

PALLIATIVE CARE AS A HUMAN RIGHT



LIZ GWYTHYER, TRUSTEE, WORLDWIDE PALLIATIVE CARE ALLIANCE,
UNIVERSITY OF CAPE TOWN, SOUTH AFRICA

The right to palliative care is enshrined in many documents and agreements. This article explains how human rights relate to palliative care and where to find the relevant information, as well as the need to remove barriers and integrate palliative care into health care.

Through active advocacy efforts and practical models of provision of palliative care, it has been recognized that palliative care is an appropriate and compassionate response to the needs of patients with life-threatening illnesses. This is true for cancer patients and for those with other chronic progressive illnesses. However, there are significant inequities in the provision of palliative care worldwide. The Worldwide Palliative Care Alliance reports that in 2011, only 136 of the world's 234 countries (58%) had one or more hospice-palliative care services.¹ In 2011, there was no known palliative care activity in 78 of the world's 234 countries (33%). Twenty-three countries had some capacity-building potential for palliative care. Ninety-one countries reported localized hospice-palliative care provision. Twenty-five countries reported that palliative care is approaching integration with mainstream health service providers, but only 20 countries (8.5%) have achieved this integration.

This inequity and significant gap in provision of palliative care has led the international palliative care community to develop strategies to improve access to quality palliative care using a human rights approach to urge states who are signatories to the International Covenant for Economic, Social and Cultural Rights (ICESCR) to meet human rights core obligations for the provision of palliative care in their countries.² There are a number of key statements that urge governments to integrate palliative care into health systems, the most recent being the Prague Charter which makes the statement that: "Access to palliative care is a human right under the right to the highest attainable standard of physical and mental health".³ However, although it seems clear that from a moral and compassionate standpoint that palliative care should be recognized as a human right, it is necessary to identify the legal foundation for this claim through the documents of the United Nations General Assembly. It is one thing to name something such as palliative care as a human right but in order for it to be legally considered a human right

there has to be a process to establish this claim. There are nine international human rights treaties⁴ (Table 1). The right to health is described within the International Covenant for Economic, Social and Cultural Rights. Each human rights treaty body is a committee of international experts to monitor the implementation of the core international human rights treaties. The Committee for Economic, Social and Cultural Rights monitors the implementation of the ICESCR. The human rights treaty bodies publish interpretation and guidance with respect to the international treaties as general comments. General comments are not international laws but are used by courts to interpret matters with regard to the treaty, such as ICESCR for matters regarding health.

What are human rights?

The Office of the United Nations High Commissioner for Human Rights states that human rights are "rights inherent to all human beings, whatever our nationality... without discrimination".⁵ The Preamble to the Universal Declaration of Human Rights (UDHR) adopted on 10 December 1948 by the United Nations General Assembly declares that "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world".⁶ Article 25 of the UDHR addresses "the right to a standard of living adequate for the health and well-being ... and the right to security in the event of unemployment, sickness, disability, widowhood, old age".

The UDHR, the International Covenant for Civil and Political Rights and the International Covenant for Economic, Social and Cultural Rights, together known as the Bill of Rights, were developed before modern hospices were established and before palliative care was developed as a discipline. However there have been a number of more recent documents that do address palliative care as a human right. The right to health is addressed within the ICESCR and in

