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## The right of palliative care for the most vulnerable in Africa is everyone's responsibility

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### Summary

*In sub-Saharan Africa over 80 per cent of needy children are unable to access palliative care services. Since the introduction of the Convention on the Rights of the Child and the African Charter on the Rights and Welfare of Children, the three countries selected for this study, South Africa, Uganda and Kenya, have committed themselves to protect and promote the rights of children. Within the broader framework of international human rights, countries are obligated to realise a child's right to health and provide adequate health care. Yet, children living in these countries with life-threatening and life-limiting illnesses suffer from physical, psychological and emotional pain. The objective of the article is to focus on the plight of seriously ill children in sub-Saharan Africa. This includes highlighting their basic human right to paediatric palliative care and the challenges they encounter in receiving the necessary help. In examining a right to health it is understood that encapsulated within that right is the*

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*availability and access to palliative care for all who require such care. It is important for states to understand that realising universal health coverage is not possible unless existing legislative and social barriers, inadequate healthcare services and training of healthcare providers are addressed. In order to improve the monitoring and evaluation of needs and services, and remove the social, political and economic barriers, state involvement is necessary. The primary argument is that it is possible to successfully implement palliative care even in circumstances where resources are limited. The approach adopted calls for an increased understanding and the buy-in of representatives of government, civil society (international and national) and affected communities all working toward a common agenda and effectively utilising existing community resources.*

**Key words:** *paediatric palliative care; life-threatening conditions; children's rights; pain relief; opioid analgesics; universal health care*

## 1 Introduction

In 2013 the United Nations Children's Fund (UNICEF) and the International Children's Palliative Care Network (ICPCN) published a report revealing that, globally, at least 21 million children require palliative care.<sup>1</sup> Of this number 98 per cent are situated in low to middle-income countries such as South Africa, Kenya and Uganda.<sup>2</sup> The report further indicated that only 1 per cent of needy children in sub-Saharan Africa were accessing palliative care services.<sup>3</sup> These figures are a concern in a world that since the late 1980s has advocated child-centred approaches and the prioritisation of children's rights as set down in the United Nations Convention on the Rights of Child (CRC).<sup>4</sup> Of importance in this context is the fact that the primary aim of the Convention is to protect and promote the rights of all children. This same child-centred focus is reflected in the UN Committee on the Rights of the Child (CRC Committee) where

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1 S Connor & C Sisimayi 'Assessment of the need for palliative care for children: Three country report: South Africa, Kenya and Zimbabwe' (2013) UNICEF & ICPCN, [http://www.unicef.org/aids/files/Palliative\\_Care\\_Three\\_Country\\_Report\\_Nov13.pdf](http://www.unicef.org/aids/files/Palliative_Care_Three_Country_Report_Nov13.pdf) (accessed 13 November 2019). The WHO defines palliative care for children as active, total care of the child's body, mind and spirit and involves giving support to the family. 'Paediatric palliative care (PPC) begins when an illness is diagnosed, and continues beyond the death of the child during the bereavement period'; 'palliative care seeks to improve the quality of life of patients diagnosed with life-threatening illnesses through prevention and relief of suffering', <http://www.who.int/cancer/palliative/definition/en/> (accessed 12 November 2019).

2 World Bank 'Country and lending groups for current 2020 fiscal year', <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519> (accessed 12 November 2019).

3 Connor & Sisimayi (n 1).

4 UN General Assembly Convention on the Rights of the Child (CRC) 20 November 1989 United Nations Treaty Series 1577 3, <http://www.refworld.org/docid/3ae6b38f0.html> (accessed 9 November 2019).

the child's right to health, as defined in article 24, is interpreted as an inclusive right. Inclusivity refers to effective, affordable and appropriate health care which extends beyond curative, rehabilitative and palliative services, adopting a holistic health care approach. It places the realisation of a child's right to health within the broader framework of international human rights obligations.<sup>5</sup>

Since the adoption of CRC and the African Charter on the Rights and Welfare of the Child (African Children's Charter)<sup>6</sup> numerous plans and programmes have been developed by government and civil society alike. Three countries in the African region, South Africa, Kenya and Uganda, were specifically selected for this study because, in addition to the provision of legislative and institutional protection for children, these countries have been identified as exemplars of palliative care development in Africa.<sup>7</sup> In addition to introducing courses on palliative care education at tertiary level, these countries are the home of regional and country-level bodies that guide and oversee the implementation of palliative care.<sup>8</sup>

Yet, in spite of these planned interventions and specific protective measures children facing life-threatening, life-limiting illnesses or chronic conditions (life-threatening conditions) continue to bear the brunt of their own vulnerability resulting in physical, psychological and emotional pain. The disturbing fact is that the capacity to address this suffering exists with adequate political buy-in and innovative planning and support from countries at an international and national level. This was recognised by the World Health Organisation (WHO) which in 2010 proposed that improved efficiency in the collection of

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- 5 UN Committee on the Rights of the Child General Comment 15: The right of the child to the enjoyment of the highest attainable standard of health (art 24) 17 April 2013 CRC/C/GC/15 para 2, <http://www.refworld.org/docid/51ef9e134.html> (accessed 15 November 2019). The right to health is clearly defined in art 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR); General Comment 14: The right to the highest attainable standard of health (art 12 of the Covenant) 11 August 2000 E/C.12/2000/4, <http://www.refworld.org/docid/4538838d0.html> (accessed 9 November 2019).
  - 6 All African states have signed the African Children's Charter; seven states have not ratified the Charter: Democratic Republic of the Congo; São Tomé and Príncipe; South Sudan, Tunisia, Morocco, Sahrawi Arab Democratic Republic and Somalia, <https://www.acerwc.africa/about-the-charter/> (accessed 8 November 2019).
  - 7 BA Fraser et al 'Palliative care development in Africa: Lessons from Uganda and Kenya' (2018) 4 *Journal of Global Oncology* 1; JY Rhee et al 'An analysis of palliative care development in Africa: A ranking based on region-specific macro-indicators' (2018) 56 *Journal of Pain and Symptom Management* 230.
  - 8 Associations such as the African Palliative Care Association (APCA) and the Palliative Care Association of Uganda (PCAU) in Uganda, the International Children's Palliative Care Network (ICPCN) in South Africa, and the Kenya Hospice and Palliative Care Association (KEHPCA) in Kenya.

local revenue and the re-prioritising of budget allocations would allow countries more funds for domestic health.<sup>9</sup>

