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Affordability of care

“One of the recommendations of *Dying in America* is to break down barriers between medical and social funding. Because often a lot of what people need towards the end of life can't be met through traditional funding models.

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*James Tulsky, chair,
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Oncology and Palliative Care,
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Government funding is essential in order to increase access to care. In some cases, governments have established subsidies for palliative care services or offer state-run services. In some countries, national pension schemes cover the costs of palliative care services (this is the case for 32 of the countries in the Index). The non-profit sector often plays a role, too. In countries such as the UK, palliative care and hospice services are strongly supported by the charitable sector.

In other cases, though, little funding is made available to patients in need of this form of care, particularly in poor countries, where neither government funding nor private insurance is available. Moreover, even if state-run programmes or subsidies are available, they may be difficult to access and poorly monitored.

In this category, countries are assessed on three indicators: availability of public funding for palliative care, the financial burden palliative care places on patients, and the availability of coverage through national pension schemes. Of these, public funding availability and the financial burden to patients receive the highest weightings, of 50% and 40% respectively.

In this category, Australia, Belgium, Denmark, Ireland and the UK top the list (and the high-income country group), while Cuba and Panama share second place with a number of richer countries in Europe (Finland, Germany, Italy, the Netherlands and Sweden) and Asia (Singapore, South Korea and Taiwan,

Figure 4.1). At the bottom of the list are the Philippines, Zambia, Zimbabwe, Ukraine and Nigeria. As well as making it into the top 10 in this category, Cuba and Panama also top the list of the Americas region, above the US, which shares third place with Chile.

The relatively high rank of the US might seem odd, since US healthcare is largely operated by the private sector and Americans pay a high price for it, both in insurance premiums and out-of-pocket costs. Yet for Americans things change dramatically after the age of 65, when they become eligible for the federally funded Medicare programme, which provides health insurance to those that have worked and paid into the system.

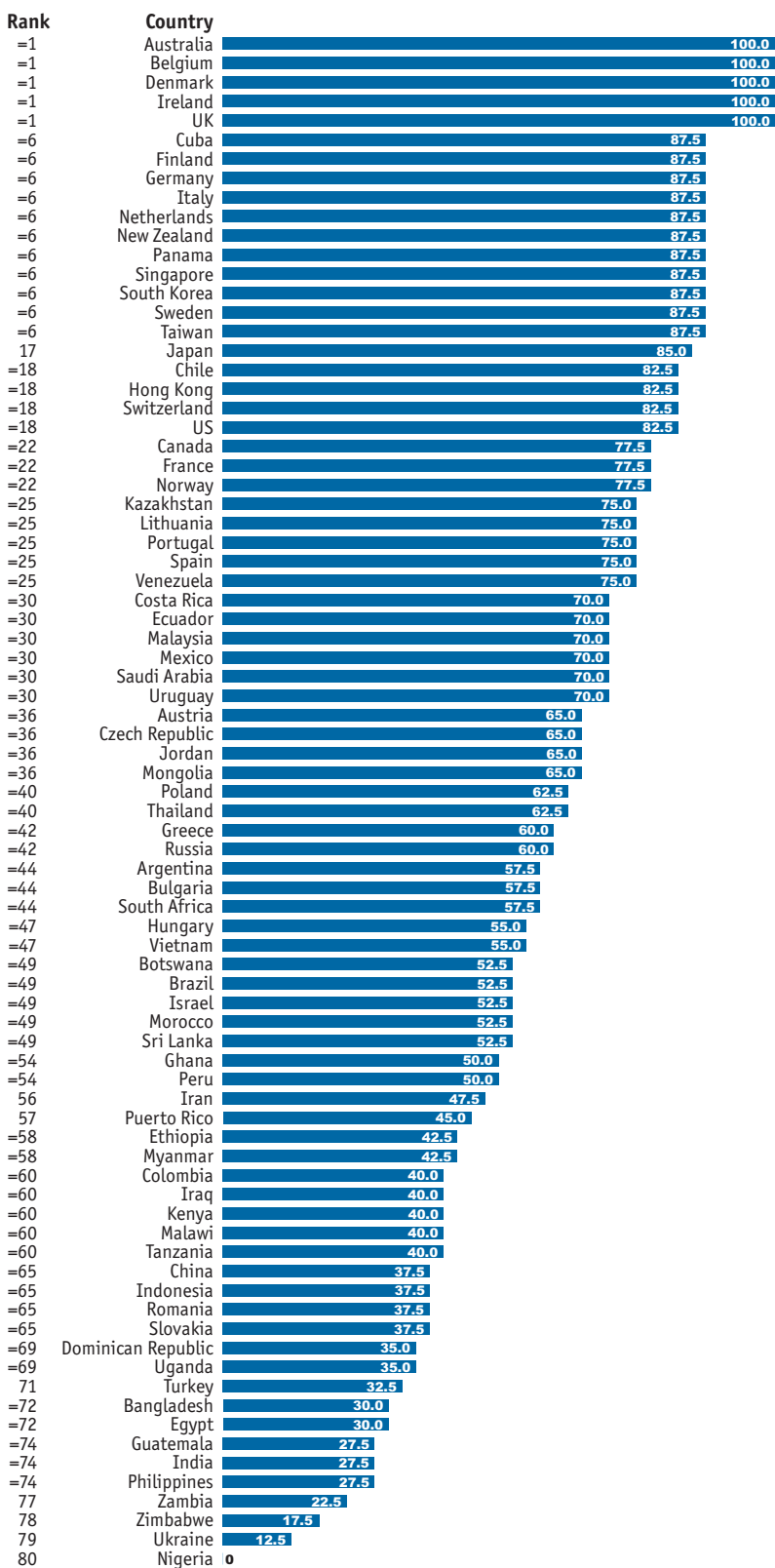
Even so, this reimbursement system has created incentives for greater use of services such as hospital stays, intensive and emergency care, resulting in late hospice enrolment—particularly as patients have to relinquish curative treatments to be eligible for reimbursements for palliative care.³⁶

Moreover, given the complex nature of the conditions of patients in need of palliative care, the US system has its flaws, says James Tulsky, chair of the Department of Psychosocial Oncology and Palliative Care at the Dana-Farber Cancer Institute in Boston.

“The financing systems in the US have created significant problems,” says Dr Tulsky, who contributed to the Institute of Medicine’s

Figure 4.1

Affordability of care category (20% weighting)



2014 *Dying in America* report.³⁷ “So one of the recommendations of the report is to break down barriers between medical and social funding,” he says. “Because often a lot of what people need towards the end of life can’t be met through traditional funding models.”

And while Australia shares first place in this category, changes in funding models as part of broader healthcare reforms in the country are creating some uncertainty for those in need of care. This is the case with community and home care, which has traditionally been funded through the Home and Community Care programme. This programme is being wound up and will be incorporated into a Home Support programme, explains PCA’s Ms Callaghan. “A huge amount of reform is happening in the way community care services are provided,” she says. “But we are unclear as to what happens to palliative care as a result of those changes.”

In many countries, affordability of care comes thanks to charitable funding. This is the case in rich countries, such as the UK, which receives the top score in the indicator measuring the financial burden to patients, indicating that 80% to 100% of end-of-life care services are paid for by sources other than the patient. However, much of this comes from charitable funding, which in the UK supports a large proportion of hospice and palliative care services.

This is also true in some developing countries. Romania, for example, scores only 2 out of 5 when it comes to availability of public funding for palliative care services (Figure 4.2). This is because although funds are available in theory, patients must meet a number of stringent requirements to qualify and must go through a torturous bureaucratic process (that even hospitals and doctors may not be familiar with), which discourages usage. However, it scores 3 in the indicator marking the financial burden to patients, which means that 40% to 60% of end-of-life care services are paid for by sources other than the patient.

This is largely because of generous charitable funding. For example, it was a UK philanthropist, Graham Perolls, who set up Romania’s leading hospice programme, Casa Sperantei, to offer free palliative care services. Casa Sperantei has received funding from charitable organisations (including the UK’s Hospices of Hope) and corporate donors, and has been the recipient of grants from USAID, the EU and the Soros Open Society Institute New York.³⁸

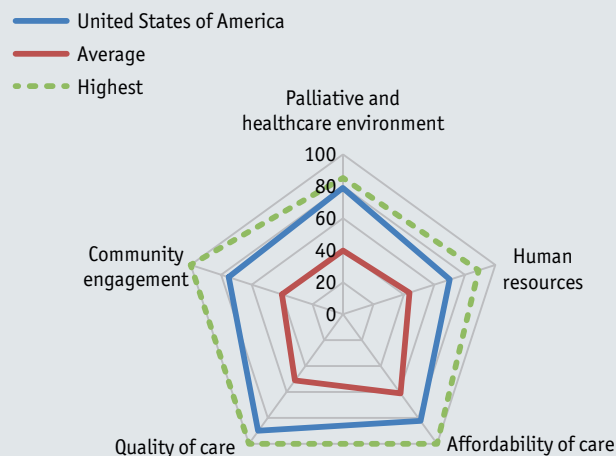
However, while such institutions have been justifiably praised for their role in initiating palliative care in many countries, Dr Payne argues that to cope with future demand, countries need to embrace the public health model of palliative care and extend palliative care into a broad range of healthcare services. “We have to move from one or two fantastic charitably funded centres,” she says. “Really we should be moving towards palliative care for all, in any beds that people are in.”

Figure 4.2: Availability of public funding for palliative care

5		4		3		2		1	
There are extensive government subsidies or programmes for individuals accessing palliative care services. The qualification criteria are clear and the process to access such funding is largely easy and smooth. Information on how to access such funding is widely available. The effectiveness of programmes is routinely and adequately monitored.		There are adequate government subsidies for individuals accessing palliative care services. The qualification criteria are clear and the process to access such programmes is largely easy and smooth. The effectiveness of programmes is unevenly monitored.		There are adequate government subsidies or programmes for individuals accessing palliative care services. The qualification criteria are clear, but funds and programmes are difficult to access. The effectiveness of programmes is not monitored.		There is a limited number of government subsidies or programmes for individuals accessing palliative care services. Where available, the qualification criteria are unclear, and funds and programmes are difficult to access.		There are no government subsidies for individuals accessing palliative care services.	
Australia	Ireland	Canada	New Zealand	Austria	Malaysia	Argentina	Myanmar	Bangladesh	Malawi
Belgium	Japan	Chile	Norway	Colombia	Mexico	Botswana	Philippines	Dominican Republic	Nigeria
Denmark	UK	Cuba	Panama	Costa Rica	Mongolia	Brazil	Poland	Republic	Puerto Rico
		Finland	Singapore	Czech Republic	Peru	Bulgaria	Romania	Egypt	Tanzania
		France	South Korea	Portugal	Portugal	China	Slovakia	Iraq	
		Germany	Sweden	Ecuador	Russia	Ethiopia	South Africa		
		Hong Kong	Switzerland	Ghana	Saudi Arabia	Guatemala	Sri Lanka		
		Italy	Taiwan	Greece	Spain	India	Thailand		
		Netherlands	US	Hungary	Uganda	Indonesia	Turkey		
				Jordan	Uruguay	Iran	Ukraine		
				Kazakhstan	Venezuela	Israel	Zambia		
				Kenya	Vietnam	Morocco	Zimbabwe		
				Lithuania					

Case study: US—Filling in the gaps

	Rank/80	Score/100
Quality of Death overall score (supply)	9	80.8
Palliative and healthcare environment	6	78.9
Human resources	14	70.2
Affordability of care	=18	82.5
Quality of care	=8	90.0
Community engagement	=9	75.0



While the Affordable Care Act—the healthcare reform legislation signed into law in 2010³⁹—has swept changes through its healthcare system, when it comes to the delivery of palliative care in the US, at position 9 in the overall Index and sixth in the palliative and healthcare environment category, health reform is not the only driver of change.

