KEHPCA
Kenya Hospices and Palliative Care Association
partnering
educating
advocating
palliative care
for all

CHILDREN'S PALLIATIVE CARE (CPC) POLICY GAP ANALYSIS IN KENYA

REPORT

2025

www.kehpca.org

KEHPCA & the WAna WAtunzwe Program

Kenya Hospices and Palliative Care Association (KEHPCA), established in 2005, serves as the national umbrella organization for hospices and palliative care providers across Kenya. The organization collaborates with stakeholders to advocate, strengthen and expand palliative care services nationwide.

> *Vision*: Quality Palliative Care for all in Kenya.
>
> *Mission*: to promote and support acceptable, accessible and affordable quality Palliative Care for individuals and families by creating networks of informed and empowered institutions in Kenya.
>
> *Goal*: To enhance provision of Palliative care and improve the quality of life of persons affected with life-threatening illnesses and their families.

One of its flagship initiatives, **WAna WAtunzwe** (Swahili for "Let the Children Be Cared For"), focuses on enhancing access to quality palliative care for children families facing life-threatening conditions. The program is **structured** around three key pillars:

1. **Healthcare Workforce Capacity Building**
   Training and equipping healthcare professionals to deliver specialized paediatric palliative care.
2. **Behaviour Change Communication Interventions**
   Engaging communities to raise awareness, reduce stigma, and promote understanding of children's palliative care needs.
3. **Policy Gap Analysis**
   Reviewing and identifying shortcomings in existing policies to advocate for improved frameworks that support access to paediatric palliative care.

This report was developed as part of the third pillar of the WAna WAtunzwe program—policy gap analysis—to inform strategic interventions. **KEHPCA recommends its utilization to guide the development of policies and guidelines concerning Children's Palliative Care**, ensuring that children with life-threatening conditions receive compassionate, comprehensive, and equitable care.

ACKNOWLEDGMENTS

KEHPCA would like to extend sincere appreciation to all individuals and organizations who contributed to the development of this report.

We are grateful to Foundation S and St. Jude Children's Research Hospital, Inc. for their financial support through project WAWA (Wana WAtunzwe) which made it possible for the development of this report.

Finally, we wish to thank all stakeholders who provided insights and feedback during the development of this report. Your contributions have been truly valuable.

No.		Organization	Designation
1.	Dr. Esther Muinga	Ministry of Health	Division of Healthy Aging, Palliative Care and Older Persons
2.	Mr. Joseph Ngutiku	Ministry of Health	Division of Neonatal and Child Health
3.	Dr. Gladwell Gathecha	Ministry of Health	Acting Head of the Division of Cancer and NCDs
4.	Ms. Peris Njibu	Council of Governors	Primary Healthcare and Partnerships Officer
5.	Dr. Godfrey Okomo	Homabay County Government	County Director of Health
6.	Dr. Jonathan Nthusi	Machakos County Government	Director of Medical Services
7.	David Musyoki	Kenya Hospices and Palliative Care Association	Executive Director
8.	Dr. Esther Nafula	Kenyatta National Hospital	Head of the Pain and Palliative Care Unit
9.	Pauline Everitt Catherine Nelson	Hospice Care Kenya	Director Project Development and Fundraising
10.	Prof. Jessie Githanga	Kenya Childhood Cancer Trust (KeCCT)	Board Member and University of Nairobi Associate Professor
11.	Dr. Supa Tunje	Kenya Paediatric Association	National Chair
12.	Dr. Zipporah Ali	Independent Palliative Care Consultant	Consultant
13.	Sidney Chahonyo	Hope for Cancer Kids	Executive Director

TABLE OF CONTENTS

ACRONYMS

1. **AIDS** – Acquired Immunodeficiency Syndrome
2. **CBO** – Community-Based Organizations
3. **CHW** – Community Health Worker
4. **CIDP** – County Integrated Development Plans
5. **CPC** – Child Palliative Care
6. **CSO** – Civil Society Organizations
7. **FBO** – Faith-Based Organizations
8. **HBC** – Home-Based Care
9. **HIV** – Human Immunodeficiency Virus
10. **HMIS** – Health Management Information System
11. **ICS** – Integrated Care Systems
12. **KEMSA** – Kenya Medical Supplies Authority
13. **KHIS** – Kenya Health Information System
14. **KII** – Key Informant Interviews
15. **KMTC** – Kenya Medical Training College
16. **LMIC** – Low- and Middle-Income Countries
17. **MDT** – Multidisciplinary Teams
18. **MOH** – Ministry of Health
19. **MTRH** – Moi Teaching and Referral Hospital
20. **NGO** – Non-Governmental Organizations
21. **NICE** – National Institute for Health and Care Excellence
22. **NHIF** – National Hospital Insurance Fund
23. **OVC** – Orphans and Vulnerable Children
24. **PCN** – Primary Healthcare Networks
25. **SDG** – Sustainable Development Goal
26. **SHIF** – Social Health Insurance Fund
27. **UHC** – Universal Health Coverage
28. **UNMHCP** – Uganda National Minimum Health Care Package
29. **WHPCA** – Worldwide Hospice Palliative Care Alliance
30. **WHO** – World Health Organization

EXECUTIVE SUMMARY

Introduction

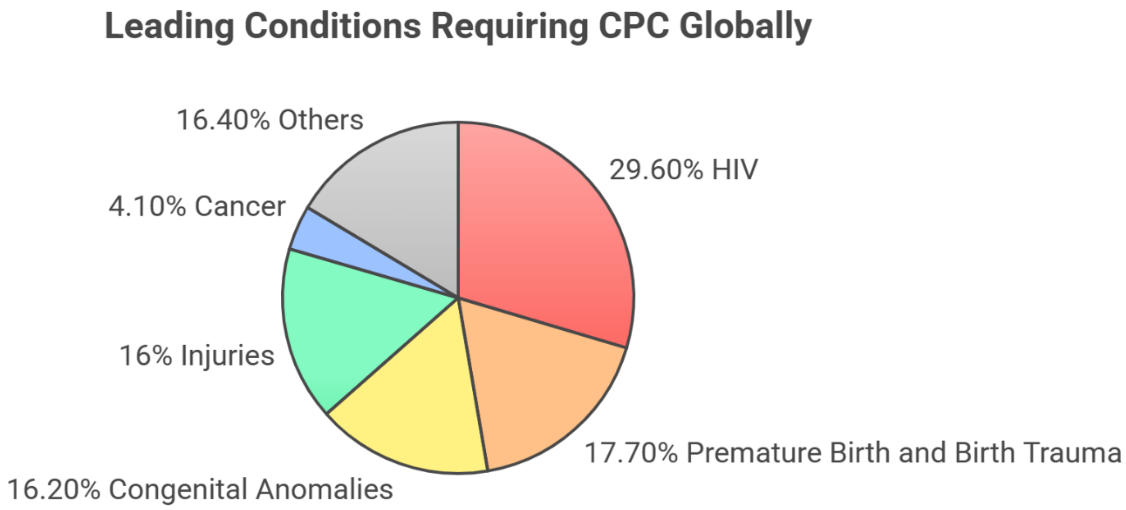
According to the World Health Organization (WHO), palliative care is an approach to healthcare aimed at improving the quality of life of patients and their families when they are facing life-threatening or life-limiting illness. This approach entails prevention and relief from suffering through early detection, comprehensive assessment and treatment of pain and other problems (physical, psychosocial and spiritual). This definition also encompasses support for both the child with child palliative (CPC) care needs and their families. According to the Kenya Palliative Care Policy 2021 - 2030[1] conditions that require CPC are categorized into:

- Potential for cure - life is threatened but not limited; and treatment success is not guaranteed.
- Period of normality despite having a fatal diagnosis
- Relentless deterioration from the time of diagnosis or before - conditions that have no cure.
- An irreversible but unpredictable disease progression

Over 360 conditions fall into within these groups, however according to the Worldwide Hospice Palliative Care Alliance (WHPCA), the leading conditions globally include human immunodeficiency virus (HIV) (29.6%), premature birth and birth trauma (17.7%), congenital anomalies (16.2%), injuries (16%), and cancer (4.1%). One of the unique aspects about CPC is that it needs to adapt as the children transition through the different stages of growth depending on the stage at which the CPC need is identified.

---

[1] **Ministry of Health, Government of Kenya**, *Kenya Palliative Care Policy 2021-2030*.



The WHPCA in the second edition of the global atlas of palliative care documented that globally approximately 4 million children are in need of palliative care. CPC has been shown to improve the quality of life of the children and their families despite the life-threatening or life-limiting conditions they have been diagnosed with. In tandem with this, CPC should be integrated into the full spectrum of Universal Health Coverage (UHC) for the fulfilment of the United Nations Sustainable Development Goal 3: health and well-being for all.

The World Health Organisation defined four pillars for the framework for palliative care; these include policy which is foundational for service delivery; education in palliative for the health service providers at the different levels of care; availability of essential medicines and medical commodities; and implementation based on the availability of the supporting resources.

Conversely, the African Palliative Care Association outlined bottlenecks that create barriers to access to CPC which cut across political-economic, socio-cultural, health system constraints.

Policy and Legal analysis on Children's Palliative Care in Kenya

Policies and laws regarding children's palliative care in Kenya aim to meet the comprehensive needs of children with life-threatening and life-limiting conditions. These policies and laws focus on alleviating pain and symptoms, providing psychological support, and, crucially, enhancing the quality of life for both the child and their family. In Kenya, the framework for children's palliative care is supported by a range of policies and legal frameworks, all designed to improve the accessibility, quality, and sustainability of these services.

The report has highlighted the different policies, laws, national strategies and policies in different thematic areas that are important to ensuring access to children’s palliative care. The thematic areas have been categorized into **access to quality palliative care**, **integration and coordination of palliative care**, **education and training** and lastly policies and laws relating to palliative care regarding **funding and resources**.

From the policy and legal analysis, there exists a general framework supporting children's rights particular to health in Kenya. However, while Kenya has made significant strides in integrating palliative care into its healthcare system, there is an absence of policy and legal provisions specific to paediatric palliative care, aside from the Cancer Act. This divulges a significant gap in the policy and legal framework on matters children palliative care.

A comparative analysis of International Best Practices highlighted from **United Kingdom**, **South Africa** and **Uganda** has brought out the different strategies implemented by the three countries that Kenya can borrow from to ensure palliative care for children is accessible to those in need. The most feasible approaches include; acknowledging paediatric palliative care as an essential healthcare service, provision of child-specific and comprehensive palliative care services to address the unique needs for children, training programs for healthcare providers including a focus on paediatric palliative care, integration of the service across all levels within the society apart from hospital level to ensure accessibility among others.

