

Global Initiative for Childhood Cancer: Increased implementation of Core Projects in Africa

Jaques van Heerden et al present a literature search of African initiatives based on Global Initiative for Childhood Cancer (GICC) core projects. They call on governments to address childhood cancer care with transparent reporting and effective use of available resources. They note that collaboration and capacity building are key to sustainable improvement of health outcomes in Africa.

In 2018, the World Health Organisation (WHO) launched the Global Initiative for Childhood Cancer (GICC) to facilitate the analysis and improvement of health systems to manage childhood malignancies¹. The GICC aims to improve the survival of childhood cancer to 60% by 2030 by focusing on six index cancers, namely nephroblastoma, retinoblastoma, acute lymphocytic leukaemia, low grade glioma, Burkitt and Hodgkin lymphoma; supporting governments to build sustainable childhood cancer programmes and increasing the capacity to manage childhood cancers on various levels¹. This ambitious project considers resource limitations prevalent in much of Africa and aims to improve health outcomes of children with cancer, with expected benefits for other children as healthcare systems improve.

Five African countries are pilot sites for the programme. These focus countries, led by their Ministries of Health, include Morocco, Ghana, Zambia, Senegal and Zimbabwe. Mali, Cameroon, South Africa and Uganda² are in the early stage of implementation. Ten core projects have been proposed to reach the 60% survival target and reduce the suffering of all children with cancer¹. The African branch of the International Society for Paediatric Oncology (SIOP), SIOP Africa, advocates focusing on seven indices that would benefit most African countries. These foci include evaluation of cancer health systems, developing cancer control plans (CCP) and cancer registries, indices for childhood cancer care, national protocols and training packages

for the childhood cancer workforce. In 2019 and 2022, the SIOP Africa conferences in Egypt and Uganda respectively, enthusiastically highlighted the GICC in light of its importance^{3,4}.

Independent from the GICC, numerous countries have developed their capacities parallel to the index outcomes of the GICC. These include partnerships with international institutions and long-term twinning collaborations. The aim of this article is to review initiatives implemented in African countries and published results to evaluate baseline outcomes.

Methodology

A literature search of African initiatives based on GICC core projects was performed on multiple online databases including PubMed Central, Google and Google Scholar. Keywords included (but were not limited to) the six index cancers, "Africa", "Sub-Saharan Africa", "outcomes" and "survival" including individual country names. Data presented at the SIOP Africa conferences, available datasets and data from ongoing research and articles published between January 2018 to October 2022 were included. A descriptive review was formulated from the results of the literature search.

Strategic project development in African countries

Paediatric cancer control strategy development

Adequate registration to document true childhood cancer incidence is lacking in most countries⁵. Underdevelopment of treating facilities contributed to high mortality compared to well-resourced countries or countries with an organised paediatric oncology management system⁵. Up until 2022 more than 90% of countries had no individual CCP. Mauritius, an upper-middle income country without any paediatric oncologists, initiated childhood cancer goals in their 2022-2025 CCP, while Uganda, a low-income country with formal paediatric oncology services, also included childhood cancer as a priority in their 2022-2025 CCP^{6,7}.

Where adult CCP correctly focus on prevention, lifestyle adaptation and screening, it is currently not possible to prevent most cancers in children as many childhood

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A paediatrician attending to a child (courtesy of Pamela Mawanda)

cancers develop from as yet undocumented inherited or sporadic genetic mutations or other unknown causes⁸. Screening is of value in families known to have retinoblastoma: organisations such as Alliance Mondiale Contre le Cancer and the International Society of Ocular Cancer provide services and training for screening and diagnosis of retinoblastoma and have made valuable contributions in many African countries^{9,10}.

The incidence of HIV-associated malignancies such as Burkitt lymphoma and Kaposi sarcoma may be decreased with effective HIV prevention and control programmes which include mother-to-child prevention programmes and antiretroviral treatment clinics¹¹.

Vaccination of children against Hepatitis B virus to prevent the development of hepatocellular carcinoma and Human Papilloma Virus (HPV) to prevent cervical and other cancers are notable successes in Africa. Although vaccination for HPV is not yet standard in males, several HPV vaccination programmes are active in Africa¹² Rwanda has already documented a decrease in the incidence and mortality rates from 34.5 cases and 25.4 deaths to 31.9 cases and 24.1 deaths per 100 000 women¹².

The most effective strategy for childhood cancer control is to focus on prompt, correct diagnosis followed by rapid referral for effective, evidence-based therapy with appropriate supportive care¹³.

Improving identification of signs of childhood cancer relies on education of both healthcare workers and the public. Reports from Tanzania and Burundi programmes demonstrated that in-person training was effective to increase awareness of healthcare workers of early warning signs of childhood cancer⁴. Active programmes educating the public and health professionals in Cameroon have increased the diagnosis of childhood cancer¹⁴, but the greatest education responsibility is borne by non-governmental organisations¹⁵, universities and nursing institutions¹⁶. Although the dissemination of the early warning signs of childhood cancer has been performed by government institutions, such as in South Africa and Morocco, these have not become part of the Integrated Management of Childhood Illness or standard practice in most African countries¹⁷. Although these education and awareness programmes are implemented at the level of institutions of learning and NGOs, they remain the responsibility of governments to fund and support.

