

## Lives That Matter (10 min read)

Access to Medicines

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In 1960s Great Britain, nobody talked about children with cancer – it was a taboo subject. Even hematologists and oncologists didn't know whether children would survive leukemia or most tumors. Since then, significant progress has been made. For example, in children's acute lymphoblastic leukemia (the commonest cancer seen in children), [survival rates](#) <sup>[1]</sup> have risen from about 20 percent in the early 1970s to 85-90 percent, at least in high-income countries.<sup>1</sup> Unfortunately, such huge strides in the treatment of childhood cancer are not available everywhere.

In the richer nations of the world, about eight in ten children with cancer now survive the disease.<sup>2,3,4,5,6</sup> In low-income countries, the chances are reversed: up to nine in ten children with cancer die, although relatively low-cost medicines or simple therapies could cure them.<sup>6,11,12,13,14</sup> This disparity is clearly unacceptable.



It is estimated that fewer than one in four cases of childhood cancer is diagnosed in Bangladesh. A mother waits patiently for her daughter's treatment in the ward at the Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh, the largest pediatric oncology specialist treatment center in the country. Photo Credit: World Child Cancer

Source: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3876649/> [2]



Al Amin with his mother at Bangabandhu Sheikh Mujib Medical University Dhaka, Bangladesh. He was diagnosed with Wilms' tumour when he was barely two years old. His mother is with him day and night, and his father provides moral and financial support. World Child Cancer covers the cost of Al Amin's treatment. Photo Credit: World Child Cancer



In many cases, childhood cancer can be cured with early treatment. Young patients in Africa sit and enjoy the warmth of the sunshine. Cancer treatment is a long, emotional, expensive, and very often painful journey. A row of children at Queen Elizabeth Central Hospital, Blantyre, Malawi. Photo Credit: World Child Cancer



Parents and relatives spend as much time as possible with their children in the cancer wards. In low-income countries, they might not have a place to stay near their children. Sometimes they may stay in a bed in the ward, but some parents have to sleep on the floor, or in the corridor. A boy being treated for cancer is happy to be with his father at Queen Elizabeth Central Hospital, Blantyre, Malawi. Photo Credit: World Child Cancer



Childhood cancers are different from adult cancers, tending to occur in other areas of the body and to respond differently to treatment. Also, different forms of childhood cancer occur with varying frequency across the world. Patient being treated for retinoblastoma (eye cancer) at Yangon Children's Hospital, Myanmar. Photo Credit: World Child Cancer



Dailiy (left), was diagnosed with leukemia, the most common type of childhood cancer. Here she and other patients in Yangon Children's Hospital, Myanmar have decorated their faces with Burmese cosmetic paste, thanaka. Sadly Dailiy lost her battle with cancer in 2016 following a relapse with the disease.

Photo Credit: World Child Cancer



A look along the rows of beds in a general pediatrics ward at Mbingo Baptist Hospital in Bamenda, Cameroon. The small door at the end of the ward opens up into the small, six-bed pediatric oncology ward – a small but significant step towards developing childhood cancer services in the region. Photo Credit: World Child Cancer.

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Many factors contribute to the huge imbalance in survival rates between nations of the world, including lack of awareness of childhood cancer among the public and health professionals, often leading to late diagnosis.<sup>6,11,12,13,14</sup> However, a stumbling block for adequate treatment and potential cure is a lack of consistent supply of cancer-fighting medications for children.<sup>15</sup> We decided to explore the complete pathway of essential medicines in nine countries, to understand why medicines do not get to where they are needed at the bedside.

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Professor Tim Eden, Founding Medical Trustee of World Child Cancer

## Asking Pediatricians

The great global inequality led us to create a survey called “Are Essential Medicines Available for Childhood Cancer in the Developing World?” with the focus on accessibility, availability, affordability, acceptability and adequate quality control.

To define the scope of the problem, we asked ten leading hospital pediatricians for their perceptions about essential medicines for treating children with cancer in nine countries: Bangladesh, Cameroon, Colombia, Ghana (two clinics), Malawi, Myanmar, Philippines, Tanzania and Zambia.