Much of the growth in palliative care services has come as a result of the coverage gaps left by US reimbursements systems, says Diane Meier, director of the Center to Advance Palliative Care at Mount Sinai Hospital's Icahn School of Medicine.

The patients responsible for the highest healthcare spending, she explains, have been those with conditions such as frailty, co-morbidity, functional impairment, heart failure, diabetes, stroke and chronic obstructive pulmonary disease; conditions responsible for the bulk of deaths in the US.

The trouble is, patients are only eligible for reimbursements for home care if, having been discharged from hospital, they have a “skills need”—that is, they require a nurse or physical therapist to help them learn to take insulin or to dress a wound.

And to qualify for hospice home care requires two doctors to say the patient is likely to die in the next six months. “And in most cases, we have no idea until the very end,” says Dr Meier.

In return for hospice care, the patient must give up insurance coverage for disease treatment. “But if you have heart failure and I give you a diuretic to take fluid off your lungs, that prolongs your life but also improves your quality of life,” says Dr Meier. “So this idea that there’s a bright line between disease treatment and palliative treatment is an illusion.”

Moreover, the traditional fee-for-service model of reimbursement in Medicare, the federal programme providing health insurance coverage to individuals over 65, has created incentives for greater use of services such as hospital stays, and intensive and emergency care. This often results in late hospice enrolment, diminishing the quality of care for those nearing the end of their lives and pushing up costs.⁴⁰

“The vast majority of people who might benefit from palliative care might not get it because they are not eligible for hospice,” says Dr Meier.

The gaps in coverage that have resulted from reimbursement restrictions and financial disincentives to provide palliative care have been filled by private philanthropic funding. From the late 1980s, this has resulted in the creation of sub-specialisations in medicine, nursing and social work, with most teaching hospitals now reporting the presence of palliative care teams and an increasing body of research, Dr Meier says.

The Affordable Care Act has also made a contribution to the development of palliative care, by shifting healthcare delivery models from volume to value.

While it has been slow to implement, the emphasis is on moving away from fee-for-service reimbursement towards a focus on population health, team-based approaches to care and shared assumption of financial risk. “And that creates a strong business case for palliative care,” says Dr Meier.

What this means is that private sector insurers—rather than the government—are driving service provision because they have recognised it is in their financial interests to prevent unnecessary hospital stays and emergency room visits.

Dr Meier sees good and bad news in this. First, the private sector is nimbler and more innovative than government. And it is easier for companies to offer palliative care services than for

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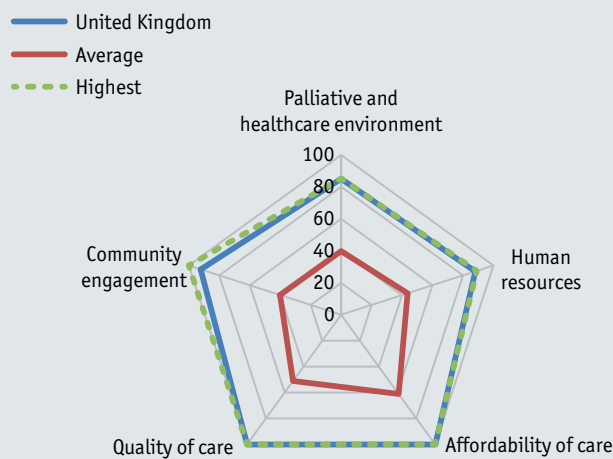
the public sector, which was famously accused of planning to run “death panels”.⁴¹

Conversely, in the long term, Dr Meier worries about the profit motive. “The obvious disadvantage is that private sector is

beholden to shareholders to provide quarterly returns,” she says. “So the worry is that important needed care that is expensive might not be offered.”

Case study: UK—Dying out of hospital

	Rank/80	Score/100
Quality of Death overall score (supply)	1	93.9
Palliative and healthcare environment	1	85.2
Human resources	2	88.2
Affordability of care	=1	100.0
Quality of care	1	100.0
Community engagement	=3	92.5



Across the world, large numbers of people die in hospital each year, yet many would rather spend their final days at home or in a hospice. In the UK, this is something the palliative care community is working to change—not only to increase the quality of care people receive but also to help the country’s National Health Service cut costs.

Recent research by Age UK, a charity, found that the average number of patients kept in hospital unnecessarily while waiting for community or social care rose by 19% between 2013/14 and 2014/15. An NHS bed costs on average £1,925 (US\$2,980) per week, Age UK estimates, compared to about £558 for a week in residential care or £357 for home care.⁴²

“It’s a very simple case,” says David Prail, until recently chief executive of Hospice UK (formerly Help the Hospices). “Evidence suggests that the vast majority of people dying in hospital don’t want to be there.” Mr Prail calls this the “silent

waiting list” of people who would rather die at home or in a community care facility.

Hospice UK believes the number of people dying in hospital could be cut by 20%. It is embarking on research to identify models in place around the country that are working towards this goal, and to assess which is having the biggest impact. “A lot of different models are being explored and that’s got to be part of the effort to get people to stay at home or get back there,” Mr Prail says. “And the feedback we’re getting informally is that you can make a difference, even if you just have that person for the last 24 hours before death.”

In some parts of the UK, patients are returned to their homes with intensive packages of care. Technology enabling remote monitoring can support this. Another option is for people to be cared for in community or nursing homes or hospices.

Marie Curie Cancer Care provides home palliative care nursing and other support. Its Delivering Choice Programme, launched in 2004, helps ensure patients are cared for in their place of choice. One study found that people who used the programme were at least 30% less likely to die in hospital, or have an emergency hospital admission or emergency department visit in the last days of life, than those who did not use it.⁴³

Hospice UK argues that as well as increasing quality of care, keeping dying people out of hospital will save NHS funds and increase the availability of hospital beds for those in need of acute care.

“Everyone agrees it’s a scandal that so many people are dying in hospitals who don’t want to be there. But it’s also blocking the public waiting list,” says Mr Prail. “So if we can get people out of hospital that don’t need to be there, even if it’s only for the last few days of life, it frees up beds.”

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David Prail, former chief executive, Hospice UK

5

Quality of care

While countries need to work to increase access to palliative care and ensure they are affordable, they must also consider the quality of the services available. A crucial part of this is ensuring that painkillers such as opioids are readily available and easy to administer. Other components of high quality palliative care include the availability of psychological support and the ability and willingness of doctors to involve patients in their own care and accommodate individual care choices. For families, bereavement services are also important as individuals struggle to cope with loss.

In this category, six indicators are used to determine the relative quality of care available in different countries: the presence of monitoring standards for organisations (which are in place in 49 of the countries in the Index), the availability of opioid painkillers and psychosocial support for patients and families, the presence of “do not resuscitate” (DNR) policies, support for shared decision-making and the use of patient satisfaction surveys.

The UK, Sweden and Australia top this list (as they do in the high-income country group) while, within Europe, the UK, Sweden and France get the highest scores. As with the human resources indicator, Australia scores highest among Asia-Pacific countries, followed by New Zealand in second position as Singapore and Taiwan share third.

Egypt is in fourth position in the Middle East and African country grouping. This is the first time Egypt, which overall does poorly in the Index (ranked equal 56th with Greece), makes it into a top five position regionally. It scores 2 out of 3 when it comes to psychosocial support, indicating that this is generally available for families and patients, and 4 out of 5 on shared decision-making, indicating that doctors generally inform patients of their diagnosis and prognosis—in fact this is enshrined in law.

Of the indicators in this category, the availability of opioids—a fundamental palliative care tool—is weighted most heavily, accounting for 30% (and hence 9% of the overall Index, since the quality of care category has a 30% weighting overall). While drugs such as morphine are inexpensive, restrictions designed to prevent drug abuse have hampered access to them. Moreover, since policymakers have focused on controlling substance abuse rather than increasing access to these painkillers, insufficient numbers of nurses and doctors are trained to administer pain control drugs in many places, particularly in developing countries.

Encouragingly, more than 30 countries in the Index score 5 out of 5 when it comes to the availability of opioid painkillers (Figure 5.2), indicating that they are freely available and accessible. However, worryingly, the use of such analgesics is hampered in the rest of the countries in the Index either because of red tape, prejudices or legal restrictions.

Even if legal restrictions are relaxed, barriers remain, says the WHPCA's Dr Connor. "We've had various initiatives to improve access to opioids but it turns out to be quite difficult to make the drugs available in individual countries," he says. Hurdles include the fact that ministries of health have to approve use of the drugs, importers and import licences have to be in place, and physicians have to be trained in their use.

