

HEALTH AND HUMAN RIGHTS RESOURCE GUIDE



FXBCENTER
FOR HEALTH & HUMAN RIGHTS

HARVARD SCHOOL OF PUBLIC HEALTH | HARVARD UNIVERSITY

HEALTH AND HUMAN RIGHTS RESOURCE GUIDE

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Health and Human Rights Resource Guide

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Fifth Edition, November 2013

Cover photograph courtesy of Sven Torfinn - Panos for the Open Society Foundations, "A paralegal nurse named Mercy and a lawyer named Johnson, both with Nyeri Hospice in Nyeri, Kenya talk with Elizabeth (center) about her health and property. She has cancer and is cared for by her granddaughter Caroline (to her left). She wants to ensure her granddaughters can inherit her property even though other relatives are trying to claim it."

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CHAPTER 5



PALLIATIVE CARE AND HUMAN RIGHTS

“ You must matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die. ”

— Dame Cicely Saunders, founder of the modern hospice movement

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Cover photograph courtesy of Sven Torfinn – Panos, Open Society Foundations, “Mercy visits Charles, a cancer patient. She sees him every week, bringing pain medication and providing him with emotional support”

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INTRODUCTION

This chapter will introduce you to key issues in palliative care and human rights. The chapter is organized into six sections that answer the following questions:

1. How is palliative care a human rights issue?
2. What are the most relevant international and regional human rights standards related to palliative care?
3. What is a human rights-based approach to advocacy, litigation, and programming?
4. What are some examples of effective human rights-based work in the area of palliative care?
5. Where can I find additional resources on palliative care and human rights?
6. What are key terms related to palliative care and human rights?

I. HOW IS PALLIATIVE CARE A HUMAN RIGHTS ISSUE?

What is palliative care?

“Palliative care is an approach that seeks to improve the quality of life of patients diagnosed with life-threatening illnesses through prevention and relief of suffering.”¹ It also addresses the psychosocial, legal, and spiritual aspects associated with life-threatening illnesses.²

Palliative care is fundamental to health and human dignity and is a basic human right.³ The United Nations Committee on Economic, Social and Cultural Rights asserted 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.”⁴ The United Nations Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment stated that he “is of the opinion 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.”⁵

Palliative care should be provided from the time of diagnosis and in tandem with any curative treatment. As the patient’s disease progresses into the terminal phase, palliative care should adapt to the patient’s changing needs. Palliative care must include psychological and spiritual services and other support in preparation for death. Palliative care programs should also tend to the needs of the family throughout the progression of the disease and into bereavement.⁶ Some programs include legal services to address power of attorney or health care proxy decisions and assistance in executing a will.

Palliative care programs are most effective when integrated into existing health care systems and at all levels of care. Programs can be designed to be provided in hospital or clinic settings, as well as the patient’s home or residential facility (such as a nursing home). Ideally, palliative programs overlap in providing care at all levels. Palliative care programs involve both the public and private sector, and can be adapted to the specific cultural, economic, and social setting.⁷

¹ UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

² Open Society Foundations, *Palliative Care as a Human Right* (2011). www.soros.org/sites/default/files/palliative-care-human-right-20110524.pdf.

³ Ibid.

⁴ UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14*, E/C.12/2000/4, para. 34 (Aug. 11, 2000).

⁵ UN Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/10/44, para. 72 (Jan. 14, 2009).

⁶ World Health Organization, *Cancer Control Knowledge into Action: WHO Guide for Effective Programs* (2007). http://whqlibdoc.who.int/publications/2007/9241547345_eng.pdf.

⁷ Ibid.

World Health Organization Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

How is palliative care a human rights issue?

The need for palliative care worldwide is great. Of the 58 million people dying annually, at least 60% will have a prolonged advanced illness and would benefit from palliative care. About 80% of the dying would benefit from palliative care to alleviate pain and suffering in their final days. Unfortunately for many, palliative care programs are either unavailable or are inaccessible. The United Nations Special Rapporteur on the highest attainable standard of mental and physical health (Special Rapporteur on the Right to Health) noted that “[p]atients suffering from severe to moderate pain, where palliative care essentially is unavailable, said they would prefer to die than continue living with untreated, severe pain.”⁸

Palliative care should be available for anyone suffering from moderate or severe pain, but below we highlight cancer and AIDs patients because of the overwhelming need for palliative care among these populations, as well as older persons and children, for whom palliative care is often an afterthought.

Cancer patients

Cancer patients are one the largest populations in need of palliative care. The World Health Organization (WHO) projects that global cancer deaths will increase from 7.9 million in 2007 to 11.5 million in 2030.⁹ In addition, new cases of cancer during the same period are estimated to grow to 15.5 million in 2030, up from 11.3 million in 2007.¹⁰ Over half of the new cancer cases each year occur in less developed countries.¹¹ And while the WHO has demonstrated that up to 90% of cancer patients can receive adequate therapy for their pain with opioid analgesics, in 2005, 80% of cancer patients did not have access to pain relieving drugs.

⁸ UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

⁹ World Health Organization, *Are the number of cancer cases increasing or decreasing in the world* (Apr. 1, 2008). www.who.int/features/qa/15/en/index.html.

¹⁰ Ibid.

¹¹ World Health Organization, *National Cancer Control Programmes: Policies and Managerial Guidelines* (2002). <http://whqlibdoc.who.int/hq/2002/9241545577.pdf>.

Pain associated with cancer can be unbearable. Pain can be caused by the cancer itself, a cause related to the cancer, a consequence caused by or related to the cancer treatment, or by a concurrent disorder.¹² To guide policy makers and health care practitioners, the WHO developed the “pain-relief ladder,” a simple three-phase guide on pain relief for people suffering from cancer.¹³ WHO also recommends treatment for the psychological suffering of cancer patients including for anxiety and depression. WHO writes, “The aim of treatment is to relieve the pain to the patient’s satisfaction, so that he or she can function effectively and eventually die free of pain.”¹⁴

People living with HIV and AIDS

There are approximately 34.2 million people living with HIV and an estimated 1.7 million AIDS-related deaths each year.¹⁵ Up to 80% of patients in the advanced stages of AIDS suffer great pain, but very few have access to pain relieving drugs or palliative care services. The Special Rapporteur on the Right to Health estimates that around 85% of people living with HIV may have untreated pain.¹⁶ Again, less developed countries experience the highest rates of HIV/AIDS infection, but have limited access to opioid medications for pain relief.

Palliative care for people living with AIDS has its own challenges. The progression of AIDS is variable and unpredictable, and people experience a wide range of complications and rates of survival.¹⁷ People with AIDS face possible opportunistic infections as well as experience different side effects from treatment for the infections and AIDS itself.¹⁸ Providing palliative care for people with AIDS must adjust to the differing needs of patients. People with HIV/AIDS also experience discrimination and stigma, influencing the individual’s access to health care, living experiences, and personal support networks. For example, “Where patients with HIV are also dependent on drugs, they may be denied access to both OST and palliative care.”¹⁹ Designers of palliative care programs should be cognizant of the additional social pressures and lack of services that AIDS patients face.

Older persons

The United Nations Committee on Economic, Social and Cultural Rights states that, with regard to the realization of the right to health of older persons, “attention and care for chronically and terminally ill persons [is important], sparing them avoidable pain and enabling them to die with dignity.”²⁰ Older persons experience increased rates of chronic and terminal illnesses, and therefore are a significant portion of the population that requires palliative care. There are about 605 million people aged 60 years and over, and WHO expects that number to increase to 2 billion by 2050, with low- and middle-income countries experiencing the most rapid changes.²¹ As the older population grows in size, palliative care programs will have to be developed or augmented to address their specific needs.

¹² World Health Organization, *Cancer Pain Relief: With a guide to opioid availability* (1996): 5. <http://whqlibdoc.who.int/publications/9241544821.pdf>.

¹³ World Health Organization, “WHO’s Pain Ladder.” www.who.int/cancer/palliative/painladder/en/. For a more detailed analysis see, WHO, *Cancer Pain Relief: With a guide to opioid availability* (1996). <http://whqlibdoc.who.int/publications/9241544821.pdf>.

¹⁴ World Health Organization, *Cancer Pain Relief: With a guide to opioid availability* (1996): 3. <http://whqlibdoc.who.int/publications/9241544821.pdf>.

¹⁵ UNAIDS, *Global AIDS epidemic facts and figures, Fact Sheet* (July 18, 2012). www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf.

¹⁶ UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

¹⁷ UNAIDS, *AIDS: Palliative Care* (Oct. 2000): 3. http://data.unaids.org/Publications/IRC-pub05/JC453-PalliCare-TU_en.pdf.

¹⁸ Ibid.

¹⁹ UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

²⁰ UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14*, E/C.12/2000/4, para. 25 (Aug. 11, 2000).

²¹ World Health Organization, “Ageing and Life Course: Interesting Facts About Ageing” (Mar. 28, 2010). www.who.int/ageing/about/facts/en/index.html.

Palliative care programs must not discriminate against people based on their age. The Special Rapporteur on the Right to Health notes that while barriers to palliative care are not unique to older persons as a group, they are “disproportionately affected due to the increased incidence of chronic and terminal illness amongst them.”²² The Special Rapporteur also queried whether older persons are less likely to receive palliative care, noting that more research is required to determine whether the distribution of palliative care services are “inequitable or whether the needs of older persons are being met through other services.”²³

Children²⁴

Children with terminal illnesses and debilitating diseases suffer from pain but are often not provided with palliative care. Children’s pain is often underestimated or even neglected because of cultural beliefs or ignorance. The International Children’s Palliative Care Network estimated that 20 million children worldwide can benefit from palliative care.²⁵ Children suffer from terminal illnesses like cancer and AIDS, as well as debilitating disabilities. For example, in 2008, the American Cancer Society estimated that 175,300 new cases of cancer occurred, and 96,400 children died from the disease.²⁶ In 2011, an estimated 3.4 million children were living with HIV/AIDS and 330,000 children were newly infected.²⁷

Palliative care seeks to improve the quality of life for a patient. “For children this also includes support of optimal childhood development, formal education, and developmental stimulation to enable the child, at every age, to live the best life possible.”²⁸ At all times, the best interest of the child must be the primary consideration.

