

## Reportage

# Cancer care for displaced children in Lebanon



Lebanon is a small country on the Mediterranean Sea that has been plagued for decades by civil war and internal strife, which result from regional wars and power struggles. Most of the Lebanese population has access to national governmental health-care plans, but these are inadequate to cover the costs of cancer care; therefore, non-governmental organisations (NGOs) are needed to alleviate financial barriers to care. In 2002, the Children's Cancer Institute was established at the American University of Beirut Medical Center (AUBMC; Beirut, Lebanon), as a collaboration between AUBMC, St Jude Children's Research Hospital (SJCRH; Memphis, TN, USA), the Children's Cancer Center of Lebanon Foundation (CCCL; Beirut, Lebanon), and the American Lebanese Syrian Associated Charities (ALSAC; Memphis, TN, USA). This collaboration supports programmatic growth (ie, specific projects aimed at developing medical programmes and services to optimise cancer care and delivery) at the Children's Cancer Institute, and the CCCL and ALSAC ensure that no family pays out-of-pocket expenses for cancer-directed care. Between 2002 and 2012, the Children's Cancer Institute grew to provide care for 35–40% of children with cancer in Lebanon, and consultations or specialised procedures for an additional 20–25%. Networks of paediatric oncologists across the country were established, using funded disease-specific programmes, in which enrolled patients could access centralised diagnosis, specialised surgeries, radiotherapy, and unified treatment plans in coordination with their referring oncologist.

With the start of the civil war in Syria in 2011, refugees fluxed across the Lebanese–Syrian border, reaching a peak of approximately 1.5 million registered Syrian refugees in Lebanon by 2015. This number is an underestimation because many refugees remained unregistered—the UN High Commissioner for Refugees stopped registering newcomers after May, 2015, per request of the Lebanese government and many children born to refugee parents remained unregistered. With Lebanon's population estimated at 4.5 million, the refugee-to-citizen ratio is at least 1:3. The age group of refugees became skewed to a younger population, there was an almost doubling of the number of children in Lebanon during a short period of 2–3 years. The effect quickly became evident in oncology, with an increase in the number of paediatric patients seeking cancer care with no health-care coverage or financial means. Costs of care for such patients were initially handled through cooperation of charity organisations, such as the Damascus-based Basma organisation that had an office in Beirut and the CCCL foundation in Lebanon.

Additionally to people from Syria, Palestinian refugees in Lebanon or displaced from Syria also did not have

health-care coverage for cancer therapy, neither did people from Iraq seeking treatment because of the aftermath of wars in Iraq that markedly weakened the health-care system. To address this acute need, the CCCL, AUBMC, SJCRH, and ALSAC proceeded with a targeted approach, by initiating a series of funding programmes in 2013, designated for displaced paediatric patients with cancer. The funding provided US\$1.0–1.5 million per year for direct patient care costs. To ensure that resources were used most effectively, eligibility was limited to patients with newly diagnosed, previously untreated cancer, excluding some high-cost interventions such as bone marrow transplantation.

In parallel, a rapid expansion of infrastructure was undertaken, including the creation of more inpatient and outpatient space; recruitment of physicians and nurses; and development of logistic support to track enrolment, eligibility, costs, and reporting. As the refugee crisis became protracted, the national paediatric oncology networks previously established for disease-specific consultation and specialised procedures were built upon, such that displaced patients who could not be treated because of limited capacity were referred within the network, and the CCCL campaigned to raise additional funds to assist in coverage of treatment costs at network hospitals across the country, enabling access to care for most patients.

Between 2011 and 2020, 805 displaced non-Lebanese children with cancer accounted for 39% of all 2049 patients seen at the Children's Cancer Institute: 20% of newly accepted patients; 50% of those receiving diagnostics, surgeries, or radiotherapy; and almost 60% of patients receiving only consultation due to medical ineligibility (relapsed disease or previous treatment), fund unavailability, or benign diagnosis. Most patients who could not be accepted at the Children's Cancer Institute were provided with a treatment plan and

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We declare no competing interests.

