

Special Article

Palliative Care as an International Human Right

Frank Brennan, MBBS, FRACP, FACHPM, LLB
Calvary Hospital, Sydney, New South Wales, Australia

Abstract

There are major disparities in the provision of palliative care around the world. In recent years, a statement of advocacy and objective has been repeatedly articulated that the provision of palliative care is a human right. This article examines the foundation for this assertion in the context of international human rights law. The strengths and weaknesses of this assertion are examined. The nature of both the right and, correlatively, the obligation on individual governments is discussed. *J Pain Symptom Manage* 2007;33:494–499. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, human rights, health

Introduction

Death is inevitable. The provision of good health care at the time of death is less so. Throughout the world, there are wide disparities in the capacity, resources, and infrastructure devoted to the care of people with life-limiting illnesses. The majority of countries have neither formal palliative care policies nor integrated palliative care services, do not meet basic international guidelines in the provision of palliative care, and have legislation or policies whose effect restricts the availability of opioids for medical purposes.

In 1992, Margaret Somerville, a preeminent scholar of medical law, wrote a seminal paper arguing that the relief of suffering is a common goal of both medicine and human rights, and

that the relief of the pain and suffering of terminally ill patients is a human right.¹ In recent years, that term has entered the discourse: a Standing Committee of the Canadian Senate,² The Cape Town Declaration,³ the European Committee of Ministers,⁴ the International Working Group (European School of Oncology),⁵ Pope Benedict XVI,⁶ and The Korea Declaration⁷ have all asserted that palliative care is a fundamental human right.

What, if any, are the foundations for articulating such a right? This article will address one answer to that question: palliative care as an international human right.

The Foundations of a Right to Palliative Care

The statement that “Palliative Care is a human right” is a powerful one. Does this assertion have any foundation beyond rhetoric? Famously, Jeremy Bentham described the articulation of rights without legal foundation as “nonsense on stilts.” Is the assertion that there

Address reprint requests to: Frank Brennan, MBBS, Calvary Hospital, Kogarah, New South Wales, 2217, Australia. E-mail: fpbrennan@ozemail.com.au

Accepted for publication: February 22, 2007.

is a right to palliative care “nonsense on stilts?” What, if any, are the foundations of legal rights to palliative care?

Legal Rights to Palliative Care

Depending on the jurisdiction in which they live, patients with life-limiting illnesses may have a constellation of legal rights underlying both pain management and palliative care. Health rights derived from national constitutions,⁸ the law of negligence,⁹ judicial statements on the basis of public interest,¹⁰ and domestic legislation¹¹ have emerged over the last two decades. They are not within the scope of this article, which is principally concerned with palliative care in the context of international human rights. Any broader discussion of the legal rights founding the provision of palliative care would need to include a discussion of these developments.

The International Human Right to Health Care

The International Covenant on Economic, Social, and Cultural Rights (ICESCR) states:

Article 12.1. The State Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

2. The steps to be taken... to achieve the full realisation of this right shall include those necessary for:

... d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.¹²

In addition, the right to health is articulated in several other international covenants.¹³

It is important to emphasize several aspects of this right to health. First, the right is not absolute, to be fulfilled immediately. At its inception, there was a clear recognition that resources varied significantly throughout the world. Rights articulated in this Covenant were seen as aspirational—rights to be achieved progressively over time to the maximum capacity of each signatory nation state. Second, the Covenant imposes obligations

solely on governments that are signatories. It does not obligate private citizens, including health professionals. Finally, there is no appeal process or mechanism for complaint. Nevertheless, signatory nations are expected to regularly report to a committee overseeing the Covenant.

There is no express right to palliative care in these United Nations documents. Nevertheless, the World Health Organization defines both health and palliative care broadly. Health includes the health of people with life-limiting illnesses. The provision of palliative care, where appropriate, is one part of a continuum of health care for all persons. Therefore, an argument can be made that a right to palliative care can be implied from the overall international human right to health. Assuming that a right to palliative care can be implied from the overall international human right to health, what, correlatively, is the content of the obligation?