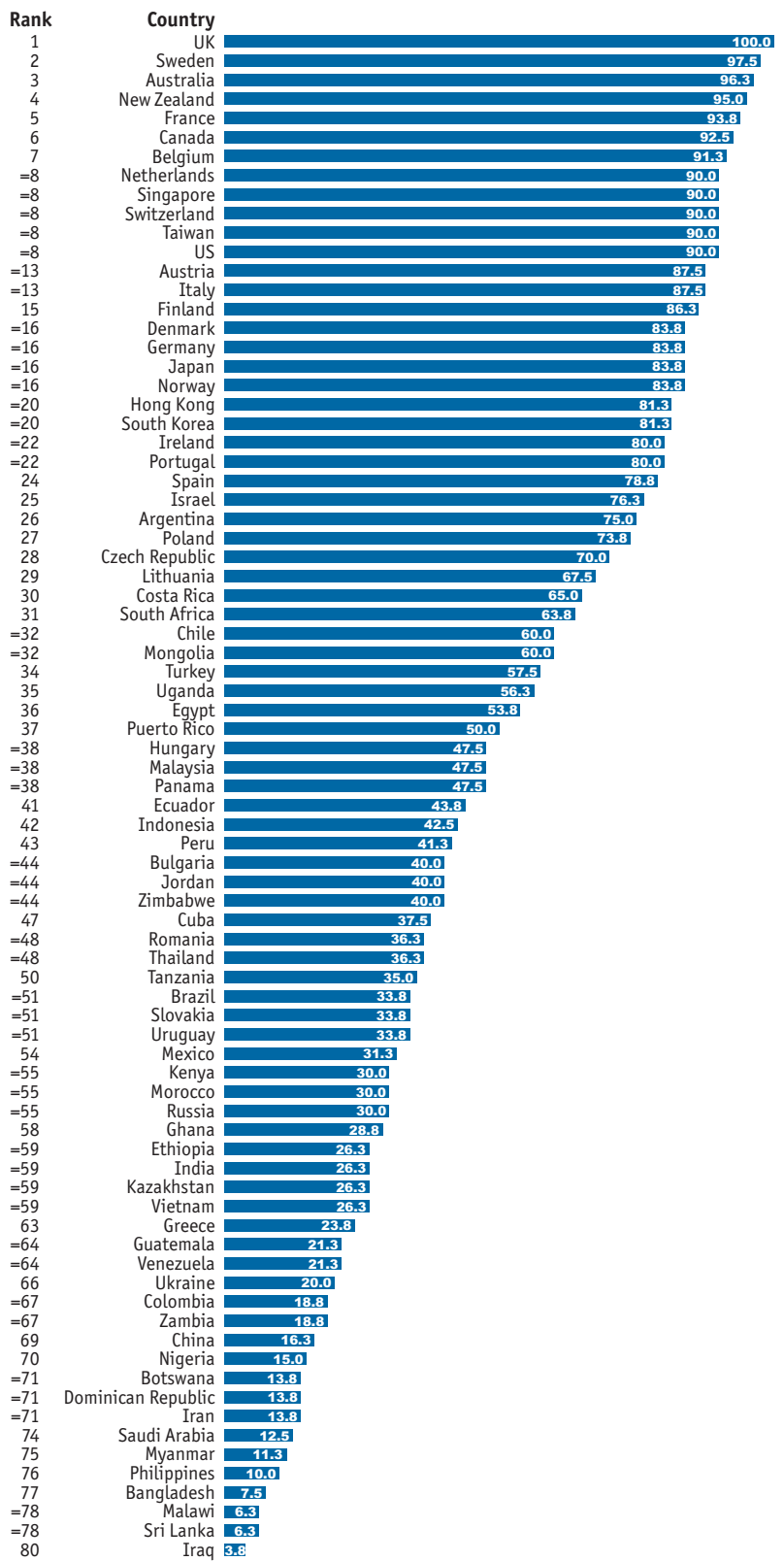
Even in countries that do well in the Index gaps are emerging. In a recent *Journal of Palliative Medicine* survey conducted in the US, which is in the top 10 in the overall Index, respondents in 2011-2013 were more likely to state that their loved ones received insufficient pain relief than respondents in 2000.⁴⁴

Nevertheless, in many places, advances are being made. First, the WHA resolution sent an important signal, acknowledging that "it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured".⁴⁵

In India, the passing in 2014 of the Narcotic Drugs and Psychotropic Substances (Amendment) Act by parliament brings legal clarity for physicians wanting to prescribe opioids to their patients.⁴⁶ While work remains to be done to train doctors and nurses, the passing of the bill represents a major step forward for India, which was criticised in a 2009 Human Rights Watch report for failing to facilitate provision of opioid painkillers to its citizens (an issue also highlighted in the report accompanying the 2010 EIU Quality of Death Index).⁴⁷ "Until recently, it was very complicated to procure and dispense morphine," says Dr Bhatnagar. "Now, it will be much easier."

Figure 5.1

Quality of care category (30% weighting)



“We’re still graduating wonderful, well-meaning clinicians, who have not been trained to have difficult conversations and to guide patients through decision making in situations in which cure is unlikely.”

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Ira Byock, executive director and chief medical officer, Institute for Human Caring at Providence Health & Services

Uganda—which is in the top 40 of the overall Index—is another success story when it comes to painkiller access. “In 1994, Uganda introduced a statute that allows properly trained nurses, medical assistants and clinical officers to prescribe oral morphine—that was very early on,” says the APCA’s Dr Luyirika. The Ugandan government, which has ring-fenced funding for the purchase of morphine, supports the free availability of oral morphine for anyone who needs it. Hospice Africa Uganda has become a centre of production and distribution of morphine for the entire country by taking imported powdered morphine and turning it into liquid, or oral, morphine.⁴⁹

In addition to making the legislative changes needed for this to happen, Uganda has worked at other levels to promote use of opioids. “It’s a much bigger programme than just policy change,” says Dr Harding. “You need to work with local police, to educate clinicians to prescribe

opioids and to help patients to take away their fear of them. Uganda focused on that chain of events and rolled it out district by district.”

As well as enabling patients to deal with physical pain, an important role for palliative care is to help people make appropriate decisions when faced with terminal illness. This is given a 15% weighting in the quality of care category.

All too often, however, not enough emphasis is given to the views of the patients themselves or those of their families. And even in countries that score well on this indicator, such as the US, which scores 5—indicating that doctors and patients are partners in care—some argue that more needs to be done to support patient choices.

This also means training doctors and nurses to have difficult conversations. Dr Byock believes

Figure 5.2: Availability of opioid painkillers

5		4		3		2		1
Freely available and accessible		Available, but access is somewhat restricted by bureaucratic red tape		Not easily available and/or access is restricted through laws and bureaucratic red tape or prejudices		Only available in limited circumstances		Illegal
Argentina	Malaysia	Chile	Turkey	Brazil	Indonesia	Bangladesh	Nigeria	
Australia	Netherlands	Jordan	Uruguay	Bulgaria	Iran	Botswana	Philippines	
Austria	New Zealand	South Africa		China	Mexico	Egypt	Russia	
Belgium	Norway			Colombia	Mongolia	India	Saudi Arabia	
Canada	Poland			Cuba	Morocco	Iraq	Sri Lanka	
Costa Rica	Portugal			Dominican Republic	Panama	Kazakhstan	Tanzania	
Czech Republic	Puerto Rico			Ecuador	Peru	Kenya	Zambia	
Denmark	Singapore			Ethiopia	Romania	Malawi	Zimbabwe	
Finland	Slovakia			Ghana	Thailand	Myanmar		
France	South Korea			Greece	Ukraine			
Germany	Spain			Guatemala	Venezuela			
Hong Kong	Sweden			Hungary	Vietnam			
Ireland	Switzerland							
Israel	Taiwan							
Italy	UK							
Japan	US							
Lithuania								

more needs to be done in this respect. “We’re still graduating wonderful, well-meaning clinicians,” he says, “who have not been trained to have difficult conversations and to guide patients through decision making in situations in which cure is unlikely.”

Research suggests this is having a negative impact on end-of-life care. In the *Journal of Palliative Medicine* report, about one in seven respondents stated that their family member had received medical treatment that they would not have wanted.

The World Health Assembly resolution

After many years of advocacy, 2014 marked a major step forward for palliative care when, at the 67th World Health Assembly (WHA) in May, the body adopted a resolution titled: “Strengthening of palliative care as a component of comprehensive care throughout the life course.”⁴⁸

“The WHA resolution sets the policy context, legitimises governments getting engaged and provides the stimulus for engagement,” says Sheila Payne, emeritus professor at the International Observatory on End of Life Care at Lancaster University.

The resolution calls for member states to integrate palliative care into national healthcare systems, to improve training for nurses and doctors and to increase access to opioid analgesics, among other initiatives. It was agreed on largely as a result of the energetic campaigning of Panama, along with several other countries. “We have to give credit to Panama and others, who put this on their agenda in Geneva,” says Andreas Ullrich, a senior medical officer for cancer control in the WHO’s Department of Chronic Diseases and Health Promotion.

Dr Ullrich says the resolution has significant implications for the future of palliative care. First, it raises global awareness of the need for palliative services. In addition, it requests

member states to take action and then report back on progress in implementing their palliative care programmes.

“The importance of a resolution is that it’s not a law or treaty but it’s at least something everybody has agreed on,” he says. “And ministers of health need to follow up—they have some kind of moral obligation to report back to the WHA.”

However, the resolution is just the start of the WHO’s work. Task forces have been established to monitor levels of access to essential medicines and to support the development of health system blueprints and tools for palliative care service delivery.

“But the biggest challenge is that there are countries where there’s nothing,” says Dr Ullrich. He identifies three categories: countries where no services exist and there is no use of opioids; those where services need to be expanded; and those where services exist but are not well organised.

He also stresses the need to work with health professionals whose training and practice has traditionally focused on healing the sick rather than caring for the dying. “Medical doctors are still trained to cure,” says Dr Ullrich. “So this is a culture change.”

Children's palliative care

The 2015 Quality of Death Index ranks countries by their provision of palliative care to adults, principally for reasons of data availability. The lack of comparable data on the provision of such care to children reflects that their needs are too often ignored in this area.

"This group has been marginalised over the years and there's no reason for them to be left out," says Joan Marston, chief executive of the South Africa-based International Children's Palliative Care Network. "But people are starting to realise that you can't exclude children—it's a human rights issue."

A number of obstacles hamper the development of children's palliative care. Their needs are diverse because of the widely different age groups, from babies to young people, and the complexity of their conditions demands more sophisticated services. Also, most of the deaths take place in low-income countries and the developing world, with few being identified as in need of care—particularly in countries with a high HIV burden.

Even in developed countries, there are challenges, communication being one. For while it is relatively easy to talk to an adult or a young person about symptoms and pain levels, this is harder with, say, a three-year-old and impossible with a baby, demanding sophisticated diagnostic skills.

Mrs Marston points to other barriers. "A lot of clinicians are afraid of looking after children, because children's care needs are so complex and because of the emotions that surround the family," she says.

Many are hesitant to dispense appropriate painkillers, too. "We know you can give morphine to a newborn but you have to work out that dose very carefully," she says. "So there's a fear of using opioids."

This has led to severe shortfalls in the availability of palliative care for children. "The UK has the best spread of children's hospice and palliative care services but they're only reaching 25% of the children who need it," Mrs Marston says.

Encouragingly, however, some developing countries are moving ahead rapidly in developing children's palliative care services. In Malawi, for example, children's palliative care is now part of national policy and the government has committed to rolling out training in the regions. In the Indian state of Maharashtra, children's palliative care is also included in state policy and its government is setting aside money for care provision.