Access to essential medicines

An important component of palliative care is access to essential drugs to alleviate pain. For many with terminal illnesses, pain and suffering caused by the illness is debilitating but can be easily treated with opioid analgesics. The International Narcotics Control Board reported that, in 2009, more than 90% of the global consumption of opioid analgesics occurred in Australia, Canada, New Zealand, the United States of America, and several European countries.²⁹ Consequently, over 80% of the world has insufficient or no access to opioid medications, and therefore have no relief from their pain and suffering.³⁰

22 UN Human Rights Council, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Thematic Study, A/HRC/18/37 (July 4, 2011). http://www2.ohchr.org/english/bodies/hrcouncil/docs/18session/A-HRC-18-37_en.pdf.

23 Ibid.

24 For technical guidance on pharmacological treatment of children and policy reform recommendations, please see World Health Organization, *WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses* (2012). http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf; World Health Organization, *Persisting Pain in Children: Highlights for policy makers* (2012). http://whqlibdoc.who.int/publications/2012/9789241548120_%20Policy%20Brochure.pdf; World Health Organization, *Persisting Pain in Children: Highlights for physicians and nurses* (2012). http://whqlibdoc.who.int/publications/2012/9789241548120_Physicians&Nurses.pdf; World Health Organization, *Persisting Pain in Children: Highlights for pharmacists* (2012). http://whqlibdoc.who.int/publications/2012/9789241548120_Pharmacists_Brochure.pdf.

25 International Children’s Palliative Care Network, “The need for Children’s Palliative Care.” www.icpcn.org.uk/page.asp?section=0001000100080002.

26 American Cancer Society, *Global Cancer Facts and Figures* (2008). www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-027766.pdf.

27 UNAIDS, *Global AIDS epidemic facts and figures, Fact Sheet* (July 18, 2012). www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf.

28 Hospice Palliative Care Association of South Africa, “Chapter 8: Legal Rights of Children in Palliative Care,” in *Legal Aspects of Palliative Care Manual* (2012). www.hpca.co.za/Legal_Resources.html.

29 International Narcotics Control Board, *Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes* (2010). http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/ife/Report_of_the_Board_on_the_availability_of_controlled_substances.pdf.

30 Ibid.

Manfred Nowak, UN Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment, and Anand Grover, UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, stated:

Governments also have an obligation to take measures to protect people under their jurisdiction from inhuman and degrading treatment. Failure of governments to take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people to suffer needlessly from severe and often prolonged pain, raises questions whether they have adequately discharged this obligation.³¹

Essential medicines

WHO has developed two lists of medicines that it considers essential for satisfying the priority health care needs of the population. They are called the Model List of Essential Medicines and the Model List of Essential Medicines for Children,³² and they serve as a guide for national and institutional essential medicines lists.³³ The Committee on Economic, Social and Cultural Rights established in General Comment 14 that states are obligated to provide “essential medicines as defined by the WHO Action Programme on Essential Drugs” as part of the minimum core obligations to realize the right to health.³⁴

In 2007, the International Association for Hospice and Palliative Care (IAHPC), in collaboration with 26 palliative care organizations, developed a list of essential medicines for palliative care.³⁵ Of the 34 medications listed, just 14 were included in the WHO Model List (most recently updated in 2011), and morphine is the only strong opioid analgesic on the WHO list. Oral morphine is particularly essential for palliative care because it provides an inexpensive option for pain management. However, especially in low- and middle-low income countries, opioid formulations that are more expensive or more difficult to use, such as injectable morphine, are only available. The high cost of these opioids hinders access to treatment. Meanwhile, the low profit margin from oral morphine is exacerbated by additional costs of unnecessarily burdensome regulatory requirements, which may further deter the pharmaceutical industry from supplying it.³⁶

International drug control conventions

Many essential medicines identified by the WHO are controlled medicines under international drug control conventions, including the Single Convention on Narcotic Drugs (1961) amended by the 1972 Protocol; the Convention on Psychotropic Substances (1971); and the United Nations Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances (1988). These medicines are controlled because of their addictive properties and likelihood for misuse.

31 Joint letter by UN special rapporteur on the prevention of torture and cruel, inhuman or degrading treatment or punishment, Manfred Nowak, and the UN special rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, to the Commission on Narcotic Drugs (December 2008). <http://www.hrw.org/news/2008/12/10/un-human-rights-experts-call-upon-cnd-support-harm-reduction>.

32 World Health Organization, *Medicines: WHO Model Lists of Essential Medicines* (March 2011). www.who.int/medicines/publications/essentialmedicines/en/.

33 World Health Organization, “Medicines: Essential Medicines.” www.who.int/medicines/services/essmedicines_def/en/index.html.

34 UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14* (2000), E/C.12/2000/4 (Aug. 11, 2000).

35 International Association for Hospice and Palliative Care, *IAHPC List of Essential Medicines for Palliative Care* (2007). <http://hospicecare.com/resources/palliative-care-essentials/iahpc-essential-medicines-for-palliative-care/>.

36 Pallium India, “The Morphine Manifesto” (2012). <http://palliumindia.org/manifesto/>.

The International Narcotics Control Board (INCB) oversees the distribution of controlled substances, as designated by the international drug control conventions. The INCB states:

*The international drug control treaties recognize that narcotic drugs and psychotropic substances are indispensable for medical and scientific purposes. However, despite numerous efforts by the Board and the World Health Organization (WHO), as well as non-governmental organizations, their availability in much of the world remains very limited, depriving many patients of essential medicines.*³⁷

It is the position of the INCB that the international drug control treaties do not prohibit the production and access to controlled substances for medicinal purposes.

Barriers to accessing essential medicines

So what are the barriers to accessing essential medicines in the majority of the world? The INCB surveyed countries, and determined the main factors affecting the availability of opioids for medical needs: concerns about addiction, reluctance to prescribe or stock controlled substances, insufficient training for professionals, law restricting activities, administrative burden, cost, difficulties in distribution, insufficient supply, and absence of policy.³⁸

Attitude and knowledge-related impediments

Health care professionals are worried about patient addiction to or dependence on opioids and therefore under-prescribe opioids for palliative care purposes. However, studies have demonstrated that prescribing opioids for pain relief does not lead to dependence.³⁹ “Many myths exist surrounding the use of controlled drugs: that they lead to addiction, do not treat pain adequately, or that chronic or terminal pain is untreatable.”⁴⁰ In part, under-prescribing is due to insufficient training for health care professionals. Without proper training, health care workers may be hesitant to prescribe or stock opioids for fear of legal implications, misunderstanding of its efficacy, or fear of addiction.⁴¹ The top three factors listed in the survey responses all correspond to knowledge and attitudinal barriers affecting the availability of opioids for medical purposes.

³⁷ International Narcotics Control Board, *Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes* (2010). http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/life/Report_of_the_Board_on_the_availability_of_controlled_substances.pdf.

³⁸ Ibid.

³⁹ UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

⁴⁰ Ibid.

⁴¹ International Narcotics Control Board, *Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes* (2010). http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/life/Report_of_the_Board_on_the_availability_of_controlled_substances.pdf; UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

Laws and regulations

National and local laws and regulations can be so burdensome that they impede the distribution of controlled substances or prohibit their use altogether.⁴² For example, “Regulations [may] also limit the substances a doctor may prescribe, or the amount that can be prescribed. Certain States require health-care workers to obtain special licences to prescribe morphine, in addition to their professional licences.”⁴³ Some countries regulate licensing of controlled medicines to health care institutions, allowing only “Level 1” hospitals to prescribe opioids.⁴⁴ In order to determine barriers to accessing essential medicines, States should examine all levels of laws and regulations for the “production, procurement, storage, distribution, prescription, dispensing and administration of opioid analgesics (and other controlled medicines).”⁴⁵

Cost

Palliative care and access to opioids are frequently promoted as a low-cost solution to pain and suffering. However, access to medicines, even if manufactured at low cost, may not be affordable for all individuals suffering from chronic illnesses. The Special Rapporteur to health explains:

*Despite this, even medicines that can be manufactured at low cost are not necessarily affordable for consumers, because drug producers incur significant regulatory costs that are passed on to consumers within the market price of the drug. For instance, Cipla, a generic manufacturer in India produces 10 mg morphine tablets sold wholesale for US\$ 0.017 each, yet the median cost of a month’s supply of morphine in low- and middle-income countries is \$112, as compared to \$53 for industrialized countries.*⁴⁶

42 International Narcotics Control Board, *Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes* (2010). http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/jife/Report_of_the_Board_on_the_availability_of_controlled_substances.pdf.

43 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

44 Ibid.

45 World Health Organization, *Persisting Pain in Children: Highlights for policy makers extracted from the guidelines on the pharmacological treatment of persisting pain in children with medical illnesses* (2012). http://whqlibdoc.who.int/publications/2012/9789241548120_%20Policy%20Brochure.pdf.

46 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

What are current practices in the area of palliative care?

