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A chronicle of crises and emergencies: (dis) continuity of care for Syrian refugee children with neglected non-communicable diseases in Lebanon

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Abstract
Lebanon's recent history has been marked by intersecting crises, including a severe economic collapse, the Beirut port explosion, and the COVID-19 pandemic. Amidst this "polycrisis," the healthcare system has become increasingly reliant on international humanitarian assistance. This paper examines how these overlapping crises have affected the provision of care for children with thalassemia, a neglected non-communicable disease (NCD), within a *Médecins Sans Frontières (MSF)* paediatric unit operating in Lebanon between 2018 and 2023. Drawing on a single-case study design, the research explores the dynamics of power between state and non-state actors as well as within international humanitarian organizations and their approaches to healthcare delivery. The study employed a mixed-methods approach, including audio diaries, interviews, document analysis, and co-development groups involving 11 staff members and 18 caregivers of Syrian paediatric patients. Participants shared insights into operational challenges, decision-making processes, and the lived experiences of navigating Lebanon's collapsing health system. Findings reveal three interconnected issues: (1) the polycrises created an unsustainable environment even for resource-rich international non-governmental organizations (iNGOs); (2) the withdrawal of humanitarian services exacerbated the suffering of structurally marginalized Syrian families reliant on no-cost thalassemia treatment; and (3) national staff experienced profound professional and personal challenges as navigated tensions between iNGO policies and patient needs, often leading to burnout and reduced well-being. The study underscores the need for a reorientation of humanitarian healthcare models in protracted crises. This includes greater equity in decision-making between international organisations and national actors, longer-term planning for chronic disease care, and deeper engagement with national staff and affected communities. Prioritising sustainability, health justice, and the lived realities of both providers and patients is essential. While rooted in the specific context of Lebanon's highly privatised and pluralistic health system, these findings hold broader relevance for fragile settings facing similar structural and political constraints.

Keywords NCDs in emergencies, Humanitarian health, Health systems resilience, Thalassemia care

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Background

Lebanon has been in a state of "permacrisis" for several decades and dealt with major emergencies and crises in the last five years. A prolonged and severe economic collapse started in late 2019 with the Lebanese *Lira* [national currency] losing more than 98% of its value by March 2023 [1]. The 2020 Beirut Port explosion (or Beirut Blast) also happened during this challenging economic crisis as well as the COVID-19 pandemic, resulting in over 190 deaths and 6,500 injuries and the displacement of 300,000 residents [2]. The World Bank estimated an economic cost of 8.1 Billion USD, further crippling a nation with a longstanding failure in governance and lack of political and economic reforms. These shocks were added to a protracted conflict in neighbouring Syria and the consequent presence of over 1.5 million refugees in Lebanon, of whom nearly 90% live in extreme deprivation. Similarly, Lebanese families are living in a never-ending cycle of financial instability and suffering due to the extremely weakened social systems and distrust in state institutions [3].

Lebanon's health system is influenced by the neo-liberal political economy of the country, with market mechanisms and private sector involvement shaping health service delivery. Before 2019, approximately half of Lebanese citizens had health coverage either from social health insurance schemes such as the National Social Security Fund (NSSF) and/or private insurance, and the other half were entitled to state support through the Ministry of Public Health (MoPH) to cover hospital admissions, and relied on a network of non-governmental organizations (NGO) led primary care network if they cannot afford private ambulatory care. The system is fragmented, with the existence of many providers including public, private, and NGO providers. The majority of hospital beds are private and concentrated in the Greater Beirut area, and out-of-pocket payments (OOP) accounted before the economic collapse for about 35% of total health expenditures [4]. The health system has further deteriorated due to Lebanon's economic collapse, leading to heightened inequitable OOP payments [4], an exodus of skilled health workforce [5], and delayed healthcare services [6]. This has exacerbated health accessibility issues, especially among Lebanese and Syrian communities living with non-communicable diseases [7, 8]. More communities became reliant on the humanitarian system and non-state actors which struggle to addressing the increasing demands of communities, and often respond with unsustainable support mechanisms [9].

Local and international non-state actors in Lebanon, including well-resourced organizations, face overwhelming challenges due to the triple crisis. For instance, the destruction of Lebanon's main port in 2020 has hindered the importation of essential medications, drastically raising costs and limiting access to treatments for chronic conditions like thalassemia [10]. Fuel shortages in 2021 led to prolonged power outages in hospitals, reducing the ability to provide care, particularly for emergencies, as hospitals ration energy and other critical supplies [11]. Additionally, medication scarcity and financial constraints have forced patients, including 29% of 253 individuals living with non-communicable diseases and participating in a survey conducted by Médecins Sans Frontières (MSF), to ration their medications even before the blast [12]. These conditions have severely impacted vulnerable populations like Syrian refugees, who are further marginalized as NGOs limit their services due to resource depletion, leaving many without the needed support [9].

These changes in the dynamics of health service delivery have worsened health outcomes, especially among vulnerable populations. For instance, the challenges to access health services due to and coupled with increased poverty and challenging socio-legal context led to worsened mental health among Syrian refugees, exacerbating their pre-existing trauma from the Syrian war [13]. Children from deprived communities also suffer from long-term health risks including food insecurity, non-communicable diseases and developmental issues. Abou-Rizk, Jeremias [14] reported a prevalence of 30.5% of Syrian children under five suffering from anemia and moderate wasting.

This paper will detail how Lebanon's polycrisis created an untenable environment for the thalassemia programme of *Médecins Sans Frontières (MSF)*, a resource-rich an international humanitarian healthcare Non-Governmental Organization (iNGO), furthering the hardship experienced by families from Syria seeking refuge within its borders and mounting pressure for staff responding to these healthcare needs. It will reflect on the compounded challenges of temporal tensions in humanitarian healthcare [15], where the urgent, short-term demands for life-saving interventions often overshadow longer-term efforts to build sustainable healthcare systems. This dynamic is exacerbated by the urbanization of refugees [16], as displaced populations move into urban settings, straining already fragile infrastructure and complicating service delivery. Patients with chronic illness require life-long treatment, and the loss a healthcare service can be a matter of life and death. Those at the lower end of the welfare continuum - women, children, refugees, illegal, sick - suffer the most in the inevitable withdrawal of humanitarian healthcare service. As a result, the ethics of exit for international NGOs comes into focus, particularly regarding the right to healthcare and accountability [17, 18], raising critical questions about their responsibilities in providing care and ensuring that their departure does not further destabilize vulnerable communities. Through these lenses, this paper will critically examine how these intersecting challenges have created a humanitarian response that, despite significant resources, could have fallen short of meeting the long-term needs of vulnerable communities.

