

Status of Palliative Oncology Care for Children and Young People in Sub-Saharan Africa: A Perspective Paper on Priorities for New Frontiers

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abstract

PURPOSE The burden of cancer disproportionately affects low- and middle-income countries. Low 5-year survival figures for children with cancer in low-income countries are due to late presentation at diagnosis, treatment abandonment, absence of sophisticated multidisciplinary care, and lack of adequate resources. The reasons for late presentation are partly due to limited awareness of cancer symptoms, high treatment costs, and facility-level barriers to timely access to treatment. Given the systemic challenges, the regional need for palliative oncology care for children care is high. Despite the enormity of the need for palliative oncology for children with cancer in Africa, its level of development remains poor. This paper presents the evidence on the status of palliative oncology care for children in sub-Saharan Africa.

METHODS This review provides an overview of the current status of palliative oncology care for children in sub-Saharan Africa, using the WHO building blocks for health systems strengthening as reference points, before proposing a forward-looking prioritized agenda for its development.

RESULTS We noted that survival rates for children with cancer remain much poorer in Africa compared with developed countries and palliative oncology care resources are scant. Our results also show low coverage for palliative oncology care services for children, lack of a critical mass of health workers with the skills to deliver the care, a lack of robust documentation of the burden of cancer, widespread lack of access to essential controlled medicines, limited funding from government and limited coverage for palliative oncology care in most cancer control plans.

CONCLUSION This review highlights priority areas for action that align to the WHO health system building blocks for strengthening health systems.

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INTRODUCTION

Epidemiologic data on childhood cancer survival are important for policy development, priority setting, and planning. As per global estimates of diagnosed cases, the 5-year net childhood survival is 37.4%; however, there are large regional variations ranging from 8.1% (4.4-13.7) in eastern Africa to 83.0% (81.6-84.4) in North America.¹ Differences in survival gaps between developing and developed countries can be as high as 70% and can be explained by gross inequities in treatment access, quality of care, and its affordability.¹ Other explanatory factors include late presentation at diagnosis, treatment abandonment, absence of sophisticated multidisciplinary care, and lack of adequate resources.¹ Reasons for late presentation include limited awareness of cancer symptoms, high

treatment costs, and facility-level barriers for timely access to treatment.²

The incidence of childhood cancer ranges from 50 to 200 per million children and 90 to 300 per million adolescents.³ These data, however, likely substantially underestimate the true incidence rates of pediatric cancer in Africa, where widespread lack of robust childhood cancer registries makes it problematic to collect surveillance data⁴ and existing data are often incomplete and provide very limited information on multiple childhood cancers.⁵ Estimates from African countries with functioning registries show an increasing incidence of pediatric cancers, for example, a survey that included 21 centers from 18 sub-Saharan African countries. For example, in a survey that included 21 centers from 18 sub-Saharan African

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CONTEXT

Key Objective

To establish the state of palliative care in pediatric oncology services in sub-Saharan Africa.

Knowledge Generated

Palliative care in pediatric oncology in sub-Saharan Africa remains largely underdeveloped. A public health systems approach prioritizing service delivery, health workforce, information systems, access to essential medicines, health systems financing, leadership, and governance should be prioritized for service development.

Relevance

Promoting equitable access to palliative care in pediatric oncology in sub-Saharan Africa can only be achieved via the public health model. We propose health systems–based strategies to support the integration of palliative care in existing pediatric oncology services.

countries, with data that differed from center to center, including cases from 1985 to 2011, the proportion of childhood cancer of all cancers ranged between 1.4% in Ghana and 10.0% in Rwanda. In Southern Africa, Kaposi sarcoma was the most common malignancy in children in Mozambique (15.8% of all cases) and the second most common in Zambia (15.6%) and in Malawi (12.4%). In Eastern Africa, Uganda recorded Kaposi sarcoma as the most common tumor in children (22.0%), whereas two Kenyan centers reported mainly Burkitt lymphoma (25.1% and 37.1%, respectively). In Central Africa, Congo classified retinoblastoma as the most common childhood cancer with an incidence of 20.1%. In Western Africa, non-Hodgkin lymphoma was the most common in Ghana (53.6%), in Ivory Coast (73.6%), and in Mali (32.7%). Nephroblastoma remains the most common solid tumor in Africa exceeding 10% of total pediatric cancers in many countries (Rwanda 21.3%, Senegal 22%, Ivory Coast 14.5%, Mali 17.6%, and Congo 15.5%).⁵