Figure 1: Mapping levels of palliative care development

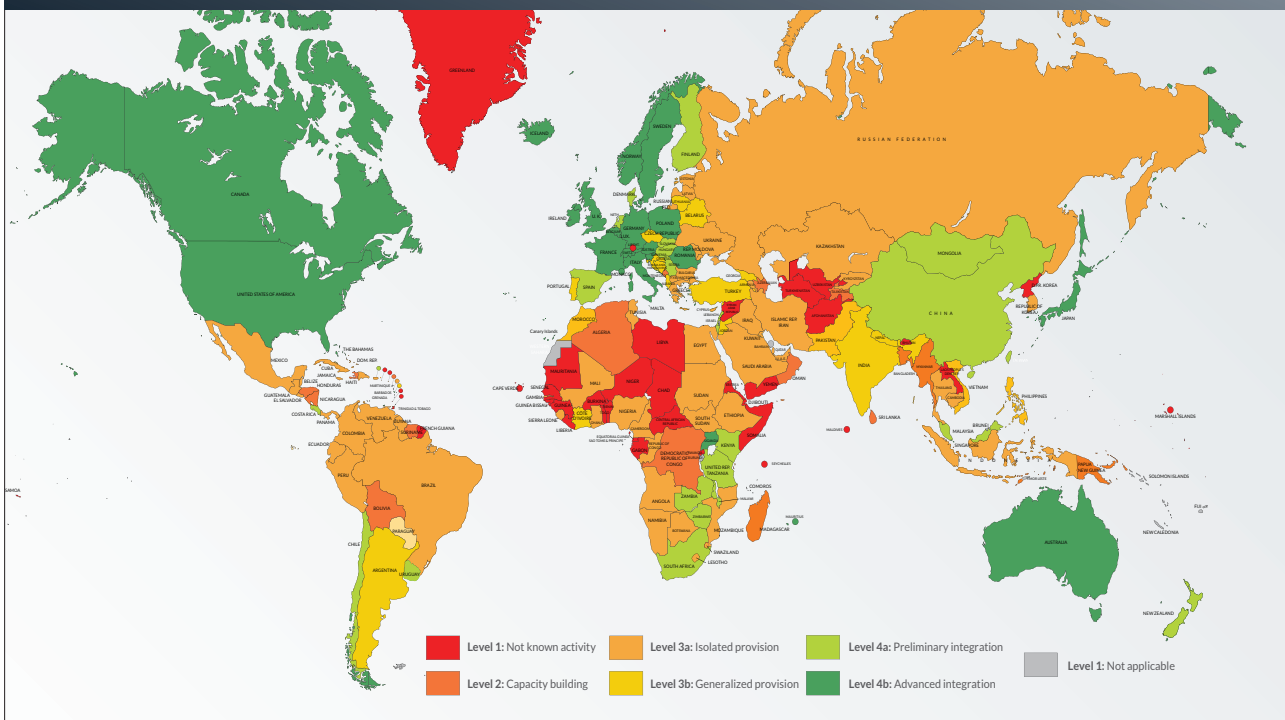


Table 1: International Human Rights Treaties

- ▶ International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)
- ▶ International Covenant on Civil and Political Rights (ICCPR)
- ▶ International Covenant on Economic, Social and Cultural Rights (ICESCR)
- ▶ Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)
- ▶ Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)
- ▶ Convention on the Rights of the Child (CRC)
- ▶ International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (ICRMW)
- ▶ International Convention for the Protection of All Persons from Enforced Disappearance (CPED)
- ▶ Convention on the Rights of Persons with Disabilities (CRPD)

Source: <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CoreInstruments.aspx>

2000 the UN Committee on Economic, Social and Cultural Rights adopted General Comment 14 which includes the statement 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”.⁷

A further source of validation of palliative care as a human right comes from the infrastructure of the UN which appoints Special Rapporteurs to advance international understanding

of how to achieve the realization of certain rights. The Special Rapporteur on the Right to Health and the Special Rapporteurs on torture and other cruel, inhuman or degrading treatment or punishment have both made key statements on the importance of palliative care and pain relief:

“Many other right-to-health issues need urgent attention, such as palliative care ... Every year millions suffer horrific, avoidable pain ... Palliative care needs greater attention” (2008).⁸

“The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel inhuman and degrading treatment. International human rights law requires that governments must provide essential medicines – which include, among others, opioid analgesics – as part of their minimum core obligations under the right to health... Lack of access to essential medicines, including for pain relief, is a global human rights issue and must be addressed forcefully...” (2008).⁹

In February 2013, Juan E Méndez, the current UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment presented a report to the UN Human Rights Council on Torture in Health Care Settings. The report focused on “certain forms of abuses in health care settings that may cross a threshold of mistreatment that is tantamount to torture or cruel, inhuman or degrading treatment or punishment”.