Specifically, this paper addresses the following research question: What are the dynamics of power between state and non-state actors and within international humanitarian organizations and their approaches to care delivery within Lebanon's healthcare system, and how do these dynamics contribute to improving or deteriorating the impact of a polycrisis on providing care for neglected noncommunicable diseases?

Specific objectives were:

- To explore the challenges posed by multiple shocks in Lebanon and their impact on a health programme run by a well-resourced iNGO and thalassemia care in general;
- To examine the experiences of staff navigating MSF decisions, the relationships with the state, and their career dynamics;
- To explore the experiences of loss felt by providers and carers in the face of multiple crises and the withdrawal of international support for the programme.

Methods

Study design and setting

This study adopted a single-case study design, focusing on a *Médecins Sans Frontières (MSF)* paediatric thalassemia unit which operated in a public hospital in Zahle, Lebanon between 2018 and 2023. The unit provided the only no-cost thalassemia service in Lebanon, treating structurally marginalised children from Syria. The organisation managed operations, recruitment and logistics from a European capital, while daily coordination was manged locally. The organisation operates on the two-tier recruitment system of international staff and national staff.

Target population and sampling process

The study involved three primary groups of participants: (i) national staff employed by MSF, (ii) international staff, and (iii) the carers of the paediatric patients. The recruitment of participants was done through purposive sampling, focusing on individuals who could provide insights into operational challenges and decision-making processes within the humanitarian healthcare setting.

A total of 11 staff and 18 care givers of the paediatric patients participated in eight co-development groups, with a median of six per group. In the first session all attendees were mothers of the paediatric patients, however the following three sessions saw increasing male representation (F4/M1; F4/M1; F2/M4). The carer participants were typically young parents in their early to mid-thirties caring for their young children with transfusion-dependent thalassemia who require bi/monthly treatment. Carer recruitment was straightforward; their children's blood transfusions to treat thalassemia took approximately six hours, meaning they had time to spare at the hospital. The staff involved in this research encompass both medical and nonmedical professions including physicians, nurses, psychologists, logisticians, human resources and finance. Other non-health personnel were also eligible to participate, including people who are underrepresented in spaces of aid such as cleaners and administration staff, in order to offer an opportunity for them to speak for and represent themselves politically, socially, culturally, spiritually, and intellectually [19].

Inequitable dimensions of power are central to this article, as organisations reinforce inequalities through making distinctions between national staff, recruited in-country, and international staff traditionally recruited from Europe and North America. A second crucial factor in this context is that, in Lebanon, many providers acquire their training and professional experience in Europe or North America. As a result, national staff hold experience comparable to their international staff colleagues. Yet discrepancies in contracts, salary, staff benefits, training and voting privileges between national and international staff remain the norm, mirroring wider geopolitical dynamics [20].

As a former MSF staff member, MG had an insight into the systems, the patterns, the multifaceted negotiations that took place around regarding staff access and resources, but she also witnessed the consequences of this work for more the aid workers subject to these dimensions. These experiences taken together led her to seek to understand more about the working culture and norms, what counts as knowledge in different spaces of aid, the consequences of prolonged aid work for its staff, and ultimately how this shapes staff and patient interaction. We strived to resist a reductive and functionalist analytical approach in the analysis. During analysis consultations, MG considered the counter-knowledge that was offered to her – different ways of seeing. Her approach to analysis stemmed from her understanding, her ways of seeing like a humanitarian aid worker and a sociologist, and related ways of knowing, enriched with those of others through analysis consultations in a cross-disciplinary analysis of the situation.

International staff had diverse nationalities including Brazil, Italy, the United States, Russia and Germany while national staff were typically from Lebanon, while some were Palestinian. Care givers of the paediatric patients were typically from Syria, in their thirties or forties with mixed literacy abilities. The children were typically under five years old. The families were from mixed socio-cultural and economic backgrounds – some families were Bedouin from rural Syria, while others were middle-class families from cities. The families typically lived in informal refugee settlements across Lebanon and were required to pay for and travel many hours to this thalassemia clinic.

Data collection methods

This article draws on four years of participatory ethnography-by proxy sociological research conducted with an independent Syrian researcher Belal Shukair (BS). This research examined MSF unit which treated children with thalassemia, a genetic noncommunicable blood disease which can be fatal in some cases if untreated. This research traced the medical project's mobilisation in 2018 to its closure in 2023, and an overview of how the methods aligned with the research objectives can be found in Table 1 Alignment of Methods with Research Objectives. Research methods included eight participatory 'co-development groups' with national and international staff (x4), and the carers of the paediatric patients (x4) who were mostly from Syria. These one-hour sequential sessions took place in parallel and participatory methods, such as voting and ranking of identified service improvements, were used in group sessions to explore what could be improved in the thalassemia service delivery. A total of four sessions took place per group, with six participants per group, allowing for carer turnover.