A primary concern is the lack of data on children whose details are never documented in cancer registries and those possibly misdiagnosed, leading to a substantial underestimate⁶ and missed opportunities for patients to be diagnosed and treated.⁷ Available data are therefore more a reflection of the number of cases of childhood cancers being identified that progress into care for treatment.⁷ These estimates continue to show a two-to-threefold increase in their incidence in low-index compared with high-index Human Development Index countries,⁸ which may be attributed to improved case finding and diagnosis of cancer.

Given the challenges inherent to disease burden and the health system related to children obtaining access and receiving quality childhood cancer care, the regional need for both primary (ie, from pediatric oncologists) and speciality (ie, trained palliative care physicians) palliative care in pediatric oncology is high.⁹ Indeed, the WHO recommends the integration of palliative care into

pediatric oncology services to improve the overall quality of care and associated outcomes.¹⁰ In high-income countries, pediatric palliative care (PPC), underpinned by a person-centered approach, improves care satisfaction and quality of life (QoL).¹¹ There is also emerging evidence for the cost-effectiveness of specialist PPC providers and their ability to improve symptom management, mitigate health-related suffering, and improve the QoL of affected children and their families' care in resource-limited settings.¹² Despite the enormous need for palliative cancer care for children in Africa,¹³ the level of service development remains poor.¹⁴ The continent is, however, attempting to prioritize the development of palliative care services as a core component of care throughout the continuum of life, in line with the World Health Assembly Resolution.¹⁰

FRAMEWORK

Providing an overview of the current status of oncologic PPC in sub-Saharan Africa and the priority needs to improve it is critical to informing person-centered service development that mirrors the needs of patients and their families and optimizes care outcomes.¹⁵ Our analysis is underpinned by the WHO health system building framework. This framework constitutes each of the following blocks: (1) service delivery, (2) health workforce, (3) health information systems, (4) access to essential medicines, (5) financing, and (6) leadership or governance.¹⁶ This framework was preferred as it offers a generic approach to building resilient health systems, as well as their monitoring and evaluation, that allows for regional comparison of strengths and gaps in health systems and for setting prioritized service development agenda. Prioritizing these building blocks helps guide a minimum scope to stimulating systems' strengthening, monitoring performance, and evaluation. Each building block is discussed in the sub-Saharan African context, with priorities highlighted to foster service development in line with the World Health Assembly Resolution.¹⁰

HEALTH SERVICE DELIVERY

Pediatric cancer care populations have a high burden of complex and multidimensional symptoms^{17,18} that are associated with severe health-related suffering.⁹ Nevertheless, the availability of PPC in the region remains critically limited, with some countries having no known activity or capacity.¹⁴ This lack of supportive care within cancer health services has been given as a justification for withdrawing active cancer treatment in some situations, thereby negatively affecting treatment outcomes.¹⁹ Given the importance of multidimensional care in the pediatric cancer service development continuum, the integration of PPC in pediatric oncology supportive care services warrants emphasis²⁰ and should be considered as *standard care*²¹ alongside traditional interventions such as transfusion medicine.

Integrated service development is also essential to ensure that children receive high-quality evidence-based services. In a systematic review that established the evidence for PPC models, interventions, and outcomes, the authors noted the lack of outcomes' evidence, among other knowledge gaps.²² Similarly, studies have highlighted the lack of appropriate outcome measures in this field,²³ despite being integral to the quality assessment and health quality improvement framework.²⁴ The lack of robust outcome measures means that assessing the effectiveness of services, or developing an evidence base for the impact of interventions, is problematic. Although tremendous progress has been made in developing appropriate outcome measures for adult palliative care,²⁵ much more work needs to be undertaken in PPC. Despite the lack of a robust evidence base, few studies conducted provide an insight into the configuration of person-centered care from the perspective of children and their families in sub-Saharan Africa,²⁶ the pressing multidimensional needs of children with cancer,²⁷ and the potential benefits of person-centered PPC in resource-limited settings.¹²