For more on the **Lebanon network of paediatric cancer care and their programmes** see *J Glob Oncol* 2016; 3: 23–30 and *Pediatr Blood Cancer* 2019; 66: e27959

For more on **funding programmes for displaced paediatric children** see *Pediatr Blood Cancer* 2019; 66 (suppl): e27989



For more on paediatric cancer care for Syrian refugees in Lebanon see *Cancer* 2018; 124: 1464–72

For more on the Global Initiative for Childhood Cancer see <https://www.who.int/publications/m/item/global-initiative-for-childhood-cancer>

referred to collaborating paediatric oncologists, with referral to the CCCL foundation or collaborating NGOs for further financial support.

Data were prospectively collected for all patients treated at the Children’s Cancer Institute, and outcomes assessed until the end of therapy. Because of funding limitations, off-treatment surveillance visits were not continued beyond the end of therapy. Tumour types were similar to those in Lebanese patients, with acute leukaemia being the most common, followed by brain tumours and lymphoma.

Despite initial concerns regarding potential barriers to continuing medical care due to families’ expected competing basic needs and the absence of an extended support system, there were only two cases of abandonment. The fact that the Children’s Cancer Institute Child Life team meets with all families and provides support and assistance in directing them to needed social services probably played a crucial role. Accordingly, tumour control outcomes were similar to those of Lebanese patients, with 147 (85%) of 172 patients in remission by the end of treatment, although no further follow-up is available for most patients beyond this timepoint. Direct costs of treatment (depending on whether treatment included surgery, radiotherapy, or chemotherapy) and admissions to hospital for complications and outpatient medications, ranged from approximately US\$10 000–125 000 per patient, with acute leukaemia and bone tumours having the most costly diagnoses.

Notably, as the Syrian crisis peaked in 2015–16, and with the drain of medical specialists from Syria, paediatric oncology units in Damascus became understaffed. Medical graduates seeking subspecialisation and training in neighbouring countries opted to travel elsewhere, rather than return to war torn Syria. In the Children’s Cancer Institute at the AUBMC, Khaled Ghanem, a Syrian trainee who graduated the paediatric oncology fellowship in 2018, took on the leadership of the major paediatric oncology unit in Damascus (Basma Pediatric Oncology Unit) operated by a successful Syrian NGO. With a new

paediatric oncology director, the unit in Damascus initiated capacity building strategies to provide quality care to a larger number of patients, including displaced children in Lebanon returning to Syria. During the past 3 years, continuing collaborations with the Children’s Cancer Institute have been useful as borders have become more accessible and a few patients started to move back to Syria. Collaborative efforts continue to help to build back the needed infrastructure and provide multidisciplinary therapy, including case discussions for diseases (such as retinoblastoma) requiring specific multidisciplinary care and review of histopathological diagnoses for challenging oncology cases.

This response to the refugee crisis in Lebanon, in terms of paediatric oncology, highlights the fact that specific NGOs and academic not-for-profit health-care institutions have almost exclusively shouldered this response. Childhood cancer is a curable disease in most patients, but requires intensive and specialised therapies that are costly, which makes it ethically imperative that this patient population is not overlooked. With absence of a government-led plan for financial coverage of health-care costs for this vulnerable population, and with international agencies directing their support to more general public health needs and prevalent diseases, displaced children with cancer were left with no access to care. The pre-existing partnership among the CCCL, AUBMC, SJCRH, and ALSAC, and their network of collaborations with the national and regional paediatric oncology units and NGOs allowed the rapid implementation of a response that entailed not only mobilisation of funds, but also a rapid expansion of needed infrastructure and resources. This response has been indispensable to offer refugee children with cancer a viable chance at a cure. The momentous effort of the non-governmental and academic sector is a huge attestation to the impact that such organisations can have in addressing the needs of populations in the absence of effective governance.

Despite the success in relieving barriers to therapy for most refugee children, more support continues to be needed. The fact that the funding mechanisms to date could not offer treatment beyond first-line therapies except for palliative care, and that some expensive procedures—such as bone marrow transplantation—are not accessible due to cost, creates distress not only to the families of affected children, but also to the health-care teams caring for them.

As the Global Initiative for Childhood Cancer led by the WHO and SJCRH works towards incorporating childhood cancer into countries’ national cancer control plans, it is imperative that these include provisions for incorporating the care of displaced children, so that no child with cancer is left out of the health-care system of the country in which they reside.

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