The Content of the Obligation

The ICESCR Committee

In 2000, the Committee overseeing the ICESCR issued a General Comment on the right to health, stating what it saw as the “core obligations” of all signatory nations, irrespective of resources.¹⁴ They include obligations to ensure access to health facilities, goods and services on a nondiscriminatory basis; to provide essential drugs as defined by the WHO; and to adopt and implement a national public health strategy. Interpreting this Comment in the context of palliative care, this would oblige nations to ensure a universal access to services, the provision of basic medications for symptom control and terminal care, and the adoption and implementation of national palliative care policies.

The World Health Organization

For palliative care, a further guide to minimum standards expected by the international community emerges from WHO recommendations. These include that all countries should adopt a national palliative care policy, ensure the training and education of health professionals and promote public awareness, ensure the availability of morphine in all health care

settings, and ensure that minimum standards for pain relief and palliative care are progressively adopted at all levels of care. The symmetry is clear: the obligations of governments, as interpreted by the Committee that oversees the international right to health, accords exactly with the recommendations of the preeminent world health body.

Recognizing the widely divergent capacities of countries, the WHO set out general recommendations for different resource settings. For countries with low resource settings, home-based care is probably the best way of achieving good quality care. In countries with medium level resources, services should be provided by primary health care clinics and home-based care. In high resource settings, there is a variety of options, including home-based care.

International Statements by the Palliative Care Community

Several international statements have been made, over recent years, asserting that the provision of palliative care is a universal right. Collectively, they represent statements of advocacy and objective. In addition, they provide a sense of the architecture and content of this purported right.

Conscious of the appalling unfolding tragedy of HIV/AIDS, the poorly met needs of cancer patients and the inadequacy of governmental response throughout the African continent, the Cape Town Declaration (2002) asserted four main propositions:

1. Palliative care is a right of every adult and child with a life-limiting disease.
2. Appropriate drugs, including strong opioids, should be made accessible to every patient requiring them in every sub-Saharan country and at all levels of care.
3. The establishment of education programs is necessary at all levels of the learning continuum.
4. Palliative care should be provided at all levels of care...While primary care is emphasized, secondary and tertiary level teams are needed to lead and foster primary level care.

In 2004, the International Working Group (European School of Oncology) released a position paper, "A New International Framework

for Palliative Care."⁵ It stated that "there should be free access to palliative care ... for all cancer patients, as a fundamental human right." Based on their definition of palliative care,¹⁵ the ESO Working Group proposed two further refinements that reflect the levels at which palliative care can be delivered: *Basic palliative care*, which should be provided by all health professionals, and *Specialized palliative care*, to be provided by a trained multiprofessional team to manage persisting and more complex problems and to provide specialized educational and practical resources to other health professionals.

The Korea Declaration emerged from the 2nd Global Summit of National Hospice and Palliative Care Associations in 2005.⁷ It stated that governments must "make access to hospice and palliative care a human right." Specifically, it called on governments to include palliative care as part of health policy; integrate palliative care training into the curricula of health professionals; ensure the availability and affordability of all necessary drugs, especially opioids; and strive to make hospice and palliative care available to all citizens in the setting of their choice.

Another significant international statement that has clear implications for the provision of palliative care was the Montreal Statement on the Human Right to Essential Medicines (2005).¹⁶ The Statement expressly linked the international right to health with the universal access to these essential medications.

In his message for the 2006 World Day for the Sick, Pope Benedick XVI stated that an essential emphasis of palliative care was the preservation of human dignity. His Holiness expressly stated that the provision of palliative care services was a human right: "...it is necessary to stress once again the need for more palliative care centers, which provide integral care, offering the sick the human assistance and spiritual accompaniment they need. This is a right belonging to every human being, one which we must all be committed to defend."⁶

Synthesizing these sources (the Committee that oversees the international right to health, the WHO and the international palliative care community), a consensus on the content of the obligation on individual governments in relation to palliative care appears to be emerging.

What Are the Difficulties in Promoting a Human Right to Palliative Care?

