

Debate

## Quality end-of-life care: A global perspective

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### Abstract

**Background:** Quality end-of-life care has emerged as an important concept in industrialized countries.

**Discussion:** We argue quality end-of-life care should be seen as a global public health and health systems problem. It is a global problem because 85 % of the 56 million deaths worldwide that occur annually are in developing countries. It is a public health problem because of the number of people it affects, directly and indirectly, in terms of the well being of loved ones, and the large-scale, population based nature of some possible interventions. It is a health systems problem because one of its main features is the need for better information on quality end-of-life care. We examine the context of end-of-life care, including the epidemiology of death and cross-cultural considerations. Although there are examples of success, we could not identify systematic data on capacity for delivering quality end-of-life care in developing countries. We also address a possible objection to improving end-of-life care in developing countries; many deaths are preventable and reduction of avoidable deaths should be the focus of attention.

**Conclusions:** We make three recommendations: (1) reinforce the recasting of quality end-of-life care as a global public health and health systems problem; (2) strengthen capacity to deliver quality end-of-life care; and (3) develop improved strategies to acquire information about the quality of end-of-life care.

### Background

Each year 56 million people die in the world [1], 85% of these in developing countries [2]. Yet little is known about the quality of end-of-life care in developing countries. This article aims to explore this problem from a global perspective and to define why it is a major global public health and health system concern.

Modern research in end-of-life care can be seen as passing through three phases. In the first phase the focus was at

the clinical level. An example of important research at this level is the WHO pain treatment ladder [3]. In the second phase the focus was at the organizational level. Early work centred on the organization of special units or services to deliver palliative care, as pioneered by Dame Cicely Saunders. More recently, the Boston-based Institute for Health Care Improvement [4], has focused on the application of rapid-cycle change quality improvement strategies to the problem of end-of-life care. The third phase, which has yet to mature, is a focus on quality end-of-life care as a public

health and health systems problem, especially at the global level. This phase is the focus of the present paper.

In many Western countries a deeper recognition for the need to improve end-of-life care is gradually emerging. It has been argued that technological advances in medicine have obscured the need for human compassion for the dying and their loved ones. There is also a growing public demand for a more holistic, integrated approach toward health, illness, death and dying. Furthermore, published literature reveals evidence that the quality of end-of-life care is often unsatisfactory for both patients and families. For example, in the United States Lynn et al. [5] found that four in 10 dying patients had severe pain most of the time. Ahronheim et al. [6] found that 47% of incurably ill patients with advanced dementia and metastatic cancer received non-palliative treatments. Solomon et al. [7] found that 78% of health care professionals surveyed reported that they sometimes felt the treatments they offered patients were overly burdensome. Hanson et al. [8] found that bereaved family members felt that communication concerning end-of-life care issues was poor. And, commenting on end-of-life care in general, Berwick contends, "evidence is mounting that the excellence of the status quo is a sentimental illusion" [9].

To address the need for improved quality end-of-life care, several major initiatives have been launched. The Institute for Health Care Improvement (mentioned above) has held a quality collaborative on end-of-life care. The Open Society Institute's Project on Death in America aims to understand and transform the culture and experience of dying and bereavement [10]. The Last Acts Campaign aims to bring death related issues out in the open and help individuals and organizations pursue better ways to care for the dying [11]. The American Medical Association, with a grant from the Robert Wood Johnson Foundation, launched a program called Education for Physicians on End-of-Life Care project [12] whose goal is to educate all physicians on the clinical competencies required to provide quality end-of-life care. The Ian Anderson Program on Quality End-of-Life Care is an extensive five-year initiative designed to improve end-of-life care at a health systems level throughout Canada [13]. There has been a good deal of development and research in the United Kingdom, as documented by the UK National Council on Hospice and Specialist Palliative Care Services [14]. The European Association for Palliative Care [15], a non-governmental organization recognized by the Council of Europe, coordinates research, education, and networking across Europe. The International Association for Hospice and Palliative Care is helping developing countries build programs that adapt to local cultures and realities [16].