Children's Palliative Care Policy Gap Analysis- Stakeholder Consultation

The stakeholder consultations highlighted critical systemic challenges and areas for improvement to provide comprehensive and equitable care for children with life-limiting conditions. Stakeholder engagement of the key experts in the sector, with a 65% response rate, revealed significant gaps in awareness, training, financing, service delivery, and governance that hinder the integration and effectiveness of CPC services.

Awareness and perceptions of CPC remain limited among healthcare providers and the public, with many associating palliative care solely with end-of-life or terminal conditions such as cancer and HIV/AIDS. Stakeholders emphasized the need for a holistic approach that addresses physical, psychological, social, and spiritual needs across a wide range of life-limiting conditions, including chronic illnesses, congenital anomalies, and neonatology. The stigma surrounding CPC, both culturally and professionally, prevents timely referrals and reduces service demand, necessitating broad awareness campaigns to redefine its scope and normalize its integration into health systems.

Human resource limitations are a significant barrier to effective CPC service delivery. There is a severe shortage of trained healthcare professionals, particularly at county levels and lower-tier facilities. Most of the counties often fail to release staff for training, and trained personnel are frequently redeployed to unrelated roles due to systemic workforce shortages. Stakeholders advocated for the establishment of accredited paediatric palliative care training programs within Kenya, supported by clear career progression pathways to retain skilled professionals and enhance service quality.

The lack of robust data and research hinders evidence-based policy development for CPC. The Kenya Health Information System (KHIS), lacks dedicated indicators for CPC, embedding it instead under cancer and HIV categories. This obscures the broader palliative care needs and limits the ability to track service delivery effectively. Stakeholders called for integrating CPC indicators into KHIS, conducting local research, and establishing a centralized data repository to guide policy and service improvements.

Inadequate financing severely restricts the accessibility of CPC services, which are largely dependent on non-governmental organizations (NGOs) and civil society organizations (CSOs). The National Hospital Insurance Fund (NHIF) did not comprehensively cover essential CPC services, focusing primarily on inpatient cancer care. The newly rolled out fund; Social Health Insurance Fund (SHIF) as anchored in the Social Health Insurance Act 2023, presents an opportunity to expand coverage, including outpatient and home-based CPC services, essential medications like morphine, and psychosocial support. Stakeholders emphasized the need for increased government budget allocations and the establishment of dedicated funding for CPC at both national and county levels.

Access to essential medicines and commodities is inconsistent, particularly at lower-tier facilities, due to regulatory and supply chain challenges. While morphine is generally available, restrictions on prescription authority and frequent stockouts hinder timely access. Stakeholders stressed the importance of expanding the essential medicines list to include paediatric formulations and empowering trained clinical officers and nurses to prescribe palliative care medications to improve service accessibility.

Service delivery for CPC is fragmented, lacking standardization and coordination across health facilities. Stakeholders identified the absence of a comprehensive, integrated CPC model and the inefficiency of referral systems as major barriers to continuity of care. Community-based and home-based care models, which are critical for equitable access, remain underdeveloped. An integrated, multidisciplinary approach that includes early screening and well-coordinated referrals is essential to bridge these gaps.

Socio-cultural factors and stigma significantly limit the acceptance and utilization of CPC services. Misconceptions about palliative care as a last-resort option and cultural taboos surrounding death and illness prevent families and healthcare providers from seeking or recommending CPC. Stakeholders highlighted the urgent need for public and professional education to demystify CPC and improve its acceptance.

Kenya's leadership and governance structures must prioritize CPC to address systemic challenges effectively. Existing policies inadequately address paediatric-specific palliative care needs, focusing disproportionately on cancer and HIV. While the Cancer Prevention and Control Act provides a starting point for CPC, there is an urgent need for comprehensive legislation and frameworks that encompass all life-limiting conditions and integrate CPC into universal health coverage (UHC) strategies.

Stakeholder collaboration and public participation are essential to developing and implementing effective CPC policies. A multi-sectoral approach involving government, NGOs, private sector players, and communities is critical. Regular monitoring, feedback mechanisms, and the involvement of diverse actors, including those with lived experiences, will ensure responsive and sustainable policy development.

In conclusion, the policy gap analysis underscores the need for a holistic, integrated approach to CPC that addresses systemic barriers, promotes equity, and ensures that all children with life-limiting conditions receive compassionate, comprehensive care.

The **key recommendations** from this study include; -

- Ensuring existing policies and laws are implemented including conducting periodic monitoring and evaluation.
- Enhancing awareness of children's palliative among stakeholders including policy makers, healthcare providers, community service providers, family members of the patients among others through advocacy
- Strengthening training and human resources
- Integrating palliative care data into the Kenya Health Information System (KHIS) to measure needs and enable centralized case tracking and monitoring.
- Increasing financing for CPC and expanding the scope of insurance coverage to include outpatient and home-based care.
- Ensuring consistent access to essential medicines and strengthening the supply chain for palliative care medicines.
- Establishing standardized community-based care models.
- Promoting stakeholder consultations and public participation

These recommendations would bridge the existing gaps, improve service delivery, and uphold the right of every child to the highest attainable standard of health particularly when it comes to children's palliative care.

1. BACKGROUND

1.1 Definition

According to the World Health Organization (WHO), palliative care is an approach to healthcare aimed at improving the quality of life of patients and their families when they are facing life-threatening or life-limiting illness. This approach entails prevention and relief from suffering through early detection, comprehensive assessment and treatment of pain and other problems (physical, psychosocial and spiritual). In its definition specifically for children, WHO cites that child palliative care (CPC) is the active total care of the child's body, mind and spirit, alongside giving support to the child's family. CPC begins at the time of diagnosis of the illness and continues as part of care regardless of whether treatment is given. Additional considerations that the definition includes are the:

- Need for healthcare providers to evaluate and eliminate the child's suffering (physical, psychological or spiritual)
- Requirement of a multidisciplinary approach, including the child's family and community
- The feasibility of providing palliative care to children even in resource-constrained contexts, and at all levels of health service delivery, and at home.

1.2 Burden of Children's Palliative Care needs

The scope of palliative care for children encompasses children between the ages of 0 and 19 years. The conditions that require palliative care comprises a broad spectrum which are categorized into 4 groups by the United Kingdom-based ACT (now Together for Short Lives). These are outlined below:

- Life threatening conditions which may be curable
- Conditions with prolonged periods of wellness due to treatments, but inevitable premature death
- Progressive conditions where treatment is exclusively palliative.
- Irreversible but non-progressive conditions

The Kenya Palliative Care Policy 2021 - 20302 also provides categorization of paediatric conditions that require palliative care. These are conditions with:

- Potential for cure - life is threatened but not limited; and treatment success is not guaranteed.
- Period of normality despite having a fatal diagnosis
- Relentless deterioration from the time of diagnosis or before - conditions that have no cure.
- An irreversible but unpredictable disease progression

There are more than 360 conditions that fall within these groups. The leading conditions include human immunodeficiency virus (HIV) (29.6%), premature birth and birth trauma (17.7%), congenital anomalies (16.2%), injuries (16%), and cancer (4.1%)3; However, there are geographical variations in the types and prevalence of conditions of CPC needs.

There are unique aspects to PC for children; some of them are the fact that children with palliative care needs can live for longer as compared to adults with similar needs[4]; as they live with these CPC needs, they transition through various stages of development (neonatal, infancy, childhood and adolescence) which alters their needs at each of these stages, along with their ability to understand their condition and outcome[5]. Additionally, the diversity of conditions which are associated with CPC needs, the uncertainty of the trajectory of these conditions and the living contexts of young people living with life-limiting conditions present unique situations[6]. All these complex aspects need to be factored into the planning for CPC programs.

---

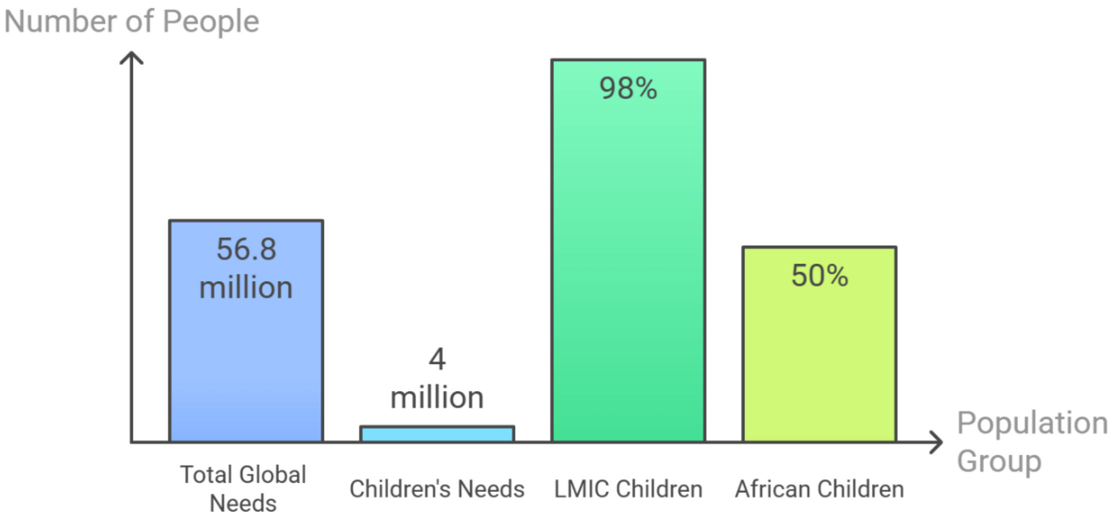
[2] **Ministry of Health, Government of Kenya**, *Kenya Palliative Care Policy 2021-2030*.

[3] **Worldwide Hospice Palliative Care Alliance**, *Global Atlas of Palliative Care*, 2nd edn, 2020

[4] **UNICEF and ICPCN**, *Assessment of the Need for Palliative Care for Children: Three Country Report: South Africa, Kenya and Zimbabwe*, 2013.

[5] **African Palliative Care Association**, *Guidelines for Using the APCA African Children’s Palliative Outcome Scale*, 2012.

