

The 2015 Quality of Death Index

Ranking palliative care across the world

A report by The Economist Intelligence Unit



Commissioned by

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Executive summary

Everyone hopes for a good death, or rather, “a good life to the very end”¹, but until recently there was little dedicated effort and investment to provide the resources and education that would make that possible. Public engagement and policy interventions to improve the quality of death through the provision of high-quality palliative care have gained momentum in recent years, and some countries have made great strides in improving affordable access to palliative care. The Economist Intelligence Unit’s Quality of Death Index, commissioned by the Lien Foundation, highlights those advances as well as the remaining challenges and gaps in policy and infrastructure.

This is the second edition of the Index, updating and expanding upon the first iteration, which was published in 2010. The new and expanded 2015 Index evaluates 80 countries using 20 quantitative and qualitative indicators across five categories: the palliative and healthcare environment, human resources, the affordability of care, the quality of care and the level of community engagement. To build the Index the EIU used official data and existing research for each country, and also interviewed palliative care experts from around the world.

In many countries, the proportion of older people in the population is growing and non-

communicable diseases such as heart disease and cancer are on the rise. The need for palliative care is also therefore set to rise significantly. In supplementary analysis we compare expected growth in the “demand” for palliative care to the existing “supply” for each country (as shown in their Index rankings). The demand analysis is based on forecasts of the burden of disease, old-age dependency ratio, and rate of population ageing over the next 15 years.

Despite the improvements this research reveals, much more remains to be done. Even top-ranked nations currently struggle to provide adequate palliative care services for every citizen. Cultural shifts are needed as well, from a mindset that prioritises curative treatments to one which values palliative care approaches that regard dying as a normal process, and which seeks to enhance quality of life for dying patients and their families.

Key findings of our research include:

- **The UK has the best quality of death, and rich nations tend to rank highest.** As in 2010 the UK ranks first in the 2015 Quality of Death Index, thanks to comprehensive national policies, the extensive integration of palliative care into its National Health Service, and a strong hospice movement. It also earns the

top score in quality of care. In general, income levels are a strong indicator of the availability and quality of palliative care, with wealthy countries clustered at the top of the Index. Australia and New Zealand come second and third overall, and four other comparatively rich Asia-Pacific countries achieve rankings in the top 20: Taiwan at position six, joined by Singapore at 12, Japan at 14, and South Korea at 18. Otherwise, European countries dominate the top 20, with the addition of the US and Canada at positions 9 and 11, respectively.

● **Countries with a high quality of death share several characteristics.** The leading countries have the following elements in place:

- A strong and effectively implemented national palliative care policy framework;
- High levels of public spending on healthcare services;
- Extensive palliative care training resources for general and specialised medical workers;
- Generous subsidies to reduce the financial burden of palliative care on patients;
- Wide availability of opioid analgesics;
- Strong public awareness of palliative care.

● **Less wealthy countries can still improve standards of palliative care rapidly.** Although many developing countries are still unable to provide basic pain management due to limitations in staff and basic infrastructure, some countries with lower income levels prove to be exceptions, demonstrating the power of innovation and individual initiative. For example, Panama is building palliative care into its primary care services, Mongolia has seen rapid growth in hospice facilities and teaching programmes, and Uganda has made huge advances in the availability of opioids.

● **National policies are vital for extending access to palliative care.** Many of the top countries have comprehensive policy

frameworks that integrate palliative care into their healthcare systems, whether through a national health insurance scheme like the UK or Taiwan, or through cancer control programmes such as in Mongolia and Japan. Effective policies can create tangible results: the launch of Spain's national strategy, for example, led to a 50% increase in palliative care teams and unified regional approaches.

- **Training for all doctors and nurses is essential for meeting growing demand.** In high-ranking countries such as the UK and Germany palliative care expertise is a required component of both general and specialised medical qualifications, while several top-scoring countries have established national accreditation systems. Countries without sufficient training resources experience a severe shortage of specialists, while general medical staff may also lack the training to use opioid analgesics appropriately.
- **Subsidies for palliative care services are necessary to make treatment affordable.** Whether through national insurance or pension schemes or through charitable funding (such as in the UK), without financial support many patients are unable to access adequate care. The top scorers in terms of affordability of care—Australia, Belgium, Denmark, Ireland, and the UK—cover 80 to 100% of patient costs for palliative care.
- **Quality of care depends on access to opioid analgesics and psychological support.** In only 33 of the 80 countries in the index are opioid painkillers freely available and accessible. In many countries access to opioids is still hampered by red tape and legal restrictions, lack of training and awareness, and social stigma. The best care also includes inter-disciplinary teams that also provide psychological and spiritual support and physicians who involve patients in decision-making and accommodate their care choices.

- **Community efforts are important for raising awareness and encouraging conversations about death.** The Dying Matters Coalition set up in the UK by the National Council for Palliative Care, a global movement of informal meetings called Death Cafés, and the US-based Conversation Project encourage people to openly discuss their end-of-life wishes and normalise the conversation about dying. Use of television, newspapers and social media by government and non-profit groups in many countries—for instance Brazil, Greece, and Taiwan—has also helped to make headway in mainstreaming awareness of palliative care.
- **Palliative care needs investment but offers savings in healthcare costs.** Shifting from strictly curative health interventions to more holistic management of pain and symptoms can reduce the burden on healthcare systems and limit use of costly but futile treatments. Recent research has demonstrated a statistically significant link in use of palliative care and treatment cost savings, a fact several high-ranking countries have recognised in their bids to expand palliative care services.
- **Demand for palliative care will grow rapidly in some countries that are ill-equipped to meet it.** Countries like China, Greece and Hungary with limited supply and rapidly increasing demand will need active investment to meet public needs. More generally,

demographic shifts to an older population, combined with the rising incidence of non-communicable diseases like diabetes, dementia and cancer, will create additional pressure for countries that already struggle to meet demand.

The EIU's 2010 Index sparked a series of policy debates over the provision of palliative care around the world. Since then, several countries have made significant advances in terms of national policy. Colombia, Denmark, Ecuador, Finland, Italy, Japan, Panama, Portugal, Russia, Singapore, Spain, Sri Lanka, Sweden and Uruguay have all established new or significantly updated guidelines, laws or national programmes, and countries such as Brazil, Costa Rica, Tanzania and Thailand are in the process of developing their own national frameworks. The momentum being gained on palliative care at a policy level has also been strengthened by the international resolution at the 2014 World Health Assembly calling for the integration of palliative care into national healthcare systems.

Each country will need to craft its own unique approach by identifying the most significant gaps, addressing regulatory and resource constraints, and forming partnerships between government, academia, and nonprofit groups. Approaches will vary by context and culture, but share the overall objective of enabling a better quality of life for patients facing death.

About the 2015 Quality of Death Index

In 2010, the EIU developed an Index that ranked the availability, affordability and quality of end-of-life care in 40 countries. The Index, which was commissioned by the Lien Foundation, a Singaporean philanthropic organisation, consisted of 24 indicators in four categories. The study garnered much attention and sparked a series of policy debates over the provision of palliative and end-of-life care 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.

In this, the 2015 version, the number of countries included has been increased from 40 to 80. The Index, which focuses on the quality and availability of palliative care to adults, is also structured differently from the 2010 version (meaning the direct comparison of scores between years is not possible). Now, the Index is composed of scores in 20 quantitative and qualitative indicators across five categories. The categories are:

- Palliative and healthcare environment (20% weighting, 4 indicators)
- Human resources (20% weighting, 5 indicators)
- Affordability of care (20% weighting, 3 indicators)

- Quality of care (30% weighting, 6 indicators)
- Community engagement (10% weighting, 2 indicators)

Each indicator is allocated a weighting in its category, and each category is given a weighting in the overall Index. Parts 1 to 6 of this paper consider in turn the overall results and scores for each of the five categories.

This year, the EIU also prepared a supplementary assessment of the need for palliative care provision, to enable assessment of the “demand” for such care alongside the quality of “supply” revealed in the main Index. This is based on three categories:

- 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%)

The results of this analysis are discussed in Part 7.

A more detailed explanation of the methodology behind the Index and the demand score calculation, and a list of frequently asked questions about the construction, composition and limitations of the research, are included as appendices to this paper.

A note on definitions

The Quality of Death Index measures the quality of palliative care available to adults in 80 countries. Although the terms “palliative care” and “end of life care” are sometimes used interchangeably, the latter is often taken to mean care delivered only in the final stages of a terminal illness. The Index is designed to measure palliative care as defined by the World Health Organization:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.”²

Introduction

As governments across the world work to improve life for their citizens, they must also consider how to help them die well. It is a challenge not to be underestimated. In many countries, older people make up an ever-growing proportion of the population. Meanwhile, the prevalence of non-communicable diseases, such as heart disease, diabetes, dementia and cancer, is increasing rapidly. Taken together, this means that the need for palliative care is set to rise sharply.

“We’ve seen unprecedented changes in the way the world population is moving, with more people over the age of 65 than under the age of five,” says Stephen Connor, senior fellow at the Worldwide Hospice Palliative Care Alliance (WHPCA). “That’s never happened in human history before and it’s going to continue to get more pronounced.”

Yet many countries remain woefully ill-equipped to provide appropriate services to these citizens. Despite improvements in recent years and greater attention to the issue, just 34 countries have above-average³ scores in the 2015 Quality of Death Index. Together these account for just 15% of the total adult population of the countries in the Index (which themselves account for 85% of the global adult population)⁴, meaning the vast majority of adults lack access to good

palliative care. (Given better palliative care is generally available in richer countries with older populations, this rises to 27% of the population aged 65 or over. The Index covers 91% of the global population of those aged over 65.⁵) Separately, the WHPCA estimates that globally under 10% of those who require palliative care actually receive it.⁶

Even those countries that do well in the Quality of Death Index cannot meet all the needs of those requiring palliative care, with evidence of shortfalls continuing to emerge in nations that—in relative terms—have highly sophisticated services.

Take the UK, which tops the overall Index. In May 2015, an investigation by the Parliamentary and Health Service Ombudsman into complaints about end-of-life care highlighted 12 cases it said illustrated problems it saw regularly in its casework.⁷ Failings included poor symptom control, poor communication and planning, not responding to the needs of the dying, inadequate out-of-hours services and delays in diagnosis and referrals for treatment.

The fact that the UK, an acknowledged leader in palliative care, is still not providing adequate services for every citizen underlines the challenge facing all countries. Because while

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*Stephen Connor, senior fellow,
Worldwide Hospice Palliative
Care Alliance*

greater numbers of people are living longer, they are not necessarily doing so in good health. Often they may have several illnesses, making the process of dying more drawn-out and demanding increasingly complex forms of treatment.

This places a heavy burden on healthcare systems, most of which are struggling to adapt—and one of the hardest shifts to make is cultural. “The biggest problem that persists is that our healthcare systems are designed to provide acute care when what we need is chronic care,” says Dr Connor. “That’s still the case almost everywhere in the world.”

This is also true in the US, another country that performs well in the Index. “Our health systems focus on diagnosing and treating diseases and are demonstrably negligent in meeting the needs of patients and families going through these difficult experiences,” says Ira Byock, executive director and chief medical officer of the Institute for Human Caring at Providence Health & Services and author of the book, *The Best Care Possible*.

The irony is that as countries struggle to cope with rising healthcare costs, palliative care could be a more cost-effective way of managing the needs of an ageing population. One recent literature review found that palliative care was frequently found to be cheaper than alternative forms of care and that, in most cases, the cost difference was statistically significant.⁸ Another recent study found that the earlier palliative care was administered to patients with an advanced cancer diagnosis, the greater the potential cost savings. If palliative care treatment was introduced within two days of diagnosis this led to savings of 24% compared with no intervention; its introduction within six days saved 14%.⁹

Yet, despite evidence of its economic benefits, a tiny proportion of healthcare research goes into research on palliative care (about 0.2% of the funds awarded for cancer research in the UK in 2010, for example, and just 1% of the US National Cancer Institute’s total 2010 appropriation¹⁰).

“A key factor limiting research is that it’s really poorly funded,” says Katherine Sleeman, clinical lecturer in palliative medicine at King’s College London. “This is something that arguably will affect every single person and yet we invest almost nothing in trying to work out how to do it better.”

More worrying, many developing countries are unable to offer basic pain management, leaving millions of people dying an agonising death.

Nevertheless, evidence of innovation is coming from unexpected quarters. Mongolia and Panama (in positions 28 and 31 respectively in the Index), are showing that even less wealthy countries can increase the availability and quality of care, relatively quickly.

And when it comes to the availability of morphine, Uganda has made striking advances in pain control through a public-private partnership between the health ministry and Hospice Africa Uganda, a pioneering institution founded by Anne Merriman—a nominee for the 2014 Nobel Peace Prize. “The government now supports the availability of oral morphine to anyone who needs it for free,” explains Emmanuel Luyirika, executive director of the African Palliative Care Association.

Some developing countries can move forward relatively rapidly because of the absence of entrenched systems, says Mark Steedman, PhD programme manager for the End-of-Life Care Forum at Imperial College London’s Institute of Global Health Innovation. “We think there are places where there’s a lot of potential,” he says. “When you’re starting from zero you can leapfrog a lot of the problems.”

Richard Harding, who developed the African programme for Cicely Saunders International (an NGO focused on research on and education about palliative care) at King’s College London, sees this principle at work in Africa. “African countries have succeeded in delivering high quality effective palliative care in the face of low

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Katherine Sleeman, clinical lecturer in palliative medicine, King’s College London

resources and overwhelming need,” he says. “And high- and middle-income countries would be wise to learn lessons from them.”