Palliative care includes some or all of the following practices:

- relief from pain;
- symptom control for physical and psychological symptoms;
- essential drugs for palliative care;
- spiritual and bereavement care;
- family-centered care;
- care by trained palliative care professionals;
- home-based care when dying and to die at home if desired;
- treatment of disease and to have treatment withheld or withdrawn;
- information about diagnosis, prognosis, and palliative care services;
- ability to designate a health care proxy for decision making and assistance with the process;
- equitable access to care and provision of services (i.e. no discrimination based on age, gender, socioeconomic status, geographic location, national status, prognosis, or means of infection);
- support system to help patients live as actively as possible until death;
- legal services to assist with estate, property, child custody and care, guardianship, power of attorney or other legal services required by the patient;
- support system to help family cope during the patient's illness and in their own bereavement; and
- services to address the needs of patients and their families, including bereavement counseling.

2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO PALLIATIVE CARE?

How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to palliative care. The tables are organized as follows:

Human right or fundamental freedom	
Examples of Human Rights Violations	
Human rights standards	<p>UN treaty body interpretation</p> <p>This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.</p>
Human rights standards	<p>Case law</p> <p>This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.</p>
<p>Other interpretations: This section references other relevant interpretations of the issue. It includes interpretations by:</p> <ul style="list-style-type: none"> • UN Special Rapporteurs • UN working groups • International and regional organizations • International and regional declarations 	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights and palliative care.

Abbreviations

In the tables, we use the following abbreviations to refer to the twelve treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights (UDHR)	None
International Covenant on Civil and Political Rights (ICCPR)	Human Rights Committee (HRC)
International Covenant on Economic, Social, and Cultural Rights (ICESCR)	Committee on Economic, Social and Cultural Rights (CESCR)
Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)	Committee on the Elimination of Discrimination Against Women (CEDAW Committee)
International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)	Committee on the Elimination of Racial Discrimination (CERD)
Convention on the Rights of the Child (CRC)	Committee on the Rights of the Child (CRC Committee)
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)	Committee against Torture (CAT Committee)
African Charter on Human and Peoples' Rights and Protocols (ACHPR)	African Commission on Human and Peoples' Rights (ACHPR Commission)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)	European Court of Human Rights (ECtHR)
1996 Revised European Social Charter (ESC)	European Committee of Social Rights (ECSR)
American Convention on Human Rights (ACHR)	Inter-American Court of Human Rights (IACHR)
American Declaration of the Rights and Duties of Man (ADRDM)	Inter-American Court of Human Rights (IACHR)

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).

Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
Torture or Cruel, Inhuman or Degrading Treatment*	Art. 5	Art. 7				Art. 37(a)
Life	Art. 3	Art. 6.1				Art. 6.1
Health	Art. 25		Art. 12	Art. 12	Art. 5(e) (iv)	Art. 24
Expression and Information	Art. 19	Art. 19(2)				Art. 13,
Art. 17						
Non-discrimination and Equality	Art. 1, Art. 2	Art. 2(1), Art. 3	Art. 2(2), 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2

*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADDDM	Americas: ACHR
Torture or Cruel, Inhuman or Degrading Treatment	Art. 5	Art. 3			Art. 5(2)
Life	Art. 4	Art. 2		Art. I	Art. 4
Health	Art. 16		Art. 11, Art. 13	Art. XI	
Expression and Information	Art. 9	Art. 10		Art. IV	Art. 13
Non-Discrimination and Equality	Art. 2, Art. 19	Art. 14	Art. E	Art. II	Art. 1(1)

Table I: Palliative care and freedom from torture and cruel, inhuman, and degrading treatment

Examples of Human Rights Violations
<ul style="list-style-type: none"> National laws restricting opioid availability and access cause cancer and AIDS patients to suffer unnecessary pain. Fearing prosecution by the state, a doctor refuses to prescribe morphine to relieve a patient's pain. A country's laws prohibit the prescription of morphine to former drug users. A former drug user is in the advanced stages of AIDS and suffers a great deal.

Human Rights Standards	Treaty Body Interpretation
ICCPR 7: No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.	None.

Human Rights Standards	Case Law
ECHR 3: No one shall be subjected to torture or to inhuman or degrading treatment or punishment.	ECTHR: Finding continued detention of a cancer sufferer where it caused "particularly acute hardship" constituted cruel, inhuman or degrading treatment. <i>Mouisel v. France</i> , 67263/01 (November 14, 2002).

Other Interpretations

SR on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment: "The de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment." A/HRC/10/44 (January 14, 2009), ¶ 72.

SR Health and SR Torture: "The failure to ensure access to controlled medications for pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment." (Letter from Manfred Nowak, Special Rapporteur on Torture, and Anand Grover, Special Rapporteur on the right to the highest attainable standard of health, to Her Excellency Ms. Selma Ashipala-Musavyi, Chairperson of the 52nd Session of the Commission on Narcotic Drugs, December 10, 2008), pg. 4.

Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment (1987).

Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, G.A. Res. 37/194, UN Doc. No. A/RES/37/194 (December 18, 1982). Available at <http://www2.ohchr.org/english/law/medicalethics.htm>.

The European Charter of Patients' Rights, Art 11: "Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative treatments and simplifying patients' access to them."

Declaration on the Promotion of Patients' Rights in Europe: "Patients have the right to relief of their suffering according to the current state of knowledge." [Art. 5.10]. "Patients have the right to humane terminal care and to die in dignity." [Art. 5.11]. WHO, Declaration on the Promotion of Patients' Rights in Europe Arts. 5.10 & 5.11 (Copenhagen: WHO, 1994).

Council of Europe, Recommendation 1418, Protection of Human Rights and Dignity of the Terminally Ill and Dying (1999). Available at <http://assembly.coe.int/documents/adoptedtext/ta99/erec1418.htm>.

Table 2: Palliative care and the right to life

Examples of Human Rights Violations	
<ul style="list-style-type: none"> Unable to obtain pain medication, an AIDS patient is unable to adhere to required treatment and continue taking antiretrovirals. As a result, the patient does not have much time to live. 	
Human Rights Standards	Treaty Body Interpretation
ICCPR 6(1): Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.	None.

Other Interpretations

HRC General Comment 6: Explaining that the right to life “should not be interpreted narrowly” or “in a restrictive manner,” and its protection “requires that States adopt positive measures . . . to increase life expectancy.” Paras. 1 and 5 (1982).

Table 3: Palliative care and the right to the highest attainable standard of health

Examples of Human Rights Violations	
<ul style="list-style-type: none"> A country does not provide for training in palliative care to its medical personnel. As a result, end-of-life patients do not receive adequate pain relief and physical, psychosocial, and spiritual care. A State provides funding only for hospitals and not for hospices and home-based care facilities. As a result, patients must either forgo treatment or remain far from their homes and families. 	
Human Rights Standards	Treaty Body Interpretation
ICESCR 12(1): The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	<p>CESCR General Comment 14: Affirming the importance of “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.” Para. 25 (2000).</p> <p>CESCR General Comment 14: Indicating that access to “essential drugs, as defined by the WHO Action Programme on Essential Drugs” is part of the minimum core content of the right to health. Fourteen palliative care medications are currently on the WHO Essential Drug List. Para. 43, (2000).</p> <p>CESCR General Comment 14: “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.” Para. 34 (2000).</p>
CRC 24(1) States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.	CRC: Noting Belarus’ “adoption of the recent Order on Child Palliative Care” but “recomm[en]d[ing] that the State party establish a funding mechanism for the provision of palliative care for children and support the palliative care services provided by non-governmental organizations” who operate without sufficient financial support. CRC/C/BLR/CO/3-4 (2011), paras. 55,56.

Table 3(cont.)

Other Interpretations

SR Health: However, many countries have failed to adapt their drug control systems to ensure adequate medication supply; those systems were often enacted before contemporary treatment methods for chronic pain and drug dependence were known or devised. That constitutes an ongoing infringement of the right to health, as the Committee on Economic, Social and Cultural Rights has elaborated that access to essential medicines is a minimum core obligation of the right, and States must comply immediately with this non-derogable obligation regardless of resource constraints. A/65/255 (August 6, 2010).

SR Health: “The failure to ensure access to controlled medications for pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment.”

European Charter of Patients’ Rights, Art. 11: “Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative treatments and simplifying patients’ access to them.”

Declaration on the Promotion of Patients’ Rights in Europe, Art. 5.9: “Patients have the right to enjoy support from family, relatives and friends during the course of care and treatment and to receive spiritual support and guidance at all times.”

WHO 1978 Declaration of Alma-Ata: The Conference strongly reaffirms that health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector.

G.A. Res. 46/91, Annex, para. 11, UN Doc. A/RES/46/91 (December 16, 1991): Older persons should have access to health care to help them to gain or regain the optimum level of physical, mental, and emotional well-being and to prevent or delay the onset of illness.

Table 4: Palliative care and the right to information

Examples of Human Rights Violations
<ul style="list-style-type: none"> • People are denied information about: hospice and palliative care services; pain management; and their diagnosis and prognosis.

Human Rights Standards	Treaty Body Interpretation
ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	CESCR General Comment 14: Health care accessibility “includes the right to seek, receive and impart information and ideas concerning health issues.” Para. 12(b)(iv), (2000).

Other Interpretations

SR Health: The Special Rapporteur is of the view that a holistic approach to health should also address the process of dying. While this report does not consider issues of patient autonomy in respect of deciding to end life, it is nonetheless necessary to ensure that patients be able to make autonomous, informed decisions regarding the quality of health during the process of dying. That includes choices about access to adequate pain relief and other necessary interventions, location of death, and the ability to refuse treatment designed to prolong life when it is not desired by the patient. This requires clear, candid and non-judgmental discussion with medical practitioners, who should be adequately trained to deal with these delicate issues in order to enable older persons to “die with dignity”, as required from a human rights prospective. A/HRC/18/37 (July 4, 2011).