A historical recounting would be incomplete without emphasizing the role of the World Health Organization [17,18]. As Kathy Foley, a leading figure in this field, writes in her review of our paper, "...[i]n developing its monograph on palliative care and cancer and the development of National Cancer Control Programs argued strongly for the need to address quality end-of-life care using the term palliative care as a public health policy issue. In advocating for governments to adopt policies for cancer care, the WHO argued that any national cancer control program, particularly in resource poor settings should have four major components: prevention, early diagnosis, treatment and palliative care" [19]. Moreover, as Nigel Sykes, Head of Medicine at St. Christopher's Hospice wrote in response to an earlier editorial we published on this topic in the *British Medical Journal* [20], "the World Health Organisation produced pioneering guidance in control of pain and other symptoms at the end-of-life [21]. In conjunction with the International Narcotics Control Board the WHO has long pressed for greater availability of morphine [22], often against the prejudice and inadequate knowledge of local medical groups" [23]. However, to our knowledge, no initiative has advocated that quality end-of-life care should be viewed as a global public health and health systems problem, and made recommendations flowing from this perspective.

In this paper, our main point is that quality end-of-life care is appropriately viewed as a global public health and health systems problem, and that this leads to recommendations on capacity strengthening and information strategies related to quality end-of-life care. We begin by addressing the question, what is quality end-of-life care? Then, we argue why it is a public health and health systems problem. Next, we examine important contextual aspects relevant to improving end-of-life care: the epidemiology of deaths, cross-cultural considerations, and existing capacity in developing countries in relation to end-of-life care. Then, we confront the difficult philosophical problem of whether it is justifiable to emphasize quality end-of-life care when so many other aspects of health care, especially in developing countries, merit improvement. Finally, we turn to our recommendations for improving the quality of end-of-life care at a global level.

#### **What is quality end-of-life care?**

One of the most useful developments in the field was the emerging focus during the 1990s on quality end-of-life care. Before this, there had been many "pieces of the puzzle," such as pain control and advance directives, that had not been brought together into an integrated focus. As a matter of terminology, we use the term end-of-life care to reflect this integrated concept, rather than the term palliative care, which conjures up images of service provision. However, a sophisticated understanding of palliative care

recognizes that specialists should not treat all patients but rather treat patients whose distress cannot be controlled by the primary physician or nurse, teach primary care groups how to deliver end-of-life care, and conduct research on end-of-life care [24]. Therefore, the terms palliative care and end-of-life care are complementary. We have not found the definitional battles between proponents of these two terms enlightening, and will not pursue these here.

But what does quality end-of-life care mean? Initial attempts to address this question were based on expert assessment. In 1997 the Institute of Medicine report on "Approaching Death" identified six elements of quality end-of-life care [25]:

- Overall quality of life
- Physical well-being and functioning
- Psychosocial well-being and functioning
- Spiritual well-being
- Patient perception of care
- Family well-being and perceptions.

The problem with this expert approach is that the aspects of quality end-of-life care identified by expert clinicians may not be the same as those identified by patients themselves. In 1999, we published a report outlining five aspects of end-of-life care from the patients' perspective: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving the burden on loved ones, and strengthening relationships with loved ones [26]. This work was built upon by Tulsky and colleagues [27], who, through surveys of dying patients, doctors, and other health care providers, further elaborated and elucidated the differences and similarities in the perspectives of each of these groups. They concluded that, "Although pain and symptom management, communication with one's physician, preparation for death, and the opportunity to achieve a sense of completion are important to most, other factors important to quality at the end-of-life differ by role and by individual. Efforts to evaluate and improve patients' and families' experiences at the end-of-life must account for diverse perceptions."

It is important to note that this patient-focussed research has been conducted in developed countries. It surely omits important elements of quality end-of-life care from a developing country perspective such as planning for orphan care (by 2010 there will be over 25 million orphans

because of AIDS [28]) and inheritance of land; these issues may be particularly important for women.