[6] **Chong, P. H., De Castro Molina, J. A., Teo, K., and Tan, W. S.**, 'Paediatric Palliative Care Improves Patient Outcomes and Reduces Healthcare Costs: Evaluation of a Home-Based Program', *BMC Palliative Care*, 17.1 (2018), https://doi.org/10.1186/s12904-017-0267-z.



Global Palliative Care Needs Distribution

The annual global burden of palliative care needs is estimated at 56.8 million people. Children with palliative care needs comprise 7% (~ 4 million) of this population[2]. Approximately 98% of the children who require palliative care live in low- and middle-income countries; furthermore, approximately half of them live in Africa [2,7].

According to a UNICEF and International Children's Palliative Care Network 2013 report, in Kenya 2 out of every 10 children has a need for CPC[3]. The main conditions that comprise the CPC needs include HIV & acquired immunodeficiency syndrome (AIDS), blood cancers and solid tumours (leukaemia, lymphomas), cardiovascular diseases, sickle cell anaemia, cerebral palsy and congenital malformations[3].

However, there is limited updated evidence on the current CPC need due to lack of standardized system for definition and quantification.

1.3 Benefits of CPC

Studies have revealed that palliative care (PC) has the potential to enhance the quality of life of the patients and their families. There is evidence that recipients of CPC and their families, particularly home-based CPC coped better with the illness and the quality of life improved despite the life-limiting nature of their illness [5].

---

[7] **World Health Organization (WHO)**, *Palliative Care*, 2020, https://www.who.int/news-room/fact-sheets/detail/palliative-care.

Research has documented that some children who have been diagnosed with conditions that require CPC may find themselves in difficult circumstances such as abandonment; financial insecurity; difficulty communicating their specific need especially for the very young and those with mental developmental challenges; ethical issues regarding participating in decision-making about their care; and sociocultural barriers due to association between palliative care and end-of-life which limit their ability to benefit from CPC [8]. As such an integrated approach towards developing a CPC policy is required to address these multifaceted challenges.

1.4 Palliative Care and Universal Health Coverage

Universal Health Coverage (UHC) is a target of the United Nations Sustainable Development Goal (SDG) number 3 which aims to achieve health and well-being for all. The continuum of UHC includes PC alongside other forms of healthcare such as PC including CPC forms an essential ingredient for sustainable development.

1.5 Facilitators and barriers of palliative care

WHO has developed a public health model to support PC in general. This model comprises the four pillars outlined below [9,10]:

- **Policy**: This is the bedrock for the provision of PC and specifically CPC. Policy will entrench CPC into the health system and provide a framework for CPC service provision. Additionally, it will form the foundation for the implementation strategy and, development of standards of care and regulations.
- **Education**: Providing education for CPC service delivery at different levels will expand access to CPC. This includes basic CPC skills for all healthcare professionals, community healthcare providers and other community members; intermediate skills for those routinely working with patients suffering from life-

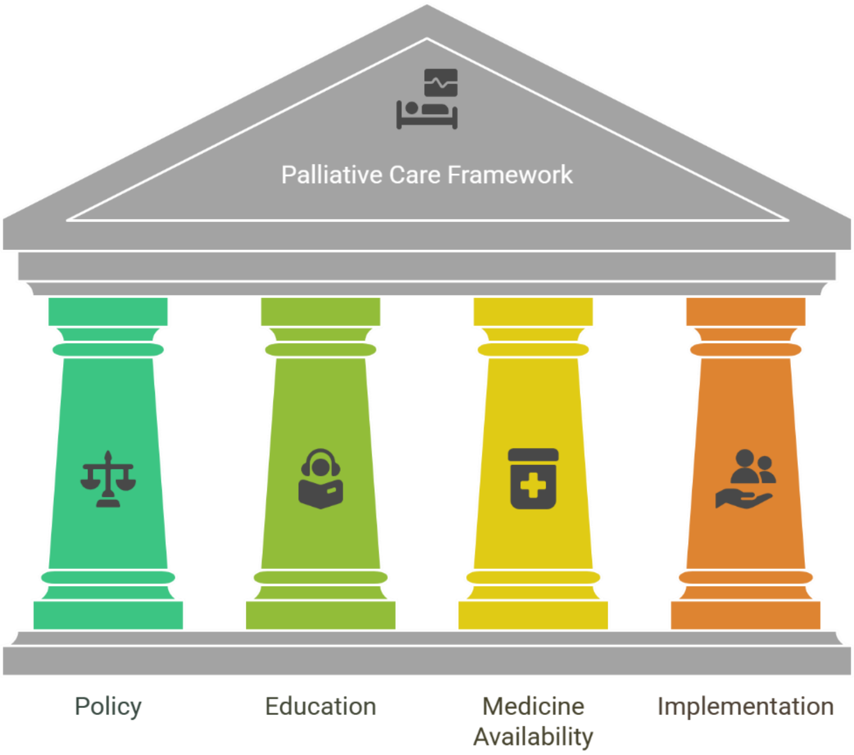
---

[8] **Sasaki, H., Bouesseau, M. C., Marston, J., and Mori, R.**, 'A Scoping Review of Palliative Care for Children in Low- and Middle-Income Countries', *BMC Palliative Care*, 16:60 (2017), https://doi.org/10.1186/s12904-017-0242-8.

[9] **Worldwide Hospice Palliative Care Alliance**, *Global Atlas of Palliative Care*, 2nd edn, 2020, https://www.thewhpca.org.

[10] **Sepúlveda, C., Marlin, A., Yoshida, T., and Ullrich, A.**, 'Palliative Care: The World Health Organization's Global Perspective', *Journal of Pain and Symptom Management*, 24.2 (2002).

threatening conditions; and specialist skills to manage conditions with complex CPC needs.



- **Medication availability**: Creating environments that ensure consistent availability of essential medicines and medical commodities required for CPC is also paramount. This includes navigating laws that restrict distribution of medications for pain control, particularly the opioids, and those that regulate prescribing by specific healthcare professional cadres; additionally, challenges related to supply chain management and costs of the medications need to be addressed.
- **Implementation**: Through the existence of policy and sustainable funding mechanisms; and the development of context appropriate CPC service delivery models that are person-centred and responsive throughout the life-course of the children and their families.

Conversely, according to the African Palliative Care Association[11], some of the barriers to CPC particularly in Low- and Middle-Income Countries (LMICs) include:

- Lack of national policies supporting CPC due to low awareness and low commitment by governments
- Barriers related to human resources for health: numbers and, knowledge, skills and attitudes towards CPC.
- Gaps in consistent availability of essential palliative care medicines, medical commodities, and regulations that restrict access to opioids. Additionally, in healthcare settings with low doctor-to-population ratio, restricting prescription to only doctors create access barriers.
- Implementation challenges due to limited funds' allocation to support CPC services.
- Psychological and sociocultural factors prohibiting disclosure of diagnosis & prognosis when life is threatened, and limited understanding of the concept of PC
- Limited health information management systems and research which encumbers the assessment of the magnitude of CPC needs, and paucity of research to generate evidence to inform policy on provision of CPC services.
- Low urbanization in LMICs and the resultant geographical barriers to accessing CPC for populations in hard-to-reach areas.

---

[11] **African Palliative Care Association**, *Guidelines for Using the APCA African Children's Palliative Outcome Scale*, 2012.

2. ANALYSIS OF POLICIES AND LEGAL FRAMEWORK FOR CHILDREN'S PALLIATIVE CARE IN KENYA

2.1 Overview

Children’s palliative care policies and laws seek to address the broad needs of children with life-threatening and life limiting conditions, emphasising relief from pain and other symptoms, provide psychological support, and most importantly, improving quality of life for both the child and their family. The framework for children's palliative care in Kenya is underpinned by various policies and legal instruments whose main objectives are to enhance accessibility, quality, and sustainability of these services.

According to the World Health Organization's Constitution, health is defined as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being.[12] From the definition of health provided by WHO, it is important to note that palliative care encompasses what would result to the state of complete physical, mental and social well-being. Therefore, any legal and policy frameworks providing for the right to health automatically includes the right to palliative care for every human being, including children.

Analysis of the legal and policy framework has been categorized into key thematic areas as highlighted below.

2.2 Access to Quality Palliative Care

Constitution of Kenya (2010)

The Constitution of Kenya is the most supreme law of the land. **Article 43** Guarantees the right to the highest attainable standard of health which undoubtedly includes the right to palliative care. Specific to children, **Article 53** provides that every child has the right to health, which includes access to palliative care.

---

[12] **World Health Organization (WHO)**, *Constitution of the World Health Organization*, https://www.who.int/about/governance/constitution.

UN Convention on the Rights of the Child

The Convention under Article 24, which provides for the right to health, asserts that State parties should recognize the right of the child to the enjoyment of the highest attainable standard of health and to treatment at health facilities. This includes palliative care and therefore, governments must strive to guarantee that palliative care for children is available, accessible and is of the highest attainable standards and quality.

According to the convention, Kenya is obliged to take steps to ensure that children in need of any form of treatment or care including palliative care have access to the care and pain treatment, being cognizant to the fact that children are entitled to special care.

Children Act (2001, Amended 2022)

The Children Act stipulates that every child has the right to the highest attainable standards of health services echoing the provisions of the Constitution. This includes ensuring they can access necessary palliative care which includes physical, mental and psychological healthcare services.

According to this Act, it is the responsibility of every parent or guardian to ensure that any child in need of healthcare can access the same in an appropriates health facility, failure to which is considered an offence.

In practice, children between the age of 16 and 18 years can seek healthcare services independently without a parent or guardian. At this age, the child can give assent to receive the care. However, a legal guardian or parent would need to give consent on the child’s behalf for the assent to be binding.

For children below the age of 16 years, a parent or guardian is the primary person required to make decisions regarding the care that will be administered. Nonetheless, all the information should be shared with the child in an age-appropriate format, and the child’s best interest being the priority during the decision-making.

Kenya Health Act (2017)

The Act reiterates the right to every person having the highest attainable standard of health care including access to palliative services. The Act further provides that it is the duty of the state to promote and fulfil the right to highest attainable standard of health by developing policies necessary to protect, promote, improve and maintain the health and well-being of all persons.

As provided for in the Act, the state should ensure the provision of a health service package at all levels of health care system including services addressing palliative care.

Kenya Health Policy 2014-2030

The goal of Kenya Health policy is to ensure all citizens including children, attain the highest standard of health in a manner responsive to the needs of the Kenya population. The Policy aims to promote equitable access to health services, including palliative care, across all levels of the health system and provide essential healthcare.

