

# CHILDHOOD CANCER CARE IN LOW-RESOURCE SETTINGS

*Youth-centered policy recommendations for country-level action*

By: Victoria Watson



***A child's ability to survive cancer in low-resource settings is a matter of competing priorities, access, and availability of treatment, which could be addressed through a national pediatric cancer strategy. To date, most countries lack this type of strategy, which prevents them from scaling up appropriate treatment interventions.***

## BACKGROUND

**Improving cancer care in low-resource settings is a child health priority.** Across all countries, cancer is now one of the leading causes of non-accidental child mortality. Currently, cancer accounts for 6.0% and 18.6% of deaths among children ages 5 to 14 years in lower- and upper-middle-income countries (LMICs), respectively, with approximately 150,000 childhood cancer diagnoses occurring in LMICs annually.<sup>1</sup> Unlike pediatric patients in high-income countries (HIC), where 80% of pediatric malignancies are cured,<sup>2</sup> young cancer patients in low-resource regions face limited, if not non-existent, treatment options after diagnoses.

Pediatric cancers differ from adult cases in how they can be addressed and treated. Unlike adult cases, pediatric cancers are rarely attributed to modifiable risk factors and thus cannot be addressed through a population-based prevention program. As a result, improving pediatric treatment must be a priority for country-wide policy and planning to decrease childhood cancer mortalities and raise quality of life. Ensuring appropriate treatment modalities for pediatric patients requires specificity: pediatric cancer patients need treatment delivery methods, technologies, psychosocial, and family support services that vastly differ from those provided to adult patients. Considering the limited access to primary care providers, medical technologies, and medicines available in LMICs, this level of specialized care is scarce, which leads to delayed diagnoses and inappropriate care. For this reason, ensuring that all health systems can provide a minimum standard of specialized care that is accessible to all young cancer patients must be a priority for global policy and planning to enable LMICs to establish a targeted national strategy that better equips their system to provide such patients the care they deserve.

## WHY IS THIS A PROBLEM?

- Longer life expectancy due to reduced communicable disease mortalities coupled with development towards manufacturing-based economies and urbanization are increasing the burden of childhood cancer among LMICs and will continue to raise the burden to a level of demand that surpasses existing health system capacity.
- Available treatment centers in LMICs are accessed via referrals through primary or secondary healthcare providers. Due to scarcity in specialized practitioners, most families consult providers or traditional healers who lack sufficient knowledge of childhood cancers to provide accurate diagnoses. For this reason, most diagnoses of childhood cancers in these regions are often delayed, preventing the patients

<sup>1</sup> Sumit Gupta et. al., *Pediatric Oncology as the Next Global Child Health Priority: The Need for National Childhood Cancer Strategies in Low- and Middle-Income Countries*, 11 PLoS MED. (2014).

<sup>2</sup> LF Ellison et. al., *Childhood and adolescent cancer survival: a period analysis of data from the Canadian Cancer Registry*, 43 . EUR J CANCER (2007).

from accessing a timely referral.<sup>3</sup> This worsens their prognosis and amenability to available treatment options.

- Patients whose symptoms worsen before diagnoses are brought to tertiary care centers which are often far away from patient's homes. Accessing far away hospitals places potentially insurmountable pressures on the family, such as transportation costs, parent's absence from the home for long periods of time, and loss of income. These challenges often lead to treatment abandonment.
- Appropriate treatment for childhood cancer requires a model of care that meets the full needs of the pediatric patient. This includes services that address psychosocial needs as well as supports for the family. These services are rarely available to pediatric cancer patients in LMICs, worsening their quality of life across the care pathway.
- Besides countries that offer insurance, families need to pay out of pocket for diagnoses and treatment. Treatment costs can prevent families from allowing their child to pursue treatment or cause financial catastrophe within the family unit.
- It is not guaranteed that care centers will be able to offer the necessary treatment, nor have equipment that is appropriate for pediatric patients. Common drugs necessary for cancer treatment listed on WHO's essential medicines list may not be affordable and thus not imported into the country, medical technology such as radiation therapy and chemotherapy are scarce, as is the medical personnel required to deliver such services.
- Palliative care and pain relief is scarce if not non-existent due to shortages in supply of essential medicines and equipment. As a result, approximately 5.3 million children world-wide experience serious health-related suffering and go without the necessary pain relief and support during the end-of-life stage of their disease progression. This suffering is often experienced by cancer patients as the disease progresses.

## **POLICY RECOMMENDATIONS TO IMPROVE ACCESS AND QUALITY OF TREATMENT IN LMICS**

- Scale up availability of simple, low-intensity treatment regimens within tertiary care centers.
- Broaden availability of specialized primary care by mandating a pediatric oncology nursing curriculum be included in all nurse training programs, including those for community-based health workers to ensure a baseline knowledge of childhood cancer. This can help improve accuracy of diagnoses and prevent the delay of referral.
- Financial coverage: prevent treatment abandonment or treatment refusal by providing financial coverage to reduce the financial burden on caregivers.
- Develop national treatment protocols to establish a baseline set of services and treatment to be provided at care centers. These protocols must reflect local capabilities yet include language that specifies requirements for psychosocial support, appropriate low-intensity treatment and equipment. To facilitate buy-in and adoption, financial incentives can be tied to the use of such protocols.<sup>4</sup>
- Include pain relief (morphine-equivalent pain treatment) for pediatric patients as part of UHC and expand hospital and community-based palliative care to ensure supportive capacity for both patients and family members during end-of-life stage.

Children and young people deserve to reasonably expect cure and quality treatment that is accessible to them and their families without factors of geographic location or socio-economic background interfering with their access to treatment. Through these policy recommendations, low-resource settings can be better equipped to provide accessible and appropriate treatment and disease management for pediatric cancer patients and their families.

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<sup>3</sup> Ian Magrath et. al., *Paediatric cancer in low-income and middle-income countries*, 14 THE LANCET ONCOLOGY (2013).

<sup>4</sup> Gupta, *supra* note 1.