Once defined, key elements of quality end-of-life care will need to be measured. Although measures are available, they tend to be focussed on the quality of care of those in hospice, or have undue respondent burden [29]. The development of measures for quality end-of-life care, including those appropriate to the developing country context, will be an important focus of future research.

This discussion of quality end-of-life care highlights that the problem of quality end-of-life care is, among other things, a problem of information. A fundamental barrier to improving quality of care at the end-of-life is the lack of information about the current state of end-of-life care among populations. This population-based thinking leads to the question of why quality end-of-life care should be seen as a global public health problem.

## Discussion

### **Why is quality end-of-life care a global public health problem?**

As noted, there are 56 million deaths per year in the world, 85 % of which are in developing countries. One can assume that each death also affects five other people in terms of informal care-giving and grieving relatives and friends — a very modest estimate, particularly in the developing world. The total number of people therefore affected each year in the world by end-of-life care is about 300 million people, about 5 % of the world's population [30]. This makes quality end-of-life care a global public health problem on the grounds of numbers of people involved.

To put this problem in perspective, there are 36 million people living with HIV, 8 million people become sick with TB annually, resulting in 2 million deaths [31] and 300–500 million cases of malaria result in 1.5–2.7 million deaths [32]. Admittedly, we do not conceptualize quality end-of-life care as a public health problem in the same way we conceptualize HIV, malaria and TB as public health problems. But this difference may have more to do with the social construction of these problems rather than any intrinsic difference between quality end-of-life care and these other problems. Like HIV, malaria, and TB, quality end-of-life care threatens the health and well being of a large population of people. The fact that we do not traditionally view end-of-life care as a public health problem is perhaps more a symptom of Western death-denying culture than any intrinsic difference between quality end-of-life care and these other global public health problems.

In addition to the sheer numbers, quality end-of-life care is a global public health problem because of the nature of the interventions that could be used to improve the problem. Improving end-of-life care will require improvements in health systems as discussed below. However, other needed interventions are more in the realm of public health, such as large-scale educational programs for public health workers and for the public, population-based strategies to destigmatize death and mainstream it into health systems, and changes in social policies in relation to, for example, orphan care.

Finally, improvement in quality end-of-life care will require health research. It is ironic therefore that of the thousands of papers published on end-of-life care in the last decade, only a few have addressed end-of-life care in developing countries. This is perhaps nothing more than another manifestation of the 90/10 gap — that 90% of medical research is undertaken on those diseases that cause 10% of the global burden of disease [33]. The same gap that affects health research more generally also affects research and practice at the end-of-life. In the sense that global health research is a crucial element of global health and development, quality end-of-life care is also a global public health problem.

#### **Why is quality end-of-life care a global health system problem?**

End-of-life care is a health systems problem in the sense that — at least in some countries — the majority of deaths occur in hospital [34]. It is a health system problem because, as noted, much research in palliative care has involved the organization and delivery of palliative care services [35]. It is a health systems problem because quality improvement techniques, such as rapid cycle change, have been applied in an effort to improve the quality of end-of-life care. Finally, it is a health systems problem because of the need to introduce quality end-of-life care into the education and accountability of health system managers and health care professionals.

However, there is a more fundamental sense in which quality end-of-life care is a health systems problem. As we have argued, improving quality end-of-life care is a problem of health information. Information about quality is recognized as a central health system concern, as exemplified by the report card movement. We have never seen information on quality end-of-life care on quality report cards. Why? Just as clinicians once put dying patients in the room at the end of the hall and never made rounds on them, health policy makers have kept the issue of quality end-of-life care outside the mainstream of their concerns. For example, despite data on mortality, and on other measures of quality of care, there is no information on quality indicators for end-of-life care in the statistical ap-

pendices of WHO's World Health Reports. There were also no measures related to quality end-of-life care among the health system performance measures in the 2000 World Health Report.