On the obligations of the health sector, the policy echoes the provisions of the Constitution which states that both national and county government, shall take legislative, policy and other measures, including the setting of standards, to achieve the progressive realisation of the right to health.

The policy also focuses on improving the quality of health services, including palliative care. To improve the quality of healthcare, the policy states that the government shall commit to ensure that delivery of health services are the most effective as is feasibly possible, establish institutes and centres of excellence to ensure availability of highly specialised quality care and allocate resources to ensure quality of care is attained.

Kenya Palliative Care Policy 2021- 2030

The main goal of the Kenya Palliative Care Policy is to expand the reach of palliative care services in Kenya by guaranteeing access to quality services at every point of demand and integrate palliative care into the Kenyan health system at all levels to ensure accessibility.

Regarding quality of palliative care, the policy provides for priority actions that both the national and county governments should put in place to ensure accessibility of quality palliative care. Among them is the development of regular updates and dissemination of national guidelines to ensure standards for provision of quality palliative care services. As a priority the policy appreciates innovation and technology as part of the guiding principles to promote delivery of quality palliative care services.

The National Palliative Care Guidelines (2013)

The guidelines vision, mission and goal envisage an effective and efficient national palliative care program to achieve the goal of providing holistic and quality palliative care services to patients and families faced with life threatening illnesses throughout the country.

Among the key areas identified by the guidelines requiring interventions to promote provision of holistic quality palliative care in Kenya includes promoting quality paediatric palliative care services.

The guidelines specifically provide for the need for palliative care for children between the ages of 0-16years to focus on the enhancement of quality of life for the child and support to the family. Additionally, it stresses that emphasis should be on pain assessment and management, psychosocial and emotional support and communication, which should be appropriate for the age and developmental stage of the child.

National Guidelines for Cancer Management in Kenya (2013)

The guidelines provide principles for care for patients with diagnoses of cancer. These guidelines also emphasise the need for accessible palliative care services for children with cancer across the country.

It expressly states that palliative care should be offered right from diagnosis alongside conventional cure-oriented treatment and not when cure is not possible.

The guidelines provide detailed protocols for high-quality palliative care for paediatric cancer patients, including pain management and psychosocial support. Generally, it also provides guidance a framework for appropriate referral systems, pain management and ethical considerations which speaks to the quality of care.

National Policy on Persons with Disabilities (2006)

Appreciating the fact that some of the children in need of palliative care are categorised under persons living with disability, the policy provides those children with disabilities, including those requiring palliative care, have equal access to health services and legal protections. One of the key policy interventions is to ensure that infants and children with disabilities have access to medical care.

Kenya Vision 2030

Health care delivery is one of the social pillars for Kenya Vision 2030. The key focus areas in the health sector include access, equity, quality, capacity, and institutional framework which includes policy development.

To improve the overall livelihood of Kenyans, the objective of the Vision 2030 is to provide an efficient integrated and high-quality affordable health care system with the highest standards of care by 2030.

2.3 Integration and Coordination of Palliative Care

Constitution of Kenya (2010)

The 2010 Constitution provides for devolution which is an important aspect to coordination of the two levels of governments in health provision and delivery.

The Fourth Schedule assigns the national and county governments distinct functions and provides for the distinct roles of both governments under the devolved systems.

On matters of health, the National Government is specifically mandated to take up leadership of health policy development, management of national referral health facilities, capacity building and technical assistance to counties including the development of norms, standards and guidelines. On the other hand, County governments are responsible for implementing national government policies and guidelines including those relating to palliative care, management of county health services, including county health facilities and pharmacies, promotion of primary healthcare and providing quality and timely data and reports including those relating to palliative care.

The above functions, if well-coordinated and implemented shall ensure that access to palliative care as a right to health is realised by children.

Kenya Palliative Care Policy 2021 - 2030

Encourages the integration of palliative care into primary health care and other relevant health services by calling for coordination and liaison of services at all levels, as guided by the WHO public health model approach for palliative care development.

To promote good leadership and governance in palliative care at national and county levels, the policy provides for the establishment of a well-coordinated palliative care leadership and governance framework with clearly defined roles and responsibilities at the national, county and institution level as a priority policy action.

Kenya Health Policy 2014-2030

The policy outlines a systematic and comprehensive model of coordination for provision of healthcare under the organisation of health service delivery systems. It echoes the provisions of the Constitution of the different functions of the two governments and further provides for both national and county referral health services. It also integrates primary care and community care services in the healthcare service delivery.

Cancer Prevention and Control Act (2012)

The act calls for cancer prevention and control to form part of healthcare and mandates the integration of palliative care within cancer treatment frameworks, ensuring coordinated care for those with cancer including children's.[13]

The National Palliative Care Guidelines (2013)

On integration and coordination, The Guidelines provides for various levels of responsibility when it comes to the implementation of palliative care. The Guidelines outlines the roles and responsibilities of different stakeholders to be involved in providing quality palliative care. When it comes to reporting systems, it provides for the role of community services providers in providing palliative care services. According to the Guidelines, community services providers shall compile reports monthly and submit to the nearest health facility, who will then submit to the county offices of health. The County offices of health shall ultimately submit quarterly reports to the Ministry of Health using the Standardized forms.

---

[13] Section 31 (1) Cancer Prevention and Control Act 15 of 2012

2.4 Education and Training

Cancer Prevention and Control Act (2012)

Apart from the Health Act, The Cancer Prevention and Control Act is the only other piece of legislation expressly providing for palliative care. The Cancer Prevention and Control Act is the only piece of legislation expressly providing for palliative care. The Act mandates the National government in collaboration with the National Cancer Institute of Kenya to provide training, sensitization and awareness programmes on the prevention, treatment, palliative care and control of cancer to employees of all national government departments, authorities and other agencies.[14]

Further, the Act mandates the Institute to liaise with the government departments responsible for education to integrate instruction on the causes and ways of preventing cancer, its treatment and palliative care in subjects taught in public and private schools at all levels starting from early childhood education development centres to primary, secondary, and tertiary levels, including informal, non-formal and indigenous learning systems.[15]

It is critical to note that if implemented, the provisions of the Act will promote the inclusion of palliative care in medical and nursing education curricula to enhance the skills of healthcare workers.

Kenya Palliative Care Policy 2021 - 2030

Under Human Resources and Education, the policy calls for training of healthcare providers to offer differing levels of palliative care providing for development of curricula and rolling out of relevant palliative care training programs at diploma and postgraduate level as a priority action.

For monitoring the impact of service delivery for palliative care, the policy provides for fourteen **institutes as the number of core curricula that should have integrated palliative care by 2030.**

---

[14] Section 29 (3) *ibid*
[15] Section 30 (1) *ibid*

Kenya Health Act (2017)

The Act, under the duties of National Government, mandates the Ministry of Health, through regulatory bodies, to develop standards of training and institutions providing education to meet the needs of service delivery.

Kenya Health Policy 2014-2030

On the provision of essential healthcare provision, the policy provides for promotion of establishment of institutes and centres of excellence to ensure availability of highly specialised quality care in the country as a priority policy strategy.

National Guidelines for Cancer Management in Kenya (2013)

Recommends continuous education and research for healthcare providers in palliative care practices as an essential component of palliative care.

2.5 Funding and Resources

Kenya Palliative Care Policy 2021 - 2030

The policy advocates for increased funding and resources to support essential palliative care medicines and commodities. Further, the policy calls for allocation of sufficient resources for capacity building for research in palliative care in collaboration with stakeholders.

In addition to the above, the policy recommends for healthcare financing including integrating palliative care benefit packages within the Universal Health Care plans and budgets.

Kenya Health Policy (2017)

The Act provides that the state shall ensure prioritization and adequate investment in research for health to promote technology and innovation in health care.

Kenya Health Policy 2014-2030

The policy provides that the primary responsibility of providing the financing required to meet the right to health lies with the national and county governments. The policy aims at allocation of sufficient resources to health services, including palliative care, to improve accessibility and quality.

Facilities Improvement Financing Act

The Act provides for a unified system to guide financial management in public health facilities, improving efficiency and effectiveness and ultimately quality health service delivery.[16]

Further, it provides for appropriation, management and use of budgeted health services revenue to supplement operations and facilitate quality service delivery in public health facilities as one of its objectives.

If implemented the Act would facilitate improved access and quality of palliative care offered to children as it would lead to improvement of infrastructure by upgrading of health facilities, resource allocation for procurement of essential and medical commodities including for PC. This would require advocacy to integrate palliative care within health service delivery packages.

2.6 Comparative Analysis of International Best Practices; Policy and Practice

2.6.1 Uganda

Uganda is recognized as a model for palliative care in Africa by the **African Palliative Care Association (APCA)**. The 2020 and the 2014 Global Palliative Care Atlases published by WHO and the World Hospice and Palliative Care Alliance (WHPCA) all ranked Uganda among countries with advanced palliative care integration.[17] The country has made notable efforts to integrate palliative care services into its healthcare systems.

---

[16] Section 3 Facilities Improvement Financing Act

[17] **Palliative Care Association of Uganda (PCAU)**, '30 Years of Palliative Care in Uganda: PCAU Energized with a New Strategic Plan', https://pcauganda.org/30-years-of-palliative-care-in-uganda-pcau-energized-with-a-new-strategic-plan/#:~:text=Palliative%20Care%20services%20have%20spread,care%20as%20an%20essential%20service.

According to the country's strategic plan, palliative care services have spread to over 80% of the districts. Currently, Uganda has no standalone national palliative care policy, but all recent health legislation and policies recognize palliative care as an essential service.[18]

Uganda has had the following notable strategies in place that has ensured they realize achievements when it comes to palliative care; -

- **Recognizing palliative care as an essential service**- The National Health Policy expressly includes palliative care as one of the healthcare services that it aims to provide for its citizens under its mission statement. Further the objective of the policy is to ensure universal access to quality UNMHCP (Uganda National Minimum Health Care Package) of promotive, preventive, curative and rehabilitative and palliative services for all prioritised diseases and conditions, with emphasis on vulnerable populations for all its people.
- **Effective Government supported Initiatives**- The Palliative Care Association of Uganda together with Uganda's Ministry of Health and American Cancer Society has established the Pain-Free Hospital Initiative. The main objective of the initiative is to integrate effective pain relief into hospital services with the aim of addressing pain management.
- **Morphine accessibility**- Uganda through the Narcotic Drugs and Psychotropic Substances (Control) Act, has made oral liquid morphine accessible for pain management, including for children, and allows nurses trained in palliative care to prescribe it. This is a significant milestone in addressing pain relief for paediatric patients. The country's decision to allow nurses to prescribe morphine was a response to the lack of doctors in rural areas, where 86% of Ugandans live. In fact, Uganda's palliative care achievements have been possible, largely due to the fact that specially trained nurses and Clinical Officers are legalized to prescribe certain controlled medicines including Oral Liquid Morphine. [19]

---

[18] **Palliative Care Association of Uganda (PCAU)**, '30 Years of Palliative Care in Uganda: PCAU Energized with a New Strategic Plan', https://pcauganda.org/30-years-of-palliative-care-in-uganda-pcau-energized-with-a-new-strategic-plan/#:~:text=Palliative%20Care%20services%20have%20spread,care%20as%20an%20essential%20service.