Table 1 Alignment of methods with research objectives

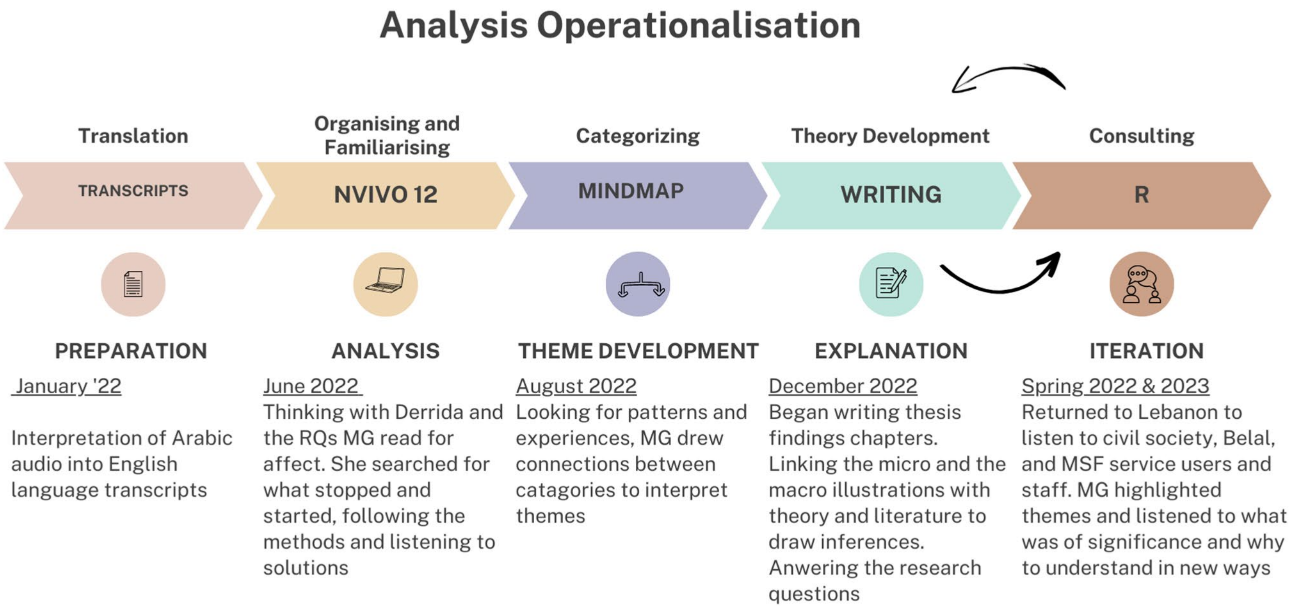
Research Objective	Research Method	Role of the Method
To explore the challenges posed by multiple shocks in Lebanon and their impact on a health programme run by a well-resourced iNGO and thalassemia care in general;	Co-development Groups	Learnt, worked and acted together in a cooperative manner, to focus on issues of joint concern, to identify challenges, and to generate positive responses in a collaborative and democratic manner
	Document Reviews	Analysed policy documents, organisational reports, and meeting notes to identify dominant narratives
	Researcher Diaries	Captured participants' reflections over time in their own words and rhythms
To examine the experiences of staff navigating MSF decisions, the relationships with the state, and their career dynamics;	Interviews	Enabled in-depth exploration of individual perceptions, contradictions, and negotiated meanings
	Co-development Group	Collaborative spaces to surface power relations and staff perspectives
	Researcher Diaries	Captured participants' reflections over time in their own words and rhythms
To explore the experiences of loss felt by providers and carers in the face of multiple crises and the withdrawal of international support for the programme	Researcher Diaries	Captured participants' reflections over time in their own words and rhythms
	Co-development Group	Created dialogical, participatory settings to validate findings and build shared understanding of the experience of loss

This main researcher (MG) conducted one semi-structured interview with BS, the local researcher to explore the methodological process and one unstructured interview with senior management to trace operational decisions and their consequences. MG asked the participant an open-ended question: 'What do you think I should know about the thalassemia service?' This interview consolidated the internal and external communications which informed this study.

Throughout the duration of this study, MSF staff prepared internal documents called 'sitrep reports' to detail meetings with local authorities, daily operational overviews, and related concerns, and to map ethical dilemmas. These documents served as a daily record written by busy project staff conveying information to headquarters.

MG spent a total of six months in Lebanon between the Summer of 2019 and end of 2023. This presence in the field helped develop rapport with staff and the families at the thalassemia unit. In 2021, while working remotely due to COVID-19, MG held a weekly meeting with staff for a check-in, alongside multiple calls with BS to share progress updates. There were multiple information flows which kept the research team informed of the daily realities for Lebanese and Syrians living in Lebanon, all of which shaped our understanding of the research data. While in Lebanon, MG kept a research diary, borrowing the templates advised by Spradley [21]. The research diary was transcribed electronically for organizing consolidated notes that capture the nuances and impressions and to support data protection [22]. Belal also kept an English language audio diary while running the co-development groups documenting his experiences and reflections throughout the study period. These diaries provided real-time insights into the researchers' observations, challenges faced, and the dynamics of the humanitarian response.

Data were analysed using a participatory thematic analysis approach. All interviews and audio diaries were translated by a local interpreter who was trained on data protection. Once completed, the transcription files were transferred securely using the University of Glasgow's file transfer service, and then uploaded into NVivo 12. Figure 1 details the operationalisation of the analytical process which followed three steps. The first step was familiarization: reading the transcripts carefully and repeatedly, and beginning the initial process of



January '22
Interpretation of Arabic audio into English language transcripts

June 2022
Thinking with Derrida and the RQs MG read for affect. She searched for what stopped and started, following the methods and listening to solutions

August 2022
Looking for patterns and experiences, MG drew connections between catagories to interpret themes

December 2022
Began writing thesis findings chapters. Linking the micro and the macro illustrations with theory and literature to draw inferences. Anwering the research questions

Spring 2022 & 2023
Returned to Lebanon to listen to civil society, Belal, and MSF service users and staff. MG highlighted themes and listened to what was of significance and why to understand in new ways

Fig. 1 Analysis operationalisation chart

descriptive coding. This approach allowed the identification of preliminary responses to the research questions and provided a foundation for further thematic analysis. The second was coding and theme extraction. The process of coding was both iterative and reflexive. Throughout the analysis, there was continuous engagement with relevant theoretical frameworks and prior empirical studies to interpret emerging patterns. Dialogue with other researchers from the University of Glasgow and between the co-authors helped connect the data to broader theoretical constructs, particularly drawing on works such as St. Pierre and Jackson [23] to shift focus from what the data means to what it does or the effects it produces. Thematic coding evolved as key themes were identified, merged, renamed, and refined. This thematic organization was supplemented by the creation of mind maps and narrative mappings to visualize the connections and relationships within the data.