The Concept of Health as a Right

In recent years, a considerable body of literature has concentrated on the right to health, especially in the context of the significant inequalities in access to health care throughout the world. Indeed, to Mann, a pioneering theorist in this area, the promotion and protection of human rights and health are “inextricably linked.”¹⁷ Other theorists have been critical of the concept of an individual “right to health,” describing it as illusory,¹⁸ meaningless,¹⁹ or, in the context of a world with limited resources, unattainable.²⁰ Others have emphasized the provision of health care in terms of equality and social justice,²¹ or as a foundation of the capability of leading a healthy life.^{22,23}

Despite these debates, critical links have been made between health and human rights by academia, governments, nongovernmental organizations, and international bodies, including agencies of the United Nations. These connections have been directed to advocacy, the provision of services, research, and defining health policy. Catalysts for these linkages have included the HIV/AIDS pandemic, women’s health issues, and gross human rights violations in the Balkans and Africa. [See the first WHO Global Strategy for the Prevention and Control of AIDS (1987). Both the International Conference on Population and Development (1994) and the Fourth World Conference on Women (1995) resulted in consensus documents expressly linking health and human rights. Similarly, statements by the UN Human Rights Commission and the Special Rapporteur for Human Rights on the international Right to Health have had, as their foundation, the promotion of health as a human right.]

The Danger of Arguing in Isolation

The World Health Organization and multiple international statements on palliative care have recognized the stark reality: at a global level, specialist palliative care services are rarely available and that in the majority of countries, only the most basic, home-based care is being provided. Clearly, this has implications for any discussion of palliative care as

a universal right. Indeed, when one examines the provision of palliative care services internationally, are we not talking about the provision of simply *good health care* that includes palliative care? For if we are focusing on the comfort of a patient with a life-limiting illness, surely that must include water, food, a habitable environment, warmth, bedding, and sanitation as much as symptom control. Indeed, it would be artificial to separate a “right to palliative care” from a general right to health, housing, water, and sanitation. All are interconnected. All determine good health, even and including at the end of life. That interconnectedness was made expressly by the General Comment on the Right to Health.²⁴

The Danger of Misinterpretation

In promoting a human right to palliative care, there is an immediate problem with interpretation. What exactly does such a right mean? A right to an integrated palliative care service? The right of access to a palliative care inpatient unit? A right to demand any intervention or resource the patient or their family sees fit? The right to a “good” and “dignified” death?

While we are increasingly equipped to deal with the challenges presented to us as health professionals, many aspects of serious illness and death are beyond our control. The right to palliative care can only mean a reasonable and proportionate response to the needs of patients. It can never mean an absolute guarantee that suffering will never occur. If an international obligation was expected at that level, no government could meet it. Equally, at an individual perspective, if the right was placed at a level of perfection, no health professional could possibly fulfill their responsibility to fulfill that right.

Enforcement of the Right

Other significant limitations to the international human right to health are the issues of adherence and enforcement. The Committee overseeing the Covenant has no powers of enforcement or sanction. Nevertheless, it does have a moral and persuasive capacity. It could reinforce statements already made by other international bodies, including the WHO and the International Narcotics Control Board, recommending that countries liberalize opioid

laws and report the true opioid requirements of their population. Furthermore, the Committee could remind signatory nations of their core obligations with respect to health in the context of palliative care.

Another significant agent for persuasion, education, and advocacy is the office of the Special Rapporteur of the Human Rights Commission on the right to health. According to its founding resolution, the Special Rapporteur can receive complaints alleging violations of this right and correspond with the relevant governments to clarify and invite comment and, where appropriate, remind governments of their obligations under international law.

Conclusion

Given the enormous unmet needs of patients with life-limiting illnesses in the world, it is not surprising that advocates have promoted the provision of palliative care as a human right. Indeed, those statements have emerged in an era where links are being generally made between health and human rights. A human right to palliative care may be implied from the international right to health care. However, that right should not be seen in isolation. If the goal is freedom from unnecessary suffering, then the provision of all possible measures to ensure that relief is met must be present—including adequate housing, nutrition, water, and sanitation. For the progressive fulfillment of a human right to palliative care, much will be required: flexible and creative public policy, greater access to opioids for medical purposes, tireless advocacy, comprehensive education, professional leadership, and continued calls upon individual compassion for this most vulnerable group of people.

Acknowledgments

The author wishes to acknowledge Professor Kathleen Foley for the helpful comments and suggestions made in the preparation of this article.