[19] **United Nations Office on Drugs and Crime (UNODC)**, *Video Transcript*, https://www.unodc.org/documents/commissions/CND/2019/Contributions/Thematic_Debate/26_Sept/Video_Transcript.pdf.

  - The main advocacy approach was that if midwives were allowed to prescribe due to their training, then palliative care trained nurses could prescribe too.
- **Integrated Data**- Another notable achievement is that the country has established new palliative care indicators and developed an integrated data collection tools into the Health Management Information System (HMIS) and the District Health Information II.

Apart from the highlighted achievements through the strategies put in place, Uganda also has specialized services for children and has training programs for healthcare providers which includes a focus on paediatric palliative care in institutions like Makerere University.

Currently, many palliative care services depend heavily on donor funding, which may not always be sustainable. Government budget allocations for such care remain insufficient. To mitigate this, under their National strategy, Uganda aims to establish a national PC fund

2.6.2 South Africa

South Africa has made steps in ensuring its citizens access palliative care, including children.

Palliative care policy and legal framework in South Africa is guided by a combination of national health strategies, frameworks, and international human rights commitments. The main guiding policy document governing palliative care is the National Policy Framework and Strategy on Palliative Care (2017–2022). The Framework and strategy recognize palliative care as a fundamental part of the health system and aims to make it accessible to all patients, including children, facing life-threatening and life-limiting conditions.

Additionally, the Cape Town Palliative Care Declaration expressly recognises the need for palliative care and provides for it as a human right for every adult and child with life-limiting illnesses. The Declaration continues to serve as a foundational document for advocacy and action in the field of palliative care, supporting ongoing efforts to address the needs of patients with life-threatening and life-limiting conditions and their families across Africa.

Palliative care in South Africa is tailored to the needs identified and the resources available in the area where the service is situated.[20]

South Africa has embraced different models of care when it comes to palliative care which are equally provided for in their National Policy Framework and Strategy. Some of the models include; -

a) Inpatient palliative care facility and Out-patient care
b) Hospital based palliative care teams- A consultative palliative care service provided by a specialist multidisciplinary palliative care team. The patient remains the responsibility of the admitting and treating team but is supported by the palliative care team. On discharge the palliative care hospice continues to provide care within the home and use the hospital for expert and team support.
c) Day Care Centres- These centres may monitor and address medication adherence, symptom management, failure to thrive, malnutrition, neglect or abuse. Programmes may be offered to assist patients and families to cope with the illness. Additional services that are available include occupational therapy or skills and counselling and medical services. Volunteers often support the day care.
d) Mobile Outreach services- A mobile palliative care team visits remote health facilities linked to the parent health facility, to see patients who cannot travel long distances to access care.
e) Comprehensive programmes- This is an integration of Hospitals, Hospices, Day Cares and Community Home Based Care Programmes- These programmes ensure a continuity of care for children from hospital to a hospice and/or Day Care Centre and the child's own home. Examples of this comprehensive model in South Africa include Sunflower House Children's Hospice and the St Nicholas Bana Pele Network in Bloemfontein, The Bigshoes Foundation hospital programme and Soweto Hospice (In-patients and outreach) Cotlands in Johannesburg and Somerset West as well as the Butterfly House network model in Paarl in the Western Cape. Most of these homes and hospices are non- governmental funded projects.

Examples of existing different local models of care include the Abundant Life project at Victoria Hospital, an integrated community palliative care model initiated at South Coast

---

[20] **International Children's Palliative Care Network (ICPCN)**, *Children's Palliative Care in South Africa: The Facts*, November 2022, https://icpcn.org/wp-content/uploads/2022/11/Children_s_Palliative_Care_in_South_Africa_-_The_Facts.pdf.

Hospice in KwaZulu-Natal and the Gauteng Centre of Excellence for Palliative Care based at Chris Hani Baragwanath Academic Hospital.

Just like in most countries who have, children's palliative care in South Africa, is provided mostly in hospital where the sick child is identified, and when the child is discharged, continues in the child's own home by visiting team members. South Africa has three in-patient children's palliative care units in the country.

South Africa works with the Community Health Worker (CHW) or Home-Based Care (HBC) Caregiver as a vital component of the primary care approach. The CHW receive monthly stipends from the Department of Health and the Department of Social Development. They have been pivotal in linking primary level facilities with the community through home visits and provision of prevention, care and support activities.

The cadre's focus in the past years has been on patients and families living with and those affected by HIV and AIDS, including support for Orphans and Vulnerable Children (OVC).

2.6.3 United Kingdom (UK)

Just like South Africa, in the UK, access to palliative care services for paediatric patients is supported by a mix of laws, policies, and healthcare service models.

One of the key policies that makes it possible to access palliative care for children is The National Institute for Health and Care Excellence (NICE). NICE plays a significant role in shaping and guiding children's palliative care in the UK through the development of clinical guidelines and quality standards. It provides for evidence-based guidelines, establishing quality standards, and promoting integrated care practices. This ensures that children with life-limiting conditions receive the highest quality of compassionate care designed to their unique needs and those of their families. NICE advocates for; -

i. the child and their family to play an active role in discussions about their care, where possible,
ii. the child to receive palliative care, including end of life care, in the place they choose and lastly,

iii. children with life-shortening conditions to be cared for by a multidisciplinary team who meet regularly to discuss the child’s care.[21]

Apart from laws and policies that support palliative care, the country’s healthcare systems structures have developed immensely to ensure palliative care is accessed by children. Most importantly, the country has included the following.

- **Integrated Care Systems (ICS)-** These systems aim to bring together various health and social care services to ensure a coordinated approach to patient care, including access to palliative services.
- **Palliative Care Networks**- Local networks facilitate collaboration between hospitals, community services, and hospices to ensure comprehensive care for children with palliative needs.
- **Specialist Palliative Care Services**- Many hospitals have dedicated paediatric palliative care teams that provide consultations, symptom management, and holistic care tailored to children and their families.

When it comes to incorporation of palliative care in the curriculum, the UK have in place professional training for healthcare providers in paediatric palliative care to ensure that staff are equipped to recognize and address the unique needs of children with serious conditions. Several universities and colleges offer courses on the subject matter.

Their approach is also very family-centred, and the family members have been integrated in the palliative care processes. Some of the hospitals such as Kentucky Children’s Hospital have systems where professionals occasionally meet the family and health care providers of the children to understand their goals, wishes and concerns.[22]

Lastly, on funding which is a very vital aspect to access of palliative care, the National Health Services allocates funding specifically for palliative care services, including those for children, ensuring that these services are accessible without financial burden on families.

---

[21] **Together for Short Lives**, *NICE Guidelines on Children's Palliative Care*, https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/nice-guidelines/.

[22] **UK HealthCare**, *Palliative Care*, https://ukhealthcare.uky.edu/kentucky-childrens-hospital/services/support-services/palliative-care.

3. METHODOLOGICAL AND ENGAGEMENT APPROACHES

3.1 Inception Phase

The policy analysis assignment commenced with an inception meeting held with KEHPCA to align expectations and secure approval for the study's proposed methodology, work plan, and anticipated outcomes. The analytical framework outlined below was instrumental in guiding the CPC gap analysis shaping both the design of the Key Informant Interview questionnaires and the subsequent data analysis. This framework was built on two key assumptions: first, that successfully identifying and evaluating existing policies and frameworks—whether facilitating or hindering children's palliative care services—depends on stakeholders' awareness of relevant policies and regulations. Second, the need for a specific children's palliative care policy would be shaped by stakeholders' perspectives.

Table 1. The Analytical Framework

Methodology	Inputs	Key Outputs
Desktop research	Status, existing legal and policy framework, existing gaps	Baseline: Where are we?
Key Informant interviews (KIIs)	Status, existing gaps & solutions (Stakeholders perspectives)	Barriers, challenges and opportunities: Why are we here?
Analysis	Detailed assessment of the status including legal and policy frameworks, existing gaps, solutions and a clear roadmap	Intervention: How to get there?
Validation Workshop	Validate draft report	Incorporate stakeholder feedback

3.2 Desktop Research

A variety of publicly available sources were reviewed, including global and regional policy documents, technical reports, and peer-reviewed articles, to gather key information on children's palliative care policy and assess the existing systems addressing this need. In addition, a comparative analysis of international best practices was conducted.

3.3 Stakeholder Engagement

As part of the CPC policy gap analysis, stakeholder engagement was conducted through semi-structured Key Informant Interviews (KIIs) with key palliative care stakeholders from various regions across the country engaged. These interviews, held both virtually and in-person, aimed to explore the status of palliative care in Kenya. The discussions centred on identifying strengths and gaps within the country's health sector to enhance CPC service delivery, as well as exploring opportunities to capitalize on and addressing threats that must be mitigated to ensure equitable access to CPC services. The insights gathered from these professionals provided a comprehensive understanding of the gaps in the system and highlighted areas for policy improvement. A detailed list of the stakeholders involved in the interviews can be found in appendix 6.1.

All interviews were audio-recorded and transcribed verbatim. For quality assurance purposes, a second step including comparison of all transcribed texts with the actual recording to ensure everything was captured as was stated by the stakeholders was carried out.

3.4 Data Analysis and Reporting

The data analysis for the CPC policy gap analysis was conducted using a structured approach, primarily focusing on qualitative data obtained through Key Informant Interviews (KIIs) and desktop research. The KIIs provided in-depth insights from stakeholders across the country, while the desktop research involved reviewing relevant policy documents, reports, and academic literature. The analysis began with organizing the qualitative data into thematic areas based on recurring patterns and issues raised by the stakeholders. Thematic analysis was employed inductively to systematically identify, analyze, and report key themes related to the provision, accessibility, and gaps in children’s palliative care services.

