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Palliative Care and Human Rights: A Decade of Evolution in Standards

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ABSTRACT

Context

Human rights standards to address palliative care have developed over the last decade.

Objectives

This paper aims to examine key milestones in the evolution of human rights standards to address palliative care, relevant advocacy efforts, and areas for further growth.

Methods

The paper provides an analysis of human rights standards in the context of palliative care through the lens of the right to health, freedom from torture and ill treatment, and the rights of older persons and children.

Results

Significant developments include:

- the first human rights treaty to explicitly recognize the right to palliative care, the Inter-American Convention on the Rights of Older Persons;
- the first World Health Assembly resolution on palliative care;
- A report by the UN Special Rapporteur on Torture with a focus on denial of pain treatment;
- Addressing the availability of controlled medicines at the UN General Assembly Special Session on the World Drug Problem;

Conclusion

Development of human rights standards in relation to palliative care has been most notable in the context of the right to health, freedom from torture and ill treatment, and the rights of older persons. More work is needed in the context of the rights of children, and human rights treaty bodies are still not consistently addressing state obligations with regards to palliative care.

The last decade has ushered in important developments in human rights standards to address palliative care. Investments by the Open Society Foundations (OSF), Human Rights Watch (HRW), and partners contributed to many of these developments. At the end of 2006, OSF's International Palliative Care Initiative and Law and Health Initiative first collaborated to support conceptual thinking and advocacy in this area. In early 2007, HRW first dedicated a senior researcher to focus on human rights documentation and advocacy in the context of palliative care. This was an unprecedented step since at the time, palliative care featured nowhere on the human rights agenda. This paper examines key milestones in the evolution of human rights standards to address palliative care, relevant advocacy efforts, and areas for further growth. It focuses on the right to health, freedom from torture and ill treatment, and the intersection of palliative care with the rights of older persons and children.

Palliative Care: A Critical Component of the Right to Health

The identification of access to palliative care and pain treatment as human rights issues first emerged among palliative care advocates and physicians, as far back as the 1990s. (1) This concept was subsequently developed through civil society declarations in 2005(2) and 2008(3), a World Medical Association Resolution in 2011, (4) and scholarly articles. (5), (6)

While the United Nations (UN) Committee on Economic Social and Cultural Rights elaborated on palliative care as a component of the right to health in August 2000, it is only in the last decade that this has received sustained attention by UN bodies and states. In its August 2000 authoritative General Comment on the Right to Health, the Committee on Economic Social

and Cultural Rights explicitly sets out that “States are under the obligation to respect the right to health by . . . refraining from denying or limiting equal access for all persons . . . to preventive, curative and palliative health services.” (7) Moreover, it defined access to essential medicines, as established in the WHO Action Programme on Essential Drugs, as part of the “minimum core content” of the right to the highest attainable standard of health.(8) Twenty palliative care medicines are currently on this list.(9) Finally, the General Comment stresses the importance of “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity,” which is a principle at the heart of palliative care.(10)

Given the dearth of attention to palliative care following the General Comment, in June 2011, HRW and OSF organized a side event at the Human Rights Council on “Access to Palliative Care: A Neglected Component of the Right to Health.”(11) This event was also cosponsored by the Permanent Missions of Brazil and Uruguay, as well as the African Palliative Care Association (APCA), HelpAge International, International Association for Hospice and Palliative Care (IAHPC), Pallium India, Joint United Nations Program on HIV/AIDS (UNAIDS), Worldwide Palliative Care Alliance (WPCA). It featured palliative care experts from India, Africa, and Latin America, who discussed pain prevalence and its impact on patients, current gaps in palliative care availability, a successful model in Uganda, and opportunities for Human Rights Council involvement. HRW provided a human rights analysis, further developed in reports on palliative care in Armenia, Guatemala, India, Kenya, Mexico, Morocco, Russia, Senegal, and Ukraine. This analysis focused on structural barriers to palliative care availability and government obligations, including “(1) a negative obligation to

refrain from enacting policies or undertaking actions that arbitrarily interfere with the provision or development of palliative care; and (2) a positive obligation to take reasonable steps to ensure the integration of palliative care into existing health services, both public and private, through the use of regulatory and other powers, as well as funding streams.”(12)

This frame creates opportunities for states to be accountable for their obligations in relation to palliative care and for civil society monitoring. The Human Rights Council side event on palliative care seemed to raise the profile of this issue among states. For instance, in 2012, during the second Universal Periodic Review of India, Uruguay raised the issue of access to palliative care, which led to adoption of the following recommendation for India: “Establish measures at the national and State level to remove obstacles in terms of access by the population to palliative medicines.” (13) While scrutiny of human obligations in the context of palliative care is an important first step, India’s response to this recommendation is still noted as pending. (14) In order to support greater accountability and engagement by civil society, the Open Society Foundations partnered with Georgetown University’s O’Neill Institute for National and Global Health Law to develop a toolkit to serve as a resource on human rights advocacy on palliative care and pain relief. The toolkit defines human rights and their relevance to palliative care, as well as guides readers through the UN Human Rights System, presenting why and how to engage and advocate for increased availability and accessibility of quality palliative care and pain relief.(15) The toolkit also contains a supplement focused on the Inter-American Human Rights System, particularly exploring how to leverage the opportunities created by the recently adopted Inter-American Convention on the Rights of Older Persons --the first human rights treaty to explicitly include the right to palliative care.(16) A draft of the

toolkit was piloted in Nairobi in 2015 and met with interest by the palliative care and human rights advocates. However, the finalized draft will only be published in October 2016 so its effectiveness remains to be seen.

