Special Article

Advancing Palliative Care as a Human Right

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Abstract
The international palliative care community has articulated a simple but challenging proposition that palliative care is an international human right. International human rights covenants and the discipline of palliative care have, as common themes, the inherent dignity of the individual and the principles of universality and nondiscrimination. However, when we consider the evidence for the effectiveness of palliative care, the lack of palliative care provision for those who may benefit from it is of grave concern. Three disciplines (palliative care, public health, and human rights) are now interacting with a growing resonance. The maturing of palliative care as a clinical specialty and academic discipline has coincided with the development of a public health approach to global and community-wide health problems.

The care of the dying is a public health issue. Given that death is both inevitable and universal, the care of people with life-limiting illness stands equal to all other public-health issues.

The International Covenant on Economic, Social and Cultural Rights (ICESCR) includes the right to health care and General Comment 14 (paragraph 34) CESCR stipulates that “States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, … to preventive, curative and palliative health services.” However, these rights are seen to be aspirational—rights to be achieved progressively over time by each signatory nation to the maximum capacity of their available resources.

Although a government may use insufficient resources as a justification for inadequacies of its response to palliative care and pain management, General Comment 14 set out “core obligations” and “obligations of comparable priority” in the provision of health care and placed the burden on governments to justify “that every effort has nevertheless been made to use all available resources at its disposal in order to satisfy, as a matter of priority, [these] obligations.”

This article describes recent advocacy activities and explores practical strategies for the palliative care community to use within a human rights framework to advance palliative care development worldwide.

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Key Words
Palliative care, human rights, equity, public health, strategy

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members facing the diagnosis of life-threatening illness are not receiving the attention and commitment from health policy makers that it require.1 There is a sense of urgency to alert governments, health professionals, and communities to the need for palliative care and to its efficacy.2 This has led to a growing call for palliative care to be recognized as a human right and obligations that flow from that right to be fulfilled—access to palliative care services for all those patients and their family members that would benefit from this care. The rationale for palliative care to be recognized as a human right has been clearly described. Brennan3 considered the foundation of a right to palliative care with regard to the ICESCR, the obligation of signatory nations, and the difficulties in promoting a human right to palliative care.

It is the consideration of these difficulties that has led to this article. Palliative care workers may view the fact of palliative care as a human right as self-evident, but we need to develop an understanding of human rights instruments and a strategy on how to use these to access to palliative care locally and internationally. How can this concept be advanced in a practical way? What steps have already been employed?

**Current Situation**

Whereas many developed countries have established palliative care services, most of these services are voluntary, nongovernmental services and do not receive the attention or funding support of government.4 Most countries do not have palliative care policies or integrated palliative care services. Clark and Wright of the International Observatory on End-of-Life Care have mapped palliative care provision worldwide4 (see Fig. 1) and have categorized palliative care provision on four levels: no activity yet identified, capacity building activity, localized provision, and approaching integration. They recognize the broadness of these categories and comment, for example, that Pakistan (in the localized provision category) has one hospital-based palliative care service for the whole country, serving a population of 158 million.5 South Africa (approaching integration) has well-established, nongovernmental organization (NGO) services, although not yet country-wide, and a few hospital-based services integrating palliative care into the formal health care sector. Within the African region, generally, coverage is generally confined to centers of excellence,6 although palliative care initiatives to advocate for opioid availability have had some success.7

Radbruch et al. notes that even in countries with an adequate standard of care and well-developed health care services, access to palliative care care is greater in urban areas and for particular patient groups such as cancer patients.8 Access to comprehensive home-based palliative care in the United States is limited to patients with a life expectancy of less than six months, an artifact of the health insurance reimbursement system; hospital-based palliative care services are growing in number but may or may not be linked to service delivery in the home or to care provided by home hospice programs during the period before death. Clinicians who perceive palliative care to be terminal care only with withdrawal of active treatment—as opposed to active management of the disease process, control of distressing symptoms, psychosocial and spiritual support—deny their patients the comprehensive care they require when facing the diagnosis of life-threatening illness. Thus, many human immunodeficiency virus (HIV) patients do not receive palliative care, as their clinicians believe that with antiretroviral treatment, palliative care will no longer be necessary. This, despite the fact that patients on antiretroviral treatment still suffer from distressing symptoms9,10 and may still die (2.9 million HIV patients died in 200511).