In many of these countries—as well as in some Eastern European nations such as Belarus, Latvia and Poland—progress on developing children's palliative care is happening due to the efforts of one or several passionate individuals. "If you look at children's palliative care, you'll always find that right at the beginning, there was someone who said, 'We need to do something about the children,'" says Mrs Marston.

She adds that listening to children themselves is also critical. "Having the child and the young person talk about their needs—that's really powerful."

6 Community engagement

When it comes to the end of life, the role of the community is important. And when communities, volunteer workers and families take on more responsibility for care, it can reduce the costs associated with hospital stays and emergency admissions. The question for policymakers is how to create the incentives and support systems needed to encourage more community involvement.

Moreover, palliative care extends beyond the medical treatment of patients. For while death is a universal human experience, in today's world people find it hard to face and are reluctant to talk about death and dying. It is therefore important for community groups to raise awareness of the role of palliative care and to encourage open discussions about end-of-life choices.

In this category of the Index, two indicators are used to assess countries' performance—public awareness of palliative care and availability of volunteer workers for palliative care. Public awareness has a weighting of 70% and volunteer workers 30%.

Belgium and New Zealand top the list in this category, while France and the UK share second place (as in the high-income country group). In the Americas, again the US and Canada top the list. But here, Brazil and Costa Rica are in third place. Meanwhile, New Zealand is first in the Asia-Pacific group, with Japan and Taiwan in position 2, while Uganda, Zimbabwe and Israel are the top three among Middle East and African countries.

In Belgium, for example, a strong network of volunteer workers exists. In New Zealand, while work remains to be done, public awareness of palliative care and advance care planning is increasing, while Hospice New Zealand, which leads the country's hospice movement, has a robust community engagement goal in its strategic plan.

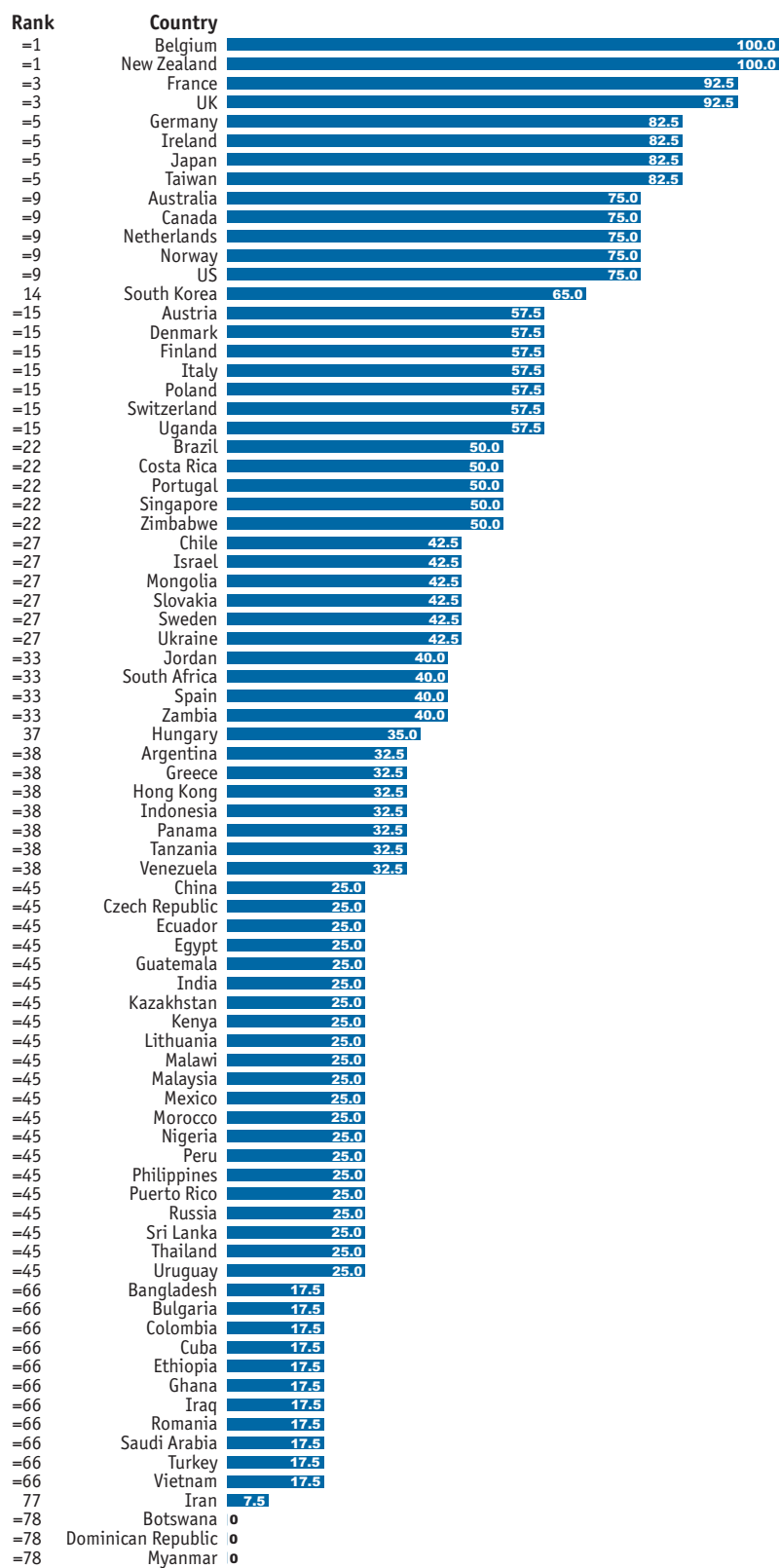
Although government and philanthropic support for palliative care clearly underpins the number and type of services on offer, networks of volunteers can help extend the reach of those services. For example, Costa Rica has developed an extensive network of day centres and volunteer teams.⁵⁰

Also often cited as demonstrating the benefits of volunteer networks is the Indian state of Kerala, where MR Rajagopal, chairman of Pallium India, and Suresh Kumar, director of the Institute of Palliative Medicine, have pioneered community-based models of palliative care.⁵¹

However, Kerala, with its long history of socialist politics and strong religious institutions, is uniquely suited to such models. The question for policymakers is how to build volunteer networks in regions where the socio-economic conditions may be very different. "There are features of Kerala that are atypical," says Dr Payne. "I very much admire what happens in Kerala, but my concern is that it does not spread."

Figure 6.1

Community engagement (10% weighting)



She cites Spain and Colombia as having models that could be replicated: through relatively new legislation Colombia is implementing a model of palliative care that integrates social support and healthcare. Spain, meanwhile, scores 4 on the second indicator in this category, meaning it generally has sufficient volunteer workers to meet the country’s needs and that some of these receive training and are involved in fundraising.

In some cases, legislation can act as a barrier to volunteer work. In France, for example, while three institutes offer training to volunteers, regulations mean palliative care units must establish a formal connection with volunteer associations and volunteers are limited in what tasks they can perform. “It’s hard to be a volunteer,” says Dr de la Tour. “The training is too long and there are many things they can’t do.” She cites activities such as organising birthday parties, making flower arrangements or doing the shopping. “And a hospice with a garden can’t have volunteers doing the gardening,” she adds.

Community efforts are also important when it comes to raising awareness of palliative care and to encourage more people to talk about death and dying. This is the goal, for instance, of the Dying Matters Coalition, a 30,000-member body established in 2009 by the UK’s National Council for Palliative Care. It aims “to help people talk more openly about dying, death and bereavement”, and to make these issues “accepted as the natural part of everybody’s life cycle.” It does so through community activities and events and the distribution of resources like DVDs, posters and leaflets, as well as its website.⁵²

More informally, in a growing number of countries a movement called Death Cafés offers meetings over tea and cakes where participants can hold open conversations on death and share their ideas and concerns with others.

Figure 6.2: Public awareness of palliative care

5		4		3		2		1	
Public has a strong understanding and awareness of palliative care services. Information on palliative care is readily available from government portals and community mechanisms.		Public has a somewhat good understanding and awareness of palliative care services. Some information on palliative care is available from government portals and community mechanisms.		Public has a mediocre understanding and awareness of palliative care services. Limited information on palliative care is available from government portals and community mechanisms.		Public has a limited understanding and awareness of palliative care services. Little to no information on palliative care is available from government portals and community mechanisms.		Public has no understanding or awareness of palliative care services. There is no information on palliative care available from government portals and community mechanisms.	
Belgium	New Zealand	Australia	Netherlands	Austria	Poland	Argentina	Malawi	Botswana	Iran
France	UK	Canada	Norway	Brazil	Portugal	Bangladesh	Malaysia	Dominican Republic	Myanmar
		Germany	Taiwan	Chile	Singapore	Bulgaria	Mexico		
		Ireland	US	Costa Rica	Slovakia	China	Morocco		
		Japan		Denmark	South Korea	Colombia	Nigeria		
				Finland	Sweden	Cuba	Panama		
				Hungary	Switzerland	Czech Republic	Peru		
				Israel	Uganda	Ecuador	Philippines		
				Italy	Ukraine	Egypt	Puerto Rico		
				Mongolia	Zimbabwe	Ethiopia	Romania		
						Ghana	Russia		
						Greece	Saudi Arabia		
						Guatemala	South Africa		
						Hong Kong	Spain		
						India	Sri Lanka		
						Indonesia	Tanzania		
						Iraq	Thailand		
						Jordan	Turkey		
						Kazakhstan	Uruguay		
						Kenya	Venezuela		
						Lithuania	Vietnam		
							Zambia		

The challenge is to scale up initiatives such as Death Cafés. “It’s a tiny part of the population accessed, and mainly the cognoscenti,” says Australia’s palliative care advocate Yvonne McMaster. Dr Sleeman agrees. “The more we talk about the issue in society the better it will be,” she says. “But the people who go to Death Cafés are people who choose to go to Death Cafés, not the average man on the street who would not have a conversation on death and dying—that’s the person you really need to engage.”

In the US, which scores 4 out of 5 on the public awareness indicator (Figure 6.2), a number of initiatives are working to encourage more

frequent and meaningful conversations about death and the end of life.

Based in the US, the Conversation Project—founded by Ellen Goodman and Len Fishman and working in collaboration with the Institute for Healthcare Improvement—helps people talk about their wishes for end-of-life care. It produces free starter kits that are downloadable from its website and offer guidance on how to initiate a conversation on death. “We want you to be the expert on your wishes and those of your loved ones,” the website tells users. “Not the doctors or nurses. Not the end-of-life experts. You.”

Palliative care and the right to die

“

The reason that assisted suicide laws are polling so well these days is that the public has a well of fear, anger and distrust about the care they will receive and how they and their families will die. And the hard truth is that this is well founded.