Finally, the research team led the process of consultation with participants – as integral part of the process of analysis and interpretation. Feedback sessions were conducted with staff in Lebanon in 2022 and 2023, where the emerging themes were presented and discussed. These sessions provided valuable insights into the participants' perspectives, ensuring that the analysis was grounded in the lived experiences of those involved in the study. Through this participatory approach, the research not only captured the complexities of the humanitarian response but also facilitated the co-creation of meaning alongside participants, centring their voices in the interpretation of the findings. A final round of discussion between co-authors was held in 2024 to prepare this article.

Ethical considerations

The research team approached the power asymmetry with contextual responsiveness rather than a rigid application of rules and guidance offered by peers and in academic literature [24]. In this research, we ought to provide 'fair' working conditions, informed by professionality, transparency and trust regarding their time spent on tasks and its respective payment [25]. Through consultation with colleagues in Lebanon to conclude an appropriate rate for the specialist skillset, while being wary of overpaying and perpetuating the economic instability which is in part fuelled by discrepancy in access to international currency we paid the researcher 10 USD$ an hour from the allocated fieldwork funds for eight hours of training; six weeks of research facilitation (approximately four hours two days a week); a four-hour analysis workshop; and a final in-depth semi-structured interview about his experiences in the research project. Paying in USD$ was important due to the instability of the Lebanese currency, which has lost over 95% of its value and cannot offer the same guaranteed purchasing power. Warnock, Taylor [24] call for researchers to reduce suspicion around payment in social sciences research and instead draw on a framework centred around the ethics of care in paying local researchers.

Three primary findings emerged from this implementation of a digital research design. First, it revealed underlying assumptions about what counts as valid knowledge generation in research. The digital design reflected the core argument of this research project: less international intervention, more localisation. Second, creating transparency and trust was challenging without in-person meetings due to the damaged infrastructure in Lebanon, and this hindered the building of relationships. Third, digital research offers opportunities for working in fragile settings. For instance, using WhatsApp helped centre the voices of affected communities in humanitarian contexts, and enabled long-term and cost-effective engagement. Given this, Belal described the design as 'super-efficient' given the limitations; 'the infrastructure in Lebanon is out of our hands and you can always find alternative ways, you're never truly disconnected' (Belal, Interview). Thus, implementing a digital design in low-resource protracted crises can achieve data generation, but to create meaningful sustainable research partnerships, aligning with principals of decoloniality, it is fundamental to meet in-person 'to exchange energies'. This also enables 'kitchen table reflexivity', the conversations in the 'waiting field' where informal discussions take place, which supports the meaningful engagement required to explore the depth of positionalities and how this shapes data generation and analysis (Folkes, 2022) [26].

The positionality of the local researcher (BS), as a young Syrian male who is an experienced participatory research facilitator and aid worker in Lebanon, enriched this project. His experiences of migration from Syria to Lebanon, due to the Syrian war, resulted in him being well placed to navigate the social, cultural and ethical dynamics during data generation in the iNGO's clinics with Syrian carers of service users. His contextual knowledge was paired with the training he received for this research project. This allowed him to reflect, respond and facilitate discussion from congruence, or 'collisions', or perhaps possible false preferences that arise in discussions by posing vignettes and fictional narratives in a realistic and relevant way [27] (Fadiman, 1999).

To abide by ethical principles during recruitment, posters were circulated with a participant information sheet and consent form via WhatsApp by MSF's staff to prospective participants, staff and parents. Staff also informed prospective participants by word of mouth. Due to COVID-19 restrictions, there could be a maximum of six participants in the co-development groups.

When participants arrived in the room, Belal gave them the participant information sheet, which they could keep if they chose to. For participants who could not read and write, information was discussed verbally and oral consent was obtained. All participants received a health pack for participation which included items like hand sanitiser, soap and facemasks. All participants were provided with tea, coffee, water and cake.

The study received ethical approval by College of Social Science Ethics Committee at the University of Glasgow (reference number 4001900800) and the Ethics Committee of the Saint Joseph University of Beirut (reference number USJ-2019-270).

Results

This section first presents the rationale behind the implementation of the thalassemia programme by MSF in Lebanon's complex humanitarian context. It then explores the impact of compounded crises on the programme and thalassemia care broadly. The section also examines the experiences of iNGO staff navigating the increasingly difficult circumstances in Lebanon including the port explosion, pandemic and economic collapse, highlighting their perspectives on operational disruptions, shifting priorities and the withdrawal of international support.

Finding a niche in a republic of NGOs

Lebanon endured an influx of aid and donor assistance in recent years. This influx has fragmented the healthcare system and prioritised different populations on the grounds of, e.g., gender, nationality, sectarianism and geography. This finding is corroborated by Facon [28], who calls Lebanon a "republic of NGOs". Hamadeh, Kdouh [29] evidenced how this fragmentation has increased confusion for patients about eligibility, complicated referral processes and disrupted drug supply networks, leading to a geographically mismatched network of clinics and specialist services [29].

In this context, the iNGO began operations in Lebanon in 2017, responding to regional instability. In an interview with a senior MSF staff member, who we call Charlotte, she explained that it is crucial for NGOs to avoid duplication of services, and that international humanitarian NGOs must *'find their niche'* to justify their intervention and daily operations. In Lebanon, the Chronic Care Centre, a local NGO, has been Lebanon's primary thalassemia provider for a large portion of Lebanese patients since 1993 [29]. This centre does not offer care to non-Lebanese citizens due to the economic collapse [30], although its staff considered before 2018 visiting the refugee camps to offer support. However, this service was subsequently left for other NGOs to provide [30].

People from Syria who registered as refugees with the UNHCR received healthcare coverage from UNHCR through contractual arrangements with NGO-run primary care centres and subsidization of secondary care in Lebanese hospitals via a third party administrator. However, not everyone was registered with the UNHCR, in part because UNHCR stopped accepting registrations in 2015 due to pressures from the Lebanese authorities. This gap led MSF to establish the thalassemia service for all nationalities, anchoring broader relater operations such as running a Paediatric Intensive Care Unit (PICU), preparing to open an Emergency Room, and mobilising a vaccine campaign in response to the pandemic.