The article highlights the harsh reality confronting many children living with life-threatening conditions. It argues that despite the promise of rights, universal health coverage and the recognition of equality and the inherent dignity of everyone,<sup>10</sup> holistic health coverage continues to elude the most vulnerable members in a country. The article proposes that the right to palliative care at national, regional and international level is an integral part of the right to health; an argument supported in terms of the definition of palliative care provided by WHO. According to the definition palliation is an important part of the overall continuum of care for seriously-ill children, and palliative care begins when the illness is diagnosed, continuing regardless of whether or not a child receives treatment directed at the disease.<sup>11</sup> The article provides a detailed outline of the barriers and challenges faced when palliative care is sought. It calls for realistic political commitment from government, without which both children and adults living with a life-threatening condition will continue to struggle to access adequate health care. Pivotal to the debate is the realisation that the provision of comprehensive paediatric palliative care (PPC) is possible, even in markedly impoverished settings. All that is required is a shift in thinking and the adoption of implementation strategies where existing resources are utilised economically and unnecessary barriers are removed.<sup>12</sup> Ultimately it is argued that a failure to provide adequate and appropriate PPC, at a time when children's rights are a priority, is a denial of the most basic of human rights, namely, the right of a child to survival and development and, at the end of life, a right to a dignified pain-free death or, as stated by Merriman, 'the right to a good death'.<sup>13</sup>

9 WHO 'Health system financing: The path to universal coverage' (2010) 10-11, [http://www.who.int/whr/2010/10\\_summary\\_en.pdf](http://www.who.int/whr/2010/10_summary_en.pdf) (accessed 15 November 2019); Connor & Sisimayi (n 1) state that with political will 'all countries can do more to raise funds for health' and countries should rethink the way monies are raised and diversify their sources of funding.

10 UN General Assembly Universal Declaration of Human Rights 10 December 1948, 217 A III Preamble, <http://www.refworld.org/docid/3ae6b3712c.html> (accessed 10 November 2019).

11 WHO (n 1).

12 AE Caruso Brown et al 'Reported availability and gaps of paediatric palliative care in low and middle-income countries: A systematic review of published data' (2014) 17 *Journal of Palliative Medicine* 1369; see also J Downing et al 'Paediatric palliative care in resource-poor countries' (2018) 5 *Children PubMed*, file:///C:/Users/09200241/Downloads/children-05-00027%20(1).pdf (accessed 15 November 2019).

13 'Anne Merriman Hospice Africa launched in Kampala' *The Independent* 18 August 2016, <https://www.independent.co.ug/anne-merriman-hospice-africa-foundation-launched-kampala/> (accessed 10 November 2019); see also General Comment 14 of the UN Committee on Economic, Social and Cultural Rights (ESCR Committee) which states that it is critical to provide 'attention and care for chronically and

## 2 Child suffering: Life-threatening conditions and HIV

### 2.1 Children's needs unmet

In Africa children are more likely than anywhere else in the world to be confronted with illness and death before the age of five years.<sup>14</sup> An often overlooked reality is that children, like adults, suffer from a range of life-threatening illnesses and conditions such as cancer, cardiovascular diseases, kidney and liver diseases, congenital anomalies (excluding heart abnormalities), HIV and AIDS, blood and immune disorders, meningitis, neurological disorders and neonatal conditions.<sup>15</sup> Of these, as indicated in the ICPCN study on the need for palliative care for children, HIV continues to impact negatively on children's lives. The study, carried out in the three sub-Saharan African countries, revealed that 'HIV-related illnesses and neonatal conditions are the greatest contributors to children's mortality. Other non-malignant but chronic conditions contribute significantly to childhood morbidity and mortality in these countries.'<sup>16</sup>

Thus, while global figures depict significant progress in the fight against HIV, the number of children becoming newly infected with HIV remains unacceptably high, especially in sub-Saharan Africa.<sup>17</sup> Reports indicate that in the period 2010 to 2018 progress made with respect to reducing the rate of new infections in children is lower than previously expected – from 280 000 to 160 000 – with 25 per cent of new infections occurring in Eastern and Southern Africa.<sup>18</sup> Ninety-one percent of the 1,8 million children living with HIV today are aged between 0 to 14 years and are situated in sub-Saharan Africa. In 2017, 110 000 (63 000 to 160 000) children aged 0 to 14 years died from AIDS-related causes; 32 000 (18 000 to 48 000) of this number were children aged 5 to 14 years.<sup>19</sup> It is a sad reality that the mortality rate among children, including adolescents, remains high because of their

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terminally ill persons, sparing them avoidable pain and enabling them to die with dignity', <https://www.escri-net.org/resources/general-comment-14> (accessed 17 November 2019).

- 14 SN Naicker et al 'Development and pilot evaluation of a home-based palliative care training and support package for young children in Southern Africa' (2016)
- 15 *Bio Medical Central (BMC) Palliative Care* 2, [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4826506/pdf/12904\\_2016\\_Article\\_114.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4826506/pdf/12904_2016_Article_114.pdf) (accessed 16 November 2019).
- 15 S Connor & MCS Bermedo (eds) 'Global atlas of palliative care at the end of life' (2014) 10 WPCA & WHO, [http://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf) (accessed 10 November 2019).
- 16 Connor & Sisimayi (n 1) 6.
- 17 United Nations Children's Fund (UNICEF) *Women: At the heart of the HIV response for children* (2018) 7.
- 18 UNAIDS Fact Sheet – Global AIDS Update 2019, [https://www.unaids.org/sites/default/files/media\\_asset/UNAIDS\\_FactSheet\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf) (accessed 16 November 2019).
- 19 UNICEF (n 17).

being uniquely vulnerable to the rapid progression of HIV, particularly when diagnosis and treatment are neither timely nor sustained.<sup>20</sup>

Within this environment children suffering with life-threatening conditions or severe disabilities should, as in the case of their adult counterparts, have the right to palliative care. As Saunders said, 'You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.'<sup>21</sup>

## 2.2 Why are children not accessing palliative care?

Studies similar to those carried out by ICPCN draw attention to the fact that children in sub-Saharan Africa live in extremely difficult circumstances.<sup>22</sup> Many children with chronic conditions are also living in households where the primary caregiver is economically vulnerable, ill or both. Unfortunately, PPC coverage remains almost non-existent or extremely low, particularly in certain parts of the region, with children unable to access much needed care.<sup>23</sup>

The ICPCN report indicated that in 2012, 545 children in Kenya received specialised palliative care (<1 per cent of the need); of approximately 264 102 patients in South Africa only 14 501 received specialised care (~5 per cent), while in Zimbabwe only 5 438 children received specialised care (~5 per cent).<sup>24</sup> Coupled with the low coverage of PPC is the fact that there is a paucity of data regarding the supply of paediatric services, the number of sites providing these services, the number of children in need of palliative care and those who are receiving care.<sup>25</sup> This lack of clarity and research, with respect to the number of children in need and limited data on accessible sites and resources, results in the inability of governments and civil society organisations (CSOs) to track the existing challenges and identify the needs of communities and health sites. This in turn results in poor coverage, planning and budgeting for children's palliative care.<sup>26</sup>

An integral part of accessing palliative care, for both adults and children, is the provision of relief from pain. Although effective and inexpensive pain medication exists there are many challenges and

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20 UNICEF (n 17) 36.

