

## Policy Brief: Palliative Care for Children Living with HIV/AIDS

### Introduction

There is a great need for palliative care for children living with HIV/AIDS. In 2015 an estimated 1.8 million children under 15 years of age were living with HIV but only 49% had access to lifesaving medicines i.e. Antiretroviral therapy<sup>i</sup>. Half of all HIV infected children do not therefore receive any treatment and, without treatment, half of all children born with HIV will die by the age of two and many will die by the age of five.<sup>ii</sup> In resource-limited settings such as sub-Saharan Africa, even those who have access to antiretroviral therapy, are struggling to adhere to treatment due to a variety of reasons such as: clinics being far from home, stigma, difficulty in administering treatment and not enough HIV medicine specifically developed for children's needs.<sup>iii</sup> These children suffer pain and distressing symptoms from the disease and need access to palliative care. Likewise, most of the millions of children who have been orphaned because of AIDS did not receive the necessary bereavement counselling and support which may lead to emotional and psychosocial complications in later life. Despite a 70% decline in the number of new infections since the year 2000, 150 000 children still became infected in 2015. Access to palliative care will relieve their suffering and that of their families.

### KEY POINTS

- 1.8 million children <15 live with AIDS
- Half of children born with HIV die by age 2 if not on treatment
- Only 49% have access to ART
- Adherence is challenging
- Pain is a common symptom in children with AIDS
- Few bereaved children have access to counselling
- Access to palliative care relieves suffering

### Defining palliative care for children

The World Health Organization (WHO) defines Palliative care for children as a special albeit closely related field to adult palliative care which includes:

- The active, total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources: it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's own homes.<sup>iv</sup>

## Pain in children

Pain is a major cause of suffering in children with HIV/AIDS, reported to occur at an average rate of 55%.<sup>v</sup> However, it is often neglected or undertreated due to a variety of reasons, including:

- Some children are unable to express their pain due to their age, lack of verbal skills or disability.
- Few health care professionals are trained and skilled at evaluating children's pain.
- Most health professionals lack competence in prescribing opioids in children.
- There is fear of using opioids for pain control due to a commonly held belief that it will lead to addiction.
- Spiritual pain is often not understood and the impact of culture is ignored.

It is important to treat pain adequately in children because untreated acute pain is responsible for considerable morbidity and even mortality; untreated acute pain can lead to chronic pain; and untreated acute pain can reset the pain threshold for the rest of the child's life.

Despite an increase in the number of children able to access treatment in 2015, 290 children died every day of AIDS related illnesses. Palliative care provides health care workers with the skills to ensure that those who die do so in dignity and peace without unnecessary suffering. It also ensures that the family is supported from diagnosis to the end of life, and throughout the bereavement period.

## Challenges

Palliative care services for children are very few or absent in most countries throughout the world, particularly in low and middle income countries. A recent study showed that over 21 million children globally need access to palliative care, with over 8 million requiring specialist palliative care services<sup>vi</sup>. In South Africa alone, there are approximately 550,000 children needing palliative care with over 200,000 needing access to specialist service, with HIV/AIDS contributing to around 50% of that need<sup>vii</sup> <sup>viii</sup>. Yet the capacity to deliver palliative care is often limited, for example in South Africa less than 5% of the children needing care are receiving it<sup>ix</sup>, which is as low as 1% in Zimbabwe<sup>x</sup>. There are many barriers to delivering palliative care to children and young people (CPC) including the fear of opioids, a lack of education, lack of integration of CPC into the health system, lack of policies on CPC and a lack of community awareness and understanding of CPC. Integration of palliative care into existing services e.g. those for children and young people with HIV, is essential in order to scale up palliative care services and improve accessibility to those in need. It is also a core component of the World Health Assembly (WHA) resolution on palliative care which also stresses the importance of palliative care within Universal Health Coverage.

### KEY POINTS

- More than 21 million children worldwide need palliative care
- 8 million children need specialist palliative care
- Services are poor or non-existent in most low and low middle income countries
- Practitioners are fearful of using opioids for children
- There are few opportunities for education in CPC
- Integration into existing services is slow

## Recommendations

1. The Integration of children’s palliative care into primary, secondary and tertiary health care services.
2. The inclusion of CPC within Universal Health Coverage and therefore all HIV services.
3. The training of all health and allied health workers in children’s palliative care, ensuring that training is provided through basic training and continuing education, intermediate training and specialist palliative care training.
4. Ensuring equitable access to pain-relieving and other palliative medicines, including opioids in formulations suitable for children.
5. To ensure that care is provided in a holistic manner i.e. providing physical, psychological, social and spiritual support.
6. To sensitise communities to palliative care, identifying individuals who may be local CPC champions.

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<sup>i</sup> Children and HIV Fact Sheet. UNAIDS, 2016

<sup>ii</sup> Children and HIV Fact Sheet. UNAIDS, 2016

<sup>iii</sup> Children and HIV Fact Sheet. UNAIDS, 2016.

<sup>iv</sup> World Health Organization, 1998 (a)

<sup>v</sup> Connor S, Sepulveda C, eds. Global Atlas of palliative care at the end of life. Geneva, CH/London, UK: World Health Organization/Worldwide Hospice and Palliative Care Alliance, 2014

<sup>vi</sup> Connor SR, Downing J, Marston J. (2017) Estimating the global need for palliative care for children: A cross-sectional analysis. *Journal of Pain and Symptom Management*.

<sup>vii</sup> Connor SR, Downing J, Marston J. (2017) Estimating the global need for palliative care for children: A cross-sectional analysis. *Journal of Pain and Symptom Management*.

<sup>viii</sup> Connor SR, Sisimayi C, Downing J, King E, Lim Ah Ken P, Yates R, Iken B and Marston J. 2014. Assessment of the need for palliative care for children in South Africa. *International Journal of Palliative Nursing* 20(3) 130-134

<sup>ix</sup> Connor SR, Downing J, Marston J. (2017) Estimating the global need for palliative care for children: A cross-sectional analysis. *Journal of Pain and Symptom Management*.

<sup>x</sup> Connor SR and Sisimayi C. (2013) Assessment of the need for palliative care for children. Three country report: South Africa, Kenya and Zimbabwe. November, UNICEF, ICPCN, London.