Gilmour, Molly (2024) *Power and participation in humanitarian aid assemblages: a case study of a paediatric Noncommunicable Disease Unit in Lebanon.* PhD thesis.

https://theses.gla.ac.uk/84172/

# Power and Participation in Humanitarian Aid Assemblages: A Case Study of a Paediatric Noncommunicable Disease Unit in Lebanon

**Molly Gilmour, MSc**

**Submitted in fulfilment of the requirements of the Degree of Doctor of Philosophy in Sociology**

**School of Social and Political Sciences**
**College of Social Sciences**
**University of Glasgow**

# Abstract

Over time, the humanitarian healthcare sector has evolved into a complex system of specialised organisations, shaped by geopolitical, cultural, social, and economic forces, that influence global social and political decision-making. Humanitarian healthcare settings can be spaces of great power inequity. This study took place in Lebanon, a conflict-affected state reliant on international humanitarian healthcare due to compounded shocks and state neglect. I explore how a pandemic, a terrible explosion and an economic collapse impacted people in one paediatric Noncommunicable Disease (NCD) unit. This research contributes to the wider debate on the necessity for long-term NCD treatment in humanitarian contexts, often offering temporary care.

This thesis explores power and participation in aid assemblages, investigating the relationships and connections between ideas, the international headquarters and on the ground project implementation. The objective was to develop the understanding of the power formation processes in humanitarian healthcare, tracing project decisions and their consequences, and whether participatory socio-culturally responsive methods support in decentering power in low-resource spaces of aid. While participatory approaches are well-studied in supporting patients and healthcare workers in the ‘Global North’, their application in the Middle East and North Africa (MENA) remains less understood. This study was conducted with Syrian families who accessed Médecins Sans Frontières (MSF) services for paediatric NCD care and MSF staff, with an independent Syrian researcher, Belal Shukair. Methods included audio diaries, interviews, document analysis and codevelopment groups, fostering a social justice-oriented methodological approach.

This research documents the micro-processes of the everyday discrimination, mechanisms and assumptions about power hierarchies in aid assemblages. There were significant methodological differences between staff and service users. Staff engaged to collectively improve the NCD service, while service prioritised concerns beyond thalassemia treatment. Lebanon’s crises exposed stark inequalities. This study details the decision-making processes and consequences of MSF’s service redesign in response to the crises, how staff resisted and reformed the structures of aid. Syrian service users described the increasingly constrained healthcare access and the tactics they used to secure care. All participants expressed a shared sense of loss amid crises. Amid the economic collapse, participants debated the value of healthcare. The analogy of a collapsing tent illustrated aid-induced precarity. While their experiences differed, their meanings were expressed in similar ways.

The aid sector, relying on precarious staff contracts and project funding, responds to healthcare needs in spaces of crises but often neglects a biosocial approach to long-term care for NCDs. I evidence that Western-centric value system construct the humanitarian healthcare sector, as value was often interpreted as value for money. Postcolonial systems erase the complexity of health, shaping how people see healthcare needs and service design. I argue that considering the value of what the healthcare means to individuals who receive it, alongside considering what it accomplishes at a macro epidemiological level, will achieve a localised, way of understanding health, reducing cultural collisions. Moreover, it will meet the increasingly needed permanent, continuity-focused health care aid to ensure that NCDs treatment is not compromised in humanitarian contexts. Taking this approach enables a move beyond traditional practices of meeting basic needs for survival towards enhancing lives.

This work is a response to the critique of humanitarian healthcare structures, the call for improved accountability, sustainability and patient centred care. This research contributes to the understanding of chronic illness management in conflict-affected settings and whether participatory approaches may prove to be a useful method in developing long-term care in humanitarian healthcare settings

Keywords: Humanitarian Healthcare; NCDs; Lebanon; Participatory Methods

# Table of Contents

# List of Tables

# Table of Figures

# Acknowledgements

When I started my PhD, I was the first in my family to earn a degree and the first in my extended family to be awarded a Masters degree; it's safe to say I had no idea what a PhD entailed, but I was curious, and had questions about aid and health justice I was eager to explore. This PhD journey has been five years of challenge (I like a challenge), and indulgence, personal growth and following my curiosity to Lebanon and Afghanistan, learning languages and more about myself and the world than I could have imagined. This thesis could not have existed without the people who have supported me unconditionally. I started my PhD in 2018, seeking to research in Lebanon, before the onset of the Covid-19 pandemic and the many heart-breaking hardships the country has endured. This presented numerous challenges and uncertainties; however, I made it to the finish line, and I would like to express my deepest gratitude to the exceptional individuals who taught, supported and guided me throughout this transformative journey. The personal and professional cannot be separated. I am grateful for the inspiration and energy that people have shared with me, as we worked together in the belief that humanitarian healthcare can be otherwise –that it can be a more equitable, sustainable, a kinder sector, embedded in solidarity.

First and foremost, I am extremely grateful to my supervisors, Dr Chris Bunn, Professor Mia Perry and Professor Kate O'Donnell, you believed I could do it before I even knew what 'it' was. In 2017 as we crafted the application for funding, to now, as you empower me to lead my own research in my next steps. Thank you for sharing your knowledge, experience, your advocacy, and your support. Cheerleading me on through the peaks and troughs and twists and turns that shape a Phd journey.

This endeavour would not have been possible without the organisations which supported me with financial and other resources, including the University of Glasgow's Lord Kelvin Adam Smith PhD scholarship. To Dr Ibrahim Bou Orm at St. Joseph University of Beirut, thank you for your time, wisdom and expertise in guiding me though my process of enquiry. Ibrahim, your supportive replies to my long emails as I designed and redesigned my PhD were a source of calm and provided a sense of clarity when there was so little at times. To Dr Darryl Stellmach and Michael Neuman and to the dedicated and curious staff at

Médecins Sans Frontières OCP and OCA: thank you for your trust in this study, especially prior to data generation as I was wading through the unknowns of qualitative enquiry. You saw the importance of this work and your support in my early career research has been invaluable, merci beacoup. I am thankful to the space, time, trust and support offered to me by Amel Association International, I admire your relentless dedication to health justice. Furthermore, I am grateful to the many other colleagues I have had through this PhD journey, who have created the time and space to support early career researchers, including Dr Teresa Piacentini and Dr Alicia Davies. To the Sustainable Futures research network, who provided me with a space to unlearn and try. Dave, I am grateful for your attention to detail, critical eye and kind words, they helped me get through the final push. Thank you to colleagues in the sociology department including Professor Les Back, Dr Gareth Mulvey, Dr Marguerite Schinkel and Jennifer McLaren for your dedication to creating and supporting our cohort. My PhD cohort have been my rock. To Dr Jessica Penney who enriched the way I see the world and knows how to keep me grounded. Who shows me what it means to research in a way that prioritises people over data. To my ‘Happy Mondays’ and ‘Write Club’ co-working crew, and to Cat, Liza, Chase, Hannah and Beth who kept me keepin’ on as we wrote, read, lunched and sometimes flailed together.

To the wonderful people I met in my Arabic language journey. To my Arabic teachers at LEVIT, to Carol Bittar and Abdelkader Boutaleb: شكرا لك على صبرك. Gen, you filled me with confidence when I needed it the most, Julia for always learning with me, and to Rob, you helped me find the balance between fun and play as we kicked about Southern Lebanon.

To my family: I am proud to come from a lineage of strong matriarchal women. Whenever there is a doubt in my mind about whether ‘I can do it’, I can hear the voices of the women in my family saying, ‘don’t be silly, of course you can’. To my late Grandmother, Mina. To my mum, Jean, I admire you starting your university journey in your late career, you inspire me to continue being a dedicated lifelong learner. To my younger brother Robert, awarded the Irish ‘income for the arts’ grant, to fund your career in emo rap, thank you for reminding me to stay creative and true to what makes us unique. I’m proud of you. To my Dad, Ian, who instilled a curious and critical nature in me, you

embrace a debate and never tire of the learning process, forever delving into books to arrive at a truth.

To the family I have created: To my wonderful flatmates over the years, Kim and Brittnee (& the ficklest of felines Raglan). To rental cars and escaping to the countryside, take aways, facemasks, life planning (life questioning), and of course MAFS UK. To my weegies, the 'tartan swim team', you have been a constant reminder that yes, there really is life outside of a PhD. I cannot wait to celebrate with you all at Dan and Jen's wedding. Big love. To my oldest friends in my village of Kilcoole. It really does take a whole village, you shaped who I am today, and I am greatful; strong minded, humble (I hope), perhaps a bit outspoken and I trust, a bitta craic; we're a village so there's too many of you to name, but I'll try. To Jessie, you are truly a dedicated friend, to Chloe (you remain an honorary Koolie), to Maeve and our shared dreams of a more equitable world, to Cillian and Oisín, you can always be relied on for a pint of the black stuff to bring me back down to earth, and to Jess Golden who has for the past twenty three years, always been there, holding up my jenga tower when it starts to sway. Go raibh míle maith agat a chairde.

Most importantly, to Belal Shukair, I am forever grateful to you, to the partnership and trust we created in our collaborative process of enquiry. This work would not have been possible without you. Thank you for your warm welcome, I admire the unrelenting strength encompassing the family you've created. This thesis is dedicated to those deemed to be 'vulnerable', those I cannot name who participated in this research, those who advocate for health justice and are dedicated to creating healthcare without borders. I promise to continue standing with you in solidarity.

شكرًا لك

# Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Printed Name: Molly Gilmour

Signature

# Abbreviations

| Abbreviation | Definition |
|---|---|
| ED | Emergency Department |
| EU | European Union |
| ICU | Intensive Care Unit |
| INGO | International Non-Governmental Organisation |
| LL | Lebanese Lira |
| LMIC | Low- and Middle-Income Countries |
| MENA | Middle East North Africa |
| MoH | Ministry of Health |
| MoPH | Ministry of Public Health |
| MSF | Médecins Sans Frontières |
| MSF-OCP | Médecins Sans Frontières Operational Centre Paris |
| NCD | Non-Communicable Disease |
| NGO | Non-Governmental Organisation |
| PICU | Paediatric Intensive Care Unit |
| PR | Participatory Research |
| WASH | Water, Sanitation and Hygiene |
| WHO | World Health Organisation |
| WFP | World Food Programme |
| UK | United Kingdom |
| UN | United Nations |
| UNHCR | United Nations High Commissioner for Refugees |

# Preface

I originally wrote that this journey began in Paris in 2020, when I arrived at Médecins Sans Frontières (MSF) headquarters to organise data generation in Lebanon. But on reflection, I believe the true origins of this story were in 2016 in Idomeni, Greece. Idomeni is the border village between Greece and North Macedonia. In 2016 it was heavily fortified by the respective militaries, which created a bottleneck for people fleeing conflict and persecution from Syria, Afghanistan and Iraq. Thousands of people found themselves stranded in Idomeni, living in makeshift camps and dire conditions.

Like thousands of others, I wanted to help. I was 22 and had recently graduated from an MSc in Sociology with a focus on forced migration and ethnic studies. I resigned from my job in Amsterdam, where I was living at the time, and travelled as an independent volunteer. I spent four months there. I worked with MSF and Save the Children to establish a cultural centre, alongside other international volunteers. Below is an excerpt from the last post of the online blog I kept during my time there. I wrote this to share with family and friends, but also so I could speak out about the injustices I saw. I am including it here as I believe it captures the passion and dedication I still carry today, giving an insight into why I do what I do. The questions I find myself wondering about in this blog post are the questions that shaped my PhD.

> Idomeni was a place I had wanted to go for so long, although that may sound bizarre. Being there, the sense of normality was surreal; daily life persisted in the camp: shops were open for business, and schools, weddings, funerals and births all took place in those fields. Yet the dynamics and hierarchical structure were often unhealthy; young good-willed European students (not too different from myself) would fundraise thousands of euros and almost ‘play God’, and in some cases personal shoppers, with that money. Many would essentially ‘adopt’ families and post pictures over social media declaring ‘my Syrian family needs x,y,z’. Survival mode for that family, no doubt. Many volunteers arrived and cooked food, served tea, chatted and made friends with those living in the camp. Activities were organised for children and adults alike; although it was a ‘bare life’, for the most part it was ‘liveable’. I heard stories of refugees not wanting to leave ‘Eko camp’ as they were too comfortable there.
>
> But the borders weren’t going to open. Volunteers were investing energy into cooking meals and making tea for the refugees, but the

> root cause was being overlooked by many - the system driving this inequality. You can only fundraise and make tea for so long. I heard Idomeni being described as ‘an adequately stocked refugee camp’.
>
> Leaving Greece, I had a bitter taste in my mouth. I was disheartened to learn that organisations such as MSF or the UNHCR, which I had put on a pedestal, were composed of error-making humans just like me.
>
> For now, as outlined on my cliché Facebook ‘Airport Check in’, I will try to apply the knowledge I have acquired and transform my energy positively and productively. I have learned the importance of collaboration between the International Development and Humanitarian Aid sectors - especially in the greater Levant region, where there is often no simple ‘hand over’ from one sector to the other. The Humanitarian Aid required in Greece was directly impacted by the ‘integration schemes’ and ‘development’ work in, e.g., Germany, and vice versa. I hope with newly acquired skills, revived energy and growing networks, I can continue to strive in this field.
>
> Thank you for taking the time to read this and I hope to update soon,
>
> Molly

(Online Blog, June 2016)

It has been seven years since I read any of my blog entries; I took them offline in 2016, and they remained raw for a long time. Working in Greece changed how I saw the world; it was my ‘epiphany’, a revelation. Below, I detail the harmful power structures I saw and tried to make sense of, the temporal tensions (‘why are they making tea? Change the system!’), the disappointment when I saw the staff of aid organisations making human errors. I wrote about how I found being a junior operations officer unfulfilling. That if I weren’t there, I didn’t think there would be a difference. That by working in aid, I lost my sense of purpose. These fears were realised when I handed in my notice to Save the Children and was told, ‘That’s fine, we’ll find someone else.’ I wrote about what I saw, what I learned, and what I believed could be better.

On my return from Greece, I secured a position in the psychosocial care unit at the Médecins Sans Frontières headquarters in Amsterdam. In January 2020, prior to PhD data generation, I wrote a position piece entitled ‘Transitioning from a practitioner to academic’ to help me identify assumptions I made in my work. In this, I wrote that working at the MSF headquarters gave me a different insight into the scale of global crises and trends. I could see the systems, the patterns, the multifaceted negotiations that took place around access and resources, but I also witnessed the consequences of this work for more experienced aid workers. My job was to support staff mental health through briefing and debriefing. I noticed how the transient lifestyle and normalisation of living in war zones takes its toll. Mental health issues are an epidemic in ‘aid land’. Alcoholism, perpetuating negative stereotypes and cynicism seemed to be expected. In so many ways, it was a toxic environment where you had to ‘earn your stripes’. My six months working in emergency response in Greece was dismissed out of hand when a colleague told me, ‘I’d hire a backpacker over you, they’ve at least been outside of Europe.’ It was made clear to me: Unless your mission was with MSF, it doesn’t count, and if you don’t have at least three missions with MSF you’re not a ‘real aid worker’. These experiences taken together led me 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.

Once I had secured MSF-OCP support for this research, I travelled to the Paris office, eager and excited at the prospect of collaboration, codesign and finally getting started on the data generation for this PhD. I was going to Lebanon, a place depicted to me over the years in a romanticised narrative through humanitarian rose-tinted glasses: Beirut, the NGO headquarters of the Middle East, a USD$ dollar laden, unpaid internship providing, aid worker’s delight. It was depicted by colleagues as a humanitarian playground (descriptions of beaches and the Beirut nightlife). I wanted to be part of this adventurous ‘aidland’ as it had been narrated to me, I wanted to ‘do good’. I sought a critical understanding of the concepts of aid that I didn’t have the words to articulate. There was something increasingly uncomfortable for me about the structures of aid: The conceptual tools that segment, that enable intervention and dollarisation for some and postcolonial submission through enacting the ‘beneficiary’ for the others. I had no easy response to this discomfort, and this PhD research was a way for me to find the literacies needed to express my unease within these structures(Tuhiwai Smith, 2021). This PhD gave me the words to articulate how humanitarian healthcare could be otherwise, how it could and should be changed to better support staff and improve patient care.

**Figure 0-1. 'Before going to save the world, please clean the dishes' Taken Greece 2016 Before 'saving the world', be accountable for your actions**

## Catching the Last Flight to Doha

In 2019 I designed a multi-site, cross-case study researching with a national Lebanese NGO (Amel Association) and an international NGO (Médecins Sans Frontières) who offered medical care in four contexts in Lebanon. This design used a postcolonial lens to explore the similarities and differences between a national organisation and an international organisation's response to the healthcare needs of structurally vulnerable residents in Lebanon.

I arrived in Lebanon on 1st March 2020 after a surprise 'going-away' party in Glasgow the night before. Once I arrived in Lebanon, I spent two weeks working with research partners to begin the ten months of data generation. On the 11th of March the World Health Organization declared a global pandemic. At mid-morning on 16th March the Médecins Sans Frontières project manager entered the office I was working from and stated, 'I've made a decision, you're going to work from home - wherever it is you consider home, we'll book you a flight.' I thought she meant my rental flat in Lebanon. Then she left the room and it set in. Fifteen minutes later she sent a voice message explaining I had best go back to the flat and pack my bags; a car would collect me in three hours as I was leaving Lebanon on a plane that night (See Figure 0-2 Catching the last flight out of Lebanon. March 2020Figure 0-2). They booked me on a plane to London via Doha, and I was to let them know where I wanted to go from there. I responded to their departing words of ‘We hope to see you in Lebanon soon!’ with ‘Well, of course, I have to come back, I need to collect data here to finish my PhD’. I left nonperishable food in a box for ‘when I return’.

On arrival in Glasgow, Médecins Sans Frontières explained that they would not continue the research partnership for the remainder of 2020 and that I could reach out in 2021 to review the collaboration. At this point I decided to suspend the PhD and accepted two full-time research posts which lasted from July 2020 to June 2021. You can find a timeline below for reference (See Figure 0-3,Figure 0-4,Figure 0-5,Figure 0-6). I initially worked on a COVID-19 project to explore the effects of lockdown measures on people seeking asylum in Scotland. Subsequently I managed community-mapping assessments to understand health and social needs in Balkh, Northern Afghanistan with a ‘think and do tank’. These two posts further shaped how I understood health, migration and humanitarian systems. From my perspective, the aid organisation in Afghanistan perpetuated the distance between ‘beneficiaries’ and the project decision-making intended to benefit them, categorising ‘beneficiaries’ as vulnerable, ‘hard to reach’ people who needed protection. By taking away their power to act, they were put at risk of abuse by the actions meant to protect them (Singh *et al.*, 2021).

By Summer 2021, after an emergency evacuation from Afghanistan due to the Taliban takeover, I was eager to resume my PhD, I was again filled with the motivation to improve the aid sector, to centre ‘beneficiary’ voices. Lebanon had changed, and my research methodology had to shift in response. In 2020 and 2021, Lebanon faced multiple shocks, including the Beirut Blast, COVID-19, and a severe economic collapse that has been ranked among the top three in the past 150 years by the World Bank. I will explore the consequences of these disasters in Chapter Two, as they are the background for this thesis’ narrative. Lebanese citizens turned to humanitarian organizations originally established for

Palestinians and Syrians. As a result, the focus of my PhD research shifted from improving humanitarian healthcare provision for ‘refugees’ in Lebanon to improving humanitarian healthcare provision in general.

The tensions and challenges I encountered in this PhD research, which you will read about in the pages of this thesis, mirror those encountered by the staff in Lebanon’s humanitarian aid sector. There is an increasing demand for humanitarian healthcare, causing tensions in how patients are prioritised, and shaped by the increasing political and societal tensions and a scarcity of fuel, electricity, and medical supplies. This challenging context created time pressures, such as the eleven-month PhD suspension described above, as well as the need to adapt research methodologies due to pandemic travel restrictions. A further complication was added with the withdrawal of the national NGO research partner, Amel Association, which explained that it no longer had the capacity to host me for data generation due to its unprecedented workload. While a cross-case study of two organisations could have provided valuable insights into the economic and cultural dimensions of humanitarian aid and how these influence patient-staff interactions, the limited resources rendered this unfeasible. As a result, I worked to re-design aspects of the study to enable remote rapid data collection, a process I will detail in Chapter Three.

To conclude, the research which forms the basis for this doctoral thesis focused on the Lebanese humanitarian healthcare sector, in a context changed by a global pandemic, racial justice movements and a political and economic collapse in Lebanon. Through this, I felt that the training I received as a social scientist did not equip me with the tools, I needed to complete this PhD. In fact, I don’t believe the tools for enquiry that were needed for this data collection necessarily existed. Rarely do we have ‘pre-designed’ methods that can also be responsive and appropriate for a setting that we haven’t engaged in before. After my evacuation from Lebanon as the pandemic unfolded, PhD colleagues and I attended methodology seminars and workshops and read textbooks to find, listen and contribute to debates on the challenges that social scientists were facing at that moment. I felt stuck imagining what other forms of methods for data collection could be used in a space on a different continent, with participants who speak a different language and have little or no access to electricity. This search to redesign was difficult to engage with as there was strict time pressure for the completion of the PhD. Yet through creating the time and space by suspending the PhD, I had the opportunity to work with Belal, who will be introduced in Chapter Three. I spoke and listened to PhD colleagues who worked remotely during the pandemic, learned from debates across the academic and aid sector on structural racism, socio-ecological responsibilities and our roles and responsibilities in this, and developed the skillset and knowledge I needed to create a revised design in a world changed by multiple shocks.