When looking more broadly, Sheila Payne, emeritus professor at the International Observatory on End of Life Care at Lancaster University, sees progress being made. “There’s a general trend in which we’re moving from the pioneer stage in many countries to people seeing how they can embed palliative care in healthcare systems,” she says. “That’s really important because that’s about sustainability.”

In a major step forward, the World Health Assembly—WHA, the forum through which the World Health Organization is governed—last year published a resolution on palliative care calling on member states to integrate it into national healthcare systems (see the box in Part 5). “That sets the policy context and legitimises governments getting engaged,” says Dr Payne. “In the policy context, that’s a big development.”

In addition, in its global action plan for the prevention and control of non-communicable diseases for 2013–2020, the WHO has included palliative care among the policy areas proposed to member states. The WHO is also shifting its focus to place more attention on non-communicable diseases.

The question that lies ahead is how quickly and effectively member states can put in place measures that can meet the recommendations of the WHA resolution and increase access to opioids and palliative care. And while developing countries need to scale up promising pioneer programmes, countries that already have sophisticated palliative care provision need to find ways to meet the growing demands of a rapidly ageing population.

However, some argue that, even without large investments, significant improvements can be made in palliative care. “The things that make a better death are so simple,” says Ros Taylor, national director for hospice care at Hospice UK. “It’s basic knowledge about good pain control and conversations with people about the things that matter—that could transform many more deaths.”

For policymakers, major issues to consider are availability of care, human resources and training, affordability of care, quality of care and community engagement through public awareness campaigns and support volunteers. These issues are covered by the five categories in the 2015 Quality of Death Index. In each, the Index looks at how countries measure up against other nations, as well as against their regional peers and those with similar income levels.



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The 2015 Quality of Death Index—
overall scores

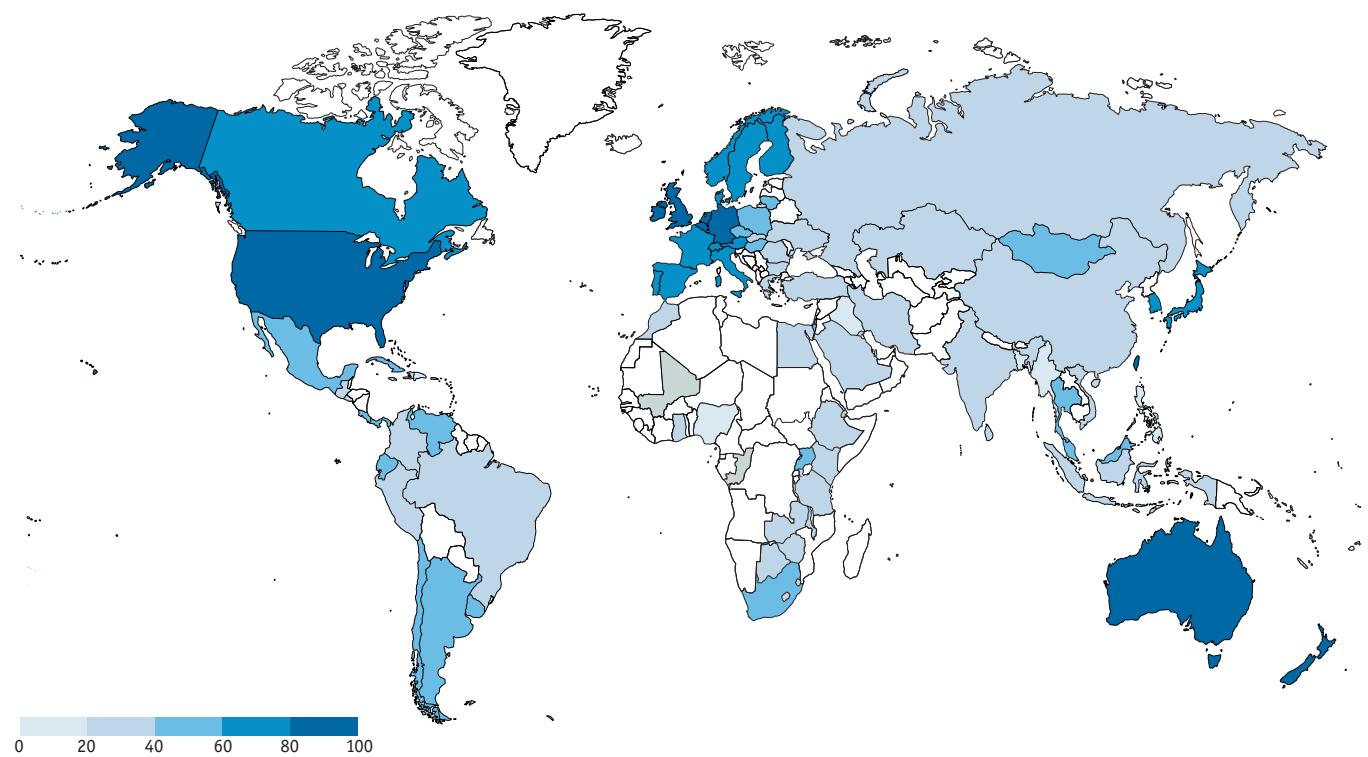
In assessing the results of the 2015 Quality of Death Index, it is no surprise to find that wealthy countries dominate the top of the list, while their poorer counterparts are clustered together in its lower sections. In fact, income levels are a strong indicator of the availability and quality of palliative care. However, there are exceptions to this rule, often in places where an individual is championing the cause or where certain circumstances—the spread of HIV-Aids

in some African, countries, for example—have been catalysts for innovation and investment.

As was the case in 2010, the UK tops the Index, followed by Australia and New Zealand (which took second and third in 2010). The UK's leading position reflects the attention paid to palliative care in both public and non-profit sectors. With a strong hospice movement—much of it supported by charitable funding—palliative

Figure 1.1

2015 Quality of Death Index—Overall scores



and end-of life care are both part of a national strategy that is leading to more services being provided in National Health Service hospitals, as the country works to integrate hospice care more deeply into the healthcare system.¹¹ “People have woken up to the fact that we may be able to save money overall for society by investing in dying better,” says Dr Sleeman.

While Australia and New Zealand are in the top three, four other Asia-Pacific countries make it into the top 20, with Taiwan at position six, Singapore at position 12, Japan at position 14 and South Korea at position 18. For these countries, government engagement has been crucial. Among other factors, Taiwan benefits from the country’s National Health Insurance, which determines insurance coverage and the level of reimbursement for specific services.¹² Japan (which performed relatively poorly in the 2010 Index, at position 23 of 40) is instituting a new cancer control programme, which is expected to prompt an increased focus on palliative care from the early stages of the disease along with the incorporation of palliative care centres into the national budget.¹³

And in Singapore, which is grappling with a rapidly ageing population, caring for people towards the end of their lives has risen up the agenda for healthcare policymakers. Singapore recently developed a national palliative care strategy and the Ministry of Health is working both to increase the number of services available and to empower individuals to make their own decisions on end-of-life care.¹⁴

However, while the European, Asia-Pacific and North American countries in the top of the Index benefit from relatively high levels of government support, several less wealthy countries with less well developed healthcare systems stand out. These include Chile, Mongolia, Costa Rica and Lithuania, which appear in the top 30, at positions 27, 28, 29 and 30 respectively.

Figure 1.2

2015 Quality of Death Index—Overall scores

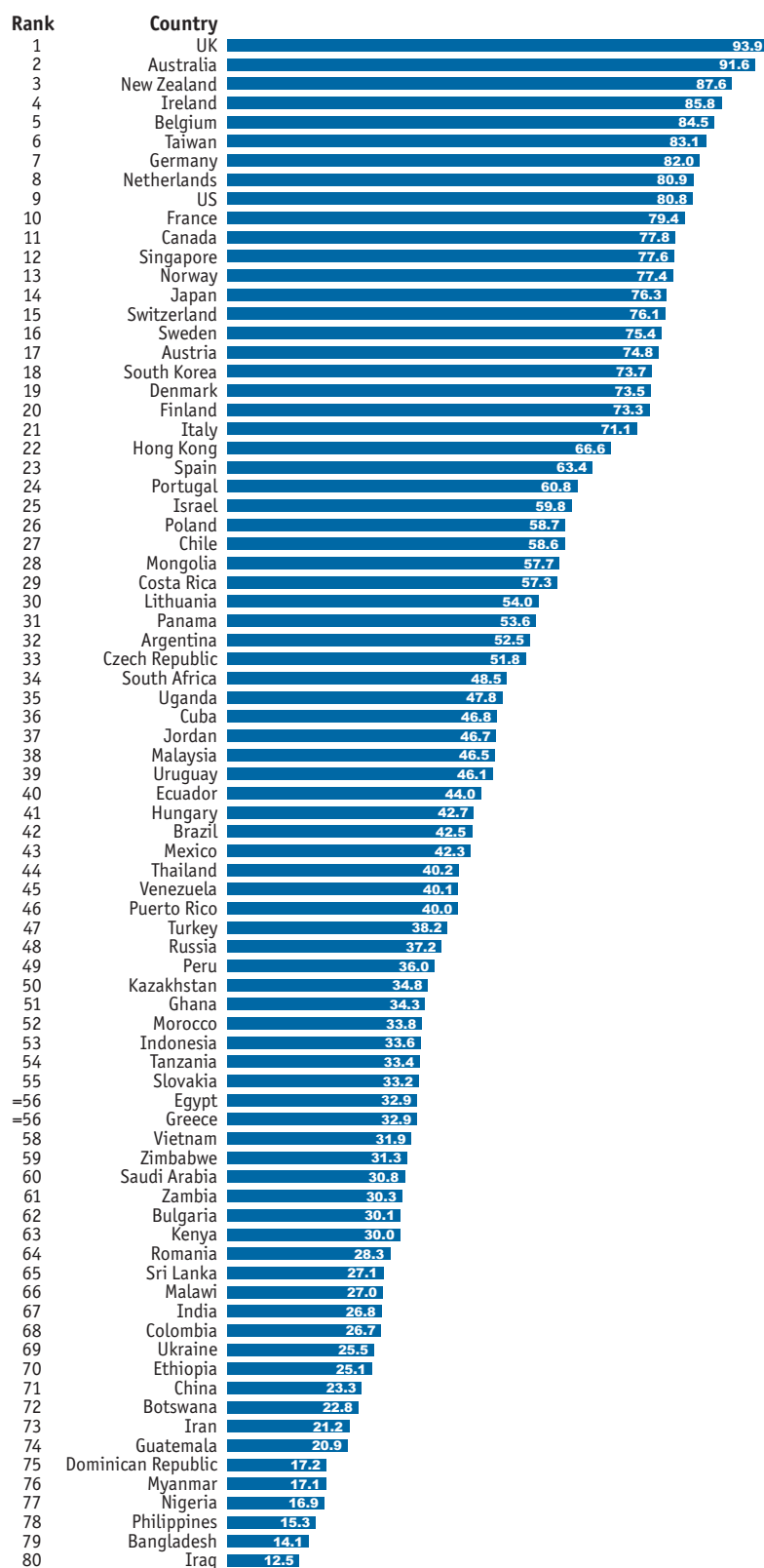
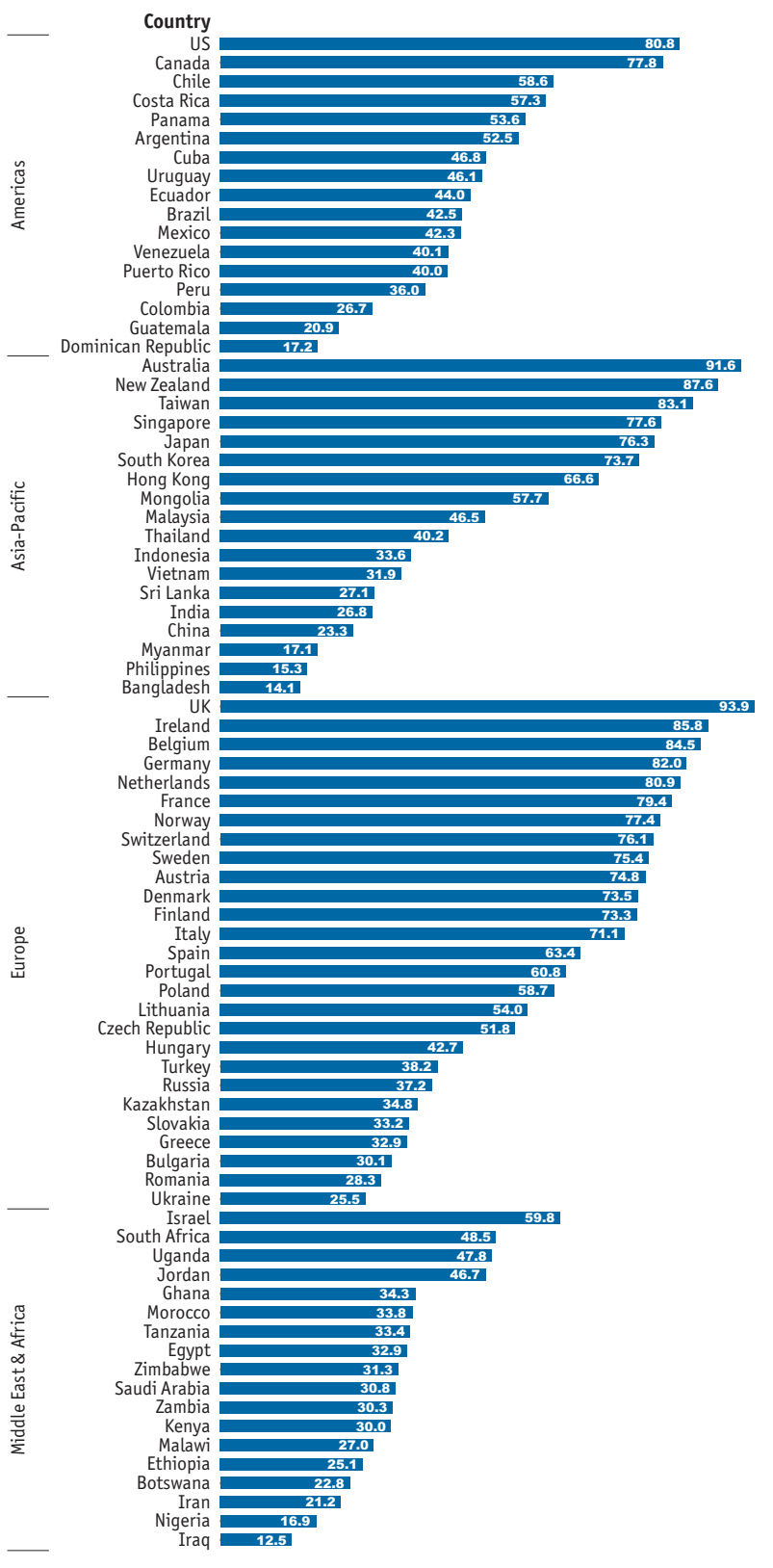