The lack of knowledge related to the end-of-life experience represents a health information deficit. It is remarkable that such a significant element of health care delivery is so poorly understood. Health systems may not want to be known as good places to die, since this may counteract the cure-oriented message underlying much of acute care. Yet the conditions of the dying are often unacceptable, and more and more people are calling for change. Even in a developed nation with universal health care such as Canada, we don't know how 222,000 Canadians who die each year fare, nor do we know how their end-of-life experience has affected others. The Canadian Senate, in its 2000 report on quality end-of-life care, recommended that the Canadian Institute for Health Care Information develop indicators for quality end-of-life care [36]. To our knowledge this is the first example of a recommendation for a national information strategy on the problem of quality end-of-life care, but at the moment it is only a recommendation.

Like for the 15% of people dying in developed countries, there is only anecdotal evidence about the end-of-life experience of the 85% dying in developing countries. This represents a major information deficit and barrier to improved end-of-life care. We will return to this information deficit in our recommendations.

#### **The epidemiological context of quality end-of-life care**

As noted, the vast majority of the world's 56 million deaths annually occur in developing countries. At the same time, most research and many of the initiatives on end-of-life care have been in developed countries. This gap is important to note since applying strategies and concepts from developed onto developing countries may be inappropriate simply because of the epidemiological context of death, let alone the cultural differences which we address in the next section. The context of deaths in developed and developing countries are different, and context matters in end-of-life care. For example, the initial model of palliative care was based on cancer patients, and this has had a significant influence on the development of palliative care. The majority of deaths in developed countries, however, are not related to cancer. Concepts and strategies applicable to the usual slowly declining tempo of cancer deaths may not be applicable to the sudden reversals of people with heart disease. This difference in context of death in developed countries may explain in part why the initial models of palliative care have unfortunately not solved the problem of quality end-of-life care in developed countries. Since the context of deaths between devel-

oped and developing countries is also different, these differences are important to acknowledge and explore in striving to improve end-of-life care.

Causes of death differ between developed and developing countries. According to estimates in WHO's World Health Report 2000, the five leading causes of death in sub-Saharan Africa are HIV/AIDS (2,154,000), acute lower respiratory infections (1,073,000), malaria (953,000), diarrhoeal diseases (765,000), and measles (514,000) [37]. Over half the deaths in these countries are attributable to infectious and parasitic diseases. In fact, infectious diseases are responsible for almost half of mortality in developing countries throughout the world. And, approximately half of infectious disease mortality can be attributed to just three diseases—HIV/AIDS, TB, and malaria. These three diseases cause over 300 million illnesses and more than 5 million deaths each year [38]. These patterns may change as the annual number of tobacco-related deaths is expected to rise dramatically, from three million to about 10 million by the year 2025 [39,40].

In the countries which make up the lowest mortality stratum in North America (Canada, Cuba and U.S.), the five leading causes of death are ischemic heart disease (551,000), cerebrovascular disease (187,000), lung/trachea/bronchus cancers (180,000), chronic obstructive pulmonary disease (118,000), and lower respiratory infections (101,000). More than 65% of deaths here are attributable to some form of cancer or cardiovascular disease. Whereas a mere 2% of deaths are attributable to infectious diseases [41,42].

In the last hundred years and with particular concentration in recent decades, the west has seen a significant shift from death occurring from infectious diseases to death occurring from degenerative conditions occurring late in life [43]. These changes have lengthened both life and the dying trajectory. In the developing world death is often a faster process and occurs earlier in life. For example, in Africa, infant mortality is close to 10%, and an average of 151 of every 1,000 children die before age five, according to World Bank statistics [44]. Although AIDS is an affliction well known in Western health care, it is a more brisk, debilitating illness in developing countries [45]. The lived experience of people in the developed world is that of death occurring largely in old age as opposed to the developing world in which a high proportion of preventable deaths occur in childhood and early adult life.