Within the report Mr Méndez describes issues relating to

Table 2: Obligations under the Committee on Economic, Social and Cultural Rights

| General comment 14 | Core obligation in the context of palliative care | The Prague Charter call to governments |
|---|--|---|
| Core obligations | | |
| To ensure the right of access to health facilities, goods and services without discrimination | To ensure the right of access to palliative care without discrimination | 4. Governments should ensure the integration of palliative care into health care systems at all levels |
| To ensure access to minimum essential food which is nutritionally adequate and safe, freedom from hunger To ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water | | |
| To provide essential drugs, defined by the WHO as Essential Drugs | To provide essential palliative care drugs, as defined by WHO | 2. Governments should ensure access to essential medicines, including controlled medications, to all who need them |
| To ensure equitable distribution of all health facilities, goods and services | To ensure equitable distribution of palliative care services | |
| To adopt and implement a national public health strategy and plan of action | To adopt and implement a national palliative care strategy and plan of action | 1. Governments should develop and adopt health policies that address the needs of patients with life-limiting or terminal illnesses |
| Obligations of comparable priority | | |
| To ensure reproductive, maternal and child health care | | |
| To provide immunization against the major infectious diseases occurring in the community | | |
| To take measures to prevent, treat and control epidemic and endemic diseases | | |
| To provide education and access to information concerning the main health problems in the community | To provide education and access to information palliative care services in the community | |
| To provide appropriate training for health personnel, including education on health and human rights | To provide palliative care training for health personnel | 3. Governments should ensure that health care workers receive adequate training on palliative care and pain management at undergraduate and subsequent levels |

denial of pain relief.¹⁰ Mr Méndez comments on negligent conduct that “constitutes ill-treatment if it leads to severe pain and suffering”. He describes how many countries do not make adequate provision for the supply of controlled medicines required to treat moderate and severe pain. He draws on reports from the World Health Organization (WHO) and from Human Rights Watch that describe inadequacy of pain treatment in countries from the developing and the developed world – that 32 countries in Africa have almost no supplies of morphine; that one-third of patients in the United States do not receive adequate pain treatment. He identifies the obstacles to effective pain management recognizing that in general: “denial of pain treatment involves acts of omission rather than commission and results from neglect and poor government policies,

rather than from an intention to inflict suffering”.

In concluding his report the Special Rapporteur on torture calls on all states to:

“Ensure full access to palliative care and overcome current regulatory, educational and attitudinal obstacles that restrict availability to essential palliative care medications, especially oral morphine.”

“Develop and integrate palliative care into the public health system by including it in all national health plans and policies, curricula and training programmes and developing the necessary standards, guidelines and clinical protocols.”¹⁰

General comment 14

General comment 14⁷ describes the normative content of article 12 of the ICESCR and distinguishes between the

right to health and the right to be healthy. Article 12 speaks of the right to the attainable standard of health taking into account a person's "biological and socioeconomic preconditions and a State's available resources". This relates closely to the palliative care concept of best possible quality of life while living with a life-threatening or life-limiting illness such as cancer.

General comment 14 also describes four essential elements to the right to health. These are availability, accessibility, acceptability and quality. What do the four elements mean in the context of palliative care?

Availability

Palliative care should be available in sufficient quantities within a country's public health facilities and other health care facilities including children's homes and care homes for the elderly. This includes health care professionals and other health care workers trained in palliative care and availability of essential palliative care medicines. It should be integrated into mainstream health care so that psychosocial support and symptom control are available from the time of diagnosis.

Accessibility

General comment 14 describes accessibility in terms of "four overlapping dimensions" – non-discrimination, physical accessibility, economic accessibility (affordability) and information accessibility. Palliative care should be accessible for all people without discrimination; including minority groups, to prisoners and other marginalized populations. It should be available to children, to older people, to people with disabilities, to people living with HIV. Palliative care should be physically accessible in a country. If patients choose to stay at home, there should be home care services that provide quality palliative care in the home. Palliative care should be available in health care facilities, and in communities. In some countries non-governmental organizations (NGOs) provide palliative care in a patient's home. Palliative care should be available in rural areas.