Collectively, these ten pediatricians see over 2,000 new childhood cancer cases per year. We asked about production, distribution, procurement, and importation of medication. The doctors’ responses confirmed our expectations, or rather the misery of the situation.

### Accessibility

All of the respondents report that more can be done to improve access to medicines of reliable quality for curative, supportive and palliative care to children with cancer in lower-income countries.<sup>15</sup> These drugs are basic, off-patent, and mostly generics listed on the World Health Organization [List of Essential Medicines for Children](#) <sup>[3]</sup>.<sup>16,17,18</sup> Every two years, WHO reviews and modifies this list. In 2013, there were 10 drugs on the list needed to treat just three of the top tumors. In 2015, the list was expanded to include nine drugs for treating eight of the most curable childhood malignancies.<sup>16,17,18</sup> Of course, the medicines are essential for treating other tumors as well. Drugs that are not on the WHO list, or on a country’s own national list, will probably not be imported.<sup>19</sup>

### Availability

All nine countries must import childhood cancer drugs, but the pediatric doctors noted procurement and import of key drugs for treating the most curable malignancies was unreliable. Reasons included inadequate worldwide production, or that the agencies or hospitals failed to renew import licenses on time, or that healthcare officials underestimated demand, or that needed drugs were not on the national list of essential medicines.<sup>19</sup>

## Affordability

None of the countries surveyed offer universal health coverage. Financial assistance included government-payment of certain medicines, philanthropy, subsidies from NGO/charitable groups, or public health insurance programs. In countries that offered subsidies for medicines, fewer than five percent of families abandoned treatment. Although treatment costs in these countries are lower than in high-income nations, over 20 percent of families had to stop treatment because they could not afford it.<sup>21</sup> Where families are living on just \$2 a day, drugs costing \$1 a day are simply not affordable unless they are subsidized.

## Acceptability

The survey revealed that palliative care is a huge issue, particularly with late-stage diagnosis. Opiates carry a big stigma, causing anxiety along the whole pathway from procuring, importing, prescribing, dispensing and using the medication.<sup>20</sup> Some doctors were afraid they would be accused of giving addictive drugs to children.