**Scope of the Problem**

The World Health Organization (WHO) estimated that in 2002, 57 million people died, 7 million of whom died of malignant neoplasm.12 Franks et al. estimated that, in the United Kingdom, 25% of people with advanced cancer will require inpatient palliative care and 65% will require home-based palliative care.13 Add to this 2.9 million people who died of AIDS-related illness during 2005,6 many in developing countries with resource constraints in delivering health care in general, and the scope of the problem starts to unfold. The statistics provide a concept of the magnitude of the problem but do not describe the suffering experienced...
nor the length or severity of the illness before death. Moreover, throughout the world, there are growing numbers of individuals who suffer and die from end-stage cardiac, respiratory, renal, and hepatic conditions and life-limiting neurological conditions. These people are likely to experience problems that also would benefit from palliative care.2

Human Rights Covenants

Both palliative care and human rights are based on principles of the dignity of the individual and the principles of universality and non-discrimination. To palliative care personnel, this creates a self-evident premise that palliative care is a human right. However, we need to look closely at the history of human rights development and the human rights covenants that have been established to pursue this claim.

The International Bill of Rights comprises the UN Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the ICESCR. Article 25.1 of the Universal Declaration of Human Rights states, “Everyone has the right to a standard of living adequate for the health of himself and his family, including food, clothing, housing and medical care and necessary social services.”14 The ICESCR Article 12.1 asserts that “the State Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”15

The ICESCR is seen as aspirational in that, in resource-constrained settings, these rights may not be immediately attainable but State Parties that are signatories of the ICESCR commit to progressive realization of the right to health over a period of time and to reporting on the steps taken to reach this goal. It is also recognized that the right to health includes a number of socioeconomic factors “such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment.”1

This raises the question of how to prioritize a population’s socioeconomic needs in working toward the realization of the rights articulated in the ICESCR. General Comment No 14 issued by the committee that oversees the ICESCR asserts that “in particular, States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services”; General Comment No 14
further describes (in the section on older persons) “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.”

Thus, palliative care is already articulated as a human right within the International Bill of Rights. Some countries have taken this further and included palliative care in official documents. In 2000, a Standing Committee of the Canadian Senate proclaimed that end-of-life care was a right of every citizen.17 In 2003, the European Committee of Ministers adopted a recommendation which stated, in part, “palliative care is...an inalienable element of a citizen’s right to health care.”18 The South African Department of Health’s Patients’ Rights Charter19 describes access to health care: “Everyone has the right of access to health care services that include: iii. provision for special needs in the case of...patients in pain, persons living with HIV or AIDS patients; v. palliative care that is affordable and effective in cases of incurable or terminal illness.”

Statements From the International Palliative Care Community

The international palliative care community has made a number of key statements, including the Cape Town Declaration (2002),20 the Korea Declaration (2005),1 and the Budapest Commitments (2007).21 The consensus is a call to governments for

1. the creation and implementation of palliative care policies
2. equity of access to services, without discrimination
3. availability and affordability of critical medications, including opioids
4. the provision of palliative care at all levels of care
5. the integration of palliative care education at all levels of the learning continuum from informal caregivers to health professionals.