HEALTH WORKFORCE

Poor cancer survival in sub-Saharan Africa has been partly attributed to poor health care systems, lack of sufficient numbers of health workers, and limited staff education and training opportunities to meet patients' and families' care needs.²⁸ Palliative care is of necessity multidisciplinary, as meeting the multidimensional needs of children and their families requires multidisciplinary teams. For example, if there is uncertainty about the outcome of treatment, child and family needs range from participating in difficult conversations (breaking bad news)—which must be sensitively addressed—and managing multidimensional symptoms and concerns, supporting family and sibling needs, and providing advance care planning before a disease's terminal phase and grief and bereavement support, all under a person-centered approach (Fig 1).^{18,29} Palliative care integration is not only important in improving

end-of-life outcomes but can also improve outcomes of children living with advanced cancer and their caregivers and families. Quality care matters irrespective of the expected treatment outcome as poor-quality deaths can result in complicated grief and bereavement outcomes, which can, in turn, contribute to poor mental health and significant morbidity in surviving family members.³⁰

The number of patients accessing PPC is low (3%), and this is explained by the poor development of PPC services. The estimated services delivering PPC stand at 4% for the AFRO African region.³¹ The 2017 Atlas for Palliative Care in Africa also indicated low availability of PPC services; the country with the highest number of service outlets was South Africa (with 20), followed by Nigeria (10), Malawi (seven), and Zambia (four).¹⁴

Pediatric oncology service development equally remains low. In 1990, only four pediatric oncology services were available in North Africa; over time, 22 centers have been opened up in 18 Francophone countries.³² In a cross-sectional study that aimed to profile the status of resources for pediatric oncology services in a cross-section of hospitals in Africa, it was shown that the care was largely provided by nonpediatric oncologists and the lack of radiotherapy services was notable (available at 55% of the 38 facilities). Broadly speaking, palliation services were reportedly available at 71% of the facilities.³³

A robust human resource workforce is pivotal to integrated pediatric palliative oncology service development. Cancer care strategies have been mainstreamed to include prevention and early detection, treatment (by surgery, radiation therapy, or chemotherapy), supportive care, palliative care, end-of-life care, and survivorship. Such complex care models demand trained multidisciplinary teams with skills to meet the multidimensional needs of patients and their families.³⁴ The status of human resource development for pediatric oncology in sub-Saharan Africa is, however, still in the embryonic stage, and consequently, the importance of capacity building through access to sustainable quality education and training cannot be overemphasized. The regional human resource inventory is characterized by too few pediatric oncologists and specialized nurses and a lack of other multidisciplinary support members (including palliative care providers).

Key players, such as the Africa Pediatric Fellowship Network, WHO technical advisors, Health Ministry funding, and the Education in Palliative and End-of-Life Care pediatrics curriculum initiative,³⁵ are training or capacity building platforms. Care providers can be trained online through continuous medical education sessions, fellowships, master's degree trainings, short courses through deployment in palliative care positions, lectures and grand rounds, bedside teaching, weekend courses, and placements in palliative care organizations. In Table 1, we provide a summary of existing courses available in Africa.

