



Review article

Common or multiple futures for end of life care around the world? Ideas from the ‘waiting room of history’



Shahaduz Zaman*, Hamilton Inbadas, Alexander Whitelaw, David Clark

School of Interdisciplinary Studies, The University of Glasgow, Crichton University Campus, Dumfries, DG1 4ZL, Scotland, UK

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ABSTRACT

Around the world there is growing interest in the manner in which care is delivered to people at the end of life. However, there is little unanimity on what constitutes a ‘good death’ and the appropriate societal responses to the issue of delivering culturally relevant and sustainable forms of end of life care in different settings are not subjects of broad agreement. In this critical conceptual paper we focus on the emerging narratives of global palliative care and offer an assessment of their implications. We relate this to calls to improve end of life care across jurisdictions and settings, attempts to map and grade the development of palliative care provision, and to the emergence of a widely recognised global ‘quality of death index’. We consider an alternative approach to framing this debate, drawn from a subaltern and post-colonial studies perspective and suggest that adopting a truly global perspective will require acceptance of the plurality of past and present local problems and issues relating to end of life care, as well as the plural possibilities of how they might be overcome. In that context, we would not aim to universalise or privilege one particular global future for end of life care. Instead of homogenising end of life interventions, we seek to be open to multiple futures for the care of the dying.

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1. Introduction

Global interest in end of life care is growing, for compelling demographic and epidemiological reasons (Cohen and Deliens, 2012). The population of the world is ageing and increasing. The number of people dying each year is set to rise. For many the process of dying will become more extended, as life threatening diseases transform into chronic conditions and the idea of a ‘terminal’ illness may mean death within years, rather than months, weeks or days. For others death may still come quickly – from new infectious diseases, natural disaster, and human made catastrophes of many kinds including war, mass migration, poverty and famine. There are many complexities in the challenge of providing appropriate care at the end of life across so many unique circumstances and contexts.

Yet how we die, what constitutes a ‘good death’ and the appropriate societal responses to the issue of delivering culturally relevant and sustainable forms of end of life care in different

settings are not subjects of broad agreement. Rather, they can be seen as a ‘contested space’, where ideas, policies, practices and professions compete to define clear solutions. Decades back Rittel and Webber (1973) argued that in a pluralistic society there is nothing that constitutes the undisputable public good and it makes no sense to talk about ‘optimal solutions’. Yet the work of the modern hospice and palliative care movement seems often to be characterised in this light – as something self-evidently beneficial to all, indeed something that constitutes a human right. In this paper we examine the emerging narratives of global palliative care and offer a critical assessment of their implications. We relate this to calls to improve end of life care across jurisdictions and settings, attempts to map and grade the development of palliative care provision, and to the emergence of a widely recognised global ‘quality of death index’. We consider an alternative approach to framing these issues, drawn from a subaltern and post-colonial studies perspective. We conclude with some reflections on how the ‘field’ might more realistically tackle the problem of making appropriate end of life care available to all who seek it.

Our work is based on a close and critical reading of published texts, papers, commentaries and reports. We also make use of a published interview and memoir in which two palliative care activists set out their experiences and views.

* Corresponding author.

E-mail addresses: shahaduz.zaman@glasgow.ac.uk, zaman567@yahoo.com (S. Zaman), hamilton.inbadas@glasgow.ac.uk (H. Inbadas), alexander.whitelaw@glasgow.ac.uk (A. Whitelaw), david.clark.2@glasgow.ac.uk (D. Clark).

1.1. Global disparities in palliative care

The global history and development of hospice and palliative care has recently been described in depth (Clark, 2016). The nineteenth-century saw major demographic and social changes in western countries that began to transform how people died. As lives lengthened, so the manner of their ending was transformed. The modernist shift in the construction of dying from a religious process to a medical one was getting underway. New modes of pain relief were brought on by the isolation of morphine and the invention of the hypodermic syringe. Medical texts began to give greater attention to the last phases of life and the medical management of the sick room when death is near (Munk, 1887). From the late nineteenth and early twentieth century, special terminal care homes and hospices were established in London, New York and several European cities as well as one Indian city (Pondicherry). Usually religiously inspired and small scale, they developed a particular philosophy of care which later motivated others, from the middle of the twentieth century onwards. Indeed some of the homes survived as institutions and made the transition into the world of modern hospice and palliative care.

By the mid-twentieth century medical, nursing and social work commentary on the care of the dying began to increase. There was a growing concern about the medical neglect of dying people, the problems associated with the 'futile' treatment of advanced disease, and the influences of a wider 'death denying' culture that made end of life issues difficult to address, both socially and culturally as well as medically.

