them from the UK and other developed nations), policy support has enabled doctors to offer painkillers to their patients. "Palliative care has been a priority in Uganda since 2000," says Anne Merriman, founder of Hospice Africa. "It's been part of the health strategic plan, which says that palliative care is an essential clinical service for all Ugandans."

The movement's success in Uganda can also be put down to training, something on which Hospice Africa Uganda spends about half of its funding. "Our biggest way of spreading palliative care is to train people," says Dr Merriman. "We started teaching medical students as soon as we came in 1993 and now everyone who has qualified since then knows what palliative care is and that's made a huge difference," says Dr Merriman. In 2002 Hospice Africa Uganda established a distance-learning Diploma in Palliative Care in partnership with Makerere University.[29]

Progress has also been made in Uganda on access to and delivery of opioids. Coming into the country in powdered form, morphine is diluted and colour coded according to its strength. "Nurses are prescribing opioids, and that's almost unheard of anywhere – normally only doctors can prescribe opioids," says David Praill of Help the Hospices. "And these are

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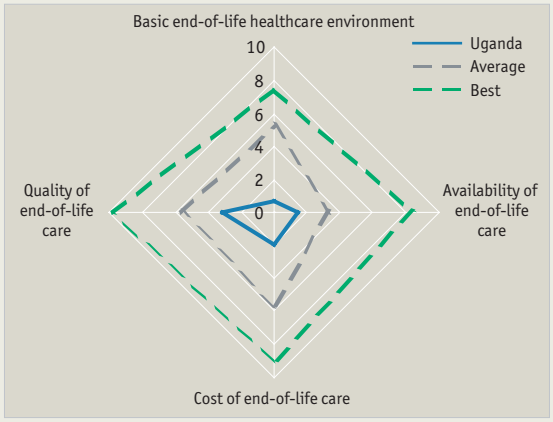
Figure 12

Uganda	Score/10	Rank/40
Overall score	**2.1**	**39**
Basic end-of-life healthcare environment	0.7	40
Availability of end-of-life care	1.5	34
Cost of end-of-life care	2.0	36
Quality of end-of-life care	3.1	36



Source: Economist Intelligence Unit.

Ugandan nurses who have been through nine months of specific training."

"Uganda is an excellent model of palliative care in Africa, with integration into national health policies, some beacon services and training programmes, and reasonable access to morphine," says the University of Glasgow's David Clark.

However, while the work of Hospice Africa Uganda and other non-governmental organisations has been remarkable, much of the population remains untouched by end-of-life care, something reflected in the Index, in which Uganda ranks poorly when it comes to categories such as Cost, Availability and Quality of End-of-Life Care. "We're reaching less than 10% of those in need, so the need is huge," says Dr Merriman. "And less than 5% of cancer patients can reach any form of care in Uganda."

[28] *Preventing chronic diseases: a vital investment*, World Health Organization, 2005
[29] IOELC, op. cit.

counsellors and community workers. "Partnerships between end-of life care services and public health services are important links to forge," he says, "so they can add value on to each other's work."

Building capacity for home-based care

Hospice and palliative care is often thought of as being delivered from within an institution, as it was in the early days of the hospice movement in Britain. However, this is not necessarily the case. In the US, for example, of the 700,000 patients who receive palliative care each year, more than 75% die at home, according to the National Hospice and Palliative Care Organization (NHPCO).

"The idea of hospice care as a building and a separate facility is a misperception," says Mr Connor of the WPCA. "Increasingly the vast majority of palliative care is home-based care."

Some hospice movements started as homecare services, as was the case in Singapore, where in 1987 pioneers from the Canossian sisters, a Roman Catholic religious order, launched a volunteer homecare initiative. (Secular in nature, this was first launched under the Singapore Cancer Society and later became the Hospice Care Association, renamed HCA Hospice Care.) Meanwhile, in many developing countries, homecare is delivered by necessity through lack of funding for any form of palliative care infrastructure.

However, Dr Gwyther of the HPCA stresses that without support services, community-based care by non-professionals can leave patients without adequate pain control or counselling. "The important thing is to build the capacity in the home-based care organisations so that if a non-professional is going into a person's home, they've still had training in palliative care," she says.

