Global haematology

Sickle cell disease care in Lebanon: resource-constrained and humanitarian crisis adaptations

Lebanon is a small country in the Eastern Mediterranean. There are 4 million Lebanese residing in the country, and according to the WHO Annual Report 2021, its adjusted GDP growth decreased by 25%. Lebanon has more refugees per capita than any other country in the world, hosting about 210 000 Palestinian refugees—the majority came after 1948, and 30 000 fled Syria after the 2011 civil war—and approximately 1·5 million Syrian refugees. Poverty among the Lebanese has increased, 30% of the population was below the poverty line at the start of Lebanon's economic crisis in 2019 compared with 80% in 2022. Poverty among Palestinian refugees also increased from 70% below the poverty line at the beginning of 2022 to 90% at the end of the year. The economic situation has had dire effects on access to healthcare and medications, with agencies providing health-care coverage for Lebanese patients (Ministry of Public Health [MOPH] and the National Social Security Fund [NSSF]) unable to cope.

Refugees, who receive healthcare in public hospitals without specialised care, face great challenges. Access to healthcare is becoming more difficult due to the rising cost of transport and hospitalisations. Comprehensive healthcare is inaccessible for refugees despite support from NGOs, the UN Relief and Works Agency for Palestine Refugees in the Near East (UNRWA), and the UN High Commissioner for Refugees (UNHCR), which focuses on primary healthcare for Syrian refugees. These agencies provide little or no support for specialty care for chronic blood disorders. Out-of-pocket payments can reach more than 25% of health-care costs and many struggle to afford these expenses.

Sickle cell disease is highly prevalent in Lebanon, the reported prevalence is 0.1% of the population, and has severe clinical manifestations leading to increased hospitalisation and early mortality, however, it receives little attention in this health-care system in crisis. Prevalence is exacerbated among the refugee communities due to the high rates of consanguinity. Severe phenotypes and disease manifestation have been reported in both Syrians and Palestinians refugees, despite the scarcity of data regarding prevalence, incidence, and mortality in this population.

The American University of Beirut Medical Center (AUBMC) is one of only two medical institutions in Lebanon with a programme for comprehensive management of sickle cell disease. Since its establishment in 2002, the Sickle Cell Programme received Lebanese patients as well as Palestinian and Syrian refugees. In the initial years, the cost of care for Lebanese patients was covered by state agencies such as the MOPH, NSSF, and the Armed Forces Insurance supplemented by philanthropic funds. There were also philanthropic funds for Palestinian patients. Since 2005, the programme can provide free transcranial doppler screening to all patients including refugees. While the programme initially supported the cost of hydroxyurea, therapy is now provided free of charge by the MOPH for Lebanese patients. For Palestinian patients, medication is provided by Health Care Society, an NGO that supports Palestinian refugees with thalassemia and sickle cell disease. Before the humanitarian and economic crisis, philanthropic funds were used mainly to supplement the cost of hospitalisations, immunisations, and specialised laboratory tests. All patients enrolled in the programme were offered the opportunity to participate in clinical research. These efforts coincided with increased demand because of the arrival of Syrian patients as the humanitarian crisis progressed (figure 1).

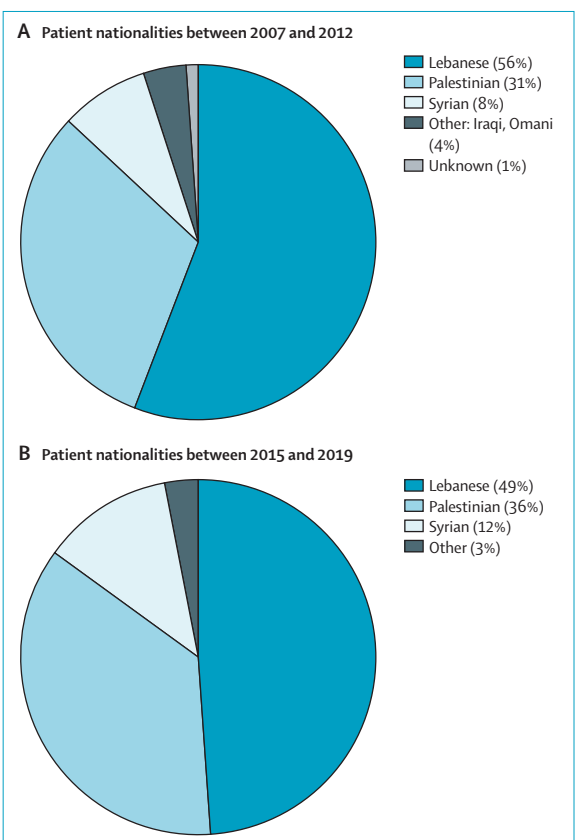

Figure 1: **The distribution of enrolled patients at the sickle cell disease programme at the AUBMC 2007–2012 (A) 2015–2019 (B)**

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For more on the **diversity within the Lebanese population** see *J Community Genet* 2015; **6:** 83–105

For more on **poverty among refugees in Lebanon** see https://www.middleeastmonitor.com/20221027-un-poverty-among-palestine-refugees-in-lebanon-jumps-to-93/