21 C Saunders 'Care of the dying – 1: The problem of euthanasia' (1976) 72 *Nursing Times* 1003-1005.

22 LE Bain et al 'Malnutrition in sub-Saharan Africa: Burden, causes and prospects' (2013) 15 *Pan African Medical Journal (PMC)* 120.

23 Connor & Sisimayi (n 1).

24 Connor & Sisimayi 7.

25 R Harding et al 'Paediatric palliative care in sub-Saharan Africa: A systematic review of the evidence for care models, interventions, and outcomes' (2014) 47 *Journal of Pain and Symptom Management* 648-649.

26 As above.

barriers obscuring access to certain medicines.<sup>27</sup> These barriers range from social, economic, structural, legal and political in nature. In Africa barriers are complex and multi-layered impacting on individuals in such a way as to limit their ability to utilise existing resources. A more inclusive approach is needed involving a broad representation of national and international stake holders – including government – therefore moving away from the traditional ‘silo approach’ to problem solving.<sup>28</sup>

### 3 International frameworks supporting palliative care as a human right

#### 3.1 Human rights framework

Over the last 30 years palliative care has revealed itself as an important component of a healthcare system and of international human rights. Although palliative care is not directly referred to in international instruments, such as the Universal Declaration of Human Rights (Universal Declaration), the International Covenant on Civil and Political Rights (ICCPR) with its two Optional Protocols, and the International Covenant on Economic, Social and Cultural Rights (ICESCR), it is part of a continuum of health care for everyone. Brennan, Gwyther and Harding state that ‘health includes the health of people with life-threatening illnesses’. It can therefore be argued that ‘a right to palliative care can be implied from the overall international human right to health’.<sup>29</sup>

This relatively recent focus on palliative care has resulted in the global and regional adoption of various policy instruments. The most important of these is the 2014 World Health Assembly Resolution (WHA67) on strengthening palliative care as a component of comprehensive care throughout the life course.<sup>30</sup> The WHA67 Resolution is the first global resolution on palliative care calling on the WHO and member states to ensure that palliative care is a core

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27 WHO ‘Palliative care: Fact sheet’ (2018), <http://www.who.int/mediacentre/factsheets/fs402/en/> (accessed 11 November 2019); Single Convention on Narcotic Drugs 1961 Preamble 1 para 3, [https://www.unodc.org/pdf/convention\\_1961\\_en.pdf](https://www.unodc.org/pdf/convention_1961_en.pdf) (accessed 10 November 2019).

28 As above; see also JE Méndez ‘Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development’ Report of the UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment A/HRC/22/53 1 February 2013 paras 51-56 and recommendations, [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf) (accessed 15 November 2019).

29 F Brennan et al ‘Palliative care as a human right’ in *Report for Open Society Institute Law and Health Initiative on Palliative Care and Human Rights* (2008) 25.

30 WHO 76th World Health Assembly (WHA67) ‘Strengthening of palliative care as a component of comprehensive care throughout the life course’ Resolution 67.19 (2014), [http://www.oeci.eu/Attachments%5CA67\\_R19-en.pdf](http://www.oeci.eu/Attachments%5CA67_R19-en.pdf) (accessed 11 November 2019).

component of health systems, improving both access to and awareness of palliative care. Other important instruments include the United Nations (UN) Political Declaration on Non-Communicable Diseases and Universal Health Coverage, where palliative care is incorporated as part of essential services.<sup>31</sup>

The overall aim of such instruments is to advocate the integration of palliative care into a country's health system and to encourage greater awareness of palliative care by both government and community. In the African region, the African Charter on Human and Peoples' Rights (African Charter) recognises the right of people to access palliative care in article 2 where it states that '[e]very individual shall have the right to enjoy the best attainable state of physical and mental health'. States are also obligated to take the necessary steps to protect the health of their people and to ensure that they receive medical attention when they are sick.<sup>32</sup> In 2012 the African Union (AU) adopted the Common Position on Controlled Substances and Access to Pain Management, the aim of which is to ensure a functioning system for managing controlled drugs and substances.<sup>33</sup> This indicates the intention to ensure delivery of the best affordable drugs to patients in need while, at the same time, preventing the diversion of drugs for the purpose of abuse.<sup>34</sup>

It is through these various frameworks that important advocacy opportunities, aimed at achieving access to palliative care and ensuring adequate pain management, can be advanced. The unavoidable reality is that when health services are inadequate individuals living with severe pain face a future without access to urgently-required pain relief medication. This fact coupled with a government's lack of commitment to address the gaps in a healthcare system negates the intention to deliver the 'best affordable drugs' to those in need, constituting, in terms of the Universal Declaration, 'cruel, inhuman or degrading treatment or punishment'.<sup>35</sup>

When extending the argument to include children the call for palliation carries with it additional concerns. An exacerbating factor for children is that, when talking about the right to health, reference is generally made to adults in the health system. This disturbing oversight results in misunderstanding or conflating children's health issues with those of adults. Paediatricians often point out that 'children are not small adults' and it is important to understand that in

31 UN 'Political declaration on non-communicable diseases' 16 September 2011, [http://www.un.org/ga/search/view\\_doc.asp?symbol=A/66/L.1](http://www.un.org/ga/search/view_doc.asp?symbol=A/66/L.1) (accessed 13 November 2019).

32 Art 16 African Charter on Human and Peoples' Rights, <https://www.achpr.org/legalinstruments/detail?id=49> (accessed 15 November 2019).

33 African Union (AU) 'African common position on controlled substances and access to pain management drugs' 5th session of AU Conference of Ministers of Drug Control (October 2012), [https://www.un.org/en/africa/osaa/pdf/au/cap\\_controlledsubstances\\_2012.pdf](https://www.un.org/en/africa/osaa/pdf/au/cap_controlledsubstances_2012.pdf) (accessed 14 November 2019).