Departures الرحلات المغادرة 17.03.2020 08 25

2 / 2

| Time | Flight | To | Counter | Remark |
|---|---|---|---|---|
| 12:20 | ME 322 | Baghdad | | Cancelled |
| 12:20 | ME 4436 | Doha | | |
| 12:30 | IA 140 | ALNAJAF | | Cancelled |
| 12:40 | KU 502 | Kuwait | | Cancelled |
| 12:40 | ME 3314 | AMMAN | | Cancelled |
| 13:10 | GF 910 | BAHRAIN | | Cancelled |
| 13:15 | RJ 3755 | AMMAN | | Cancelled |
| 13:50 | G9 386 | Sharjah | | Cancelled |
| 14:00 | ME 4414 | ABU DHABI | | Cancelled |
| 14:05 | ME 324 | ERBIL | | Cancelled |

**Figure 0-2 Catching the last flight out of Lebanon. March 2020**

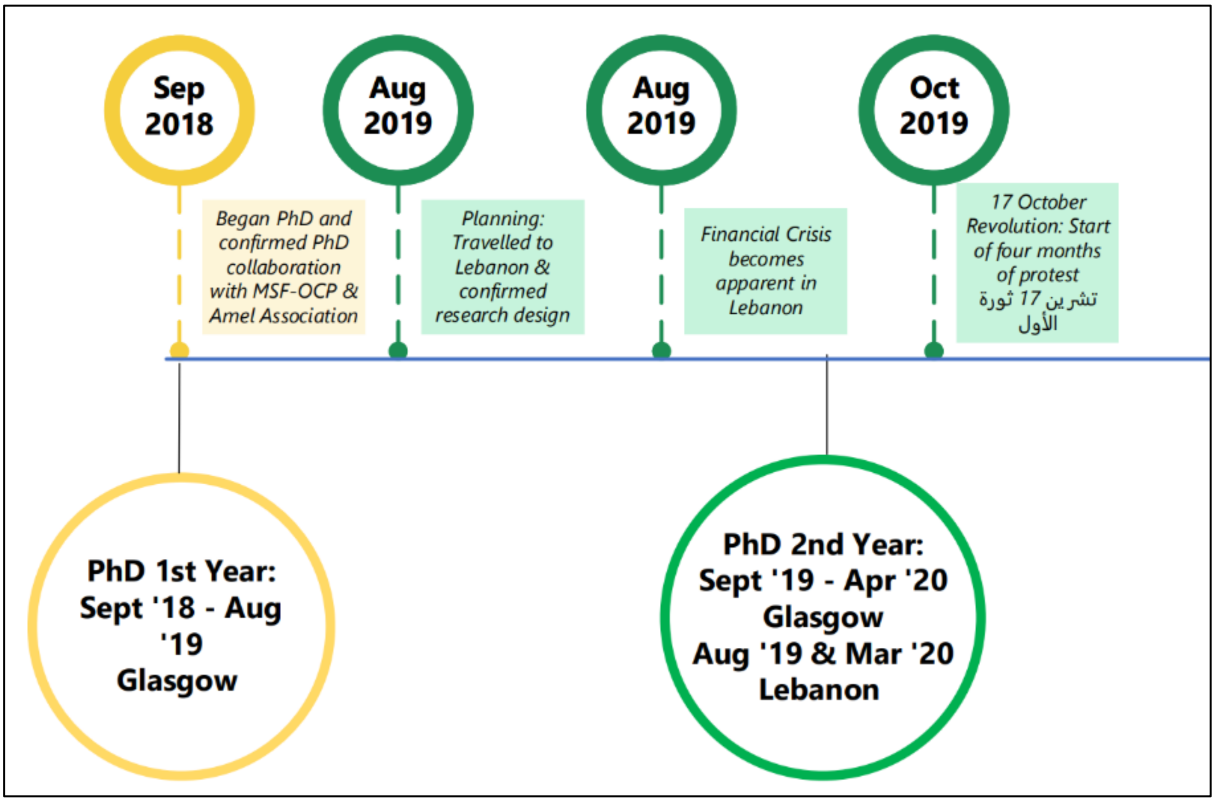


Figure 0-3 PhD Project Timeline, 2018 and 2019

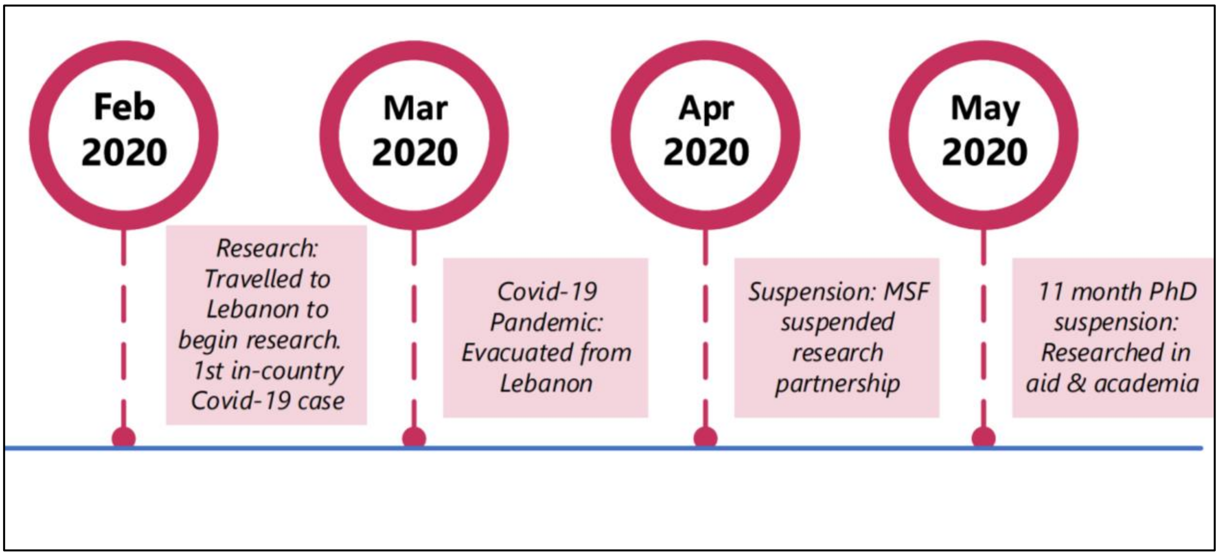


Figure 0-4 PhD Project Timeline, 2020

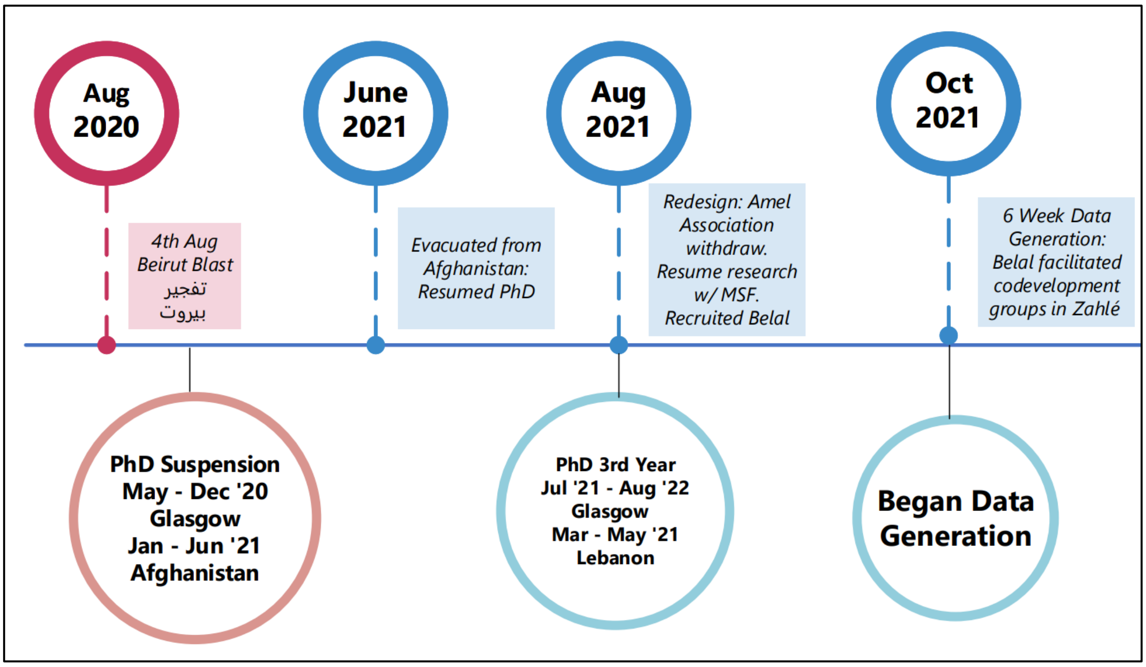


Figure 0-5 PhD Project Timeline, 2020 and 2021

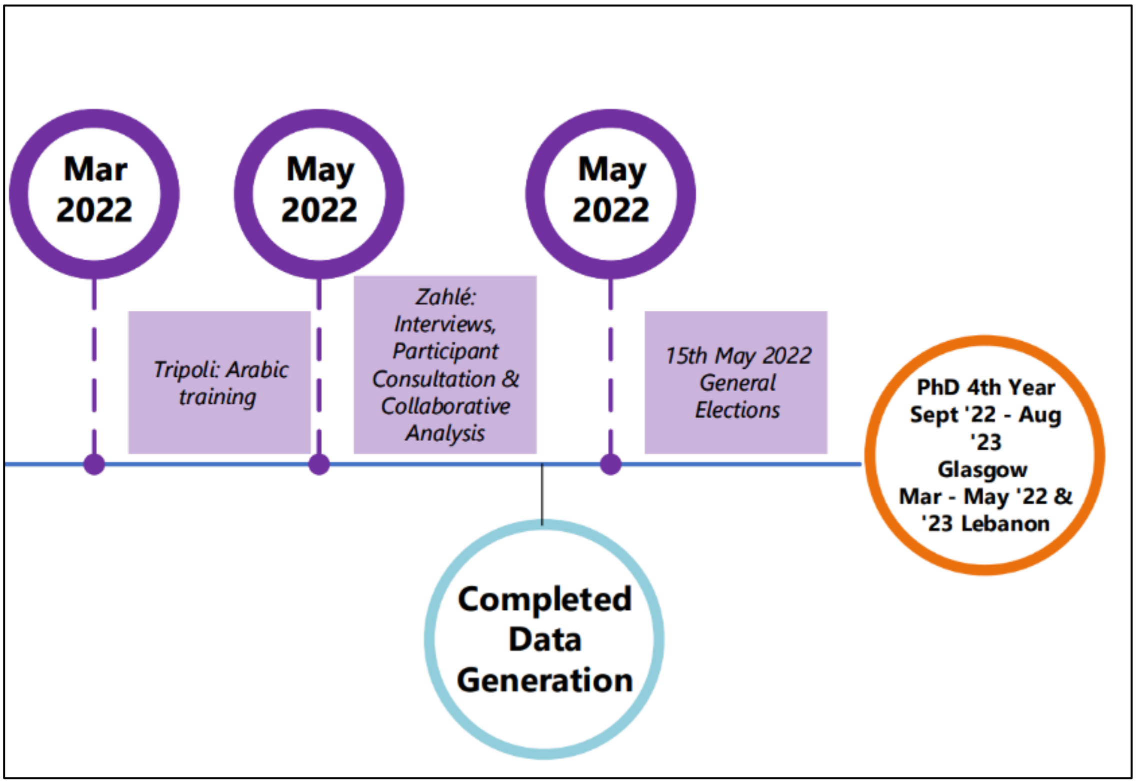


Figure 0-6 PhD Project Timeline, 2022 and 2023

# Chapter 1 Introduction

The aim of this research was to explore how humanitarian healthcare in Lebanon could be improved. I saw the potential in a participatory approach, which I term a ‘co-development group’, as a means for improvement. This case study research investigated an MSF-delivered thalassemia service to understand the opportunities and challenges of participatory programme design in humanitarian healthcare. I traced the decision-making processes of the thalassemia service as it adapted to the pandemic, the economic collapse and the Beirut Blast. Thalassemia is a genetic blood disorder that affects the production of haemoglobin, resulting in reduced red blood cells and anaemia. It is inherited and can cause fatigue, weakness, and other health complications. Thalassemia mainly effects people in the Middle East and South Asia. Thalassemia treatment requires frequent blood transfusions and iron chelation. MSF-OCP Lebanon operated from a Lebanese Ministry of Health (MoH) hospital to provide the only no-cost thalassemia service for Syrians in Lebanon. Concerning healthcare, the scope of this study was to explore the provision of secondary healthcare by a humanitarian organisation, and specifically how long-term treatment is provided by an organisational structure that is inherently temporary.

The study set out to address three research questions.

RQ1: Can a co-development group be used to meaningfully engage staff and service users to collectively improve humanitarian healthcare in Lebanon

RQ2: How were the MSF project and its service users affected by the multiple crises in Lebanon?

RQ3: What challenges did the MSF project and its service users experience due to the multiple crises?

Considering the various socio- and geo-political dynamics of this project, it is important to clearly delineate the scope of this work. This research focuses on one international humanitarian healthcare unit. There is a network of public and NGO healthcare services in Lebanon, yet exploring this complex and fractured system was outside the scope of this doctoral research (Republic of Lebanon Ministry of Public Health, 2018). This study focuses on one noncommunicable disease (NCD) unit as a case study to understand how humanitarian healthcare systems operate and the consequences of this in today's biopolitical world (Foucault, 2003). This thesis does not seek to test or measure health or the effectiveness of humanitarian aid, nor to design a culturally appropriate intervention. Rather, this thesis contributes to unpacking the meanings of international humanitarian healthcare programmes for their service users and develops the understanding of the consequences of humanitarian structures for staff. Through doing so, thesis seeks to improve humanitarian healthcare for patients, their families who support them, and the staff working to care for them. The pages of this thesis detail the perceptions and experiences of the operational changes in response to the multiple crises in Lebanon over the two-year period of 2020 and 2021. I develop the evidence needed to understand the contextual conditions of how and when a participatory approach can be used when working in humanitarian healthcare settings (Pamela; and Jack, 2008, p. 545).

This research is multidisciplinary and draws on work from anthropology, sociology, community development, public health, nursing studies, political science and human geography. While questions of humanitarian healthcare's international staff perspectives have been considered in 'aidnographies' (Hilhorst, Jansen and Change, 2010; Gould, 2004; Apthorpe, 2011; James, 2022; James, 2020b) or by researching with patients receiving humanitarian healthcare (James and Lees, 2022; Huschke, 2014; Dijkzeul and Wakenge, 2010), few studies have explored the intersecting experiences of national and international staff and service users. This research contributes to the wider debate on the necessity for long-term NCD treatment in humanitarian contexts, which often provide temporary care. I have sought to find ways to centre patient voices and decentre power from European headquarters, to move away from the standardised European ways of knowing and doing in international humanitarian healthcare systems. I hope that through the intensive study of this thalassemia unit, knowledge related to experiences of care and the social and cultural constructs of health can be collated and shared to inform future humanitarian healthcare design.

## Thesis Structure and Chapter Summaries

This thesis is divided into seven chapters. **Chapter One** offers a brief introduction to the research objectives and significance of this study. **Chapter Two** engages with existing literature to historicise the structures which have shaped the humanitarian aid sector, reflecting on the categorisation process therein, its harms and how the sector has created its present-day norms. For instance, I reflect on the sector's guiding principles of practice such as 'neutrality' and consider the inherent political and relational power reinforced by systems of aid. Moreover, I introduce operational challenges in the sector, including the difficulties in forecasting futures for long-term care. Moving from structures of aid, I proceed to detail the existing research focusing on spatial realities in humanitarian action, including urbanisation, the structural violence that people are subject to, and how this determines their health. I conclude this section by considering the role of culture in health. Finally, the literature review assesses the role of humanitarian aid in Lebanon today. I draw on various studies to detail the political and economic state, Lebanon's approach to refugee rights and how taken together, these factors have shaped its society. I detail the Syrian and Lebanese international relations, health systems and health needs today in Lebanon. I conclude with a theoretical review, underpinning the research on which this doctoral thesis is based. Theories of power, postcolonialism and the ways in which social and cultural collisions permeate the aid sector are threads that weave this thesis together across its seven chapters.

**Chapter Three** describes and reflects upon the methodological approach I took when navigating the shifting process of enquiry which required me to respond to the rapidly changing research context, ethical considerations and address power dynamics as I adhered to research reflexivity. I detail the reflexive and participatory methodologies I deployed, the participants I worked with, and the ways in which I weaved theory and praxis when investigating the possibilities of participatory research in spaces of aid. Chapter Three details the exploratory study of this single case (thalassemia service), with multiple units (staff, service users and headquarters), which is best suited to describe a phenomenon in its natural real-life context (Yin, 2009).

Methodologically, this research applied a mosaicked methodological approach. Although not conducting an ethnography, I drew on insights from proxy-ethnography with Belal, the local researcher, as a pragmatic response to the methodological challenges created by Covid-19. The methods which generated this data include my research diaries of my time in Lebanon and Belal's audio diaries which he completed after data generation. I conducted a semi-structured interview with Belal to learn more about his methodological experience in this project and with a senior manager at Médecins Sans Frontières alongside analysing MSF archival data to provide context to the thalassemia project. Finally, Belal and I conducted participatory codevelopment groups and analysis consultations. The participatory codevelopment group design borrows principles from participatory learning and action (PLA), running for one-hour sessions weekly over four weeks. The first session focused on topic creation (first co-development group). The participants then organised these topics into categories (second co-development group), then ranked these categories in order of importance (third co-development group). The final co-development group placed an emphasis on actions that could be co-created and undertaken to create a positive change in humanitarian healthcare.

This chapter describes the thematic and case study analysis, how I interpreted the shared and divergent meanings articulated in this study. I thought with a social constructivist and critical theoretical paradigm through the analytical process; I explored the complexities of language, power structures, and the blurred boundaries between reality and representation. Throughout this thesis I include photos, videos, soundscapes and vignettes in both English and Levantine Arabic to bring these spaces to life, to not only read but to hear and see the realities of providing and receiving humanitarian healthcare in Lebanon.

**Chapter Four** is the first findings chapter. It considers the opportunities and challenges of participatory methodologies for researching humanitarian healthcare. I reflect on the relational power hierarchies and space in the knowledge creation process. I detail the successes and challenges of researching with staff and service users. I evidence the necessity of research responsiveness in fragile settings by drawing conclusions about what I learned when deploying participatory practices in humanitarian healthcare.

**Chapter Five** traces the chronicle of crises in Lebanon and how humanitarian healthcare is characterised by shifting sands. I explore how a pandemic, a terrible explosion and an economic collapse impacted people in one NCD unit. I describe how these multiple crises shaped my participants' lives, what knowledge and values informed project decisions, and how taken together there were both shared and divergent effects and consequences for staff and the families treated at the NCD unit. I consider how participants adapted tactics to navigate competing controls amidst increasing hardship.

This leads to **Chapter Six**, which teases out how the participants in this study made sense of their precarious lives in Lebanon, and the structures of aid which they provide and received, in shared ways. While their experiences of the context differed, I draw on the concept of precarity, using the analogy of a 'collapsing tent', to illustrate how the fragility inherent to humanitarian healthcare can be a shared mechanism for understanding. I evidence the processes of loss amidst the crises, and how people collectively experienced the harsh economic determinants of health. I unravel their shared and divergent expressions of the 'value' of health and healthcare. I narrate how all participants in this study experienced the temporal tensions in spaces of aid and 'felt stuck' in different ways. I summarise this chapter by concluding that all participants sought a future of long-term healthcare for children living with thalassemia.

The concluding chapter, **Chapter Seven**, ties together the theoretical threads and analysis of power, postcolonialism, precarity and participation, which shaped my participants' experiences and perceptions of humanitarian healthcare in Lebanon. I reflect on the limitations of this study and propose recommendations for further research. Indeed, throughout this thesis I call for an urgent decentring of Western power in humanitarian healthcare as we know it and the centring of patient-voices, and I advocate the ways in which humanitarian healthcare could be otherwise – otherwise configured, otherwise provided, otherwise designed. Throughout this study, it was not clear what this 'otherwise' looked like for me, as I had not seen it in practice yet, but the investigation and conclusions of this study bring a new perspective of what this could be.

## A Note on Terminology and Translation

The terms ‘migrant’ and ‘refugee’ do not represent individuals or communities; instead, they represent state-imposed structural harms and relations of governance. As I will detail in the literature review, there are many categories in the humanitarian system. I use the term ‘person subject to the asylum system’, to evidence this structural violence. I use the term ‘refugee’ in quotes to illustrate the irony of the term given the almost total absence of refugee status and resettlement for Syrian families in Lebanon. Many of my participants sit between the norm, the exception in jurisdiction, and reside somewhere else living ‘lives of indistinction’(Bauman, 1990). My participants live in the informality, living in informal settlements, working in the informal economy and accessing informal health services as they are determined ‘illegal’. When discussing the findings of this study, I sometime use the term ‘service user’ to differentiate from staff because the participants did not always delineate their relation to the patients, the children treated by Médecins Sans Frontières. I acknowledge the inherent consumerist activity within this term, yet I choose this term over ‘recipient’ or ‘beneficiary’ due to the absence of recognition of patient agency in these terms. I use the term ‘international staff’ rather than ‘expatriate’ (or ‘expat’) due to the constructed whiteness in the latter term, and ‘national staff’ rather than ‘local staff’ as it depicts the two-tier system on the grounds of nationality, as both international and national staff are local to the site of this study in Lebanon.