Figure 1.3

2015 Quality of Death Index—Ranking by region



Mongolia is an impressive case. The driving force behind the increase in palliative care in the country is Odontuya Davaasuren, a doctor who is helping to build a national palliative care programme, pushing to change prescription regulations to make generic opioids available, training palliative care specialists, and working to include education on palliative care in the curricula for doctors, nurses and social workers. “She’s a brilliant teacher, leader and visionary,” says the WHPCA’s Dr Connor. “And leadership is critical to any change process in anywhere in the world.”

By contrast, some countries that might be expected to perform more strongly, given their rapid recent economic growth, rank at low positions in the Index. India and China perform poorly overall, at positions 67 and 71 in the Index. In the light of the size of their populations, this is worrying.

In China’s case, a rapidly ageing demographic presents additional challenges. The adoption of palliative care in China has been slow, with a curative approach dominating healthcare strategies. This may be about to change, as recent shifts in policy, mainly at the municipal level, indicate greater government support and investment in hospice and palliative care services.

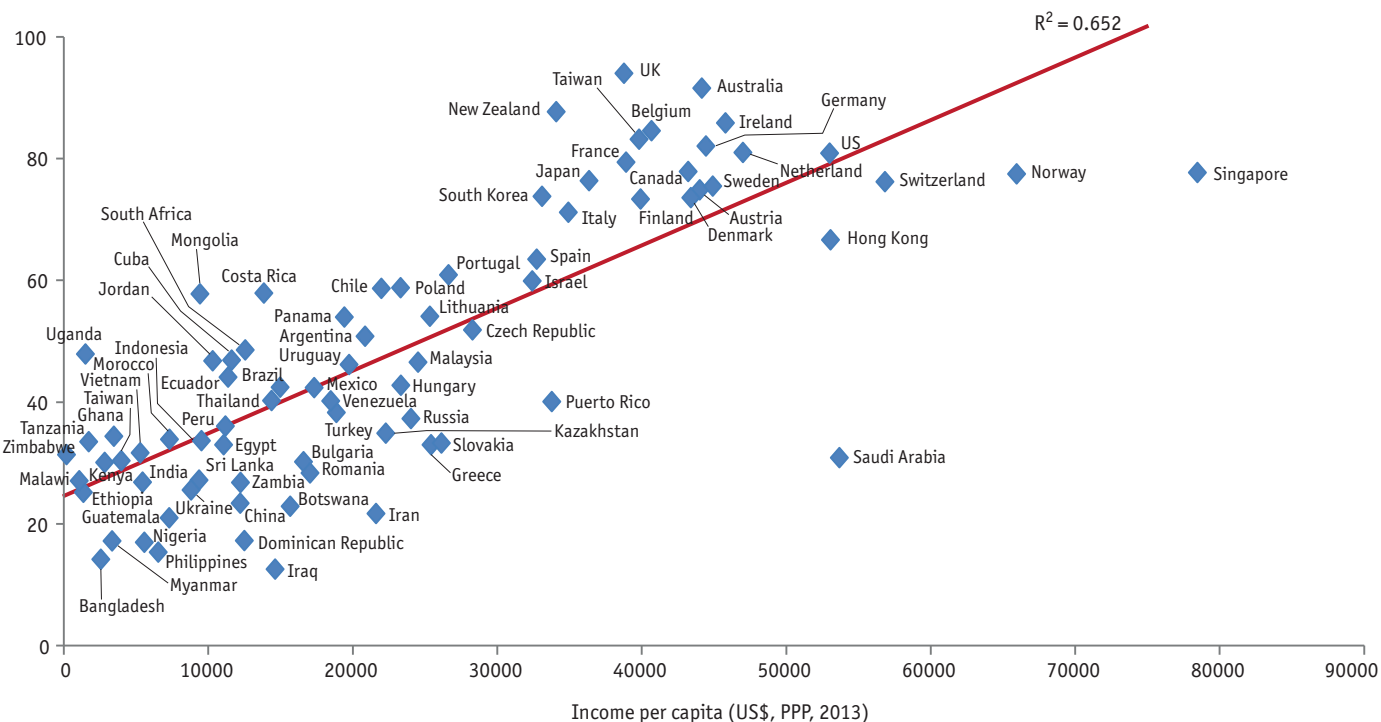
Regional variations are present in the Index, and there are surprises here, too. In the Americas, the US and Canada top the list, as might be expected. But Chile is in third place, making it a leader in Latin America—with the highest number of palliative care services in the region.¹⁵ Chile’s position in the Index reflects the efforts made to incorporate palliative care into healthcare services and to develop policies for access to opioids since the country launched its palliative care programme in 1996.^{16, 17}

Figure 1.4

Correlation with per-capita GDP

(2013, US\$, ppp)

Quality of Death overall score (100=best)



Income levels correlate quite strongly with relative success in delivering palliative care services (as Figure 1.4 demonstrates). The top 10 countries in the Index are all high-income countries, although within the high income group, some countries experiencing economic difficulties—such as Greece (equal 56th place) and Russia (48th)—can be found among the poorer performing nations (Figure 1.5).

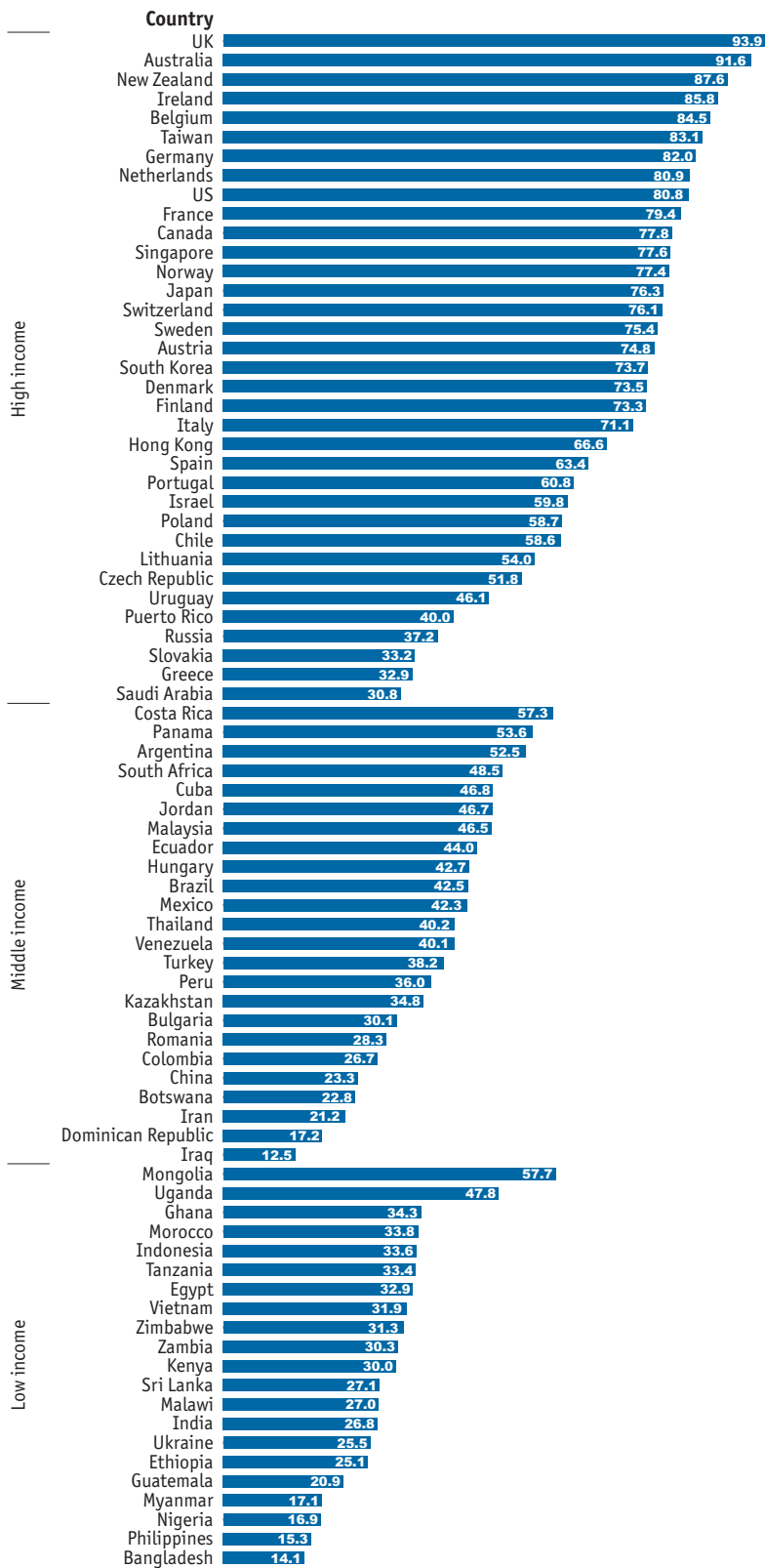
Within regions a similar principle applies. Israel (a high income country) and South Africa (a middle-income country) earn the first and second highest scores among the 18 Middle Eastern and African countries. Meanwhile, four of the last five countries in the Index—Myanmar, Nigeria, the Philippines and Bangladesh—are low-income

countries. However, some countries do not perform as well as one might expect, given their wealth. This is the case for Singapore, for example, which does not make it into the top 10, and Hong Kong, which is only at position 22 in the Index.

In the case of Singapore, the government is working to catch up following years when it invested relatively little in palliative care. “Singapore has one of the fastest ageing populations in the world but until about 25 years ago, we had a young population,” says Cynthia Goh, chair of the Asia Pacific Hospice Palliative Care Network. “So we built up a pretty good acute care system, but when it comes to chronic diseases and end of life, there is a lot of catching up to do.”

Figure 1.5

2015 Quality of Death Index—Ranking by income group



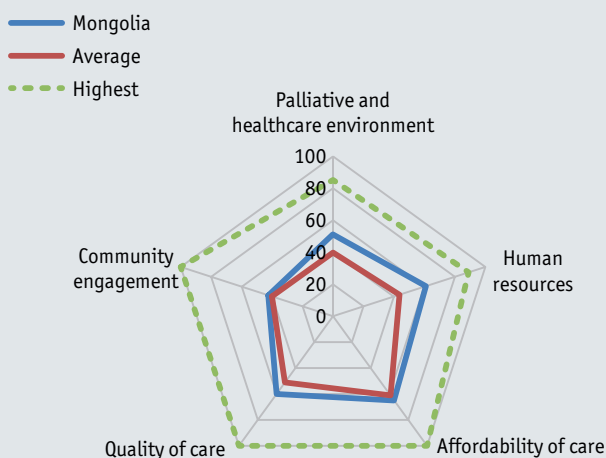
Note: Low income countries are those that had 2013 GNI per capita of less than US\$4,125; middle income countries more than US\$4,125 but less than US\$12,746; and high income countries more than US\$12,746.

The discrepancies that emerge between income and Index performance and the presence of outliers such as Mongolia are in themselves enlightening. They serve to demonstrate that there are no simple answers for countries when it comes to providing the care that is so essential for their ageing and dying citizens.

A complex range of factors—economic, social, cultural and political—need to be taken into account before palliative care can be delivered effectively. By factoring in everything from certifications for specialist palliative care workers to the availability of opioid analgesics, the following five categories that together constitute the Index provide insights into why some countries are succeeding while others are failing.

Case study: Mongolia—A personal mission

	Rank/80	Score/100
Quality of Death overall score (supply)	28	57.7
Palliative and healthcare environment	24	51.3
Human resources	21	61.1
Affordability of care	=36	65.0
Quality of care	=32	60.0
Community engagement	=27	42.5



When in 2000 the Mongolian Palliative Care Society (MPCS) was established, it marked the start of efforts to fill a gaping hole in palliative care services. Until then, the country had no hospices or palliative care teaching programmes, it used just 1kg of morphine each year, and no government policy on palliative care existed.¹⁸

“We did not even have the terminology for palliative care,” explains Odontuya Davaasuren, the driving force behind the creation of palliative care services in Mongolia.