”

Ira Byock, executive director and chief medical officer, Institute for Human Caring at Providence Health & Services

While the voices calling for more and better palliative care are growing louder, so are those advocating for the right to die. Both camps would argue that they are supporting a better quality of death. Yet those working in palliative and hospice care argue that legalising assisted suicide should not be seen as an alternative to good palliative care.

In some countries, granting citizens the right to die is on the agenda. Around the world, lawmakers are considering or introducing legislation to allow terminally ill patients to take their own lives.

In February 2015, for example, Canada's supreme court ruled that adults suffering extreme, unending pain would have the right to doctor-assisted suicide.⁵³ In the UK, the Assisted Dying Bill was defeated in parliament in September 2015, despite some polls showing a majority of the public supported it.⁵⁴ And in Australia, some states and territories have been considering introducing legislation, while a federal bill on assisted suicide has been drafted. “It's a very active space,” says Ms Callaghan of Palliative Care Australia.

In some places, such legislation has existed for many years. In the US, for example, the state of Oregon has allowed its citizens to take self-administered lethal medications prescribed by a doctor since 1997 under the Death With Dignity Act (DWDA).⁵⁵ The state of Washington passed a similar law in 2008,⁵⁶ as did Vermont in 2013.⁵⁷

In Europe, meanwhile, Switzerland's law permitting assisted suicide has been in force since 1942.⁵⁸ In 2014, Belgium extended its 2002 euthanasia law to children,⁵⁹ while in the Netherlands legislation that went into effect in 2002 went a step further, permitting both assisted suicide and euthanasia under certain conditions.^{60, 61}

But while the right to die is a reality in some countries and the subject of debate in many others, advocates for palliative care argue that this reflects an inability to care adequately for people at the end of their lives. “Euthanasia

is not a substitute for palliative care,” says Ms Callaghan.

Increasing debate about assisted dying represents a failure for the field, says Dr Byock. “The reason that assisted suicide laws are polling so well these days is that the public has a well of fear, anger and distrust about the care they will receive and how they and their families will die,” he says. “And the hard truth is that this is well founded.”

In his book *Being Mortal*, writer and surgeon Atul Gawande suggests that the high number of people seeking assisted suicide in the Netherlands is not a measure of success. “Our ultimate goal, after all, is not a good death but a good life to the very end,” he writes.⁶²

Of course, there will always be cases where palliative care cannot end suffering. Dr Gawande goes on to say he would support laws permitting prescriptions allowing people to end their lives when suffering at the end of life is unavoidable and unbearable.

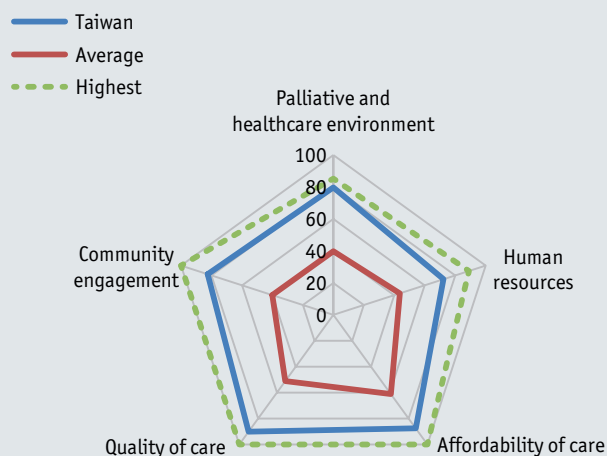
And, as Dr Gawande argues, giving people the option can alleviate their anxiety, even if they never use the lethal medications. Barbara Coombs Lee, president of Compassion & Choices, a US-based non-profit organisation that pushes for greater patient choice at the end of life, agrees. “It bestows enormous peace of mind,” she says. “It's knowing it's there that is the primary impact.”

It is telling that in Oregon, for example, the number of recipients of DWDA prescriptions is always substantially higher than the number of deaths resulting from the drugs.⁶³ “There will still be people for whom this is about control and that is never going to change,” says Dr Tulskey of the Dana-Farber Cancer Institute.

However, Dr Tulskey argues that most people who receive good palliative care will not choose to hasten their death. “In general, if you can manage the symptoms and the social and psychological issues that come up at the end of life, it should not be necessary.”

Case study: Taiwan—Leading the way

	Rank/80	Score/100
Quality of Death overall score (supply)	6	83.1
Palliative and healthcare environment	5	79.6
Human resources	9	72.2
Affordability of care	=6	87.5
Quality of care	=8	90.0
Community engagement	=5	82.5



Taiwan ranks near the top of the Quality of Death Index, coming first in Asia and sixth overall. Its high position is the result of a number of factors. Firstly, the availability of palliative services has steadily grown in recent years, with hospice programs increasing more than 50% to 77 programs during 2004 to 2012, and hospital-based palliative care teams multiplying from 8 to 69.⁶⁴ Taiwan ranks fifth overall in the palliative and healthcare environment category as a result. In human resources terms it also does well: in addition to an increase in palliative care teams, other medical specialists in related fields such as nephrology or neurology are receiving training on palliative care and now incorporate it into their treatment plans.

Palliative care services are also affordable: Taiwan has the second-highest score in this category (together with a host of richer countries). Taiwan's National Health Insurance (NHI) system plays a central role in the provision of palliative care, by determining insurance coverage and the level of reimbursement for specific services. While previously only cancer patients were eligible, in the last five years coverage has been extended to include several other types of illness, and reimbursement levels have increased for both home visits and hospital-based care, providing more incentive for institutions to offer palliative care.

The quality of palliative care in Taiwan is high (it is tied for eighth place in this category), with a focus on improving the quality of a patient's last days. Major steps have been made in recent years: Dr Siew Tzuh Tang, a professor at Chang Gung University School of Nursing, reports substantial improvement in several end-of-life indicators between her team's national surveys in 2003/4 and 2011/12. For example, while less than half of terminally ill cancer patients were aware of their prognosis in the first survey, this number increased to 74% by 2012. Use of aggressive medical treatments for cancer patients in the last month of life, such as CPR and intubation, also declined over this period.

Community engagement, in particular to break down cultural taboos against discussing death, has also been a focus. Such taboos are still widespread, but proponents of palliative care are attempting to change that by introducing discussions of life and death into the education system from primary school through university, and by changing the mindset of patients.

"Family members feel that for the patient to die without CPR is not filial," says Dr Rongchi Chen, chairman of the Lotus Hospice Care Foundation. "But we are trying to teach people that filial duty and love should find its expression in being with the family member at the end of his or her life, and in encouraging acceptance of disease and peaceful passing."

According to Ching-Yu Chen, professor emeritus at NTU Hospital, one of Taiwan's innovations in the area of palliative care has been the emphasis on spiritual care as even more important than symptom management. Organisations like the Lotus Hospice Care Foundation have provided training for Buddhist monks and nuns to provide spiritual support as part of palliative care. Dr Rongchi Chen estimates that around 70% of Taiwan's population identify as Buddhist, and reports very positive responses by patients and their families to the presence of Buddhist chaplains.

A glimpse of the future of palliative care

Taiwan is also a pioneer in technological advances to improve efficiency while enhancing patient rights and palliative care experience. To take one example, all Taiwanese citizens have an insurance card with their medical information, and elderly patients are encouraged to make specific end-of-life decisions about their wishes in the event that a "do not resuscitate" (DNR) decision needs to be made. This information is then linked directly to their insurance card, so that registering at any health care facility brings up this information.

Tzuchi University Hospital has also piloted an innovative program for remote monitoring of palliative care, using smartphones and tablets as a platform for tracking patients'

medical conditions and for enabling communication between caregivers and medical specialists through Skype. The platform also includes online care instructions and community resources, and is available in six different languages to ensure that foreign health aides are also able to use the service. Dr Yingwei Wang, chief of the Heart Lotus Hospice at Tzuchi General Hospital, reports that the outcomes and caregiver feedback have been very promising, and expects that the program will be expanded in coming years.

The use of new platforms is welcomed in tech-savvy Taiwan,

and this kind of innovation will be essential to keep pace with the health care needs of Taiwan's ageing population. "The proportion of our population over 65 has doubled from 7% to 14% in just 20 years," said Dr Wang, with many elderly patients living in rural areas with limited access to palliative care. Efforts to provide community hospitals with additional training and access to palliative care experts are underway, including a nationwide bi-weekly conference call that links palliative care practitioners to share their experiences and discuss recent cases.

7 The 2015 Quality of Death Index— Demand vs supply

In debates about how to improve care for dying people and those living with incurable non-communicable diseases, healthcare providers and policymakers are focused on increasing the availability and quality of care. However, while individual programmes may stand out, the success of countries in meeting the needs of their citizens also depends on a critical factor: the size of the gap between demand and supply.

For this reason, an important component of the 2015 Quality of Death Index is a new demand section, which analyses countries' relative need for palliative care. While the supply Index is based on twenty indicators in five categories, the demand analysis is based on three indicators:

- The burden of diseases for which palliative care is necessary (60% weighting)
- The old-age dependency ratio (20%)
- The speed of ageing of the population from 2015-2030 (20%)

Given that patients with certain diseases are more likely to require palliative care⁶⁵, the first indicator measures the burden of those diseases for each country. This is given the highest weighting considering its importance in the literature around palliative care: prevalence of diseases such as cancer and Alzheimer's will drive demand for palliative care services. The second and third factors take into account that palliative care will be more urgently needed the older a population is, and the more rapidly it is

likely to age. These age-related indicators are given equal weight and importance.