Regarding translation, for the most part, I worked with Carol Bittar, my Levantine Arabic teacher, to translate quotations from colloquial Arabic into British English. But in some cases, where a word or phrase conveys something less easily translatable, I kept the source phrasing. In an attempt to avoid the othering of non-European languages, I do not italicise these.

In chapter six, I chose to write with colloquial Arabic to centre participants’ voices. Including Arabic in one chapter, rather than throughout the thesis, was a decision dictated by the time and finance required in collaborating with an interpreter for multilingual analysis of a doctoral research project. Resources enabled me to collaborate with Carol, the interpreter, for one findings chapter.

I chose to centre patient voice in colloquial Arabic in this thesis for social justice reasons, and in chapter six specifically, for analytical reasons.

In chapter six, I sought to uncover some of the nuance and linguistic decisions I made in the iterative, interpretative, analytical and linguistic processes of the thematic analysis. I illustrated how I concluded the themes by centring participants' original words and their meaning alongside an English translation. This compares to Chapter Four, which details the study by its methodological components, or Chapter Five, the case study of three events in Lebanon, structural decisions which are comparatively more transparent.

I hope that including Arabic in this thesis, if only in one chapter, unsettles the familiar anglonormativity, that English is the legitimate language for research communications. Through writing this multilingual chapter, I sought to illustrate the inaccessibility of English-language scientific publishing for most, the harmful process of taking a voice in Arabic and offering it back in English. This decision was an effort to normalise multilingual outputs, improve transparency, to represent the multilingual reality of research projects and re-centre participants' voices.

# Chapter 2 Literature Review and Conceptual Perspectives

This literature review is divided into three sections. Part One, entitled 'Structures of Aid', focuses on the structures governing humanitarian aid and practice. I detail the politicisation of international humanitarian aid and the consequences for staff and the people they mobilise to help. I then review the empirical research to contextualise the development of 'refugee studies' and how it affects humanitarian staff and those they care for. Next, I review studies on the everyday practice and challenges of aid. I unpack the access and spatial concerns around providing care for staff and how health, culture and mobility intersect to create specific obstacles for life seekers needing care.

Part Two of the literature review examines studies in Lebanon to provide an overview of what shapes the lives of people in the MSF thalassemia unit. Specifically, it presents Lebanon's recent history including its economy, its politics, its health system's impact on contemporary health needs, and the role of INGOs (International NGO) in addressing these needs.

Finally, Part Three of this chapter briefly summarises the primary theorists who shaped my understanding and my interpretation of data underpinning this thesis.

## Part One | Structures of Aid

Research into the structures of humanitarian aid has increased in recent decades, in conjunction with the growth of the sector itself. Studies of the sector have focused on staff experiences and organisational challenges in conflict settings (Smirl, 2015; Malkki, 1995; Weissman, 2004); the moral dilemmas and humanitarian ethics in practice (Slim, 1997; Fassin, 2011); and political and economic influence in humanitarianism and the commercialisation of aid (Barnett, 2018). (Redfield, 2005) has detailed the sociocultural influence on the whiteness of aid, and what the term 'effectiveness' means for the sector has been debated by scholars including Donini (2007). Scholars have debated the definition of humanitarian aid, as providing food and clothing does not in itself equate to being 'humanitarian' (Barnett, 2011b). According to Barnett, humanitarian organisations can be both political and apolitical, and can either accept constraints (e.g., being limited by legislation to providing a bed for the night or bins, see Figure 2-1 Providing Material Aid Within Political Constraints. Zahlé, Lebanon, 2020) or seek to change constraints through advocacy (Barnett, 2011a).

Taking this broad overview as a starting point, I will now detail the political nature of aid, given the significant role of politics in aid and Lebanon. Previous research has suggested that it is not possible to disentangle the political from the humanitarian or the ethical from the political (Barnett, 2011b). Humanitarian action is constantly confronting political boundaries, and this complicates the delivery of care and creates tensions between humanitarian principles and political realities. Ultimately, humanitarian organisations must work in partnership with governments and inter-governmental bodies who preside over global economics and the political systems which ultimately create and control migration (Donini, 2007). Indeed, aid itself can be a tool for political ends.

Many organisations in the humanitarian sector strive to maintain impartiality while navigating their relationships with governments. For instance, organizations often must adhere to donor state agendas to secure funding, including prioritising the funding guidelines of state agencies like USAID in the United States. Humanitarian programmes adhere to a utilitarian application of funding in low-resource and culturally diverse contexts, where staff work to facilitate trust and sustain peace-building (Harrell-Bond, 1986). Similarly, aid organizations must work with actors in-country to navigate complex in-country logistics and relationships, such as obtaining entry permits and importing medical supplies and water sourcing in desert regions. Humanitarian organisations enact the humanitarian principal of témoignage, meaning to bear witness and speak out against oppressive state actors. Yet scholars have depicted humanitarianism as having a ‘shrinking space’ which can leave their staff vulnerable to deportation and/or coercion by states to keep silent if they want to retain access to provide care (Magone, Neuman and Weissman, 2012) and avoid the increasing attacks on healthcare (Akbarzada and Mackey, 2018).

There is a consensus that humanitarian aid can be interpreted as a political act; to intervene is an act that demands control, autonomy and the ability to speak out, all of which must be negotiated with the respective state (Magone, Neuman and Weissman, 2012). At the time of writing, there is an increasing anti-migrant rhetoric across Europe which the aid sector has termed the ‘New Grand Compromise’(Arar, 2017). Arar (2017) argues that this is a compromise in which the Global North funds humanitarian aid to the Global South to contain ‘refugee’ populations. Such a deal includes the premise that the Global North will eventually resettle some of the population, yet in Lebanon – where approximately 1.5 million ‘refugees’ reside - only 7,490 people were resettled in 2022 (Amnesty International, 2023). People are being used as political bargaining chips, as the European Union (EU) Resettlement Scheme and United Kingdom (UK) Vulnerable Persons Relocation Scheme are being used as a tool for exerting influence over countries on the margins of Europe such as Türkiye and Libya. This further exacerbates the structural violence people are subject to at a time of increasing anti-immigrant rhetoric and polarisation.

To conclude, I have pointed in this section to several lines of research that establish how by virtue of the fact that they are operating in politicised spaces, aid organisations cannot be free from politics, as politics shapes what is and is not possible (Pallister-Wilkins, 2022). Humanitarian aid organisations must determine what form of ‘humanitarianism’ they enact, which requires them to navigate the moral and political dimensions and consequences of each positioning (Barnett, 2011a). On one end of the spectrum, taxonomies include emergency relief, ‘saving lives’, the giving of ‘gifts’ and the powers with which these acts are entangled (Fassin, 2007), and at the other end of the spectrum are acts like ‘speaking out’ against the violence and seeking to change the system and fix the structural causes of health inequity. Yet there is a growing body of literature, which I will detail later in this chapter, which proposes that this latter form of humanitarianism is neo-colonial, containing an assumption of knowing the answer, and a degree of white saviourism (Pallister-Wilkins, 2022). How to speak out and how much, and how to intervene and for how long are important questions and constant sources of debate in humanitarian organisations due to the politicised nature of this work.

**Figure 2-1 Providing Material Aid Within Political Constraints. Zahlé, Lebanon, 2020**

## Conceptualising a Category

I will begin this section by detailing the origins of the ‘refugee studies’ discipline, outlining its chronology and some gaps in the literature at present. The first serious discussions and analyses of factors related to ‘refugee studies’ emerged through the 1980s. Historically, research investigating related topics used migration studies as a departure point for theoretical development. Yet influential theories in this discipline focus on economic drivers, rendering them incompatible with many push and pull factors shaping ‘refugee studies’ (FitzGerald and Arar, 2018). In recent years, the discipline has focused on the challenges people subject to the asylum system experience during their integration into the ‘Global North’, where refugee studies institutes are based. However, most host countries for refugee populations are in the ‘Global South’ rendering a large proportion of literature in the refugee studies field, such as

English language training, irrelevant to most refugee populations' everyday lives (FitzGerald and Arar, 2018). Research that proposes to develop the understanding of the realities and associated challenges for refugee populations must shift from a Northern paradigm.

There has been increasing debates over how people’s ‘refugee’ status and background have been conceptualised and categorised by the academy and in practice (Crawley and Skleparis, 2018; Goodman and Speer, 2007; Zetter, 1991). Indeed, it is a discipline and research based around a label that can perpetuate the marginalising discourse constructed through the category ‘asylum seeker’, which has great harms on people’s lives (O'Doherty and Lecouteur, 2007; Rowe, 2014; Zetter, 1988). As I addressed earlier in this thesis, this is an area where I trip up, backtrack and pivot as I shift between terms like ‘life seeker’, ‘person with a refugee background’, ‘person subject to the asylum system’, and so forth as each term has a deeply politicised meaning. These terms are politicised and weaponised, and ‘refugee studies’ and associated disciplines have played a crucial role in this.

One theoretical issue that is debated in the field is whether the parameters of taxonomies related to ‘refugee’ should widen, normalising the use of more categories, to reflect the multitude of terminologies and associations that exist in legal practice (categories can include ‘asylum seeker’, ‘refugee’, ‘sans-papiers’, ‘humanitarian protection’, ‘discretionary leave’, ‘undocumented’, ‘illegal’, ‘family reunion’ and ‘indefinite leave to remain’). Leading journals in the field, such as the *Journal for Refugee Studies,* are publishing literature with terminologies including ‘Development Induced Populations’, ‘Climate Change Refugees’, and ‘Internally Displaced Populations (IDPs)’ alongside those with the statutory refugee status. Yet this is challenged by Chimni (2008), who argues that academics should not integrate the political narrative into academia and should instead transition from ‘refugee’ to terminology such as ‘forced migrant’, a more precarious migration status with no legal protection. The implications of this could be detrimental to human rights. Such categorical fetishism aims to capture the complex drivers of migration, but rather than providing care, such categorisation of peoples can reinforce privilege and hierarchy on faulty foundations. Categories relating to ‘refugees’ are political tools and are more often used to marginalise than to advocate (Crawley and Skleparis, 2018).

The notion of people being deserving and undeserving is one of the most important debates in this scholarship as it speaks to the crux of the intentions behind the categorisation (Holmes and Castañeda, 2016), evidenced by life seekers fleeing the recent war in Ukraine (Rosstalnyj, 2022). The institutionalised moral distinction between the deserving and undeserving poor needing ‘charity’ can be traced to the seventeenth century in ‘Elizabethan poor laws’ (Hindle, 2004). This distinction continues to be reinforced today in constructing distinctions in legal deservingness between terms like ‘refugee’ and ‘migrant’ on the grounds of war and economy, when the reasons underpinning forced migration are in fact multifaceted (Zetter, 2007; Kirkwood, 2017). Roger Zetter argues that the term ‘refugee’ is ‘fractioned’ by institutional powers to create a new population management strategy and to justify the process of ascribing different refugee populations different levels of deservingness, as evidenced by the different entitlements related to the Syrian and Ukrainian resettlement programmes (Zetter, 2007).

The way people of refugee backgrounds perceive their identity during the asylum process and how bureaucrats perceive them and assign the refugee label often do not align (Castles, 2003). The term ‘refugee’ carries connotations of helplessness and illegality, despite its well-intentioned origins. Grouping diverse populations under a single ‘refugee’ category hinders identity formation and a deeper understanding of one's sense of self. Stewart Hall states that identities are created through rather than outside difference (Hall, 1996). This negotiation of the self is an important process to pay attention to when researching ‘refugee-related’ issues. People sacrifice a lot of what they value in their own identity positions to meet the requirements of a ‘refugee’ status. Once a person secures residency, new identities can be created that juxtapose this labelling, as illustrated by Killian and Johnson (2006) when they describe first generation people stating boldly, ‘I’m not an immigrant,’ and in the opening sentence of Hannah Arendt’s ‘We Refugees’, which states, ‘In the first place, we don’t like to be called “refugees”’ (Arendt, 2009).

Alameddine and Kerbage (2021) evidence that people utilise mental health services as a way to legitimise their refugee claims, and as a way to perform vulnerability in a harmful asylum system. ‘Refugee services’ that were established to support people in their asylum process have been evidenced as reinforcing harmful behaviours which are performed by people seeking asylum (Huschke, 2014). Scholars have evidenced that patients use health services as a gateway to statutory refugee status as humanitarian organisations provide evidence of ‘vulnerability’ to support their claim (Alameddine and Kerbage, 2021, p. 650).

Several studies have demonstrated how mental health illnesses are created and reinforced by the humanitarian system for the patients they mobilise to serve and for staff through vicarious trauma and being exposed to many of the same conditions as the patients they treat (Lopes Cardozo *et al.*, 2012; Pottie *et al.*, 2015; Ager *et al.*, 2012; Alameddine and Kerbage, 2021; Huschke, 2014). The evidence presented in this section suggests that humanitarian healthcare mobilises to cure patients, yet the systems they operate and are part of often contribute to illness itself. However, all of the studies reviewed remain narrow in focus, as they only researched either staff or patient groups’ experiences, suggesting future scope for researching with all population groups.

## Decolonising aid, again. A just cause or oxymoron

Discussions on ‘decolonizing aid’ and related research have increased since the research for this PhD began in 2018, and these discussions have shaped the basis of this thesis (The New Humanitarian, (2022)). As a result, public discourse and debates have shifted and published literature has followed suit. The literature review in this thesis captures a portion of this transition where scope allows.

A number of studies have critiqued the motivations underpinning humanitarian relief. According to Rutazibwa (2019) humanitarian aid is a form of colonialism, inherently contradictory to its supposed purpose. She argues that while good intentions exist within the sector, the international humanitarian healthcare system itself causes harm to many, echoing scholars cited earlier in this chapter. Rutazibwa (2019, p. 66) suggests that critically examining and reflecting upon the inherited colonial structures of the humanitarian aid sector is key to mitigating these harms. Despite efforts towards localisation, there has been little genuine shift in power dynamics, and she argues that to claim that there has been any true change in power structures is an act of self-delusion (p. 67). Chimni (2008) contextualises the research underpinning the sector, specifically the ‘forced migration studies’ discipline against the backdrop of colonialism and humanitarianism. He argues that that they are both Western interferences of culture and power. He characterises humanitarian provision as an act that ‘is at all times the carrier of cultural meanings even as it brings material assistance and relief to people in distress. The cultural meaning of humanitarian practices shapes and is in turn shaped by the political ideas of an age’ (p. 21).Chimni (2008) deduces that much research conducted by the ‘Global North’ in the ‘South’ legitimises intervention and creates harm, illustrating his argument with studies which have justified armed intervention, the withdrawing of resources or the tightening of border security.

Douzinas explains that the Global South is represented in contemporary discourse, reinforced by the aid sector, as ‘the suffering mass and the radical evil-doer, the subhuman and the inhuman rolled into one’, and that it is this depiction that creates the justification for intervention (Douzinas, 2007). Indeed, humanitarianism's aim is to alleviate suffering, but it cannot as suffering is part of the human condition (Barnett, 2011b). Douzinas (2007) argues that the desire to spread a perceived superior Western worldview is just as strong today as it was during colonial times, and that this is achieved today through means such as humanitarian interventions. Ultimately, there is a consensus that to enter an unfamiliar context to provide humanitarian assistance is to assume the relief that is needed, and it is these assumptions that underpin colonial thought (Rajaram, 2002). To conclude, research has identified the ways in which humanitarian aid is a form of neo-colonialism. It has inherited colonial structures which shape the conditionality of care (Magone, Neuman and Weissman, 2012), cultural influence (Chimni, 2008), power dynamics and geopolitical interests (Pallister-Wilkins, 2021).

## Constructing the Humanitarian ‘Beneficiary’

As research has shown, aid organisations construct categories such as ‘beneficiary’, ‘migrant’, ‘recipient’ and ‘service user’ which reinforce unequal power dynamics (Smirl, 2008; Yeoh and Kim, 2022). Harrell-Bond (1986) was one of the first academics to publish a critique of humanitarian aid operations. This notable work called for other academics to follow suit as it highlighted the important contributions that social scientists can make to ensure that aid operations are held accountable in the role that they play in the humanitarian aid sector. More recent studies have found that although aid organisations have moved away from the explicit rhetoric of suffering subjects, an implicit narrative of passive sufferers remains, which Yeoh and Kim (2022) conclude as being detrimental to relations between staff and the people they mobilise to serve. These categories deploy racialised logic. In humanitarian healthcare, people are often called ‘beneficiaries’ rather than ‘patients’ by the organisation. This draws on concepts which symbolise social conflicts, referring to different types of human bodies construed on the grounds of so called Global ‘North’ or ‘South’ countries (Omi and Winant, 1993).

Rajaram (2002) conducted an analysis of an Oxfam programme in Sri Lanka. The research found that aid staff were depicted as having complex, individual lives, whereas ‘refugees’ were depicted as a homogenous group, having collective needs with simplified lives. The author concluded that the aid sector reinforces the damaging societal connotations of the term ‘refugee’ (Rajaram, 2002); that aid beneficiaries are often depicted as helpless victims and the aid organisations and their staff as the saviours of the ‘refugees’. The uncritical assumptions underpinning decision-making processes are based on Western ways of knowing, and this harms recipients because in order to secure access to aid, one must adhere to eligibility requirements such as ‘gender’ and ‘age’ which are understood through a Western lens, rather than taking the local social and cultural natures of such terms into consideration (Rajaram, 2002).

Such power dynamics are relational and are subject to resistance and reproduction. Saperstein, Penner and Light (2013) call for more research on the racial formation in institutions; by researching the unconscious and conscious consequences of organising a workplace in this way at a micro, meso and macro level, they argue this approach will reveal the social dimensions which reproduce structural inequality on a larger scale.

Eastmond (2007) explores the aid provider and aid recipient relationship through a narrative analysis of ‘refugee’ lives in ethnographic studies to understand how best to move towards just representation in the humanitarian practice and research. Eastmond identified that it is crucial to incorporate cultural, historical, social, and political contexts when interpreting and representing a person’s reality. While a person’s migration journey brings about significant changes, she argues that it is crucial not to make assumptions about what these changes are, what they mean for them, a person’s needs, or the loss they experience, such as the notion of "home". She illustrates this in the context of the asylum or research process whereby people are expected to ‘tell the truth’, yet people’s narratives are creative constructs and interpretations of the past in a specific context. Ultimately, one’s ‘truth’ is influenced by many cultural, historical and social influences, and dates, places and names can be lost due to trauma (Eastmond, 2007). Hannah Arendt asserts that humanitarian testimony establishes two forms of humanity and two sorts of life in the public space: there are those who can tell stories and those whose stories can be told only by others (Arendt, 2013). Researchers and aid organisations research, interpret and construct narratives of what it means to be a ‘refugee’, often depicting them as homogenous groups. When examining the knowledge production tensions between reality and representation, Eastmond concludes that unfortunately for many ‘refugees’, their stories are either not deemed relevant or credible, or are not heard at all (2007, p. 261).

Building on the issue of telling stories of others, Lutz and Collins (1991) discuss the significance of photographs in *National Geographic*, a scientific magazine with a focus on ‘Third World’ countries. The subject’s gaze is determined by the photographer and can radically alter the subject’s agency and shift the meaning for the audience. A person’s interpretation of this gaze is subject to their own cultural, political and economic backgrounds; yet the editorial staff of organisations who use such photographs for campaigns have been found to hold huge power over the interpretation of these images. Lutz and Collins (1991) demonstrate that this power is also held in the communications and fundraising departments of large INGOs, who commission photographers to take photographs that suit their fundraising campaign, or more specifically, to take photographs which depict refugees as needing their services to ensure that donations continue to be made. A direct gaze from a refugee into the camera explicitly shows who has the right to look at whom. In photographs which include Westerners, the Western reader can more easily see themselves and become more aware of their place in the world and the implications of their actions (Lutz and Collins, 1991). Research has demonstrated how the sector constructs and reinforces the concept of a ‘refugee’ to generate funding and to justify intervention. People’s identities are stripped of culture, history and meaning and subsequently recreated to match the needs of the aid sector. After exploring the intricate interplay of social, cultural, political, and economic dynamics between aid organisations and recipients, the focus now shifts toward examining power dynamics and neo-colonialism within staff interactions.