This began to change in western countries such as Britain and the United States from the early 1960s. This was first manifested in a body of new writing on the subject and then in the establishment of new services at the community level, which coalesced around modern 'hospice' principles. These new settings not only provided specialist care for those close to death, but also began to promulgate associated teaching and research. The work of Cicely Saunders and her associates was key to this (Saunders, 1966), but social science critiques of care at the end of life also played their part (Glaser and Strauss, 1965, 1968). The new approaches sought to promote dignity at the end of life, to address problems of pain and other symptoms, to encourage the involvement of different disciplines, including volunteers, and to acknowledge that suffering has several dimensions – physical, social, psychological and spiritual (Saunders, 1964).

By the mid-1970s this orientation was taking on the name 'palliative care' (Overy and Tansey, 2013). Quite quickly it found advocates within the health care system, building on the achievements of the hospice founders who had been largely oriented to endeavours outside of the mainstream in free-standing charitable, non-government and non-profit organisations. It also began to gain interest in many countries around the world. Originally, the focus of this work was on those dying from cancer, but this soon began to change. The benefits of palliative care for people with other non-communicable conditions came to be recognised and in due course life threatening infectious disease also attracted the attention of palliative care specialists. In some quarters there was also a desire to move the initial point of intervention further back in the disease trajectory so that 'early' palliative care could be offered, rather than introducing palliative care only in the very final stages of life. In due course, as we shall see, this led to numerous definitional and terminological debates within the field. Despite these, palliative care continues broadly to be associated with care when death is approaching and if palliative care is not necessarily synonymous with end of life care; the former is certainly a part of the latter. There is also a growing distinction between 'specialist' and 'generalist' palliative care (Quill and Abernethy, 2013). The former

is seen as the preserve of those who use advanced skills and conduct research and education focussed exclusively on people with palliative care needs, often in settings dedicated to this purpose. The latter is seen as an array of skills that can be practised in a variety of settings where those with palliative care needs make up only a portion of those being served. Within the literature it is often unclear which of these is being described and it is easier to track the development of the first than the second.

Another critical feature in this trajectory has been the linkage between palliative care and public health. From the early 1980s the World Health Organization (WHO) turned attention to the global problem of cancer pain relief and then to the wider issue of palliative care. Seeking what would now be called scalable solutions to these issues, WHO began to use the language of public health to define and endorse the principles of palliative care in the global context (Clark, 2016).

The WHO estimates that there were approximately 54.6 million deaths worldwide in 2011 and that over 20 million people every year could benefit from palliative care at the end of life (WHO, 2014). The majority of these (69%) are adults over 60 years old and some 6% are children. The highest proportion (78%) of adults who could benefit from palliative care at the end of life are living in low and middle-income countries, but the most developed levels of palliative care provision are found in the higher-income countries. Those dying from non-communicable diseases represent around 90% of the burden of end of life palliative care. The top conditions are cardiovascular diseases, cancer, and chronic obstructive pulmonary diseases. The vast majority (98%) of children in need of palliative care at the end of life also belong to low and middle-income countries, and within this group 83% are in the lower income categories, where the highest need is found. In addition, the rise of infectious diseases such as HIV/AIDS and multidrug-resistant tuberculosis, as well as complex humanitarian emergencies occurring in many developing countries also cause suffering and require pain control and palliative care for patients and support for their families – opening up new areas for palliative care intervention (Knaul et al., 2015).

Despite the number of people dying in low and middle-income settings, very little is known from a research perspective about how palliative and end of life care are being structured and delivered in developing countries. One systematic review showed that 90% of palliative care studies focus on just a few specific European countries (Pastrana et al., 2010). Another indicates that most international palliative care research (involving two or more countries) is taking place in high income settings (Clark et al., 2016). We note the English language limitations of this literature, but consider it unlikely that much relevant work has been published in other languages. With only a few exceptions (the Nordic countries, Romania, Spain, Turkey) specialist end of life care and thanatological journals are published in English.

A gross inequity between developed and developing countries can be found in access to pain control. High-income countries account for nearly 92% of medical morphine consumed in the world, but comprise only 17% of the total population. In contrast, low- and middle-income countries, representing the remaining 83% of the world's population, account for a mere 8% of the total morphine consumption (INCB, 2011). Whilst the consumption of opioids for medical purposes is increasing in North America, Western and Central Europe and Oceania, everywhere else this is not the case (Berterame et al., 2016).

Likewise, global mapping of the levels of palliative care development shows wide variations with regard to the preparedness of health systems for palliative care in developed and developing countries (Lynch et al., 2013). The situation varies from informal family-based palliative care alone, to isolated clinical care service

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