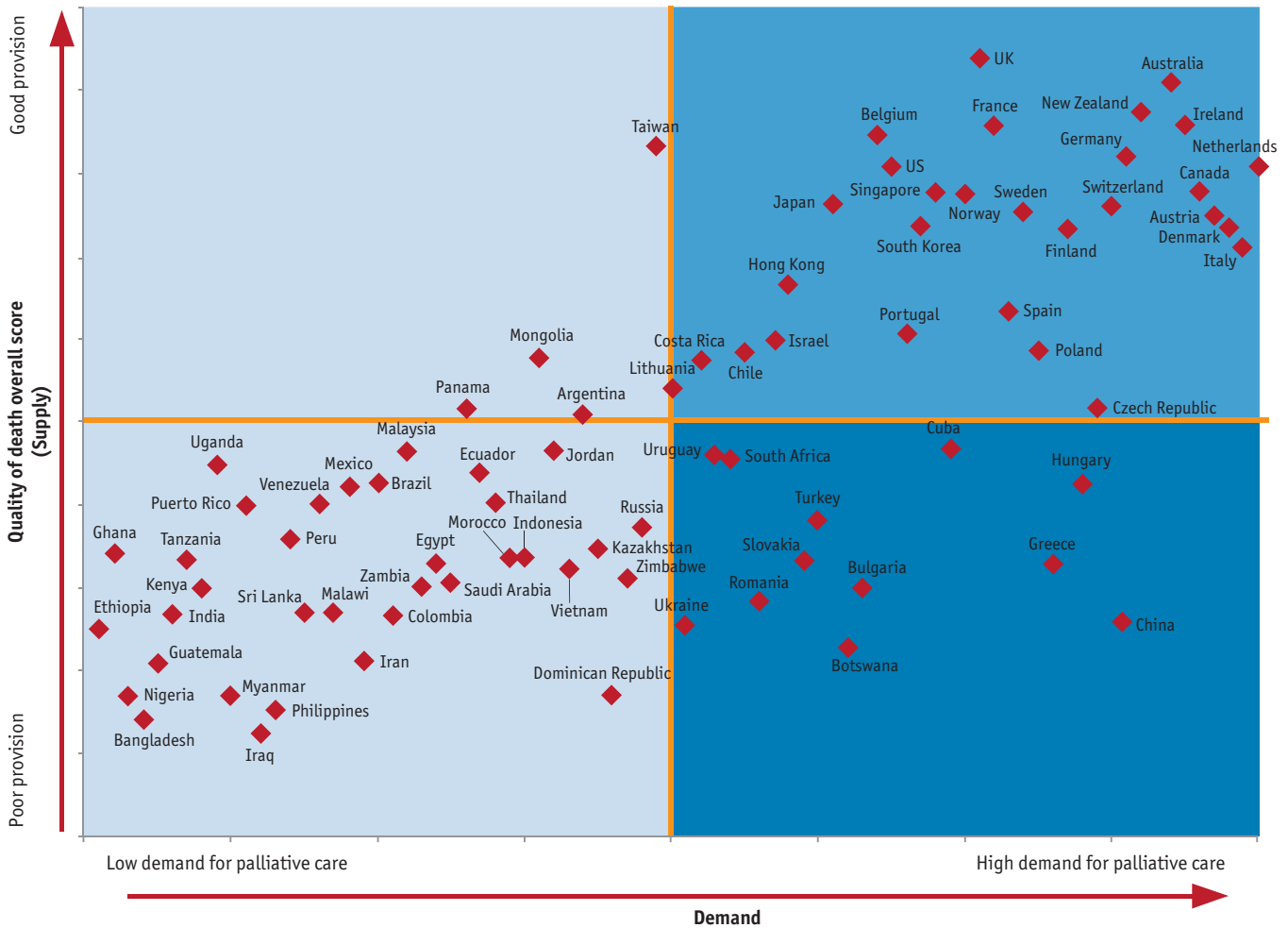
Taking the results of the headline supply Index and mapping them against the results of the demand analysis (Figure 7.1), it is possible to gain a picture of where the greatest gaps in palliative care provision exist worldwide. Countries in the top right-hand corner of the chart—such as Australia, New Zealand, the UK, the Netherlands and Canada—have high demand but also relatively good provision. For them, the gap is narrowest.

Those in the bottom left-hand corner of the scatter chart have low provision but also low demand. Most worrying are those countries on the right-hand side of the chart (indicating that demand is highest) but that do less well when it comes to provision. These include Bulgaria, Cuba, Greece and Hungary—and, in the most striking case, China.

China is one of the few lower income countries with high demand for palliative care, partly due to rising incidence of conditions such as cardiovascular disease, with this accounting for one-third of all deaths in China in 2012.⁶⁶ Moreover, China's demographic profile, with more than 13% of the population expected to be aged 65 or over by 2020 according to EIU estimates, compared to 11% globally (and 6% in India), implies greater need for palliative care—and healthcare in general. "China's ageing population will be a serious challenge

Figure 7.1

Palliative care demand vs supply



for the health system,” says Ning Xiaohong, an oncologist at Peking Union Medical College Hospital.

“Palliative care is not the only treatment [needed by] the ageing population,” says Cheng Wenwu, director of the Department of Palliative Care at Fudan University Cancer Hospital. “But as increasing demand for medical care [due to the ageing population] places a burden on clinics and hospitals, palliative care facilities will be needed to help relieve some of that pressure.”

Looking at countries on the left side of the chart, in spite of their relatively low current

demand, many will also need to work hard to meet rising future need as the incidence of non-communicable disease increases and their populations grow older. The demographic ageing process is fastest among developing countries. Of the 15 countries that now have more than 10 million older people, seven are developing countries.⁶⁷

In Nigeria—near the bottom of the demand analysis—the challenge is the country’s size, says Dr Luyirika. “Nigeria has a very big and diverse population and it’s a big country too, so to make an impact, they need to more than triple their efforts,” he says. “There are lots of

initiatives that are happening but because of the huge population, it's difficult to say they are making progress. The coverage is still very low."

In general, in countries with low demand, this state of affairs is changing rapidly. As overall healthcare provision improves and people live longer and the incidence of non-communicable diseases rises, demand for palliative care will only increase in years to come. In Sub-Saharan Africa, for example, the World Health Organization expects the incidence of cancer to increase by 127% and cardiovascular diseases (including stroke) to increase by 105% between 2012 and 2030.⁶⁸

Of course, it is worth remembering that even in countries where high demand is being met by

high-quality services, the picture is complex. "In the UK [which is in the top bracket of the demand analysis], we are polishing the brass—we've got good care and we're doing well," says Dr Sleeman. "But then I spend a lot of time saying we're not doing enough, the population is ageing and we're spending too much money on things that don't improve people's outcomes at all."

And while he is talking about the situation in the US—which is also near the top in terms of demand—the comments of Dr Byock could be applied worldwide. "The time for incremental change is over," he says. "And we'd better hurry because with the ageing of the population and the continued growth of chronic illness, the trends are not in our favour. We have to move swiftly."



Conclusion

As seismic demographic shifts bring home the scale of the challenges facing governments in providing for ageing populations, palliative care has risen up the agenda since the EIU published its first Quality of Death Index. Of course, changes in the methodology of the Index since 2010, as well as an increase in the number of countries included, mean it is not possible to make direct comparisons. However, it is clear that some countries are stepping up their efforts to ensure all citizens have access to palliative care.

For example, Japan, which performed relatively poorly in the 2010 Index, is now at position 14, reflecting recent initiatives such as its increased attention to palliative care for cancer patients. And while in 2010, the Indian state of Kerala was a lonely beacon of hope in a country otherwise failing to provide its citizens with suitable painkillers and palliative care, initiatives are emerging in other parts of the country, while recent legislative changes will make it considerably easier for Indian physicians to prescribe morphine.

Other promising policy advances have been made since 2010, such as Colombia's 2014 palliative care law, for example. In Panama, there is optimism that legislative changes will pave the way for the creation of a medical specialty

in palliative care and easier access to opioids. And the World Health Assembly resolution on palliative care creates a powerful incentive for all member states to develop palliative care policies.

Nevertheless, it should not be forgotten that for most countries—even those that occupy the highest ranks of the Index—much work remains to be done to ensure that those in need of care are not neglected. And in much of the developing world, access to palliative care is either a rarity or non-existent.

For wealthy nations with sophisticated healthcare services, the challenge is moving from a culture of curing illness to managing long-term conditions. Instead of viewing palliative care as a cost centre, as is often the case in the US, greater recognition is needed of the economic benefits of palliative care in terms of reduced hospital stays and avoided emergency room visits.

In developing countries, ageing populations, rapid urbanisation and increasingly unhealthy lifestyles mean healthcare systems must cope with rising rates of chronic disease such as lung cancer and diabetes while they still battle against child and infant mortality and infectious diseases.

But while the challenges they face may be different, a number of crucial interventions could help all countries improve the quality of care and make it available to greater numbers of people. These include:

- Creating a legislative framework that provides for easier access to painkillers such as opioids and training healthcare workers to administer these drugs
- Creating mechanisms that make palliative care more affordable for those that need it
- Integrating some level of palliative care training into the education of all healthcare professionals
- Increasing access to home- and community-based palliative care
- Providing support for the families and voluntary workers who can extend access to care
- Increasing public awareness of palliative care
- Encouraging more open conversations about death and dying

While education and training clearly involve investment, not all these interventions necessarily require substantial expenditure. And, as studies have found, palliative care can be highly cost effective when compared with the alternatives.

As far greater numbers of people live longer but with one or more conditions—requiring complex treatments—palliative care can ease the burden on healthcare systems and reduce pain and suffering for the individual. There is even evidence to suggest that palliative care not only enhances quality of life—in some cases, such as lung cancer and end-stage breathlessness, it can even extend life.^{69, 70}

Whether it is to cut costs, increase quality of life or improve patients' survival, developing palliative care services should be a priority for every healthcare system worldwide. Countries will need to act fast. Given the inevitable increase in demand, if governments are not to become negligent in meeting the needs of tens of millions of individuals and families going through what are difficult and painful experiences, a business-as-usual approach will no longer suffice.

Appendix I: Quality of Death Index FAQ

What is the Quality of Death Index? Why was it developed?

In 2010 The Economist Intelligence Unit (EIU) developed an Index that assessed the availability, affordability and quality of end-of-life care in 40 countries. The study, commissioned by the Lien Foundation, was the first that objectively ranked countries in the provision of palliative and end-of-life care. The study garnered much attention and sparked a series of policy debates around the world. As a result, the Lien Foundation commissioned a new version of the Index to expand its scope and take into account global developments in palliative care in recent years.

The Quality of Death Index was developed as a policy-focused tool to complement and expand on the existing literature around palliative care. It is the only study that ranks the quality of provision of palliative care at the country level. Since its first publication in 2010 there have been several regional and global studies assessing palliative care. The research with the largest coverage of countries is the *Global Atlas of Palliative Care at the End of Life* (2014)⁷¹, developed by the World Health Organization and Worldwide Hospice Palliative Care Alliance. The study outlines global need for palliative care and barriers to its development, and classifies 234 countries in four major groups of palliative

care development (rather than individually). Other influential research studies include the *EAPC Atlas of Palliative Care in Europe* (2013)⁷², developed by the European Association for Palliative Care, which outlines services, policies and strategies in 53 European countries, and the *Atlas of Palliative Care in Latin America* (2012, 2015)⁷³ which presents the palliative care situation in 19 Latin American countries.

The 2015 Quality of Death Index has several distinctions from these papers: it is wider in scope than the regional studies and more in-depth in its methodology compared to the *Global Atlas of Palliative Care at the End of Life*. The 2015 Quality of Death Index also offers an objective framework to compare and rank palliative care developments in 80 countries. No other study ranks such an extensive list of countries: the Index covers 85% of the world's population and 91% of the population aged above 65.

What does the 2015 version of the Index cover?