## The Two-Tiered Systems of Staffing

Countries emerging from colonial rule, including Lebanon, which secured administrative power in 1944, were susceptible to infrastructural and bureaucratic challenges (Said, 2001). For instance, the 1916 Asia Minor Agreement (more commonly known as the Sykes-Picot agreement) entailed British and French state actors creating colonial spheres of influence over the former Ottoman Empire, creating countries in areas which had previously been divided among ethnic, linguistic and religious lines (Hughes, 2016). The historical and contemporary geopolitical motivations which have resulted in - and responds to - the current regional conflicts have been caused by foreign interference and abuse of power, and they fuel current debates over industry-wide critical reflections and ethics of practise across the aid sector. Omi and Winant (1993) argue that racialised projects interpret and explain racial dynamics in a way to organise and distribute resources inequitably. This has been evidenced in international humanitarian aid through the unequal treatment of staff in areas such as salary, training, and safeguarding, which tends to favour staff from the Global North (Pauletto, 2018; Hujale, 2019; Farah, 2020; Smirl, 2015).

Local staff and local NGOs are employed by INGOs to retain flexibility while also leveraging local knowledge to support project implementation. Aveling and Martin (2013) explore what constitutes a successful working partnership between INGOs, which are often Global North institutions, and national NGOs, who often act as implementing partners for humanitarian interventions. The project often begins with organisations determining the funding stipulations and creating the Monitoring and Evaluation guidelines. Aveling and Martin (2013) attribute this as establishing an immediate power imbalance between the two organisations from the very beginning. This imbalance prevents shared decision-making as national partners are limited to roles of service delivery rather than service design (Lowndes and Sullivan, 2004).

Aveling and Martin (2013) define such local partnerships as ‘instrumental partnerships’ as international NO staff utilise nationals to achieve their goals. This differs from what they define as ‘transformative partnerships’, whereby there is a mutual respect for all knowledge. In their paper, which is based on a case study of health interventions in Cambodia between 2005 and 2008, Aveling and Martin (2013) identified that local staff felt that targets were unfeasibly high and that some program strategies were culturally unacceptable and unlikely to lead to behaviour change, but when national staff raised their concerns, their feedback was not put into project reports. Aveling and Martin (2013) summarise this power as ‘historically established, socio-culturally inscribed patterns of relations’, as partnerships between national and international staff and organisations were characterised by hierarchical relationships from the start.

There is a call for the localisation of aid to prevent this hierarchy of knowledge and inequal relational power, and this approach was platformed at the World Humanitarian Summit and the Grand Bargain (Gibbons and Otieku-Boadu, 2021; Metcalfe-Hough, Fenton and Poole, 2019). Locally led humanitarian action supports INGOs by working with and building upon capacities, capabilities, processes, and practices already to hand (Barakat and Milton, 2020). Gibbons and Otieku-Boadu (2021) explain that centrally holding resources retains the speed necessary for emergency response and warn against complete localisation due to the potential for it to undermine principled humanitarian action; they suggest the need for a complementarity response between the international and local NGOs.

The mirroring of global inequality inherent within the two-tier system of people categorised as either ‘expat’ and ‘local’ staff, and the harms of this, have been substantiated (Redfield, 2012a; Ager *et al.*, 2012; Choudry and Kapoor, 2013; Atterton, 2021; Farah, 2020; van Voorst, 2019; Fassin, 2007). van Voorst (2019) interviewed 30 humanitarian practitioners to explore the differences in practices and paradigms in what is known as ‘spaces of aid’, a term coined by Smirl (2015) or ‘aid land’, a term used in anthropological and ethnographic studies of the aid industry (aidnographies - see (Apthorpe, 2011; van Voorst, 2019; Mosse, 2011).

What she found through her exploration was that there are inconsistencies between how international and national staff perceive problems, and how best to address the issues they identify. van Voorst (2019) concludes that there are heterogeneous paradigms, a pluriverse, or beliefs and frameworks in practice. This results in disagreements about what is considered an appropriate or valid approach, resulting in ineffective practice. However, the paradigm that often prevails in these spaces is a Western frame of seeing and knowing. Smirl (2015) conducted the first in-depth study of what is colloquially referred to as aid land. Through an in-depth study of the Aceh tsunami and Hurricane Katrina, she details how humanitarian staff relations were shaped by the materials in the space (SUVs, barbed-wire encircled compounds). She describes how this in part results in staff being a ‘closed tribe’, often insular and paranoid, people who do not welcome critique from ‘outsiders’ (Smirl, 2015, p. 13).

International organisations reinforce inequalities through making distinctions between national staff, recruited in-country, and international staff who are typically recruited from Europe. Discrepancies in contracts, salary, staff benefits, training, positions, and voting privelages between national and international staff are the norm (Fassin, 2007). A former Save the Children employee shared their experience of the inequalities between national and international staff treatment by declaring that national staff are paid four times less than their international counterparts, despite similar levels of experience and education (Pauletto, 2018). Evidence suggests that trust and open communication must be established between national and international staff if humanitarian aid operations are to improve efficiency and culturally responsivity.

Healthcare staff working in conflict affected settings often face the same dangers as those they are intending to treat, and are at risk of environmental insecurity, rebel groups and disease exposure. Moreover, employees are increasingly becoming a target in war zones. In 2016, the World Health Organisation reported that nearly 700 medical personnel were killed since the beginning of the Syrian crisis and in Aleppo alone 95% of doctors were killed or fled (World Health Organisation, 2016). One operational strategy that aid organisations have in place to mitigate risk is emergency evacuations, which are implemented when the risk to life is assessed as being fatal. Yet, the harmful two-tier system of humanitarian aid means that in an escalation of violence, aid organisations conduct an emergency evacuation to safeguard international staff while national staff employees remain in-country: ‘When you’re appointed as a national staff, you know that if anything happens, if there’s war, the organization will evacuate the Western staff and leave you behind’ (Pauletto, 2018). In aid, certain staff and patient lives are prioritised by aid organisations over others, underpinned by a racialised logic with geopolitical interests.

Didier Fassin is a French sociologist who has extensively studied humanitarian action and the act of ‘saving lives’ in humanitarian healthcare. He proposes the paradox that aid alleviates suffering while perpetuating structural inequalities amongst tiered staff and patients. He concludes that humanitarian medical intervention is a ‘politics of life’ as it inherently necessitates that there is a selection of ‘who to save’ in spaces of aid (Fassin, 2007). Power and control are inherent to saving lives. Foucault, a French philosopher and social theorist, explored the relationships between power, knowledge, and discourse. A Foucauldian analysis of the tiered systems of aid staff raises questions about the segmentation of staff in the social hierarchy, and whose lives are prioritised in ‘aid land’ and who is deemed more valuable, revealing a great distinction in the racial governance between ‘expat’ and ‘local’ (Foucault, 2003). Research has shown that the inherent paradox of humanitarian structures which creates and reinforces inequalities must be addressed to improve humanitarian aid, to think with local ways of knowing, to improve staff support and create patient-centred care.

## Practice of Aid: The Humanitarian Aid Sector’s Professionalisation

I will begin by discussing the advancements that humanitarian organisations have made in recent decades and some challenges that have arisen from this. Humanitarian interventions have advanced significantly since their establishment in the 1970s to the Westernised sector we know today. Haphazard at the beginning, humanitarian healthcare organisations established context-specific skills, streamlined operational efficiency, and established public relations to respond to and learn from public critique (Redfield, 2005). All organisations, especially as they grow, are prone to dysfunction, and as humanitarian organisations are sites of power which have the authority to intervene, the result can be 'emancipation' or 'domination' (Barnett, 2011b).

The critiques of humanitarian aid organisations in public discourse, the media, and by academics have been abundant. As an illustration Choudry and Kapoor (2013) edited a volume of articles which critique 'NGOization' on the grounds of their complicity with markets, states and neo-imperialism. What is unique about the humanitarian aid sector is its unusual and industry-specific flexibility with national and international law. In Harrell-Bond's (1986) seminal work on humanitarian aid, she critiques an aid programme in what was then southern Sudan. She detailed a landscape in which aid organisations expected foreign governments to approve their operational plans without question. In contrast, international development projects are often formed with national governments. Her critique of aid at the time deduced that 'refugee organisations are becoming more and more an almost impregnable system, protected by the strong shell of their mandate to dispense what is regarded as charity' (Harrell-Bond, 1986, p. xi). Moreover, the humanitarian aid sector faced public critique around accountability in the 1990s in its response to humanitarian catastrophes including the Rwandan Genocide, a conflict that scholars and practitioners acknowledge was prolonged by aid (Barnett, 2011a) and the Croatian War of Independence, in which humanitarian aid failed to protect victims (Mooney, 1995). More recently there are many 'lessons learned' from the West African Ebola outbreak (Farrar, 2019; Moran, 2017; Nguyen, 2019). Taken together, these unintentional harms caused by the sector's operations continue to fuel its professionalisation to meet calls for accountability and oversight.

In 1965 the International Committee of the Red Cross (ICRC) published what are known as humanitarian principles, including 'humanity, impartiality, neutrality', which shaped norms and values in the sector's development (Labbé and Daudin, 2015). The United Nations Office for the Coordination of Humanitarian Affairs General Assembly adopted these principles in 1991 and added the principle of 'independence' in 2003. Over time the sector evolved into a complex system of established and specialised relief organisations who influence social and political decision-making processes at a global level (Waters, 2001). All these efforts were made to instil professionalism and accountability for affected populations, or 'beneficiaries'. Yet scholars have voiced concerns over how such bureaucratisation and institutionalisation can lead to indifference and the privileging of certain forms of knowledge over others  (Barnett, 2011b; Waters, 2001).

One framework created for humanitarian standards and accountability is the 'Humanitarian Charter and Minimum Standards in Humanitarian Response', tools that were developed to measure 'effective coordination' (OCHA, 2012; The Sphere Project, 2011). However, these were critiqued by academics and aid workers, who deemed them 'unpragmatic and rigid' due to their idealistic framework, which cannot be readily applied to emergency contexts (Robertson *et al.*, 2002). One guiding concern for aid practitioners and scholars is the question of what evidence is needed to justify humanitarian intervention. Many of the indicators that have been used to date in the sector for assessing evidence-based practises for humanitarian intervention are predominantly quantitative (Robertson *et al.*, 2002). Scholars have proposed alternative ways of measuring value, such as by incorporating humanitarian principles. As an illustration, ways to comprehend effectiveness could include 'the effectiveness of alleviating suffering' and 'intercultural competencies of staff' (Robertson *et al.*, 2002). Scholars agree that there must be a broad scope that incorporates different forms of data when assessing the quality of care and the necessity for humanitarian healthcare interventions.

A demand for 'professional humanitarians' has increased in recent years. Human resourcing issues are arising in many 'middle aged' institutions which were unforeseen at the establishment of the sector, such as retirement packages, maternity leave and paternity needs. As organisations sought to retain experienced staff, support and working conditions improved. Moreover, employees who were formerly in the private sector joined headquarter managerial positions to improve 'productivity'. This is in part to compensate for the sector's 'short term memory', as international management staff rotate on six-month contracts (Hayden, 2023). However, these trends raised concern as staff worried that a shift in moral principles had taken place, shifting from 'volunteerism' to 'just a job' (Redfield, 2005). A second concern related to pay. While pay may seem modest in the context of a Northern head office, a basic rate of pay in European cities converts to a healthy sum in low- and middle-income countries (LMIC). Concerns of national staff working for money rather than a ‘humanitarian ethos’ continue to be heard across the sector (Redfield, 2005). The sector continues to reform and grow; since 2000 the number of international aid workers has tripled (OECD, 2019; Hoelscher, Miklian and Nygård, 2015). While research has focused on securitisation and epidemiological issues for staff in humanitarian medical intervention, there has been comparatively little research into staff culture, conduct and wellbeing amid their day-to-day responsibility of aid provision (for securitisation see Duffield (2001) and (Spearin, 2001) and for health concerns, see (Asgary and Junck, 2013; Pottie *et al.*, 2015)). Evidence suggests that there is a need to explore whether this professionalisation is improving the lives of patients who organisations mobilise to serve, and improving the equality between staff who work to care for them.

## The Challenges of Seeing Like a Humanitarian

Given the irregularities of migration and seeking refuge, it is difficult for humanitarian organisations to forecast the needs and numbers of people seeking refuge. This results in difficulties in long-term project planning, as healthcare needs can be difficult to foresee. This relates to temporal tensions as patients seek long-term provision. The consequences of this have been debated by scholars including Brun (2016) and more recently Cowling (2020), who conceptualises what it means to ‘See like a humanitarian’ and asks related questions about *how* and *who* organisations see. In addition, I ask *how far* they can see.

As an illustration of the challenges of ‘seeing’ like a humanitarian, an editorial in *Nature* titled ‘Data on movements of refugees and migrants are flawed’ highlights the challenges that international bodies face when administering humanitarian relief ('Data on movements of refugees and migrants are flawed,' 2017). For instance, there are far more Internally Displaced Persons (IDPs) than statutory refugees, meaning that most displaced populations are not necessarily registered with an official body (FitzGerald and Arar, 2018). Palestinian refugees, a total of 5.3 million globally, also fall outside the scope of ‘refugee’ as they fall under the protection of United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA). Scholars have demonstrated why the numbers of registered refugees must be viewed with caution. Political parties can distort numbers for political purposes and countries may inflate numbers to receive more international aid funding or strengthen their arguments for border security (FitzGerald and Arar, 2018).

Demography is a necessity for operational planning. In order to plan the materials and staff required, quantifying the number of people is necessary. However, harms arise through the interpretation and utilisation of this data - for instance, misinterpreting needs assessments for healthcare provision or coercing people to choose a category that they do not align with. Worse, the evidence generated by aid organisations and academics could create statistical spectacles to justify harmful migration policies, to increase surveillance and, in turn, deteriorate human rights (Stierl, 2022). For istance, Ingleby (2012) demonstrates how some countries reduce the numerous and complex ‘social determinants of health’ through the over-simplification of ‘socio-economic determinants’ of health to prevent the recording of a person’s ethnicity or nationality, and thus reinforcing prejudice. The author demonstrates the unintended harms of this, as migration and ethnicity, which shape societal inequity, are being systematically unaccounted for (Ingleby, 2012). As such, generating and recording data, to *see refugees* and associated needs for evidenced-based operations and planning are open to harm. However, as Stierl (2022) argues, the point is not to evidence the harms of border regimes, but to change them. By engaging with the politicised nature of this work, including the increasing securitisation of the border regime, increasing evidence to inform patient-centered humanitarian healthcare is an equally difficult but essential task.

Scholars have demonstrated how the humanitarian healthcare sector favours the quantification of data. (Ormel *et al.*, 2020a) call for the further application and adaptation of participatory approaches to humanitarian settings, and more specifically, methods which can capture the complexity of humanitarian health projects. Taking this as a springboard, I reviewed the literature on qualitative, participatory, collaborative research practices in spaces of aid.

To date, research into understanding service-user experiences and practices of working with participants to co-design services in humanitarian contexts stems from engineering disciplines (Robinson, Halford and Gaura, 2022; Green, 2006). Design is defined as a ‘value-oriented pursuit’, and in humanitarian healthcare, the designer of the humanitarian service or product seeks to bring improved wellbeing and dignity to the users of humanitarian services (De Lauri, 2020, p. 98). Ultimately, the goal of humanitarian action, as outlined in the humanitarian charter, is to improve dignity (The Sphere Project, 2011; De Lauri, 2020). But what people consider valuable for their wellbeing changes by context; value is shaped by culture. It is fluid. Moreover, what 'dignity' means for the affected population is relational and changes in line with the services available and socio-legal status. It is imperative that staff have the tools and evidence needed to incorporate this into their service design. Taking all this together, there is a necessity for a diverse range of research tools that can be culturally responsive.

As I have cited, the forecasting of futures in humanitarianism creates temporal tensions between staff, patients and headquarters. Brun (2016) argues that humanitarian aid workers frame healthcare through a narrative of emergency aid crises. She details how staff understand spaces of aid as a space to be flexible and retain a practice of temporary, deploying solutions with a utilitarian ethics. As a result, patients feel stuck, seeking sustainable healthcare solutions and a value system that equally prioritises the life-changing outcomes of the care they receive alongside the monetary value (Brun, 2016; Leaning, Spiegel and Crisp, 2011). There is a divergence of priorities and value systems for staff and patients in humanitarian projects (Brun, 2016). The ways in which international humanitarian staff see, know and forecast the future create the unintended consequence of removing the patient voice, perhaps misunderstanding the care they need in the design of healthcare services in a bid to retain low-cost, flexible operations.

Drawing on Randolph Martin's work on NGO field security (1999), it is clear that patient-centred service design can play a crucial role in fostering acceptance and trust in fragile settings. Establishing trust with local populations is essential for managing security risks with local actors. Security management is comprehended in a triangle of i) acceptance, ii) protection, and iii) deterrence. It is necessary to balance all three in conflict zones, but if the local community accepts the NGO, out of acceptance comes security. They will then have to focus less on protection through materials like radios and barbed wire, or on means of deterrence such as guards. There are evidently many incentives for NGOs to improve their relations with the community local to where they work.

Furthermore, improving patient trust by centring patient voices in healthcare design supports patients to present early, decreasing the risk of diseases common in shock-affected settings such as cholera and scabies. It is also pertinent to comprehend local staff perspectives and to support them in having the resources they need to provide care, preventing staff from being blamed for noncompliance. Finally, this improves accountability and adherence to the charters and standards governing the sector, for instance the Sphere Standards (The Sphere Project, 2011), MSF Charter (Médecins Sans Frontières, 2022), and the Core Humanitarian Standard on Quality and Accountability (CHS Alliance, 2014). To conclude, while the necessity to provide healthcare in response to crises prevails, research has demonstrated why it is also crucial to design and implement culturally responsive tools to incorporate the patient voice in a service design.

## Adapting Aid to Life Outside 'The Camp'

The rapid urbanisation taking place across the globe is reshaping where and how humanitarian healthcare providers operate, as more than half of the world's refugees now reside in non-camp settings (Spiegel, 2010). The global phenomenon of rapid urbanisation offers an alternative place of settlement for people subject to the asylum system. This contrasts with the vast refugee camps that acted as the foundation for the refugee studies literature. The city can provide alternative, albeit often more precarious prospects for affected populations, including economic opportunities, alternative accommodation, and an option for migrating further if required. For some, it offers the ability to remain undocumented and live a life 'under the radar', away from immigration officials and the possibility of being deported. Countries on the margins of Europe, such as Greece, Italy, Turkey and Lebanon, are places of transience for some life-seekers from Afghanistan, Iran and Pakistan. People can live undocumented in cities for years, waiting to earn money and further their journey to a country where they believe they will receive better treatment and have a better chance at asylum (Papadopoulou, 2004). This results in a context whereby these life-seekers need to travel to a healthcare clinic rather than the clinic coming to them through mobilised healthcare operations in a refugee camp. This results in an increasing need to understand the experiences of patients who live in cities, towns, and informal settlements. Traveling across a state for humanitarian healthcare, and the resources this requires, is a relatively new consideration for humanitarian operations.

Rapid urbanisation in low and middle-income countries results in poor planning and substandard housing; this, in turn, increases the risk of disaster from earthquakes and floods in these often slum-like contexts (Zetter and Deikun, 2010). Climate change is exacerbating the difficulties of living in these settings; there is increasing difficulty in accessing clean drinking water. Furthermore, Spiegel (2010) details how droughts result in a decrease in sanitation and an increase in the spread of communicable diseases. While there is greater autonomy to living in a city, humanitarian agencies have less ability to maintain and improve living standards and monitor and provide healthcare intervention as required.

Castaneda (2013) found that people living subject to the asylum system in Berlin experienced headaches, stomach problems and fungal infections. The author found these illnesses were caused by living in an unhealthy environment defined by low income, a lack of transportation, lack of health insurance, exploitative work, social stigma, and irregular access to adequate sanitation and housing. Quesada (2012) details how, as a means to prevent this, many states create ‘refugee services’ with specialist expertise and training, spaces where the acute structural factors that cause diseases are meant to be considered. However, Quesada (2012) details unintended harms by creating specialist NGO ‘refugee services’. Although they are temporary solutions created to reduce the pressure on state services and ensure that populations can avail themselves of the support required, the consequence is that they segregate services for ‘refugee’ and ‘everyone else’. This is likely to reinforce stigma and inequity and hinder positive community development in urban spaces.

Pottie *et al.* (2015) argue that to improve humanitarian medical operations, we must reimagine humanitarian aid. UN bodies and NGOs are adapting operations to urbanisation. One illustration of how this is being achieved is by pivoting from food parcels in camps to providing people with bank cards with a weekly allocated amount (Pitel, 2017). This allows people with refugee status to pay for travel and purchase food in local supermarkets rather than relying on food banks. Mobile clinics are often proposed as a solution in urban areas, returning to the value system of aid workers going to where the patients are, rather than patients having to navigate violent structures to travel to stationary clinics. Madsen (2004) evidences the harms of everyday politics for undocumented migrants in the city of Johannesburg, and specifically details the risks people faced when travelling across the city to access health and social care. Pottie *et al.* (2015) evidenced that mobile clinic supported care for those too scared to travel across cities to clinics and offered a promising intervention in urban settings. At a time of increasing detention, deterrence and global restrictions in health policies based on residency status, humanitarian healthcare in cities needs to be reimagined. Castaneda (2013) has evidenced how healthcare professionals can feel hesitant to offer treatment because of a person's residency status as there can be possible repercussions, and there can be a lack of feasibility for long-term treatment because of restrictive state policies. This necessity to introduce alternative means for vulnerablised and illegalised populations in how they access healthcare provides people with the ability to exercise options, moving away from structural violence to promoting social equity (Farmer, 2001).

