

Training Session Plan

Introduction to Palliative Care and Human Rights



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The International Federation of Health and Human Rights Organisations (IFHHRO)

IFHHRO forms a unique network of active organisations committed to the protection and promotion of health related human rights. Members and observers are human rights groups which address health-related rights violations, medical associations involved in human rights work, and organisations that have been created specifically to mobilize health workers for human rights protection.

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Learning Objectives

- To become aware of the relation between palliative care and human rights
- To become familiar with the most relevant international and regional human rights standards related to palliative care



Target Group

Health workers with little to no knowledge about health related human rights



Duration

90 minutes



Materials

- Sheets of flipchart paper
- Markers
- Masking tape



Training Aids

1. Palliative Care Rights
2. Case Studies Palliative Care
3. Chapter 4 'Palliative Care and Human Rights' of the Health and Human Rights – A Resource Guide, Open Society Institute and Equitas, 2009. Available online at: www.equalpartners.info



Handouts

1. Most relevant international and regional human rights standards related to palliative care¹



Session Plan

The session works best in combination with general introductory sessions about human rights in relation to health. The introductory sessions and sessions related to the role of health workers can be found online in the IFHHRO Training Manual 'Human Rights for Health Workers' at www.ifhhro-training-manual.org.

Preparation

It is suggested to select video material to show at the start of this session for 10 minutes to introduce at least one aspect of palliative care. Suggestion for a documentary to select a fragment from is *The Two Faces of Opium*, BBC documentary, 23 min. Online at: <http://www.rockhopper.tv/programmes/138/>

Photocopy the cases and the handout.

¹ From: *Health and Human Rights – A Resource Guide*, Open Society Institute and Equitas, 2009, Chapter 4. Available online at: www.equalpartners.info

Prepare two sheets of flipchart paper each with 3 columns with the following headings:

| <i>Sheet 1</i> | | | <i>Sheet 2</i> | | |
|----------------|----------------|---------------|----------------|----------------|---------------------|
| individual | health workers | civil society | institution | national level | international level |
| | | | | | |

Step 1 Video (10 minutes)

Show a (fragment of a) video about an aspect of palliative care.

Step 2 Introduction to palliative care (10 minutes)

Discuss the video briefly and ask the participants whether they know what palliative care rights are. Don't explain these rights in detail but stimulate the participants to come up with a few answers. When at least 6 different palliative care rights are mentioned continue with the next step. See Training Aid 1 for the main rights and name some if the participants don't come up with enough answers.

Step 3 Group work (20 minutes)

Divide the participants in 6 small groups. Distribute the case studies from Training Aid 1 together with a sheet of flipchart paper and a marker. Each case will be worked on by two different groups. Each participant also receives Handout 1: Most relevant international and regional human rights standards related to palliative care. Ask the groups to write their answers to the three questions on the sheet of flipchart paper.

Step 4 Discussion (25 minutes)

Hang the sheets with answers where everyone can see them. Make sure that the sheets addressing the same cases are next to each other for easy reference. Discuss all cases briefly by comparing the answers of the two groups that worked on that case and provide additional information if necessary.

The UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, mentioned in one of his reports that the non-accessibility of palliative care is a form of inhuman treatment. Ask participants if they share his opinion, why or why not?

Step 5 Extra Questions (20 minutes)

Introduce the prepared sheets of flipchart paper with the six columns and ask in plenary:
- What steps do you suggest to improve the situations described in the case studies?
Write the answers in the corresponding columns and facilitate discussion.

Step 6 Conclusion (5 minutes)

Conclude the session by summarizing the discussion.

Training Aid 1 – What are Palliative Care Rights?²

Palliative care embraces human rights that are already recognized in national laws, international human rights documents, and other consensus statements.

Palliative care rights include the **right to**:

- Pain relief
- 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
- Receive 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
- Name a health care proxy for decision making
- Not be discriminated against in the provision of care because of age, gender, socioeconomic status, geographic location, national status, prognosis, or means of infection.