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And when it comes to full hospice services delivered at home, the savings are not necessarily that great over in-patient care. Professor Radbruch of the EAPC cites the example of Germany, where new legislation allows reimbursement for homecare. "It costs about 200 euros a day for full provision of care at home, which is the same amount as a hospice would charge," he says.

Technology may eventually be able to change this. For a start, in some of the world's poorest and most remote rural areas, mobile phones are helping connect people with end-of-life care. "Mobile phones have made a tremendous difference," says Dr Merriman of Hospice Africa. "Almost everybody can reach someone near them who has a mobile phone. And we offer a 24-hour service so when they call us, we get back to them."

In Taiwan, healthcare professionals have long been able to connect patients at home with their hospice physicians via videophone and, more recently, have been able to monitor the condition of patients via web-enabled mobile phones. "All these technologies mean the patient can stay at home," says Professor Wang of Tzuchi University.

Software from IBM, for example, allows personal medical devices used for patient monitoring to stream data from routine evaluations directly into an electronic personal health record, giving physicians more timely feedback on their patients' conditions. These systems can also be used in conjunction with interactive online applications such as Google Health and Microsoft's HealthVault.

Mr Keckley of Deloitte sees tremendous potential in such systems for end-of-life care. "Home monitoring devices, distance medicine and the ability to leverage family members as part of health coaching are all innovations that make end-of-life care more cost effective, more accessible and better," he says.

Such technologies could also help more people to stay in their homes for longer, or to die at home—something that would be seen as progress for those who advocate for the right for more people to die at home. In the US, for example, NHPCO research found that while 80% of Americans said they wished to die at home, of the 2.4m dying every year, fewer than 25% actually did so.

The importance of training

In addition to factors such as policy support and access to opioids, capacity building is an essential factor in spreading access to end-of-life care, from providing specialist education for physicians and nurses to better equipping volunteers and community workers. Training in other disciplines, such as counseling, is also important when considering the broader issues that end-of-life care must address.

"Our biggest way of spreading palliative care is to train people," says Anne Merriman of Hospice Africa. "And 50% of our work and of our finance goes into training people."

While Dr Merriman's efforts are supported through philanthropic funding and international aid, some countries underpin their policy support with robust training programmes. In Australia, for example, a specialty-training programme has been available since the 1980s. And while Canada has no specialty-training schemes, the country has developed core competencies and curricula in all 17 medical schools. Health programmes in schools of social work and nursing are currently working on including content on palliative care, according to Sharon Baxter of the Canadian Hospice Palliative Care Association.

Unsurprisingly, countries that rank poorly in the Quality of End-of-Life Care category of the Index also do badly when it comes to training, with China and India among the poor performers. In China, there is no government funding for training, according to Luo Ji-Lan of the Chinese Association for Life Care. Meanwhile, in India, Human Rights Watch has highlighted the fact that, because neither palliative care nor pain treatment are government priorities, healthcare workers do not receive the necessary training to provide these services.

However, even in developed countries, training in end-of-life care remains insufficiently well established. "There's still a problem, starting at the ground level, in that the vast majority of healthcare professionals in most countries don't have palliative care skills," says Stephen Connor of the WPCA.

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5. Conclusions

While few would argue against the need for more funding for end-of-life care, money is not the only barrier to the accessibility and quality of that care. Many factors hamper progress in this field—from cultural taboos and lack of understanding of end-of-life care, to the geographic dispersal of populations in some countries and the futile use of life-preserving medical technologies in places such as the US.

Of course, sufficient funding is important, particularly in developing countries where scarce financial resources and the magnitude of competing problems means there is often little money left with which to pay for hospice and palliative care services. High-level political commitment also plays a vital role, as long as it is matched with coordinated policy. Legislation improving access to opioids—as well as instruction for physicians and community workers in their administration—will be crucial if millions around the world are not to be left to die in agony. A strategy without access to basic drugs will not help those needing care. Technology, too, may help doctors manage their patients' conditions remotely, allowing more people to stay at home for longer.

However, the human factor should not be underestimated, for end-of-life care is about far more than medical treatments and painkillers. Certainly, a lack of trained doctors and nurses is one impediment to improving quality of death. But end-of-life care must be a multi-disciplinary effort. Complex psychological problems arise when death is in view, particularly when it comes to the death of children. And counselling is necessary not only for the dying, but also for their families, requiring sensitive personal care that extends beyond death, through the grieving process. The cost of such services is hard to measure in numbers or in dollars.