In addition, the findings from the KIIs were compared and cross-referenced with the results from the desktop review to highlight consistencies, discrepancies, and gaps. This comparative analysis helped to create a comprehensive view of the current landscape of children's palliative care in Kenya, providing a foundation for identifying policy gaps. The synthesis of this data ultimately informed the development of the CPC policy analysis gap report, which outlined key recommendations for policy development and improvement. However, the report is yet to undergo a validation process to ensure the accuracy and relevance of the findings.

4. STAKEHOLDERS' VIEWS ON THE GAPS IN EXISTING POLICIES FOR CHILDREN'S PALLIATIVE CARE

The stakeholder engagement process for the CPC gap analysis achieved a response rate of 65%. This strong participation provided valuable insights into the current landscape of CPC service delivery. The following section highlights the key thematic areas that emerged from the analysis, offering a deeper understanding of both the strengths and challenges within the sector.

4.1 Stakeholders' Awareness and Appreciation of the Scope of Children Palliative Care

The stakeholders provided a broad and holistic description of children's palliative care, emphasizing its role in addressing both physical, spiritual and emotional aspects of life-limiting illnesses. They collectively agree that palliative care encompasses a wide range of diseases affecting children, including chronic conditions such as sickle cell disease, heart diseases, chronic respiratory illnesses, and cancer. It also extends to neonatology, where even new borns suffering from conditions like perinatal asphyxia or congenital malformations are considered for palliative care, challenging the common misconception that neonates cannot feel pain.

Palliative care, as described by the stakeholders, is not only focused on symptom management but is also deeply rooted in improving the overall quality of life for both the patient and their family. The care provided should be aimed at addressing the physical, psychological, social, and spiritual needs of the child, with a strong emphasis on family involvement and support.

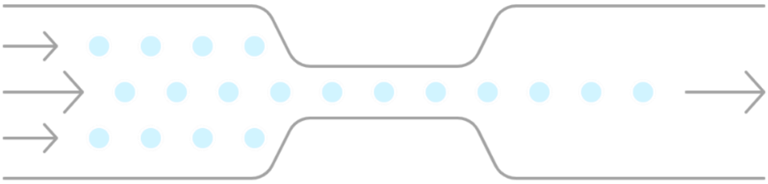
The holistic approach to children's palliative care should be seen as an integral component of the continuum of care which also includes curative, preventive, rehabilitative, and supportive care.

However, the stakeholders noted that despite the breadth of palliative care needs, the major focus for these services leaned heavily towards cancer and HIV. Moreover, while the general public perceived palliative care as a last resort 'when curative interventions had failed' majority of the stakeholders highlighted that this perception was also shared amongst some of the health care providers. This resulted in stigmatization of palliative care that impacted negatively on demand for it. The stakeholders stressed the importance of extending the definition of palliative care beyond cancer and HIV, which are often seen as the primary condition requiring such care. They emphasized that integration of palliative services into the spectrum of health service delivery will ‘normalize it’ and increase demand for and access to it.

4.2 Human Resources for Children’s palliative care

Stakeholders expressed a range of views regarding the human resource challenges in children’s palliative care, emphasizing the need for a trained and adequately supported workforce at all levels of healthcare. Several issues emerged which threaten the successful provision of child palliative care services in the country.

One major concern is the limited availability of personnel trained to provide palliative care to children, particularly in lower-level hospitals. Stakeholders cited that counties are not releasing their staff for training even when opportunities are available, highlighting a gap in the alignment between county-level responsibilities and national healthcare priorities.



Limited trained staff hinders palliative care access for children.

Stakeholders stressed the importance of ensuring that every county has trained personnel to meet the palliative care needs of children. They went on to further state that even when healthcare providers receive training in palliative care, they are not deployed to work in palliative care departments in the county health facilities. They are instead deployed in areas where there are health worker shortages. As such their work environments do not empower them to apply the newly acquired knowledge and skills.

There was a strong call for training institutions to establish comprehensive programs for palliative care, with a focus on paediatric palliative care. Stakeholders advocated for the setting up in-country training courses to reduce reliance on international training programs in countries like India and South Africa. Having accredited and recognized courses locally would encourage more healthcare workers to pursue this training, which in turn would expand the health workforce available to provide child palliative care. Additionally, most stakeholders emphasize the need for these training programs to receive accreditation from the professional regulatory bodies and include career progression pathways, ensuring that those trained in palliative care can advance in their careers and remain motivated to work in the field.

Despite these challenges, the country has made notable progress in palliative care training. Some tertiary institutions already offer training such as the Moi Teaching and Referral Hospital (MTRH), Kenya Medical Training College (KMTC), the Aga Khan University and Nairobi Hospice, NGOs and international organizations provide short online courses. Furthermore, there are several well-trained palliative care specialists in the country. However, the existing training resources are insufficient to meet the scale required, underscoring the importance of further investment.

In conclusion, most of the stakeholders advocate for the inclusion of palliative care modules in the curriculum of most healthcare-related courses. This would ensure that healthcare professionals across the board are sensitized on the needs of children requiring palliative care, allowing for early identification and intervention. Moreover, ensuring that those trained are given the necessary support and time to implement what they have learned is essential to building a resilient and capable workforce.

4.3 Health Management Information Systems

Data plays a crucial role in the development of effective policies in any country, as it provides the evidence needed to understand current challenges, track progress, and make informed decisions. Moreover, having a central repository for this data offers additional advantages by consolidating information from various sources into one accessible platform. The Kenya Health Information System (KHIS) serves as the central database for all health conditions in the country. However, it lacks specific indicators to measure the magnitude of need and track service delivery for CPC. Currently, PC is embedded within cancer and HIV indicators, rather than being recognized as a standalone category.

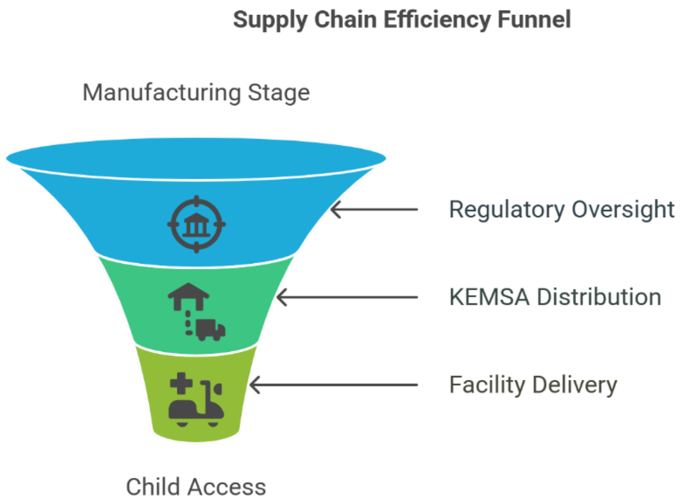
Majority of the stakeholders highlighted the KHIS as a potential platform where palliative care could be integrated. Embedding palliative care data within existing health information systems is seen as crucial for creating a seamless flow of information, particularly for patient referrals and cross-linkage between different healthcare facilities. This integration would ensure that vital information is shared across the system, improving the continuity of care.

Another key issue raised is the need for local research. Majority of the stakeholders stressed the importance of conducting research within Kenya to generate context-specific data that reflects the country's unique challenges and opportunities in children's palliative care. Local research is viewed as essential for understanding where the country currently stands, identifying gaps, and setting realistic goals for improvement. Without this data, majority of the stakeholders felt that progress in developing and implementing effective palliative care policies will be limited.

The allocation of resources for data collection and analysis was another area of concern. While some efforts are being made to gather data, these are minimal and not comprehensive enough to support the broader needs of palliative care services. Most of the stakeholders called for a more strategic and coordinated approach to data collection, emphasizing the need for a repository of palliative care data that can be used for progressive research and policy development. This repository should encompass not only cancer and HIV but all life-limiting conditions affecting children, providing a holistic view of palliative care needs across the country.

4.4 Financing for Children's Palliative Care

Financing for palliative care in Kenya primarily relies on support from non-governmental organizations (NGOs), civil society organizations (CSOs), and philanthropic entities. These organizations play a crucial role in sustaining palliative care services, often stepping in where government funding and healthcare infrastructure fall short.



One of the primary challenges identified is the skewed allocation of funding within the health system, which heavily favours communicable diseases.

Majority of the stakeholders' pointed out that the government's focus tends to be on high-burden diseases associated with significant morbidity and mortality, while neglecting the financial needs of palliative care services. This imbalance limits the financial resources available for palliative care services, which are crucial for improving the quality of life for children with serious illnesses.

A specific issue raised is the lack of comprehensive social health insurance coverage for palliative care under the National Hospital Insurance Fund (NHIF) that has transitioned to Social Health Insurance Fund (SHIF). NHIF benefits package covers primarily treatment for conditions like cancer but does not extend to essential palliative care medications such as morphine and support for psychosocial care. Most of the stakeholders emphasize the need to enhance the benefits package under the insurance fund to include the full spectrum of palliative care services and medications, ensuring that families can access these services at an affordable insurance cost. Additionally, the consideration of palliative care should extend beyond cancer to encompass all the clinical conditions that present with palliative care needs.

Inadequate budgetary allocations and financial planning at both national and county levels was also a significant concern. Majority of the stakeholders' advocated for increased health budgetary allocations specifically for palliative care, with proper monitoring to ensure that funds are effectively utilized for essential services. They recommended that palliative care should be a priority in county health plans and integrated into major documents like the County Integrated Development Plans (CIDP) and budget plans.

There was also a call for a dedicated budget line for paediatric palliative care to address specific needs, such as training healthcare workers, integrating palliative care into curricula, and securing essential medicines and medical commodities. The lack of a clear budget for these aspects undermines the quality and accessibility of palliative care services.

4.5 Essential Medicines and Commodities

Morphine is a critical medicine for effective pain management in children with palliative care needs. Given its importance as an essential medicine, it was encouraging to hear from majority of the stakeholders that morphine is generally available across various levels of the healthcare system.

However, a major concern raised by stakeholders is the inconsistent access to essential palliative care medications across healthcare facilities. While morphine is available even at lower-level facilities, accessing it remains a significant challenge due to systemic and regulatory barriers. One key issue is the requirement for a doctor to countersign morphine prescriptions, despite doctors not being stationed at these lower-level facilities. This requirement can result in patients being unable to access the required medications if doctors are not available at these facilities. Furthermore, stockouts and gaps in procurement processes exacerbate the issue, making it difficult for patients to receive continuous care.