The European Charter of Patients’ Rights, Art. 3: “Every individual has the right of access to all kinds of information regarding their state of health and health services and how to use them, and all that scientific research and technological innovation makes available.”

The Declaration on the Promotion of Patients’ Rights in Europe: Art. 2.2: “Patients have the right to be fully informed about their health status, including the medical facts about their conditions; about the proposed medical procedures, together with potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis, and progress of treatment.”

European Convention on Human Rights and Biomedicine, art 10(2): “Everyone has the right to know any information collected about his or her health.” See also Explanatory Report, para. 65-70 (providing interpretation of rights to private life and information contained in Art. 10 (2)).

Table 5: Palliative care and the right to non-discrimination and equality

Examples of Human Rights Violations
<ul style="list-style-type: none"> • A country decides that it is not worth investing precious resources in providing care for the elderly. • Former drug users are denied access to opioid-based pain medication. • A state provides only limited health services to non-citizens and refugees, denying them access to palliative care.

Human Rights Standards	Treaty Body Interpretation
<p>ICESCR 2(2) The States Parties to the present Covenant undertake to guarantee the rights enunciated in the present Covenant shall be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, birth or other status.</p> <p>ICESCR 3 The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all economic, social and cultural rights set forth in the present Covenant.</p> <p>ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p>CESCR General Comment 6: “The range of matters” for which discrimination on the basis of age is acceptable “is very limited.” In fact, States parties “are obliged to pay particular attention to promoting and protecting the economic, social and cultural rights of older persons.” Paras. 12 & 13 (1995).</p> <p>CESCR General Comment 6: Emphasizing the need “to eliminate any discriminatory legislation and the need to ensure the relevant budget support” for the elderly. Para. 18 (1995).</p> <p>CESCR General Comment 6: Upholding “the right of elderly persons to the enjoyment of a satisfactory standard of physical and mental health” and urging of “a comprehensive view, ranging from prevention and rehabilitation to the care of the terminally ill.” Para. 34 (1995).</p> <p>CESCR: Recommending that Bulgaria “take affirmative action for the well-being of older people,” in light of their increasing number. [ICESCR, E/2000/22 (1999) 46, para. 238].</p> <p>CESCR: Noting “with satisfaction” Finland’s inclusion of age as a prohibited ground of discrimination in its constitution. [CESCR, E/2001/22 (2000) 73, para. 433].</p>

Human Rights Standards	Case Law
<p>ECHR 14: The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.</p>	<p>ECtHR: The Court considered “the applicant’s complaints that she has been discriminated against in the enjoyment of the rights guaranteed under that provision in that domestic law permits able-bodied persons to commit suicide yet prevents an incapacitated person from receiving assistance in committing suicide.” However, it found no violation of Article 14 because it would be too difficult to judge who is incapable of committing suicide and would undermine the law’s purpose to protect life and to safeguard against abuse. <i>Pretty v. The United Kingdom</i>, no. 2346/02, para 86 (April 29, 2002).</p>

Other Interpretations

SR Health: The right to health clearly proscribes discrimination in respect of age, including within palliative health care services. States are obliged to respect the right to health by refraining from denying or limiting equal access for all persons to palliative health services (E/C.12/2000/4, para. 34). Age-based discrimination that is sanctioned on the basis of risk/benefit profiling cannot under any circumstances be considered appropriate in the context of palliative care, which aims to improve quality of life, rather than its length. A/HRC/18/37 (July 4, 2011).

3. WHAT IS A HUMAN RIGHTS-BASED APPROACH?

“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”⁴⁷

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”⁴⁸ They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).⁴⁹ With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”⁵⁰

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

⁴⁷ Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

⁴⁸ For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf.

⁴⁹ Ibid.

⁵⁰ Ibid.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.⁵¹ Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

⁵¹ Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

How can a human rights-based approach be used?

A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS-BASED WORK IN THE AREA OF HARM REDUCTION?

This section contains **six examples** of effective human rights-based work in the area of palliative care and human rights. These are:

1. Litigation to Ensure Access to Morphine in India
2. Petitioning the State Human Rights Commission for Access to Palliative Care in India
3. Regulatory Reform in Romania
4. Advocating for Access to Pain Relief through United Nations Mechanisms
5. Integrating Legal Services into Palliative Care
6. Integration of Patients' Rights Standards in Hospice Accreditation in South Africa

Example I: Litigation to Ensure Access to Morphine in India

Project Type

Litigation: Public Litigation Case (No. 942/98) in the Delhi High Court (Dr. R.B. Ghooi).

The Organization

This is an example of public interest litigation on behalf of cancer patients without access to morphine for palliative care. In 1998, a private citizen, Dr. Ravindra Ghooi, filed a lawsuit on behalf of cancer patients in India. He requested that the court provide rationalization of procedures for the supply of morphine for medical purposes.

The Problem

In 1985, the Narcotic Drugs and Psychotropic Substances Act (NDPS) enacted strict controls on the manufacture and distribution of morphine in India. This had a tremendous impact on the use of morphine for medical purposes. Supplies of medical morphine plummeted from over 750 kilograms per year in 1985 to only 56 kilograms per year in 1996. Thus, while India was the major exporter of opium to the world, patients with severe pain did not have access to morphine. Moreover, a whole generation of doctors graduated without experience in using morphine for palliative care purposes and unaware of its potential for treating patients.

Dr. Ghooi filed a lawsuit after the death of his mother. His mother had breast cancer, but due to a previous history of diabetes and a stroke, she was not a candidate for aggressive cancer therapy. Nonetheless, she suffered from significant pain. Her physicians were not able to obtain even 1 mg of morphine for her treatment. Dr. Ghooi himself advocated on behalf of his mother, encountering bureaucratic barriers and expending time and money meeting with government officials, but was ultimately unsuccessful.

Procedure

After exhausting his administrative remedies, Dr. Ravindra Ghooi filed a lawsuit in the Delhi High Court.

Arguments and Holding

In 1998, the High Court affirmed, “It is a right of patients to receive any medication they need, particularly morphine.” The Court then directed the state government to speedily attend to morphine requests and to pending hospital applications for morphine licenses. It further encouraged patients to approach the court if unsatisfied.

Commentary and Analysis

Litigation

This court case worked in tandem with other advocacy efforts to increase access to palliative care medications. In 1999, the Pain and Palliative Care Society formed to develop community-based palliative care provision in India. Over the next seven years, the Society helped to establish twenty outreach palliative care programs throughout Kerala. By 2002, eight of the twenty-eight states in India amended their rules governing access to morphine.

Additionally, Indian physicians, WHO, and academic experts in the US joined together to reform the barriers to pain management. In 1994, Indian physicians formed the Indian Association of Palliative Care (IAPC)—disseminating knowledge of palliative care through regular conferences and a journal. IAPC, the WHO and academic experts in the US worked together with the national Government of India, their counterparts in a number of states, numerous physicians, and their respective pain and palliative organizations throughout India.

International Law

Nearly every government in the world is a signatory to three international drug control conventions: the Single Convention on Narcotic Drugs of 1961 (the primary treaty regulating opioid compounds and their precursors), the 1971 Convention on Psychotropic Substances (designed to control psychoactive drugs) and the 1988 Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances. These treaties aim to control the illicit use of non-medical uses of opioid drugs, but at the same time recognize the medicinal properties and scientific uses of pain medication. For instance, the Single Convention provides that: “the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and that adequate provision must be made to ensure the availability of narcotic drugs for such purposes.”⁵²

Foreign Law

Many countries wrote their opioid control laws in a different era. At the time the laws were written, countries understood addiction to be characterized by withdrawal symptoms upon cessation of use. Since opioids always produced withdrawal symptoms upon cessation, lawmakers across the world believed that opioid use inevitably led to dependence. We now understand addiction as defined by compulsive behavior and continued use despite harm or drug-related problems, whether or not physical dependence is present. Therefore, the laws of many countries reflect an outdated understanding of addiction.

⁵² United Nations, Single Convention on Narcotic Drugs, 1961, as amended by the 1972 Protocol mending the Single Convention on Narcotic Drugs, 1961, Preamble, p. 1; Accord United Nations, Convention on Psychotropic Substances, 1971, Preamble, p. 1.

Example 2: Petitioning the State Human Rights Commission for Access to Palliative Care in India

Project Type

Advocacy

The Organization

Located in Kerala, India, the Institute of Palliative Medicine, Calicut (IPM), is the first World Health Organization Collaborating Center (WHOCC) in the developing world and the fifth WHOCC in Palliative Care in the world overall. The IPM is the leading training institution for palliative care in Asia.

The Problem

In India, medical professionals do not receive training in palliative care as part of their medical education. Also, India has no palliative care policy and most states continue to implement strict drug control laws even on medicines with palliative care purposes. Terminally ill patients in Kerala could not obtain needed palliative care from trained professionals or pain relief medication.

Human Rights Commission Decision

www.kshrc.kerala.gov.in/archives.htm

Report

Economist Intelligence Unit, Ranking end-of-life care around the world (highlighting Kerala's program on pg 24-25). http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Actions Taken

A cancer patient and the Director of the Institute of Palliative Medicine petitioned the State Human Rights Commission for the provision of palliative care in government hospitals in the State of Kerala.

Results and Lessons Learned

The Human Rights Commission issued its recommendations in 2006, giving the Government 30 days to produce an action-taken report. The recommendations declared palliative care as part of the right to life guaranteed under Article 21 of the Constitution. To this end, the Human Rights Commission directed the government to make palliative care a compulsory part of medical education and practice by, among other things:

- taking steps to include palliative medicine in the curriculum of nursing and undergraduate medical students;
- providing training in palliative care to medical staff in government and private hospitals;
- setting up a pain and palliative care hospital in every district; and
- providing enough medicines for relieving pain.