This presents problems when it comes to funding models, particularly in the US where the current healthcare system rewards medical providers for procedures rather than outcomes and hospices are paid on a daily basis, usually regardless of length of care. As more and more people spend longer living with chronic illness, the challenge will be to come up with payment models that reflect this. And as governments rely more heavily on family members, they will also have to address the opportunity cost for those individuals in giving up work to look after a relative.

Many therefore see an important role for community-based care along the lines of that provided in the Indian state of Kerala, where teams of committed volunteers deliver services to patients in the home. Yet while homecare is seen as desirable and more affordable, in order to match the quality of care delivered in an in-patient setting, significant amounts of training are required before patients suffering from chronic illnesses can receive quality care at home.

Governments and providers are in a race against time—however quickly they can beef up their end-of-life care infrastructure, they may still not be able to meet the even faster pace at which their citizens are reaching an age or condition where they need those services. So while calls echo around the world for end-of-life care to become enshrined in national and international policy as a human right, the reality is that—even if it achieves that status—for much of the world's population, such a commitment will exist on paper only.

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Appendix: Index methodology

The Quality of Death Index measures the current environment for end-of-life care services across 40 countries. The Index scores countries across four categories—Basic End-of-Life Healthcare Environment, Availability of End-of-Life Care, Cost of End-of-Life Care and Quality of End-of-Life Care—comprising 24 individual indicators. The indicators fall into three broad categories:

Quantitative indicators: Eleven of the Index's 24 indicators are based on quantitative data—for example, life expectancy and healthcare spending as % of GDP.

Qualitative indicators: Ten of the indicators are qualitative assessments of countries' end-of-life care standards, for example "Public awareness of end-of-life care", which is assessed on a scale of 1-5 where 1=little or no awareness and 5=high awareness.

Status indicators: Three of the indicators describe whether something is or is not the case, for example, "Existence of a government-led national palliative care strategy", for which the available answers are Yes, No or In Progress.

Data sources

A team of in-house researchers from the Economist Intelligence Unit collected data for the Index in February 2010. Wherever possible, publicly available data from official sources have been used. Primary sources included the World Health Organisation, international healthcare industry groups and national statistical offices. A complete list of sources is included in the table of indicators at the end of this appendix.

Indicator normalisation

In order to be able to compare data points across countries, as well as to construct aggregate scores for each country, the project team had to first make the gathered data comparable.

To do so, the *quantitative indicators* were "normalised" on a scale of 0 to 10 using a min-max calculation, where the score is the standard deviation from the mean, with the best country scoring 10 points and the worst scoring 0.

Qualitative indicators were normalised by rebasing the range so that scores lie between 0 and 10. For example "Political instability risk" is a rating in the range 0-100. This rating is normalised by dividing by 10.

Status indicators were normalised as a two (or three) point rating. For example "Existence of a government-led national palliative care strategy" is normalised so that "Yes" scores 10, "In Progress" scores 5 and "No" scores 0.

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Index construction

The Index is an aggregate score of all of the underlying indicators. The Index is first aggregated by category—creating a score for each category (for example, Basic End-of Life Healthcare Environment)—and finally, overall, based on the composite of the underlying category scores.

To create the category scores, each underlying indicator was aggregated according to an assigned weighting. The category scores were then rebased onto a scale of 0 to 10.

Example calculation of "Basic end-of-life healthcare environment" category score for Australia

Indicator	Normalised indicator score		Weight		Weighted score
Political instability risk	8.50	x	5.00%	=	0.43
GDP per head ($ at PPP)	6.70	x	7.50%	=	0.50
Old age dependency ratio	5.09	x	7.50%	=	0.38
Life expectancy at birth	9.85	x	7.50%	=	0.74
Healthcare spending (% of GDP)	4.50	x	15.00%	=	0.68
Number of hospital beds per 1,000 non-accidental deaths	3.08	x	7.50%	=	0.23
Number of doctors per 1,000 non-accidental deaths	6.74	x	10.00%	=	0.67
Number of nurses per 1,000 non-accidental deaths	6.15	x	10.00%	=	0.62
Social security expenditure on health	0.00	x	15.00%	=	0.00
National pension scheme coverage	9.22	x	15.00%	=	1.38
Basic End-of-Life Healthcare Environment (sum of weighted scores)					**5.63**