For more on the **incidence of sickle cell disease in Lebanon** see *PLoS One* 2014; **9:** e105109

For more on **consaguinity among the Syrian population** see *J Immigr Minor Health* 2020; **22:** 1347–67

For more on **sickle cell disease manifestations in Middle East Arab countries** see *Indian J Med Res* 2011; **134:** 597–610

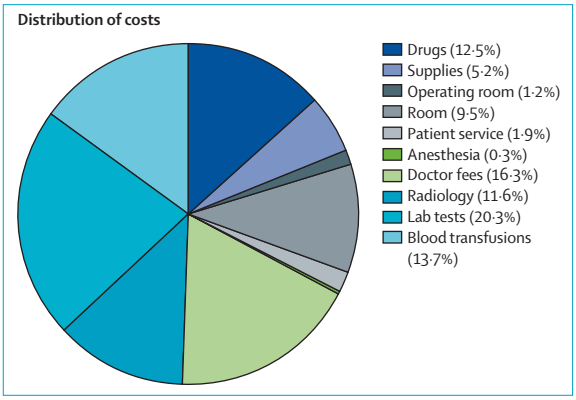

Figure 2: **Yearly healthcare cost distribution for sickle cell disease patients registered in the AUBMC programme**

Refugees with sickle cell disease in Lebanon suffer both, the hardships of disease-associated complications and major socio-economical barriers hindering quality care and increasing morbidity and mortality. Barriers to quality care in Lebanon include socioeconomic status, racial discrimination, lack of sufficient funding, lack of access to disease-specific facilities, and lack of knowledgeable providers, especially for pain management. The mission of the Sickle Cell Programme at AUBMC was providing all patients with sickle cell disease residing in Lebanon an equal chance to receive a disease-specific, patient-centred care to ameliorate morbidity and decrease mortality.

To estimate the yearly cost of care of the programme, we did a retrospective review of the medical charts of the patients enrolled and all hospital bills generated at AUBMC. 220 patients were followed up for 5 years; 91 (41%) had been hospitalised during this period, a total of 335 hospitalisations with an average hospital stay of 5 days. The annual cost per patient was around US$950. Figure 2 shows the cost distribution.

To address this financial burden, we recognised that an overarching funding infrastructure was necessary. AUBMC put together multiple funding resources under one governing body, the Sickle Cell Programme at AUBMC. Our team currently consist of 3 physicians, a coordinator, a genetic counselor, and a specialised nurse. In addition to government agencies, such as the MOPH, NSSF, and the Armed Forces Fund, the programme receives funds from two private philanthropic organisations (AUB Sickle cell fund and the Syrian Refugee Fund) and the NGO Health Care Society, which funds aid for Palestinian refugees. We created a funding infrastructure capable of covering the cost of routine haematology clinic visits to ensure proper compliance with treatment and management protocols, diagnostic and follow-up blood tests needed to adjust medication dose, and management of side effects. Imaging, including annual transcranial doppler screenings, and specialist clinic visits and annual eye exams, were also covered. Initially, vaccinations and medications were also covered. However, we successfully negotiated shifting cost of hydroxyurea and iron chelators to government funds, and they are now provided free of charge by the MOPH when available. In addition, the fund covers emergency room visits, unexpected hospitalisations and transportation for patients who live in the suburbs.

Recently, we developed a collaboration with the Rotary Club in Beirut—an international organisation that provides humanitarian services—to secure donations of hydroxyurea from the Rotary Club in India. These donations allow patients to continue treatment without significant interruptions despite the severe shortages in the country since 2021. In 2018, the programme also became an active partner in ARISE–African Research and Innovative Initiative for Sickle cell Education initiative–funded by the European Union's Horizon 2020 research and innovation programme. This interagency and multidisciplinary staff exchange programme facilitates the sharing of best practices in disease management and allowed us to send staff members on secondments to the UK for capacity building and knowledge transfer.

Focusing the funds into the specialised programme led to the delivery of quality care from experienced individuals at the minimum cost possible. We reduced costs by setting restrictions, as judged adequate by the team, on the number of admissions, and on costly lab tests and procedures. We developed treatment guidelines for pain and outpatient management of fever. The team advocated for increased use of generic hydroxyurea with high compliance. Patients are seen routinely at least once every 3 months for follow up. If admission to AUBMC is not possible, we coordinated admission to other facilities covered by UNRWA and UNHCR while managing the case remotely. We started to offer free genetic counseling sessions with outreach campaigns to reduce the risk of disease among consanguineous couples, increasing refugee participation in these sessions. We also gradually managed to cover out-of-pocket expenses, reducing the cost of care by 30% to our patients.

Policy makers should recognise that the refugee situation in Lebanon is no longer a transient crisis and efforts should be made to address genetic disorders with high prevalence among the community. We have shown that it is feasible to provide comprehensive care for patients with sickle cell disease in a low-income setting. To succeed, specialised care must be centralised while offering remote support (telehealth) and education. Establishing a structured programme resulted in support from both, funding agencies and patients, and allowed us to treat all patients.

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