The recommendations also include substantive guidelines for palliative care training, stating that training should inform medical professionals on (i) communication, (ii) legal decision making, (iii) pain in cancer patients, (iv) medical complications in patients with terminal illness, (v) psychiatric and neuro problems of patients with terminal illness, and (vi) spiritual support to terminal patients with terminal illness.

The Government took several steps to develop the palliative care program in Kerala. First, it adopted a Palliative Care Policy (2008). The policy outlines the Government's commitment to palliative care, proposed a new law to ensure availability of palliative care medicines, and established the guidelines on palliative care education for health care professionals.

“The detection of cancer in a parent is a calamity for the children, spouse and affected parent. During the last days of our mother’s life, we alternately watched her for signs of pain, keeping an eye on the amount of (weaker) painkillers in hand. We spent a fortune in time and money on meeting Government officials—we knocked on the door of every Government official concerned with narcotic control. We were surprised to find that the officials were sympathetic to our case; clerks and officers who are labeled as bureaucratic, were courteous and kind. We received tons of sympathy, but not a milligram of morphine.”

–Ghooi RB. “A mother in pain”. *The Lancet* 1998; 352;1625.

Second, the Government amended the Kerala Narcotic Drugs and Psychotropic Substances Rules (1985) in 2009. This modified the laws on procuring and dispensing morphine, and simplified the process of licensing for health care centers. With the amendment of this law, morphine became more available and shortages were no longer a problem. The Government also issued a brochure on the Standard Operating Procedures (SOP) involved in applying for licensing, and how to procure and dispense morphine (available at www.instituteofpalliativemedicine.org/sop.pdf).

The palliative care program in Kerala has become a model for palliative care initiatives in developing countries. Today, there are more than 200 community based organizations that provide palliative care services and more than 300 government initiatives. In addition to strong high-level policy guidance, a community level organization called the Neighbourhood Network in Palliative Care (NNPC) was created in 2001. NNPC is instrumental to the palliative care success in Kerala through its provision of thousands of palliative care volunteers, who are supported by medical professionals.

Pain and Palliative Care Society

Medical College, Calicut, Kerala, India

Web: www.painandpalliativecare.org

Institute of Palliative Medicine Calicut

Medical College, Calicut, Kerala, India

Web: www.instituteofpalliativemedicine.org

Example 3: Regulatory Reform in Romania

Project Type

Regulatory Reform

The Organization

A team of health care workers in Romania worked with the Pain & Policy Studies Group at the University of Wisconsin to convince Romania's regulators that a change in that country's opioid control policy was necessary.

The Problem

Romania's drug-control policies were more than 35 years old and imposed an antiquated regulatory system on pain medication based on inpatient, post-surgical management of acute pain. This restricted prescription authority of opioids to only in-hospital patients who had just undergone surgery, making access to opioid treatment difficult for patients with severe chronic pain due to cancer or AIDS.

Actions Taken

In 2002, a Romanian team composed of health care professionals, representatives from narcotic authorities and the ministries of health, social welfare, and insurance industry -- all working on cancer, HIV/AIDS, pain, and palliative care issues -- attended an International Palliative Care Initiative (IPCI) workshop on ensuring the availability of opioid analgesics for palliative care.

The Romanian team returned home and advocated for the creation of a national commission to reform Romania's opioid control policies. To convince regulators that a change in opioid law was needed, the team cited to Romania's patient rights law, which stated, "The patient has the right to palliative care in order to die in dignity." (24/2003, Cap VI, art. 31). The Ministry of Health agreed to form a Palliative Care Commission (PCC) to study the matter. Finding that Romania's opioid control policies fell short of WHO guidelines, the PCC invited the Pain & Policy Studies Group from the University of Wisconsin to collaborate in the preparation of recommendations.

Results and Lessons Learned

Altered legislation and regulation

Based on the resulting report, the Ministry of Health drafted legislation to replace the old narcotics law. Parliament passed this into law in 2005.⁵³ The Pain and Policy Studies Group then worked with the Ministry of Health on implementing regulations. In 2006, the Ministry of Health approved the regulations.⁵⁴

Additional Resource

WHO, Achieving Balance in National Opioids Control Policy: Guidelines for Assessment (2000). www.medsch.wisc.edu/painpolicy/publicat/oowhoabi/oowhoabi.htm

- This document served as a basis for the legislation. It outlines the need to balance modern pain management with obligation to control non-medicinal or recreational use of opioids.

⁵³ Law no. 339/29.11.2005 on the legal status of narcotic and psychotropic plants, substances and preparations. Official Journal no. 1095, December 5, 2005.

⁵⁴ Government decision nr. 1916/2006 regarding approval of regulations of law 339/2005. Monitorul Oficial (Official Journal) 18/11.01.2007.

Greater authority to prescribe opioid medication

The new law grants greater authority to professionals to prescribe opioids and fewer restrictions on dosages and disease requirements. Special authorization is no longer necessary to prescribe opioid medications for outpatients (patients not admitted to a hospital). As well, non-specialists can prescribe opioids after receiving certified training. The law eliminated both dosage limitations and restrictions to approved diseases,⁵⁵ freeing health care professionals to prescribe opioids for any condition and in any dosage. Every doctor has the authority to prescribe strong opioid medications, according to his/her medical judgment.

Educating doctors

With this radically expanded authority to prescribe opioid medications, it was important for doctors to receive education on pain management. Article 54 of the regulations provided that: “Universities of medicine and pharmacy, the Ministry of Public Health, the College of Physicians from Romania, the College of Pharmacists from Romania and professional or scientific societies, as well as other suppliers of professional training shall take measures for the regular organization of training, courses for adequate therapy of pain and prescribing, use and legal status of narcotic and psychotropic plants, substances and preparations.” Romania is currently conducting a country-wide effort to educate health care professionals in the use of opioid analgesics. With a 15-month grant from the Open Society Institute, Hospice Casa Sperantei took the lead in training physicians in palliative care. The curriculum includes 20 hours of classroom teaching on two consecutive weekends, and six hours of clinical practice in each physician’s practice setting. After completing the course, physicians receive a certificate from the Ministry of Health.

Results

The new law and regulations were a result of a four-year project between local professionals, international experts and national authorities. The new legislation and regulations meet the WHO guidelines and increase access to palliative care medicines.

Hospice Care Sperantei

Brasov, Romania

Email: hospice@hospice.ro

Website: <http://www.hospice.ro>

Website English: <http://www.hospice.ro/en/>

University of Wisconsin, Pain and Policies Study Group

Madison, Wisconsin, USA

Website: www.painpolicy.wisc.edu

⁵⁵ Under the old law, doctors could only prescribe opioids to patients suffering from advanced cancer or with obliterative arteritis with necrosis. Law no. 73/29.12.1969 on the legal status of narcotic substances and preparations. Official Journal 154/29.12.1969). Dec. 1969.

Example 4: Integration of Patients' Rights Standards in Hospice Accreditation in South Africa

Project Type

Standard-setting

The Organizations

Hospice and Palliative Care Association of South Africa (HPCA). Founded in 1988, the HPCA is a professional membership organization for hospice and palliative care organizations. It operates in all nine provinces of South Africa and has 189 member and affiliated hospitals. One of its core missions is to ensure professional palliative care services and to guarantee a high standard of care for patients and their families. Patient rights are central to HPCA's philosophy—providers view themselves as advocates for their patients—and would thus have to figure prominently in criteria developed.

The Council for Health Service Accreditation of Southern Africa (COHSASA). COHSASA grew out of the Faculty of Medicine at the University of Stellenbosch's Pilot Accreditation Programme for South African Health Services. In 1996, COHSASA began operating as an independent, non-partisan unit. It has since developed health accreditation programs for hospitals, sub-acute care, psychiatric facilities and programs, and primary health care clinics. Their mission is to “assist healthcare facilities in developing countries to deliver quality healthcare to their clients through sustained improvement, using internationally recognised standards and based on patient safety principles and operational research.”

The Problem

Patients with HIV/AIDS, cancer, chronic disease, terminal illness, other patients, and the elderly often suffer moderate to severe pain, and palliative care helps to relieve their pain and suffering. South Africa, for example, has approximately 5.6 million people living with HIV/AIDS and approximately 69,000 people with cancer. It is therefore necessary to develop a standard of care and an accreditation program for palliative care programs across the country to encourage hospital and hospices to meet and maintain minimum quality standards—a strategy that could improve patient safety and better the overall quality of care.

Example from South Africa:

Legal Aspects of Palliative Care Manual (2nd Edition, 2012)

This manual addresses the legal and human rights problems facing people with life-threatening illness. It now not only includes case studies, legal recommendations, and resources, but has been restructured as a training manual with step-by-step lessons for hospice and palliative care staff and legal practitioners.

www.hpca.co.za/Legal_Resources.html

Actions Taken

- HPCA developed palliative care standards for the accreditation of hospices in South Africa, incorporating key protections for patient rights.
- In 1994, a HPCA Standards Committee was created to work with the COHSASA, the accrediting body for facilities in compliance with health professional standards, to formulate comprehensive palliative care standards for hospices.

- The Committee developed standards covering 13 key areas with patient rights as one of them. Patient rights language is further embedded throughout.
- A chapter on patient rights addresses processes to: identify, protect and promote patient rights; inform patients of their rights; include the patient and the patient's family, when appropriate, in decisions about the patient's care; obtain informed consent; educate staff about patients' rights; and guide the organization's ethical framework.