34 AU (n 33) 2.

35 Méndez (n 28) para 39; see also art 5 of the African Charter.



the trajectory of a child's illness, his or her resilience and response to treatment will differ from that of an adult.<sup>36</sup>

## 4 International frameworks protecting the rights of children

### 4.1 Children's rights

Numerous international instruments provide specific rights and protections for every child. Because of their status as children, children are accorded special treatment having access to the same rights as adults and to rights that apply to them specifically.<sup>37</sup> Of the many instruments and laws directed at children the two relevant instruments that refer to the protection, support and rights of children are CRC<sup>38</sup> and the African Charter on the Rights and Welfare of the Child (African Children's Charter). These instruments, founded on earlier declarations on children at an international level, introduced the idea that children are not beneficiaries but subjects of international law and are provided with 'special protections' implemented in the form of the best interests of the child.<sup>39</sup>

### 4.2. Child palliative care as a human right

Of the two instruments discussed, CRC is said to be the most comprehensive document setting out children's rights, yet neither CRC nor the African Children's Charter makes specific reference to the care or protection of children suffering from life-threatening conditions.<sup>40</sup> CRC identifies four broad principles, often termed 'the four 'P's'. These four 'P's' are viewed as fundamental to the overall protection and welfare of children and are cited as participation by children in decisions affecting them; the protection of children against abuse, discrimination and all forms of neglect and exploitation; the

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36 R Harding, L Sherr & L Gwyther 'Pediatric palliative care in sub-Saharan Africa: A systemic review of the evidence for care models, intervention and outcomes' (2014) 47 *Journal of Pain and Symptom Management* 649; see also UNICEF (n 17).

37 D Colgan 'Policy networks in action: A comparative case study of two projects aimed at addressing childhood vulnerability' unpublished PhD thesis, University of Witwatersrand, 2015 123; see also J Sloth-Nielsen 'A developing dialogue: Children's rights, children's law and economics: Surveying experiences from Southern and Eastern African law reform processes' (2008) 12 *Electronic Journal of Comparative Law*, <http://www.ejcl.org/123/art123-5.pdf> (accessed 10 November 2019).

38 It has been said that CRC is the most comprehensive document on the rights of children.

39 For the purposes of CRC, a child is defined as 'every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier' (art 1); see also T Kaime *The African Charter on the Rights and Welfare of the Child: A socio-legal perspective* (2009) 14.

40 Although neither instrument makes specific reference to paediatric palliative care, the UN Committee on the Rights of the Child refers to it in General Comment 15; see UN Committee on the Rights of the Child (n 5).

prevention of harm to children through the systems in place; and the provision of assistance to children for their basic needs enabling a child's growth and development.<sup>41</sup> The principles contained in CRC, therefore, provide the foundation on which the argument for child palliative care as a right is based.

When applying rights in terms of CRC and the African Children's Charter, both highlight the importance of the best interests of the child. In article 3 of CRC the best interests of the child are seen as 'a primary consideration', and in article 4 of the African Children's Charter the best interests of the child are seen as 'the primary consideration'.<sup>42</sup> Article 4 of CRC also requires that state parties undertake all appropriate legislative, administrative and other measures to implement the rights recognised in the Convention. These positive obligations contained in article 4 of CRC are not similarly reflected in article 4 of the African Children's Charter as general obligations of states are found in article 1 of the Charter. In terms of article 1 other human rights instruments are seen to complement the protections offered by the African Children's Charter.<sup>43</sup>

Nonetheless, the protection offered by both instruments provides the means to support an argument that state parties have a duty to ensure the survival and development of every child. This is supported by the child's inherent right to life (article 6 of CRC and article 5 of the African Children's Charter) and the child's right to enjoy the highest (article 23 of CRC) or 'best' attainable standard of health (article 14 of the African Children's Charter). Taken further, this means that even though palliative care is not highlighted as a specific right in CRC, it is fundamental to the well-being of a child that is living with a life-threatening condition. Thus, state parties have a responsibility to ensure that no child living with such an illness or condition is deprived of his or her right to access the necessary healthcare services and, as such, a child should not be subjected to further suffering. This call for access to palliative care was recognised by the UN Committee on the Rights of the Child (CRC Committee) which welcomed the commitment of Belarus to palliative care for children and the country's adoption of an Order on Child Palliative Care.<sup>44</sup>

The UN Special Rapporteur on the Right to the Highest Attainable Standard of Health similarly raises the argument that there is an

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41 J Korbin & D Krugman *Handbook of child maltreatment: Volume 2 of child maltreatment* (2013) 543.

42 UN Committee on the Rights of the Child (n 5) paras 12-15; see also M Gose *The African Charter on the Rights and Welfare of the Child* (2002) 26.

43 Gose (n 42) 29-31.

44 The Committee recommended that state parties establish a funding mechanism to provide palliative care for children and support palliative care services provided by NGOs; see Committee on the Rights of the Child '56th session Consideration of Reports Submitted by States Parties Under Article 44 of the Convention Belarus' (2011), [www2.ohchr.org/english/bodies/crc/docs/co/CRC.C.BLR.CO.3-4.doc](http://www2.ohchr.org/english/bodies/crc/docs/co/CRC.C.BLR.CO.3-4.doc) (accessed 15 November 2019).

important relationship between the right to health and a young child's right to survival and development.<sup>45</sup> In reports by Special Rapporteurs on health and torture, specific comments were made about the importance of palliative care as a child's right, pointing out that it should be 'an obligatory part of healthcare services' and regarded as one of the interventions made available across the continuum of care.<sup>46</sup> It was also stated in General Comment 15 of 2013 that state parties have an obligation to ensure the survival, growth and development of the child and to systematically identify the risks and protective factors that underlie the child's life, survival, growth and development so that evidence-based interventions may be designed and implemented to address a wide range of determinants during the child's lifetime.<sup>47</sup>

This recognition of the right to PPC is an important step towards acknowledging specific vulnerabilities and the needs of a child living with a serious illness. However, the reality is that such recognition does not automatically translate into addressing the child's needs and the real proof of commitment lies in the adequate allocation of resources and the provision of relief from pain and suffering. This allocation of resources is a multi-level consideration that calls on all stakeholders to work together for a common aim. In this context of collaboration states need to consider a variety of issues ranging from removing barriers and improving access to controlled medication, providing adequate services with skilled staff and facilities, developing an increased understanding and knowledge of palliative care and consistently monitoring and evaluating existing needs and available resources.<sup>48</sup>

## 5 Right to paediatric palliative care for children in Africa

### 5.1 Sub-Saharan Africa

State parties have an obligation to protect and care for children and to ensure the adequate provision of palliative care for a child living with a life-threatening condition. The question that arises in the case

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45 Dainius Puras (OHCHR) Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Statement made at the 70th session of the General Assembly 22 October 2015.