A second way that Pottie *et al.* (2015) propose to reimagine humanitarian healthcare is by supporting cultural mediators to work with international staff in humanitarian medical interventions, alleviating the translation work for local staff and improving communication in diagnosis, treatment and recovery. Similarly, Quesada, Hart and Bourgois (2011, p. 351) argue that more culturally appropriate methodologies need to be adopted to reflect the intersecting structural violence that people subject to the asylum system are subject to. They claim that this will 'rectify the misdiagnosis, blame, and maltreatment that accompany the experience of poverty and cultural subordination' (Quesada, Hart and Bourgois, 2011, p. 342). Embracing culturally responsive methodological approaches can support staff in providing care for patients who are subject to myriad influences on their health, including forced migration and structural violence, alongside the intersection of culture and health.

Pottie *et al.* (2015) conclude by suggesting further research into the reasons migrants either stop or continue their migration route, as this will inform best practises on proceeding with either a mobile clinic or a permanent clinic. However, for sustainable services that meet the needs of affected populations, there is a wealth of evidence that shows they must be initiated and created by local populations, as this will offer ownership and flexibility, allowing the project's services to be nurtured and developed (Mazur, 1988).

## Health and Culture

Predominant conceptual models of health and illness at the global level reflect Eurocentric values of individualist societies and overlook the structure and dynamics of family and community systems in non-Western, collectivist cultures in the Majority World (Aubel and Chibanda, 2022). Napier *et al.* (2017) argue that healthcare practitioners must rethink their assumptions about what makes us healthy. For the international humanitarian healthcare sector, who often manage operations from European headquarters, it is imperative to critically evaluate cultures and assumptions, considering what health means for local healthcare campaigns and systems in each context. As Chimni (2008) has demonstrated, healthcare practises and inherent knowledge are informed by culture. This requires the humanitarian healthcare sector to find a balance between emergency response and 'cultural adaptation'.

Without considering what structural violence cannot explain, healthcare practitioners can miss the role of culture. Consequently, healthcare can create reductive cultural stereotyping, which hinders practical understandings of health and illness (Napier *et al.*, 2017). Cultural stereotyping can be perpetuated in low-resource settings by the fear of not having access to resources, such as medications and food. This increases distrust between patients and healthcare providers, resulting in further social tensions. The necessity to incorporate culture into humanitarian understandings of health is great, and I have only had the scope to provide a brief overview in this section. An effective humanitarian response requires aligning healthcare with those who understand and experience it, alongside developing social trust and belonging in spaces of care.

**Figure 2-2 Marking the 17 Oct Revolution, or ثورة. Beirut, April 2023**

# Part Two | Economics, Politics and Refuge in Lebanon

To introduce Lebanon today, I will first provide an historical overview of Lebanese Syrian international relations focusing on the 1975-1990 Civil War period. I will then provide you with an overview of the economic and political context of Lebanon, including recent societal resistance, followed by an overview of health systems, humanitarian aid, and refugee response. The issues in Lebanon are complex and dynamic and cannot be covered in their entirety in this thesis, but this overview provides the political, economic and historical contextualisation of Lebanon, its politics and refugee response to support a clearer inquiry into its healthcare structures

## The Lebanese Civil War; Syrian and Lebanese Relations

Relations between Syria and Lebanon are multifaceted and revolve around Syrian political influence and military intervention in Lebanon. This section will provide a brief overview of Syria's interference in Lebanon, focusing primarily on the Lebanese Civil War, to contextualise the contemporary tensions in which Syrian refugees live.

Historically, during the four centuries of Ottoman rule, from its conquest in 1516 to the end of the Great War in 1918, Mount Lebanon was a geographical region of greater Syria (Weinberger, 1986). When France gained a mandate over Syria and Lebanon post WWII, country borders were ambiguous and fraught, leading some in Syria to consider that Lebanon's enlargement was at Syria's expense. This resulted in claims that Lebanon was rightfully part of Syria (Weinberger, 1986, p. 31)

While there was comparatively little economic interest, Syria retained a great political interest in Lebanon over time. During the 1960s, Syria could not acquire the political influence to control Lebanon it desired, due to the regionally influential role of Egyptian president Nasir, who provided Lebanon with political guidance (Weinberger, 1986, p. 114). Lebanon's democratic system along with its neoliberal openness to global markets and governance, detailed later in this chapter, was in stark contrast to Syria's ambitious socialist, authoritarian ruling, and was deeply unsettling for the Syrian regime (Weinberger, 1986, p. 82). Lebanon's economy prospered in the 1960s, providing employment to many Syrians and, significantly, during this time Lebanon was a place of refuge for Syrian political exiles. Throughout this time, Syria sought to contain its neighbour's democratic influence (Weinberger, 1986). After President Nasir's death in 1970, Syrian influence in Lebanese policy and political elections increased. The military has often been Syria's primary dominant political faction due to the absence of a coherent national identity and direction, which continues to fuel Syria's regional leadership ambitions, influenced by its international isolation in the post-cold war period (Weinberger, 1986; Knudsen, 2005).

While this introductory section focuses on the role of Syrian intervention in Lebanon, this cannot be understood without unravelling the Palestinian Resistance movement in Lebanese conflicts. The Palestinian Liberation Organisation (PLO) was established in 1964. After the 1967 six-day Arab-Israeli war, Palestinian leadership sought to secure a geographical base which was close to Israel for military activity. Southern Lebanon met this criterion, yet Lebanon was a reluctant host (Weinberger, 1986, p. 122). Robert Fisk (2001) in his highly regarded book 'Pity the Nation', details a chronology of events of the Lebanese Civil War. He narrates how in 1970 PLO guerrillas were driven out of Jordan and established headquarters in Beirut and proceeded to attack Israel from Sothern Lebanon. This resulted in Lebanon, an already weak state, hosting Palestinian guerrilla activities that further divided Lebanese political and civil divisions. Moreover, this perpetuated Syrian political and military interference given Syria's alignment with the Palestinian Resistance Movement as a reason for the countries interest in the state's activities (Weinberger, 1986).

The Lebanese Civil War (1975-1990) was in response to many factors including political, economic and sectarian tensions alongside Palestinian guerrilla presence. Scholars such as Weinberger (1986) argued that the Palestinian Resistance played a catalytic rather than causative role in the civil war (p. 116). The Palestinian cause in Lebanon became a domestic cause for many Lebanese, a way to engage with pan-Arab relations, and troubled the delicate societal balance (Owen, 1976). The armed groups in the civil war were fractured, resulting in the perpetuation of regional instability along socio-economic, sectarian and ideological lines (Weinberger, 1986; Fisk, 2001).

At the onset of the Lebanese Civil War in 1975, as Christians massacred Palestinians and Palestinians massacred Christians in response, Syria expressed concern for the Palestinian cause (Fisk, 2001). Syria used multiple modalities throughout the Lebanese Civil War to influence its outcome as it sought to be a successful diplomatic mediator on the global stage, championing the Palestinian Resistance and elevating Syria's credentials in the region. Weinberger (1986) explains that in the early stages of the war in 1975, Syria tried diplomatic means to resolve the conflict. When these proved unsuccessful, in the Spring of 1976, Syrian authorities ordered Palestinian guerrilla units to intervene in Lebanon in an attempt to defuse the conflict. Finally, Syria directly intervened militarily by sending 12,000 Syrian Army troops into Lebanon for direct military engagement in June 1976 and occupied all but southern Lebanon (Fisk, 2001). This invasion of Lebanon by Syrian troops, was construed later under the title the ‘Arab League peacekeeping force’ (Knudsen, 2005). The decision-making behind this incremental process of Syria’s intervention in the Lebanese war is vague due to the secretness of the Asad regime. Yet in 1976, the Syrian Information Minister Ahmad Iskandar Ahmad explained that they intervened in Lebanon to i) prevent partition, ii) establish peace in Lebanon, iii) protect the Palestinian Resistance, and iv) help Lebanese to rebuild their country (Weinberger, 1986, p. 141).

This Syrian invasion resulted in an Arab summit meeting held in Saudi Arabia, leading to the 1976 cease-fire (Makdisi and Sadaka, 2003). A primary condition of this ceasefire was for all armed factions to hand in heavy weapons, yet many failed to do so (Fisk, 2001, p. 105). This retention of arms, alongside persistent fighting in the South between the Phalangist Christians, who were paid, trained and commanded by Israel against Palestinians, was used to justify the continuity of the Syrian military presence. This Syrian presence angered Israel, who considered it a serious security threat. In 1977, Tel Aviv informed the US that they no longer wanted Syrian military in Lebanon, as they sought to increase military action against Palestinian groups at the Southern border but did not want Syrian involvement (Fisk, 2001, p. 105). Syrian forces subsequently left the south, and in 1978 the Israeli army invaded southern Lebanon in response to PLO attacks. The United Nations peacekeeping force (UNIFIL) were sent to Southern Lebanon and remain there at this time of writing in 2024, one of the longest peacekeeping forces in UN history (Fisk, 2001, p. xvii; Knudsen, 2005).

Conflict persisted in Lebanon through the 1980s, often used as a proxy battle ground for regional warring countries, specifically Syria, Palestine, Iran, and Israel. These conflicts caused death and destruction in the state. Fisk (2001) in ‘Pity the Nation’, wrote that in 1982, Israeli troops attacked Syrian forces in the Bekaa valley, surrounded West Beirut and demanded that PLO and Syrian forces evacuate in a bid to improve their nations security. This led to the evacuation of 11,000 PLO men by Western militaries. Through the 1980s two reconciliation conferences, aiming to create peace in Lebanon, failed in Switzerland, while for civilians the massacres continued, with abduction and torture often resulting in death for many Western journalists and international state officials. In 1987 an increase in conflict between Druze and Shia armed groups and a number of failed elections led thousands of Syrian troops to return to the streets of Beirut to the anger and despair of many Lebanese citizens. In 1989 General Michael Aoun, a Christian military leader, declared war on the Syrian Army to free Lebanon of foreign occupation, yet efforts failed as the Syrian Army alongside its Lebanese allies took siege in East Beirut (Fisk, 2001, p. xvii). One year later, in 1990, Aoun was forced to surrender as the 1989 Taif Accord, a set of agreements which negotiated peace in Lebanon, were implemented. These agreements necessitated political restructure and brought an end to the civil war.

## Post-War Lebanon

The 1989 Taif Agreement, also known as the 'Charter of National Reconciliation', stressed the importance of Syrian – Lebanese relations for peace, and addressed many of the imbalances of power inherent within the Constitution of Lebanon and demanded the demobilisation of militias and the withdrawal of Syrian troops (Knudsen, 2005, p. 12). Yet through the 1990s, Syrian influence remained strong in Lebanon and earned Lebanon the title of 'Syria's soft underbelly'. Throughout the 1990s, Lebanon hosted vast corruption networks benefiting the Syrian elite, and up to 40,000 military troops remained alongside a pervasive Syrian intelligence network (Yacoubian, 2006). This stirred great anger in Lebanon. In 2005 former Lebanese Prime Minister Rafik Hariri urged Syria to withdraw its forces from Lebanon and in response, he was assassinated by a suicide bomb in Beirut. This killing follows a history of assassination in response to Lebanese politicians speaking out regarding Syrian political interference, both pro and anti-Syrian politicians have been assassinated, most significantly Prime Minister Rashid Karami (1987) and two Presidents (Bashir Gemayel 1982, René Moawad 1989) (Knudsen, 2005).

This assassination, 30 years after the beginning of the civil war, brought Lebanon back to the centre of international attention due to its strained relations with Syria. This again led to increased international pressure on Syria to withdraw military troops as necessitated by the Taif peace agreement and comply with the UN Security Council resolution 1559 (Knudsen, 2005). The assassination of Prime Minister Hariri further entrenched societal division, as Lebanese pro-Syrian politicians faced civilian opposition, leading to the 2005 'Cedar Revolution' or the ‘Independence Intifada’. These state-wide demonstrations sought to hold leaders accountable for political crises and to uncover the ‘truth’ behind Hariri’s assassination (Knudsen, 2005). Syrian troops eventually withdrew in 2005. Knudsen (2005) concludes that the Taif agreement and Pax Syriana led to the displacement and disguising of Lebanese social, political, and economic tensions, during which Syria’s influence in Lebanon increased, to the extent that the author described this as an ‘inner colonial process’ (Knudsen, 2005, p. 20).

The Taif agreement shaped politics in Lebanon today. Nagle (2019) applies Foucault’s theory of bio-politics, ways to manage and control life, to post-conflict governance by Lebanese politicians (Foucault, 2003). Nagel argues that post-conflict states such as Lebanon, in a bid to heal trauma, can support the creation of ‘victimised’ identities. These collective victimised identities, he argues, create depoliticised effects and ‘docile bodies’ (Nagle, 2019, p. 406). In the Tarif Agreement, which ended the Civil War in 1989, there was no mention of victims or reconciliation, and none of the warlords who had led the conflict and killing of approximately 144,00 civilians was held accountable (Nagle, 2019, p. 411). The Lebanese state called these amnesia laws a necessary condition for peace. Militias were transferred to public administration and became security forces, and warlords secured positions in the cabinet. Civil society groups in Lebanon approached the UN to try to create a ‘truth and reconciliation’ movement, like in South Africa. However, Nagle explains that the advice they received was that Lebanon is a country of compromise, that the UN did not want to undermine the balance of power or antagonise the ruling elites. Nagle argues that in Lebanon, victims are stripped of legal and political rights to a ‘bare life’, that to compromise requires a maintenance of solidarity with the oppressors (Agamben, 2002; Nagle, 2019, p. 416). This peace-maintaining balance of power between sects in the Lebanese state is complex and dynamic and often operates on unstable ground.

Hicham Safieddine (2019), a Middle East scholar, narrates in ‘Banking on the State: The Financial Foundations of Lebanon’ the formation of the contemporary Lebanese banking system, through its independence from France and separation from Syria. He details how, during decolonisation processes, political figures believed that central banking was key to the economic sovereignty of a state. Unlike other states in the region, such as Syria, Lebanon took a strict laissezfaire approach to the economy and relied on free-market capitalism to dictate the state's economic development. Those in power, who were primarily educated in the Western style at the American University of Beirut, did not want the state to regulate any banking processes and hoped to create a 'Switzerland style' banking approach in the Lebanese state. This created a lack of transparencies and regulation in the Lebanese banking system, which persists today. As an illustration, Landry *et al.* (2020) point out that Lebanon is ranked 137 of 180 for corruption by Transparency International.

The people of Lebanon have suffered at the hands of its government in different ways over time. In 2015, activist Assaad Thebian started the #YouStink movement, a response to the state's failure to manage waste collection in Lebanon. This slogan had a double meaning, as it called on the government to change their electoral law to create more transparency. Thousands of people began taking to the streets as they believed that if the failing system of governance in Lebanon didn't change, the state would fail (Journal of International Affairs, 2020). Thebian describes Lebanon as being hijacked by a coalition between the ultra-conservative sectarian clerks and neo-capitalist warlords who do all they can to silence Lebanese voices; he outlines that 0.68% of depositors own 50% of the deposits in the banks, and that fewer than 500 families own two-thirds of the economy (Journal of International Affairs, 2020, p. 245). Lebanon's wealth is centralised to a select minority who are reluctant to reform. This reluctance to reform is at the expense of public services as the World Population Review documents that Lebanon is the seventh most indebted country in the world (% GDP) (World Population Review, 2023). Middle East newspaper 'Al-Monitor' documented that in 2018, France, Lebanon's former colonial administrator, organised an international conference (CEDRE) which secured $11 billion in aid for the state. They offered this financial aid on the condition that there would be significant reforms to the state's governance (Taleb, 2020). But Lebanon never implemented these reforms, and thus the aid was not provided by the international community. This led to mass demonstrations across the country, the most prominent of which was October 17th 2019, when people gathered in Beirut to call for the stepping down of the political elite (Taleb, 2020).

In an interview, Assaad Thebian reflected on his perception of politicians in Lebanon, who he describes as ‘militia leaders, mafiosos, warlords, who are watching you all the time’ (Journal of International Affairs, 2020, p. 240). For him, your sect determines everything in Lebanon: where you are born, when you die, and if you do not conform to your sect, you are kicked out of the system. Thebian explains that each sect attends a different school which teaches from different history books and operate under different personal status laws: he delineated how ‘there’s Christian Lebanon, Muslim Lebanon, Druze Lebanon, Shia Lebanon and the Sunni Lebanon’ (Journal of International Affairs, 2020, p. 240). However, Safieddine (2019) argues that understanding the relationship between finance and politics is essential for a comprehensive analysis of Lebanon's complex socio-political context, he believes people must move beyond the narrow focus of sectarianism.

Lebanon’s economic collapse was exacerbated by the catastrophic explosion in the port of Beirut on 4th August 2020, which severely damaged about 40% of the country's capital, left 300,000 of the city's residents with devastated dwellings, injured 6,500 and killed 190. This again speaks to concerns of accountability, as senior politicians were aware of the ammonium nitrate that contributed to the disaster and the dangers it had posed for over six years, yet failed to remove these explosives from the port (Abouzeid *et al.*, 2020b). Following the port explosion, people took to the streets in protest, but also to support the port explosion clean-up efforts (Fares, Musharrafieh and Bizri, 2021, p. 6; Abouzeid *et al.*, 2020a). Bajis *et al.* (2023) took a grounded theory approach to exploring the impact of what they term the ‘triple whammy’ of the economic collapse, COVID-19 and the Beirut Blast on community pharmacists. They detail that the World Bank estimates that the cost of the physical damage from the port explosion is between $3.8–4.6 billion and economic losses are between $2.9–3.5 billion (p. 2). After the Beirut Blast, there was a great surge in international donations, with almost $300 million in coordination funds from the United Nations (Abouzeid *et al.*, 2020b). In their qualitative study with community pharmacists in 2020, they found a widespread sense of despair due to the collapsing health system in Lebanon. The interviewees called for structural and financial reforms (Bajis *et al.*, 2023). The state was notably absent in the Beirut

Blast; no one was held accountable. Research has shown that Lebanese citizens describe feelings of distrust and feel uncared for by the Lebanese state.

An article in *The Lancet* by Abouzeid *et al.* (2020b) declares that the blast created a new humanitarian emergency in Lebanon. France’s president visited Lebanon again, after the port explosion on 4th August 2020, during which time the Lebanese state again promised to reform governance. France recruited an international auditor and restructuring company to conduct an audit on the Lebanese central bank, a key requirement for many international donors. But due to secretive banking laws, the auditors did not have access to the data required. This resulted in the organisation resigning in November 2020 (Taleb, 2020). No reform took place, and the Lebanese state continues to be ruled by the same elite that has been in power since the Civil War. The geopolitical influence in Lebanon, from the East and West, remains a source of tension for people in the state. Research has painted a picture of a deeply unequal society ruled by a government held to little accountability.

In February 2021, in an interview with Dr Rami Khouri from the American University of Beirut, he reflected on how for him, it didn’t use to be this way. He articulates that what made Lebanon distinguishable from its surrounding Arab states was that people had the space to express themselves culturally, politically, and socially. The country formerly embraced religious and cultural pluralism. He identified that this was the reason the universities and arts flourished. Yet, with sadness, he explained that this space no longer exists, describing Lebanon as ‘another failed Arab state’ in which the population is politically helpless and economically poor (Sprusansky, 2021). For Khouri, the government and its citizens are unhappy, yet they are unsure how to operate otherwise. Hezbollah, a Shiite Islamist militant and political organisation, continues to exist in response to the failed state and foreign intervention, while most Western states continue to label the group a terrorist organization. Khouri explained that by simply blocking the group, states are not dealing with the root cause of the issue that continues to facilitate Hezbollah’s existence: social inequity alongside the constant harassment and occupation of Israel in the country's south.

The Lebanese dollar has been in freefall in recent years. The currency has devalued by approximately 80% since 2018 (Abouzeid *et al.*, 2020b). In March 2021, the *Financial Times* explained that the minimum monthly wage of LL675,000 per month was worth just $67.50 (Cornish and Szalay, 2021). There has been a detrimental increase in food insecurity, and families in Lebanon do not have enough to eat (UNHCR, 2022). The situation is dire for most people in Lebanon but particularly the most structurally vulnerable, as the UNHCR estimates that nearly 90% of some refugee populations live in poverty in Lebanon (Bosqui, 2020, p. 2). Many people's concerns have turned to securing food rather than political reform. While Lebanese society had demanded political reform, eradicating the structures that perpetuate corruption, Assad Thebian explains that after three months, in January 2020, the protests in Lebanon stopped (Thebian, 2020). The percentage of those living in extreme poverty in May 2020 was 23%, according to *The Lancet,* and in June 2020 the state was facing severe food shortages and the inflation of food costs had led to a risk of famine (Abouzeid *et al.*, 2020b). Thebian points to Maslow's hierarchy of needs and highlights that many people in Lebanon no longer have access to food or housing, and are funnelling their energy into trying to survive rather than protesting in the streets (Thebian, 2020). This is corroborated by Taleb (2020) who noted that the end of the protests was in part to the extreme brutality people were subject to from politicians and security forces when taking to the streets.