Results and Lessons Learned

In 2005, the HPCA/Cohsasa standards for hospice accreditation were published and recognized by the International Society for Quality in Health Care Incorporated (ISQua). 26 hospices are currently fully accredited in 2012.

Hospice Palliative Care Association of South Africa (HPCA)

Cape Town, South Africa

Email: info@hpca.co.za

Website: www.hospicepalliativecaresa.co.za/

COHSASA (Council for Health Services Accreditation of Southern Africa)

Cape Town, South Africa

Email: queries@cohsasa.co.za

Web: www.cohsasa.co.za

Example 5: Integrating Legal Services into Palliative Care

Project Type

Legal Services

The Organization

Founded in 2005, the Kenya Hospices & Palliative Care Association (KHPCA) is a national advocacy organization that works to represent palliative care providers in Kenya. The mission of KHPCA is to make palliative care available to those who are in need by making palliative care in Kenya more affordable, accessible and of higher quality.

The Problem

The provision of legal services can play a critical role in improving the quality of life for patients and families dealing with life-threatening illnesses. Legal services can address human rights violations that negatively affect a patient's health and contribute to his/her and families' peace of mind and well-being by providing answers to urgent and often difficult questions. Integrated health and legal services allow for both holistic care and increased access to justice, taking the law out of the courtroom and private offices and into the community. Common legal needs include: "[a]ccess to health services and other social benefits, empowerment to make medical decisions, writing wills, planning for children and other dependents, [and] protecting/disposing of property."⁵⁶ Approximately 1.5 million Kenyans live with HIV/AIDS, and approximately 45,000 Kenyans live with some form of cancer. Since many patients with HIV/AIDS and cancer suffer from moderate to severe pain, there is a clear need to provide quality palliative care in Kenya.

Kenya Hospices & Palliative Care Association (KHPCA)

- Region: Eastern and Southern Africa
- Field of work: treatment, care and support; training of palliative care staff in hospitals; and legal assistance.
- Populations served: people living with HIV; patients with cancer, non-communicable diseases; TB patients; and children with life-limiting illnesses.
- Staff: 7 full-time, 1+ volunteers.

Actions Taken

KHPCA recently surveyed three hospices in Kenya to assess the medical and legal rights involved in palliative care. The study focused on patients, medical practitioners, legal practitioners, volunteers and caregivers. After learning the results of the survey, KHPCA developed and administered a project to create a more holistic approach to health care—providing health and legal services for patients in need.

Results and Lessons Learned

The survey revealed that there is limited access to palliative care; inadequate information regarding patient suffering; a general lack of awareness on patients' rights; discrimination against those with life-threatening illnesses; and a need to review laws and policies to incorporate palliative care into the public health system of Kenya.⁵⁷ From the study, KHPCA concluded that:

⁵⁶ David Musyoki, Kenya Hospices and Palliative Care Association, 3rd Kenya National Palliative Care Conference 2012 65 (Sept. 12-14 2012). Available at: http://kehpc.org/conference/wp-content/uploads/2012/09/conference_final_programme.pdf

⁵⁷ David Musyoki, Kenya Hospices and Palliative Care Association, Incorporation of Legal and Human Right Issues in Palliative Care. Available at: <http://kehpc.org/wp-content/uploads/AT39.pdf>

There is need to train all those involved in the care of these patients on the palliative care approaches. In such settings, there is need to have standard protocol in dealing with such patients, striking a critical balance between the ethical-legal concerns with humane approach to care. Early diagnosis & referral, the presence of family will help in modifying the disease trajectory, hence improving patients' quality of life.⁵⁸

To address these gaps between legal rights and the provision of palliative care in Kenya, KHPCA has worked with several hospices to empower hospice workers, patients and their families on their palliative care rights. Additionally, KHPCA is now a key partner with the Kenyan Government in enhancing pain relief and palliative care throughout Kenya. Specifically, KHPCA works with the Kenyan Government to develop and implement national palliative care guidelines; develop curricular and training materials for palliative care; train health care providers and care givers on palliative care; conduct awareness campaigns on palliative care targeting policy makers public, media, health care personnel and regulators; advocate for legislation and policies that support palliative care; and integrate palliative care services into the national health services.⁵⁹

Kenya Hospices & Palliative Care Association (KEHPCA)

Nairobi, Kenya

Email: info@kehPCA.org

Website: www.kehPCA.org

Additional Resources

National Cancer Control Strategy: Republic of Kenya, Ministry of Public Health and Sanitation and Ministry of Medical Services, National Cancer Control Strategy 2011-2016. <http://kehPCA.org/wp-content/uploads/Kenya-National-Cancer-Control-strategy.pdf>.

KHPCA Resources on Palliative Care:

Kenya Hospices and Palliative Care Asso. http://kehPCA.org/wp-content/uploads/kehPCA_brochure.pdf

Patient Information Sheet.: http://kehPCA.org/wp-content/uploads/pain_brochure.pdf

Palliative Care Patients' Rights. http://kehPCA.org/wp-content/uploads/pc_rights.pdf

What is Power of Attorney. <http://kehPCA.org/wp-content/uploads/attorney.pdf>

Guidelines to Making a Will. <http://kehPCA.org/wp-content/uploads/a%2owill.pdf>

Conference Report

African Palliative Care Association, Palliative Care: An Essential Part of Medical and Nursing Training (March 24-25, 2011, Nairobi, Kenya). <http://kehPCA.org/wp-content/uploads/education%2oconference.pdf>

⁵⁸ David Musyoki, Kenya Hospices and Palliative Care Association, 3rd Kenya National Palliative Care Conference 2012 65 (Sept. 12-14 2012). Available at: http://kehPCA.org/conference/wp-content/uploads/2012/09/conference_final_programme.pdf

⁵⁹ Republic of Kenya, Ministry of Public Health and Sanitation and Ministry of Medical Services, National Cancer Control Strategy 2011-2016 30. Available at: <http://kehPCA.org/wp-content/uploads/Kenya-National-Cancer-Control-strategy.pdf>

Example 6: Advocating for Access to Pain Relief Through United Nations Mechanisms

Project Type

Advocacy

The Organization

Founded over 30 years ago, Human Rights Watch (HRW) is a leading independent organization that protects and defends human rights across the globe. They conduct objective and rigorous investigations and engage in vigorous advocacy efforts.

The Problem

Governments have the positive obligation to protect their people from unnecessary pain related to a health condition. Additionally, governments have a negative obligation not to arbitrarily interfere with the provision of essential health services.

Millions require controlled medications, like morphine, for treatment of moderate to severe pain. However, in over 150 countries across the world, access to palliative care medication is virtually non-existent. These medicines are unavailable or inaccessible in many countries because of overregulation and/or problems with supply and distribution systems for controlled medicines. Governments that report low consumption of morphine to the International Narcotics Control Board relative to the number of its citizens suffering from HIV/AIDS or cancer indicates a substantial gap between those suffering and in need of pain management and the actual accessibility of palliative care medicines

Human Rights Watch

Health and Human Rights Division

As part of Human Rights Watch's long commitment to defending human rights, the organization has been reporting on issues related to health and human rights for many years. Human Rights Watch's work has examined how such rights as freedom of speech, expression, assembly and information; freedom from discrimination and arbitrary detention; property rights; bodily autonomy, protection from violence, cruel, inhuman and degrading treatment and torture; and the right to health care intersect with the realization of the right to health. Investigations and advocacy have particularly focused upon the health of vulnerable populations, including women, children, displaced persons, lesbian, gay, bisexual, transgender (LGBT) persons, drug users, ethnic and racial minorities, and migrant workers.

www.hrw.org/sites/default/files/related_material/HRW_healthbrochure_low.pdf.

Actions Taken

Human Rights Watch advocates for palliative care as a human right, including increased access to medications to manage and relieve pain. Its advocacy efforts include country reports and outreach to UN human rights bodies, including the Commission on Narcotic Drugs and the World Health Assembly. Actions taken include:

1. Country reports documenting gaps in policy and practice relating to palliative care in Thailand, Russia, Ukraine, the United States, Canada, Kenya, China, Bangladesh, India, and Kazakhstan, among other countries. Reports available at: <http://www.hrw.org/en/news/2009/03/09/un-drug-summit-undo-decade-neglect#pain>.

- Submission to the Human Rights Committee and the Committee Against Torture regarding Cameroon's Fourth Periodic Report (26 August 2009). Report available at: <http://www.hrw.org/es/news/2009/08/26/submission-human-rights-committee-regarding-cameroon-s-fourth-periodic-report>; www.hrw.org/en/news/2009/08/26/submission-committee-against-torture-regarding-cameroon-s-fourth-periodic-report.

Both reports advocate for the government of Cameroon to effectuate low-cost reforms to remove barriers and ensure adequate supply of opioid medications to treat tens of thousands of Cameroonians experiencing pain and suffering moderate to severe pain associated with cancer, AIDS, and other health conditions.

- Joint Statement of the International Harm Reduction Association and Human Rights Watch, Interactive Dialogue with the Special Rapporteur on Torture at the Tenth Session of the Human Rights Council (12 March 2009). www.hrw.org/en/news/2009/03/12/joint-statement-international-harm-reduction-association-ihra-and-human-rights-watch.

The Human Rights Council was urged to reject restrictive drug policies which perpetuate the denial of access to essential medicines, to reject such approaches by the UN Committee on Narcotic Drugs (CND), and to mainstream human rights into international drug policy.

- 'Please, Don't Make Us Suffer Anymore...': Access to Pain Treatment as a Human Right (2009). www.hrw.org/en/news/2009/03/02/un-stop-needless-suffering.