46 ICPCN 'UN report highlights palliative care for children as a right' 25 September 2015, <http://www.icpcn.org/un-report-highlights-palliative-care-for-children-as-a-right/> (accessed 15 November 2019); Open Society 'Public health fact sheet: Children's palliative care and human rights' (2018), <https://www.opensocietyfoundations.org/uploads/2d02a07d-c1a0-4474-8c63-17ec62b00056/child-rens-palliative-care-human-rights-20151008.pdf> (accessed 17 November 2019).

47 Committee on the Rights of the Child (n 5) paras 16 & 32.

48 AF Brooke et al 'Palliative care development in Africa: Lessons from Uganda and Kenya' (2018) 4 *Journal of Global Oncology* 1; see also ICPCN report (n 1) and UNICEF (n 17).

of countries in the sub-Saharan region is whether measures have been put in place to protect children's rights in a feasible and effective manner.

In many sub-Saharan countries the need to access palliative care remains acute, but for children living with a life-threatening condition the options are limited.<sup>49</sup> In these circumstances Amery states that 'palliation and symptom relief are the only realistic option for most African children with advanced cancers and AIDS'.<sup>50</sup> Despite global and regional commitments to improve children's access to palliative care and pain relief, states are confronted with competing priorities which are further exacerbated by a lack of adequate resources and specialised skills. These issues bring about implementation failures with governments not following through on intended policy plans or programmes, often needing to rely on other sectors in society to fill existing gaps.<sup>51</sup>

The CRC Committee drew attention to the fact that many state parties often leave the provision of palliative care services to non-governmental organisations (NGOs) that struggle to survive without adequate funding or support from their respective government institutions.<sup>52</sup> In South Africa, Kenya and Uganda NGOs provide the majority of palliative care services while the governments offer minimal or piecemeal assistance.<sup>53</sup> Countries such as South Africa and Uganda have expressed an intention to address these limitations in the future.<sup>54</sup> In 2017 the Human Rights Commission (HRC) in Uganda called for the input of both government (the Ministry of Health) and civil society (palliative care organisations) in compiling its twentieth annual report for the Ugandan Parliament, as mandated by the Constitution, ensuring that the voices of all responsible stakeholders were represented in their report.<sup>55</sup>

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49 The availability of paediatric palliative care indicates that only an estimated 20% of children in these countries will be cured of cancer, compared with 80% of children in high-income countries; see Caruso Brown et al (n 12) 1369.

50 J Amery (ed) *Children's palliative care in Africa* (2009) 26.

51 There are several competing challenges placing a strain on the capacity of health care professions in sub-Saharan Africa, such as the additional burden of treating HIV/AIDS; see Amery (n 50).

52 UN Committee on the Rights of the Child (Belarus) (n 44) para 56; see also UN Committee on the Rights of the Child (n 5) paras 100 & 101.

53 L Gwyther et al 'The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa' (2018) 108 *South African Medical Journal* 86-89; UN Committee on the Rights of the Child (n 5).

54 The South African government finalised a national policy on palliative care which was approved in April 2017 by the National Health Council, a body that includes representation from government and civil society, <https://hpca.co.za/download/national-policy-framework-and-strategy-on-palliative-care-2017-2022/> (accessed 16 November 2019).

55 Uganda Human Rights Commission 'Progress, challenges and recommendations on palliative care in Uganda' Invitation to 20th UHRC annual report consultation meeting 5 December 2017 (signed 14 November 2017).

Such implementation challenges that are faced by advocates for palliative care, call on countries to ensure state involvement in the form of practical, innovative and effective responses. This means not only addressing the problem through improved resource allocation and the removal of barriers to increase access, but also understanding the extent of the problem through, for example, evidence-based or evidence-informed interventions. Unfortunately, the necessary state buy-in is not apparent. It is of concern that limited attention was given to PPC during the 28th through to the 33rd ordinary sessions of the African Committee of Experts on the Rights and Welfare of the Child (African Children's Committee) despite the huge burden of chronic non-communicable diseases and HIV among children on the continent, and following the adoption in 2014 of the first ever global resolution on palliative care, WHA67.19.<sup>56</sup>

## 6 Barriers

### 6.1 Socio-economic, regulatory and knowledge barriers

In sub-Saharan Africa the barriers confronting both states and individuals in accessing and utilising palliative care resources are nuanced and complex. These barriers range from social, economic, structural, political and legal in nature. In the social context, families themselves may be conflicted about different treatment options, unsure of the choice between hospital-based treatment or home-based palliative care. Individuals and minority groups may face barriers such as discrimination and disempowerment from institutions or other community members. At an economic level, individuals may struggle to access healthcare facilities because of high transport costs and, in certain areas, the cost of healthcare services. At a structural level, institutions may not have adequate skills or knowledge or may lack institutional standards for the provision of children's palliative care.<sup>57</sup> From a legal or regulatory perspective, many drug control laws and practices in place, to protect against substance abuse, have resulted in limited availability and accessibility of opioid analgesics for children. This final barrier, the lack of availability of controlled medicines, represents a major global health problem and is viewed by

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56 It is important to note here that the specific need to advance children's palliative care in Africa is a relatively new development in the region. The last sessions of the African Children's Committee were an opportunity to evaluate progress in terms of the 2014 WHA67 Resolution, particularly regarding the implementation of recommendations, the challenges met and advances made. Unfortunately, there was no reference to palliative care, <https://www.acerwc.africa/sessions/> (accessed 16 November 2019).

57 United Nations Office on Drugs and Crime (UNODC) 'Ensuring availability of controlled medications for relief of pain and preventing diversion and abuse: Striking the right balance to achieve optimal public health outcome' (2011) Discussion Paper 8-10, [https://www.unodc.org/docs/treatment/Pain/Ensuring\\_availability\\_of\\_controlled\\_medications\\_FINAL\\_15\\_March\\_CND\\_version.pdf](https://www.unodc.org/docs/treatment/Pain/Ensuring_availability_of_controlled_medications_FINAL_15_March_CND_version.pdf) (accessed 15 November 2019).

the authors as an area where fundamental change can have widespread benefits.<sup>58</sup>

In Africa the lack of access to pain relief medication is exacerbated by the exodus of medical doctors from rural areas – more than 80 per cent of doctors on the continent locate themselves in major towns. This means that many rural children are unable to access pain medication. Countries where the laws strictly limit access to controlled substances can cause unnecessary pain and suffering for young children with serious illnesses. With few doctors and overly-restrictive laws, it is increasingly challenging to supply pain medication to patients in distant, inaccessible rural areas. African countries have one of the lowest doctor to patient ratios in the world with many doctors remaining far removed from rural communities.<sup>59</sup>

An additional concern for children located in sub-Saharan Africa is the socio-economic status of their family or caregivers. In communities already battling issues relating to poverty and inequality, the ability to access specialised health facilities for children in need is even more of a challenge. A weak healthcare system with limited resources negatively impacts on these vulnerable members of a community. Where the health infrastructure and supply of medicine are inadequate the resulting shortages of resources, both human and medical, lead to the unnecessary suffering of children requiring specialised care. In this environment affected children are cared for in their own homes or within the community.<sup>60</sup> In addition to the financial and emotional burden this situation places on the extended family and community, caregivers also require further support through improved access to relevant information. To be able to provide informed and sensitive care and assist in the reduction of a child's suffering calls for specialised education and specific skills which include an understanding the developmental needs of a child.<sup>61</sup>

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58 UNODC (n 57) 4; see also Connor & Sisimayi (n 1) 49.