In 2014, the World Health Assembly (WHA) adopted a groundbreaking resolution on palliative care—its first resolution on this topic. This Resolution, WHA67.19, called upon the World Health Organization (WHO) and member states to improve access to palliative care as a core component of health systems, improving funding, training, and availability of palliative care services. (17) It emphasized that this requires partnerships between government and civil society and called on the WHO to include palliative care in global health strategies, develop guidance, technical assistance, and monitor progress. The resolution built on years of advocacy by HRW, OSF, and partners. This involved briefings during prior assemblies and WHO executive board meetings, meetings with individual WHO staff members, and the development of coalitions between civil society and UN member states, which bore fruit in 37 countries cosponsoring the WHA Resolution. (18)

HRW, OSF, and partners further worked to increase attention to access to controlled medicines, including opioid analgesics, in global policy debates. A decade ago, access to opioid medicines was not even on the radar of the UN Commission on Narcotic Drugs or UN Office on Drugs and Crime. Only the International Narcotics Control Board made periodic statements, noting problems with limited availability of controlled medicines in many countries. (19) Rather, global drug policy focused on controlling drugs as “a grave threat to the health and well-being of all mankind.” (20) HRW, OSF, and partners worked to counter this narrative through

briefings with these various agencies and coalition-building with drug policy NGOs and a number of UN member states. (21)

The tide began to turn in 2009. That year, UN member states negotiated a new political declaration at the Commission on Narcotic Drugs, along with a 10-year action plan “on international cooperation toward an integrated and balanced strategy to counter the world drug problem,” which contained references to access to controlled substances for medical purposes. (22) The commission adopted resolutions on the issue in 2010 and 2011 and added controlled medicines as a standing item to its agenda in 2010. In 2011, the International Narcotics Control Board issued a detailed report on the topic. Additionally, the UN Office on Drugs and Crime published a discussion paper and initiated a review of its model drug law. The 2014 Joint Ministerial Statement of the Commission on Narcotic Drugs contained several paragraphs on the issue. (23) In 2016, the UN General Assembly Special Session on the World Drug Problem adopted a consensus document that, for the first time, included a stand-alone section on controlled medicines and called for countries to take steps to ensure their availability. (24)

Denial of Pain Treatment and Freedom from Torture and Ill Treatment

“The pain was so bad that my whole body seemed to break. We would call the ambulance every 2 to 3 hours because I could not stand the pain. It was intolerable to live like that.”

—Vasilii, a 66-year-old cancer patient from Ukraine (25)

Given the scale and extent of suffering, the failure of governments in many countries to ensure the adequate availability of pain treatment services not only raises questions of whether these countries live up to their obligations under the right to health, but also of state obligation to ensure freedom from torture and cruel, inhuman and degrading treatment (CIDT or ill treatment). The last decade has brought important clarifications of standards in this area.

In 2009, the former UN Special Rapporteur on Torture, Cruel, Inhuman or Degrading Treatment or Punishment (Special Rapporteur on Torture), Professor Manfred Nowak, noted that “the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment.” (26) In 2013, the following Special Rapporteur on Torture, Professor Juan E. Mendez, reaffirmed this in his landmark report on torture and ill treatment in health settings.(27) He explained, “When the failure of States to take positive steps, or to refrain from interfering with health-care services, condemns patients to unnecessary suffering from pain, States not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment.”(28) He further articulated a test for whether denial of pain relief constitutes torture or ill treatment:

- “the suffering is severe and meets the minimum threshold under the prohibition against torture and ill-treatment”;
- “the State is, or should be, aware of the suffering, including when no appropriate treatment was offered”; and
- “The Government failed to take all reasonable steps to protect individuals’ physical and mental integrity.” (29)

Additionally, he provided guidance to states on their obligations, addressing policy gaps and regulatory, educational, and attitudinal obstacles to full access to palliative care:

- “Ensure that narcotic drug control laws recognize the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering; review national legislation and administrative procedures to guarantee adequate availability of those medicines for legitimate medical purposes.”
- “[O]vercome current regulatory, educational, and attitudinal obstacles that restrict availability to essential palliative care medications, especially oral morphine.”
- “Develop and integrate palliative care into the public health system by including it in all national health plans and policies, curricula and training programs and developing the necessary standards, guidelines, and clinical protocols.” (30)

