
FROM THE EDITOR

Palliative care as a human right

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world.

—the Universal Declaration of Human Rights (preamble, U.N. General Assembly resolution 217, December 10, 1948)

The Universal Declaration of Human Rights, adopted and proclaimed by the United Nations General Assembly (resolution 217A III) on December 10, 1948, is the modern era's first and most commonly accepted statement of "human rights" in the world today. The 30 articles of the declaration establish the civil and political, economic, social, and cultural rights of all people. Many nations have incorporated the provisions of the declaration into their constitutions. It is a statement of principles with an appeal to every individual and every social organization to promote and guarantee respect for the freedoms and the rights it defines. Under the Charter of the United Nations, member states are pledged to take joint and separate action to promote universal respect for, and observance of, human rights and fundamental freedoms. This is a legal obligation. The Universal Declaration of Human Rights is the authoritative statement of what those human rights and fundamental freedoms are.

ARE "PALLIATIVE CARE AND PAIN TREATMENT" FUNDAMENTAL HUMAN RIGHTS?

This is a question that has been forced to the forefront by a bold international initiative of worldwide organizations in the fields of palliative care, hospice, pain, cancer, HIV, and psycho-oncology. On Monday, August 4, at the XVII International AIDS Conference

in Mexico City, the International Association for Hospice and Palliative Care (IAHPC), the Worldwide Palliative Care Alliance (WPCA), and many organizations from around the world, including the International Psycho-oncology Society (IPOS) issued a Joint Declaration and Statement of Commitment calling for the recognition of Palliative Care and Pain Treatment as Human Rights. The Declaration and Statement was jointly developed and signed by representatives of numerous international and regional organizations from Africa, Latin America, Eastern Europe, Western Europe, Asia, and North America.

Certainly the global situation regarding the adequate provision of palliative care and pain control is alarming. According to data from the World Health Organization (WHO) and the International Narcotics Control Board, only a minority of the more than 1 million people who die each week receive palliative care to alleviate their suffering. Developing countries, which represent about 80% of the world's population, account for only about 6% of global consumption of morphine, a mainstay therapy for palliative care and pain control. "Even today, many health care plans, laws and treatment strategies for life-limiting conditions, such as cancer and HIV/AIDS, do not allow adequate access to palliative care and pain management," reports Liliana De Lima, Executive Director of the IAHPC and one of the major forces behind this initiative. She further points out that "patients have physical symptoms and special psychosocial and spiritual needs which require appropriate care. Their family members and their caregivers also suffer the emotional and social consequences of the diseases and their treatments. With adequate palliative care and pain treatment, most patients and their families can be relieved from their suffering, and the quality of their lives can be improved significantly. We want to bring this to the attention of policy makers and funders with this Declaration so that palliative care is included as a component of care in addition to prevention, early detection and active treatment."

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WHAT IS THE BASIS FOR CONSIDERING PALLIATIVE CARE AND PAIN TREATMENT HUMAN RIGHTS?

The Joint Declaration and Statement of Commitment calling for the recognition of Palliative Care and Pain Treatment as Human Rights uses the U.N.'s Universal Declaration of Human Rights and several more recent documents from the WHO and others, as support. The Universal Declaration of Human Rights recognized the rights of everyone "to life," to freedom from "torture" and "cruel, inhuman or degrading treatment" (Article 5), and "to a standard of living adequate for health and well-being" (Article 25). The State parties of the International Covenant on Economic, Social, and Cultural Rights recognize "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" (Article 12), creating the "conditions which would assure to all medical service and medical attention in the event of sickness." The United Nations Committee on Economic, Social, and Cultural Rights specifically states that parties are "under the obligation to respect the right to heal by, inter alia, refraining from denying or limiting equal access for all persons . . . to preventive, curative and palliative health services." The Committee further affirmed the importance of "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity." Additionally the Committee indicated that access to "essential drugs, as defined by the WHO Action Programme on Drugs" is part of the minimum core content of the right to health and that 14 medications listed on the IAHPC List of Essential Medicines for Palliative Care are currently on the WHO Model List of Essential Medicines.

Sharon Baxter, Executive Director of the Canadian Hospice Palliative Care Association and Chair of the WPCA Advocacy Committee said, in the press release announcing the release of the Joint Declaration and Statement of Commitment calling for the recognition of Palliative Care and Pain Treatment as Human Rights, "This is an unprecedented collective effort by representatives from healthcare and patient advocacy organizations from around the world working together to achieve seven specific goals in palliative care and pain management. The Declaration will be used by non-governmental organizations, professional organizations, federations, alliances and civic-minded individuals to bring palliative care and pain treatment to the attention of policy makers, regulators, governments and organizations in order to improve the care of patients with life-limiting conditions, and to provide support to their families and loved ones."

The seven goals in the Joint Declaration are:

1. Identify, develop, and implement strategies for the recognition of palliative care and pain treatment as fundamental human rights.
2. Work with governments and policy makers to adopt the necessary changes in legislation to ensure appropriate care of patients with life-limiting conditions.
3. Work with policy makers and regulators to identify and eliminate regulatory and legal barriers that interfere with the rational use of controlled medications.
4. Advocate for improvements in access to and availability of opioids and other medications required for the effective treatment of pain and other symptoms common in palliative care, including special formulations and appropriate medications for children.
5. Advocate for adequate resources to be made available to support the implementation of palliative care and pain treatment services and providers where needed.
6. Advocate for academic institutions, teaching hospitals, and universities to adopt the necessary practices and changes needed to ensure that palliative care and pain positions, resources, personnel, infrastructures, review boards and systems are created and sustained.
7. Encourage and enlist other international and national palliative care, pain treatment, related organizations, associations, federations, and interested parties to join this global campaign for the recognition of palliative care and pain treatment as human rights.

The Joint Declaration and Statement of Commitment is scheduled to be presented in meetings sponsored by cancer, palliative care and pain management, and psycho-oncology organizations throughout the rest of 2008. The IAHPC and WPCA invite all interested organizations and individuals to read and sign the Declaration. To read and sign the Declaration, visit http://www.hospicecare.com/resources/pain_pallcare_hr/.

WILL WE CONVINCED ANYONE THAT PALLIATIVE CARE AND PAIN TREATMENT ARE HUMAN RIGHTS?

I suspect that there have been and will be many reactions to this Joint Declaration and human rights initiative. These reactions will range from enthusiastic and naive idealism to nihilistic pessimism. One of my initial reactions was that all medical

care is a human right, not only palliative care. We could easily have an equally compelling reason to choose access to general medical care or mental health care as human rights issues that affect millions and millions of people living in poverty around the world and in prosperity here in the United States. As the current President of the International Psycho-oncology Society, I chose to strongly support this initiative, as did the entire IPOS Board, despite a lack of specific inclusion of the importance of psychosocial, existential, and spiritual domains of palliative care. Certainly we must start somewhere and we must take a stand on an issue, and we must start the process now. We are in a time of change

and transformation. We must not only further the science and practice of palliative care and the related disciplines of pain management and psycho-oncology, we must learn to be advocates for our patients, for our mission, for what we truly care about in this world. This is a start: a bold, heroic, and glorious beginning.

For additional information, please see: International Association for Hospice and Palliative Care: www.hospicecare.com, Worldwide Palliative Care Alliance: www.wwpca.net, or International Psycho-oncology Society: www.ipos-society.org.

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