59 WHO reported that over 44% of WHO member states have fewer than one physician per 1 000 of the population and that the African region has access to only 3% of health workers, yet more than 24% of the global burden of disease. WHO *Density of physicians*, [https://www.who.int/gho/health\\_workforce/physicians\\_density/en/](https://www.who.int/gho/health_workforce/physicians_density/en/) (accessed 17 November 2019). See also World Bank Data, [https://data.worldbank.org/indicator/SH.MED.PHYS.ZS?name\\_desc=true](https://data.worldbank.org/indicator/SH.MED.PHYS.ZS?name_desc=true) (accessed 15 November 2019).

60 Children depend on adults to represent their interests. Thus, children may be said to be doubly vulnerable, as discussed by D Ewing 'Children's experiences of the link between poverty and unemployment in the context of HIV/AIDS' in P Graham (ed) *Inheriting poverty? An economic research agenda for realising the rights of children* (2006) 89.

61 The approach adopted in PPC is holistic in nature encompassing the child's spiritual, emotional, physical and educational development, accounting for the impact of stress and the child's need to play; Naicker et al (n 14). In such an environment care should come to the patient at home via a care team led by a palliative care nurse; when needed a wider team will be referred to which includes doctors, social workers and spiritual counsellors.

Barriers related to accessing care for life-threatening conditions affect children at multiple levels. This may be illustrated through the example of paediatric care for children diagnosed with cancer in Uganda. There is only one specialised paediatric oncology ward, located at the Uganda Cancer Institute in Kampala, where all children diagnosed with cancer are referred to for treatment. Cancer treatment consumes both resources and time, taking approximately two weeks to prepare for treatment and averaging three weeks for the treatment cycle. This process, coupled with the cost of clinical investigations, medicine, food, accommodation and transport to and from the hospital, drains the resources of most families, resulting in their defaulting on treatment. This negatively impacts on the survival of affected children, even in the case of curable childhood cancers.<sup>62</sup>

The aim is to neither intentionally inflict suffering or harm on a child with a serious illness, nor to deprive the child of the right to access existing resources (human, material, technological or scientific) to alleviate such suffering. Therefore, it is essential to identify these key barriers which, once removed, would aid those in need of access to palliative care resources.

## 6.2 Legal barriers

### 6.2.1 Effect and impact

One notable barrier standing in the way of effective pain treatment is the introduction of unnecessarily restrictive drug control mechanisms through legislation. For many countries in Africa access to pain relief is strictly regulated in order to prevent the misuse of controlled substances, such as morphine and other opioids. Unfortunately, such stringent control measures interfere with a person's ability to access the necessary treatment. In these countries laws and policies appear to focus more on the prevention of drug abuse than on pain relief.<sup>63</sup>

In South Africa, Kenya and Uganda a distinction is made between two forms of legislation, one aimed at the licit medicines market and the other at the illicit drug market.<sup>64</sup> Legislation aimed at the licit medicine market determines the 'who and what' of prescribing, whereas that for the illicit drug market focuses on preventing the abuse of certain controlled substances. In Kenya the Pharmacy and Poisons Act,<sup>65</sup> and in South Africa the Medicines and Related

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62 Kawempe Home Care in Uganda, through New Hope children's hostel, caters for 30 children and their caregivers, waiting to access cancer treatment at UCI-Kampala. Children and caregivers spend between two to six months at Kawempe Home Care; <http://kawempehomecare.org/children/> (accessed 10 November 2019).

63 DG McNeil 'Drugs banned, many of the world's poor suffer in pain' *New York Times* 10 September 2007, <http://www.nytimes.com/2007/09/10/health/10pain.html> (accessed 15 November 2019).

64 Personal communication Andy Gray, University of KwaZulu-Natal, March 2018.

65 Ch 244 of the Laws of Kenya (updated 2012).

Substances Act,<sup>66</sup> set the basis for the control of medicines for licit use. Other legislation that impacts on the control of the licit market relates to the registration of health care practitioners such as medical practitioners, dentists, nurses and pharmacists.<sup>67</sup> In Kenya legislation that refers to the illicit use of controlled drugs and substances is the Narcotic Drugs and Psychotropic Substances Control Act of 1994. In South Africa the Drugs and Drug Trafficking Act of 1992 together with the Prevention and Treatment for Substance Abuse Act of 2008 covers the illicit drug market.

Currently in Uganda the vacillation between strictly regulating or allowing greater access to certain controlled substances is being played out through legislative reform. The introduction of the Narcotic Drugs and Psychotropic Substances (Control) Act in 2015 is a retrogressive step after the progressive application of the National Drug Authority (Prescription and Supply of Certain Narcotic Analgesic Drugs) Regulations 24 introduced in 2004 (Regulation 24). This shift in law indicates the ongoing uncertainty that exists in the application of both types of legislation. It is an uncertainty that constantly plagues advocacy efforts towards improving access to palliative care and pain relief. According to WHO the manner in which legislation is weighted, for both licit and illicit medicine control, should not be a mutually-exclusive exercise. The WHO believes that the most effective 'drug control regime' would be the one that is able to strike a balance between the primary considerations raised in both by allowing pain relief to relieve suffering while ensuring that these medicines are not diverted to the illicit drug market.<sup>68</sup>

### 6.2.2 *Legal control over nurse prescribing*

In African countries such as Kenya and South Africa the laws and practices that control the prescription of pain relief medication ensure that, through application of law, only trained medical practitioners or dentists can prescribe specific forms of medication.<sup>69</sup> In South Africa the South African Nursing Act 2005 allows nurses to prescribe and administer, in certain circumstances, schedule 0-4 drugs. The regulations do not allow nurses to prescribe stronger medication, such as morphine and other opioids (schedule 5-6), which are necessary for the pain relief of people with life-threatening conditions. In Kenya the Narcotic Drugs and Psychotropic Substances (Control) Act) 1994 sets

66 Medicines and Related Substances Act 101 of 1965.

67 In South Africa, the Health Professions Act 56 of 1976; the Nursing Act 35 of 2005; and the Pharmacy Act 53 of 1974.

68 WHO 'Ensuring balance in national policies on controlled substances: Guidance for availability and accessibility of controlled medicines' (2011) 1, [http://apps.who.int/iris/bitstream/10665/44519/1/9789241564175\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/44519/1/9789241564175_eng.pdf) (accessed 11 November 2019).