HRW calls on the UN General Assembly to consider access to pain relief medication. It highlights the causes of poor availability, including "failure to put in place functioning supply and distribution systems; absence of government policies to ensure their availability; insufficient instruction for healthcare workers; excessively strict drug-control regulations; and fear of legal sanctions among healthcare workers."

- Global State of Pain Treatment: Access to Medicines and Palliative Care (2011). Available at: <http://www.hrw.org/sites/default/files/reports/hhro511W.pdf>.

HRW uses publicly available data on the consumption of pain medicines to illustrate the unmet need for pain treatment. It also presents the results of a survey of healthcare workers in 40 countries regarding the main barriers to better pain treatment and palliative care.

- Report of the Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment, A/HRC/22/53 (February 1, 2013). Available at: http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

The Special Rapporteur cites to evidence collected by Human Rights Watch of human rights abuses in health care settings, including denial of morphine and other drugs for pain management.

Results and Lessons Learned

HRW's continued advocacy has brought attention the issues of the international narcotics conventions and access to essential medicines for palliative care. Their reports highlight the issue areas and document human rights violations.

Human Rights Watch
New York, USA
Website: www.hrw.org

5. WHERE CAN I FIND ADDITIONAL RESOURCES ON PALLIATIVE CARE AND HUMAN RIGHTS?

A list of commonly used resources on palliative care and human rights follows. It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. Other Statements and Declarations
- D. Palliative Care as a Human Rights
- E. Palliative Care – General Resources
- F. Essential Medicines and Human Rights
- G. Litigation and Legal Services
- H. Key Populations – Cancer Patients
- I. Key Populations – Children
- J. Key Populations – Older Persons
- K. Key Populations – End-of-Life Care
- L. Key Populations – HIV and Aids Patients
- M. Key Populations – People who use drugs
- N. Key Populations – TB Patients
- O. Multimedia
- P. Advocacy and Training Manuals
- Q. Websites

A. International Instruments

Binding

- UN Office on Drugs and Crime, Single Convention on Narcotic Drugs (1961; amended 1972). www.unodc.org/unodc/en/treaties/single-convention.html.

Nonbinding

- UN Committee on the Rights of the Child, *General Comment No. 3: HIV/AIDS and the Rights of the Child*, CRC/GC/2003/3 (March 17, 2003). www2.ohchr.org/english/bodies/crc/comments.htm.
- UN Committee on the Rights of the Child, *General Comment No. 4: Adolescent Health*, CRC/GC/2003/4 (July 1, 2003). www2.ohchr.org/english/bodies/crc/comments.htm.
- UN Economic and Social Council, *Treatment of pain using opioid analgesics*, ECOSOC Resolution 2005/25 (July 22, 2005). www.un.org/en/ecosoc/docs/2005/resolution%202005-25.pdf.

- UN General Assembly, *Declaration on the Protection of All Persons from Being Subjected to Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, Resolution 3452 (XXX), A/RES/30/3452 (1975). <http://www.un-documents.net/a3or3452.htm>.
- UN General Assembly, *Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, A/RES/37/194 (1982). www.un.org/documents/ga/res/37/a37r194.htm.
- UN General Assembly, *Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, A/RES/37/194 (1982). www.un.org/documents/ga/res/37/a37r194.htm.
- UN General Assembly, *Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases*, Resolution A/66/L.1 (September 16, 2011). www.un.org/ga/search/view_doc.asp?symbol=A/66/L.1.
- UN General Assembly, *Declaration of Commitment on HIV/AIDS*, Resolution S-26/2 (August 2, 2001). www.un.org/ga/aids/docs/ares262.pdf.
- UN General Assembly, *Political Declaration on HIV/AIDS*, A/RES/60/262 (June 15, 2006). http://data.unaids.org/pub/report/2006/20060615_hlm_politicaldeclaration_ares60262_en.pdf.
- UN General Assembly, *Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS*, A/RES/65/277 (July 8, 2011). www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610_un_a-res-65-277_en.pdf.
- UN Office on Drugs and Crime: Commission on Narcotic Drugs, Resolution 53/4 (March 2010). www.unodc.org/documents/commissions/CND-Res-2000-until-present/CND53_4e.pdf.
- WHO, *Declaration of Alma-Ata* (September 6-12, 1978). www.who.int/publications/almaata_declaration_en.pdf.
- WHO and International Narcotics Control Board, *Assistance Mechanism to Facilitate Adequate Treatment of Pain using Opioid Analgesics: Joint Report of the Director-General of the WHO and the President of the INCB* (March 2, 2007). www.who.int/medicines/areas/quality_safety/Joint_Report-WHO-INCB.pdf.
- WHO, *Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines* (2011). www.who.int/medicines/areas/quality_safety/guide_nocp_sanend/en.
- WHO, Expert Committee on Drug Dependence: 34th Report (2006). whqlibdoc.who.int/trs/WHO_TRS_942_eng.pdf.
- WHO, *Cancer prevention and control*, World Health Assembly Resolution 58.22 (May 2005). www.who.int/entity/ipcs/publications/wha/cancer_resolution.pdf
- WHO, *Model List of Essential Medicines* (2011). www.who.int/medicines/publications/essentialmedicines.

B. Regional Instruments

Nonbinding

- Active Citizenship Network, *European Charter of Patients' Rights* (2002). www.patienttalk.info/european_charter.pdf.
- Council of Europe, *Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care* (November 12, 2003). www.uni-klu.ac.at/pallorg/downloads/iffpallorg_europarat_english_version.pdf.
- Parliamentary Assembly, *Protection of Human Rights and Dignity of the Terminally Ill and Dying*, Recommendation 1418 (1999). <http://assembly.coe.int/documents/adoptedtext/t99/erec1418.htm>.

- Parliamentary Assembly, *Protection of the human rights and dignity of the terminally ill and the dying*, Recommendation 1418 (1999). <http://assembly.coe.int/Mainf.asp?link=/Documents/AdoptedText/ta99/EREC1418.htm>.

C. Other Statements and Declarations

- American Medical Association, House of Delegates, *Palliative Care and End-of-Life Care*, Resolution 3, A-05 (2006). www.ama-assn.org/resources/doc/hod/a-06bot.pdf.
- Association of Nurses in AIDS Care, *Palliative Care: Position Statement* (2006). www.nursesinaids.org/i4a/pages/index.cfm?pageid=3300.
- Connor S et al., “Declaration on palliative care and MDR/XDR-TB,” *The International Journal of Tuberculosis and Lung Disease* 16, no. 6 (June 2012): 712-713. www.ncbi.nlm.nih.gov/pubmed/22613682.
- Eastern and Central Europe Palliative Care Taskforce, *The Poznan Declaration, 9th Palliative Medicine Advanced Course* (1998). www.oncology.am.poznan.pl/ecept/declaration.php.
- European Association for Palliative Care et al., *The Prague Charter*, www.eapcnet.eu/Themes/Policy/PragueCharter.aspx.
- International Association for Hospice and Palliative Care & Worldwide Palliative Care Alliance, *Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment as Human Rights*. <http://hospicecare.com/about-iahpc/contributions-to-palliative-care/human-rights>.
- International Association for the Study of Pain, *Declaration of Montreal: Declaration that Access to Pain Management is a Fundamental Human Right* (2011), www.iasp-pain.org/PainSummit/DeclarationOfMontreal.pdf.
- International Federation of Health and Human Rights Organisations, *Access to Adequate Pain Treatment* (March 31, 2011). <http://xa.yimg.com/kq/groups/20454159/1912587409/name/IFHHRO%20Position%20Statement%20Pain%20Treatment.pdf>.
- Pogge T, “Montreal Statement on the Human Rights to Essential Medicines,” *Cambridge Quarterly of Healthcare Ethics* 15, no. 2 (2006). www.economyandsociety.org/events/Pogge_background_paper2.pdf.
- Sebuyira M et al., “The Cape Town Palliative Care Declaration: Home-Grown Solutions for Sub-Saharan Africa,” *Journal of Palliative Medicine* 6, no. 3 (2003): 341-343. www.ncbi.nlm.nih.gov/pubmed/14509478.
- Second Global Summit of National Hospice and Palliative Care Associations, *Declaration on Hospice and Palliative Care [Korea Declaration]* (March 2005). www.coe.int/t/dg3/health/Source/KoreaDeclaration2005_en.pdf.
- World Medical Association, *Resolution on the Access to Adequate Pain Treatment* (October 2011). www.wma.net/en/30publications/10policies/p2.

D. Palliative Care as a Human Right

- Amon J and Lohman D, “Denial of Pain Treatment and the Prohibition of Torture, Cruel, Inhuman or Degrading Treatment or Punishment,” *Interights Bulletin* 16 no. 4 (November 4, 2011): 172-184. www.hrw.org/sites/default/files/related_material/2011.12%20InterRights%20Bulletin%20Article_only.pdf.
- Breitbart W, “Palliative care as a human right: update.” *Palliative Support Care* 9, no. 4 (2011): 345-349. www.experts.scival.com/mskcc/pubDetail.asp?t=pm&id=82055165950&o_id=28.
- Brennan F et al., *Palliative Care as a Human Right* (Open Society Institute, January 2008). www.opensociety-foundations.org/sites/default/files/pchumanright_20080101.pdf.