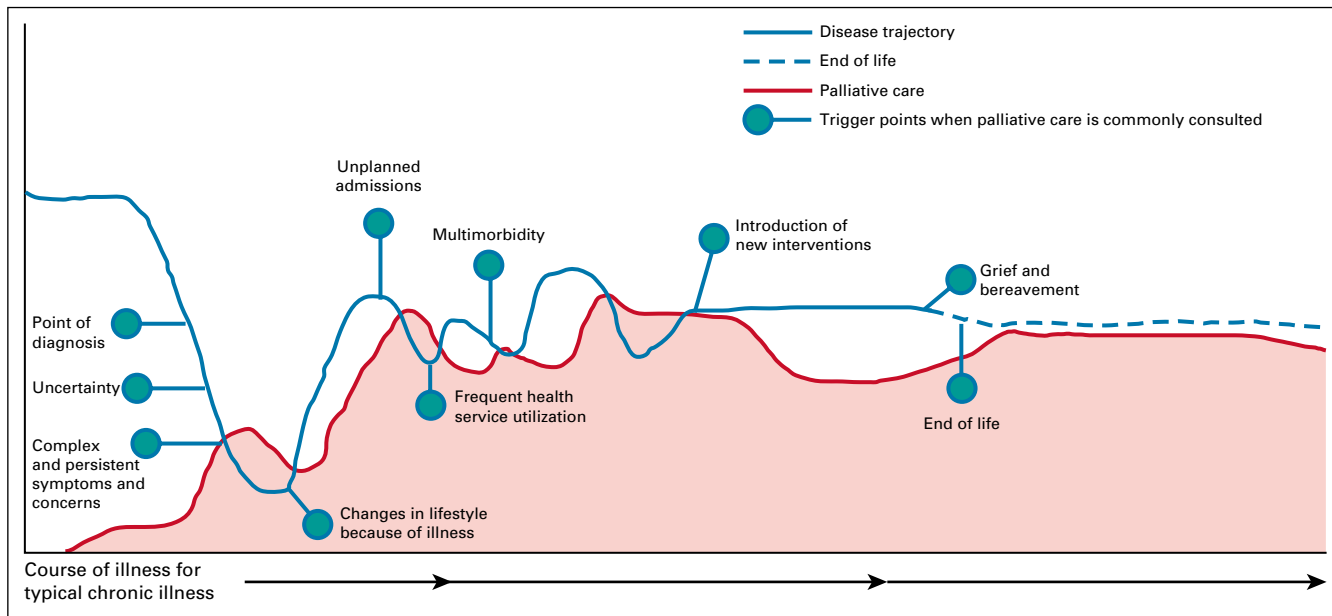


FIG 1. Trigger points for palliative care along the disease trajectory.

Approximately nine countries in Africa have a national palliative care plan or program to strengthen the development of a public health primary care approach to ensure access to this essential service,³⁶ and continuous development of education and training opportunities has been recorded in the region,³⁷ with curricula integrating PPC. These should serve as an opportunity to strengthen pediatric cancer services by integrating PPC to deliver care that meets the needs of patients and their families. Importantly, such plans are insufficient without adequate budgetary support, a critical consideration.

HEALTH INFORMATION SYSTEMS

Robust health information systems are pivotal to service development. The lack of quality local data is a barrier to evidence-based practice, data-driven decision making, and the development of services tailored to the needs of African populations.³⁸ For example, data on the incidence and prevalence of cancers are largely lacking because of the limited coverage of national cancer registries, which compromises documenting gaps and reporting morbidity and mortality data. In 2012, the African Cancer Registry Network reported that only 22 of the 54 countries in sub-Saharan Africa (40.1%) were contributing to this database, and this only slightly increased to 25 (46.3%) in 2014.³⁹ Even where such registries are available, the data quality is largely poor and, as such, the region routinely relies on estimates to understand the extent of the cancer burden.

The registry of cancer cases becomes more complicated with childhood cancers—given their low incidence compared with those for adults—as large populations may be required to generate substantial measures of disease burden.⁴⁰ The lack of data sharing efforts is also a challenge

in this field as partners continue to work in silos. For example, the African Cancer Registry Network does not share data publicly, which makes health services research challenging. The increasing concerns over and development of global privacy laws exacerbate this problem. This is a highly political issue, but it calls into question how to fund registries, what is the purpose of a registry, and who owns the data and rules to gain access. Another concern is the lack of a metric for survival despite its importance in planning and decision making.⁷ Incidence is needed to compute survival, but the latter is often ignored as adult registries de-emphasize it, instead focusing on risk prevention rather than treatment. Without detailed epidemiologic data collection by paying attention to critical demographic factors such as age, sex, and cancer type, profiling the cancer burden is difficult. Several factors contribute to this systemic problem, including lack of funding, difficulties in case finding, limited diagnostic capacity, lack of treatment facilities, low public awareness, and the general poor development of health information systems.⁴⁰