69 D Line (ed) 'The 2015 quality of death index: Ranking palliative care across the world' (2015) *The Economist* 42, <https://www.eiuperspectives.economist.com/healthcare/2015-quality-death-index> (accessed 14 March 2018); see also Brooke et al (n 48) 1-10.



out a framework for the control of specific drugs. In terms of this Act only certain registered healthcare practitioners are authorised to prescribe, administer or supply narcotic drugs or psychotropic substances. This means that a trained palliative care nurse or clinical officer cannot legally prescribe morphine.<sup>70</sup>

For most high and some middle-income countries, universal health coverage<sup>71</sup> is close to being achieved. Other countries, including low-income countries such as Rwanda and Ethiopia, are making rapid progress towards this goal. In every case, the countries achieving universal health coverage increased the supply and quality of health services through reducing barriers preventing people from accessing necessary health care.<sup>72</sup> Rwanda's legislation governing narcotic drugs and psychotropic substances, in terms of article 17(4), allows a qualified (registered) midwife or nurse to prescribe narcotics such as morphine.<sup>73</sup>

In the last decade Ugandan legislation has changed with respect to nurses prescribing narcotic and psychotropic drugs. In 2004 Regulation 24<sup>74</sup> authorised clinical officers and nurses, as palliative care specialists, to prescribe narcotic analgesic drugs. This was reversed in 2015 when the Narcotic Drugs and Psychotropic Substances (Control) Act was passed which once again limited nurses' prescribing of certain controlled substances.<sup>75</sup>

To counter the impact of such a retrogressive law the Ugandan government made a commitment to collaborate with CSOs in working towards improved access of pain relief medication and to remove legislative barriers for those needing palliative care. This resonates with the recommendations of the 2016 United Nations General Assembly Special Session (UNGASS) outcomes on the World Drug Problem which called for greater collaboration between different

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70 Sec 3 Narcotic Drugs and Psychotropic Substances (Control) Act 4 of 1994.

71 According to WHO, UHC means that all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship; [http://www.who.int/health\\_financing/universal\\_coverage\\_definition/en/](http://www.who.int/health_financing/universal_coverage_definition/en/) (accessed 15 November 2019).

72 The Elders 'Universal health coverage: Position paper' May 2016, <http://theelders.org/sites/default/files/final-uhc-position-paper-for-web.pdf> (accessed 15 November 2019).

73 Law N 03/2012 of 15 February 2012 governing narcotics, drugs, psychotropic substances and precursors in Rwanda; <https://www.mindbank.info/item/2415> (accessed 16 November 2019).

74 The National Drug Authority (Prescription and Supply of Certain Narcotic Analgesic Drugs) Regulations 24 of 2004.

75 The Narcotic Drugs and Psychotropic Substances (Control) Act 2015, <https://www.parliament.go.ug/documents/1264/acts-2015> (accessed 16 November 2019).

sectors in government (health, education, justice and law enforcement) and CSOs.<sup>76</sup>

Other countries, such as Kenya and South Africa, continue to debate the possibility of broadening nurse prescribing regulations to address access issues. The time is ripe for policy makers to reconsider existing restrictive regulatory practices and to take definitive steps in addressing the multiple anomalies introduced through legislation. Any legislative change must account for the concerns voiced by multiple sectors, ranging from health professionals, patients and law enforcers to policy makers. This calls for effective dialogue between all stakeholders where misconceptions and assumptions are broken down and understanding takes place.

### 6.3 The call to address children's suffering

#### 6.3.1 *Obligations and commitments*

The oversights experienced with respect to promoting and ensuring access to children's palliative care can also be noted within frameworks developed that aim at guiding governments in the formulation of national child protection policies and child rights programmes. The instruments developed are generally inadequate, with limited provision for palliative care services and little opportunity for the implementation of evidence-based research and the monitoring of outcomes. The Uganda Children (Amendment) Act 2016 identifies the need to prepare and maintain a national data base on children, yet does not specifically identify or address the needs of seriously-ill children.<sup>77</sup> The Act acknowledges rights set out in CRC and the African Children's Charter. Section 4(1)(l) states that every child shall have the rights contained in these instruments 'with appropriate modifications to suit circumstances of Uganda that are not specifically mentioned in this Act'.<sup>78</sup> This provides the opportunity to argue in favour of recognising PPC as a human right in Uganda, particularly in light of the burden of life-threatening conditions confronting children in the country.

In the Kenya Children Act the right of every child to health and medical care is recognised, stating that responsibility for providing such care rests with parents and the government.<sup>79</sup> The Act also mentions the need to 'design programmes for the alleviation of the

76 United Nations Office on Drugs and Crime (UNODC) Outcome Document of the 2016 United Nations General Assembly Special Session on the World Drug Problem, New York, 19-21 April 2016.

77 The Uganda Child Act 2003, subsequently amended by the Uganda Children (Amendment) Act 2016, <https://ulii.org/ug/legislation/act/2016/59> (accessed 16 November 2019).

78 Sec 4(1)(l) Uganda Children (Amendment) Act 2016.

79 Sec 9 Children Act [Kenya] 8 of 2001, <https://www.refworld.org/docid/47975f332.html> (accessed 16 November 2019).

plight of children with special needs or requiring special attention'.<sup>80</sup> In South Africa the Children's Act adopts a holistic view of children living with disabilities or chronic illnesses. It calls for the recognition of a child's right to develop and survive in society, accounting for the child's emotional, psychological, spiritual and physical needs.<sup>81</sup> No direct reference is made to palliative care or pain relief, although the Act does generally mention providing special care 'as and when appropriate' and the need to provide 'necessary support services'.<sup>82</sup> In most of the frameworks developed there is little indication of specific programmes or activities aimed at advancing palliative care for seriously-ill children and limited indication of a commitment to utilise evidence-based research in order to establish data on existing demands and services in this area of need.

### 6.3.2 *Drawing attention to hidden suffering: The unheard voices*

It is unfortunate that many child protection policies and programmes address the public side of a child's vulnerability, focusing on specific issues or specific groups of vulnerable children.<sup>83</sup> This approach, sometimes referred to as the vertical approach, includes violence against children, the protection of displaced children, migrant children, child justice, child trafficking, sexual exploitation, teenage pregnancy, child labour, immunisation and nutrition, all of which are important and notably visible.<sup>84</sup> The hidden side of child suffering often is neglected or goes unnoticed. The call for a more systematic and evidence-based approach to interventions may best address these hidden vulnerabilities of children whose needs are often overlooked because of limited visibility.