It was in 2000, after attending a conference in Stockholm of the European Association for Palliative Care, that Dr Davaasuren decided to take action. On returning to Mongolia, she made visits to patients with her postgraduate students and recorded the conversations with families. “I saw so much suffering in families—not just physical but also psychological and economic,” she says.

Funding from the Ford Foundation and the Open Society Foundations helped Dr Davaasuren in her efforts to build

awareness among the public, health professionals and policymakers, to develop specialised training in palliative care, and to increase access to painkilling drugs.

However, Dr Davaasuren admits that the work has not always been easy, particularly as when she started neither the public or health ministry officials were aware of the existence of palliative care services. “No one talked about it,” she says. “And policymakers are very conservative, so it was very difficult to change the laws and regulations.”

While much work remains to be done to accommodate everyone in need of care, as a result of Dr Davaasuren’s efforts the situation today is vastly improved. Ulaanbaatar, the capital, now has ten palliative care services (with the largest facility at the country’s National Cancer Center). Outside the city, provincial hospitals now accommodate patients in need of palliative care.

Palliative care is also now included in Mongolia’s health and social welfare legislation and its national cancer control program. Since 2005, all medical schools and social workers receive palliative care training. And, since 2006, affordable morphine has been available.¹⁹ In 2013, Dr Davaasuren says, the country started non-cancer palliative care provisions, outpatient consultation and nursing, home care, and spiritual and social services.

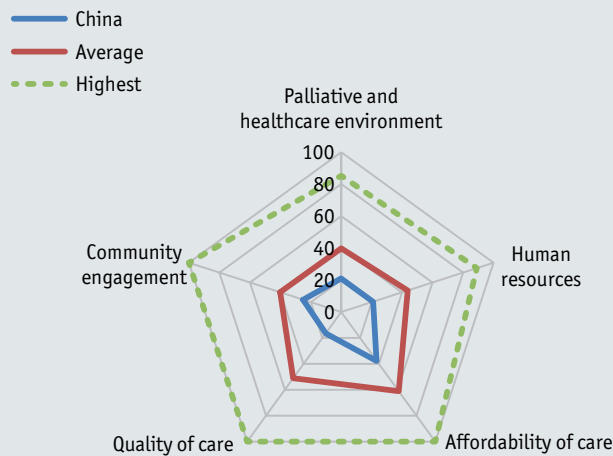
All this is reflected in the Index, in which Mongolia makes it into the top 30 in the overall ranking (at position 28) as well as in three of the Index’s categories (palliative and healthcare environment, human resources and community engagement). It ranks first among its peers in the “low income” bracket—around ten points ahead of the second-ranked country in this group, Uganda. Plotting Index scores against per-capita income (see Figure 1.4) reveals that Mongolia overachieves by some margin given its resources.

The next challenge, Dr Davaasuren says, is to expand the provision of non-cancer and paediatric palliative care services while also increasing the availability of home care and services for those living in the provinces.

For Dr Davaasuren, the ability for those in pain and with incurable diseases to receive palliative care is not just a case of expanding services to meet rising need—it is about meeting a basic human right.

Case study: China—Growing awareness

	Rank/80	Score/100
Quality of Death overall score (supply)	71	23.3
Palliative and healthcare environment	69	21.1
Human resources	70	21.0
Affordability of care	=65	37.5
Quality of care	69	16.3
Community engagement	=45	25.0



The adoption of a palliative care approach in China has been slow, with most healthcare resources focused on curative treatment. Although the national Ministry of Health officially endorsed the establishment of palliative care departments in hospitals in 2008,²⁰ public awareness of and access to palliative care is still limited. Outside of China's 400 specialised cancer hospitals, there are only a handful of charity hospitals and community health centres that offer palliative care services to patients.

China's overall rank of 71st out of 80 countries reflects this limited availability and the poor quality of palliative care in general. Service accessibility stands at less than 1% with most hospices concentrated in the urban areas of Shanghai, Beijing and Chengdu; there is no national strategy or guidelines; use and availability of opioids is limited; and patient-doctor communication is poor.²¹ In addition, if care is not covered by charitable donations the financial burden on patients can be quite high. As with most medical treatments in China, public subsidies do not fully cover the cost and patient contributions are required.

A recent shift in government policy, mainly at the municipal level, signals a trend of greater support and investment in hospice care services. Cities like Shanghai, Shenzhen and Tianjin have set new targets and policies to increase access

to palliative care. Shanghai planned to add 1,000 beds for hospice patients by the end of 2014, some in hospitals and some in community-based health care centres,²² and Tianjin recently added hospice care to the official list of government-funded social services.²³

Shi Baoxin, director of the Hospice Care Research Center at Tianjin Medical University, says that despite improved awareness and expansion of palliative care in China over the past 20 years, it's still early days. "It's hard for hospice care to develop mainly because of the lack of education about death," Dr Shi says, adding that this also makes effective psychological treatment of dying patients more challenging.

This lack of awareness extends to medical professionals. Ning Xiaohong, an oncologist at Peking Union Medical College Hospital, says that teaching of palliative care concepts in medical training is extremely limited, which means that most practicing professionals have never been exposed to essential concepts or techniques. In response, Dr Ning is developing an online course on palliative care to be used on an annual basis.

Cheng Wenwu, director of the Department of Palliative Care at Fudan University Cancer Hospital, agrees that the lack of professional knowledge and low public awareness mean that both patients and doctors focus on curative treatments, and don't think about palliative care options. However, public awareness is gradually increasing, spread via TV and newspapers and also word of mouth. Dr Ning reports an increase in the last few years, and says she now sees some patients at her clinic coming in with questions about palliative care options.

Without government subsidies, financial costs are a major challenge, as palliative care is generally not supported through the national health security system. Songtang Hospice in Beijing was one of the earliest palliative care institutions, founded in 1987, and currently cares for around 320 patients. While the costs of care are relatively low, on average RMB1,000-2,000 (US\$160-320) per month, patients still struggle to afford it, says Li Wei, the hospital's founder.

In addition to financial barriers, cultural beliefs also hinder the widespread use of palliative care. According to Dr Li, most

“The biggest challenge is to change people's minds, to let them know that society can take good care of their parents in the late stages of illness and help them die with dignity.”

Li Wei, founder, Songtang Hospice, Beijing

Chinese still follow the tradition of “raising children to care for you in old age,” and many families feel that to outsource care of relatives, even in their final days, is unfilial.

“The biggest challenge is to change people’s minds, to let them know that society can take good care of their parents in the late stages of illness and help them die with dignity,” Dr Li says. The impact of the one-child policy, often leaving individuals caring for two parents and four grandparents, will lead to even more demand for outside resources to provide support.

The most innovative aspects of providing palliative care in China are not technical, but cultural. According to Dr Shi, “We follow the Western ideas for hospice treatment, but our

main improvement is to apply Chinese traditional culture to psychological counseling, for example we do research to understand how people of different classes and ages think of death, to figure out how to help them psychologically.”

Meanwhile, Songtang Hospice has worked with many volunteers who provide psychological and emotional support to patients, in the process educating community members about palliative care. Public awareness is also growing through scattered social media efforts, such as an online campaign on “Choice and Dignity” founded by the children of senior Communist Party members, which encourages visitors to sign living wills.²⁴

2

Palliative and healthcare environment

Given the avalanche of demand heading towards governments around the world, an important indicator of countries' success in delivering palliative care is the extent to which services are available—whether in hospices, hospitals, care homes or people's own homes. To assess this, the Index uses a range of indicators, including a nation's overall spending on healthcare, the presence and strength of government policies on palliative care, the availability of research-based policy evaluation and the capacity to deliver palliative care services.²⁵

In this category, in which the UK tops the list, six of the top 10 countries are European, along with Australia, Taiwan, the US and New Zealand. Regionally, some surprises emerge. Among Asia-Pacific countries, it is notable that Vietnam and Mongolia make it into the top 10. And in the Americas, while as expected the US and Canada top the list, Chile is in fourth place. This, says Eduardo Yanneo, chairman of the Montevideo-based Latin American Association for Palliative Care, is "because it has one of the oldest national programmes in the region, with government support since the beginning."

Not all high-income countries perform well in the Index. Hong Kong is relatively low in the overall ranking of this category, at position 28—lower than Panama (at position 25), a middle-income country, and Mongolia (at position 24), a low-income country. Hong Kong scores relatively poorly in terms of overall healthcare spending, the availability of research-based

policy evaluation and its capacity to deliver palliative care services.

National policies play a vital role in extending access to palliative care. As a result, the presence and effectiveness of government policies receives a 50% weighting in this category (and because this category is given a 20% weighting in the overall Index, this indicator represents 10% of the entire Quality of Death score).

While changes in methodology and scope mean direct comparisons with the 2010 Index are not possible, several countries have made policy advances that are reflected in a higher ranking in the 2015 Index. Singapore was at position 18 in 2010—roughly midway down the 40-country list—and is now at position 12 out of 80 countries, having developed a national palliative care strategy that was accepted in 2012 and is now being implemented.

India, which was at the bottom of the list in the 2010 Index, is at a slightly higher position in 2015—at 51—reflecting a stronger indication of government commitment. While the budget allocation for India's 2012 National Program for Palliative Care was withdrawn, elements of the strategy remains in place and, as a result, some teaching programmes are emerging across the country. Moreover, recent legislative changes have made it easier for doctors to prescribe morphine in India.

Meanwhile, Japan—which only just made it into the top half of the 2010 Index—is at 14 in the 80-country 2015 listing. Various initiatives have strengthened palliative care services in Japan, such as the 2012 Basic Plan to Promote Cancer Control Programs, which includes provision of holistic care to cover patients’ and families’ pain and distress from diagnosis onward, and the launch that year of a Care for Life-threatening Illnesses programme of palliative care education for paediatricians.

In addition, to cite some other examples (not all of which were included in the 2010 Index), Colombia, Denmark, Ecuador, Finland, Italy, Panama, Portugal, Russia, Spain, Sri Lanka, Sweden and Uruguay have all established new or significantly updated guidelines, laws or national programmes in recent years, and countries such as Brazil, Costa Rica, Tanzania and Thailand are in the process of developing their own national frameworks.

For the most part, the countries scoring highly in the overall Index are also those that have the most effective national palliative care strategies. Mongolia—where palliative care is included in the country’s health and social welfare legislation and its national cancer control programme²⁶—does far better than may be expected due in part to its strength in this indicator.

Other examples of the importance of national planning in improving palliative care provision are commonplace. In Colombia, a law signed into effect in 2014 gives patients with terminal, chronic, degenerative and irreversible conditions the right to palliative care services “through an integrated treatment of pain and other physical, emotional, social and spiritual symptoms”. Under the law, the health system and the government are obliged to offer palliative care services throughout the country, to educate health professionals and to ensure opioids are available at any time.²⁷ “It’s early

Figure 2.1

Palliative and healthcare environment category (20% weighting)

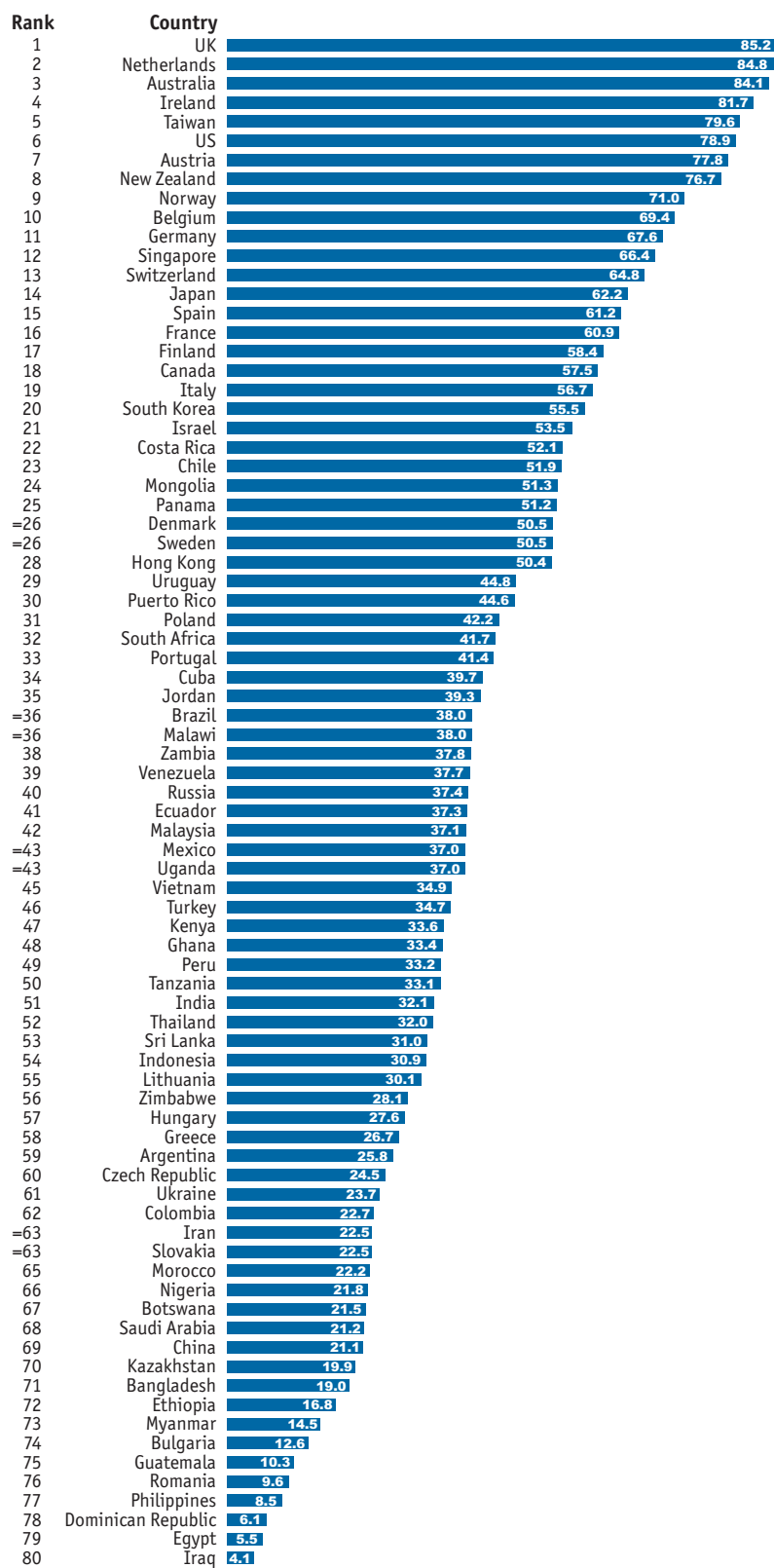


Figure 2.2: Presence and effectiveness of government-led national palliative care strategy

