April 3, 2023

Response of the International Association for Hospice and Palliative Care

to OHCHR call for

**Examples of** **Human Rights-Based Approach to Universal Health Coverage**

**Introduction**

Palliative care (PC) is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers. (International Association for Hospice and Palliative Care, n.d.) [1] The High-Level Declaration on Universal Health Coverage adopted in 2019 by all UN member states included palliative care as an essential service. (United Nations Resolutions, 2019)

At the outset, we must declare that we can cite no extant examples of *member states* that have included PC as part of a *human-rights based approach* to UHC. Examples of member states that include palliative care in nationally funded policies are Chile (Cruz, 2023), Colombia (Pastrana, 2022), Costa Rica (situación del cuidado paliativo en costa rica, n.d.) , Thailand [ (2019)] (National Policy on Palliative Care in Thailand, 2017) and Uruguay (Cuidados Paliativos, 2022). Other member states (ie Australia, the UK, and Canada) have national PC policies and strategies framed as constitutional rights and but not under an explicitly HRB approach.

We identify the normative framework, global service gaps, and implementation challenges, concluding with resources produced by African regional and national member states and NGOs to begin filling gaps in certain areas, such as access to medicines. The vast majority of palliative care services in G20 states and the Majority World are delivered by non-governmental and faith-based organizations operating with scarce resources in community settings.

There is space for much work to be done at OHCHR to raise awareness among member states of the related HR mandates and system-level benefits of palliative care to communities, households and individuals. The two Independent Experts on the Enjoyment of all Human Rights by Older Persons have drawn attention to the global palliative care service deficits with regard to older persons, and the Human Rights Council in 2021 approved a resolution 83/1 that recognized those deficits and urged governments to take action to remedy them.

**Normative Framework and Human Rights Instruments** Palliative care is a component of the right to life and security of the person (UDHR), and to the highest attainable standard of physical and mental health (ICECSCR). Other relevant instruments include the Convention on the Rights of the Child (CRC), the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention Against Torture (CAT). It is explicitly included in several articles of the Inter-American Convention on the Human Rights of Older People and addressed in General Comment 14 (CESCR, 2000).

**The 2021 OHCHR Report (United Nations OHCHR, 2021) i**s the most comprehensive recent summary of the normative framework (for footnote cites see original document):

143. From a normative perspective there is no explicit reference to the right to palliative care in Article 25 of the UDHR or in Article 12 of the ICESCR which guarantee the right to the highest attainable standard of health, or in any other of the principal United Nations human rights treaties. It has been argued that the right to palliative care can be derived from the rights to the highest attainable standard of health that appear in a number of UN human rights treaties and also that a denial of palliative care might also amount to cruel, inhuman or degrading treatment in violation of the International Covenant on Civil and Political Rights (ICCPR), the Convention against Torture and other treaties containing protections against cruel, inhuman or degrading treatment or punishment.178

144. The Committee on Economic, Social and Cultural Rights has referred briefly to palliative care in three of its general comments, in each case a general reference in the context of ensuring the availability of ‘preventive, curative and palliative care services’ to all.179 There has been no detailed discussion of the nature and extent of the right, although the Committee’s general elucidation of the right to health is relevant to palliative care. The right does not appear to have been a priority issue in the Committee’s dialogue with States parties under the reporting procedure: a search of the UHRI database for the use of the term ‘palliative’ in the Concluding observations of the CESCR up to the end of 2020 produced just four references. These were all in concluding observations in which the Committee noted that States parties have an obligation to ensure that ‘all persons in the State party’ including migrants, refugees and asylum-seekers, ‘have equal access to preventive, curative and palliative health services, regardless of their legal status and documentation’.180

145. Nor has the issue assumed a higher profile in the work of the other treaty bodies. A similar search in relation to documents of the Committee against Torture produces one, tangential reference related to the difficulties in the provision of palliative services in a situation of armed conflict following the use of a particular type of weapon.181 There appears to be no more extended discussion of the issue in the practice of that Committee. Similar searches of the Concluding observations of the Human Rights Committee produce no results, while in the case of the Committee on the Rights of Persons with Disabilities just one result was returned.182

**Demographics of need and global health relevance** Palliative care is particularly relevant to maternal and child health, to older persons, to persons with disabilities, and to persons suffering from chronic, communicable, and non-communicable diseases. The World Health Organization recognizes that only 14% of people who need PC globally receive it. (WHO, n.d.) More than 80% of the world’s population have no effective access to essential palliative care medicines on the WHO Model List. (Annual Report Supplement, 2023)

PC is the essential health service that can relieve serious health related suffering (SHS) associated with communicable, chronic and terminal illness. Experts estimate that SHS will increase in all regions, with the largest proportional rise in low-income countries (155% increase between 2016 and 2060). By 2060, an estimated 48 million people (47% of all deaths globally) will die experiencing SHS, which represents an 87% increase from 26 million people in 2016. 83% of these deaths will occur in low-income and middle-income WHO member states. Globally, SHS will increase most rapidly among older persons (aged 70 years and above --183% increase between 2016 and 2060). In absolute terms, it will be driven by rises in cancer deaths (16 million people, 109% increase between 2016 and 2060). The condition with the highest proportional increase in SHS will be dementia (6 million people, 264% increase between 2016 and 2060). (Sleeman, 2019)

Barriers to implementation of national and regional strategies and member state approval in 2014 of WHA Resolution 67/19 on “Strengthening of palliative care as a component of comprehensive care throughout the life course,” which urges Member States to

1. to develop, strengthen and implement, where appropriate, PC policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, *and universal coverage schemes*; (emphasis added)

include lack of

* understanding of the PC approach in the context of human rights and UHC
* awareness of the benefits of PC to patients, families, communities and health systems
* health worker training (nurse, physician, pharmacist, spiritual care professional) training in basic PC and prescribing of essential PC medicines.

added to

* insufficient funding of public health systems and privatization of health services by the corporate sector.

**Selected Examples: African UHC/PC Resources**

A guiding principle of **Kenya’s** national Palliative Care Policy is “Fair distribution of resources to guarantee accessibility to quality palliative services at every point of demand, especially for the vulnerable, marginalized and underserved *in line with universal health coverage*.” (Government of Kenya, 2021)

Two other African resources, one national, one regional, explicitly providing for palliative care as part of UHC include the following:

* Essential Palliative Care Package for Universal Health Coverage in Uganda (UHC Palliative Care, 2021)
* The African Palliative Care Essential Palliative Care Package for UHC 2019 (UHC, 2019)

**Links to World Health Organization Resources on UHC and Palliative Care**

WHO UHC Compendium <https://www.who.int/universal-health-coverage/compendium/interventions-by-programme-area>

Other (not explicitly UHC related) resources: <https://www.who.int/news/item/05-10-2021-who-takes-steps-to-address-glaring-shortage-of-quality-palliative-care-services>

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