
FROM THE EDITOR

Palliative care as a human right: Update

As I sit down to write this update on the global initiative to recognize Palliative Care (including psychosocial cancer care) and Pain Treatment as Human Rights, it is perhaps ironic that I have spent the entire morning watching the television coverage of the 10th Anniversary Memorial Services for the September 11, 2001 victims of the terrorist attacks on the United States. I was most personally affected by the attacks on, and the eventual collapse of, the World Trade Center twin towers that killed some 3,000 of my fellow New Yorkers, as I watched and smelled the acrid smoke that filled the air some 60 city blocks from my offices at Memorial Sloan-Kettering Cancer Center. “Human Rights”! What about the “Human Right to Life”? a right that was so heinously violated on that infamous day 10 years ago? Paradoxically, it is this “Human Right to Life” that constitutes a significant basis for the “Human Right to Health Care,” a component of the argument for Palliative Care and Pain Treatment to be viewed as Human Rights.

On Monday, August 4, 2008, at the XVII International AIDS Conference in Mexico City, the International Association for Hospice and Palliative Care (IAHPC), the Worldwide Palliative Care Alliance 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. What has happened over the last three years? What progress have we made?

WHERE THE STORY BEGINS: THE BASIS FOR CONSIDERING PALLIATIVE CARE AND PAIN TREATMENT HUMAN RIGHTS

The 2008 Joint Declaration and Statement of Commitment calling for the recognition of Palliative Care and Pain Treatment as Human Rights used

the United Nations’ Universal Declaration of Human Rights and several more recent documents from the World Health Organization and others, as support. 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.

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.

The objective of the 2008 Joint Declaration and Statement of Commitment calling for the recognition of Palliative Care and Pain Treatment as Human Rights, was the hope that the Declaration would 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 specific goals in the Joint Declaration were: (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 hospital 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 BEGINNINGS OF PROGRESS

Thankfully, progress has been made on several fronts. I will describe some of that progress (below), but focus more on what I have learned about what is necessary for enacting change in each of our countries and regions utilizing a Human Rights ad-

vocacy framework for producing such change. During my tenure as President, IPOS created an IPOS Human Rights Task Force in 2008. We have held Symposia on Psychosocial Cancer Care as a Human Rights Issue at IPOS World Congresses in Vienna, Quebec City, and have one planned for this year in Antalya Turkey on October 19, 2011.

MY EDUCATION IN MEDICAL HUMAN RIGHTS ADVOCACY BEGINS

Thanks to Kathleen Foley of the Open Society Foundation, and Adrian van Es M.D, Executive Director of the International Federation of Health and Human Rights Organizations (IFHHRO), I was invited to participate in an extraordinary workshop intended to train leaders of international medical organizations in the basics of Health-Related Human Rights Advocacy. IFHHRO is an interesting medical human rights organization. IFHHRO promotes the monitoring of health-related human rights, including the right to health, and believes that there lies a huge potential in the health profession that could be mobilized for the promotion and protection of human rights, by applying medical expertise. To increase the involvement of doctors, nurses, paramedics, and other health workers, IFHHRO members are doctors' associations interested in human rights work, human rights groups paying attention to health-related rights violations, or organizations that have been especially created to mobilize health professionals for human rights protection (www.ifhhro.org).

The workshop took place on January 20–21, 2011, outside of Utrecht, the Netherlands, in an isolated lodge, in the woods of the town of De Bilt, called the Hotel de Biltsche Hoek. The setting was certainly conducive to work, contemplation, and bonding with the international array of extraordinary participants. The goals of the workshop were (1) to increase participants' understanding of access to pain relief and palliative care as a human rights issue, (2) to familiarize participants with the international human rights mechanisms that can be used to further the concept of pain relief, palliative care, and even psychosocial cancer care as a human right, (3) to specifically develop a World Medical Association resolution on access to pain relief and learn how to advocate for such medically related human rights issues, and (4) identify opportunities for participants to work together in the future to advance medical and cancer care human rights issues internationally and in each country and region.