There is uncertain funding of palliative care services. In some countries palliative care is fully funded by the state and NGOs also receive state funding. In many developing countries palliative care is funded through donations from communities or corporate donations with little contribution from the state. Patients requiring palliative care are often not medically fit to work and if they do not have medical insurance, they are not able to pay for palliative care services. In many countries hospices provide palliative care free of charge to patients and rely on donations to be able to fund the services.

Patients and their families should have sufficient access to information about palliative care services and the option of palliative care. Ideally, palliative care should be a well-publicized service within communities. Patients with cancer should receive the information from their doctors so that palliative care would go hand in hand with definitive treatment and would be available for support at any stage of the illness. Currently, the discussion about including palliative care is often delayed until late in the course of the illness.

Acceptability

Palliative care services should be respectful of medical ethics and, indeed, palliative care training includes strong emphasis on bio-ethics as there are often challenging decisions to be made about end-of-life care. Palliative care services should be respectful of culture, gender and age; respecting confidentiality and aiming to improve quality of life of patients and family members.

Quality

Health facilities, goods and services must also be scientifically and medically appropriate and of good quality. They should follow minimum standards that are appropriate to the individual country's resources.

General comment 14 also describes that the right to health for older persons should include measures "aimed at maintaining the functionality and autonomy of older persons; and attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity".⁷ There should be the same recognition of needs of children, adolescents and younger adults when faced with life-threatening and life-limiting illness.

The Committee on Economic, Social and Cultural Rights describes "core obligations" and "obligations of comparable priority". These are summarized in Table 2 and relevance to palliative care summarized as well as the call to governments included in the Prague Charter. The concept of core obligations has not been universally accepted. Many governments have rejected the core obligations approach while still embracing socioeconomic rights and the concept of progressive realization of these rights. So while describing the core obligation set out in General comment 14, we recognize that this may not be the approach to implementation of the rights described in IESCR taken by many governments. For example, the South African Constitutional Court in the landmark Treatment Action Campaign case (2002) recognized that the South African government could not meet all basic needs but ruled that the government's obligation nonetheless is to seek to meet these needs, acting reasonably to provide

access on a progressive basis.⁸

Some of the core obligations noted in Table 2 are equally important in palliative care, such as adequate nutrition, shelter, sanitation and safe, potable water. It is also important to focus on prevention of illness such as immunization against HPV to prevent cervical cancer and healthy lifestyle to limit non-communicable diseases. We need to recognize that child health care should include paediatric palliative care when necessary.

WHO public health strategy for palliative care

In 2002, Stjernswärd described the Ugandan success in integrating palliative care into the country's health system through engaging a government public health approach.¹¹ Drawing on this success WHO recommends four "low-cost foundation measures" for integrating palliative care into a country's health system. These are 1) developing and implementing policies for palliative care; 2) educating health care workers in palliative care and creating awareness of palliative care services within communities; 3) ensuring drug availability, in particular essential analgesic medication; and 4) developing palliative care services within the public health sector.¹²

Barriers to palliative care

Doyle and Woodruff, writing for the International Association of Hospice and Palliative Care *Manual of Palliative Care*¹³ describe a number of barriers to palliative care that they classify as physician factors, patient factors, social factors and access factors. Lack of education in palliative medicine translates into lack of understanding of the role of palliative care and lack of integration of palliative care into clinicians' practice. One of the physician barriers described is the lack of communication skills to address end-of-life issues. There are a number of difficult conversations that doctors may need to have as a patient's disease progresses and it is important the doctors become skilled in having these conversations so that patients and family members can be fully informed about the illness and can make choices that are appropriate to their circumstances and preferences.¹⁴ Doctors may be reluctant to refer patients to palliative care if they do not have an understanding or belief in the discipline. They may also be reluctant to hand over care to another doctor and unfortunately may also be guided by a fee for service structure and concerns about loss of income. Patient factors that are a barrier to palliative care include denial in patients that often hope or believe that the prognosis is better than what they are told; they may have an unrealistic expectation of the disease's response to treatment; there

may be disagreement about treatment options between patient and family members; there is frequently a lack of advanced care planning. Lack of informational access may be as a result of patients or family members not being receptive to the information or choosing to ignore the information about palliative care services.¹³ Social factors that may be barriers to accessing palliative care include poverty; living in a rural community; being part of disempowered or marginalized groups such as refugees, prisoners, the homeless. Dissonance between the patient's culture and the culture of the care service may be a barrier. Western palliative care started with a strong Christian foundation and many organizations still use Christian symbols that may deter patients from other religions using the services. Palliative care workers are trained to be sensitive to these social and cultural issues and involving carers from the patient's social and cultural community can help to overcome these barriers.