² From: *Health and Human Rights – A Resource Guide*, Open Society Institute and Equitas, 2009, Chapter 4. Available online at: www.equalpartners.info

Training Aid 2 - Case Studies Palliative Care

Photocopy the cases, number of photocopies depend on the number of participants in each group. Total number of groups will be 6 and two groups will work on the same case. Cut the cases along the line.

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Case 1

Mrs. Petrova, 68 yrs old, suffers from terminal cancer. Colon carcinoma was diagnosed two years ago, and she underwent resection and chemotherapy. About 18 months later, liver secondaries were discovered, as well as peritonitis carcinomatosa. She has much pain, fatigue, and suffers from nausea, anorexia, and loss of weight.

She can hardly afford to see a doctor, and the doctor has no access to morphine. Even with regular pain therapy (paracetamol and NSAID) she still has considerable pain, severely affecting her quality of life.

Her caretakers are her grandchildren of 12 and 14 years. She divorced a long time ago. She lives in a small apartment in the suburb of a big city.

1. Describe how her situation should be addressed appropriately according to state-of-the-art standards.
2. What health related human rights are violated in her position? Use the handout.
3. Which mechanisms cause the violations of her health related rights?

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Case 2

Mr. Ivanov, 72 yrs old, suffers from terminal heart failure and COPD GOLD iv. He receives inhalation therapy and heart support medication. However there is no oxygen therapy available, and there is no access to morphine should his doctor deem this appropriate. He has pains at times, but mostly severe dyspnoea and fatigue.

He is a widower living on a small village farm. His children live far away, and his single care giver is his neighbour, 66 years old, who has her own disabilities.

1. Describe how his situation should be addressed appropriately according to state-of-the-art standards.
2. What health related human rights are violated in his position? Use the handout.
3. Which mechanisms cause the violations of his health related rights?

Case 3

You are one of the three doctors working in a small scale hospice. The hospice was established 8 years ago as a new facility in your provincial town and serves many people. It was a new development to create hospices but the recent economic recession threatens the very existence of the hospice. Resource allocation to hospitals has been favoured recently, and you have been told that unless you find strong sponsor support, your hospice will have to close down.

1. Describe the situation of your hospice in perspective of the Right to Health.
2. What health related human rights are violated? Use the handout.
3. Which mechanisms cause the violations of the health related rights?

Handout 1 - Most relevant international and regional human rights standards related to palliative care³

Overview

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

- **To document** violations of palliative care rights
- **To advocate** for the cessation of these violations
- **To sue** governments for violations of national human rights laws
- **To complain** to regional and international human rights bodies about breaches of human rights agreements.

In the tables on the following pages, examples of human rights violations related to palliative care are provided. Relevant human rights standards are then cited, along with examples of legal precedents and provisions from patient right charters and declarations, interpreting each standard.

Abbreviations

In the tables, the seven treaties and their corresponding enforcement mechanisms are referred to with the following abbreviations:

| Treaty | Enforcement Mechanism |
|---|--|
| 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 All Forms of Discrimination Against Women (CEDAW Committee) |
| Convention on the Rights of the Child (CRC) | Committee on the Rights of the Child (CRC Committee) |
| African Charter on Human and People's Rights (ACHPR) & Protocols | African Commission on Human and People's Rights (ACHPR Commission) |
| [European] Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) | European Court of Human Rights (ECtHR) |
| European Social Charter (ESC) | European Committee of Social Rights (ECSR) |

³ From: *Health and Human Rights – A Resource Guide*, Open Society Institute and Equitas, 2009, Chapter 4. Available online at: www.equalpartners.info