The list of participants was indeed quite impressive and inspiring. I had the honor to represent the International Psycho-oncology Society (and made every effort I could to emphasize that the “pain” of cancer

was not merely physical, requiring opioid analgesics, but also an experience of suffering with psychological, existential, and spiritual components that could not be split off from the concept of adequate pain relief). I was joined by participants who represented the International Association for the Study of Pain (as well as the European and Thai chapters), The International Association of Hospice and Palliative Care, the Worldwide Palliative Care Alliance, The Union of International Cancer Control, The International Children's Palliative Care Network, The African Palliative Care Association, The European Association of Palliative Care, The World Federation of Anesthesiologists, The Global Initiative on Psychiatry from Tblisi, the World Medical Association and representatives from the British, Indian, South African, and Malaysian Medical Associations, the International Council of Nurses, and others. It was an international array of leaders of influential organizations, and what we had in common was a desire to improve pain and palliative care treatment, and a sense of bewilderment and ignorance as to how to use a human rights framework to advocate for our causes.

The workshop did focus to a great degree on adequate pain treatment as the paradigm for medical human rights advocacy action. The impetus for the meeting came from the growing influence of the 2008 Joint Declaration and Statement of Commitment calling for the recognition of Palliative Care and Pain Treatment as Human Rights, mentioned above. Continuing efforts to promote this commitment resulted in a document that was presented as a report to the United Nations Human Rights Council in 2009. In a report to the Human Rights Council, the United Nation Special Rapporteur on Torture and other Cruel, Inhuman, or Degrading Treatment or Punishment noted that: "*the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment of punishment*" and that "*all measures should be taken to ... overcome current regulatory, educational and attitudinal obstacles to full access to palliative care*" (Human Rights Council, 2009). The United Nations Human Rights Council sounds like a formidable body with great influence, and it is. However, what we came to learn in this workshop is that the United Nations, although the Human Rights Council and multiple international conventions and declarations, has the ability to bring countries together to make commitments to human rights policies, but has no enforcement capabilities. So the United States can have a health care system where 45 million people are uninsured and have limited access to medical care is a violation by the United States of a variety of Human Rights Conventions (e.g., The International Bill of Human Rights) it

has signed on to, the United Nations can make recommendations, however it has no enforcement capabilities and as such cannot force the United States to comply with the international United Nations covenants it has signed. The cold hard fact is that, with the exception of two regional Human Rights Courts (e.g., the European Court of Human Rights), there is little legal recourse to have nations comply with human rights treaties they have violated. The battle must take place in each individual country and within the health care or cancer care policies of each country. It lies to us who are the health care providers to exert pressure on medical organizations and governments to alter health care policies that violate human rights, or to use human rights arguments to advocate for better treatment of cancer pain, provision of palliative care, and psychosocial support for cancer patients.

HEALTH AS A HUMAN RIGHT: BASICS

Human Rights have 4 basic characteristics. Human Rights are: (1) Fundamental to human dignity and development; (2) Universal, they apply to everyone and everywhere, (3) Inalienable, they cannot be taken away from an individual; and (4) Indivisible, they are inexorably connected to each other and cannot be selectively applied.

The Sources of Human Rights are derived from International Conventions and Treaties: Covenant on Economic, Social and Cultural Rights; Covenant on Civil & Political Rights; Convention Against Torture; Convention on the Elimination of all forms of Racial Discrimination; Convention on the Elimination of all forms of Discrimination Against Women; Convention on the Rights of the Child; Convention on the Rights of Persons with Disabilities. Additionally, they are derived from Regional Human Rights Treaties: African Charter on Human and People's Rights; European Convention on Human Rights; European Social Charter, The American Convention on Human Rights and Economic, Social and Cultural Rights. Finally, a number of National Constitutions (e.g., Ecuador, Australia) guarantee human rights, and in particular the right to health. These are all binding documents, which suggest that the fulfillment of the human rights enshrined in them can be theoretically be enforced, but the enforcing agent is not always clear. Clearly, governments who are bound to the conditions of these documents must be held accountable and governments have three types of obligations: Government Obligations include: Respect, refrain from violating human rights in your country; Protect, prevent others from violating human rights in your country; and Fulfill, take measures necessary for the progressive (and resource feasible) realization

of human rights in your country. Clearly, it is at the individual government policy level where each of us can be most effective in utilizing a human rights advocacy argument to influence governmental cancer care policies.