At a service delivery level, health management information system development initiatives continue to take a strong hold in Africa and mandatory reporting of many disease entities by all health facilities is required by most African ministries of health.⁴¹ Some countries—although a small minority (ie, Uganda and Malawi)—in sub-Saharan Africa are now commendably leveraging these platforms to integrate palliative care indicators into the national health management information system.^{42,43} This is important not only for monitoring service performance and coverage but also for generating longitudinal data to inform large-scale quality evaluations and the development of area-based

TABLE 1. Examples of Palliative Care or Rehabilitation Courses Offered in Africa

Institution	Palliative Care or Rehabilitation Course	Course Description and Other Notes
Institute of Hospice and Palliative Care in Africa (at Hospice Africa Uganda)	Health Professionals Course in Palliative Care	This is a 5-day course for doctors, clinical officers, registered nurses or midwives, pharmacists, and dispensers. Participants are introduced to a wide range of palliative care topics to equip them with modern methods of pain assessment and management of patients with cancer, HIV, or AIDS at any stage of the disease in resource-limited settings. It also aims at improving communication and clinical skills. The course takes a holistic approach
Institute of Hospice and Palliative Care in Africa (at Hospice Africa Uganda)	Rapid Morphine Prescribers Course	This 6-week course is offered to clinical officers who want accreditation as morphine prescribers. The course has nine modules that aim to equip clinical officers with the knowledge and skills needed to prescribe morphine as part of a holistic palliative care service
Institute of Hospice and Palliative Care in Africa (at Hospice Africa Uganda)	Diploma in Clinical Palliative Care	This diploma in clinical palliative care is a 1-year full-time course or a distance learning course that provides clinical officers, registered nurses, and midwives the skill set needed to legally prescribe morphine and deliver specialized palliative care. This course combines theoretical course work with intense field training. This course is key to educating experienced health care workers in the field of palliative care so that they become focal persons to provide this vital care in their communities
Institute of Hospice and Palliative Care in Africa (at Hospice Africa Uganda)	Diploma in Palliative Care	This is a 1-year program given as a distance learning course for clinical practitioners interested in palliative care and attracts students across Africa. It is also offered by the institute in affiliation with Makerere University. The institute teaches the program, and the Diploma is conferred by Makerere University. Students who successfully complete this program can join the degree program in the second year
Institute of Hospice and Palliative Care in Africa (at Hospice Africa Uganda)	Bachelor of Science in Palliative Care	This degree is a 3-year distance learning program open to clinical practitioners with an interest in palliative care. It is aimed at a diverse audience and attracts students from across Africa. This program is offered by the institute in affiliation with Makerere University. The institute teaches this program, and Makerere University confers the degree upon successful completion of the coursework. Applicants with a diploma in palliative care from any recognized institution of higher learning can join the program in the second year
Institute of Hospice and Palliative Care in Africa (at Hospice Africa Uganda)	Postgraduate Diploma in Palliative Medicine	The postgraduate diploma in palliative care is a distance learning program designed for health professionals with a bachelor's degree in palliative care or any allied health-related discipline. The health professional should be working in or intending to work in the area of palliative care or supportive care. Health care professionals with a master's degree in health care science can also enroll in this program A student who completes the postgraduate diploma successfully can join the master's program in the second year
Institute of Hospice and Palliative Care in Africa (at Hospice Africa Uganda)	Master of Science in Palliative Care	The master's degree in palliative care is a 2-year distance learning program taught by the institute and awarded by Makerere University. It is designed to train and develop specialists and leaders in clinical palliative care, research, and education and create a critical mass of palliative care specialists in sub-Saharan Africa to facilitate the integration of palliative care into national health care systems and manage integrated palliative care. The program is open to health care professionals with a bachelor's degree in palliative care or any other health-related degree. Health care workers with a master's degree and those with a postgraduate diploma in palliative care can also enroll in the course

(Continued on following page)

TABLE 1. Examples of Palliative Care or Rehabilitation Courses Offered in Africa (Continued)