Health programme and system resilience tested by multiple shocks

This subsection examines the impact of conflicting approaches from state and non-state actors on thalassemia care during the successive crises. Staff cited the fractured health system as a barrier to coordinated crisis response.

Several staff participants emphasized their efforts to collaborate with the state to improve sustainability and continuity of care, yet many components of the health system operated in silos preventing a coordinated and timely response from non-state actors. For instance, the medical procurement systems – described as rigid, complicated, and expensive – faced additional strains after the Beirut blast. The port and many surrounding areas including a main MoPH warehouse were destroyed, and the iNGO had to rely on private planes for medication imports. Additionally, staff were critical of tax regulations on medications which further hindered their ability to provide care effectively and/or more efficiently by hindering access to essential medicines and drastically increased operational costs. Moreover, participants explained that sustainability of the thalassemia service was not adequality planned by MSF as the high treatment costs were an inherent barrier to finding project partners, either another NGO or the MoPH, due to the high expertise associated costs required for the treatment.

One participant highlighted the fragmentation of the healthcare system in Lebanon along with the mismanagement of multiple shocks and the volatile socio-political environment as key factors exacerbating the ability of MSF to secure other resources for the programme and/or referral to public hospitals. One staff member described how public hospitals, post-crisis, refused NGO referrals unless drugs like magnesium were supplied – a shift reflecting both rising costs and worsening system fragmentation. iNGO staff also reported that the public health infrastructure became a significant obstacle, with public hospitals charging them rent to operate within their facilities. International staff participants explained that in Lebanon the hospitals were described as being '*run like a business*' (Research Diary, May 2022). A senior staff member reported that *'treating thalassemia is expensive, requiring significant resources like a blood bank and generator power, with monthly treatment costs reaching up to £450'* [10]. In an interview, senior management explained that working in Lebanon is unlike working in Sub-Sharan Africa such as Chad or South Sudan, where often costs are lower as they are not charged tax, and salaries and expertise are lower.

The economic crisis also impacted the financial stability of communities seeking thalassemia care. Affected by the devaluation of the Lebanese currency and the quasi-collapse of all public health financing schemes, many Lebanese patients have turned to NGOs like MSF instead of private clinics or hospitals, which have become increasingly unaffordable. Unlike Syrian refugees, Lebanese patients do not qualify for UNHCR financial coverage, placing the entire financial burden of their treatment on NGOs. Staff members emphasized their commitment to providing equal care to Lebanese patients, adhering to the humanitarian principle of impartiality. However, the differences in care provision fuelled tensions between Lebanese and Syrian communities, particularly as Lebanese individuals face medication shortages while witnessing aid being distributed to Syrian refugees. Such disparities have sparked hostility, culminating in incidents like the burning of an informal settlement. Despite these challenges, staff recognize the inherent need for individuals to prioritize their families' well-being over their local community, which complicates the dynamics of community support in the economic crisis.

The COVID-19 emergency added more challenges. Some staff praised aspects of Lebanon's COVID-19 response, but others – especially with international experience – criticised public communication and awareness. One national staff member, whom we call Muhammad, was working in Canada at the beginning of the COVID-19 pandemic. For him, there were stark differences in what he termed Lebanon's '*level of culture and awareness in society*'; he explained *'with all the education and health promotion in Canada, things got better, but here in the Middle East nothing changed'* (Muhammad, Staff, Co-development Group Two). He concluded that the lack of proactive public awareness reduced blood donations for thalassemia patients, especially in informal settlements. Similarly, efforts to secure blood donations became very difficult after the Beirut Blast due to the public's focus on helping the blast victims.

In response to these increasing challenges, the iNGO decided to withdraw services when they perceived that the increased costs of treating a low number of children were to become unsustainable [9].As cited on their website, the iNGO's position to close the project aligned with the rationale that '*humanitarian actors cannot replace the healthcare system of an entire country*' [31], and the Lebanese state was criticized for not taking enough responsibility to contribute to elements of thalassemia care, such as providing essential medicines.

> *'Sadly, we do not always find ourselves able to support. The quantities in our clinics and stocks are limited and even if we manage to get an extra order it takes time, because of the importation delays. Due to the complicated and often chaotic public system, shipments of drugs are often taking eight months to reach us, which is simply too long in the context of a health care emergency […] We remain com-*

> *mitted to delivering impartial medical care to the most vulnerable people to the best of our ability, but necessary action needs to be taken by the Lebanese authorities to ensure that essential medical services are provided to the people. They need to act so that medication, supplies and fuel are accessible in the country. Humanitarian actors cannot replace the health system of a whole country' [31].*

Charlotte, a senior staff member, emphasized the utilitarian rationale behind this decision, comparing the high-cost thalassemia care in Lebanon with the low-cost treatment for malnutrition in Afghanistan. Ultimately, the organization reallocated resources to those countries.

Participants in this research reported a variety of reactions and opinions when asked about project closure. Staff members, especially national staff, approached this from a need for health justice. They emphasized the importance of prioritizing vulnerable patients and ensuring equitable access to care, particularly in the face of limited resources. There was a consensus on the need to prioritise this health justice approach, which contrasts with the current focus on optimizing resource allocation within the humanitarian sector. Others blamed their organization for hesitating to promote their health services within both Lebanese and Syrian communities due to management's fear of overwhelming limited resources while aiming for high patient number targets. This reluctance led to unmet targets, resulting in an inefficient program that eventually faced closure.