Table 1: Palliative care and freedom from 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 | Precedents and Interpretations |
| <p>ICCPR 7 No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.</p> <p>ACHPR 5 Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited.</p> <p>African Women's Protocol 4(1) All forms of exploitation, cruel, inhuman or degrading punishment and treatment shall be prohibited.</p> <p>ECHR 3 No one shall be subjected to torture or to inhuman or degrading treatment or punishment. See also:</p> <ul style="list-style-type: none"> Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 4(1) "All forms of exploitation, cruel, inhuman or degrading punishment and treatment shall be prohibited." European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment | <p>ECtHR: finding continued detention of a cancer sufferer where it caused "particularly acute hardship" to constitute cruel, inhuman or degrading treatment [Mouiel v. France, 38 EHRR 34, para. 34 (2004)].</p> <p>See also:</p> <ul style="list-style-type: none"> A right to avoid unnecessary pain and suffering is an important part of most patients' rights charters. For instance, the European Charter of Patients' Rights sets out: "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 care treatment and simplifying patients' access to them." [art. 11]. The Declaration on the Promotion of Patients' Rights in Europe, promulgated by a WHO European Consultation, similarly asserts: "Patients have the right to relief of their suffering according to the current state of knowledge...Patients have the right to humane terminal care and to die in dignity." [art. 5.10, 5.11]. |

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 | Precedents and Interpretations |
| <p>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.</p> <p>ACHPR 4 Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right.</p> <p>ECHR 2(1) Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.</p> | <p>HRC: 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." [HRC GC 6, paras 1, 5].</p> |

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 | Precedents and Interpretations |
| <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>12(2) The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for....</p> <p>(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;</p> <p>(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.</p> <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.</p> <p>ACHPR 16(1) Every individual shall have the right to enjoy the best attainable state of physical and mental health.</p> <p>16(2) States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.</p> <p>ESC 11 – The right to protection of health</p> <p>With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed...</p> <p>(2) to provide advisory and educational facilities for the promotion of health...</p> <p>See also:</p> <ul style="list-style-type: none"> • CRC 24, African Charter on the Rights and Welfare of the Child 14 (child's right to the highest attainable standard of health). | <p>CESCR: affirming the importance of "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity." [CESCR GC 14, para. 25].</p> <p>CESCR: 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. [CESCR GC 14, para. 12].</p> <p>CESCR: "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." [CESCR GC 14, para. 34].</p> <p>See also:</p> <ul style="list-style-type: none"> • Under the Declaration on the Promotion of Patients' Rights in Europe, promulgated by a WHO European Consultation, "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." [art. 5.9]. |

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. • People are denied information about pain management. • People are denied information about their diagnosis and prognosis. | |
| Human Rights Standards | Precedents and Interpretations |
| <p>ICCPR 19(2) Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.</p> <p>ACHPR 9 (1) Every individual shall have the right to receive information.</p> <p>ECHR 10 (1) Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises.</p> <p>(2) Every individual shall have the right to express and disseminate his opinions within the law.</p> <p>See also:</p> <ul style="list-style-type: none"> • European Convention on Human Rights and Biomedicine, art 10(2): "Everyone has the right to know any information collected about his or her health." | <p>CESCR: health care accessibility "includes the right to seek, receive and impart information and ideas concerning health issues." [CESCR GC 14, para 12].</p> <p>See also:</p> <ul style="list-style-type: none"> • Under the European Charter of Patients' Rights, "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." [art. 3]. • The Declaration on the Promotion of Patients' Rights in Europe emphasizes, "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." Moreover, "[p]atients have the right to choose who, if any one, should be informed on their behalf." [art. 2.2, 2.6]. |

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 | Precedents and Interpretations |
| <p>ICCPR 26 All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.</p> <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>ACHPR 2 Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status.</p> <p>See also:</p> <ul style="list-style-type: none"> • International Convention on the Elimination of All Forms of Racial Discrimination, art. 5(e)(iv) • Convention relating to the Status of Refugees • European Convention on Human Rights and Biomedicine, art 3 (equitable access to health care) • European Convention on Citizenship and the Convention Relating to the Status of Stateless Persons | <p>CESCR: “[T]he 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.” [CESCR GC 6, paras 12,13].</p> <p>CESCR: emphasizing the need “to eliminate any discriminatory legislation and the need to ensure the relevant budget support” for the elderly. [CESCR GC 6, para. 18].</p> <p>CESCR: 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.” [CESCR GC 6, para. 34].</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> <p>CERD: calling upon states to protect the adequate standard of health of non-citizens and refugees by ensuring their equal access to palliative health services. [CERD/C/NOR/CO/18 (CERD, 2006), para. 21; CERD/C/BWA/CO/16 (CERD, 2006), para. 19].</p> |