Examining recent data one may assume that the global picture for health — and by implication for end-of-life care — is encouraging. In 1955, the world average of life expectancy was 48 years; by 1995 it had risen to 65 years. However, this positive trend masks the fact that improve-

ments are not universal. In 16 countries, life expectancy declined between 1975–1995 [46]. In much of sub-Saharan Africa, AIDS, in combination with declining economies and health care delivery systems, is having a powerful effect on health, the nature and experience of dying, and life expectancy. In Uganda, for example, AIDS is the leading cause of death in young adults, and life expectancy between 1995–2000 was 32.7 years [47]. Seven countries in sub-Saharan Africa now have life expectancies below 40 years; by 2010, 11 countries are expected to have life expectancies near 30 years [48].

It is easy to make too much of the differences in causes of death in developed and developing countries. We do not want to enter into those debates here. Rather, we simply want to sound a cautionary note. Strategies to improve end-of-life care depend on context including the patterns of death, this context varies around the world, and these contextual features must be taken into account to enhance the opportunities for success of any concepts and strategies to improve end-of-life care.

#### ***The cultural context of quality end-of-life care***

Because culture significantly influences how we see the world, any effort to understand or improve quality end-of-life care in the world must be sensitive to cultural considerations. Cultures are much deeper than their traditions, extending to fundamental differences in modes of reasoning grounded in the way the world is perceived. Furthermore, it is known that attitudes toward end-of-life care is relative to particular cultures, societies, and times [49]. Often, when people planning or providing health care and recipients of health care come from different cultural backgrounds, they interact under the influence of unspoken assumptions that are so different that they prevent effective communication and initiatives may break down all together [50–52]. Simply applying Western perspectives on end-of-life care to developing nations is unrealistic, and apt to fail.

Although Western culture is diverse, evolving and increasingly views health and illness in a broader context, Western medicine remains largely based on scientific, rational and objective principles. Ultimately this is as much a cultural construction as any non-Western philosophic or health-related belief system. Disease is perceived as being largely under the control of science [53]. Because of the institutionalization of death, many people may expect medical solutions at the end-of-life. Death is often perceived as a failure of medical care. Demand for aggressive treatment at the end-of-life can become extreme and unrealistic. Research in North America shows that 18 per cent of lifetime costs for medical care are apt to be incurred in the last year of life [54].

The growing concern about death and dying arose in the 1950s and 1960s as science became increasingly questioned. This concern was coupled with an emerging cultural trend toward planning and controlling major life events [55], a tendency concentrated in educated groups [56]. This trend is reflected in the debates about advance directives and euthanasia.

Some of the early hospices were founded by people with Christian beliefs, or in religious institutions. Therefore, some aspects of the palliative care/hospice care movement are rooted in Christian heritage and have philosophic underpinnings that may be foreign to many people in the developing world who see the world from a different philosophic or religious perspective. The direct application of traditional hospice/palliative care programs to the developing world may therefore be problematic.

An important cultural distinction in Western medicine is that it is assumed that the person experiencing the illness is the best person to make health-care decisions. However, many non-Western cultures perceive the family or community as vital in receiving and disclosing information necessary to decision making and to the organization of patient care. Furthermore significant differences exist in gender roles. Particularly in the developing world, caregiving has been and continues to be overwhelmingly the responsibility of women [57]. Although men may also be caregivers, these roles are not culturally perceived as significant aspects of their lives. Unfortunately, because much discussion and policy formation have been from male perspectives, the individual and social significance of female procreative and caregiving roles has often been ignored. These differences require respect, understanding and careful cross-cultural consideration.

Many people in developing countries hold profoundly different views of the nature, cause and meaning of health, illness, death and dying than those in the developed world. The concept of explanatory models of illness reflect the cultural understanding of what illness is, how it occurs, why it exists and what measures can be taken to prevent or control it [58]. In Western medicine, the primary explanatory model of illness focuses on abnormalities in the structure and function of body organs and systems. Most non-Western cultures tend to perceive illness in a much broader and far less tangible manner — for example, some Africans may perceive health and disease as separate entities, influenced by external forces such as witchcraft, revenge or other social causes [59]. These belief systems are often referred to as traditional belief systems. Western culture however is ubiquitous, the vast majority of explanatory models of illness are now intricately blended between Western and traditional perspectives.

