Children's Palliative Care and Human Rights

Palliative care for children with life-limiting illness is the active total care of the child's body, mind, and spirit. It begins at diagnosis and continues regardless of whether the child receives treatment directed at the disease. It seeks to control all forms of suffering related to the illness, including pain. It involves social, psychological, spiritual, and legal support to siblings, parents, and other close family members. Effective palliative care for children requires health professionals trained to assess symptoms, care for children of different ages and developmental stages, and to provide medicines in pediatric formulations. Care may be provided in tertiary care facilities, community health centers, and at home. The child's best interest must inform all aspects of the treatment and care, and the child's rights must be protected at all times.

There is a great and unrecognized need for children's palliative care.

- Medical advances have reduced infant and child mortality rates and, at the same time, improved the survival rates of children with severe and life-limiting pathologies.[1] It is estimated that at least seven million children could benefit from pediatric palliative care every year. The vast majority live in low and middle-income countries (98 percent) and almost half are concentrated in Africa (49 percent).[2]
- Congenital anomalies represent roughly 25 percent of the palliative care needs of children worldwide, followed by neonatal conditions (15 percent), malnutrition (14 percent), meningitis (13 percent), HIV/AIDS (10 percent), cardiovascular disease (six percent), endocrine, blood and immune disorders (six percent), and cancer (six percent).[3]
- The quality of life of children in need of palliative care is often impaired by respiratory, gastrointestinal, cardiovascular, and other distressing symptoms. Pain is the most prevalent symptom, experienced by 80 percent of children with cancer; 67 percent of children with progressive non-malignant diseases; and 55 percent of children with HIV/AIDS.[4]
- Although the means and knowledge exist to relieve many symptoms experienced by children—particularly pain—they are often unavailable or inaccessible.[5] Information on the global level of pediatric palliative care provision does not currently exist,[6] yet it is useful to establish a comparison with the provision of antiretroviral therapy. Children living with HIV, for example, are one third less likely to receive this treatment than adults.[7]

Children's Rights & Palliative Care
UN Convention on the Rights of the Child

Among the most relevant articles are:

- » Article 2 **(non-discrimination):** includes the prohibition of discrimination on the grounds of age, e.g., children must not receive inferior pain treatment to adults.
- » Article 3 (**best interest**): the best interest of the child must be a primary consideration in the provision of palliative care.
- » Article 6 **(right to development):** children need support for physical, emotional, intellectual, social, cultural, and spiritual development.
- » Article 12 **(right to be heard):** the views of the child should be taken into account and given due weight according to their age and stage of development, e.g., this requires that appropriate pain assessment techniques are available for children.
- » Article 13 (**right to information**): children must receive accurate information about their illness and symptoms.
- » Article 24 **(right to health):** governments must ensure that palliative care for children is available, accessible, acceptable, and of good quality.
- » Article 28 **(right to education):** education is part of a child's optimal development and should be integrated in the provision of palliative care.
- » Article 31 **(right to play):** children have the right to leisure, to engage in play and recreational activities, which should be included in palliative care provisions.
- » Article 37 **(freedom from torture):** no child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment, such as denial of pain relief.

Children have distinct and specific palliative care needs.

- The 2014 World Health Assembly Resolution on Palliative Care affirms the need for countries to ensure the availability of internationally controlled medicines like morphine in pediatric formulations.[8] Such formulations allow accurate administration of doses to children of widely varying age and weight, and take into account children's capabilities for drug administration, tolerance to medicine-related toxicity, and taste preferences.[9]
- Treating pain in children often requires access to morphine. Generic morphine is not protected by patent and can be administered in home-based settings. It can cost as little as a few U.S. cents per unit.[10] Oral morphine is preferable to injections, which children often fear, and which must be administered multiple times per day.[11]

> "He had severe pain sometimes, especially some abdominal pains . . . There were times that he would use those pain killers paracetamol and Brufen [ibuprofen] and the pain would . . . just persist . . . I could tell he was in a lot of pain because he was just stiffened and you could see he was really struggling because there were sounds he was making. So I could say that he died in pain."
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> *—Mother of 5-year-old Gerard K., HIV/AIDS patient from Kenya*[1]