The overall Index score is calculated in the same way as the category scores—that is, as the weighted sum of the category scores, rebased onto a scale of 0-10. An example is shown below:

Example calculation of overall score for Australia

Category	Normalised category score		Weight		Weighted score
BASIC END-OF-LIFE HEALTHCARE ENVIRONMENT	5.63	x	20.00%	=	1.13
AVAILABILITY OF END OF LIFE CARE	6.91	x	25.00%	=	1.73
COST OF END OF LIFE CARE	9.00	x	15.00%	=	1.35
QUALITY OF END-OF-LIFE CARE	9.13	x	40.00%	=	3.65
Overall score (sum of weighted category scores)					**7.86**

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List of categories, indicators and their weightings in the Index

Indicator	Unit	Source	Weight
BASIC END-OF-LIFE HEALTHCARE ENVIRONMENT	**Rating 0-10, 10=best**	**Weighted sum of indicator scores in this section**	**20.00%**
Political instability risk	Rating 1-100, 100=highest risk	EIU RiskBriefing	5.00%
GDP per head ($ at PPP)	USD at PPP	EIU CountryData	7.50%
Old age dependency ratio	%	EIU CountryData	7.50%
Life expectancy at birth	Years	US Census Bureau International Data Base	7.50%
Healthcare spending (% of GDP)	% of GDP	WHO Statistical Information System	15.00%
Number of hospital beds per 1,000 non-accidental deaths	Hospital beds per 1,000 non-accidental deaths	WHO / EIU calculation	7.50%
Number of doctors per 1,000 non-accidental deaths	Doctors per 1,000 non-accidental deaths	WHO / EIU calculation	10.00%
Number of nurses per 1,000 non-accidental deaths	Nurses per 1,000 non-accidental deaths	WHO / EIU calculation	10.00%
Social security expenditure on health	% of general government expenditure	WHO	15.00%
National pension scheme coverage	%	OECD participation data for the eligible workforce; various national sources	15.00%
AVAILABILITY OF END OF LIFE CARE	**Rating 0-10, 10=best**	**Weighted sum of indicator scores in this section**	**25.00%**
Availability of hospices and palliative care services per million population aged 65 and over	EOL facilities per million 65+	EIU calculation	35.29%
Availability of volunteer workers for end-of-life care support	Rating 1-5	Ratings based on volunteer counts from country-specific palliative care workforce reports	23.53%
% of death touched by end-of-life care	Rating 1-10	Expert interviews / EIU estimates	17.65%
Existence of a government-led national palliative care strategy	(Yes / In progress / No)	Ministries of Health published documents	23.53%
COST OF END OF LIFE CARE	**Rating 0-10, 10=best**	**Weighted sum of indicator scores in this section**	**15.00%**
Availability of public funding for end-of-life care	Rating 1-5	European Association of Palliative Care, interviews	40.00%
Financial burden to patients for available end-of-life care services	Rating 1-5	EIU calculation	50.00%
Average payment by patient for end-of-life care service per week	USD / week	Interviews, published literature	10.00%
QUALITY OF END-OF-LIFE CARE	**Rating 0-10, 10=best**	**Weighted sum of indicator scores in this section**	**40.00%**
Public awareness of end-of-life care	Rating 1-5	Ministries of Health, country palliative care advocacy organisations	25.00%
Training for end-of-life care in medical schools	Rating 1-5	European Association of Palliative Care	10.00%
Availability of pain killers	Rating 1-5	Pain Policy Center's comparisons of consumption vs. need, interviews, European Atlas of Palliative Care	10.00%
Accreditation for end-of-life care providers	(Yes / No)	"Palliative Care in the European Union", May 2008	15.00%
Doctor-patient transparency	Rating 1-5	Interviews, published literature	20.00%
Government attitude towards end-of-life care	Rating 1-5	Ministries of Health published documents	10.00%
Do not resuscitate (DNR) policy	(Yes / No)	Alzheimer Europe Assessment, Aug 2009	10.00%

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