For many people in developing countries stronger religious and cultural observances and community support may ameliorate much of the need or expectation for "specialized" approaches to end-of-life care. In many societies in the developing world many people are barely exposed to other views — traditional beliefs of death being the will of God or a natural consequence of the cycle of life may be profoundly comforting and nurture a fatalistic acceptance and stoicism toward death. Introducing death as a "specialized" service — by viewing suffering as a treatable, medical phenomenon — raises a profound ethical questions as to whether it in the developing world-would it be at odds with existing cultural and religious perspectives on suffering, death and their meaning [60].

The health care infrastructure of some developing countries may be minimal, and focused on disease prevention. Discussions of death, in this context, may be shunned as they are a reminder of the gross inadequacies of the health care system. As with Western nations effective pain control is problematic, although the roots of the problem are different. In developing nations pain control is impeded by a lack of opioids and a fear of Western style drug problems, which may greatly limit the use of analgesics.

These cultural considerations lead to the conclusion that any effort to improve quality of end-of-life care in developing countries must be carefully tailored, and include people from developing countries, who will be sensitive to the cultural context. Bringing end-of-life care into the main stream may fit well with the worldview of many developing cultures, as life and death are more often viewed as integrated [61].

#### **Capacity for end-of-life care in developing countries**

We could identify no systematic data about capacity to deliver quality end-of-life care in developing countries.

Health care initiatives in the developing world must deal with inadequate infrastructures, poor administrative systems, the extreme poverty of many patients, restricted opioid prescribing and minimal educational opportunities for health care staff [62]. Clearly, these are not the conditions for building specialized programs. Aggressive high-tech approaches at the end-of-life are not feasible. A further impediment to improving end-of-life care in the developing world is that a majority of health care spending, both public and private, goes to curative efforts — hospitals in urban areas often account for more than 80% of total health care costs. Although changing quickly, the majority of the population in the developing world continues to live in rural areas [63].

"Grass roots" palliative care initiatives in developing nations such as Zimbabwe and South Africa [64] are funded

at a very low level and are often left to deal with assisting social needs which arise out of the effects of extreme poverty exacerbated by illness. Yet there are early encouraging results from *The Foundation for Hospices in Sub-Saharan Africa* which has the mandate of helping the existing hospices sustain and expand their programs. Additionally, the program teaches basics of HIV/AIDS care and prevention. Family members are instructed in care-giving techniques, and are also given an essential orientation of how HIV/AIDS is and is not transmitted [65]. Introduced 9 years ago, Hospice Uganda, a model palliative care Initiative in Africa, has been particularly successful [66]. It focuses on pain relief and cultural diversity and is an integral part of the nation's health plan. On a global level, St Christopher's Hospice has trained leaders of hospice programs in 37 countries [23]. In addition, the British charity *Help the Hospices* has recently set up a forum for hospices and palliative care around the globe [67]. The International Association of Hospice and Palliative Care (IAHPC) is the only global volunteer organization dedicated to bridging the gap in palliative care between the developed and developing world. This volunteer organization observes that the principles of attention to detail, community care, low cost interventions, and family education about care, are truly universal [68]. Unfortunately, at this time these programs reach only a small minority of people at the end-of-life.

The urban elite of many developing nations are often the only recipients of Western style palliative care. This group and the rural masses live in different worlds. In India, and other developing nations, palliative care for cancer patients exists often for the privileged and reaches only a minority of cancer patients [69]. Again, small local initiatives in the area of pain control have shown encouraging results [70].