References

1. Somerville M. Human rights and medicine: the relief of suffering. In: Cotler I, Eliadis FP, eds. International human rights law: Theory and practice. Montreal: Canadian Human Rights Foundation, 1992:505–522.
2. Standing Committee on Social Affairs, Science and Technology. Quality end-of-life care: The right of every Canadian. Final report of the Subcommittee to Update Of Life and Death. Ottawa: Senate of Canada, 2000.
3. Sebuyira LM, Mwangi-Powell F, Perira J, Spence C. The Cape Town Palliative Care Declaration: home-grown solutions for sub-Saharan Africa. *J Palliat Med* 2003;6(3):341–343.
4. Council of Europe. Recommendation 24 of 2003. Adopted by the European Committee of Ministers on November 12, 2003.
5. Ahmedzai SH, Costa A, Blengini C, et al. A new international framework for palliative care. *Eur J Cancer* 2004;40:2192–2200.
6. Pope Benedict XVI. Message of His Holiness Benedict XVI for the Fifteenth World Day of the Sick 2006; Available from http://www.vatican.va/holy_father/benedick_xvi/messages/sick/documents/hf_ben-xvi. Accessed April 1, 2007.
7. The Korea Declaration. Report of the Second Global Summit of National Hospice and Palliative Care Associations, Seoul, March 2005. Available at http://www.worldday.org/documents/Korea_Declaration.doc. Accessed April 1, 2007.
8. Treatment Action Campaign v. Minister of Health (Kwa-Zulu-Natal). Constitutional Court of South Africa, 2002.
9. Estate of Henry James v. Hillhaven Corporation. No. 89 CVS 64 (North Carolina Superior Court Division), 1991.
10. In the High Court of Delhi at New Delhi Extraordinary Civil Writ Jurisdiction Civil Writ Petition No. 942 of 1998—Orders.
11. California Bus and Prof. Code, s.2190.5, 2241.6 and 2313 (West 2004); Medical Treatment Act (1994), Australian Capital Territory, s23(1); Consent to Medical Treatment and Palliative Care Act 1995 (South Australia), s.17(1).
12. International Covenant on Economic, Social and Cultural Rights (1966), Article 12.
13. Universal Declaration of Human Rights, Article 25; Article 12 of the Convention on the Elimination of All Forms of Discrimination against Women; Article 24 of the Convention on the Rights of the Child; and Article 5(e) (iv) of the Convention on the Elimination of All Forms of Racial Discrimination.
14. Committee on Economic, Social and Cultural Rights. General Comment No. 14. “The rights to the highest attainable standard of health (Article 12 of the Covenant).” 22nd Session April–May 2000 E/C 12/2000/4, para 43.
15. “... the person centred attention to physical symptoms and to psychological, social and

existential distress and cultural needs in patients with limited prognosis, in order to optimize the quality of life of patients and their families or friends.”

16. Montreal Statement on the Human Right to Essential Medicines. Reprinted in <http://www.ethics.harvard.edu/download/pogge2.pdf>. Accessed April 2, 2007.

17. Mann JM, Gostin L, Gruskin S, et al. Health and human rights. In: Mann JM, Gostin L, Gruskin S, Grodin MA, Annas GJ, eds. *Health and human rights: A reader*. New York: Routledge, 1999:7–20.

18. Goodman T. Is there a right to health? *J Med Philos* 2005;30:643–662.

19. O’Neill O. *Autonomy and trust in bioethics* (Gifford Lectures, 2001). Cambridge: Cambridge University Press, 2002:78–79.

20. Cranston M. *What are human rights?*. New York: Basic Books, 1973.

21. Farmer P, Gastineau N. Rethinking health and human rights: time for a paradigm shift. *J Law Med Ethics* 2002;30(4):655–666.

22. Sen A. *Development as freedom*. New York: Oxford University Press, 1998:87–110.

23. Nussbaum M. Capabilities, human rights and the universal declaration. In: Weston BH, Marks SP, eds. *The future of international human rights*. Ardsley, NY: Transnational Publishers, 1999: 25–64.

24. Committee on Economic, Social and Cultural Rights. General Comment No. 14. “The Rights to the highest attainable standard of health (Article 12 of the Covenant).” 22nd Session April–May 2000 E/C 12/2000/4, para 3.