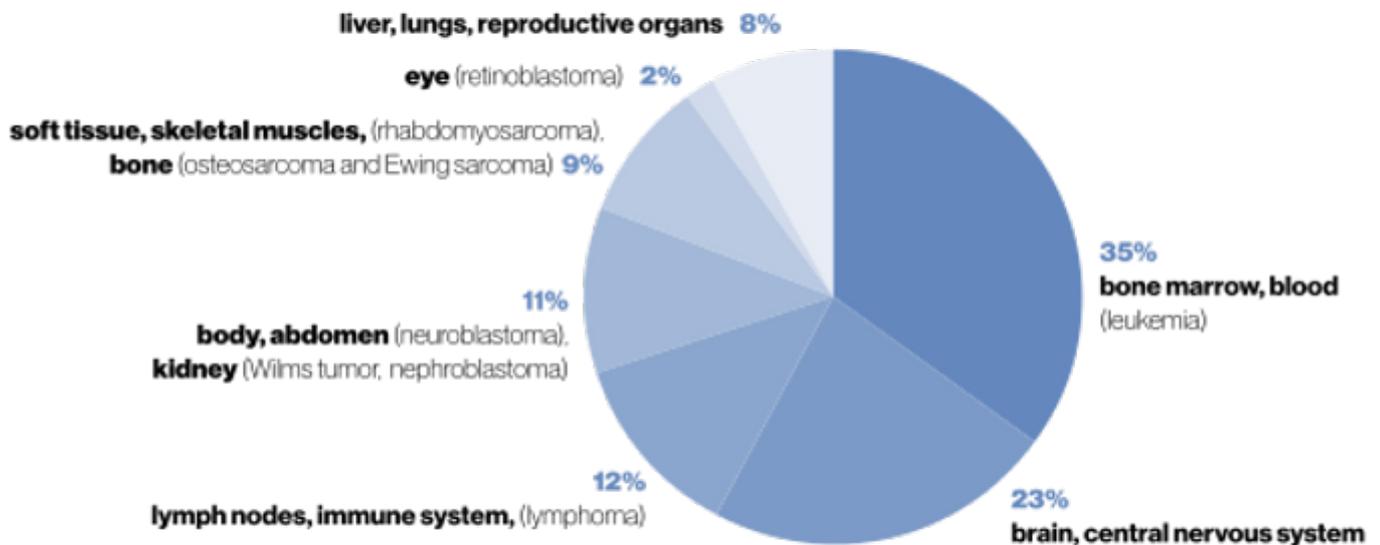
## Adequate quality control

Even more worrying is the quality of drugs. Most medicines were imported in these countries from India (most frequent) and China, as well as Argentina, Brazil, South Korea, Cyprus, and Malaysia. In parts of Africa and Asia, between 50-70 percent of imported medicines are declared to be ineffective, fake or counterfeits.<sup>22</sup> Some doctors reported lower effectiveness and higher toxicity than expected, despite using well-documented successful therapeutic protocols.

Ours was a small study, but the insights gained reflect reports from colleagues worldwide that WHO Essential Medicines for cancer are not consistently produced in adequate amounts to meet needs, and not distributed, procured and imported reliably. And when the family can't afford their child's therapy – this includes all or some of the medicines, transport to and from the clinic, or having to take leave from work – parents might refuse therapy for their child, or not complete all the treatments.

# Young Patients

Most common childhood cancers



Cancer occurrence varies across regions. In Sub-Saharan Africa, for example, higher rates of kidney and eye cancers are reported.

Sources: International Agency for Research on Cancer, International Incidence of Childhood Cancer, WHO

Other well-known factors also contribute to low childhood cancer survival rates in developing countries. When no treatment is possible, the cancer diagnosis has often come too late, because no one recognized the symptoms, or facilities are so far away that patients make the long journey only after the disease is in advanced stages. In other cases, the child may have co-morbid diseases, such as tuberculosis or HIV. Sometimes, parents don't believe that the cancer can be cured. In a number of regions, particularly outside of big cities, hospitals lack pathologists, oncologists and trained staff, or the facilities for long-term care.

To help overcome these and other barriers to treatment, more than 50 international twinning partnerships between medical organizations in wealthy nations with those in lower-income countries have been established worldwide. These allow health personnel, patients and families work together to help more children to survive.<sup>10, 11,12,13, 14</sup>

These programs are helpful, but we need to do more. What the survey revealed ultimately is the need for consistent follow-through on every aspect of treating childhood cancer. In developing countries, the public is often not aware of children's cancer. We need to educate families. We need to teach medical professionals to learn how to recognize and diagnose cancer. At the same time, we in developed nations need to build on international partnerships that will provide training and financial support.

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Professor Tim Eden, Founding Medical Trustee of World Child Cancer

According to the International Agency for Research on Cancer, some 300,000 children and youth under age 19 are diagnosed with cancer per year.<sup>2</sup> But every year 80,000 to 100,000 children die needlessly from curable cancer diseases, most of whom (80 percent) live in low-income countries. And, diagnosis of cancer and deaths appear to be increasing as overall child mortality in low-income countries of the world is declining.<sup>7,8,9,10</sup>

All of the relevant medical, pharmaceutical and governmental bodies – along with the United Nations and the World Health Organization – urgently need to work together to find solutions to the lack of accessibility, availability, affordability, acceptability and adequate quality control of the WHO Essential Medicines. We know what to do. It's time to act. Together, we can save these children.

**This is a guest post by the authors of the study**

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Elizabeth Burns, Head of Programmes, World Child Cancer

World Child Cancer is a London-based charity that works to improve access to cancer diagnosis and care for children in developing countries.

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#### Links

[1] <http://www.cancerresearchuk.org/about-cancer/type/all/treatment/statistics-and-outlook-for-acute-lymphoblastic-leukaemia>

[2] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3876649/>

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