Views of illness and help-seeking behaviour in the developing world are in rapid transition. A study done in Northeast Thailand on the experience of villagers dying at home revealed that biomedical theories of disease coexisted or have been supplanted by traditional beliefs about illness [71]. When patients involved with the minimal health care system are diagnosed with terminal diseases they are quickly sent home to die. Family and community provided ample psychosocial care — fortunately the developing world often has three generation families which are able and willing to care for the dying (although this may no longer be the case in countries that have been devastated by AIDS). Community and traditional healers, however, are on their own to consult and provide diagnosis, treatment and palliative care.

An excellent example of how the end-of-life can be improved without high-tech solutions is the WHO Cancer Program [72]. This initiative works with local govern-

ments to establish national cancer control programs (NCCP) to address the cancer problem at the country level in accordance with the epidemiological, social and economic situations. This comprehensive approach assesses the cancer burden and defines priority objectives within the areas of prevention, treatment and palliation. With careful planning the establishment of NCCP offers the most rational means to achieve cancer control, even where resources are severely limited.

For example, under the auspices of the WHO Cancer and Palliative Care Program of Latin America, physicians, health care workers and government officials met to identify problems and strategies for the delivery of palliative care [73]. This meeting led to the regular exchange of knowledge and ideas. Methods for parenteral hydration were developed. Several countries found methods for the low cost production of opioids. The number of groups involved increased to include physicians, psychologists, nurses, pharmacists, volunteers, pastoral care workers, governments officials, hospital administrators, pharmaceutical companies, and representatives from non-governmental organizations — all focusing on cost-effective means of improving the end-of-life for palliative patients. As a result, measurable outcomes have changed dramatically in much of Latin America. The number of patients treated by palliative care groups has increased more than 10 times in six years. Opioid use has increased and the cost of drugs has decreased. Faculties of medicine are conducting education in palliative care both at the undergraduate and postgraduate level. National and provincial governments have developed palliative care policies. Such approaches have been developed elsewhere in the world for cancer patients. Therefore, similar interventions can be developed with a broader mandate for end-of-life care.

An important consideration in planning for improved end-of-life care in the developing world is that more medical care does not necessarily lead to better health. The common indicators of medical care — rates of infant mortality, lost days due to illness, and life expectancy — are shown to be improved by only 10% [74]. This further demonstrates the need for patient derived indicators for measuring the quality of end-of-life care.

Improvements in end-of-life care function independently of the overall economic development of a nation. For example, in Latin America Bruera has noted that some countries (Cuba, Chile and Costa Rica) have well developed palliative care systems while others (Mexico and Brazil) did not [75].

Death in the developing world is most often seen as an integral part of life. Consequently, the Western "specialization" of death may already be a contributing factor to why

traditional Western approaches to end-of-life care have had so little effect in the developing world. Integrating local, culturally based perspectives of health, illness and dying in combination with building national consensus to changes in policies, and procedures, are apt to have a greater effect on improving end-of-life care in the developing world than implementing contemporary Western medical advances. The issue of strengthening capacity in end-of-life care is one to which we will return in our recommendations.

**"If the lives of people in developing countries don't matter, why should their deaths?"**

Before turning to our recommendations, we need to confront a thorny philosophical question underlying any effort to improve end-of-life care in developing countries. We live in a world where the life expectancy is 80 years and rising for people in many developed countries, and 40 years and falling for people in many developing countries. As noted, many of the deaths in developing countries are preventable. Underlying these inequities in health are inequities in knowledge and wealth. It is a reasonable challenge to any global effort to improve end-of-life care to ask, "In such an unjust world, where apparently the lives of many people in developing countries do not matter, why should their deaths?" (A less blunt version of this question would be to ask whether a focus of quality end-of-life care is justifiable when many of the deaths in developing countries are preventable.)

We think this is a fair question. Indeed, in our view, the inequities in global health represent one of the principal ethical challenges in the world today. However, we think it is a classical *tu quoque* error in logic to argue that because the lives of people in developing countries do not seem to matter, their deaths should not matter either. This is not an either/or choice. Both the lives and the deaths of people in developing countries should matter, and we should do something about both. Put another way, even if someone must die prematurely because of the injustice of global health inequality, it is doubly unjust for that person to be condemned to an agonizing death racked by preventable pain. Moreover, by focusing on improving end-of-life care, itself a significant humanitarian crisis, we may be laying the groundwork for a more comprehensive, humane and ethical health care systems in developing countries.