Majority of the stakeholders also noted that while essential medicines for palliative care are crucial, they are not always adequately included in the essential medicines lists or considered in county-level procurement plans. The current essential package for paediatrics includes only a limited number of drugs, and stakeholders advocated for an expanded list that includes more palliative care medications specifically tailored for children regarding formulations. They emphasized that the CPC policy should foreground the need for an essential medicines list for children which includes essential medicines for CPC.

Another significant issue is the control of oral morphine prescriptions; presently, oral morphine can only be prescribed by specially trained palliative care professionals[23] who are very few in number and not equitably distributed across the country. Stakeholders argued for the expansion of prescription authority to improve access to palliative care medications at lower-level facilities where such specially trained cadres are not always present.

4.6 Health Service Delivery Model

Majority of the stakeholders acknowledged that the lack of standardization of care integration, and coordination are significant issues affecting the accessibility and continuity of care for patients with life-limiting conditions. Unlike diseases such as HIV and cancer, which are structured within specific programs, there is no comprehensive structure for palliative care in general. It was also noted that palliative care is not standardized across healthcare facilities, leading to variations in how care is provided. Without clear guidelines and protocols, patients experience inconsistent care depending on where they are treated. This lack of a standardized care approach means that conditions requiring palliative care are often overlooked, with little to no integration within existing healthcare frameworks.

---

[23] Ministry of Health Kenya Essential Medicines List 2023

Another critical issue that was also raised is the inefficiency of the system for referral and coordination of care across the different service delivery levels. Patients often have to travel long distances to receive palliative care, such as from rural areas to major hospitals like Kenyatta National Hospital, only to be referred back to their local health facilities without proper coordination between the care providers. This creates a gap in ensuring continuity of care for patients transitioning between different levels of the healthcare system.

Additionally, most of the stakeholders emphasized the need for a more functional home-based and community-level palliative care model. For instance, in European models, qualified professionals provide community-based palliative care linked to healthcare facilities. In Kenya, however, community care remains underdeveloped, with a lack of skilled healthcare workers at the community level to support this approach. This results in patients being unnecessarily referred to higher-level facilities.

Stakeholders also expressed that there is a need for better coordination within hospitals and between different levels of care. They suggested assigning dedicated personnel to manage access to palliative care services, guiding patients and caregivers through the system more effectively. Furthermore, a call for a more proactive and integrated approach that involves multidisciplinary teams of healthcare professionals was put forth whereby palliative care begins early, once a diagnosis is made. However, this is not happening in practice, as palliative care is often introduced too late. Early screening and a comprehensive referral network are needed to ensure timely access to care. Additionally, the Primary Healthcare Networks (PCNs) model for implementing the primary healthcare approach is another opportunity that could be explored; the PCN model includes multidisciplinary teams (MDTs) which can enhance access to CPC using a person-centred approach.

4.7 Socio-cultural Factors, Population Awareness and Health Literacy

There was a general concern for most of the stakeholders about the widespread myths, misconceptions, and cultural stigmas surrounding palliative care, particularly when it comes to children. These misconceptions exist not only among the general public but also among healthcare professionals, including specialists who should be advocating for palliative services.

One of the most prevalent misconceptions is that palliative care is solely for those who are at the end of life or are dying. Many doctors, for instance, were said to associate palliative care with giving up on a patient, particularly when it comes to children.

When it comes to communities in Kenya, there is a cultural taboo around discussing death, especially in relation to children. The very idea that a child might need palliative care is considered taboo, making it difficult to introduce conversations about such services early in a child's treatment journey. This leads to delayed referrals and often prevents families from accessing the full scope of care that could improve their child's quality of life.

Due to these misconceptions and stigma, even when paediatric palliative care facilities are developed, they would be underutilized. Stakeholders noted that efforts to establish dedicated facilities for children have failed in some instances because families and healthcare workers are hesitant to engage with palliative services, fearing it signals a loss of hope or inevitability of death.

It was noted that both healthcare workers and the general public have limited knowledge about what palliative care truly entails. They lack a comprehensive understanding of the broad scope of palliative care, which is not limited to end-of-life support but also includes managing pain, improving quality of life, and providing emotional and psychological support for patients with chronic or life-limiting conditions. In light of this, majority of the stakeholders therefore stressed the urgent need for more education and awareness creation on palliative care, not just for the public but also for healthcare workers.

4.8 Supply Chain Management

One of the primary concerns raised by stakeholders is the inconsistency in the supply of essential medicines for palliative care. This inconsistency impacts the availability of key drugs, especially in lower-level healthcare facilities, leading to disruptions in the care of children with life-limiting illnesses.

Additionally, the process of introducing new medicines into the Kenyan market is fraught with regulatory challenges, especially when it comes to unregistered products. Before a new palliative care medicine can be made available, it must go through the Pharmacy and Poisons Board for approval. This regulatory process often involves significant delays, loops, and hurdles, preventing timely access to lifesaving or life-enhancing medications for children in need of palliative care.

To tackle the supply chain challenge, majority of the stakeholders emphasize the importance of strengthening the Kenya Medical Supplies Authority (KEMSA) to ensure the efficient procurement and distribution of palliative care medicines. KEMSA plays a crucial role in the supply chain, but its capacity to manage the consistent supply of palliative care drugs needs enhancement. Improving KEMSA's processes for procuring, storing, and distributing medicines, including palliative care drugs, would help address supply gaps and ensure that these medications reach all corners of the country in a timely manner. Further to this, there is a consensus by many of the stakeholders that a more structured and programmatic approach is necessary to manage the supply chain of children's palliative care medicines. These includes; -

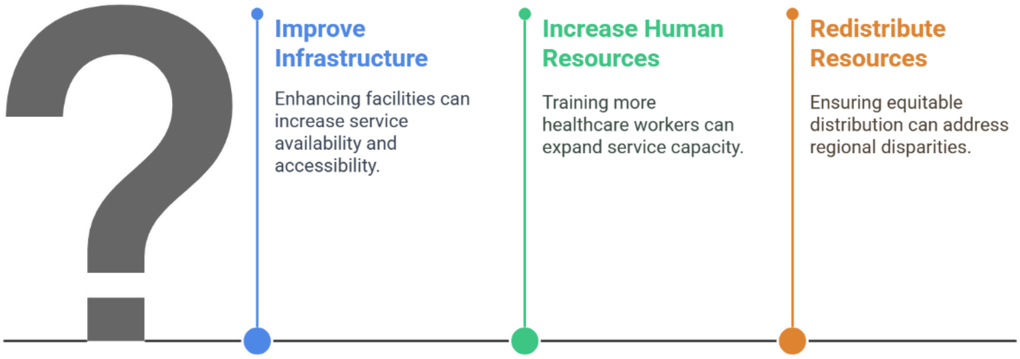
- creating a program that can ensure the continuous availability of essential medicines,
- mitigate supply chain disruptions, and
- ensure that medications are available at all levels of care, including at the community level where many children requiring palliative care reside.

Lastly, stakeholders strongly advocated for exploring partnerships with the private sector to ensure a more consistent supply of palliative care medicines and essential commodities.

4.9 Health Infrastructure

One of the key challenges mentioned is the scarcity of healthcare facilities where children's palliative care is available.

How to address the scarcity of children's palliative care facilities?



Majority of the stakeholders expressed concern over the public sector's inability to meet the demand for children's palliative care services. The lack of infrastructure is compounded by limited human resources and insufficient training for healthcare workers to provide these services.

This shortage is a significant barrier, particularly for vulnerable populations who rely on public healthcare. The problem is exacerbated by an uneven distribution of resources, with urban areas often better equipped than rural regions.

Most stakeholders advocated for a holistic approach where palliative care is recognized as an essential part of healthcare for children with life-limiting conditions. They emphasized the need to integrate palliative care services at all levels of the healthcare system, ensuring it is regarded as a critical necessity rather than an afterthought. Such integration would enhance the quality of life for children and their families and significantly strengthen the healthcare infrastructure for paediatric palliative care.

The development of child-friendly formulations was also highlighted, to cater to the specific needs of paediatric patients. There are concerns about stigma and reluctance among healthcare workers regarding the use of strong medications for children, which can be mitigated through proper training and awareness.

4.10 Leadership and Governance

Leadership and governance in the health sector are crucial for shaping policies, setting strategic direction, and ensuring accountability to achieve improved health outcomes. Effective leadership involves making informed decisions that prioritize public health needs, optimize resource allocation, and foster collaboration among key stakeholders. Governance, meanwhile, ensures that robust systems are in place to regulate healthcare delivery, uphold standards, and maintain transparency. Strong leadership and governance are essential for driving reforms, improving service delivery, and ensuring equitable access to quality healthcare for all.

Majority of the stakeholders noted that the current palliative care (PC) policy provides a starting point for leadership and governance in the sector. However, it falls short in adequately addressing child palliative care (CPC). The constitutional guarantee of the right to the highest quality healthcare services and the government’s commitment to Universal Health Coverage (UHC) under the Sustainable Development Goals (SDGs) can be leveraged to drive CPC. UHC is intended to cover the full spectrum of health services, including curative, preventive, rehabilitative, and palliative care.

4.11 Public Participation and Stakeholder Engagement

A broad-based engagement in the development and implementation of children's palliative care policy was echoed by most of the stakeholders. They stressed the need for a collaborative and inclusive approach, involving a wide range of actors from different sectors. This includes healthcare providers, community-based organizations (CBOs), faith-based organizations (FBOs), non-governmental organizations (NGOs), civil society groups, and government bodies such as the Ministry of Health, the Ministry of Education and the Ministry of Agriculture, health professionals' training institutions, professional associations and regulatory bodies, and persons with lived experiences of palliative care needs. Engaging these diverse stakeholders ensures that the policy is comprehensive, addressing the various aspects of care, training, and resource allocation needed for children's palliative care.

Moreover, majority of the stakeholders called for continuous dialogue between key players, such as healthcare professionals, county and national leaders, caregivers, regulatory bodies, and professional associations. This ensures that the policy reflects the needs and experiences of those providing care, as well as the families and children receiving it. They also highlighted the role of donor organizations, politicians, and development partners in supporting policy implementation and funding, advocating for their involvement from the early stages of policy development.