The role of CCPs is to address systemic factors contributing to suboptimal paediatric cancer care and

to formulate solutions. Late presentation to healthcare facilities, great travel distances, high treatment costs, and facility-level barriers to timely access to treatment have been identified as factors. Studies from Childhood Cancer 2030 Network have proven the cost-effectiveness of paediatric oncology care¹⁸. In 2014, the Collaborative Wilms Tumour (WT) Africa Project implemented adapted WT treatment guidelines in six sub-Saharan African countries, using simple and low-cost interventions to reduce treatment abandonment. These social support interventions significantly reduced treatment abandonment from 23% to 12%, ($p=0.009$) with fewer deaths during treatment (21% vs 13%, $p=0.06$)¹⁹.

Palliative care involves the alleviation of all forms of suffering associated with life-threatening or -altering diseases. This includes alleviation of pain, symptom management during treatment, assistance with emotional, spiritual and psycho-social suffering, as well as end-of-life care. With the high burden of childhood cancer in Africa, the need for expanded palliative care programmes is acute²⁰. Currently Egypt, Kenya, Malawi, South Africa and Uganda have established national palliative care plans or programmes with continuous development of education and training opportunities. These programmes are being extended to other regions including Ethiopia, Niger, Togo and Lesotho²⁰.

Analysis of cancer health systems

The GICC focus countries evaluate their health systems with the guidance of the WHO. The WHO also assists countries lacking paediatric oncology services, such as Burundi, to initiate the development of childhood cancer teams²¹. The aim is for countries to develop paediatric cancer control programmes independent of adult CCP, as the needs and priorities of children at various stages of development differ vastly from those of adults⁸.

The ongoing SIOP Global Mapping Project maps global paediatric oncology services and was initiated in Africa. The findings from 48/54 reporting African countries demonstrated vast disparities: seven countries reported no paediatric oncology services at all, only nine could provide chemotherapy, surgery and radiotherapy and only three were able to provide stem cell transplantation²². This information aids governments and policymakers to identify gaps in health care to align resources toward interventions.

Positive outcomes have already been documented in certain GICC focus countries: Morocco has published survival data for the six index cancers, confirming that the country already achieves the target of 60%²³. In Ghana the evaluation secured complete national funding for the management of four index cancers². Independent from the GICC, Uganda has evaluated the health systems including the needs of childhood cancer²⁴. Ethiopia reported a childhood cancer incidence of 8 per 1000 children²⁵; that the major reasons for abandonment of care were cost of treatment and extended travelling times to treatment facilities²⁶. Part of these efforts is the development and standardisation treatment guidelines for the six index cancers. SIOP has worked to harmonise treatment protocols and guidelines in collaboration

Strengthening and linking cancer registries

In Africa there is no vital health statistics system that can accurately represent the true incidence of childhood cancers, leaving cancer registries are thus often the sole source of information⁴². International efforts driven by the International Agency for Research on Cancer, the WHO, and the African Cancer Registry Network in partnership with individual country registries efforts are increasing cancer surveillance expertise within Africa by providing training and technical assistance⁴². South Africa and Ethiopia have dedicated national childhood cancer registries, while 25 countries have general cancer registries that include paediatric data. These registries are not designed to report survival outcomes. Therefore individual research projects are still important to evaluate the baseline survival outcomes for six GICC index cancers in Africa¹.

Advocacy

Advocacy is an important tool in the enhancement of childhood cancer care. SIOP Africa, the WHO GICC, non-profit organisations and research entities create awareness, highlight limitations in resources and guide education of the public and governmental stakeholders¹⁵. The aim is to decrease diagnostic delays, improve outcomes and improve quality of life for patients and survivors. Advocacy pertaining to the appropriate use of resources is of vital importance. In Africa, fostering parent groups and lending a voice to survivors motivates further improvement of services and provides information to the general public¹⁵. Advocacy to governments should include programs for sustainable paediatric oncology healthcare, standardised care in the paediatric oncology community and childhood cancer awareness to referring health services, traditional healers and the general public to further improve childhood cancer management.

Of great relevance to Africa is advocating for the right to life-saving cancer treatment of displaced children and refugees, who have higher mortality rates [4].

Focus towards 2030

Childhood cancer advocacy should be amplified. Research capacity should be expanded to analyse and publish African data to disseminate true incidence and survival data. To achieve the goal of 60% survival by 2030, governments and funders must prioritise improvements in staffing ratios, infrastructure, patient support, research, monitoring and evaluation.

The importance of investing in childhood cancer registries and childhood cancer control programmes cannot be understated. Clinical, academic and research expertise should be shared across the continent, whilst junior staff and emerging researchers are capacitated to meet the demands of increasing numbers of children with cancer being diagnosed and referred to appropriate centres.