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There is a comprehensive strategy for the development and promotion of national palliative care. It has a clear vision, clearly defined targets, an action plan and strong mechanisms in place to achieve targets. In federal-structure countries, there are strong and clearly defined strategies that individual states must follow. These mechanisms and milestones are regularly reviewed and updated.		There is a well-defined, government-led strategy for the development and promotion of national palliative care. It has a clear vision and specific milestones. There are mechanisms in place and guidelines on implementation. It is mostly well implemented, even in federal-structure countries.		There is a government-led strategy for the development and promotion of national palliative care. This has a broad vision, and loosely defined milestones (no specific targets). There are limited mechanisms in place that aim to achieve milestones. In federal-structure countries, states are not mandated to follow the national strategy; i.e. it is only prescriptive in nature		There is a government-led strategy for the development and promotion of national palliative care. However, it is merely a statement of broad intent. It does not contain a clear vision or specific milestones to achieve. There are no clear mechanisms in place to achieve the strategy.		There is no government-led strategy for the development and promotion of national palliative care.	
Australia Ireland Netherlands New Zealand	Singapore Taiwan UK	Austria Belgium Chile Finland France Germany Hong Kong Israel Italy	Japan Mongolia Norway Panama South Korea Spain Switzerland US	Brazil Canada Costa Rica Cuba Denmark Ecuador Ghana India Indonesia Jordan Kenya Malawi Malaysia Mexico Peru Poland	Portugal Puerto Rico Russia South Africa Sri Lanka Sweden Tanzania Thailand Turkey Uganda Uruguay Venezuela Vietnam Zambia Zimbabwe	Argentina Bangladesh Botswana China Colombia Czech Republic Ethiopia Greece Hungary	Iran Kazakhstan Lithuania Morocco Myanmar Nigeria Saudi Arabia Slovakia Ukraine	Bulgaria Dominican Republic Egypt	Guatemala Iraq Philippines Romania

days,” says Dr Payne. “But there are things happening there that show great promise.”

In Spain, it was the 2007 launch of a national strategy that led to an increase of 50% in the number of palliative care teams and unified regional approaches to palliative care, according to Javier Rocafort Gil, former president of the Spanish Association for Palliative Care.²⁸

The relationship between healthcare spending and availability of palliative care is more complex. (In this category, government spending on healthcare—which is used as a proxy for palliative

care spending, for which comparable data are not always available—is given a 20% weighting, so represents 4% of the overall Index; Figure 2.3.) For example, while the US is at top of the list when it comes to healthcare spending (equivalent to 17.9% of GDP in 2012), it is only at position 6 in this category of the Index. And while the UK tops the list in this category, it falls to position 17 looking at healthcare spending alone (9.4% of GDP).

Singapore is an even more dramatic outlier, since its Central Provident Fund—a comprehensive social security system based on

a savings plan that is compulsory for all working residents—covers a large proportion of national healthcare costs, with individuals paying for healthcare out of their fund. However, in recent years, falling birth rates and smaller family units have meant that, when it comes to caring for the elderly and dying, the traditional system of care by relatives has broken down. As a result, Singapore has had to raise its healthcare spending. The government has increased healthcare coverage for the elderly while the national healthcare insurance programme has been enhanced, dramatically improving affordability.

The discrepancies reflect differences in the way palliative care is delivered around the world. For while governments are responsible in some places, a variety of organisations, from philanthropic groups to religious institutions, extend the reach of those services in many countries.

The US, for example, has a high level of spending on palliative care through the government-funded reimbursement for hospice care through Medicare, the federal programme providing health insurance coverage to all individuals over the age of 65.

In the UK, the hospice movement, which delivers much of the country's palliative care, is funded largely through charitable donations. In Singapore, too, the charitable sector was behind the hospice movement. "A group of volunteers identified a gap in the services, and it was a gap the government at the time wasn't prepared to work on," explains Dr Goh. However, she says, while the voluntary sector continues to run the services, the government now funds them, providing approximately 30-60% of their financial requirements.

Figure 2.3

Correlation with spending on healthcare

(% of GDP, 2012)

Quality of Death overall score (100=best)

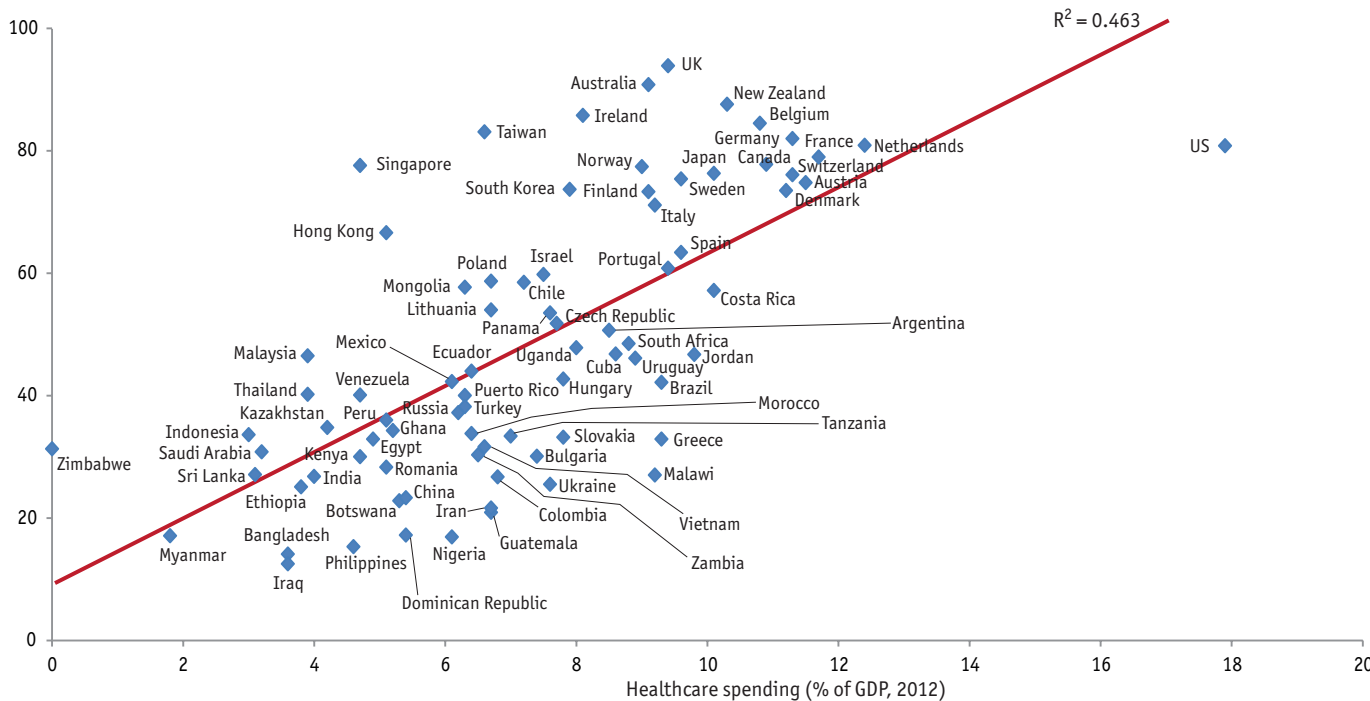
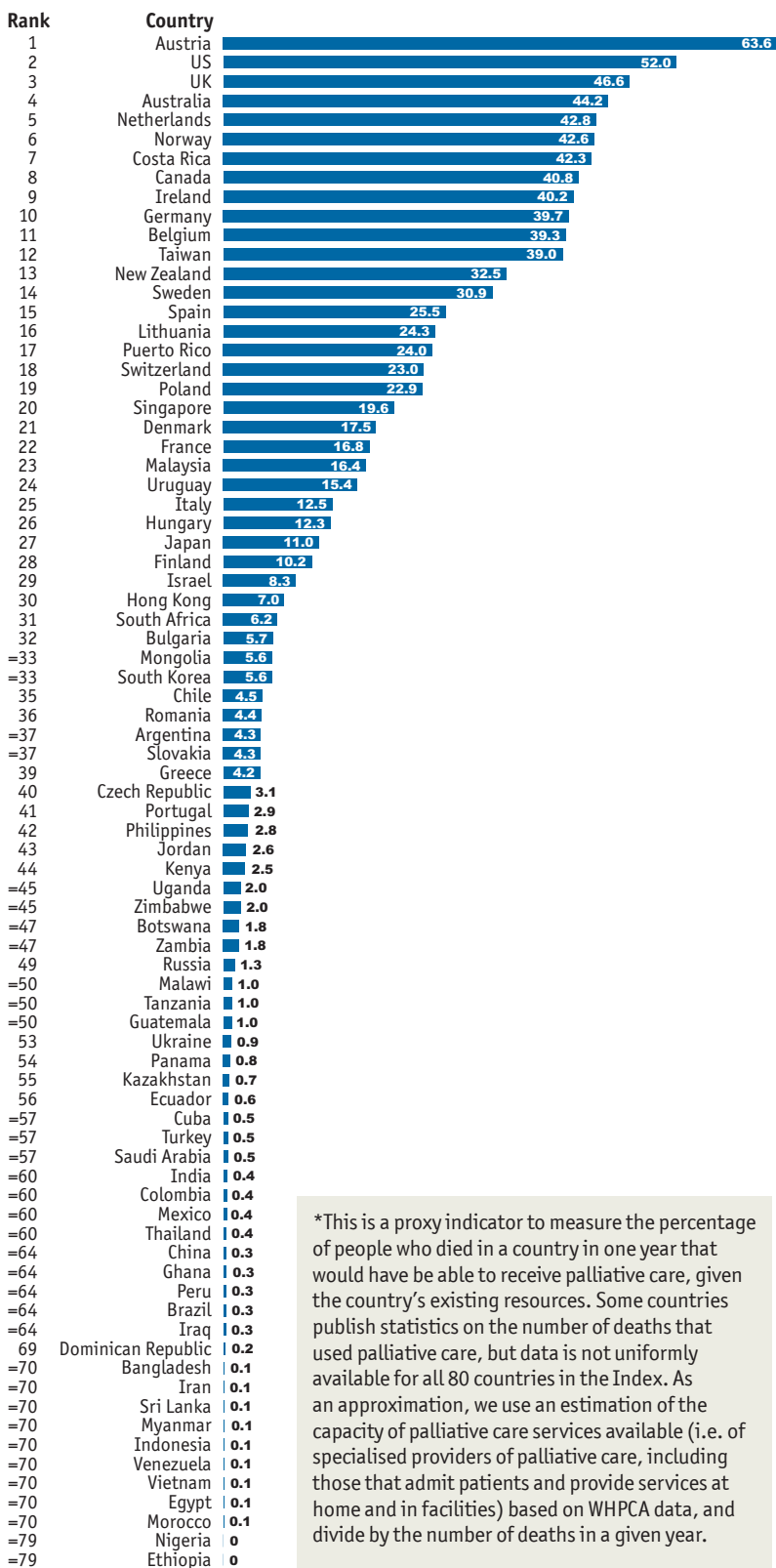


Figure 2.4

Capacity to deliver palliative care* (%)



*This is a proxy indicator to measure the percentage of people who died in a country in one year that would have been able to receive palliative care, given the country's existing resources. Some countries publish statistics on the number of deaths that used palliative care, but data is not uniformly available for all 80 countries in the Index. As an approximation, we use an estimation of the 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) based on WHPCA data, and divide by the number of deaths in a given year.

Similarly, of the large network of hospices in South Africa, most are non-governmental organisations, with churches also providing services. South Africa has developed a highly integrated model of palliative care through its hospice movement, says Dr Harding. "Their hospices don't just focus on end-of-life care," he says. "They are out in the community providing TB control, family education, diagnosis, infection control and going into clinics to provide basic HIV care."

Yet even in countries that have robust policies and funding for palliative care, gaps in provision exist—gaps that may increase with the rise in the proportion of older citizens in the coming years.

In Australia, which ranks second in the overall Index and third in the palliative and healthcare environment category, responsibility for healthcare is devolved to the states, which can lead to inconsistency in care delivery.