This 'hidden suffering' underlies many implementation failures despite the broad policy frameworks, programmes and plans developed at national and international levels. Suggested intervention plans and strategies – such as the recommendations by the WHO – call for improved monitoring and evaluation of needs and services in relation to palliative care and allocation of resources, including improved access to medication.<sup>85</sup> In terms of Resolution WHA67.19, passed at the 67th session of the World Health Assembly in Geneva, Switzerland, member states are urged to 'assess domestic palliative care needs, including pain management medication requirements, and promote collaborative action to ensure adequate supply of essential medicines in palliative care, avoiding shortages'.<sup>86</sup> The

80 Sec 32(2)(o) Children Act (n 79).

81 Sec 11 Children's Act 38 of 2005.

82 Secs 11(2)(b) & (c) Children's Act.

83 JD Fluke & F Wulczyn 'A concept note on child protection systems monitoring and evaluation' (2010) UNICEF Working Paper 2-3.

84 As above.

85 WHA67.19 (n 30).

86 As above; Resolutions and Decisions 1(5).

current lack of research and limited data collection<sup>87</sup> relating to palliative care, specifically PPC, indicate that various government institutions and commissions or child care programmes are failing to adequately implement the required monitoring or evaluation programmes called for in terms of WHA67.<sup>88</sup>

An important part of the approach, recommended by WHO and in terms of WHA67, calls for partnership development and increased collaboration between international agencies and with stakeholders involved in advocating children's palliative care.<sup>89</sup> This means that policy or programme implementation lies not only with the relevant government department or ministry, but also requires the involvement of specialised national and international bodies that have the protection and promotion of children's rights as a core mandate, of which UNICEF is one example.<sup>90</sup> These international and national CSOs have a duty to respond to a country's palliative care needs, working in collaboration with the state while also holding the state to account. To this end, UNICEF is mandated to advocate the protection of the rights of all children, developing and supporting opportunities that ensure the growth and survival of children. Through advocacy efforts of such organisations attention can, and must, be drawn to the suffering of children in sub-Saharan Africa.

At regional and country levels, institutions such as human rights commissions and organisations similar to the African Children's Committee need to also play a role in bringing such issues to the fore. Offices such as the National Child Council (NCC) in Uganda and the Human Rights Commission in both South Africa and Kenya should partner with government and civil society in determining palliative care needs and in monitoring the implementation of policies introduced by governments in terms of the international policy framework.<sup>91</sup>

The WHO further recommends that state parties introduce a public health strategy that will assist governments in integrating palliative care into a country's healthcare system. The strategy that is developed needs to address a broad variety of issues including (i) the development of appropriate policies; (ii) the availability of effective medicine; (iii) building awareness and educating stakeholders such as policy makers, health care workers and individuals in communities,

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87 Caruso Brown et al (n 12).

88 WHA67.19 (n 30); Resolutions and Decisions 1(1) & (5) and 2(2) (3), (7),(9) & (10). Kofi Annan points out, when commenting on malnutrition in Africa, that '[t]his shows how crucial it is to invest in data. Data gaps undermine our ability to target resources, develop policies and track accountability. Without good data, we're flying blind. If you can't see it, you can't solve it'; <https://www.nature.com/articles/d41586-018-02386-3> (accessed 17 November 2019).

89 WHA67.19 (n 30); Resolutions and Decisions 2(8).

90 As above; see also UNICEF [https://www.unicef.org/publicpartnerships/files/UNICEF\\_Mission\(1\).pdf](https://www.unicef.org/publicpartnerships/files/UNICEF_Mission(1).pdf) (accessed 16 November 2019).

91 R Pfund & S Fowler-Kerry *Perspective on palliative care for children and young people: A global discourse* (2010) 19-20.

about palliative care; and (iv) implementing palliative care at primary, secondary and tertiary care levels.<sup>92</sup>

## 7 Conclusion

'At the moment pain is only a problem for those who suffer, for everyone else it is someone else's problem' (Dr Rajagopal).<sup>93</sup>

No child living with a life-threatening condition should be deprived of his or her right to access healthcare services. Yet, of the 21 million children needing palliative care worldwide, only 210 000 in sub-Saharan Africa access care. The challenges are wide-ranging with legislative and social barriers, inadequacies in healthcare services and a lack of evaluative evidence. With limited evidence of palliative care needs, resources and the provision of care services, many sub-Saharan countries will struggle to appropriately determine the extent of the problem and to address the challenges. A primary purpose of this article is to show that, with the appropriate buy-in by government, civil society and business, palliative care can successfully be implemented even in an environment where resources are limited. The answer lies in implementing a broad multidisciplinary approach and making innovative, effective use of available community resources within an evaluative framework.

Addressing the palliative care needs of children in sub-Saharan Africa lies beyond the capacity of a single institution or organisation. In environments of complexity a collaborative, multi-layered approach is called for. The strategy is to involve a diverse range of stakeholders – from health professionals and patients to law enforcers and policy makers – using dialogue to break down misconceptions and develop a greater understanding in order to work toward a common goal.

Strong advocacy through stakeholder networks and partnerships can act as the voice for those unable to speak for themselves, utilising a variety of methodologies – from lobbying to litigating – to mobilise for change. Through advocacy states are reminded of their obligations and challenged to re-evaluate existing policies and restrictive laws. Advocacy efforts call on decision makers to recognise and hear the

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92 WHO 'Strengthening of palliative care as a component of integrated treatment within the continuum of care' in 134th session of the World Health Assembly (2014) para 19, [http://apps.who.int/gb/ebwha/pdf\\_files/WHA67/A67\\_31-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_31-en.pdf) (accessed 17 November 2019). Primary level care refers to care closest to where the person lives such as care by clinics, community health centres and home care teams that bring palliative care to patients at home. Secondary, tertiary and quaternary level care is progressively more technical care for complex health problems. Treatment and care are provided at district hospitals, regional or secondary hospitals and at tertiary hospitals and often include research and teaching.

93 'Why are so many people denied the painkillers they need?' *BBC News* 21 May 2018, <http://www.bbc.com/news/world-asia-india-44152429> (accessed 17 November 2019).

voice of the voiceless, to take account of the suffering and to respond appropriately. Failing to do so is a fundamental denial of a child's right to survival and development and, in the case of a child living with pain, may sentence the child to further unnecessary suffering. The fact that the voices of children are not heard does not mean that their suffering is not significant.