Institution	Palliative Care or Rehabilitation Course	Course Description and Other Notes
Mulago School of Nursing (Uganda)	Advanced Diploma in Palliative Care Nursing	This diploma is a 1-year full-time course taught by the Mulago School of Nursing and Midwifery. The program is open to health care workers with a certificate in nursing, midwifery, psychiatry, and comprehensive nursing with an A level certificate
Mildmay Uganda Hospital (Uganda)	Higher Diploma in Children's Palliative Care	This diploma includes eight modules that are taught in 8 weeks (face-to-face), with a period of 6 weeks between the modules. The 6 weeks in between modules are used for clinical placement and assignments. It targets health care workers who are already professionals in their areas of specialty, especially doctors, clinical officers, nurses, physiotherapists, counsellors, social workers, psychologists, and spiritual leaders
Nairobi Hospice in collaboration with Oxford Brookes University (Kenya)	Diploma in Palliative Care	This diploma includes programs to help develop skilled palliative care practitioners in Africa, whose practice will be underpinned by thoughtful application of the principles of palliative care, critical understanding of relevant theory and research, high-quality assessment and clinical management skills, and a self-reflective and sensitive approach to patient care. Applicants must be a registered health care or social care professional (ie, having membership in an approved professional body or equivalent) in the country in which they are currently practicing, have a minimum 1-year experience of professional practice, and be currently employed in, or have access to, a suitable practice setting
The National Cancer Institute, Cairo (Egypt)	Master's degrees in Pain Management and Palliative Care incorporated in the curriculum of the oncology nursing program	Not stated
University of Cape Town (South Africa)	Diploma in Palliative Care	Students should have at least a bachelor's degree in a field related to palliative care. This is a blended learning course at NQF 8. Students must have this degree to enter the MPhil in palliative care
University of Cape Town (South Africa)	MPhil (palliative care)	This course includes research components and advanced palliative care competencies
University of Cape Town (South Africa)	Short Course in Basic Palliative Care	This short course in basic palliative care is a 40-hour online course
University of Cape Town (South Africa)	Short Course in Palliative Care for Oncologists	This course is designed to upskill and integrate palliative care in the oncology registrar program. It is a blended learning program in which the university provides online support and academic oncology departments give face-to-face teaching
University of Malawi (Malawi)	Bachelor of Science (BSc) in Palliative Care	This course aims to provide training in palliative care that is suited for Malawi and the sub-Saharan context. It provides for multiple exit opportunities. Some learners exit with a university diploma, whereas others exit with a degree. Because of its modular arrangement, the course is being provided full time, but plans are underway to transition to a block release program. Some learners may exit the course after completing four semesters. If they have successfully completed the course units for the period, they will get a Diploma in Palliative Care or a diploma in Nursing or Clinical Medicine. This course requires a working experience of at least 2 years in the clinical or nursing area. It is registered with a relevant regulatory body (eg, Medical Council of Malawi or the Nurses and Midwives Council of Malawi)

Abbreviation: NQF, National Qualifications Framework.

quality improvement plans to enhance efficiency in service delivery. These countries are, however, just two beacon sites.

At the child and family level, there is a dearth of evidence on best care models and outcomes in PPC.²² In Africa, patients with cancer can receive care at home, within communities, in outpatient settings, or in the inpatient ward. Data must therefore be captured across these care models. Although most countries have data at the health facility level, community-based health information systems remain largely underdeveloped; however, this is where the majority of patients are cared for and where data are most needed. Additionally, the care pathways experienced by children with different types of cancers have not been documented in the region. These pathways could inform the development of interventions geared toward promoting the detection of early signs, early referrals from all key points of health care systems, and enrollment into pediatric oncology programs to reduce late presentation rates, which have long been documented as a cause for poor prognosis.⁴⁴

Moreover, the WHO consistently recommends person-centered health systems to optimize care outcomes. Now that progress is being made in configuring person-centered PPC and in developing person-centered outcome measures, regional efforts to promote the implementation of these measures in cancer care should be prioritized. The African Children's Palliative Care Outcome scale is a novel promising outcome tool that measures the physical, social, and psychologic well-being outcomes of the child and their family. In this way, integrated pediatric cancer care services will be more responsive to the needs of children and their families, as evidenced by such practices being associated with improved communication among patients, families, and health care providers, improved care satisfaction, and some health outcomes.^{11,45} Although evidence for the effectiveness of palliative care has been demonstrated in adult populations, prospective intervention-related data in pediatrics is scant. For example, a randomized prospective clinical trial by Temel et al⁴⁶ demonstrated that early palliative care can improve the QoL and median survival time of patients with metastatic non-small-cell lung cancer, whereas some of the best pediatric-related data include studies such as the one conducted in Asia that demonstrated that home-based PPC in the last year of life reduced hospital admissions and medical costs and improved QoL.¹² Notably, as stated earlier, a robust evidence base does not exist for children, especially in resource-limited settings.

