Quality indicators for palliative care: Debates and dilemmas
Sheila Payne, Carlo Leget, Carlo Peruselli and Lukas Radbruch
Palliat Med 2012 26: 679
DOI: 10.1177/0269216312450123

The online version of this article can be found at:
http://pmj.sagepub.com/content/26/5/679
Quality indicators for palliative care: Debates and dilemmas

Meaningful engagement in palliative care is widely believed to enhance the quality of life and quality of care for patients and their families. It is embedded within the mission statement of the European Association for Palliative Care (EAPC), which seeks to ‘bring together many voices to forge a vision of excellence in palliative care that meets the needs of patients and families. It strives to develop and promote palliative care in Europe through information, education and research using multi-professional collaboration while engaging with stakeholders at all levels’ (www.eapcnet.eu).

The purpose of this editorial is to draw together the debates about quality indicators for palliative care that have been highlighted in the lively blogs posted on the EAPC site (www.eapcnet.wordpress.com) since April 2012. The context to the debates that emerged was the opportunity to influence the World Health Assembly’s adoption of a global health indicator for non-communicable diseases (NCDs) that focused on palliative care for the first time. This was not a stand-alone indicator, but one of 12 indicators that could provide the framework to influence health for the next decade or so. It is noteworthy that this is the first time that palliative care has received major attention in global health politics. The proposed indicator was ‘Access to palliative care assessed by morphine-equivalent consumption of strong opioid analgesia (excluding methadone) per death from cancer’. It was the selection of this indicator that is so controversial. The debates hinged around the question of whether it is better to have an indicator, even if not ideal, than none at all. There are also tensions around the suitability of indicators for palliative care that had to be applicable across the world, even when there is great diversity in demographic and epidemiological challenges, socio-economic resources, health care systems, and in the availability and access to palliative care services. It is recognised that indicators should be readily measurable, and a prerequisite that data could be collected by all countries. Another tension that emerged was between proponents of ‘advocacy’, where the intent is to promote a course of action based on beliefs and values about ‘a greater good’ or from those where a rigorous analysis of the best available scientific evidence to ensure sustainability and to reduce harm to other population groups was the main driver. It also raises questions about where such discussions are held: is it in research journals and professional conferences or in the public media? Indeed, what is defined as ‘best evidence’ is also a debate and hotly disputed.

The content of the indicator

In our view a distinction should be made between the problems associated with the content of an indicator and those relating to challenges in measurement. Arguments in support of the proposed indicator centred on the need to increase access to strong analgesics for patients dying in pain. There is evidence that cancer pain management is poor and that, even where health professionals have received education about effective pain control, there remain many individual, organisational and national-level barriers to the effective relief of suffering. For example, the Morphine Manifesto highlights the plight of patients in developing countries where legal, attitudinal and other barriers may prevent or severely limit the supply of medication in preparations that are suitable and affordable.

In comparison, there were concerns about promoting the erroneous belief that palliative care is merely linked to the relief of pain in cancer patients, and to those in the end stage of disease. This fails to emphasise early intervention and multidisciplinary aspects of palliative care, as well as the principles of ‘pain total’ management, where attention to psychological, social, spiritual and existential suffering needs to be addressed alongside physical symptom control. The distinction between pain management and palliative care services should be acknowledged. By focusing upon cancer deaths, there may be an unfortunate association between strong analgesic use and dying, whereby cancer patients may receive inadequate pain relief because they are not in the terminal stage. There has also been debate about the inherent dangers of strong opioids and recognition that there is a potential for iatrogenic effects in their indiscriminate use. In some developed countries opioids are mainly used to deal with non-cancer-related pain and there is a danger that by prioritising high opioid consumption there will be over use in patients with non-malignant pain conditions, which is an undesirable outcome. Even within cancer care, recent pain control guidelines recommend the use of a range of interventions to effectively manage pain in addition to opioids. The exclusive focus of...
the indicator upon cancer patients may have the unintended effect of making it even more difficult for non-cancer patients to get access to palliative care or even adequate pain relief, and may increase opioid use in patients who should not be given it.

**Challenges in measurement**

What about the quality and feasibility of the proposed indicator as a tool? The principles of measurement mean that any indicator should be both valid and reliable, and demonstrate sensitivity and specificity. The proposed indicator makes an assumption that there are accurate data on opioid consumption by cancer deaths. Arguably, opioid consumption per capita and cancer deaths are data that are widely routinely collected and therefore do not pose additional demands on governments or health care systems. This is a considerable advantage and may enable international comparisons between countries that share the same socioeconomic, legislative and cultural contexts. However, Willem Scholten has argued strongly about the appropriateness of the indicator, as a poor indicator may be relatively meaningless, because it fails to accurately reflect the actual situation relating to palliative care in a particular country.

It is extremely difficult, if not impossible, to propose a single indicator for palliative care that can be utilised globally in both resource-rich and resource-poor countries. Palliative care research has to continue its search for a set of robust yet culturally appropriate indicators that take account of the fact that palliative care may take place in settings varying from the intensive care unit of a highly technical acute care hospital, to nursing homes for older people and the domestic home; they must also have applicability in resource-poor settings focusing on a public health approach without access to specialist palliative care. Previous attempts to measure the quality of death have used up to 26 indictors and this methodology has also been criticised. The National Consensus Project for Quality of Palliative Care in the United States have defined eight domains, starting from the World Health Organization (WHO) definition of palliative care, and are developing and testing quality indicators for each of these domains. This suggests that we need different indicators for different quality domains in palliative care. Our experience in Europe demonstrates that there are too many difficulties with standardisation and terminology in different places to make a simple counting of ‘palliative care services or personnel’ a reliable indicator. It is important to measure what you want to know, not only what is easy to count.

On the other hand, we have to realise that we are arguing from the rather comfortable position of mostly high developed countries here in Europe, and acknowledge that for most countries in the world it is seen as a major accomplishment that palliative care has been named as one of 12 indicators, on the same level as access to basic medicines and technologies, which is another one of the indicators. From an advocacy perspective, or using a public health approach, this is indeed a major achievement. As researchers we have to point out the flaws and biases in the proposed indicator. We may also have to start producing sound research on its validity and sensitivity, using model programmes of palliative care for NCDs to evaluate its sensitivity to change, and comparing countries with high and low indicator counts to describe the differences in palliative care for NCDs in detail. In a mature discipline it is helpful to respectfully acknowledge that a diversity of views may be expected. We cannot aim to resolve all the dilemmas that were posed and we are aware of many international research projects and national workgroups that seek to investigate quality indicators. This may just be the beginning of the discussion and it certainly is the call for more research.

**References**


Sheila Payne
Division of Health Research, Faculty of Health and Medicine, Lancaster University, UK

Carlo Leget
School of Humanities, Tilburg University, The Netherlands

Carlo Peruselli
Biella Hospital, Italy

Lukas Radbruch
University of Bonn, Germany

University Hospital Bonn, Germany

Corresponding author:
Professor Sheila Payne, President of the European Association for Palliative Care, Director of the International Observatory on End of Life Care, Help the Hospices Chair in Hospice Studies, Division of Health Research, Faculty of Health and Medicine, Lancaster University, Lancaster LA1 4YJ, UK.

Email: s.a.payne@lancaster.ac.uk