> *'There was something strange. When we came our hospitals [were] empty, we used to say we need to do better communication, [but] they [management] didn't want to, they are afraid to spread the news like UNHCR, they didn't want to spread the knowledge and say there's a project here for the Lebanese as well, professionalism was lacking, they were afraid more people would come.' (Leila, Staff, Co-development Group Three).*

International staff were taken aback by a second unforeseen effect of the economic collapse – the realization that Lebanese patients had a lack of acceptance towards their services. Charlotte, a senior manager, admitted staff often asked, *'Where is everyone?'*, referring to the absence of Lebanese patients presenting at the newly opened emergency room. When speculating on why this might be in an interview, Charlotte summarised that *'working in Lebanon, like many middle-income countries, is very difficult. It's difficult because there's a lot of actors, it's difficult for access, it's difficult for recognition and trust'* (Research Diary, May 2022). She suspected that Lebanese patients perceived humanitarian medical services as inferior, associating them with lower quality due to the use of generic drugs and their association with care provided to refugees. Having previously accessed private healthcare, many Lebanese were reluctant to seek treatment in facilities serving Syrian refugees or to use unfamiliar medications. This stigma, rooted in perceptions of quality and social status, contributed to the low uptake of MSF services despite growing needs. Consequently, the thalassemia unit incurred high costs while serving relatively few patients, unlike the emergency room which saw higher turnover – ultimately influencing the organisation's decision to close the programme.

Humanitarianism in complex settings: staff experiences in Lebanon

In this part of the analysis, we reflect on the dynamics of decision making and staff experiences within the humanitarian sector in volatile and fragile settings, especially in relation to short-term programmes that may not have been planned or implemented according to health needs.

Participants had increasing concerns about the "pop-up humanitarianism" reflecting the temporary nature of aid responses in complex crises and the uncertainty and insecurity from the lack of long-term solutions [32]. This dilemma, between the aim to provide temporary relief and dignity in adherence to the organization values, versus carefully considering the financial viability amid a lack of political and financial reforms in Lebanon created a psychological toll for the participants of this research. The research team noted increasing concerns regarding the purpose, accountability, and legitimacy of aid organizations, echoing critiques of the UN and broader humanitarian system; citing that the iNGO was '*turning into the UN*' that it's '*getting too big and it's kind of past its critical phase now*' (Research Diary, May 2022). The majority of staff shared the concern that their voice would not be heard or considered amid institutional changes and decisions are made at a higher level.

The experiences of both international and national staff in this research also highlight the precarious nature of humanitarian work, with various challenges including the demanding job nature, emotional isolation and barriers to immersion in the local culture and context. International staff often face short-term employment contracts (ranging from six to twelve months), complicating their ability to establish a sense of home or stability. The low pay (starting at £800 per month) further exacerbates their inability to maintain a permanent residence, trapping them in a cycle of redeployment and financial insecurity. The living conditions within "compound" settings of humanitarian housing – when working in remote areas – hinder the formation of meaningful relationships, leading to a sense of isolation among international aid workers. Staff like Charlotte share experiences of feeling trapped in perpetual migration for income and career advancement, alongside a yearning for belonging and purpose. This precarious lifestyle results in a lack of material welfare and emotional support networks, as colleagues come and go.

Mobility, the practice of working across borders, is at the heart of much international humanitarian practice. Frequent relocation leads to a loss of contextual project knowledge, contributing to the "short-term memory" of the humanitarian sector. This phenomenon creates a divide between international staff and local populations, hindering genuine solidarity and understanding. The separation caused by language and cultural differences especially in distal areas – where most humanitarian projects operate – perpetuates harmful perceptions of "otherness," fostering an Orientalist gaze that reinforces neo-colonial attitudes, and normalizes the superiority of Western knowledge over localized ways of understanding [33]. Nevertheless, the dedication to humanitarian principles and work, despite coming at the cost of a sense of belonging, shapes the humanitarian identity. Separation from family, migrating in search of a better life, seeking a home and feeling uncertain of the future evokes feelings of uncertainty and vulnerability for international aid workers. This sense of precariousness in their unknown journeys and associated risks are similar for Syrian families, although their experiences and sense of freedom are different. Finding mutual vulnerabilities, as illustrated between staff and service users, can act as a basis for solidarity and support in moving towards health justice and more equitable forms of coexistence [34].

Our data identified palpable tensions among national staff within a constant atmosphere of stress and anxiety affecting trust and morale among all staff. Moreover, national staff reported an inherent job insecurity due to the temporary nature of humanitarian projects in a "failing state" like Lebanon. Yasmin, a Lebanese staff member shared the affect of the project's: *"This is really sad, because everywhere they know that here there is paediatric service and now we are just telling them 'we are closed.' We don't even know where to go. And in this last phase we were closing we were not even standing with the message we will support other hospitals to pay".* This precariousness negatively impacts their physical and mental health, as well as their attitudes toward their organization. This also creates vulnerability as they rely on their employers for stability in a context marked by economic decline and social unrest. This insecurity fosters feelings of anger and alienation, as highlighted by academic perspectives on the social consequences of precarity by scholars such as Guy Standing, and diminishes their power within the organization.

Finally, international staff participants explained that the stigma and distrust among Lebanese communities vis-à-vis iNGOs' services – often seen as inferior due to the use of generic medications and their association with refugee populations, as presented earlier – complicated their work on the ground and affected their morale. Moreover, due to Lebanese state constructed illegality, many Syrian families were confined to remote informal settlements, constrained by legal and financial barriers and often unaware of the service due to limited outreach. Staff described this dual exclusion – driven by stigma, restricted mobility, and insufficient communication – contributing to a sense among staff that their efforts were undervalued or misunderstood. These experiences highlight the broader challenges of delivering humanitarian care in middle-income contexts, where fragmented systems, political sensitivities, and social perceptions shape both access and acceptance.

Loss in the face of multiple crises and the iNGO withdrawal

All participants in this study made sense of the multiple transitions the thalassemia unit underwent by conveying a sense of loss, revealing both shared and divergent perspectives on how the multiple crises impacted their lives in Lebanon. This included fears about the potential loss of employment, materials, relationships, and patient health due to service closures.

International staff expressed feelings of loss related to various transitions within the thalassemia unit, including fluctuations in the forecasted project funding, resource reductions from headquarters, and service closures. International management staff stated in an external publication report that '*We wished we could do more to respond to the needs but we are limited by the very high price of the thalassemia drugs*' (Médecins Sans Frontières, 2020a). Both international staff and patients experienced spatial loss due to the closure of the programme's location within the public hospital. To avoid loss of investment, the medical equipment purchased for the thalassemia unit was handed over to the Ministry of Public Health (MoH). However, Charlotte expressed scepticism about the MoH's capacity to maintain this treatment due to funding and expertise shortages. These challenges highlight the conceptual failures in forecasting a future in humanitarian aid.