In the 2010 version, we focused on end-of-life care for adults. In this version we have revised the scope to refer to palliative care for adults. Palliative care, which the WHO defines as the approach to improving the lives of patients facing life-threatening illness, has a wider scope

than end-of-life care. End-of-life care typically refers to care in the last days of a patient's life.

Research for the 2015 Index also includes analysis of demand for palliative care, which offers an opportunity to study where gaps between provision and need for palliative care is most pressing. The results of this demand analysis are presented separately in Part 7 of the paper.

How different is the 2015 Index from the 2010 version?

In the 2015 version the number of countries included has been increased from 40 to 80. The Index is also structured differently from the 2010 version.

In developing the revised framework the EIU conducted an in-depth literature review and consulted an expert panel of advisors. Based on their feedback and palliative care developments in the last five years, we have removed some indicators for which data was not uniformly available or reliable (such as average payment by patient for end-of-life care); added new ones (such as availability of psychosocial support for patient and families, which had gained importance in the literature); and refined the scoring methodology in others (for example, the indicator around the existence of a government policy now not only assesses

presence of a policy, but also the effectiveness of its implementation). The 2010 version ranked countries based on 24 indicators in four categories; the 2015 version ranks 80 countries based on 20 indicators in five categories.

As the two versions are different in scope and framework, direct comparisons of a country's ranking between 2010 and 2015 are not possible.

Why do we have five categories in assessing palliative care?

In our literature review and consultation with our expert advisory panel, and building from the 2010 Index, the EIU research team found that several key themes were crucial in the provision of the palliative care environment (see table below).

Refer to the full methodology below for descriptions of indicators in each category, data sources, the data normalisation process and the scoring criteria for qualitative indicators.

What is the demand analysis?

The demand analysis assesses countries on their need for palliative care based on three indicators: burden of diseases that often require palliative care, the proportion of elderly in a country and how quickly this proportion of elderly is changing. For the first time in palliative care research, our Index analyses the provision of

Category	Justification
Palliative and healthcare environment	This category includes indicators assessing the general palliative and healthcare environment, as well the existence of a well-articulated, effective and widely implemented government strategy.
Human resources	Trained specialists, medical professionals and support staff are key in ensuring available services are delivered in a professional and high-quality fashion.
Affordability of care	Where care is available, it needs to be affordable. In this category we assess public funding as well as out-of-pocket expenses for accessing palliative care.
Quality of care	Quality of care is the most important category in the Index. It assesses various dimensions of quality, including the availability of strong opioid analgesics (morphine and equivalents), monitoring standards in organisations and the availability of services such as psychosocial support for patients and their families.
Community engagement	The role of the community is important in palliative care, especially as volunteer workers are vital in the provision of care. In this category, we assess the availability and training for volunteer workers, and public awareness of palliative care.

palliative care (or “supply” environment) in the context of “demand” for palliative care. This offers a unique opportunity to identify countries where policy change and palliative care development is most pressing.

See the full methodology in Appendix II for descriptions of data used, sources and assessment criteria.

How was the Index constructed?

Using the 2010 version of the Index as a baseline, we first conducted an in-depth review of developments in palliative care in the past five years. We also consulted with our expert advisory panel, which included:

- Cynthia Goh, chair, Asia Pacific Hospice Palliative Care Network
- Stephen Connor, senior fellow, Worldwide Hospice Palliative Care Alliance
- Liliana de Lima, executive director, International Association for Hospice and Palliative Care
- Emmanuel Luyirika, executive director, African Palliative Care Association
- Sheila Payne, emeritus professor at the International Observatory on End of Life Care at Lancaster University

In collecting data for the Index, we reviewed plans, policies and academic papers for each country, and conducted interviews with in-country professors, medical professionals and other experts. Our interviews helped triangulate information derived from desk-based research.

The Index consists of qualitative and quantitative indicators. For qualitative indicators, our EIU research team developed a framework to score countries, usually on a scale of 1-5 (where 1=worst and 5=best). We then consulted our expert advisory panel on weights for indicators and categories, as well as to review Index findings.

Data for indicators are normalised on scale of

0-100; that is, the maximum value for any one indicator becomes 100 and the minimum 0, and values in between are turned into appropriate scores on that scale, like percentages. These values are multiplied by their assigned weights and added together to get the category scores. Then each category score is multiplied by its weight and then added together to get the overall score.

The results of the Index are the sole responsibility of the EIU.

What are the limitations of the Index?

The Index assesses the quality and availability of palliative care services for adults only. Palliative care for children is equally important, but a paucity of data makes such analysis difficult.

In terms of indicators, we faced data limitations in our assessments around human resources and availability of services. In the Human Resources category, ideally we would have considered the availability of doctors and nurses working primarily in palliative care. Such data, however, is not widely available. Instead, we used data on total number of doctors and nurses collected by the World Health Organization.

In the Palliative and Healthcare Environment category, data for “Capacity to deliver palliative care services” was not available for a number of countries. As a proxy, this indicator measures the percentage of people who died from palliative care-related deaths in a country in one year that would have been able to receive palliative care, given the country’s existing resources. We use an estimation of the capacity of palliative care services available, based on WHPCA data, and divide by the number of deaths in a given year.

For qualitative indicators, we scored countries based on policies, plans and developments up until December 2014. This meant that new developments in 2015 (such as in Canada, where nationwide policies were recently implemented)

are not considered. For quantitative indicators, data for 2014 was often not available. We referred to the most recent year where data was available for most countries.

The scores for the Index reported in this paper are based on the weights for each indicator and category assigned by the EIU at the conclusion of its research, after due consideration of the evidence and expert opinions given throughout the research process. However, these weightings are not necessary a final judgement on relative indicator importance.

In our analysis of demand for palliative care, we estimated relative burden of disease by collecting data on numbers of deaths in 2012 (latest available figures) for 12 diseases identified by *Global Atlas of Palliative Care at the End of Life* (2014). Data for prevalence of diseases would be a better measure, but such information was not uniformly available. Mortality by disease is derived from medical information on death certificates and coding of causes following the WHO-ICD system. The reliability of data collected can vary as a result of errors when issuing death certificates, problems with diagnosis and coding of cause of death.

How should the Index be used?

The Quality of Death Index, constructed by the EIU with the help of palliative care experts, is a tool. It is meant to be used as a framework in identifying palliative care issues at the national level, with the opportunity for countries to compare provision with countries in the same region or income groups. It can also be used to assess demand for palliative care, which can support planning of future quality and affordable palliative care.

The headline results of the Index are presented in this paper and in an accompanying infographic, while detailed country profiles are available in a separate appendix. A version of the workbook in MS Excel is available for download online at www.qualityofdeath.org. This workbook includes a range of analytical tools: users can examine the strengths and weaknesses of a particular country, while any two countries may be compared directly and individual indicators can be isolated and examined. Where the EIU has created new datasets through internal, qualitative scoring, users can see the justification for the scoring in the commentary section of the workbook. Users may also change the weights assigned to each indicator and category.

Appendix II: Quality of Death Index Methodology

The Quality of Death Index consists of two separate rankings:

- Supply of palliative care: ranking the overall environment of palliative care provision—the availability, affordability and quality of palliative care
- Demand for palliative care: ranking burden of diseases and ageing in countries as a reflection of palliative care need

Country selection

To select the 80 countries in the Index, we started with groupings in the *Global Atlas of Palliative Care* published by the Worldwide Hospice Palliative Care Alliance (WHPCA). We selected countries classified as Level 3a (countries with isolated provision of palliative care), Level 3b (countries with generalised provision of palliative care), Level 4a (countries with preliminary health system integration) and 4b (countries with advanced health system integration).

Next, we removed countries with small populations (under 2m) and small economies (under US\$10bn nominal GDP in 2013), and, to ensure balanced geographical coverage, placed upper limits on the number of countries we included in each region. We also made several exceptions where countries did not meet our

initial population and economic size criteria (eg Botswana, Malawi and Zimbabwe) to ensure a fairer regional representation.

The final selection consists of 18 countries in Africa and the Middle East, 17 in the Americas, 18 in Asia-Pacific and 27 in Europe. Of the 80 countries included, 21 are low income, 24 are middle income and 35 are high income, according to definitions used by the World Bank (in which low income countries are those that had 2013 GNI per capita of less than US\$4,125⁷⁴, middle income countries more than US\$4,125 but less than US\$12,746 and high income countries more than US\$12,746.) Our Index represents approximately 85% of the world's population and 91% of the population aged above 65.

Overall score (“Supply”)

The Quality of Death Index overall ranking assesses the availability, affordability and quality of palliative care for adults in these countries. The Index scores countries across 20 indicators grouped in five categories:

- The **Palliative and Healthcare Environment** category sets the context for our overall assessment of palliative care provision. Indicators in this category show the broader healthcare environment and palliative care environment, as well as the availability of palliative care services.

- The **Human Resources** category is a reflection of availability of trained medical care professionals, as well as quality of training. We assess not just specialists in palliative care, but also training in palliative care for general medical practitioners.
- The **Affordability of Care** category ranks countries according to the affordability of palliative care services, with an emphasis on the availability of government funding for palliative care.
- The **Quality of Care** category assesses the presence of standards, guidelines and practices that provide high standards of palliative care.
- The **Community Engagement** category assesses the availability of volunteers, an integral part of palliative care provision, and public awareness of palliative care.

The indicators used fall into two broad categories:

- **Quantitative indicators:** four of the Index's indicators are based on quantitative data—for example, healthcare spending as a percentage of GDP and number of doctors per 1,000 palliative-care-related deaths;
- **Qualitative indicators:** 16 of the indicators are qualitative assessments of a country's palliative care environment, for example, "Presence and effectiveness of government-led national palliative care strategy" which is assessed on a scale of 1-5, where 1=no national strategy exists and 5=a comprehensive, well-defined and implemented national strategy exists.

Data sources

The Economist Intelligence Unit's research team collected data for the Index from July 2014 to

December 2014. Wherever possible, publicly available data from official sources are used for the latest available year. The qualitative indicator scores were informed by publicly available information (such as government policies and reviews), and country expert interviews. Qualitative indicators scored by The Economist Intelligence Unit are often presented on an integer scale of 1-5 (where 1=worst, 5=best).

Indicator scores are normalised and then aggregated across categories to enable an overall comparison. Normalisation uses the function:

$$\text{Normalised } x = (x - \text{Min}(x)) / (\text{Max}(x) - \text{Min}(x))$$

where $\text{Min}(x)$ and $\text{Max}(x)$ are, respectively, the lowest and highest values in the 80 countries for any given indicator. The normalised value is then transformed into a positive number on a scale of 0-100. This was similarly done for quantitative indicators where a high value indicates more available, affordable and high-quality palliative care provision. (In simpler terms, normalisation takes the maximum value for any one indicator and makes it 100 and the minimum 0, and turns values in between into appropriate gradations on that scale.)