ACCESS TO ESSENTIAL MEDICINES

Lack of access to essential medicines largely contributes to the recognized inequity in the survival rates for patients with pediatric cancer and difficulties in treating symptom-related distress. Cure rates in developed countries exceed 80%, but remain very poor in developing countries,

where up to 90% of cases occur.⁴⁷ The WHO 2017 Global Cancer resolution, which includes childhood cancer in its cancer control mandate, highlights survival inequity as a major concern requiring attention,⁴⁸ and as such, equitable access to essential medication should remain a priority. Measuring access to essential medicines remains a global challenge and a largely under-researched area and receives less attention when reporting on the Sustainable Development Goals.⁴⁹ The situation is even more wanting when it comes to profiling access to pediatric chemotherapeutics.⁵⁰ The International Society of Pediatric Oncology pointed out the urgent need for data on access to chemotherapeutics, with a strong recommendation that this should be tracked in the essential medicines list for children.⁵¹ The tracking of performance on availability can inform progress in interventions such as those of the Clinton Health Access Initiative and the American Cancer Society to increase access to cancer treatment in developing countries⁵² and promote health as a human right.

The combination of limited and poor resource management, both human and financial, results in inadequate treatment infrastructure that disproportionately affects children with cancer.¹ Stefan et al reported the status of diagnostic and treatment facilities in Africa from 16 population-based cancer registries and showed that many centers lacked adequate diagnostic and treatment facilities, leading to the underdiagnosis of pediatric cancers. The study also highlighted that many childhood cancers had higher incidence rates on the continent than in developed countries.⁴⁰

HEALTH SYSTEM FINANCING

Generally, funding for palliative care is limited and few financial resources are available for PPC. Funding has been further affected by the 2008 global economic downturn, and the number of palliative care committed donors has been declining over time. Large donors who have left palliative care include the Diana, Princess of Wales Memorial Fund palliative care initiative and President's Emergency Plan for AIDS Relief.⁵³ The situation has been further exacerbated by the economic consequences of the COVID-19 pandemic, pushing the already marginalized care approach to the peripheries of many international funding agendas. Given the evidence that palliative care improves many outcomes, including potential survival,⁴⁶ it is important to further strengthen the evidence base for cost and cost-effectiveness¹² and inform advocacy efforts toward the integration of palliative care into Universal Health Coverage (UHC).

LEADERSHIP AND GOVERNANCE

States partly demonstrate their commitment to treating cancer by establishing national cancer control plans. These plans detail strategies to address the population burden of cancer through interventions to reduce its incidence, morbidity, and mortality and enhance the QoL of those at

risk of or experiencing cancer. These plans outline the interventions required, how they will be implemented, who will be involved, the resources needed, and how they will be monitored and evaluated. In a global analysis on availability of cancer control plans, in the low-income cluster (n = 24), 22% had a national cancer control plan *and* a national communicable disease control plan, 67% had non-communicable disease control plan alone, 7% had a national cancer control plan alone, and 4% others. In the low-middle-income cluster (n = 38), 53% had a national cancer control plan *and* a national communicable disease control plan, 39% had national communicable disease control plan alone, and 8% had a national cancer control plan alone.⁵⁴ Almost all African countries fall within the group without national cancer control plans, resulting in cancer interventions for children and adults that are poorly planned and resourced. This adversely affects health promotion, cancer prevention, early diagnosis, treatment, rehabilitation, and palliative care. Additionally, only 26% of the plans assessed in low-income countries included PPC.⁵⁴

FORWARD-LOOKING PRIORITIZED AGENDA

Clearly, although some African countries have ongoing processes to deliver better palliative care for children and young adults with cancer, in the majority of sub-Saharan Africa, palliative care in pediatric oncology remains critically underdeveloped and neglected. To address the inequitable access to pediatric palliative oncology care, a multipronged agenda is essential. Following the WHO health system building blocks, this agenda includes the following:

- Health service delivery

Prioritize the development of person-centered PPC, combined with research initiatives to build an evidence base for the effectiveness of appropriate models of care.