"There isn't an equitable spread of funding across the country," says Liz Callaghan, chief executive of Palliative Care Australia (PCA). "You'd hope it would be based on what the population needs. Everyone talks about it, but that's very far away. In some states funding for palliative care is extremely low so the multidisciplinary team might be just a doctor and a nurse."

But while increased government funding for healthcare might seem to be the answer, this may not always be the case. In the US, tighter scrutiny of healthcare spending by both government and private insurers could actually be a force driving increased use of palliative care, as it becomes clear that palliative care is a cost-effective alternative to hospital admissions.

As part of this, health systems' and hospitals' reimbursements are increasingly being tied to quality measures, including whether patients are readmitted within 30 days. In Pennsylvania,

for example, Medicaid—the federally funded healthcare programme for low-income Americans—does not reimburse healthcare providers for all 30-day readmissions.

“If we take care of a Medicaid patient and they come back, the cost of the second readmission is on us,” says David Casarett, director of hospice and palliative care at the University of Pennsylvania Health System. “So the attention to 30-day readmissions is starting to drive a lot of interest in palliative care.”

The preference of many people to die at home is another reason hospice infrastructure needs to be balanced with the availability of outpatient palliative care. And as countries are faced with rapidly ageing populations and healthcare resources become more tightly stretched, more and more palliative care will need to take place outside formal hospice or hospital settings.

“Everyone is getting older, deaths are becoming more complicated, the number of deaths per year is increasing and hospices only cater to about 6% of all deaths,” says Dr Sleeman. “So there’s no way we’ll ever have enough in-patient beds.” A proxy indicator measuring the capacity to deliver palliative care, based on the services available compared to the number of deaths (Figure 2.4), illustrates the scale of the challenge facing most countries, with the highest (Austria) still reaching just 64% and the majority of countries—all but 28—under 10%.²⁹

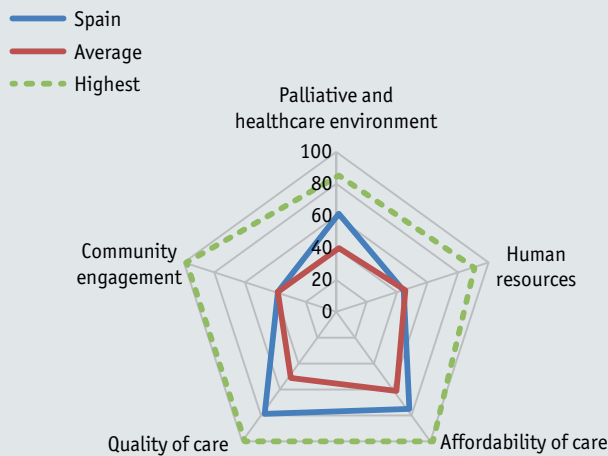
Dr Sleeman argues that care homes and people’s homes should be the focus for the extension of palliative care services. “It means putting less emphasis on a unit catering to only 22 people at a time but taking skills and professionals into the community,” she says. “That’s the future.”

“
You’d hope [palliative care funding] would be based on what the population needs. Everyone talks about it, but that’s very far away.

”
Liz Callaghan, chief executive, Palliative Care Australia

Case study: Spain—The impact of a national strategy

	Rank/80	Score/100
Quality of Death overall score (supply)	23	63.4
Palliative and healthcare environment	15	61.2
Human resources	36	42.6
Affordability of care	=25	75.0
Quality of care	24	78.8
Community engagement	=33	40.0



The developments in palliative care in Spain that followed the 2007 launch of a national palliative care strategy³⁰ demonstrate what can be achieved when standards are co-ordinated across a nation.

The country has long had pockets of excellence: in Catalonia, extensive palliative care services have been available since 1990 through the Catalan Health Care System, with more than 95% of the region covered by palliative care services by 2005.³¹ But in a country where healthcare falls under the authority of 17 regional health systems, unifying approaches to palliative care has done much to increase access to services.

“It was the determinant for the development of palliative care in Spain,” says Javier Rocafort Gil, former president of the Spanish Association for Palliative Care. “The strategy ensured that every regional ministry of health would work together in the same manner.”

Since 2007, another important development in palliative care development has been the involvement of “la Caixa” banking foundation, which has supported the integration of 29 psychological and spiritual care teams into the country’s palliative care network.

Even before the launch of the national strategy, Spain—which is at position 23 in the overall Index and 15 in the palliative and healthcare environment category—had from the 1990s developed a strong network of homecare services.

“It’s cultural, because in Spain people want to die at home,” says Professor Rocafort Gil, who is now medical director at the Fundación Vianorte Laguna at Madrid’s Universidad Francisco de Vitoria. “But it’s also because primary care is very strong—much of the initial development in specialist palliative care in Spain was in primary care teams.”

And while Spain has only two dedicated hospices, services very similar to those found at hospices are available at the country’s medium- and long-term stay hospitals.

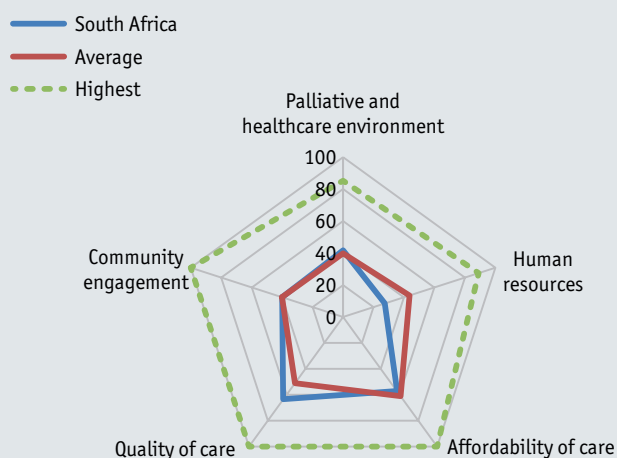
However, despite its strength in many areas of palliative care, Spain still has work to do. “We are close to having the number of units in home care and hospital teams we need,” explains Professor Rocafort Gil. “But we are still far from having enough units for children.”

Moreover, while at universities more than half of medical students now undertake basic and intermediary palliative care programmes, accreditation for specialist palliative care teams is still lacking. This, says Professor Rocafort Gil, will require further regulation. And while laws passed in 2003 and 2004 give every Spanish citizen the right to receive palliative care at home or in hospital, only three regions—Andalusia, Aragon and Navarra—have the kind of detailed legislation covering palliative care that he argues should be implemented across the whole country.

Spain’s strengths and weaknesses highlight the fact that, even in countries that have broad access to high-quality services, the interplay of policy, legislation and training remains critical if service provision is to meet rising demand for care.

Case study: South Africa—Raising the palliative care profile

	Rank/80	Score/100
Quality of Death overall score (supply)	34	48.5
Palliative and healthcare environment	32	41.7
Human resources	59	27.5
Affordability of care	=44	57.5
Quality of care	31	63.8
Community engagement	=33	40.0



With better availability of medicines than many African countries and the continent's highest number of hospices, South Africa is at position 34 in the Index, the highest-ranking African country. In fact, patients from neighbouring countries such as Swaziland, Namibia and Botswana receive care in South Africa, explains Emmanuel Luyirika, executive director of the African Palliative Care Association.

Support for palliative care in South Africa derives from a variety of sources. In addition to government funding, the country has a strong non-governmental hospice movement—offering both outpatient and in-patient services—with the

Hospice Palliative Care Association of South Africa among the leaders. Meanwhile, religious institutions also have hospitals that offer palliative care.

“The country has the biggest number of functional hospices on the continent,” says Dr Luyirika. “That puts South Africa on a different level.”

While South Africa is not the strongest performer in the Index in the human resources category (it is at position 59), in many ways, it has forged ahead in training and skills provision. “It’s relatively well developed,” says Dr Luyirika. “In fact, the first master’s degree in palliative care was offered by the University of Cape Town.” The university’s postgraduate diploma in palliative medicine—a distance-learning programme—caters to experienced healthcare professionals such as doctors, nurses and social workers.³²

The country’s other strength, Dr Luyirika adds, lies in its long history of integrating palliative care into training for those working in family medicine departments.

The need to help those with HIV-Aids has also prompted the development of non-profit initiatives, supporting palliative care. The Thogomelo Project, for example, has established support groups for caregivers.³³

Meanwhile, South Africa has played a prominent advocacy role in global debates, with the health minister issuing a statement on palliative care at the 2013 African Union meeting in Johannesburg.

“The department of health has been instrumental in causing other bodies like the African Union, the World Health Organization and the International Narcotics Control Board to recognise palliative care,” says Dr Luyirika. “South Africa has been instrumental in ensuring that palliative care is given a higher profile at the global level.”

3

Human resources

“
If every [health professional] has palliative care in their basic education, then no one will come out not understanding pain management, how to communicate with patients and families or that psychological, social and spiritual care are part of palliative care, not an optional extra.”

”

Sheila Payne, emeritus professor at the International Observatory on End of Life Care at Lancaster University

The rising need for palliative care means countries will need to spend more equipping doctors and nurses to provide it. Part of this means providing appropriate training for end-of-life care workers in medical schools. However, to meet growing demand, this training also needs to be incorporated into the teaching for all doctors and nurses, with palliative care expertise a required component of both general and specialised medical qualifications.

In this category of the Index, countries are assessed on the availability of specialists in palliative care and practitioners with general medical knowledge of palliative care; the presence of certifications for palliative care; and the number of doctors and nurses for every 1,000 palliative care-related deaths (to gauge the burden relative to the need for palliative care).

Of these, the availability of specialised palliative care workers is given the highest weighting, at 40% of this category (and 8% of the overall Index, as the human resources category is weighted 20% of the overall Index; Figure 3.2). Countries that score 5 in this indicator have professionally or nationally accredited specialist training for their core palliative care teams. By contrast, a score of 1 indicates an absence of certification or accreditation and a severe shortage of palliative care professionals.

General medical knowledge of palliative care is also important (accounting for 30% of this category), with scores of 5 awarded to countries where all nurses and doctors have a good

understanding of palliative care, and palliative care is compulsory in doctor and nurse training schools and healthcare professionals receive professional training throughout their careers. For those scoring 1, there is no such knowledge or training available.

In this category, at the top of the list is Australia, followed by the UK and Germany. Singapore and Taiwan make it into the top 10 in this indicator, but Asia's poorer, more populous nations do worse. India, for example, has a shortage of specialised care professionals and accreditation for palliative care is not yet the norm. However, the country is working towards changing this, according to Sushma Bhatnagar, head of anaesthesiology, pain and palliative care at the All India Institute of Medical Sciences' Dr B R Ambedkar Institute-Rotary Cancer Hospital.

Dr Bhatnagar highlights various teaching programmes that have emerged across India since the government introduced a national palliative care policy in 2012. This includes a major national initiative launched by the Indian Association of Palliative Care. “They are organising essential courses in palliative care in almost all 30 centres,” says Dr Bhatnagar. “So it's good news for the country.”

Meanwhile, in countries that perform well in this category, some see room for improvement. While Australia is in first place, for example, Yvonne McMaster, a retired palliative care doctor

and advocate for palliative care, identifies gaps in human resources infrastructure.

She cites the case of New South Wales, which is home to one-third of Australia's population. "In the rural and regional areas outside the Sydney metropolitan cluster, most palliative care is done by nurses," she says. "There are only four specialist doctors in New South Wales outside the Sydney area. And even though more are being trained the funding isn't being provided for the positions."

Despite France's position at 10th in this category, gaps in training still exist. For example, while master's degrees in palliative care are available for doctors once they have qualified, little attention is paid to it during their initial training. "For doctors, there are only 10 hours in all of their training to study palliative care," says Anne de la Tour, head of the department of palliative care and chronic pain at the Centre Hospitalier V Dupouy. She adds that nurses have no recognition in terms of salary or status for having a specialisation in palliative care.

Uruguay performs relatively well in this category, coming within the top 25 countries and in the top three in the Americas. Yet Dr Yanneo, of the Latin American Association for Palliative Care, highlights weaknesses. The main problem, he says, is that the government's initial human resources focus has not led to the development of a robust palliative care discipline. "Unfortunately, these efforts did not have sufficient, timely and adequate support from university and government authorities," he says.

In fact, he points to "improving education and certification in the discipline" as one of the biggest challenges faced by most Latin American countries.