Geha, Kanaan and Saliba (2020) reflect on the narrative of *'community serendipity'* used after disasters: how communities pull together beautifully, demonstrating the strength of humanity. Yet they argue such narratives are only appropriate for disasters like floods or earthquakes - acts of God that were unforeseen. Lebanon's recent crises were preventable. For six years, the ammonium nitrate and picric acid were stored in the Lebanese heat. Day by day, the situation worsened. Geha, Kanaan and Saliba (2020) describe a situation whereby the citizens of Lebanon are coerced into subordination in exchange for food, enacting the 'docile body'; they critique the aid sector in Lebanon which profits from people's misery (Nagle, 2019; Geha, Kanaan and Saliba, 2020, p. 359) The world *resilience* was used to describe how Lebanese people had recovered from many conflicts, to which the authors assert: 'Enough resilience, I cannot hear that word anymore. We do not want to be resilient, we want to live'

(Geha, Kanaan and Saliba, 2020, p. 360). Geha, Kanaan and Saliba (2020) call on their fellow Lebanese citizens to refuse resilience and opt for resistance, to resist the corrupt regime governing their lives.

## The ‘No Response’ State Response to Life Seekers

The Syrian war has passed its tenth year and continues to displace people into Lebanon as recently as 2022 (UNHCR, 2022). Beginning in 2012, the Lebanese government’s initial policy was ‘no response’- i.e., no refugees, no camps and no representation.

It is important to recognise that this reflects how, in many ways, the state treats Palestinians too, presenting a hostile almost no-response stance to any refugee group (Andersen, 2016). Because of the scope of this review, however, I will focus on research produced with Syrian populations in Lebanon, for whom it was left to the UNHCR to provide support  (Stel, 2020). Unlike Türkiye and Jordan, the state did not allow formal camps, which resulted in informal settlements which remain today. When the Lebanese Government intervened in 2015, it was to suspend UNHCR operations (Anholt, 2020). Lebanon created a higher level of securitization toward refugees compared to other regional states (Secen, 2021). Secen (2021) argues that the initial inaction swiftly shifted to reactionary securitization because of Lebanon’s history of hosting ‘refugees’. The Palestinian refugee camps in Lebanon were used as recruitment grounds for Al-Fatah and the Palestine Liberation Organization (PLO) during the Lebanese Civil War from 1975 to 1990 (Secen, 2021).

The state takes a hostile approach to Syrian refugees and continues to call for their return and emphasise their temporary residence. The Lebanese Government has increasingly created a difficult environment for refugees to reside in, such as enforcing illegal detention and ambiguous rules governing the high residency fees. Moreover, the state has made residency permits for UN and NGO staff who support refugees difficult to secure, as the state perpetuates a narrative that NGOs encourage refugee populations to stay (Anholt, 2020, p. 301). Taken together, the lives for people from Syria in Lebanon, especially those displaced by the war, is difficult as they are illegalised, face deportation and have few or no rights to a house, to work or to healthcare to sustain their life.

The ‘no response’ response taken by the Lebanese state created liminal, informal and vulnerable informal settlements which meant that in 2021 (the year of the data generation for this thesis), approximately 20% of Syrian refugees resided in these informal settlements (Stel, 2021). Drawing on qualitative case studies and critical policy analysis, Nora Stel depicts the politics of uncertainty for refugee governance in Lebanon. She details how no permanent structures or Water, Sanitation and Hygiene (WASH) services can be built in these settlements. This results in unsanitary conditions, completely uninhabitable during the Lebanese winter (Stel, 2021, p. 5). These settlements are targeted, raided and destroyed by state security forces who seek to deport ‘illegal’ Syrians. Yet she evidences how the camp residents are a relied upon but exploited workforce, meaning that these informal camp spaces and their residents are denied, upheld, abandoned and used, all at the same time (Stel, 2021, p. 5). Tamirace Fakhoury (2020), a social scientist at the Lebanese American University, notes how Lebanon’s fragmented refugee governance structure enables maltreatment and may be a deliberate approach by the state, listing ‘refugees’ as displaced persons and entrusting the UNHCR with service provision until the ‘displaced persons’ return (Fakhoury, 2020, p. 165).

Syrians who registered as ‘displaced’ in Lebanon before 2015 received a certificate from the UNHCR. When Lebanon prevented the UNHCR from registering people as ‘refugees’, people who arrived and sought legal status after this had to find a sponsor and pay a fee of $200 (p. 166). Municipalities have occasionally implemented ambiguous curfews, and other actors such as landlords and security guards often limit refugees’ access to spaces. Deportation rights have been devolved to security institutions, creating a dangerous scenario in which people are at any moment at risk of deportation and the harms this entails (Fakhoury, 2020, p. 166). The Lebanese state indirectly coerces Syrians to return as they do not want to be seen as breaking the principal of non-refoulement (Human Rights Watch, 2021). Human Rights Watch outlines that from July to November of 2018, between 55,000 and 90,000 refugees returned to Syria under localized agreements not overseen by UNHCR, in response to the oppressive regime imposed by the Lebanese state. More recently, in 2021, the

UNHCR found that Syrian refugees continue to intend to return to Syria ‘one day’, but 89% of those surveyed in Lebanon said they would not return in the next 12 months (UNHCR, 2021b, p. 6). In 2019, the Lebanese Minister for Foreign Affairs criticised the European Union and UNHCR for providing funding for refugee support in Lebanon and overtly requested that they divert these funds to Syria rather than continue ‘to encourage refugees to stay in Lebanon’, while Lebanon’s former First Minister took an opposing stance and encouraged donations and funding into Lebanon (Fakhoury, 2020, p. 169). Syrian lives were thus used as political chips in a geopolitical negotiation.

As research has evidenced, the economic collapse in Lebanon has created an everyday emergency for many Syrians in Lebanon, people already subject to structural violence and ‘illegalised’. Life-seekers from Syria must now make impossible choices between paying for healthcare and food, and securing such necessities often results in the perpetuation of debt and poverty. Humanitarian crises have both immediate and lasting effects on people’s health, which I will detail later in this review. The crisis in Lebanon has led to many physical and mental health challenges for everyone, but particularly for those most vulnerable, and the healthcare system is severely deteriorating (Bajis *et al.*, 2023; Shallal *et al.*, 2021; Abouzeid *et al.*, 2020a; Mjaess *et al.*, 2021). To conclude this brief overview of Lebanon’s approach to Syrians ‘displaced’ by the war, scholars agree that the chaotic migration governance by the Lebanese state acts as a deterrence, a measure of control and expulsion for people who migrate to seek asylum (Stel, 2021, p. 2).

## Health Systems in Syria and Lebanon

This section provides a literature review of experiences of healthcare in Syria prior to the war to provide insight into healthcare needs and systems experiences, and how these may shape expectations of care in Lebanon. For the past two decades, Syria and Lebanon have experienced an epidemiological transition from communicable to non-communicable disease (Alawa *et al.*, 2020).

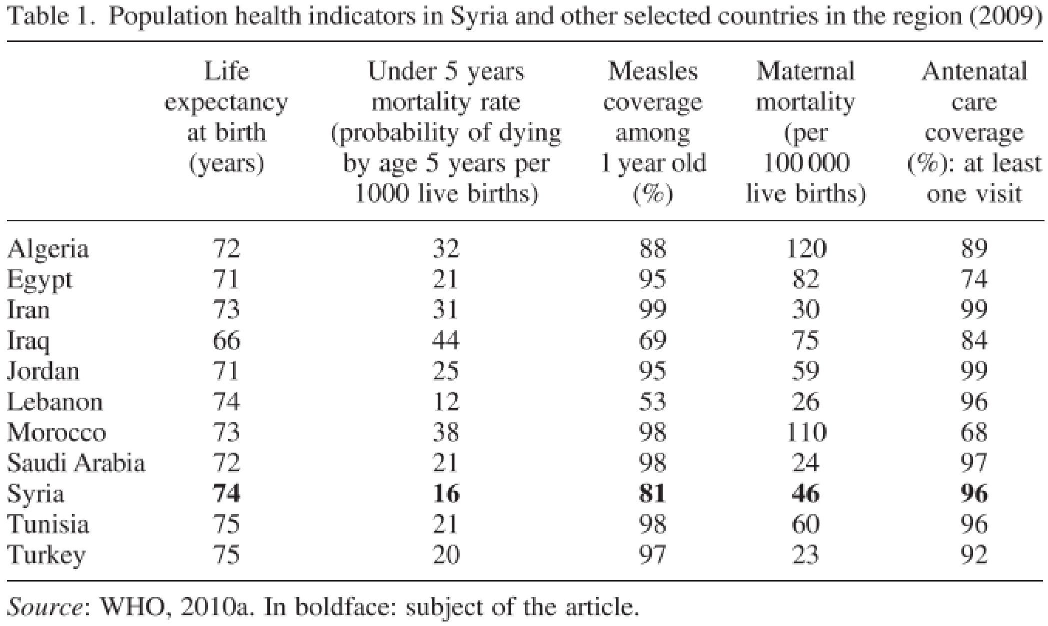


Table 1. Population health indicators in Syria and other selected countries in the region (2009)

| | Life expectancy at birth (years) | Under 5 years mortality rate (probability of dying by age 5 years per 1000 live births) | Measles coverage among 1 year old (%) | Maternal mortality (per 100 000 live births) | Antenatal care coverage (%): at least one visit |
|---|---|---|---|---|---|
| Algeria | 72 | 32 | 88 | 120 | 89 |
| Egypt | 71 | 21 | 95 | 82 | 74 |
| Iran | 73 | 31 | 99 | 30 | 99 |
| Iraq | 66 | 44 | 69 | 75 | 84 |
| Jordan | 71 | 25 | 95 | 59 | 99 |
| Lebanon | 74 | 12 | 53 | 26 | 96 |
| Morocco | 73 | 38 | 98 | 110 | 68 |
| Saudi Arabia | 72 | 21 | 98 | 24 | 97 |
| Syria | **74** | **16** | **81** | **46** | **96** |
| Tunisia | 75 | 21 | 98 | 60 | 96 |
| Turkey | 75 | 20 | 97 | 23 | 92 |

*Source*: WHO, 2010a. In boldface: subject of the article.

Figure 2-3 Population Health Indicators in MENA Region 2009

Before the war, Syria had one of the strongest healthcare systems in the region and its healthcare system was starting to implement positive reforms, including state planning for a national health insurance scheme (Mershed, Busse and van Ginneken, 2012). Syria had good indicators of paediatric and maternal health care prior to the war relative to the region; for context, Figure 2-3 provides a regional overview of population health indicators in Syria in 2009 (Mershed, Busse and van Ginneken, 2012, p. 168).

Mershed, Busse and van Ginneken (2012) conducted a qualitative study of 19 household in pre-war Syria to understand perceptions of the healthcare systems. They concluded that people perceived the healthcare system as having 1) limited resources amidst a growing population; 2) insufficient service quality and quantity; and 3) a lack of accountability.

Kherallah *et al.* (2012), colleagues from the Syrian International Coalition for Health, detailed the healthcare systems in Syria before and during the war, and forecasted needs for after the war. Writing in 2012, at the beginning of the war, they reflected on five areas for reform in the Syrian healthcare system: 1) patient inequity; 2) lack of transparency; 3) lack of coordination; 4) high turnover of staff; and 5) inadequate training of healthcare professionals. They concluded that there were concerns over provision of standardised care and quality assurance in the deteriorating Syrian health systems (Kherallah *et al.*, 2012). For instance, they highlighted their concerns for people with chronic illnesses, citing that approximately 50% of people had stopped their treatment because of the deterioration of the Syrian conflict (Kherallah *et al.*, 2012). This study revealed that in 2012, the Syrian conflict created a shortage of drugs and equipment due to international sanctions. Alhaffar and Janos (2021) found that this continues to hold true, as they evidenced that in 2021 approximately half of the health facilities in Syria had been destroyed and 70% of healthcare professional staff had emigrated, resulting in chronic pressure on the healthcare staff and the resources needed to care for patients.

MacVinish *et al.* (2023), colleagues working at Médecins Sans Frontières, detailed their findings from an MSF-run thalassemia ward in Northeast Syria, which ran between 2017-2019. They shared their experiences of the great challenges they faced in supply planning for the blood bank in a conflict zone as blood was not in adequate supply and their patients often left to join the conflict; moreover blood was often needed for trauma patients during periods of more active conflict while security risks hindered blood drives (p. 5). Médecins Sans Frontières ultimately closed the project because of reduced staff. The remaining staff moved to the trauma and maternity departments. MacVinish *et al.* (2023) examine the hurdles of providing secondary care in active conflict, low resource settings. They highlight the gaps in evidence of implementing thalassemia care in humanitarian settings and the importance of the improved quality of life for patients and their families. Non-communicable diseases (NCDs) are expensive to treat and require long-term care in secondary clinics. This is difficult to attain in a state experiencing ‘white coat emigration’, state sanctions hampering the import of medications, and attacks on healthcare, to name but a few factors impacting long-term care. Remaining healthcare resources can be reallocated to primary care, resulting in a lack or total absence of referrals for elective surgery and nonurgent medical interventions (Kherallah *et al.*, 2012, p. 52).

Lebanon’s health system is neo-liberal, as market mechanisms, competition, and private sector involvement mediates the delivery of healthcare services. As Alawa *et al.* (2020, p. 710) state, approximately 50% of Lebanese people had medical insurance in 2019, and that state support for citizens covers only 10% of hospital costs and 20% of examination costs. Moreover, it is fractioned into state, private and NGO providers. For instance, prior to the Beirut Blast, the Ministry of Public Health oversaw a network of 236 primary healthcare centres, of which 190 were operated by NGOs, and 85% of hospital beds were in private clinics (DeJong, 2020). Similar to Syria, healthcare services in Lebanon are also collapsing due to the multiple shocks previously described. Healthcare workers in Lebanon have faced pay cuts, protracted delays to healthcare equipment and power cuts due to the decline of the Lebanese lira in recent years (Bizri *et al.*, 2021). Private hospitals have faced difficulties in paying salaries and maintaining their equipment. For instance, The American University of Beirut's Medical Centre laid off 850 employees between 2018 and 2020 Alawa *et al.* (2020, p. 709). As a result, healthcare has become harder to access due to this lack of infrastructure, but also because of high costs (Mjaess *et al.*, 2021). In a cross-sectional descriptive survey completed by (Alawa *et al.*, 2020, p. 710) in Lebanon, they found that 78.9% of the 417 people from Syria and 67.7% of the 319 Lebanese citizens cited not seeking medical help due to having no funds or medical insurance to cover the treatment.

To alleviate the risk of overburdening the Lebanese services, and in turn mitigating the risk of friction over an already fragmented and uncoordinated healthcare system between local Lebanese populations and refugees, the UNHCR implemented a partnership network with NGOs to offer support to 'refugee populations' in accessing healthcare (Amnesty International, 2014). The UNHCR subsidises healthcare costs, resulting in Syrians registered with the UNHCR prior to 2015 having access to primary healthcare centres for $2. For treatment, the UNHCR contributes 75% of the payment from $100 to $2,900. As a result, Syrian refugees pay for 25% of the total cost (UNHCR, 2021a). However, the UNHCR do not cover the expenses for refugees with long-term conditions requiring specialist long-term treatment or diagnostic tests for illnesses including cancer, chronic haematological conditions (which includes thalassemia), endocrine, or immunological and neurological conditions (UNHCR, 2021a). Alhaffar and Janos (2021, p. 4) conclude that for many people from Syria with chronic illnesses 'the majority of refugees are left to their fate, and the small acts of NGOs and informal healthcare workers'. Research has evidenced that people with chronic illness experience some of the biggest barriers in accessing care. As the economic situation deteriorates and both Lebanese citizens and Syrian refugees in Lebanon continue to struggle to finance healthcare and humanitarian and state subsidies continue to be cut due to the protracted conflict, the need for regular screening for NCDs will go unmet, and thus people will go undiagnosed and untreated (Alawa *et al.*, 2020, p. 714).

Hamadeh *et al.* (2021), who are staff at the Lebanese Ministry of Public Health, argue that the multiple Lebanese conflicts have led the Lebanese public health system to be both resilient and adaptable. They illustrate the harms of the influx of aid workers and their donors in recent years, who have fragmented the healthcare system and prioritised different populations on the grounds of, e.g., gender, nationality, sectarian, geographic and religious lines. This finding is corroborated by Facon (2021), who calls Lebanon a republic of NGOs. Hamadeh *et al.* (2021) evidenced how this fragmentation has increased confusion for patients about eligibility and increased the complexity of referral processes and drug supply networks, leading to high levels of staff turnover and a geographically mismatched network of clinics and specialist services (Hamadeh *et al.*, 2021).

Efforts have been made by overarching NGO bodies to work with local systems; for instance, the Regional Refugee Resilience Plan (3RP) was launched in 2014. It is a humanitarian operations plan coordinated by the UN, which includes 270 humanitarian and development actors to support refugee hosting countries surrounding Syria, including Lebanon (Anholt, 2020). The 3RP works to complement the ‘humanitarian development nexus’ which stemmed from the World Humanitarian Summit, an approach which seeks to support handover between the aid and development sectors and includes host-communities into planning assistance for sustainability. This nexus building was identified as particularly crucial for middle-income countries where there are qualified professionals and existing administrations. Anholt (2020) highlights that many aid workers are used to operating in spaces where there is almost no government in place, where they must set up working systems, yet in Lebanon, state systems such as import regulations exist, a dynamic that many aid workers are not used to. This plan was to support aid workers in leveraging and supporting existing economic systems and infrastructures through localisation.

Hamadeh *et al.* (2021) argue that NGOs do not have a sufficient overarching supervisory body, and as a result the increasingly under-funded and fragmented healthcare system must change. There is an absence of public health strategies, quality control, priorities, campaigns, and reforms. Hamadeh and colleagues propose a designated spokesperson who can clarify to the humanitarian agencies, who operate in an emergency response *modus operandi*, that the state's public health system must be supported to maintain a long-term approach to recovery and reform for the public good in Lebanon to plan for better future public health (Hamadeh *et al.*, 2021, p. 5).

## Health Needs in Lebanon

Due to the structural violence they are subject to, many people from Syria in Lebanon live in hazardous conditions, either in informal settlements or in overcrowded precarious urban housing, resulting in high-risk coping strategies which increase risks to health (Al-Hajj *et al.*, 2021, p. 24). An earlier section of this literature review has evidenced the harm of the asylum system to a person's health. Similar harms were evidenced in Lebanon by Habib *et al.* (2020), who in 2017 surveyed 1,902 Syrian households in informal tented settlements (N children = 8,284) to explore the health needs of children. The authors found that 74.3% of the households assessed were severely food insecure and many households lived in poor ventilation, damp and cold conditions with little access to WASH facilities, which has caused the children to suffer from respiratory problems and infectious diseases (p. 333). A third of children were reported to have one health condition, the prevalence of acute illness (including cold, flu, fever and diarrhoea) in the last three months was 24.2%, and the prevalence of chronic illness, such as asthma, anaemia and eye problems, was 11.9% (Habib *et al.*, 2020, p. 327). The authors concluded that food insecurity was significantly associated with poor health, evidencing the harmful social determinants of health for families living in informal settlements (Habib *et al.*, 2020, p. 330).

Fouad, Barkil-Oteo and Diab (2021) colleagues at the American University of Beirut, discuss what they call the 'triple-fold' crises of COVID-19, the Beirut Blast and the economic collapse. The specifically detail the mental health effects of the years of crises in Lebanon. They write that for Syrian families living in informal settlements during the COVID-19 pandemic, the Ministry of

Public Health advised people to both physically distance and implement careful hygiene practices, advice which was almost impossible to implement and resulted in increasing stress and worry. They argue that the traumatic events in of the Syrian conflict, compounded with the daily violence of living in Lebanon, has created a mostly unaddressed need for mental health support. Bosqui (2020) argues that the toll of the collective trauma, including job loss, societal poverty, increase in domestic abuse, the Beirut Blast and the global pandemic and loss of loved ones, has led to a national mental health crisis for all nationalities across Lebanon. Fouad, Barkil-Oteo and Diab (2020, p. 3) detail the increasing mental health support offered by NGOs, but they found that patients held concerns about practitioner backgrounds, trust, and security, particularly among Syrians who did not have a legal status.

Another health concern relates to food insecurity, which is deteriorating rapidly in Lebanon, leading to both over and undernutrition. Moreover, it has lifelong effects if suffered in early life, including noncommunicable diseases, obesity and brain development problems (Abou-Rizk *et al.*, 2021). According to the World Food Programme (2021), approximately half of Syrian families in Lebanon remain moderately to severely food insecure despite humanitarian assistance, and approximately 22% of Lebanese people are also facing food insecurity. Shallal *et al.* (2021) described the economic crisis as ‘a crises within a crises’. Research conducted by Abou-Rizk *et al.* (2021) assessed the prevalence of anaemia and the nutritional status of Syrian mothers and their children under five in Lebanon (n=433). The prevalence of anaemia was 21.7% among mothers, and children under five years showed a higher prevalence of anaemia at 30.5% with medium levels of wasting. The authors outlined that anaemia had increased over time, evidencing the deteriorating population health (Abou-Rizk *et al.*, 2021, p. 9). The authors compared their findings to a 2013 study conducted by UNICEF with Syrian paediatric patients in Lebanon and found that while stunting levels had dropped by half, wasting and underweight levels had increased sharply (Abou-Rizk *et al.*, 2021, p. 18). Of their research participants, 82% were registered with the UNHCR, yet only 8.9% were receiving e-vouchers for food assistance from the World Food Programme (Abou-Rizk *et al.*, 2021, p. 20). The authors concluded that the mothers and children in this study needed long-term strategies to support their nutrition, to alleviate poverty and provide sustainable livelihoods. For the Syrian families, they provided the example of efforts to protect and support breastfeeding and family planning support. To conclude, research has evidenced how the multiple shocks in Lebanon are detrimental to public health.