- Health workforce

Opportunities for regional learning exist to share resources and identify avenues for training through established centers of excellence in different parts of Africa. Attempts should be made to leverage existing networks, such as the African Organization for Research and Training in Cancer, the International Society for Pediatric Oncology Africa, the Society for Neuro-Oncology Sub-Saharan Africa, the East African Center of Excellence in Oncology at the Uganda Cancer Institute, the African Cancer Institute, and the Africa Radiation Oncology Network.

Approximately nine countries have a national palliative care plan or program, and continuous development of education and training opportunities has been recorded in the region,³⁷ with curricula integrating PPC. These should serve as an opportunity to strengthen pediatric cancer services by integrating PPC to deliver care that meets the needs of patients and their families.

- Health information systems

Additional effort is needed to support African countries to develop palliative care indicators within the context of pediatric cancer care.⁵⁵ Countries should further be supported to integrate these indicators into large databases to track national-level performance and identify areas for improvement. It is also important to ensure that such data are captured across the disease trajectory, from diagnosis and treatment to remission, survivorship or end-of-life care, and bereavement.⁵⁶

- Access to essential medicines

There is an acute need to collect data on the availability of essential medicines in the region to aid the tracking of performance in interventions geared toward scaling access to essential medicines. Moreso, it is urgent that the inequities in treatment access are addressed to improve the QoL and survival rates for children with cancers. There are regional efforts to increase access to cancer and symptom-related treatment, and access to affordable medicines is one of the interventions. Some initiatives include those by the American Cancer Society, the Clinton Access Initiative, and IBM, which are scaling up access to more affordable generic cancer medicines.

- Health system financing

Financing for cancer control and treatment should be integral to regional response strategies and should be integrated into all control plans. PPC plans should be integrated into all national cancer plans to facilitate PPC funding.

- Leadership and governance

For health systems to deliver a person-centered approach, PPC should be integral to regional and national cancer control plans.²⁹ As the region advances the UHC coverage agenda, integrated pediatric cancer palliative care should be central to efforts to address inequity in access to quality care for this vulnerable segment of the population.⁵⁷ A minimum package for palliative care under UHC for Africa has been proposed,⁵⁸ and regional partners should advocate for its inclusion in their national health policies and guidelines.⁵⁹

We realize that this agenda is partly premised on local, intracontinental, and international training and on advocacy partnerships to mitigate the negative impact of woefully inadequate provision of pediatric oncology palliative care services. Foremost, regional co-operative blocks, such as the East African Community, the Southern African Development Community, and the West Africa Development Union, need to embrace the strategies proposed by the Union for International Cancer Control and the African Palliative Care Association, to embrace basic national cancer control policies for each country in their respective subregion. Second, the regional blocks should include cancer and pain or palliative medicines within their national essential drug list and leverage policy to train professional nurse prescribers for pain or palliative medicines, particularly for children and

young adults with cancer. This effort mandates the establishment and strengthening of local training programs intended to promote the integration of PPC in mainstream oncology services and the extension of pediatric palliative oncology care to the primary care level, thus improving the referral and follow-up of children and young adults with palliative care needs during cancer care.

In conclusion, health systems for pediatric oncology services in sub-Saharan Africa are largely characterized by a lack of well-resourced national cancer control plans and

inadequate financing, resulting in poor or no cancer diagnostic and treatment and training infrastructure, limited or no human resource capacity, and poor or no access to palliative care. Additionally, the level of PPC development in the region remains inadequate and continues to lag behind that for adult palliative care.¹⁴ Given the evidence that children with cancer face multidimensional symptoms and concerns across the disease trajectory, countries must prioritize funding for and integration of PPC within pediatric oncology.

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DISCLAIMER

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