**Summary**

**How can we improve the quality of end-of-life care in the world?**

Quality end-of-life care in the world is a large-scale problem that admits of no simple solutions. However, conceptualizing quality end-of-life care as a global public health and health systems problem, as we have done in this pa-

per, does lead to certain clear conclusions about the sorts of initiatives that will help to improve this problem.

**Recognizing end-of-life as a global public health and health system problem**

The very construction of end-of-life care as a global public health and health systems problem is itself a useful contribution because it mainstreams this issue in global public health and health policy circles. The way we construct social problems has great influence on how we address them. Constructing quality end-of-life care as a global public health and health systems problem, as we have done in this paper, presents it as a potentially mainstream concern of public health and health policy makers. This construction could be reinforced by editors of general medical journals concerned with global public health and health systems issues such as *NEJM*, *JAMA*, *BMJ*, *Lancet*, and *CMAJ*. By conceptualizing quality end-of-life care as a global public health and health systems problem, it also falls under the scope of WHO's initiatives on health system performance, a point to which we will return below.

**Capacity strengthening**

Capacity strengthening is increasingly recognized as a crucial tool for social change on global public health and health systems issues. As we have noted, we could find no systematic data about capacity to deliver quality end-of-life care in developing countries. The first step therefore will be an assessment of existing capacity for delivering end-of-life care in developing countries; information which could be obtained in part through country specific case studies described below. The next step will be to strengthen existing capacity. It is recognized that "bottom up" approaches to capacity strengthening, with strong participation from people in developing countries, are more effective than "top down" approaches led only by people from developed countries. This will be doubly true for efforts to improve quality end-of-life care in developing countries in light of the important cultural considerations in relation to death as outlined above. Both individual and institutional capacity will need strengthening. The scope of this capacity strengthening should be broad. For example, traditional healers may serve as effective champions of quality end-of-life care in some settings because they are closely connected with shared values and community beliefs. Obviously knowing a culture's chief sources of power, whether it is mythological, social or political, is essential to the development of effective, well-accepted health care initiatives. Ultimately, every clinician caring for dying patients should have clinical competencies that promote quality end-of-life care, and educational initiatives such as the EPEC project or Ian Anderson Program referred to above could be built upon. The Open Society Institute has made a major impact on capacity for addressing end-of-life care in the US through its Project on



Death in America (PDIA). It has begun to work in Eastern Europe. It seems the time might be ripe for a global effort at strengthening capacity in end-of-life care by creating a Project on Death in the World (PDIW). We have recently outlined a vision for capacity strengthening in global health ethics, and this too should include attention to the problem of quality end-of-life care [76,77].

#### Information strategies

The problem of quality end-of-life care is, among other things, a problem of lack of health information. It seems difficult to know how to improve quality end-of-life care without any understanding of what the current level of quality is, what determines it, and how improvement could be measured. We have mentioned that no national health system to our knowledge systematically collects information on quality end-of-life care of its dying citizens. This is an obvious first step and one where countries with well developed health "info-structures," such as Canada, could make an important contribution to global public health. In addition, important research could be done to include questions on quality end-of-life care in existing survey instruments, such as a health and nutrition household survey conducted in developing countries. A set of country-specific case studies would provide useful evidence on which to base any global effort to improve end-of-life care. Indeed, we will know that the problem of quality end-of-life care has truly been globalized when the World Health Organization devotes a World Health Report to end-of-life care, and when quality end-of-life care indicators are routinely included in WHO's annual indicators of health system performance.

#### Competing interests

None declared.

#### Authors' contribution

Peter A. Singer and Kerry W. Bowman both conceptualized, wrote, and edited this paper. All authors read and approved the final manuscript.

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