Furthermore, stakeholders identified gaps in the engagement with the private sector and called for better mapping of private healthcare providers' roles in palliative care.

To ensure successful policy implementation, stakeholders emphasized the importance of regular monitoring and feedback from all levels, including community and patient perspectives, to guide strategic planning and improvements in service delivery. This broad engagement will help create a more sustainable, well-rounded policy that supports the long-term integration of palliative care for children into the healthcare system.

5. CONCLUSION, RECOMMENDATIONS AND ROADMAP TO CHILDREN'S PALLIATIVE CARE IN KENYA

5.1 Conclusion

The policy gap analysis of children's palliative care reveals critical areas for improvement across Kenya's healthcare system. There is a need for a holistic approach that addresses physical, emotional, and spiritual needs while integrating palliative care with other health services.

While there is a general legal and policy framework supporting health and children's rights in Kenya, only the Health Act and the Cancer Prevention and Control Act expressly provides for palliative care. This Act underscores the importance of integrating palliative care within cancer treatment, recognizing the critical need for pain relief, psychosocial support, and quality of life improvements for paediatric cancer patients. This need underpinned in the Act principally on matters cancer care gives the implication that palliative care in children is largely required by children diagnosed with cancer whereas cancer takes up a smaller percentage of children in need of palliative care.

Thus, while Kenya has made significant strides in integrating palliative care into its healthcare system, the absence of explicit legal provisions and policies for paediatric palliative care, aside from the Cancer Act, reveals a gap in the legal framework. To ensure all children with life-limiting conditions receive adequate care, there is a need to develop and enforce specific laws, policies, strategies and/or guidelines dedicated to paediatric palliative care, expanding beyond cancer care to encompass all relevant health conditions.

This absence of an explicit framework is also seen with the Palliative Care Policy which does not exhaustively provide for children's palliative care, who have unique needs when it comes to palliative care.

With the existing challenges, including a focus on cancer and HIV, inadequate training resources, and insufficient data, there is a clear call for broader integration and standardization of palliative care. Enhancing financing, expanding coverage in health insurance, and improving data collection are essential to advancing palliative care services. Addressing systemic barriers and developing a robust, community-based model will be crucial for ensuring comprehensive and equitable care for children with life-limiting conditions.

In addition, Kenya can borrow from South Africa and the United Kingdom to integrate the important aspects into its system. Some of the policies and practices being implemented in the above two countries if applied in Kenya would ensure that children access palliative care. Policies should move from policy to practice.

5.2 Recommendations

1. Policy Implementation and Monitoring

Kenya has established a legal and policy framework to support paediatric palliative care, which provides for access and quality palliative care, integration and coordination, education and funding. Effective implementation and continuous improvement of these frameworks are essential to ensure that all children in need receive compassionate and comprehensive palliative care, particularly with the palliative care policy. It is important to strengthen the implementation of existing policies through robust monitoring and evaluation mechanisms.

2. Enhance Awareness and Expand the Scope of Children's Palliative Care and increase stakeholder collaboration

Develop and implement national awareness campaigns that clarify the full scope of children's palliative care. These should target both healthcare professionals and the public to address misconceptions that palliative care is solely for end-of-life scenarios. This holistic definition also needs to be entrenched in the child palliative care policy.

Further, it is key to engage stakeholders, including government, private sector, non-governmental organisations and international partners, to advocate for stronger paediatric palliative care services and promote interdisciplinary collaboration to ensure holistic care for children with life-limiting conditions.

Engaging a palliative care champion who would amplify and advocate for the need would also make it possible to increase awareness creation.

3. Strengthen Human Resources and Training

Establish accredited local training programs specifically in paediatric palliative care and ensure career progression pathways for healthcare workers as echoed in different policy and legal frameworks to ensure availability of highly specialised quality care in the country.

4. Develop a National Palliative Care Indicators

Integrate palliative care data into the Kenya Health Information System (KHIS) to facilitate the measurement of palliative care needs and enable centralized tracking and monitoring of cases across all relevant conditions. Additionally, promote research by securing funding and incorporating palliative care into the national research agenda to support evidence-based improvements in service delivery. To ensure evidence-based policy development and implementation, it is important to adopt a culture in which research plays a significant role in guiding policy formulation and action to improve the health and development of the people of Kenya as reiterated in the Palliative Care Policy.

5. Improve Financing for Children's Palliative Care

Advocate for the inclusion of comprehensive palliative care services in the national social health insurance scheme - the Social Health Insurance Fund (SHIF). Although the new scheme now covers inpatient services, it should also be extended to outpatient and home-based care. Further, the government should ensure dedicated budget lines for paediatric palliative care at the national and county levels and ensure equitable distribution of the funding and resources.

6. Ensure Consistent Access to Essential Medicines

Expand the national essential medicines list to include a comprehensive range of palliative care drugs tailored to children. Streamline procurement and distribution systems through KEMSA to ensure availability across all health facilities.

7. Establish a Community-Based Health Service Delivery Model and Streamline Coordination of Care across all Service Delivery Levels

Develop and implement a structured home-based and community-level palliative care models linked to healthcare facilities, ensuring continuity of care across the health system. Additionally, develop communication channels to enhance well-coordinated upwards and downwards referral of clients within the healthcare system.

8. Strengthen the Supply Chain for Palliative Care Medicines

Reform the regulatory process for introducing new palliative care drugs and strengthen KEMSA's role in managing the consistent supply of medications. Establish a structured approach for distributing medicines to all healthcare levels.

9. Enhance Health Infrastructure for Paediatric Palliative Care

Integrate palliative care services into all levels of the healthcare system, with a focus on expanding infrastructure and services in under-resourced rural and urban areas.

10. Promote Broad-Based Stakeholder Engagement and Public Participation

Establish a multi-sectoral approach to policy development and implementation, involving a broad audience of stakeholders including healthcare professionals, NGOs, government bodies, and private sector actors. Ensure regular monitoring and feedback mechanisms.

5.3 Roadmap

The Palliative Care Policy provides for annual, mid-term and end-term reviews.

The first step is therefore to review the Policy and conduct and monitoring vis a vis the impact level indicators to ascertain whether the needs of children are being met or not.

Given that the policy barely provides for palliative care for children. The second step after monitoring, should be the revision of the policy to provide for the unique needs of children in need of palliative care.

The policy states that the MOH may revise the policy depending on emerging issues.

The third step to the road-map should be to develop specific action plans and guidelines for paediatric palliative care within the broader health policy framework that would form part of a national strategy for paediatric palliative care.

BIBLIOGRAPHY

PRIMARY SOURCES- ACTS OF PARLIAMENT, NATIONAL STRATEGIES AND POLICIES

1. **Cancer Prevention and Control Act**, 2012, Government of Kenya
2. **Children Act**, 2001, amended 2022, Government of Kenya
3. **Constitution of Kenya**, 2010.
4. **Facilities Improvement Financing Act**, 2023, Government of Kenya
5. **Government of Uganda**, *Narcotic Drugs and Psychotropic Substances (Control) Act*, 2023.
6. **Kenya Health Policy 2014-2030**, Ministry of Health, Government of Kenya.
7. **Kenya Palliative Care Policy 2021-2030**, Ministry of Health, Government of Kenya.
8. **Kenya Vision 2030**, Government of Kenya
9. **National Guidelines for Cancer Management in Kenya**, 2013, Ministry of Health, Government of Kenya.
10. **Ministry of Health, Uganda**, *The National Health Policy*, Government of Uganda, 2010.
11. **UN Convention on the Rights of the Child**, 1989.

SECONDARY SOURCES- INTERNET SOURCES AND JOURNAL ARTICLES

12. **African Palliative Care Association**, *Palliative Care in Africa: Delivery*, n.d., accessed 22 August 2024, https://www.africanpalliativecare.org/what-we-do/awareness/palliative-care-africa-delivery.
13. **African Palliative Care Association**, *Guidelines for Using the APCA African Children's Palliative Outcome Scale*, 2012.
14. **Chong, P. H., De Castro Molina, J. A., Teo, K., and Tan, W. S.**, 'Paediatric Palliative Care Improves Patient Outcomes and Reduces Healthcare Costs: Evaluation of a Home-Based Program', *BMC Palliative Care*, 17.1 (2018), https://doi.org/10.1186/s12904-017-0267-z.
15. **Connor, S. R., Connor, S., Claire, W., Ma, M., and Jaramillo, E.**, *Global Atlas of Palliative Care at the End of Life*, 2nd end, 2014, http://www.thewhpca.org.

16. **International Children’s Palliative Care Network (ICPCN)**, *Children’s Palliative Care in South Africa: The Facts*, November 2022, https://icpcn.org/wp-content/uploads/2022/11/Children_s_Palliative_Care_in_South_Africa_-_The_Facts.pdf.
17. **Sasaki, H., Brousseau, M. C., Marston, J., and Mori, R.**, 'A Scoping Review of Palliative Care for Children in Low- and Middle-Income Countries', *BMC Palliative Care*, 16.1 (2017), https://doi.org/10.1186/s12904-017-0242-8.
18. **Sepúlveda, C., Marlin, A., Yoshida, T., and Ullrich, A.**, 'Palliative Care: The World Health Organization’s Global Perspective', *Journal of Pain and Symptom Management*, 24.2 (2002).
19. **Together for Short Lives**, *NICE Guidelines on Children's Palliative Care*, https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/nice-guidelines/.
20. **UK HealthCare**, *Palliative Care*, https://ukhealthcare.uky.edu/kentucky-childrens-hospital/services/support-services/palliative-care.
21. **UNICEF and ICPCN**, *Assessment of the Need for Palliative Care for Children: Three Country Report: South Africa, Kenya and Zimbabwe*, 2013.
22. **World Health Organization (WHO)**, 'Palliative Care', 5 August 2020, https://www.who.int/news-room/fact-sheets/detail/palliative-care.
23. **Worldwide Hospice Palliative Care Alliance**, *Global Atlas of Palliative Care*, 2nd edition, 2020, https://www.thewhpca.org.

Funding Partners

Foundation S
THE sanofi COLLECTIVE

St. Jude Children’s Research Hospital®
Finding cures. Saving children.

This Report was developed by RT Associates Advocates and Medwise Solutions Consultancy Ltd.

Kenya Hospices and Palliative Care Association

P.O. Box 20854, 00202

Top Plaza, 2nd floor, Suite 2-2

Kindaruma Road off Ngong Road

Nairobi, Kenya

www.kehpca.org