The role of the health care professional in improving patients' access to palliative care

In terms of human rights, governments have three levels of obligation: to respect, protect and fulfil these rights. But people are not simply passive recipients of the benefits of human rights, they can demand that their rights are fulfilled and upheld. London describes agency as "critical to a human rights approach"¹⁵ and states that: "Rights alone are not enough, but need to be coupled with community engagement".¹⁶ Who leads this community engagement and who encourages and supports the agency of the vulnerable individual requiring palliative care? Chochinov eloquently expressed the lack of agency afforded vulnerable individuals requiring palliative care when he addressed the Canadian Senate Standing Committee on Social Affairs, Science and Technology: "Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak".¹⁷

Patients living with cancer and their family members are very powerful advocates when they are encouraged and supported to speak about their needs and demanding their human rights. A particularly powerful series are the Life Before Death (www.lifebeforedeath.com)¹⁸ and Treat the Pain (<http://treatthepain.org>)¹⁹ videos series setting out the imperative for good palliative care and pain management.

Communities are also often quiet on the imperative for good end-of-life care. Death is not a comfortable topic of conversation or discussion and communities choose not to consider the need for palliative care or ignore information about palliative care because of this discomfort. These

societal constraints make it important for health care professionals who work with patients with advanced life threatening or life-limiting illnesses to take on the role of advocating for palliative care and to encourage patients and family members to speak out and let their plight be known.

To speak particularly about oncologists, oncology nurses and oncology social workers and palliative care workers engaged in the care of cancer patients, there are a number of important ways we can improve care of cancer patients as their illness progresses. We should ensure our own knowledge and skills of clinical oncology and of palliative care are well developed and up-to-date and recognize that palliative care is not only for the end of a life. We should incorporate palliative care into everyday practice, while recognizing that difficult symptoms or psychosocial problems may warrant specialized palliative care. We should explore our own comfort in working with patients whose disease is no longer curable. We should ask about distressing symptoms, manage them effectively and review the response to symptom management. We should develop the skills and find the courage to have difficult conversations about withdrawing treatment that is no longer able to cure or contain the cancer. We should discuss options for care and explore patients' fears so that we can either reassure them or explain how we will deal with problems that might develop. It would be of benefit to have a palliative care nurse or physician as part of the oncology unit team.

Conclusion

In summary, we should offer individualized care appropriate

to patient preference and stage of illness that includes quality palliative care.

We should also be the voice for the voiceless and advocate for palliative care policies in our countries, for clinical guidelines and protocols guiding palliative care practice; for palliative care training in our nursing and medical schools; for access to essential palliative care medicines in our own countries, and in countries worldwide, in order to relieve the suffering of patients in pain; and we should advocate for appropriate palliative care services in health care facilities, care homes and for home palliative care services so that patients and families can access the care they need. ●

Dr Liz Gwyther has postgraduate qualifications in family practice and palliative medicine. She is CEO of Hospice Palliative Care Association of South Africa (HPCA); a Trustee of the Worldwide Hospice Palliative Care Alliance (WPCA); and a director of the following organizations - African Palliative Care Association, ehospice, Networking AIDS Community of South Africa (NACOSA), and Pain Society of South Africa.

She is a senior lecturer at the University of Cape Town where she heads the Palliative Care team within the School of Public Health and Family Medicine. She is also the convener for the postgraduate programmes in palliative medicine. Her special interests are women's health and palliative care and human rights in health care. In 2007, she was awarded the SA Medical Association's Gender Award for Human Rights in Health and the SA Institute of Health Managers Leadership in Health Systems award. She is a member of the editorial board of the Journal of Pain & Symptom Management published in the USA.

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