Conclusion

Prioritising children's health is an investment in the economy of any country. Africa has taken up the challenge to achieve the goal set out by the WHO in the GICC, s. Published baseline indicators demonstrating

high survival rates in some countries give hope to others yet to achieve this goal. Governments should address childhood cancer care with transparent reporting and effective use of available resources. Collaboration and capacity building are key to sustainable improvement of outcomes in Africa.

Further reading

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with regional partners such as Franco-African Paediatric Oncology Group (GFAOP), CanCARE Africa, St Jude Global and Global HOPE to foster clinical capacities relevant to individual countries²⁷.

During the 2022 SIOP Congress in Barcelona, the WHO African Regional Office and the Franco-African Group for Paediatric Oncology announced a collaboration agreement to improve paediatric oncology services in Francophone Africa.

Childhood cancer workforce training

A core multidisciplinary team is essential to manage childhood cancer and should include, at a minimum, paediatric oncologists, surgeons, radio-oncologists and nursing staff¹. Further members of the team include pharmacists, radiologists and psycho-social support staff.

Training and continued education should be prioritised to achieve the GICC goals¹. Multiple standardised training programmes are increasing in Africa with African and international resources providing online, in-person and hybrid training and research courses¹⁵. The GFAOP training programme is tailored to the resources available in Francophone Africa while highly specialised training is provided in Egypt for modalities such as stem cell transplantation and neuro-oncology²⁸. The SIOP POINTE Training Database collates available training programmes available to doctors and nurses²⁹.

During a recent Education Programme Assessment Tool session, hosted by St Jude Global Health, 25 training centres demonstrated well-rounded paediatric oncology training programmes in eight Anglophone countries. The African School of Paediatric Oncology was established in 2012 with support from the Sanofi Espoir Foundation to increase the number of paediatric oncologists in Francophone Africa³⁰. Brazilian institutions under Aliança Amarte, support informal training of paediatric oncologists for Lusophone African countries including Angola, Mozambique and Guinea Bissau³¹. The Aslan Foundation is an international partner supporting training and services in Ethiopia.

Baseline standards for the provision of safe and effective nursing care in LMIC have been published by the SIOP Global Health Network nursing working group³². In-person nursing training has been established in countries such as Ghana, Morocco and South Africa, while the Global HOPE programme provides a distance-based learning platform teaching basic principles of childhood cancer nursing care in Malawi, Uganda, and Botswana³³.

Although less abundant, paediatric surgery training and radio-oncology fellowships are increasing in Africa with support from established countries such as South Africa and Egypt, international training programmes and the GFAOP.

Defining national standards and guidelines for index cancers

The development of sustainable childhood cancer programmes in Africa is only possible by involving governments who view it as a public health priority³⁴. In conjunction with national stakeholders, childhood cancer societies, global health authorities and NGOs with

field experience can recommend staffing levels for the paediatric haematology/oncology wards, components of speciality, psychological and psychosocial care³⁵. Countries without paediatric oncology services or paediatric oncologists, for example Somalia, South Sudan and Mauritius, should receive increased focus. Both curative and palliative care are of vital importance, while late effects should be monitored and managed in the increasing cohort of children who survive cancer^{36,37}. Standardisation is not only important for clinical services but should include diagnostic services such as pathology, radiology and basic laboratory services.

Standardised guidelines for the six index cancers address upwards of 60% of childhood cancers, which are highly curable even in limited resource settings. The Collaborative Wilms Tumour Africa Project implemented an adapted treatment guideline for Wilms tumour in limited resource settings. This multi-national prospective study reported an end-of-treatment survival of up to 68.5% compared to previous survival rates of less than 40%¹⁹.

National strategies should focus not only on cure and survival, but also on retention of children in care by limiting abandonment. The GICC advocates for the alleviation of treatment costs with National Health Care initiatives and universal access to treatment. By empowering parents through intensive counselling, and providing social and financial support, more children complete treatment. The “Towards Zero Percent Abandonment” project significantly decreased death during treatment from 21% to 13% and abandonment of treatment from 23% to 12%, emphasising the critical role of a caregiver for improved survival³⁸. The implemented strategies included full cover of transport costs, free medical treatment, a tracking system to remind patients of appointments and more systematic and improved counselling of parents of the need to complete treatment.

Essential Medicines and Technologies Strengthening

Lack of computerised tomography, magnetic resonance imaging, nuclear isotope imaging and pathology services impedes the accurate and timely diagnosis of malignancies³⁹. Increased diagnostic capacity plays an important role in improving survival⁴⁰. Although core chemotherapy agents are listed in the WHO essential medicines list, many agents are not available, whilst targeted therapies, considered standard of care in high-income settings, are not affordable in most African countries. Even when chemotherapy is available, restricted access to radiotherapy or paediatric surgical expertise hinder or delay treatment. Judicious investment in diagnostic modalities could limit costs by decreasing diagnostic delay and increasing the number of children who present with early stage disease⁴¹. Without government involvement or creative funding solutions to procure and sustain these services, access will remain restricted.