Categories and weights

The EIU research team assigned category and indicator weights after consultations with internal analysts and external palliative care experts. The first three categories—Palliative and Healthcare Environment, Human Resources and Affordability of Care—are each allocated a weighting of 20% of the full index. The Quality of Care category is weighted 30%—making it the most important category. Community Engagement is weighted at 10% of the full index.

The following table provides a brief description of indicators, data and weights:

Indicator	Unit	Year	Source	Weight	Description
Palliative and healthcare environment				20%	
Healthcare spending	% of GDP	2012	World Health Organization (WHO)	20%	Government healthcare expenditure as a percentage of GDP
Presence and effectiveness of government-led national palliative care strategy	EIU rating	2014	EIU analysis	50%	Comprehensiveness of strategy in terms of vision, goals and objectives; effectiveness of strategies in terms of implementation mechanisms and presence of specific milestones and provision of regular review. 5= There is a comprehensive strategy on national palliative care development and promotion. It has a clear vision, clearly defined targets, action plan and strong mechanisms in place to achieve targets. In federated-structure countries, there are strong and clearly defined strategies that individual states must follow. These mechanisms and milestones are regularly reviewed and updated. 1= There is no government-led palliative care development and promotion strategy
Availability of research-based policy evaluation	EIU rating	2014	EIU analysis	10%	Presence of government-led/supported research and funding for palliative care study and improvement. 5: There is a government-led (or government-supported) research unit that regularly collects comprehensive data to monitor quality of the country's palliative care system. The body is well-funded. Studies involve surveys with healthcare professionals, hospitals/hospices and patients. The findings influence the country's palliative care strategy and development. 1= There is no data collected around the country's palliative care system. There is no available funding for such research. There is no evidence-based change.
Capacity to deliver palliative care services	%	2011	WHPCA, EIU analysis	20%	Estimated capacity of palliative care services available (i.e. of specialised providers of palliative care, including those that admit patients and provide services at home and in facilities) divided by the number of deaths in a given year.
Human resources				20%	
Availability of specialised palliative care workers	EIU rating	2014	EIU analysis	40%	Availability of healthcare professionals with specialised training in palliative care. 5= There are sufficient specialised palliative care professionals, comprising of doctors, nurses, psychologists, social workers etc. Voluntary workers should have participated in a course of instruction for voluntary hospice workers. The specialist palliative care training for the core care team is accredited by national professional boards. 1= Doctors and nurses working outside palliative care have no knowledge of palliative care. There is no compulsory course in medical schools on palliative care.
General medical knowledge of palliative care	EIU rating	2014	EIU analysis	30%	Quality of basic and specialised medical training in palliative care for doctors and nurses. 5= All doctors and nurses working within or outside palliative care have a good understanding of palliative care. Palliative care is a compulsory course during doctor and nurse training in schools. Doctors and nurses also regularly get professional training throughout their career. 1= Doctors and nurses working outside palliative care have no knowledge of palliative care. There is no compulsory course in medical schools on palliative care.

Indicator	Unit	Year	Source	Weight	Description
Certification for palliative care workers	EIU rating	2014	EIU analysis	10%	Presence of professional body for certification of palliative care workers (doctors and nurses). 1= There is a national-level professional body accrediting palliative care workers. 0= There is no national-level professional body accrediting palliative care workers.
Number of doctors per 1,000 PC-related deaths	Per 1,000 PC-related deaths	2012	WHO, EIU calculation	10%	Measure of human resource availability (doctors) in hospitals/hospices as an indication of availability of palliative care service.
Number of nurses per 1,000 PC-related deaths	Per 1,000 PC-related deaths	2012	WHO, EIU calculation	10%	Measure of human resource availability (nurses) in hospitals/hospices as an indication of availability of palliative care service.
Affordability of care				20%	
Availability of public funding for palliative care	EIU rating	2014	EIU analysis	50%	Presence and effectiveness of government subsidies/programmes for palliative care services. 5= There are extensive government subsidies or programmes for individuals accessing palliative care services. The qualification criteria are clear and the process to access such funding is largely easy and smooth. Information on how to access such funding is widely available. Effectiveness of programmes is routinely and adequately monitored. 1= There are no government subsidies for individuals accessing palliative care services.
Financial burden to patients for available palliative care services	EIU rating	2014	EIU analysis	40%	Reflection of effectiveness of funding use. 5= 80-100% of end of life care across hospitals, hospices, home care etc. is funded by sources other than the patient. 1= 0-20% of end of life care is funded by sources other than the patient.
National pension scheme coverage of palliative care services	EIU rating	2014	EIU analysis	10%	Coverage of palliative care services in country's pension/insurance scheme 3= The national pension/insurance scheme adequately covers palliative care services. 1= The national pension/insurance scheme does not cover palliative care services.
Quality of care				30%	
Presence of accreditation and monitoring standards for organisations	EIU rating	2014	EIU analysis	20%	Presence and scope of monitoring standards for organisations delivering palliative care; enforcement and review mechanisms. 1= National standards for palliative care exists. 0= National standards for palliative care does not exist.
Availability of opioid painkillers	EIU rating	2012, or latest available year	International Narcotics Control Board, EIU analysis	30%	Availability of morphine and morphine equivalents. 5= Freely available and accessible, 1= Illegal
Availability of psychosocial support for patients and families	EIU rating	2014	EIU analysis	15%	Availability of psychosocial support for patients and families. 3= Psychosocial support is widely available and used in palliative care both for families and patients. 1= Psychosocial support is almost never available for families and patients.
Presence of Do Not Resuscitate (DNR) policy	EIU rating	2014	EIU analysis	10%	Whether DNR policy has a legal status or not 2= Yes 1= No
Shared decision-making	EIU rating	2014	EIU analysis	15%	Extent to which diagnostic and prognostic information is shared with patient. 5= Doctors and patients are partners in care. Patients are fully informed of their diagnosis and prognosis. 1= Doctors rarely share prognosis with patients.

Indicator	Unit	Year	Source	Weight	Description
Use of patient satisfaction surveys	EIU rating	2014	EIU analysis	10%	Use of patient outcome and satisfaction surveys in the improvement of service provision. 5= There is widespread use of patient satisfaction surveys for patients and their families based on government guidelines. The survey is comprehensive and covers pain management, coordination of care and other service provision by doctors, nurses and other healthcare professional involved. These findings are regularly used to improve quality of service and care. 1= There is no use of patient satisfaction surveys.
Community engagement				10%	
Public awareness of palliative care	EIU rating	2014	EIU analysis	70%	Public awareness and information around of palliative care. 5= Public has a strong understanding and awareness of palliative care services. Readily available information on palliative care is available from government portals and community mechanisms. 1= Public no understanding and awareness of palliative care services. There is no information on government portals and community mechanisms on palliative care.
Availability of volunteer workers for palliative care	EIU rating	2014	EIU analysis	30%	Availability of volunteer workers for the care of palliative care patients. 5: There are sufficient volunteer workers to meet the needs of the country's palliative care system; volunteer workers are mostly in the care of patients and they receive regular training in the care of patients. 1= There are very few volunteer workers in palliative care services, and they are mostly not well-trained in the care of patients.

Demand for palliative care

Each country is also given a score measuring its need for palliative care. This score is a composite of three indicators:

- **Burden of disease:** the mortality rate of diseases identified by the WHO as most requiring palliative care. We assume that the higher the mortality rate, the greater the prevalence of these diseases and therefore a greater need for palliative care
- **Old age dependency ratio:** the proportion of persons aged above 65 as a proportion of persons aged 15-64. A higher proportion indicates a greater need because there is a smaller group to carry the burden from an ageing population.
- **Speed of ageing:** the annual rate of growth (2015-30) of the population aged above 65. A higher proportion indicates a rapidly ageing population, and therefore greater need for palliative care.

Burden of disease calculation

The Economist Intelligence Unit built on the research conducted by the WHO in estimating the need for palliative care in each country. The WHO found that the following diseases required palliative care at the end of life: Alzheimer's disease and other dementias, cancer, cardiovascular diseases, cirrhosis of the liver, chronic obstructive pulmonary diseases (COPD), diabetes, HIV-Aids, kidney failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis and drug-resistant tuberculosis.

The Economist Intelligence Unit collected adult mortality rates (aged 15+) for each of the above diseases for the latest available year (2012). Where mortality rates were not available, we made estimations based on countries with similar income and demographics. Mortality rates for each disease were collected as a proportion of total deaths for those aged above 15 in 2012.

We then applied the pain prevalence rate to each

disease and country. Pain prevalence rates are taken from the *Global Atlas of Palliative Care at the End of Life* and are an authoritative means to estimate palliative care needs. These measure degree of pain for each disease (but do not consider length of suffering). Pain prevalence rates are as follows:

Alzheimer's disease and other dementias: 47%
Cancer (malignant neoplasms): 84%
Cardiovascular diseases: 67%
Cirrhosis of the liver: 34%

Chronic obstructive pulmonary disease: 67%
Diabetes: 64%
HIV-Aids: 80%
Kidney failure: 50%
Multiple sclerosis: 43%
Parkinson's disease: 82%
Rheumatoid arthritis: 89%
Drug-resistant tuberculosis: 90%

Finally, to get each country's burden of disease score, we added the 12 individual disease scores. An illustration is as follows:

Argentina

Total number of deaths (aged 15+) from all causes in 2012: 302,290

Disease	Alzheimer's and other dementias	Cancer (malignant neoplasms)	Cardiovascular diseases	Cirrhosis of the liver	COPD	Diabetes	HIV/AIDS	Kidney failure	Multiple sclerosis	Parkinson's disease	Rheumatoid arthritis	Drug-resistant TB
Number of deaths	3,671.19	66,373.80	73,594.35	6,688.39	26,110.46	9,480.64	3,583.30	6,846.80	111.04	1,183.40	295.42	206.99
Pain prevalence rate	47%	84%	67%	34%	67%	64%	80%	50%	43%	82%	89%	90%

Burden of disease for Argentina = $(3,671/302,290) * 47\% + (66,373/302,290) * 84\% \dots (206/302,290) * 90\% = 0.4644$

Demand for palliative care indicators and weights

Indicator	Unit	Year	Source	Weight	Description
Burden of disease	Score	2012	WHO, EIU calculation	60%	Calculated as number of deaths by palliative care diseases (list of 12 diseases identified by WHO), divided by total number of deaths in country, multiplied by pain prevalence rate.
Old age dependency ratio	%	2014	EIU, UN Population data	20%	Percentage of persons aged over 65 as a proportion of working-aged individuals (15-64)
Speed of ageing	%	2015-2030	EIU analysis	20%	Annual rate of growth of population of persons aged above 65, 2015-2030

Endnotes

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