Figure 2-4 Revolution. Beirut, April 2023

## Part Three | Theoretical Review

This study is guided by theories of postcolonialism, biopolitics, critical pedagogy, and the biosocial to understand the complicated relationship between the individuals (service users and staff at the micro-level) and the structures of aid (macro-level), but also to understand the postcolonial and socio-cultural value systems that render certain forms of life either undeserving or deserving through temporary humanitarian healthcare. I move between the empirical evidence and existing theory to make nuanced explanatory inferences from multiple perspectives as to how and why decisions are made about people’s lives and what forms of resistance and reforms are taking place in the sector to move towards new, local or multiple ways of seeing and knowing.

Theories of the effects of postcolonialism stem from the Middle Eastern diaspora in the 19th and 20th centuries, whereas theories of decolonialism stem from the South American diaspora and can be traced as far back as the 15th century (Bhambra, 2014). I apply a postcolonial critique as it was developed and relates to the geographical region and structures of humanitarian aid in Lebanon. Edward Said’s theory of Orientalism is pertinent to this. A prominent Palestinian-American scholar, Said’s writing on power, representation, and cultural identity is an invaluable tool when working in the struggle for refugee rights and equality in the Middle East. According to Said, Orientalism is ‘a way of coming to terms with the orient that is based on the orient’s special place in European Western experience’, furthermore he defines it as a ‘western style for dominating, restructuring and having authority over the orient’ (Said, 1978, p. 119). Orientalism is an interconnected set of ideas, institutions, policies and narratives, served as an ideological basis for French and British colonial rule (Said, 1978). In his work *Orientalism Reconsidered* (1985), Said reflects on the lack of progress in decolonising Orientalism and the unwillingness to address the ethical problems embedded in global structures. He argues that political and epistemological forces fuel this reluctance, perpetuating coloniality. While Said’s concept of Orientalism didn't focus on everyday interactions, I apply it as a lens for analysis, analysing how the Occident’s gaze and representation of the Orient shapes everyday interactions. I unravel the nuances in negotiations to consider the role of agency in the contestation of hegemonic power, a concept originating in the Prison Notebooks of Marxist theorist Antonio Gramsci who defined hegemony as a process of intellectual domination embedded in the ruling class across society. This creates a context where the ruling classes interests are universal interests and other discourses are excluded in the production of thinking and seeing , see Gramsci (2011). I also think with think with scholars including Thomas (1994); Cooper and Stoler (1997) when analysing negotiations of power. The Western gaze shapes the global discourse surrounding countries affected by Orientalism, including Lebanon and Syria. This gaze influences how and why intervention occurs in Middle Eastern countries. In line with Said, I argue that in order to break the cycle of hegemonic power, the international humanitarian healthcare sector must embrace local ways of knowing (Said, 1985).

In Chapters One and Two, I detailed and justified my conceptualisation of key concepts such as ‘refugee’ in this field of research, drawing on related theoretical underpinnings used in this study. I sought to frame this research through social theory embedded in local ways of knowing to Syria and Lebanon. However, Hanafi and Arvanitis (2015) of the American University of Beirut demonstrate in *Knowledge Production In The Arab World* that social science plays a small part in knowledge production, which is heavily fragmented. With a focus on Lebanon and Jordan, they evidence how social theory is a political and ideological activity and is thus underfunded and marginalised. They illustrate that social scientists pontificate rather than offering concrete solutions due to the danger of being visible in authoritarian states (p. 11). They explain that social research is often funded through international aid, which means it does not have a localised agenda. Similarly, Baggini (2018, p. 47) reflects on the history of philosophy in what he calls ‘the Arab world’ and shows how traditionally social science and philosophical research more broadly cannot be understood without consider how the piety of the societies in which they are situated shapes their process of enquiry. Compared to other geographies, the concept of ‘the Arab world’ had a weaker framework that I could draw on. Where possible, I thought with geographically and culturally embedded theoretical perspectives, but I also incorporated social theorists from across the globalised world to consider the different perspectives and ideas that create the international humanitarian sector. While many of the concepts throughout this thesis stem from Western contexts, I believe that they hold analytical relevance for contemporary humanitarian structures more broadly.

As I detailed in Chapter Two, power and control are inherent to saving lives. For this reason, I consider French philosopher and social theorist Michel Foucault’s work when exploring the relationships between power, knowledge, and discourse. A Foucauldian analysis of the tiered systems of aid staff raises questions about the segmentation of staff in the social hierarchy and whose lives are prioritised in ‘aid land’ (i.e., who is deemed more valuable), revealing a great distinction in the racial governance between the categories of ‘expat’ and ‘local’ (Foucault, 2003). Inspired by Foucault, I draw on Didier Fassin’s conceptualisation of humanitarianism as a politics of life and the moral economy in humanitarianism to consider the efficacy, moral politics and ethical implications of humanitarian healthcare intervention (Fassin, 2007).

The work of American physician and anthropologist Paul Farmer, specifically his concept of 'biosocial', informed the analysis and conclusion drawn for Research Question Three: 'What challenges did the MSF project and its service users experience due to the multiple crises?' (Farmer, 2001). I align with his biosocial approach to health, which holds that addressing both the biological and social dimensions of health is essential for achieving more equitable and effective healthcare outcomes. I evidence the challenges patients faced, drawing on this concept of biosocial, as well as his conceptualisation of 'structural violence', which is in turn inspired by the work of Galtung (Farmer, 2004; Galtung, 1969). This concept holds that to deny a person care when the resources exist for treatment is structural violence. This work is informed by David Napier's work on culture in health. This study considers the role of culture when interpreting meanings of sickness and healing cross-cultural interactions in the thalassemia unit and the consequences of cultural collisions in health care. Napier's conceptualisation of cultural competency and patient-centred healthcare informed the analytical process in this research, particularly with regards to cultural stereotyping and its resulting harms (Napier *et al.*, 2014; Napier *et al.*, 2017). Here, I want to define what I mean by the term 'culturally responsive' methodologies. Culture is separate from race or ethnicity. Culture is everyday practise and meaning making. Culture is a system of interrelated values active enough to influence and condition perception, judgement, communication and behaviour in a given society (Airhihenbuwa, 1995). It is what frames our sense of reality and, rather than being static, is fluid and emerging. Our health is shaped by our culture, as it is relative to our ways of living, lifestyles, traditions, value systems, and to the intellectual and emotional features of society.

This work conceptualises spaces of aid as an assemblage (Deleuze and Guattari, 1988). In this thesis, aid is conceptualised as an arrangement of heterogeneous entities (actors, discourses, practices, material elements) connected and caught up in a power struggle, held together (or not) as 'events' through constantly evolving relations between their constitutive parts (Deleuze and Guattari, 1988; Hagan, 2022). I examined the transitory moment where particular interactions came tougher, considering when things failed to hold, exploring the ‘not yet’ of project decisions, project closure, handover and the consequences for people and things (materials) in the space of aid. This conceptual approach has been applied to other research studies focused on the humanitarian (geo)political implications of people subject to the asylum system; see Hagan (2022), who explored makeshift encampments in border zones. Throughout the research and its analysis, I considered the assemblages of people, materials, and cultures in temporary spaces of aid, how together they remained perpetually uncertain, held in temporal tensions (Brun, 2016). This approach enabled me to see absence. When conceptualising the space, I build on the work of Smirl (2015), who evidenced the significance of the materials in aid land and how this spaces interactions and reinforces Western ways of knowing and the cycle of hegemonic power. Seeking alternative forms of praxis, I turn to scholars like Deleuze and Guattari (1988), who argue for non-hierarchical thinking in assemblages to understand, and in turn reform, the relationships and connections between ideas and between the headquarters and the implementation of the project on the ground.

When seeking to understand everyday interactions in aid, inspired by and building on the seminal work by Smirl (2015), I consider the ‘tactics’ adopted by staff and families at the thalassemia unit. The term 'tactics' refers to the everyday acts of resistance – swift and time-pressed actions - employed by individuals who lack institutional power to navigate around its oppressive force (de Certeau, 1988). Michel de Certeau is a French social theorist whose most notable work is *The Practice of Everyday Life* (1980), in this work he conceptualises the strategies and tactics people employ as an apparatus for resisting power in daily life practices. Drawing on this, particularly in Chapter Five, I analyse the tactics and strategies my participants employed when negotiating, imposing, and resisting power in the Médecins Sans Frontières thalassemia unit.

Chapter Two evidenced how humanitarian aid has developed into a sector with governing bodies and guiding principles. The effects of the development, implementation and resistance of norms and governing structures are evidenced throughout the pages of this thesis. Many scholars before me have traced and theorised the ethics, value systems and moral economy of humanitarian healthcare. Tony Waters (2001) in *Bureaucratizing the Good Samaritan: The limitations of humanitarian relief operations* argues that the increasingly formalised and rigid structures of aid work that the sector is moving towards is taking the ‘human’ out of ‘humanitarianism’ for the sake of efficiency. Hugo Slim is a leading scholar in humanitarian ethics who writes extensively about the tensions of humanitarian principles in practice during aid delivery (Slim, 2015). I consider the ‘moral economy’ of humanitarian healthcare, which is illustrated in the temporal tensions in the thalassemia unit, as Médecins Sans Frontières operations and much of its international staff resist fixed territories, a form of nomadism (Deleuze and Guattari, 1988). As I have noted already, a reoccurring theorist throughout this thesis is Fassin (2005, p. 365), who defines the moral economy as the economy of the moral values and norms of a given group at a given moment. Fassin extends the conceptual understanding of the moral economy of care through exploring the tensions between the politics of life and humanitarianism.

Many scholars call for an alternative value system to guide the delivery of humanitarian aid. For instance, Leaning, Spiegel and Crisp (2011) call for the sector to pivot from what they argue is a governing utilitarian ethics system to resource management, to adapt and transform its care by embracing a frame of relative need. They outline that by considering the value of the resource transfer alongside the value of what it means to the individual at a localised level rather than considering cross-state disparities internationally, the sector can move towards patient-centred care. Scholars Brun (2016); Leaning, Spiegel and Crisp (2011) detail how patients feel stuck, seeking sustainable healthcare solutions and a value system that equally prioritise the life-changing outcomes of the care they receive alongside the monetary value. These concepts urge a shift away from contemporary aid and development systems towards a post-development framework, such as those which incorporate pluriversal ways of knowing, shifting paradigms towards cultural diversity (Acosta, 2020). The paradigm embedded in the Sustainable Futures Global research network informed the theoretical framework for this research. Through attending events and symposiums, I learnt the prospects in embracing a pluriversal paradigm that incorporates local ways of knowing. I searched for these pluriversal ways of knowing in humanitarian practice through this study.

Another way in which I explore the relational power of aid is through a conceptualisation of the racialisation formation process, as defined by (Omi and Winant, 1993). In their book *Racial Formation in the United States: From the 1960s to the 1990s*, Michael Omi and Howard Winant (1993) explore the concept of racial formation and its significance in understanding how race and racism operate. Through applying the concept of racial formation, I consider the ways in which the racial categorisation of staff is being continuously shaped and reformed, as well as the role of Médecins Sans Frontières in the production and perpetuation of these racialised categories. I pay particular attention to the everyday contestation of race, and how Médecins Sans Frontières is reforming within the wider societal discourse of ‘decolonisation’. Manuel Castells' book *A Sociology of Power: My Intellectual Journey* is a reflection on his work in which he offers insights into the understanding of power and society (Castells, 2016). This book is an important part of my theoretical framework as it details the significant role of information and communication in contemporary society, which is crucial to the decision-makes processes of staff in the workplace and patients who seek medical care. This theoretical framework illustrates the significance of social networks for healthcare information in this study.

In Chapter Six, I theorise spaces of aid as an entity which forms ‘precarious lives’, people subject to the asylum system stuck in liminal spaces (Butler, 2004). In her book *Precarious Life*, Butler (2004) details how vulnerability is intersectional; it is relational and therefore some lives are more ‘grievable’ than others. She argues that vulnerability is unavoidable in our society, conceptualised by the term ‘precariousness’, while ‘precarity’ refers to the inequalities in life stemming from socio-economic and political institutions. The interconnectedness of individuals is a key aspect, with Butler asserting that embracing our own precariousness allows us to acknowledge and empathize with the precariousness experienced by others. This conceptualisation was applied by other scholars in ‘refugee studies’, such as recent research by Yohannes (2021), who theorises the asylum system and humanitarianism through Butler’s concept of ‘precarity’. Yohannes (2021) argues people subject to the asylum system have an existence which is identified by non-viable life and ungreievable death. He argues that by reducing refugees to numbers through quantification, humanitarian institutions conceal the inhumanity and dehumanisation that are rife in the sector (p. 246).

Conceptualising participation and collaboration in aid assemblages is one of the primary objectives of this thesis. One of the foundational works in conceptualising participation for social justice is by Brazilian educator Paolo Freire, with his transformative approach to praxis in *Pedagogy of the Oppressed* (Freire, 2005). Freire (2005) argues that any situation in which some individuals prevent others from engaging in the process of enquiry is one of violence, and that the means used are not important; to alienate human beings from their own decision-making is to change them into objects. When considering how humanitarian aid can be redesigned, I incorporate two primary elements of Freire's theory in this research practice. First, as I will detail Chapter Three, this research encourages active participation and collaboration through dialogical pedagogy. Second, the research methodology in this study applies a problem posing approach in aid assemblages, encouraging staff and service users to identify and analyse problems relevant to their lives in a social justice-oriented design. A second theoretical framework central to this thesis and its conceptualisation of participation is the concept of 'deliberative democracy' by Chantal Mouffe (1999), whereby she challenges the notion of a completely rational and consensus-based deliberative process. A central feature of the narrative of this thesis is one of many negotiations, a form of conflict. Mouffe advocates working with conflict as it is a necessity for democracy; she argues that with open, respectful, and inclusive debates, conflicting views can be listened to and debated. I draw heavily on Mouffe's promotion of pluralist democracy when interpreting and concluding how structures of aid can be redesigned as I worked with emotion, pursued consensus, and sat in the site of contestation. Waters (2001) outlined that such collaborative processes are absent in humanitarian aid service design, that future programming must listen to what refugees themselves think, want and need instead of what others think they need or deserve. One of the primary arguments in his book *Bureaucratising the Good Samaritan* (2001) is that what is missing in the bureaucratised feedback loop is a response from the actual consumers of the food, water, and medical and relief supplies (p. 41).

Moving from theory to practice, many scholars and aid organisations have shared their empirical findings from studies that have explored participatory approaches to ‘refugee research’, which guided me in design, implementation and interpretation. Anderson (2019) shared findings on behalf on the UNHCR on how to ‘tear down the walls’ to participation with women and girls in conflict-affected settings; similarly, the Andrea Cornwall (2003) reflects on how to work to centre women’s voices in participatory development. Doná (2007) details the role of power in participation in ‘refugee research’ and argues that through considering the ‘microphysics of power’ rather than considering which participants are more or less powerful in the context, researchers should consider how participants are both undergoing and exercising their power to move towards centring participant voice. When working with Belal, I turned to scholars such as (Singh *et al.*, 2021; Lokot, 2021), who promote reflexivity and critical practice in research. Pincock and Bakunzi (2021) critically assess how ‘refugee researchers’ are employed to work in refugee-centred research and summarize practical ways to undertake ethical research, which I worked with on this design. Specific to Lebanon, I was influenced by learnings from Jirmanus, Ziadee and Usta (2021b), who write about the relational power in their participatory approach to research in Lebanon’s informal settlements. For participatory methods to be successful, they advise researchers working with Syrians living in Lebanon’s informal settlements to work with existing power structures rather than insisting on universal commitment to horizontal power sharing among all. Taking this as a starting point, I will now close this chapter and introduce the methodology chapter, in which I will discuss in detail how I utilised these theories to inform the methods used to generate data for this research project. I will detail the participants I worked with, specifically Belal and the staff and service users in this project. I will detail the methods we used, how we collectively considered improvements to humanitarian healthcare, the research site, and the analytical processes.

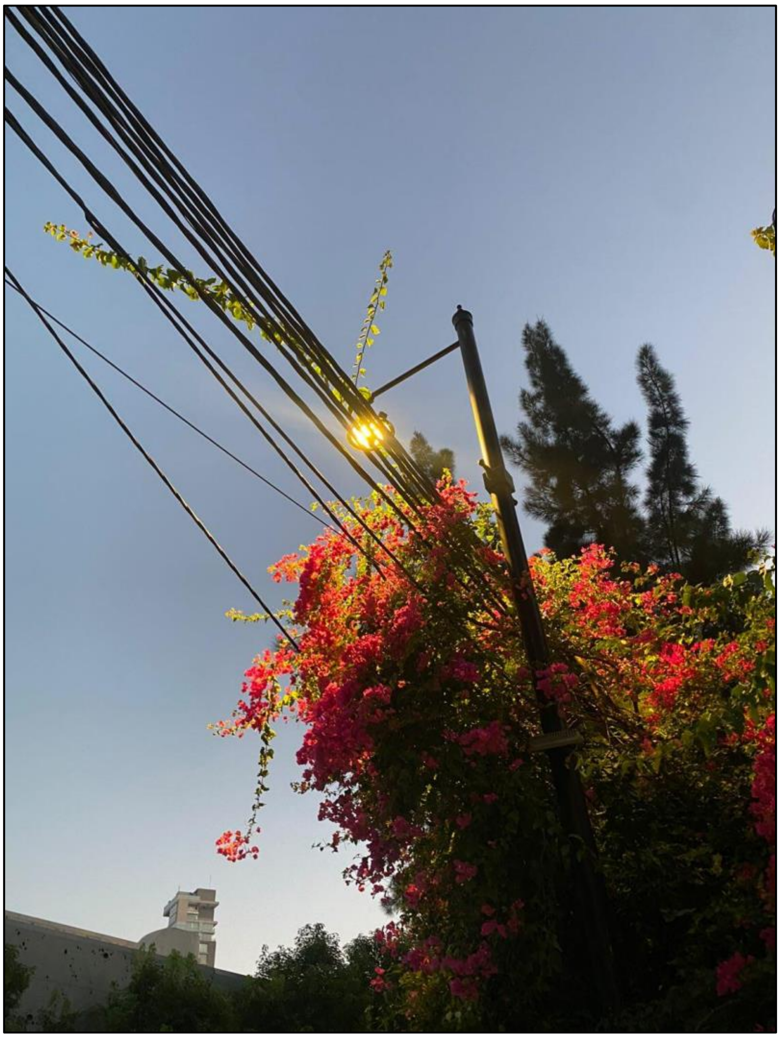


**Figure 2-5 Light shining through the entanglements. Achrafieh, Beirut, Lebanon Taken July 2023. Credit: Genevieve O'Connor**

# Chapter 3 Methodology

In this chapter I detail how I designed and implemented a methodology to explore the realities of living with and treating thalassemia in Lebanon, and how to address the urgent gap in secondary healthcare for structurally marginalized people, as identified in the literature review. Specifically, I provide an overview of how I operationalized this research, examining the specific research methodologies and values which guided this study. This chapter includes a discussion of my research aims and questions, and how I sought to create a space which centered decolonial practice with people of refugee backgrounds. I then highlight each of the methods used in this project: research diaries, interviews, and the 'co-development groups', which I will discuss in detail. Finally, I detail the analytical approach, the theories which informed this, and the study's limitations.

**Figure 3-1 No Entry – Love – Hope. Beirut, Lebanon**
**Taken July 2023. Credit: Genevieve O'Connor**

## Research Questions

The research questions in this doctoral research stem from my professional experience working in aid, in conjunction with the literature review conducted at the beginning of this PhD, alongside the redesign necessitated by COVID-19 and the multiple crises in Lebanon which changed the landscape of this PhD. The doctoral research upon which this thesis is based sought to answer the following questions:

RQ1: Can a co-development group be used to meaningfully engage staff and service users to collectively improve humanitarian healthcare in Lebanon

RQ2: How were the MSF project and its service users affected by the multiple crises in Lebanon?

RQ3: What challenges did the MSF project and its service users experience due to the multiple crises?

## Researching in Lebanon: A Republic of NGOs

As detailed in Chapter One, this study researched with Syrians of refugee backgrounds and staff working at a Médecins Sans Frontières service in Lebanon. Chapter Two evidenced the fragility in the lives of people from Syria living in Lebanon. Here I will present you with some key information to serve as a memory aid for the context of this study.

Lebanon, with a population of approximately 6.8 million people, faces a contested number of refugees due to its refusal to grant statutory refugee status and the associated legal protection. Estimates suggest there are around 1.7 million refugees (according to Al-Jazeera) or about 1.5 million (according to the European Commission) displaced people in Lebanon, originating from conflict-affected countries like Syria, Palestine and Iraq (Vohra, 2021). These individuals lack legal protection and rely heavily on humanitarian services. This study aims to understand the consequences of an increasing number of residents relying on humanitarian healthcare.

