Five years ago a report that ranked end-of-life care across the world was commissioned and published by the Singapore-based philanthropic organisation Lien Foundation. The report showed substantial variation between the 40 countries included and stressed the importance of access to opioids, state funding and a national policy in order to provide high-quality end-of-life care. The Lien Foundation has recently published a revised and updated edition of that report.

The new report is a larger piece of work than its predecessor and surveys palliative care in 80 countries. While the first report focused on ‘end-of-life care’, the new one uses the broader term ‘palliative care’. Its aim is to provide a framework for countries to identify palliative care issues and assess demand for palliative care, as well as enable people to compare countries in the same region or income group. Ultimately the report intends to support the planning of high-quality, affordable palliative care services. Like all league tables, it certainly generates curiosity and media attention, but is ranking palliative care development useful?

How the rankings were established

In order for people working in palliative care to translate the findings of the report into something meaningful that will help them improve services, knowing how the rankings were established is essential. They are based on a range of qualitative and quantitative data sources. Several measures were used and weighted according to their perceived importance. These measures are:

- The palliative care and healthcare environment (framework for the provision of palliative care and healthcare): 20%
- The human resources (training and development of medical and other staff working in palliative care): 20%
- The affordability of care (availability of publicly-funded care and financial burden on patients): 20%
- The quality of care (existence of monitoring guidelines, availability of opioids, meaningful involvement of patients and model of partnership): 30%
- The engagement of the community (involvement of volunteers, public awareness and community engagement): 10%.

A five-person expert advisory panel provided guidance to the researchers and, in addition, 120 palliative care experts from around the world were interviewed. It is unclear how the five people on the expert advisory panel were selected; however, the majority of the 80 countries included in the analysis were represented in the impressive list of experts interviewed.

The report features country-specific case studies that provide a cultural background and add to the interest and ease of reading. The case study about Mongolia shows how one person can make a real and lasting difference to a country; in Taiwan, it is technological developments that are
contributing to palliative care development; in China, where there is a cultural expectation that children will care for their parents in old age and ill-health, the country’s one-child policy has a negative impact.

No outcome measurement
Palliative care is at varying stages of development both within and between countries and continents. The countries that obtained the highest rankings shared key characteristics such as:

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

Some of these measures were derived from previous mapping exercises of palliative care services across Europe4–6 and the world.7

While the report does an excellent job of measuring the structures that support the delivery of palliative care, the outcomes of service provision are not measured. The European Association for Palliative Care has recently published a White Paper which suggests that outcome measurement is key to understanding different models of care and allows national and international comparisons.8 This may be something that could be considered for future editions of the Lien Foundation report.

Addressing the challenges ahead
The report highlights many of the challenges ahead for palliative care globally; to cite but a few: the inevitable increasing demand for services; aging populations with a higher incidence of non-communicable diseases; access to services for people with a non-cancer diagnosis; and the continuing emphasis on acute rather than chronic care.

Evidence provided in the report suggests that the inclusion of palliative care at a national policy level is a key factor in the specialty being developed and accepted nationally. The WHO has identified palliative care as an important global public health issue,9 and has made palliative care an integral part of its non-communicable disease global action plan.10 In 2014, the World Health Assembly (WHA) issued a resolution aimed at strengthening palliative care.11 This provides a foundation for countries to start addressing some of the challenges. At European Union level, a research project assessing the quality of care provided to older people in long-term care settings (PACE) is currently under way in six countries.12 Studies such as this will hopefully lead to innovations in practice that transcend country and culture.

Access to opioids and education
Pain and symptom management is the cornerstone of palliative care, yet issues with access to opioid medication for pain management persist. What is clear from the report is that basic pain medication is often not available, particularly in developing countries: data presented indicate that opioids are only freely available in 33 of the 80 countries included in the report. This places increased emphasis on the findings of research projects such as the European Union-funded ATOME (Access to Opioid Medication in Europe) initiative, which worked with governments and public health officials to improve access to opioids in twelve countries in central and eastern Europe.13,14

Education is key not only to improving access to opioids but also to providing high-quality palliative care. The emphasis on healthcare worker education in the report is well founded. It is essential to consider education and training for all members of the multidisciplinary team. The predicted demographic changes coupled with the increased demand for palliative care services make education and training a top priority. Workforce planning and availability of staff to deliver services in the future need to be considered as a matter of urgency.

Low- and middle-income countries
Recent evidence suggests that, although palliative care is perceived as being expensive, it is actually a cost-effective way to provide quality care.15 The latest Lien Foundation report suggests that funding is a key element in providing responsive palliative care.
services, but that it is not the only factor. Some countries with limited resources, such as Uganda and Mongolia, have succeeded in establishing some level of palliative care provision. This is often achieved through the hard work of a handful of palliative care advocates or pioneers who are determined to set up palliative care services in their country or region; when this is the case, the sustainability of services is an issue and adequate succession planning is essential. Researchers have also confirmed that using innovative approaches such as international partnerships and community-based programmes can make a difference in low- and middle-income countries. 36

Omission of paediatric palliative care

Paediatric palliative care is an emerging specialty worldwide. The WHO estimates that there are approximately 20 million children with palliative care needs,7 the majority of which live in low- and middle-income countries. Children have been omitted in this report, but there is a compelling argument to use, in a future report, a similar framework in order to establish global rankings of the provision of palliative care for children.

The top five countries in the report have not changed since 2010: they are, from first to fifth position, the UK, Australia, New Zealand, Ireland and Belgium. However, these countries still have work to do. This is clearly demonstrated by frequent complaints made by the public regarding end-of-life care.17,18 There are regular reports of delays in diagnosis and treatment, and of poor communication and planning at the end of life.19 This shows that, regardless of ranking, ongoing improvements are always required.

Conclusion

Is the ranking of palliative care across the globe useful? On the day the report was published, most major media outlets in the UK – including The Guardian20 and the BBC21 – carried the story, with headlines stressing that the UK was in first position, thus unwittingly helping to fulfil one of the recommendations of the report, which is to increase the public’s awareness and knowledge of palliative care. Beyond this immediate media interest, the Lien Foundation’s ‘Quality of Death Index’ clearly shows a correlation between national wealth and palliative care ranking, but also gives examples of less wealthy countries that have made great strides. Its emphasis on a well-educated workforce is well founded. It highlights many issues, starting with the unacceptable lack of access to opioids in many countries. It also highlights the progress made so far, encapsulated by the 2014 WHA resolution.11 So yes, all in all, the ranking of palliative care across the globe is useful as a tool to boost palliative care development.

Declaration of interest

The author declares that there is no conflict of interest.

References

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