This should be a priority for Chile, says Cecilia Sepulveda, former head of the National Cancer Control Programme at Chile's ministry of

Figure 3.1

Human resources category (20% weighting)

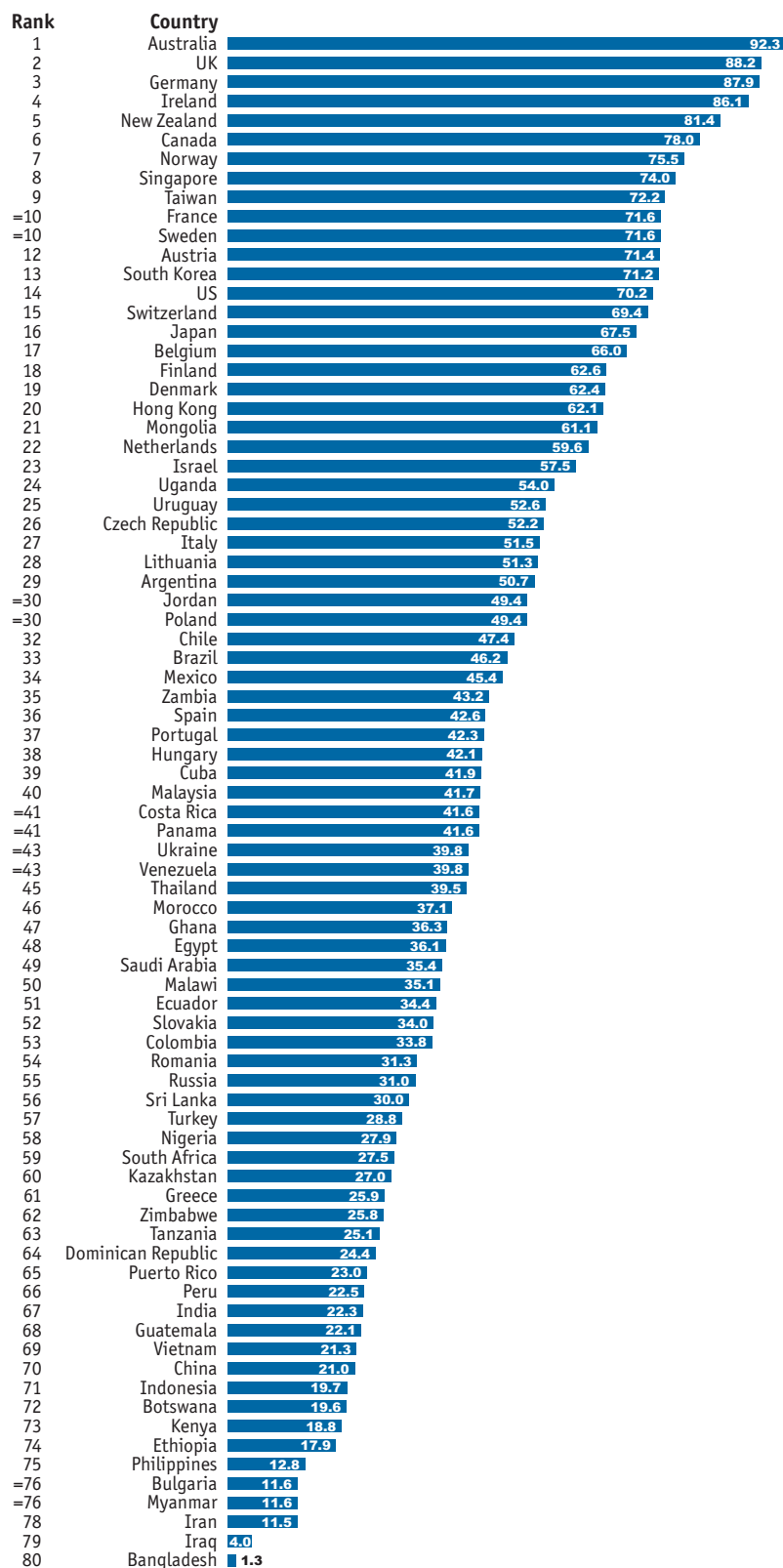


Figure 3.2: Availability of specialised palliative care workers

5		4		3		2		1	
There are sufficient specialised palliative care professionals, including 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.		There is an adequate number of specialised palliative care professionals, but in some support functions (psychologists, social workers etc), there are shortages. Specialist palliative training is accredited by national professional boards, but this can be inconsistent at times.		There are specialised palliative care professionals but there are shortages of physicians, nurses and other support staff. Specialist palliative care training is generally not accredited by national professional boards.		There is a shortage of specialised palliative care professionals, and accreditation of specialist palliative care training is not the norm.		There is a severe shortage of specialised palliative care professionals and accreditation is non-existent.	
Australia Germany	UK	Austria Belgium Canada Finland France Hong Kong Ireland Italy Japan	Netherlands New Zealand Norway Singapore South Korea Sweden Switzerland Taiwan US	Argentina Brazil Chile Costa Rica Cuba Czech Republic Denmark Ecuador Egypt Hungary Israel	Lithuania Mexico Mongolia Morocco Poland Portugal Spain Thailand Uganda Ukraine Uruguay Venezuela	Botswana China Colombia Dominican Republic Ethiopia Ghana Greece Guatemala India Indonesia Jordan Kazakhstan Kenya Malawi Malaysia	Myanmar Nigeria Panama Peru Puerto Rico Romania Rusia Saudi Arabia Slovakia South Africa Sri Lanka Tanzania Turkey Vietnam Zambia Zimbabwe	Bangladesh Bulgaria Iran	Iraq Philippines

health. “There’s no specialist palliative care officially recognised by universities and medical societies,” she says. “We also need to have different levels of training—one is specialised; the other is for the family doctors, so they can provide palliative care as part of primary care. That is not there yet, although there are some initiatives to try to move in that direction.” Dr Yanneo agrees. “Perhaps the greatest deficiency in this country is the lack of advanced education in the discipline,” he says.

For some, the priority should be to start including palliative care in the basic education

of every single health professional. “It might take a long time to make the change,” says Dr Payne. “But if everyone has palliative care in their basic education, then no one will come out not understanding pain management, how to communicate with patients and families or that psychological, social and spiritual care are part of palliative care, not an optional extra.”

In the US—which falls outside the top 10 in this category, at position 14—medical schools should be required to train doctors to assess and treat pain and to communicate more effectively

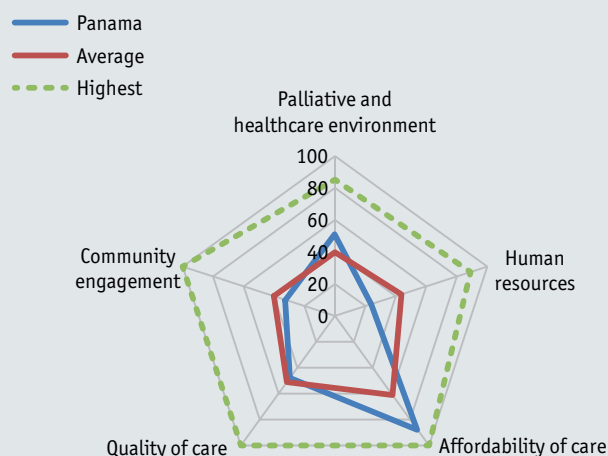
with patients and families about treatment decisions, argues Dr Byock. He believes academic institutions should be testing doctors on these skills as part of gaining their medical degrees.

“But they’ve made only incremental improvements in medical training and education over the past 10 years,” he says. “There have been some improvements but those are small compared to what’s needed.”



Case study: Panama—Palliative care is primary care

	Rank/80	Score/100
Quality of Death overall score (supply)	31	53.6
Palliative and healthcare environment	25	51.2
Human resources	=41	41.6
Affordability of care	=6	87.5
Quality of care	=38	47.5
Community engagement	=38	32.5



Since 2010, when the country introduced its national palliative care programme, Panama has tripled the number of patients being served from about 1,000 to about 3,000 in 2014. Driving this and other advances has been the country's emphasis on a primary care approach to developing palliative care.

This is particularly relevant to smaller, less wealthy countries, argues Gaspar Da Costa, palliative care co-ordinator at Panama's ministry of health and the country's palliative care champion. "Palliative care is part of primary care," he says. "If you treat it as a specialisation, it's a problem for small countries because they cannot afford specialised care. We need teams that have palliative care training."

Much of the work to increase access to services has therefore focused on training. A national standard palliative care programme provides advice to professional caregivers as well as technical guidance on issues such as information systems

and processes for obtaining medicines and supplies. Palliative care programme co-ordinators are present in Panama's 14 health regions, as well as health staff who are trained in basic hospice and home care services and care for patients with advanced disease.³⁴

These investments appear to be paying off. Panama now shares sixth place in the affordability of care category of the Index (with Cuba and a mix of richer countries). It is in the top 30, at position 25, in the palliative and healthcare environment category and ranks at position 31 in the overall Index and in second place in the middle income grouping of countries.

Meanwhile, Panama has also acquired a global profile in the world of palliative care, since it played a prominent role in the drafting and adoption in 2014 of the resolution on palliative care at the World Health Assembly in Geneva (see box on page 43).

"Panama was very involved," says Dr Connor. "It did a brilliant job of being persistent and championing the effort." Much of this was as a result of individual leadership. "Jorge Corrales, counsellor of the permanent mission of Panama to Geneva, took this on as a person passion."

"The Panamanian team was very collaborative with civil society," he adds. "And that's the way it should work. They really took on board all our suggestions."

Increasing the quality of care remains a challenge (Panama slips to position 38 in this category of the Index), partly due to the tight regulation of access to opioids. "The problem is that the law governing opioids has not changed since 1954," explains Dr Da Costa.³⁵ He also highlights the need for the creation of a medical specialty in palliative care, as well as increased training of the primary care teams in palliative care (Panama slips to position 41 in the human resources category of the index).

The next task, says Dr Da Costa, is to push for legislative change. However, since support for a change in the law has already been expressed at the executive level of government, he is optimistic that the National Assembly will make the change.

4

Affordability of care

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.

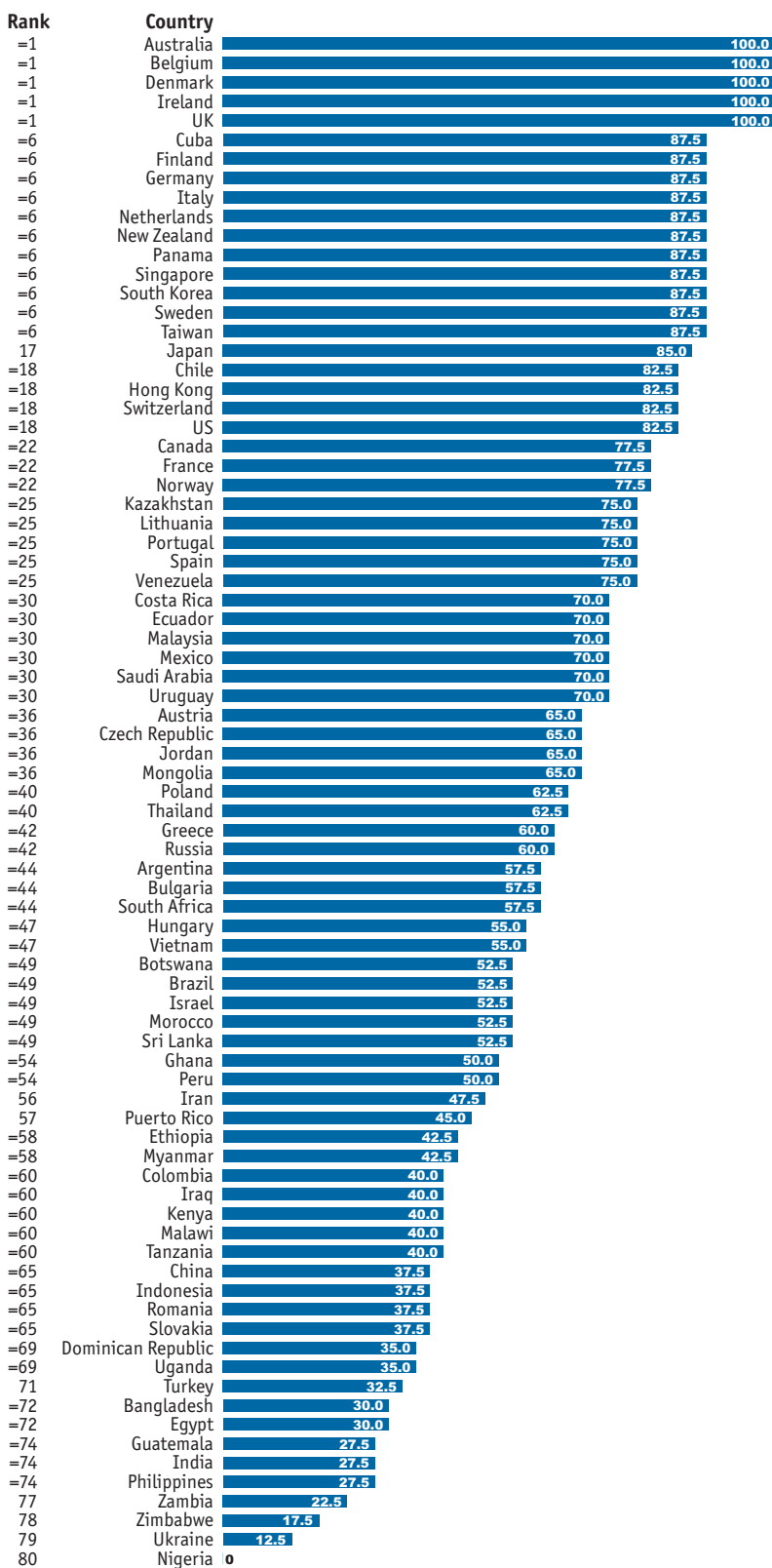
“The financing systems in the US have created significant problems,” says Dr Tulsky, who contributed to the Institute of Medicine’s

“
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.

”
James Tulsky, chair, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute

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.”