National staff reported the heaviest emotional toll of service closures, while both international and national staff faced temporary contract issues and the prospect of moving on. For instance, Leila who worked as a staff nurse explained the affect of the loss of a patient's life and how the support her colleagues offered to parents when grieving for their lost child took its toll on staff, '*even for us, in this hospital, we have no mental health support and we have a PICU [Paediatric Intensive Care Unit] for example*,' said Leila; she explained that as national staff they had to cope with '*what is happening*': situations that were not *'their fault'*, caused by the structural violence that the patients at their clinic lived in. National staff expressed concerns that patients, particularly those requiring ongoing treatment for thalassemia, would face critical challenges, as the loss of services was a matter of life and death. To mitigate possible unemployment after project closure, the iNGO offered training and staff support, which most national staff showed little interest in dedicating extra time to an organisation where they saw no future.

Patients and carers at the lower end of the welfare continuum, including many of the families from Syria and Lebanon in this research were disproportionately affected by the eroded health system, which drove them to rely on humanitarian support. Service users expressed three forms of loss: biographical loss (e.g. what it means to be a child from Syria), loss of a home, and loss of family. While these intersect in many ways, the distinct ways in which they shaped how service users made sense of their health and healthcare journeys to the thalassemia unit provide an understanding of migration and the broader social determinants for humanitarian healthcare.

Many participants shared how they had lost their dignity and identity since arriving in Lebanon. Maryam, a mother whose child was treated for thalassemia explained *'At the clinic, it's the same, the Lebanese entered without having to stand in the queue. They were expelling us as if we were animals and we were not human in front of them. We notice prejudice and indifference to the Syrian people'.* Many participants in this study detailed the ways in which they felt disregarded or mocked by healthcare professionals when they presented with an illness. Another illustration was that one participant's child was turned away from a healthcare service, and subsequently died. The consequences of these experiences for many participants were an overall loss of trust in health institutions.

Participants shared stories of their children being bullied in the informal settlement for having thalassemia. Zahra detailed that '*Whenever my son goes out to play with the kids at the camp, the kids bully him, saying, "He's sick, let's not play with him". They don't know what the illness is, they think it's contagious'*. Parents narrated the ways their children were losing out on their childhood due to their illnesses, for instance Jamal shared the difficulties he experiences with his daughter: *'She always asks me, "Dad, why is it just me?"* She cries every time I take her to the hospital and says, *"Don't take me; take my other sibling instead'.* For children who have already endured the hardships associated with fleeing war and the violence of growing up in a state where they are illegalised, the consistency of care from trustworthy thalassemia staff and family support is essential in mitigating further harm.

Parents also detailed the implications of losing a house on health. Their homes in Syria were away from pollution, a quiet space with privacy. Zahra summarised that *'if the society you're living in is good, then you are good, if it's not, then you're not'.* A home evokes a sense of connection, both a material and socialised space, a sense of belonging that is integral to a person's wellbeing [35]. Participants identified that living in informal settlements or overcrowded, and squalid housing often created sickness and hindered their recovery process. Hence, migration itself was a determinant of health.

Participants highlighted the loss of family support and the impact it had on their health; Umm Mohammad explained that she felt that she could cope due to the support of her family, whereas Jamal was *'totally alone'* as a single parent caring for his children. Families share the burden of one member's ill health. Yasmin, a mother summarised that *'For me, the most important thing is my children's wellbeing, that they get cured of the disease that affected the life of the whole family'*. Many parents had originally planned for more children, but due to the hardships they experienced caused by their child's thalassemia, they decided not to have any more children. Jamal explained, '*If having children is related to finding a blood donor and going through all of this, then I prefer not having children anymore'*. Many parents suffered from the deaths of their children caused by thalassemia, including Amira, who lost her elder daughter to thalassemia.

These resultant losses, for both present and future patient care, reflect broader issues within the humanitarian aid framework, evidence the need for a more sustainable and trustworthy approach to healthcare for chronic illness patients. Layla, a Lebanese nurse remarked on the project closure by summarising that: *When the NGOs came to Lebanon, things weren't that bad but after they leave Lebanon, the situation is going to be worse than ever".*

Discussion

This paper offered a unique empirical contribution to understanding how international humanitarian responses to neglected chronic non-communicable diseases such as thalassemia are shaped – and ultimately constrained – by the interplay between protracted fragility of local political economy and health systems and structural limitations of the humanitarian system itself. These intersecting forces shape not only the design and sustainability of interventions but also profoundly affect the experiences and wellbeing of healthcare providers, carers, and patients. Three interrelated findings emerged from this research. First, Lebanon's overlapping crises created an untenable operational environment even for a resource-rich iNGO like MSF; secondly, the subsequent withdrawal of services compounded the hardship of Syrian families, and thirdly, staff felt “stuck” in their efforts to navigate both iNGO decisions and the mounting challenges faced by patients leading to decreasing well-being of national staff.

Lebanon’s healthcare system is fragmented and under significant strain, due to compounded shocks on decades of state neglect, insofar as in 2021 MSF described it as a context comparable to a conflict setting (Doctors Without Borders, 2021). As a result, Lebanon’s health system became more reliant on humanitarian and NGO-offered healthcare, a sector which prioritises primary care in favour of secondary or tertiary healthcare due to the comparatively higher costs and necessary continuity care. Moreover, to prevent duplication of efforts in a saturated NGO environment, iNGOs had to ‘find their niche’ to justify intervention and continued presence. MSF’s decision to deliver thalassemia care – a high-cost, neglected NCD – was a strategic response to unmet needs, particularly among unregistered Syrian refugees. However, the compounding effects of economic collapse, the Beirut port explosion, and the pandemic dramatically raised operational costs and strained coordination with national authorities. This ultimately shaped MSF’s decision to withdraw, defending this decision by stating that *‘Humanitarian actors cannot replace the health system of a whole country’* (Doctors Without Borders, 2021).