Strategies to Implement Palliative Care Into Health Care Systems

A key partner in palliative care development worldwide is the WHO. There are a number of important clinical and policy guide books that assist health care workers in managing pain and other distressing symptoms, and policy makers in implementing cancer control and palliative care programs. WHO recommends a public health strategy to assist governments in integrating palliative care into the country’s health care system. The main elements of this strategy are 1) policy development; 2) drug availability; 3) education of policy makers and health care workers and improving community awareness regarding the service of palliative care; and 4) implementation of palliative care at primary, secondary, and tertiary care levels.22

This strategy is mirrored in the initiative developed by the European Association of Palliative Care, the International Association for Hospice and Palliative Care (IAHPC), and the Worldwide Palliative Care Alliance (WPCA), namely the Budapest Commitments.13 The focus of this initiative is to help individuals and national palliative care organizations to develop effective strategies to meet the needs of patients requiring palliative care. The proposed areas of work are drug availability, policy development, palliative care education, quality of care, and palliative care research. None of the basic initiatives of palliative care education, policy development, and legislation to ensure availability of essential palliative care drugs are costly, and all governments could subscribe to these activities. The growth of palliative care that is culturally appropriate, affordable, and effective in resource-poor settings demonstrates the feasibility of palliative care provision. This growth goes some way to allaying fears that invoking a legislative catalyst for provision would prove too expensive and ultimately unsustainable.

Addressing Barriers to Palliative Care Development

Although it appears to be a straightforward exercise to ensure accessibility of palliative care to all patients requiring this service, there are still a number of significant barriers to implementing the essential elements of the right to palliative care: availability, accessibility, acceptability, and quality. These barriers include lack of political support and awareness; social and cultural issues; “opiophobia” and “opioignorance”...
Effective pain management is an essential component of palliative care and is emphasized in the WHO definition of palliative care. Pain management is a strong and emotive aspect of palliative care that policy makers, health care workers, and community members are able to understand, often better than the complexities of components of comprehensive palliative care, and can be used as the first step in promoting access to palliative care. In 2004, the International Narcotics Control Board published the per capita use of morphine for medical purposes for all countries for the previous year. Six nations accounted for 79% of all analgesic morphine consumption. Countries comprising 80% of the world’s population used 6% of the world’s consumption of morphine for medical purposes. This represents an appalling discrepancy in achieving equity of access to pain-relieving medications and is a strong advocacy focus.

**From Theory to Practice**

The last year has seen significant activity in employing an approach based on human rights to advance both pain management and palliative care.

1. Conference presentations and workshops have assisted in creating awareness of human rights documents and mechanisms among palliative care professionals with practical advice on how to engage government in discussion to recognize the need to integrate palliative care into health care systems.

2. Following sustained advocacy by the IAHPC and the WPCA, two United Nations Special Rapporteurs on Human Rights issues have made clear and explicit statements to the international community linking pain management and palliative care to human rights. In a statement made to the UN Human Rights Council in 2008, the Special Rapporteur on the Right to Health placed palliative care firmly within the obligations that derive from the international right to health:

   Many other right-to-health issues need urgent attention, such as palliative care. Every year...
millions suffer horrific, avoidable pain…. Palliative care needs greater attention.28

Similarly, in a joint statement, the UN Special Rapporteur on the Right to Health and the Special Rapporteur on Torture, after reviewing the inadequacies of pain management and palliative care around the world, stated that:

The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel inhuman and degrading treatment. International human rights law requires that governments must provide essential medicines—which include, among others, opioid analgesics—as part of their minimum core obligations under the right to health. …Lack of access to essential medicines, including for pain relief, is a global human rights issue and must be addressed forcefully….29

3. Regional Advocacy Workshops for palliative care and accessibility of essential pain medication. The Wisconsin Pain and Policy Study Group has been active in various parts of the world—Eastern Europe, India, and sub-Saharan Africa—to assist palliative care organizations in influencing governments with regard to opioid legislation.30

4. Submission to the UN Human Rights Council on HIV/AIDS. In October 2008, a joint submission was made by the IAHPC, the WPCA, and the International Association for the Study of Pain (IASP) to the UN Human Rights Council. In summary, it outlined the human rights implications of pain management and palliative care for patients with HIV/AIDS and their families. It reminded the council that the UN Joint Programme on HIV/AIDS (UNAIDS) and the Declaration of Commitment on HIV/AIDS by the UN General Assembly both indicated the commitment of the United Nations to promoting a human rights perspective on the care and management of HIV/AIDS. It stated that palliative care, generally, and pain management, in particular, for patients with HIV/AIDS, is undertreated, poorly resourced, and subject to multiple barriers. It stated that most nations have signed one or more UN human rights instruments that contain the right to health care.