The Special Rapporteur’s report on torture in health care settings marked a shift when the prohibition against torture began to be more systematically applied to health care settings. In early 2011, a coalition of organizations—including OSF, HRW, and partners—working to combat severe human rights violations in health care settings, launched the Campaign to Stop Torture in Health Care, aiming to increasing state accountability for these abuses. (31) The Campaign recognized that it is precisely because health care settings are not considered places of abuse that they are poorly monitored and violations continue. (32)

This use of the torture and ill treatment lens has important implications for addressing denial of pain treatment. It clarifies that the state obligation to remedy this violation is immediate, non-derogable, and not contingent on available resources. (33) This has provided advocates with a new tool to engage governments and challenge problematic policies, while drawing increased

international attention to this issue.

Palliative Care and Older Persons' Rights

In recent years, as the human rights community has paid increased attention to the rights of older persons, there have also been important developments related to palliative care standards. In 2012, the United Nations Office of the High Commissioner for Human Rights recognized that the human rights system had overlooked violations experienced by older persons, including rights related to end of life and palliative care. (34) Since then, this has continued to be discussed in the UN Open-Ended Working Group on Ageing, with a view to eventually developing a UN Convention on the rights of older persons. In 2014, the UN appointed the first Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte.(35) Her 2015 report emphasizes that “States should ensure the availability and accessibility of palliative care for all older persons in need, particularly those who suffer from a life-threatening or life-limiting illness. Training, and adequate and affordable medication and therapeutic measures, should be provided in public and private care settings.” (36)

The various regional human rights systems have also started to focus on the rights of older persons. A landmark development was the adoption of the Inter-American Convention on the Rights of Older Persons in 2015.(37) Notably, it is the first human rights treaty to explicitly refer to palliative care in the text, requiring countries to provide access to palliative care without discrimination, prevent unnecessary suffering and futile procedures, and appropriately manage problems related to the fear of death.(38) It also mandates that countries establish procedures to

enable older persons to indicate in advance their will and instructions with regard to health care interventions.(39)

While Europe did not go so far as to establish a new treaty, in 2014, the Council of Europe adopted non-binding recommendations on the Promotion of Human Rights of Older Persons. These recommendations dedicate a specific section to palliative care, which sets out that older persons should be entitled to access palliative care “in a setting consistent with their needs and preferences, including at home and in long-term care settings.” (40)

While the African human rights system has also taken steps to protect the rights of older people, the normative framework is further behind. After almost eight years of discussions, in January 2016, the African Union finally adopted the Protocol to the African Charter on Human and Peoples’ Rights on the rights of older persons. (41) Civil society had attempted to include provisions on palliative care, yet its latest draft—the final version is not yet published—only discusses “Care and Support” for older persons in broad terms.(42)

Palliative Care and Children’s Rights

The intersection of palliative care with children’s rights is an area where there is room for further development and implementation of standards.(43) WHO sets out a tailored definition of palliative care for children as “the active, total care of the child’s body, mind and spirit,” involving the child’s family and “a broad multidisciplinary approach.” (44) The UN Committee on the Rights of the Child recognizes palliative care as an important component of children’s

health, critical to growth and development. (45) However, it has rarely looked at this issue in reviewing country reports. A notable exception is its review of Belarus in 2011, when the Committee explicitly recommended that the State establish a funding mechanism for children's palliative care and support the services provided by non-governmental organizations. (46) Civil society has taken the initiative, developing a "Charter of Rights for Life Limited and Life Threatened Children" (47) and the Trieste Charter, focused specifically on "The Rights of the Dying Child." (48) These instruments reflect some of the principles enshrined in the UN Convention on the Rights of the Child, (49) referring to important rights such as the "right of the child to participate in decisions affecting his or her care" (50) and the "right to be listened to and properly informed about his/her illness, with due consideration to his/her wishes, age and ability to understand." (51)

Conclusion

In this way, the last decade has seen an important strengthening of human rights standards in relation to palliative care. This has been most notable in the context of the right to health, freedom from torture and ill treatment, and the rights of older persons. Particularly groundbreaking were the WMA resolution on palliative care, Special Rapporteur on Torture's report on torture in health care settings, and an Inter-American convention that explicitly recognizes a human right to palliative care. However, more work is needed in the context of the rights of children, and treaty bodies are still not consistently addressing state obligations in the sphere of palliative care.

While human rights advocacy has contributed to standards and legal obligations regarding palliative care, it has also brought a fundamental concern with people, amplifying their voices. As HRW relates, “In all our projects, we sought to include the testimonies of people with incurable illnesses, as well as those of their families. These testimonies provided powerful and specific evidence of the consequences of the lack of access to pain medicines and palliative care, and they humanized the issue and the need for change.” (52) People dying in their homes and villages do not have the ability to go into the streets and cry out and are often invisible. Human rights advocates have sought to give voice to their suffering and an end to needless pain.

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