Our study also highlights how humanitarian responses to neglected chronic non-communicable diseases were marked by abrupt transitions, short planning cycles, and limited investment in long-term care – features that align with what Pallister-Wilkins [32] calls *‘pop up humanitarianism’*. The emergency modus operandi which governs the operation of medical NGOs, decontextualises future health care needs in favour of being stuck in the present [15]. Taken together, this creates uncertainty and insecurity, as all actors are prevented from planning for the future and pursuing long-term goals. This has subsequently shaped employees’ understanding of their purpose (Brun, 2016).

The shortcomings of thalassemia service provision in Lebanon are further illuminated by the concept of structural violence (Farmer, 2004). The short-term, emergency-driven logic of humanitarian care often sidelines chronic conditions, disproportionately affecting displaced populations who are already marginalized by other systemic factors such as legal and economic constraints. In Lebanon, this dual structure – state neglect and humanitarian temporariness – normalizes exclusion and deflects responsibility for long-term care. As our findings show, both staff and patients bear the consequences: staff experience moral distress and limited agency, while patients face preventable suffering within a reactive and crisis management-oriented system.

The consequences of structural and operational issues of health programmes extend beyond health outcomes, compounding broader socioeconomic vulnerabilities of vulnerable populations. Fakih [36] reported that in order to continue to feed themselves, households in Lebanon were giving up on the quality of what they eat, on education or health care, and are even skipping some meals, as approximately 85% could no longer afford to buy basic foodstuffs during the economic crisis [36]. Through the theme of loss, this article narrated how the scarcity of resources also fuelled tensions between Lebanese and Syrians and resulted in conflict, negative stereotyping, and a decline in the quality of healthcare. Carer participants detailed how limited medication supplies were prioritized for Lebanese individuals, creating fear, a distrust of medical services, and societal tensions, which negatively impact well-being. This finding is consistent with that of Spiritus-Beerden, Verelst [37] who found that emergencies and their aftermaths give rise to discrimination towards refugees due to increased fear, resulting in stigmatisation.

The families who participated in this study relied on their informal networks to secure resources and for support, exacerbating their distress and leading to a higher risk of negative health outcomes. For the paediatric patients, the impact of poverty, lack of education, malnutrition, and untreated medical conditions are likely to impact their families for generations to come. Evidence from the Dutch Hunger Winter (1944–45) and the Chinese Famine (1959–1961), shows the association between early life malnutrition and adult body size, schizophrenia and type 2 diabetes [37–39]. There is an increasing likelihood of an *intergenerational transmission of illness and chronic poverty* for the families who participated in this research, rather than the transmission of positive assets and capital such as land, livestock, status, education, and kin group [40].

Another important finding in this study was the “invisible labor” of decision translation that national staff were compelled to undertake while working for MSF [41]. They were responsible for translating the difficult operational decisions made by the organisation in response to Lebanon’s polycrises to the patients and their families. Moreover, they translated the increasing hardship families were experiencing back to senior management. This echoes reflections in the literature [42], including James M [43] who documented the significance of national staff in the success of humanitarian action due to their central role as ‘switchers’ in the politics of humanitarian fixing and brokerage.

Our research also documents clear parallels between the consequences of the ‘burn out jobs’ and increasingly neo-liberal model of many global healthcare systems [44]. National staff, in particular, often face working conditions that mirror those experienced by patients. As demonstrated in this study, they are frequently tasked with demanding translation work – both linguistic and cultural – between patients and/or carers, and senior management. Addressing these challenges and improving the working culture of international humanitarian aid requires enhanced communication from headquarters to field-level staff. Such efforts are essential to foster trust, strengthen accountability, and boost morale in humanitarian healthcare delivery.

Taken together, the losses articulated by staff and patients in this study reflect the inherent limitations of humanitarian health responses in protracted crises, reinforcing calls in the literature to align care provision with principles of health justice and social equity [45]. While humanitarian aid can offer critical relief and a sense of dignity amidst uncertainty, its structure remains fundamentally short-term. This case illustrates the tipping point at which an organisation – confronted by rising operational costs, limited impact, and/or lack of state partnership – deems a project unsustainable. The decision to withdraw was framed as a principled trade-off: maintaining fidelity to institutional values while responding to perceived greater needs elsewhere. Yet, the findings also highlight the urgent need for iNGOs to reconsider how emergency frameworks might be adapted in contexts where chronic conditions persist and national systems are unlikely to assume responsibility. This may require reimagining sustainability – not solely as state handover, but as strategic investment in longer-term care pathways, flexible funding mechanisms, and closer engagement with national staff and communities to support continuity and accountability, even in fragile settings.

Conclusion

This study offers critical insights into the structural and operational challenges of delivering chronic disease care in protracted crisis settings, using Lebanon's highly privatised and pluralistic health system as a case in point. While the Lebanese context is shaped by a unique mix of neoliberal health governance, economic collapse, and political fragility, the dynamics observed – such as fragmented service delivery, short-term humanitarian mandates, and the marginalisation of both patients and frontline workers – are mirrored in other crisis-affected middle-income countries. To improve alignment between funding priorities and lived realities, we propose actionable steps for key stakeholders. INGO senior management should embed chronic care planning into emergency response frameworks, adopt flexible funding models, and avoid premature exit strategies where state uptake is unlikely. International staff require stronger context orientation, and more equitable collaboration with local actors. National staff, often bearing the emotional and operational weight of humanitarian delivery, must be meaningfully involved in programme design, communication, and decision-making. These recommendations are essential not only to improve health outcomes but to reshape humanitarian practice toward greater equity, sustainability, and accountability in fragile and protracted contexts.

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Author contributions
M.G. conceived the study and developed the study protocol and the tools. M.G. coordinated the data collection and analysed the data with support from I.R.B. All co-authors (M.G. and I.R.B.) contributed to the interpretation of data, prepared the manuscript after critical revisions of previous versions, and approved its final version.

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Data availability
No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
The study protocol and questionnaire were reviewed and approved by the ethics committees of the University of Glasgow (reference number 4001900800) and Saint Joseph University of Beirut (reference number USJ-2019-270). All study participants provided an informed consent to participate in this research.

Consent for publication
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Competing interests
The authors declare no competing interests.

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