- Cohen J, “Palliative care advocacy using the international human rights framework”, <http://cop.health-rights.org/teaching/161/Palliative-care-advocacy-using-the-international-human-rights-framework>.
- Harding R, “Palliative Care: A Basic Human Right,” *Insights* 21, no. 8 (February 2006). www.dfid.gov.uk/r4d/PDF/Outputs/IDS/insights_health8.pdf.
- Human Rights Watch, *Global State of Pain Treatment: Access to Palliative Care as a Human Rights* (2011). www.hrw.org/sites/default/files/reports/hhro511W.pdf.
- Human Rights Watch, *Please Do Not Make Us Suffer Any More: Access to Pain Treatment as a Human Right* (2009). www.hrw.org/sites/default/files/reports/healtho309web_1.pdf.
- Human Rights Watch, *Unbearable Pain: India’s Obligation to Ensure Palliative Care* (2009). www.hrw.org/en/reports/2009/10/28/unbearable-pain-o
- Human Rights Watch, *Uncontrolled Pain: Ukraine’s Obligation to Ensure Evidence-Based Palliative Care* (2011). www.hrw.org/sites/default/files/reports/ukraine0511WebRevised.pdf.
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- Lohman D, Schleifer R and Amon J, “Access to Pain Treatment as a Human Right,” *BMC Medicine* 8, no. 8 (January 20, 2010). www.hrw.org/en/news/2010/03/01/access-pain-treatment-human-right.
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- Silva P, “For the Terminally Ill, Freedom from Pain Is a Human Right”, *Voices*, Open Society Foundations, May 24, 2011. www.opensocietyfoundations.org/voices/terminally-ill-freedom-pain-human-right.
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- UN Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/10/44, January 14, 2009. www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.44AEV.pdf.
- Worldwide Palliative Care Alliance, *Access to pain relief: an essential human right: A report for World Hospice and Palliative Care Day 2007*, www.worldday.org/reports.

E. Palliative Care - General Resources

- Casarett J, “Special Section: Brief Global Reports on International Palliative Care Projects,” *Journal of Pain and Symptom Management* 40, no. 6 (2010). www.jpsmjournal.com/issues?issue_key=So885-3924%2810%29X0006-9.
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6. WHAT ARE THE KEY TERMS RELATED TO HUMAN RIGHTS IN PALLIATIVE CARE?

A

Acute pain

Pain that has a known cause and occurs for a limited time. It usually responds to analgesic medications and treatment of the cause of the pain.

Addiction

A commonly used term describing a pattern of drug use that indicates physical or mental dependence. It is not a diagnostic term and is no longer used by the World Health Organization (WHO).

Advance medical directives

Used to give other people, including health care providers, information about a patient's own wishes for medical care. Advance directives are important in the event patients are not physically or mentally able to speak for themselves and make their wishes known. The most common types of advance directives are the living will and the durable power of attorney for health care. A Do Not Resuscitate (DNR) is also a form of an Advance Medical Directive.

Analgesic medications

Medications used to prevent or treat pain.

B

Bereavement

The act of grieving the loss of a significant other.

C

Cancer

An abnormal growth of cells which tend to proliferate in an uncontrolled way and, in some cases, to metastasize (spread).

Caregiver

Any person who provides care for the physical, emotional, or spiritual needs of a family member or friend.

Chronic pain

Pain that occurs for more than one month after an injury has healed, that occurs repeatedly over months, or is due to a lesion that is not expected to heal.

Complementary therapies

Approaches to treatment that are outside of mainstream medical practices. Complementary therapy treatments used for pain and/or comfort include: acupuncture, low-level laser therapy, meditation, aroma therapy, Chinese medicine, dance therapy, music therapy, massage, herbal medicine, therapeutic touch, yoga, osteopathy, chiropractic treatments, naturopathy, and homeopathy.

Community based care

Medical and social service care often provided by volunteer trained members of the community.

D**Death**

The end of life in a biological organism, marked by the full cessation of its vital functions.

Do Not Resuscitate (DNR) orders

A DNR is a medical directive that gives consent from the patient, his/her advocate or from a medical physician that the patient is not to be treated for cardiac or respiratory arrest. This directive is used when treatment of the patient will not be beneficial or successful to the quality or longevity of the patient's life. This is usually the case in the seriously and terminally ill, and/or the frail and elderly. These directives do not mean that comfort measures will be withheld.

Dignity

The quality of being worthy, honored, or esteemed. Human rights are based on inherent human dignity and aim to protect and promote it.

Durable power of attorney

A person who is dying may appoint someone else to manage their finances and to make economic decisions on their behalf. This person is referred to as the "agent."

E**End-of-life care**

Doctors and caregivers provide care to patients approaching the end of life that is focused on comfort, support for the family, and treatment of psychological and spiritual concerns.

Essential medicines

Medicines that satisfy the priority health care needs of the population. Essential medicines are intended to be available at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at a price the individual and the community can afford.

Ethics

A system of moral principles and rules that are used as standards for professional conduct. Many hospitals and other health care facilities have ethics committees that can help doctors, other healthcare providers, patients, and family members in making difficult decisions regarding medical care. This may vary with religious and cultural backgrounds.

G**Grief**

The normal process of reacting to a loss. The loss may be physical (such as a death), social (such as divorce), or occupational (such as a job). Emotional reactions of grief can include anger, guilt, anxiety, sadness, and despair. Physical reactions of grief can include sleeping problems, changes in appetite, physical problems, or illness.

H**HAART**

Highly active anti-retroviral therapy.

Health care proxy

A written instrument in which an individual legally delegates authority to another person to make certain health-related decisions on their behalf.

Home based care

Medical and social care provided by trained health care professionals or volunteers in a person's home.

Hospice

A care program that provides a centralized program of palliative and supportive services to dying persons and their families, in the form of physical, psychological, social, and spiritual care; such services are provided by an interdisciplinary team of professionals and volunteers who are available at home and in specialized inpatient settings.

Hospice care

Care designed to give support to people in the final phase of a terminal illness, and focused on comfort and quality of life, rather than a cure. The goal is to enable patients to be comfortable and free of pain so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they sometimes provide services away from home -- in freestanding facilities, in nursing homes, or within hospitals. The philosophy of hospice is to treat the whole person by providing support for the patient's emotional, social, and spiritual needs, as well as addressing medical symptoms.

I**Informed consent**

The process of making decisions about medical care that is based on factual, open, and honest communication between the health care provider and the patient and/or the patient's family members.

L**Life-limiting illness**

An illness with a prognosis of a year or less to live.

Life-threatening illness

An illness serious enough that a patient may die.

Living will

A legal document which outlines the direction of medical care a patient wishes to have or not to have. The living will is used only if the patient becomes unable to make decisions for him/herself, and will be carried out as the patient has directed in the document.

M**Medical power of attorney**

A document that allows any individual to appoint another person to be their agent and make decisions for them should they become unable to make decisions for themselves.

Multidisciplinary team

A group of individuals representing different medical disciplines who work together to care for a patient and family.

N**Nursing home**

A residential facility for persons with chronic illness or disability, particularly older people who have mobility and eating problems. This is also called a convalescent home or long-term care facility.

Nutrition Hydration

Intravenous (IV) fluid and nutritional supplements given to patients who are unable to eat or drink by mouth, or those who are dehydrated or malnourished.

O**Opioid**

A type of medication related to opium. Opioids are analgesics used in acute and chronic pain. Opioids include morphine, codeine, and a large number of synthetic (man-made) drugs like methadone and fentanyl.

Opportunistic infections

Infections caused by organisms that usually do not cause disease in a person with a healthy immune system, but can affect people with a poorly functioning or suppressed immune system.

P**Pain**

An unpleasant feeling that may or may not be related to an injury, illness, or other bodily trauma. Pain is complex and differs from person to person, as related to the individual's pain threshold.

Palliative care

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care for children

Represents a special, albeit closely related field to adult palliative care for children with life threatening or chronic disorders and their families. Includes active total care of the child's body, mind, and spirit; family support; and a multidisciplinary approach that includes the family and makes use of available community resources.

Palliative care standards

Standards reflecting the level of care a patient and family can expect to receive when dealing with a diagnosis of a life-limiting illness.

Permanent guardianship of minor children

Offers a parent the option of permanently placing their child (a minor) in the care of another person.

Power of attorney for personal care

A legal document that specifies one or more individuals a patient would like to make medical decisions on his/her behalf if unable to do so on their own.

Psychology

Science dealing with phenomena of the mind, the conscious subject, or self.

Psychosocial care

Care given to meet a constellation of social, mental health, and emotional needs.

R**Rehabilitation**

Treatment for an injury, illness, or pain with the goal of restoring partial or full function.

S**Social work**

Work carried out by professionals concerned with social problems, their causes, their solutions, and their human impacts. Social workers work with individuals, families, groups, organizations, and communities, as members of a profession committed to social justice and human rights.

Spiritual care

Providing the necessary resources to address and support people's values and beliefs, provided these values and beliefs place no individuals at risk. It is based on treating each person with respect and dignity, promoting love, hope, faith, and helping vulnerable people to find the strength to cope at times of life crises when overcome by despair, grief, and confusion.

Suffering

Absence of any power to control or to meaningfully influence a perceived process of one's own disintegration.

Symptom management

Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of symptom management is to prevent or treat as early as possible the symptoms of the disease, side effects caused by treatment of the disease, and psychological, social, and spiritual problems related to the disease or its treatment. Also called palliative care, comfort care, and supportive care.

T**Terminal**

A progressive disease that is expected to cause death.

Treatment withholding

When treatment is considered to be ineffective, disproportionate, or of no value to the patient's quality of life, it may be withdrawn or withheld.

Treatment withdrawal

The ending of treatment that is medically futile in promoting an eventual cure or possible control of the disease.

W**Will**

A legal document that allows a person to leave any portion of his/her estate and any specific positions to any other person or organization.

Withholding care

Not offering a specific treatment to a patient.

Withdrawing care

Withdrawing a treatment that has already started in a patient.