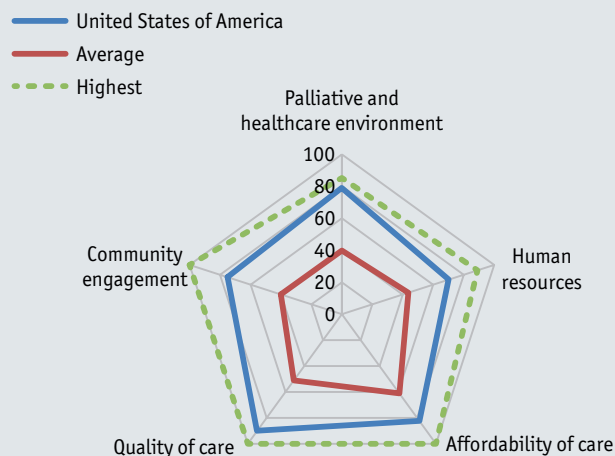


Figure 4.2: Availability of public funding for palliative care

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	Ecuador	Portugal	China	Slovakia	Iraq	
		Germany	Sweden	Ghana	Russia	Ethiopia	South Africa		
		Hong Kong	Switzerland	Hungary	Saudi Arabia	Guatemala	Sri Lanka		
		Italy	Taiwan	Jordan	Spain	India	Thailand		
		Netherlands	US	Kazakhstan	Uganda	Indonesia	Turkey		
				Kenya	Uruguay	Iran	Ukraine		
				Lithuania	Venezuela	Israel	Zambia		
					Vietnam	Morocco	Zimbabwe		

Case study: US—Filling in the gaps

	Rank/30	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

“
This idea that there’s a bright line between disease treatment and palliative treatment is an illusion.

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Diane Meier, director, Center to Advance Palliative Care

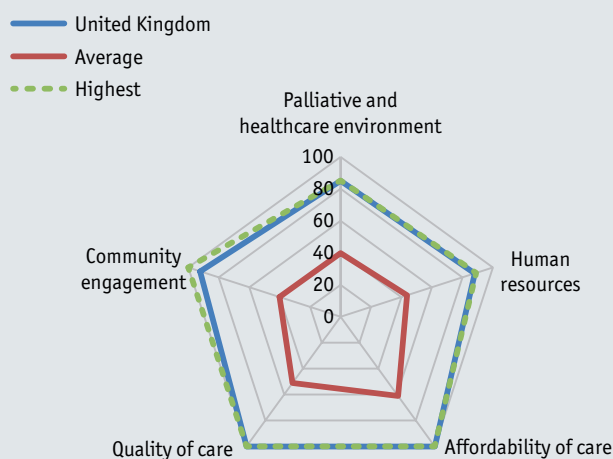
the public sector, which was famously accused of planning to run “death panels”.⁴¹

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.”

“The evidence suggests that the vast majority of people dying in hospital don’t want to be there.”

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.

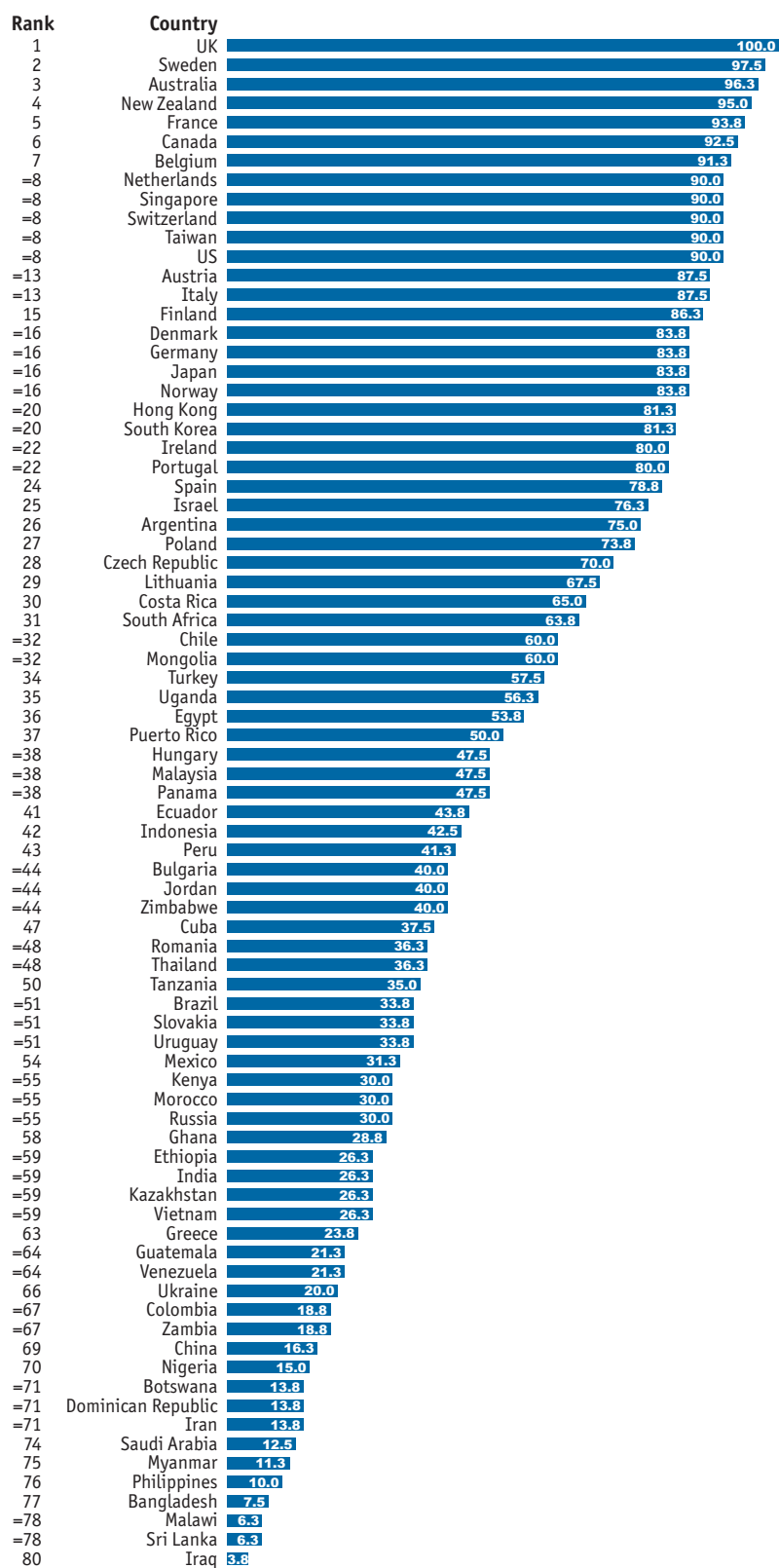
Even in countries that do well in the Index gaps are emerging. In a recent *Journal of Palliative Medicine* survey conducted in the US, which is in the top 10 in the overall Index, respondents in 2011-2013 were more likely to state that their loved ones received insufficient pain relief than respondents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

”
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	Uganda			
Germany	Spain			Guatemala	Ukraine			
Hong Kong	Sweden			Hungary	Venezuela			
Ireland	Switzerland				Vietnam			
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.

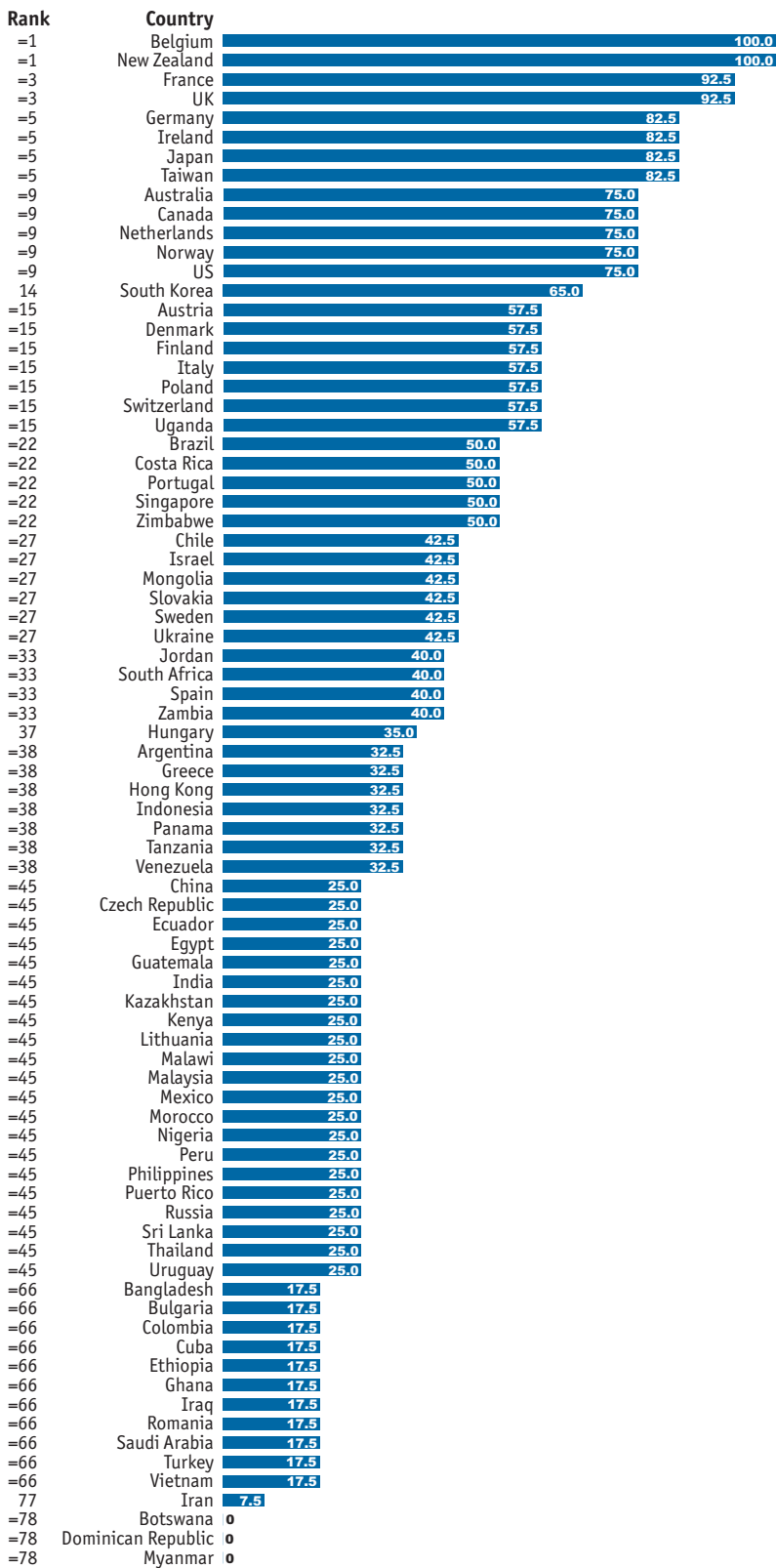
Although government and philanthropic support for palliative care clearly underpins the number and type of services on offer, networks of volunteers can help extend the reach of those services. For example, Costa Rica has developed an extensive network of day centres and volunteer teams.⁵⁰

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 France	New Zealand UK	Australia Canada Germany Ireland Japan	Netherlands Norway Taiwan US	Austria Brazil Chile Costa Rica Denmark Finland Hungary Israel Italy Mongolia	Poland Portugal Singapore Slovakia South Korea Sweden Switzerland Uganda Ukraine Zimbabwe	Argentina Bangladesh Bulgaria China Colombia Cuba Czech Republic Ecuador Egypt Ethiopia Ghana Greece Guatemala Hong Kong India Indonesia Iraq Jordan Kazakhstan Kenya Lithuania	Malawi Malaysia Mexico Morocco Nigeria Panama Peru Philippines Puerto Rico Romania Russia Saudi Arabia South Africa Spain Sri Lanka Tanzania Thailand Turkey Uruguay Venezuela Vietnam Zambia	Botswana Dominican Republic	Iran Myanmar

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.

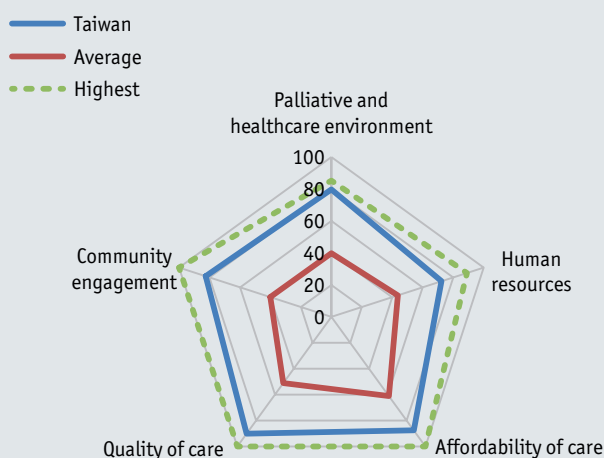
And, as Dr Gawande argues, giving people the option can alleviate their anxiety, even if they never use the lethal medications. Barbara Coombs Lee, president of Compassion & Choices, a US-based non-profit organisation that pushes for greater patient choice at the end of life, agrees. "It bestows enormous 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 Tulsky of the Dana-Farber Cancer Institute.

However, Dr Tulsky 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

- ¹ In the words of Atul Gawande; *Being Mortal: Medicine and What Matters in the End*, Profile Books, 2014
- ² WHO Definition of Palliative Care, available at <http://www.who.int/cancer/palliative/definition/en/>
- ³ This relates to the mathematical average of the scores in the Index; it does not necessarily imply that countries with above-average scores provide satisfactory palliative care across all factors considered in the Index
- ⁴ Aged over 15, based on UN population estimates for 2015 except Taiwan, 2010 census data
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²⁵ See note on Figure 2.4

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²⁹ See note on Figure 2.4

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⁷⁴ The World Bank defines countries with GNI per capita between US\$1,045 and US\$4,125 as lower-middle income countries. In the Index, we have combined the World Bank's low income and lower-middle income countries in one low-income bracket.

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