Human Rights Relevant to Health Care and Pain Treatment include: the Right to Health; the Right to Life; Freedom from Torture, Cruel, Inhuman, and Degrading Treatment; Right to Non-Discrimination and equality/equal access; Right to Information. These are all specifically included in the international and regional conventions and treaties listed above as the sources of human rights. What is most important, however, is an explication of what the Right to Health and Health care truly means.

The right to health does not mean the right to be healthy, but rather the right to the highest attainable standard of physical and mental health. On the basis of existing treaties and conventions the *Meaning of the Right to Health and Health Care* includes: the Right to the enjoyment of a range of facilities, goods, services, and conditions necessary for the realization of the highest attainable standard of health (a health care system); conditions for maintaining good health (clean air, potable water, safe working conditions, vaccinations, etc.). *Each Government must make assure 4 essential standards that the right to health imposes*: Availability; Accessibility (financial, physical, non-discriminatory, information); Acceptability (culturally, ethically, human dignity), and Quality (of facilities, goods and services).

Finally there are several *cross cutting elements* in Basic Human Rights Relevant to Health Care. Accountability: this refers to national, regional and international procedures that require a government to show, explain, and justify what it is doing to realize human rights and the right to health for all. This takes place every few years when countries are obliged to report to the United Nations Human Rights Council and can be reprimanded or admonished if they are underperforming (the United Nations can't force them to do anything specific, but can exert influence). Non-discrimination: this means that people's chances to enjoy good health are not to be disadvantaged because of their sex, race, religion, culture, disability, health status, socio-economic status, sexual orientation, age, language. Participation: this refers to the active involvement of people and groups in health-related decision making that affects them.

CURRENT STATUS OF PROGRESS

At this remarkable meeting I describe above, several specific products emerged. The International Association for the Study of Pain, in 2010, had produced a consensus statement called "the Declaration of Mon-

treau," a declaration that access to pain management is a fundamental human right (Declaration of Montreal, 2010). This declaration was then worked on at the IFHHRO meeting in Bilt and produced an IFHHRO Position Statement on "Access to Adequate Pain Treatment." The link to this statement is: <http://ifhhro.org/about-us/position-statements>. The position statement can be downloaded there in English, Spanish, and French. Finally, this position statement was taken up by the British Medical Association and submitted a resolution on "Access to Adequate Pain Treatment" to the World Medical Association (WMA). This resolution will be voted on during the WMA General Assembly in Montevideo between October 12–15, 2011. The goal of this resolution is to empower health professionals who play a major role in improving the access to essential medicines and in the development of necessary policies to ensure availability and accessibility of adequate pain treatment. Human Rights Watch, along with partners in the Open Society Institute and others held a side event on palliative care, co-sponsored by Council members Brazil and Uruguay, at the United Nations Human Rights Council in June 2011. The hope is that this event will raise visibility within the United Nations Human Rights Council that will lead to a resolution by the Council on the need for improved cancer pain control and palliative care in the coming year.

What I learned at this conference on health Care Human Rights Advocacy, I tried to share with our readers as outlined above. I am now more aware of the basis of the argument that aspects of health care, that the readers of *Palliative & Supportive Care* are interested in, can clearly be argued and advocated for on the basis of Human Rights Law. What I also learned is that the organizations and institutions I thought would have policed and enforced such human rights issues have little enforcement capability, and additionally have many other human rights issues on their agenda. So it really does fall to each of us, in our own national and international professional societies, and in advocacy with our own national governments, to be the agents of change. Together we are stronger, but the responsibility lies with each one of us. As Barack Obama was fond of saying while campaigning for the United States Presidency almost 3 years ago, "we are the ones we have been waiting for!"

Editor's Note

For members of IPOS, The IPOS Human Rights Task Force has an extensive collection of all the documents referred to in this article plus other readings. This can be accessed at the following link: http://www.ipos-society.org/members/members_human_rights.aspx. By the way this is a good reason to become a

member of the International Psycho-oncology Society
www.ipos-society.org

Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, UNITED NATIONS Doc. A/HRC/10/44, January 14, 2009, para. 68, 72, and 74(e)

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WILLIAM BREITBART, M.D., F.A.P.A., F.A.P.M.
Editor-in-Chief