- Children´s pain is often underestimated and neglected. Assessing it is particularly challenging when children are young or unable to communicate how they feel.[12] Fear of treatment may prevent them from expressing pain. Repeated painful procedures may cause increased anxiety and pain perception.[13] It is also difficult to assess pain in children who have suffered chronic pain all their lives and do not know a pain-free state.[14]
- Children's palliative care requires knowledge of child psychology because serious illness, pain, hospitalization, and invasive medical procedures may be profoundly traumatizing. It also requires identifying and dealing with child abuse or maltreatment. Research suggests that severely ill children may be especially vulnerable to exploitation, abuse, and neglect.[15]
- The impact of the child's condition on parents and siblings must be taken into account. It is important that families are provided emotional, social, spiritual, and legal support. Often in the case of HIV/AIDS, multiple people in the family are infected. Parents may be cared for by young children, young children may be cared for by older relatives (placing physical and emotional stress on them), or children may be cared for by other children. These situations require specific care.[16]

Respect for children's human rights must inform pediatric palliative care.

- The principle of the child's best interest, enshrined in article 3 of the UN Convention on the Rights of the Child (CRC), is a primary factor in all interactions with children. For example, treatment decisions for aggressive cancers must consider both the child's physical and emotional well-being, as well as his or her views.
- Children have a right to express their views on treatment decisions, and for those views to be given appropriate weight, depending on their age and stage of development. To enable this, special efforts must be made to ensure the child's right to information about the illness. Child-appropriate communication must be ensured (article 12 of the CRC).[17]
- For children to exercise their rights, such as their right to education and right to play, palliative care advocates have sought to further clarify the rights of children with palliative care needs. They have developed initiatives such as the Trieste Charter, or Charter of the Rights of the Dying Child,[18] and the International Children's Palliative Care Network Charter of Rights for Life Limited and Life Threatened Children.[19]

International human rights law recognizes the right to palliative care for children.

- Under article 12 of the International Covenant on Economic, Social and Cultural Rights (right to health), article 7 of the International Covenant on Civil and Political Rights (freedom from torture), and article 24 of the CRC (child's right to health), countries are obliged to take steps to ensure that patients have access to palliative care and pain treatment, bearing in mind that children are entitled to special care and assistance.
- The UN CRC Committee explicitly refers to palliative care as a component of children's right to health. It also interprets children's right to health to include the right to grow and develop to one's full potential.[20]
- The UN Committee on Economic, Social and Cultural Rights understands that providing access to essential medicines is one of the core obligations deriving from the right to health.[21] There are 13 palliative care medications currently on the WHO List of Essential Medicines for Children—while 20 palliative care medications are included in the List of Essential Medicines for adults. These include oral and injectable morphine.[22]

"Palliative care for young children is an obligatory part of health-care services . . . [They] have the right to receive the necessary physical, social, psychosocial and spiritual care to ensure their development and promote their best possible quality of life . . . Health systems must have adequately trained professionals to assess and treat pain in children of different ages and developmental stages and ensure the availability of paediatric diagnostic procedures and palliative care medicines in paediatric formulations..."[II]

"Children are particularly vulnerable to certain human rights violations, including torture and other forms of ill-treatment . . . The [UN] Human Rights Committee, the European Court of Human Rights and the Inter-American Court of Human Rights, have [all] recognized the need for States to provide special measures or heightened "due diligence" to protect the personal liberty and security of every child . . . Children experience pain and suffering differently to adults owing to their physical and emotional development and their specific needs . . . The threshold at which treatment or punishment may be classified as torture or ill-treatment is therefore lower in the case of children, . . ."[III]

"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."

—UN Special Rapporteurs on Health and Torture[IV]

Without urgent and concerted action to make palliative care available for children, vast suffering will continue.

Governments should take the following steps:

- Develop a national palliative care strategic plan with a specific focus on the needs of children, addressing obstacles and setting benchmarks to ensure progress.
- Ensure children's palliative care is progressively available, accessible, acceptable, and of sufficient quality for all, without discrimination, particularly supporting home-based pediatric palliative care.
- Eliminate regulatory barriers that restrict the availability of and access to essential palliative care medicines for children, especially oral morphine.
- Include pediatric formulations of essential medicines for pain treatment and palliative care in the national lists of essential medicines.
- Integrate children's palliative care into the curriculum and training programs of medical, nursing, and other health care professionals—with training on communicating with child patients and their families, taking into consideration the child's age, maturity, family dynamics, and clinical context.

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