5. Collaboration between Human Rights Watch and the international palliative care community to highlight the need for opioid use for medical purposes with the Narcotic Drugs Committee at the United Nation. The committee overseeing the ICESCR is preparing a general comment on the issue of discrimination. A submission has been made to the committee by the IAHPC, the WPCA, and the IASP describing discrimination in the provision of, and access to, both pain management and palliative care. The submission argued that draconian domestic opioid laws, policies, and practices that restrict opioid availability, accessibility, and affordability constitute a significant discrimination against patients in pain and the dying. Other examples of de facto discrimination in the provision of pain management and palliative care are laws, policies, and practices that fail to provide adequate health care services in rural and remote areas or fail to provide adequate health care services for children, patients with HIV/AIDS, indigenous persons, persons with disabilities, prisoners, women, refugees, and stateless persons.

6. World Hospice Palliative Care Day. The 2008 theme for this day was Palliative Care as a Human Right. Concurrent with World Day, the IAHPC and the WPCA promulgated the Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment as Human Rights (2008).31

7. In October 2008, the African Palliative Care Association hosted a meeting in Nairobi for heads of African medical and nursing schools to encourage the integration of palliative care into medical and nursing training and to develop plans on how to accomplish this.

8. The IASP has designated the year October 2008 to October 2009 as the Global Year Against Cancer Pain.32

It is particularly encouraging to note the statements by the special rapporteurs. These statements are a major breakthrough. They not only represent the most explicit linkage of
human rights with pain management and palliative care made to date by representatives of the United Nations, but they also provide clinicians and advocates a clear recommendations to present to the health ministries of individual countries. Clinicians and advocates may argue for the integration of palliative care into health care systems on the basis of evidence and a medical and moral imperative. These arguments are more powerful when supported by clear statements of national obligations articulated by senior members of the UN system.

**Shadow Reports on Individual Countries**

All nations that are signatory to the International Covenants that contain the right to health care are expected to report to committees overseeing those covenants on the progress of their compliance with that obligation. NGOs may submit shadow reports on that country’s performance. It is planned that the coalition of the IAHPG, the WPCA, and the IASP will commence submitting shadow reports on the status of palliative care and pain management of individual nations.

It is important to build on the advocacy and policy initiatives of palliative care workers worldwide to ensure that patients and their families facing the problems associated with life-threatening illness are afforded the care they require in whatever country and setting they live. We recommend contact with national, regional, and international palliative care associations to share learning and to strategize mechanisms to influence policy.

**Conclusions**

The growing consensus between the disciplines of palliative care, public health, and human rights provides an opportunity to collaborate in advancing the access to palliative care for patients and family members facing the diagnosis of life-threatening illness. It strengthens our mandate to act as advocates for this group of people who because of their illness or grief have not had the capacity to demand the services they need. As Chochinov stated in his eloquent address to the Canadian Senate Standing Committee on Social Affairs, Science and Technology: “Unfortunately, in end-of-life care, we do not have a vocal constituency. The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.”

Recent initiatives have emphasized that with clear strategy and effective action we can achieve policy change and promote integration of palliative care into public health programs. The development of expertise in using human rights mechanisms improves palliative care professionals’ effectiveness in discussions with health policy makers.

The human rights approach to advancing palliative care development serves to coalesce a broad medical, moral, and legal imperative—that the care of patients with life-threatening illness is a fundamental responsibility of governments, societies, and health professionals.

**Acknowledgments**

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