Lebanon has been called a ‘Republic of NGOs’ due to the increasing structural reliance on humanitarian services caused by the increasing poverty levels perpetuated by the decreasing availability of healthcare services (Facon, 2021). Lebanese activist Assaad Thebian explained in an interview how the structuralised sectarian system led to a nationwide collapse of state services and perpetuated the severely inequitable distribution of wealth (Thebian, 2020). This mismanagement is illustrated through public health crises, including the Beirut Blast, which killed 219 people; the waste disposal failure; the emigration of healthcare professionals; extended power cuts; and food insecurity and medication shortages, which have resulted in avoidable death (Human Rights Watch, 2021). Taken as a whole, most residents in Lebanon rely on international humanitarian healthcare organisations for services, including the procurement of medicines. Lebanon is an extreme case for studying humanitarian healthcare practice which favours temporary systems and quantifiable results, in part due to donor influence. In many ways, this is the crux of this study: How do people experience the effects of this concentrated humanitarian nexus, both during operations and in their aftermath?

In order to protect participants' anonymity, I will not disclose the specific location where the co-development group methods were undertaken. What I will share is that they took place within a Médecins Sans Frontières-operated thalassemia service located in a Lebanese public hospital. The service users resided in informal settlements on the outskirts of urban areas. While certain healthcare NGOs ran mobile medical clinics on occasion, most healthcare providers they accessed were based in towns and cities, necessitating transportation arrangements. These marginalized residents, who were subjected to irregular access to basic amenities, also contended with escalating levels of political and social discrimination, which coupled together with social and political health determinants.

The daily interactions that Syrians endure in Lebanon are shaped by the histories that precede them. There are social tensions between Lebanese and Syrians, as the three-month siege in 1981 by the Syrian Arab Army (SAA) during the Lebanese Civil War continues to shape Lebanese people's memories and associated emotions and perceptions relating to Syria and Syrians. A report by the UNDP found that 58% of Syrian and Lebanese surveyed in the location of this research study reported that the relationship was worsening, and listed it as a negative or very negative relationship (Center for Operational Analysis and Research, 2021). Consequently, Syrian populations often face discrimination when seeking healthcare or purchasing medication and food. The increasingly scarce resources due to the economic collapse are prioritised for the Lebanese by the Lebanese. This results in worsening food insecurity, exploitation in the competition to sustain livelihoods, and other related social determinants of health. As identified in Chapter Two, there are alternative public healthcare services available for Syrian refugees, but this study is focused on the humanitarian sector specifically; incorporating the role of public services is beyond the scope of this research. To conclude, the context of this study was a humanitarian healthcare service which operated from a public health hospital in Lebanon.

## Researching Thalassemia

This study focuses on the parents and carers of children living with thalassemia, and the staff working to care for them, as an illustration of how humanitarian healthcare mobilises to service conflict-affected populations living with noncommunicable diseases (NCDs). In Chapter Two, I provided an overview of how humanitarian healthcare organisations generally respond to individual crisis events with temporary, flexible and responsive humanitarian healthcare operations. Moreover, I also detailed the increasing necessity for NCD treatment in the Middle East and how changing healthcare needs also mean there is a need for more permanent, continuity-based care.

I will now detail what thalassemia is to contextualise this research study and its findings. Thalassemia is a group of genetic disorders of haemoglobin which are endemic to the greater Middle East, South Asia and Mediterranean basin (Médecins Sans Frontières, 2019). The word 'thalassemia’ comes from Greek ‘thalassa’, which means ‘the sea’, and ‘emia’, meaning ‘blood’ (National Center for Biotechnology Information, 1998). It is prominent in other conflict-affected countries such as Afghanistan and Pakistan, where families struggle to access treatment due to violence (Médecins Sans Frontières, 2019).

Thalassemia is caused by altered genes, and the more altered the person’s genes are, the more severe their thalassemia is (Médecins Sans Frontières, 2019). Care requires regular blood transfusions and iron chelation therapy to prevent iron overload from the blood transfusions (Hokland *et al.*, 2023). Beta thalassemia patients must have regular blood transfusions in order to survive, and chelation is absolutely necessary (Hokland *et al.*, 2023, p. 212). If these treatments are not provided, patients will suffer organ damage and possibly death. Novel therapies include bone marrow transplant, stem cell transplantation and gene therapy; however, these therapies are expensive and are unavailable in the stressed economies of the greater Middle East and North Africa region (Hokland *et al.*, 2023). Hokland *et al.* (2023) do not expect any novel drugs or treatment to be accessible to patients in Low- and Middle-Income Countries for decades.

These novel treatments exist, but due to the structural violence caused by the economic and political situation, patients cannot access the care they need (Galtung, 1969). The harms caused by thalassemia are avoidable. Hokland *et al.* (2023) detail that providing adequate blood transfusions and iron chelation is problematic due to the fragile environment that many healthcare practitioners work in within the region; they list countries such as Sudan, Lebanon and Oman. For this reason, this research contributes to the understanding of chronic illness management in conflict-affected settings.

If you are a carrier of the thalassemia trait, you are often symptom free, so many parents in this study did not know they had the thalassemia trait. It only became apparent when they had a child with thalassemia. Beta-thalassemia major is a debilitating, life-shortening illness. Alpha-thalassemia in its severe form can cause death for a foetus. The management of symptoms is linked to the resulting anaemia and implications on this for their organs (Hokland *et al.*, 2023). Hokland *et al.* (2023) acknowledge that most people living with thalassemia live in conflict-affected countries, and they cannot access the latest developments in care. Moreover, even in countries with advanced healthcare settings, people suffer from comorbidities due to the transfusion-dependent thalassemia (i.e., thalassemia major).

In Lebanon, there is one NGO thalassemia centre for Lebanese citizens, called the Chronic Care Centre (Abi Saad *et al.*, 2014). It is an NGO established in 1993, and it is where all Lebanese thalassemia patients are treated. This centre does not offer care to non-Lebanese citizens due to the economic collapse (Hokland *et al.*, 2023, p. 201). People from Syria who registered as refugees with the UNHCR received healthcare payment coverage from the UNHCR, but not everyone was registered with the UNHCR, in part because they stopped accepting registrations in 2015. Prior to the economic collapse (before 2018) staff from the Lebanese Chronic Care Centre would have visited the refugee camps offering support, but this service was subsequently left for other NGOs to provide (Hokland *et al.*, 2023, p. 204). This is why the Médecins Sans Frontières service in this study was lifesaving.

Prior to 2018, patients received thalassemia medications from the MoPH, but due to the port explosion and the economic collapse, medications are now difficult to access. One healthcare professional explained that they are deeply frustrated at not being able to provide thalassemia care for refugees and that INGOs need to organise better cooperation to serve refugees in Lebanon (Hokland *et al.*, 2023, p. 206). One healthcare professional who works at the national NGO 'Chronic Care Centre' explained that a potentially curative option was available in Beirut, but the government does not cover the cost due to the economic collapse. Therefore, they did not consider the cure an option for their patient due to the prohibitive cost (Hokland *et al.*, 2023, p. 210). To conclude, there are limited options for non-Lebanese citizens for thalassemia care. Palestinians could access UNRWA, who ran paediatric treatment (UNRWA, 2023), and MSF ran paediatric treatment for all nationalities, although the vast proportion of their patients were Syrians (Médecins Sans Frontières, 2020c). However, their service was only available for patients under the age of 15. MSF provided diagnosis, blood transfusions, iron chelation therapy, and psychosocial support (Médecins Sans Frontières, 2020a). Médecins Sans Frontières closed their thalassemia service in 2023, handing it over to a national NGO who could not secure funding for this care (Former MSF staff, Email Communications, July 2023). Médecins Sans Frontières committed one year of funding to the service, which will run out at the end of 2023.

Thalassemia treatment is not routine for an (I)NGO to provide. MSF ran a clinic in north-western Syria for two years, from 2017 – 2019. These operations evidenced the ability of an INGO to provide this care during a protracted conflict. However, the logistics of running a blood drive in the population led to challenges, alongside social factors for patients, which led to hurdles in adherence to therapy (MacVinish *et al.*, 2023). This PhD study further evidences how managing a complex care programme in a low resource context is challenging and the consequences of this for staff and patients, and the families that care for them.

To document the opportunities, challenges and experiences of long-term care provision, I chose to research thalassemia in Lebanon. There has been an increase in thalassemia cases in Lebanon due to migration from Syria, and recent studies have shown that thalassemia is increasingly being diagnosed outwith the greater Middle East due to global migration trends (Hokland *et al.*, 2023). This research explores the diagnosis, management and treatment of thalassemia in

Lebanon, a protracted crisis setting. This responds to MacVinish *et al.* (2023) call for studies that explore the impact of a humanitarian thalassemia programme for patients and families in conflict settings in order to provide the insights needed to evaluate the success of thalassemia programmes.

**Figure 3-2 Illustration by Nader Tabri**

## Researching with Médecins Sans Frontières (MSF)

This research was supported by Médecins Sans Frontières (MSF) Operational Centre Paris (OCP). MSF is an international humanitarian medical non-governmental organisation (NGO) of French origin that primarily works in conflict zones and countries affected by endemic diseases. It is synonymous with humanitarian healthcare. MSF first started working in Lebanon in 1976, their first time operating in a warzone (Médecins Sans Frontières, 2020b). The organisation manages operations, recruitment and logistics from Paris, while daily coordination is often managed from a state’s capital, for instance Beirut. This geographical distance can have both positive and negative implications for operations; positive as operating from HQ in Paris ensures stable access to the resources needed for management in a stable setting, but negative because this distance from the daily operations may hinder the realization of healthcare needs and required responses. The organisation operates on a two-tier recruitment system: 1) international staff, who work in management roles and are primarily recruited from Europe and North America, and 2) national staff, who work at all levels, and are recruited within the country of operation.

Edward Said declares that any separation of the Orient (such as Lebanon) and the Occident (such as France) is one of imaginative geography and that this separation cannot go unchallenged (Said, 1985). This separation is the starting point for much of my inquiry, which explores the segregation and confinement on the grounds of geographical imaginaries (Said, 1985, p. 6). Said argues that the power inherent within this segregation can be witnessed through institutional defensiveness. I seek to explore how Orientalist styles of thought are created, reproduced, negotiated and contested in this Médecins Sans Frontières-run thalassemia clinic.

A reminder for the reader: Before this PhD, I was an MSF staff member. I identify as an aid worker. This positionality affected the research process. It influenced how I was received during my research design (as I was often introduced as a ‘former staff member’ or ‘fellow MSFer’) and I believe it influenced the spaces I was granted access to. Being an aid worker is a central part of my identity and I do not have detachment or distance from this project. The research objective of improving working practices is therefore personal (England, 1994). When sharing my positionality with staff, it created great rapport, and it was a common ground for connection, facilitating trust. I do not consider my positionality a limitation; rather it is a central influence on the research process and something I remain mindful and transparent of.

I began dialogue with MSFs research unit in 2019, and subsequently discussed research opportunities with their operations department at headquarters, then at coordination and field level in Lebanon. (For a timeline, see Figure 0-3, Figure 0-4, Figure 0-5, Figure 0-6, page xxii.) I shared detailed accounts of the project, my own background and objectives, and the proposed research questions, methods and design. After an initial email discussion with ‘CRASH’, MSF’s Research Unit in Paris, I travelled to meet the Operations Managers in Paris in 2019 to discuss the research proposal before they forwarded this to the coordination team in Lebanon. I was invited via email to fly to Paris, a nonchalant invitation to meet at their office. On arrival I was aware that perhaps they may had forgotten. The receptionist didn’t know who I was or who

I was referring to, so I wandered the halls knocking on doors asking for my contact by name. ‘Who?’ ‘Oh, right’. We spoke for ten minutes: a cigarette break and a coffee in the office’s garden. This feeling of uncertainty and doubt over our partnership continued through my research. Later that year, in August 2019, I travelled to Beirut, where I met with the Head of Mission to finalise the logistics of the research prior to submitting ethical and risk approval to the University of Glasgow and Université Saint-Joseph de Beyrouth. Université Saint-Joseph de Beyrouth provided research support through the entirety of this PhD. I consulted with CRASH and the country’s Head of Mission for all decision-making to ensure that the questions and approach were feasible, sensible, and relevant in the context of Lebanon’s multiple shocks and changing needs.

## Researching with Belal Shukair: ‘what I'm trying to do even with all these difficult circumstances’

In September 2021, I recruited a researcher, Belal Shukair a young Syrian researcher living in Lebanon, to facilitate the participatory co-development groups for this research project. This recruitment was in response to the redesign caused by COVID-19 that I detailed in Chapter One. The scarcity of electricity in Lebanon (one hour of electricity available at most) meant that remote data collection was not feasible.

In September 2021, I created a one-page PDF job advertisement in English which I circulated via my networks in Lebanon. After interviewing ten researchers who had enquired about the position, I selected Belal based on our shared view of the world. When I asked Belal how he wanted to be introduced in this thesis, he wrote the following passage: ‘Belal Shukair, a young Syrian researcher based in Lebanon. I believe in equality, freedom, participation and human rights. For me, learning is a never-ending and continuous process and that's what I'm trying to do even with all these difficult circumstances’ (Whatsapp Voice note, November 2023). This remote working partnership was created and sustained by Whatsapp voice notes. It required immediate mutual trust and the navigation of inherent power dynamics relating to positionality and our unequal access to resources. I will examine what I learned from this working relationship methodologically later in this thesis. For now, I will document how this recruitment shaped the research methods and design.

The starting point for me in this recruitment was to critically reflect on what kind of economic and intellectual privilege participating in this research involved (Bhambra, 2014). The research was reliant on collaboration with a researcher, as is often the case in lower-income cross-cultural settings (Stevano and Deane, 2019). Relationships dependent on financial transactions perpetuate power imbalances, and I was conscious that whoever I recruit will be a 'contract researcher', manual labourers in the research team who do the invisible domestic labour of academic research (Dumeden, 2012). This researcher would aid in creating the network and linkages needed to generate the data, the people and the space that bring it into being (Gupta, 2014), to create the reciprocal triangular relationship between the researcher, researched, and research assistant that is shaped by agency, power, resistance and finance. These relationships would undoubtably shift overtime, in part, in response to workloads and payment (Gupta, 2014). I will dedicate the next few paragraphs to considering how paying a researcher for this study may have shaped the quality of the study, its design, its process and outcomes (Thapar-Björkert and Henry, 2004; Stevano and Deane, 2019).

Many research assistants work multiple jobs to supplement their income. The quality of the data received would be directly influenced by the financial amount I chose to pay. This choice determines the level of detail the researcher can include in their report and the format in which they present the information. The extent to which they can dedicate time and energy to drafting notes after data generation also depends on this financial commitment. As Deane and Stevano (2016) warn, research assistants may apply varying degrees of coercion in the process of data generation with participants when striving to deliver a 'good result' for their employer. Perhaps in the hopes of securing future paid positions, in this project or through recommendations, researchers may skew methodological results and share misleading representations of the research process, reporting an fallacious flawlessness in the methodological process (Deane and Stevano, 2016). The financial incentive would also influence the *outcomes* of the project, as I was reliant on a paid researcher to support in project output and dissemination. This reliance may be mutual, as the researcher may be hoping to be 'liked' and thus be 'used' financially (Molony and Hammett, 2007). I was aware that the financial transaction would determine the ability and level of commitment, and the quality of the work, due to the realities of the precarious economic life in Lebanon.

I approached the power asymmetry, shaped by this financial transaction, with contextual responsiveness rather than a rigid application of rules and guidance offered by peers and in academic literature (Warnock, Taylor and Horton, 2022). I sought to provide 'fair' working conditions, informed by professionality, transparency and trust regarding their time spent on tasks and its respective payment (Stevano and Deane, 2019). Warnock, Taylor and Horton (2022) 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 researchers. The authors call for researchers to cultivate a sense *for* participants in their project. Nevertheless, I was cognizant of what might be a blurred line between friend, companion and manager and how this could perpetuate a financially determined power asymmetry between the researcher and I, which would be impossible to hide but may be rendered unspoken (Warnock, Taylor and Horton, 2022).

This research was surrounded by, and indeed its purpose is in part the alleviation of, poverty (Molony and Hammett, 2007). Molony and Hammett (2007, p. 296) caution that researchers in these relationships can be seen as a 'soft touch' and an easy opportunity to secure money by people in desperate circumstances. Recruiting researchers has also been proposed as being a philanthropic gesture, providing a much needed income to a structurally vulnerable population (Molony and Hammett, 2007). I was uncomfortable about such a paternalistic approach. I sought a reciprocal agreement, in which I secured the knowledge needed for the Doctoral degree, and the recruited researcher secured money and further experience facilitating participatory research.

I consulted with national and international 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 fueled by discrepancy in access to international currency. However, 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. As a result, I paid Belal 10 USD$ an hour from the PhD 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.

To better understand the relationality of power in this project, Belal completed a positionality statement. I discuss this later in this chapter, and you can find a list of prompts in the appendix. As Belal worked with people from Syria, Lebanon and Europe, these audio diaries and positionality statements were crucial to understanding the relations of power underpinning spatial dynamics. This was key to understanding the possibilities of knowledge production in this space (Bhambra, 2014, p. 120). Belal shaped the design and methods of the co-development groups as he saw fit and sensible. We had candid discussions throughout the project to manage both of our expectations and to make sure workloads were feasible; collaborative planning was crucial to this working relationship. This changed over time, through the data generation, analysis and dissemination stages.

Belal's positionality, as a young Syrian male who is an experienced participatory research facilitator and aid worker in Lebanon, enriched this project in a way that I could not have foreseen during the 2021 redesign. The main difference of the research re-design was that I was no longer the generator of co-development group data. Belal's 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 MSF's clinics with Syrian service users. His contextual knowledge 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 (Fadiman, 1999). His positionality and the cultural responsiveness this enabled when facilitating the participatory co-development groups would not have been possible for me, as an Irish researcher with intermediate Arabic who had only spent two months in Lebanon. While there are many methodological implications of being removed as the data generator, I believe this revision enriched the design. Exploring ways to decenter power by using participatory socio-culturally responsive methods in low-resource spaces of aid are the primary objectives of this thesis.

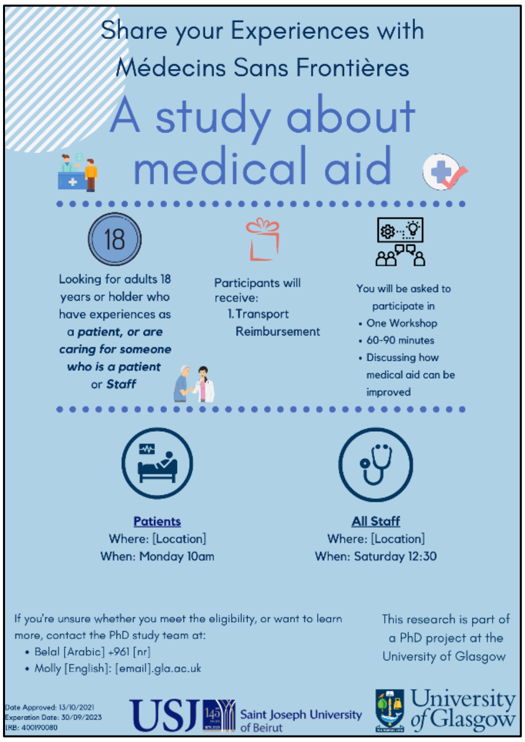
## Troubling the Categorisation Process

I will now outline the logic behind participant selection in this study. When creating this research design, I sought to understand power formation and contention in spaces of aid. Power is generated through interactions, by actors (staff and service users in this study), shaping institutions according to their own values, norms and knowledges through the process of dominance and counter-protest (Castells, 2016). As an illustration, the categorization of 'refugees' as people either deserving or undeserving of healthcare rights derives from this constructed status and creates harm (Zetter, 2007), as does the two-tiered system for staff which I detailed in Chapter Two. For this reason, as is typical in the Sociological discipline, this research was generated with all actors in the bounded case of the thalassemia unit. This enabled me to understand norms, social life, and the structures of the institution to capture the relationality of power.

A European logic of homogeneous categorization through hierarchical dichotomies is embedded within the structures of aid (Bhambra, 2014). I am employing this Hegelian logic to comprehend the Orientalist relationship between the 'self' of an international aid worker and a perceived otherness to explore the humanitarian sectors activity. I considered who occupied the categories, how these were understood to be common sense, and what this reveals about inequality in spaces of aid (Saperstein, Penner and Light, 2013, p. 165). I incorporated the two-tiered categorisation of staff into the design as it enabled me to explore how social boundaries become translated into organisational practice, for instance through mimicry of international by national (Bhabha, 1984). I assess what the humanitarian categorisation means in practice in accessing opportunities, support, and access to information for decision-making (Saperstein, Penner and Light, 2013; Bhabha, 1984). I argued in the second chapter that the tiered racialised logic sustains inequality as European headquarters favour European languages and take practices of whiteness for granted, perpetuating mimicry and Orientalist practices, which shapes staff-staff and staff-service user interaction (Carter, 2005, p. 369; Bhabha, 1984; Said, 1978).

Another illustration that I sought to explore in this design is related to competing understandings of race and ethnicity and what these mean – how they shape what it means to be a ‘Syrian Bedouin’ for instance, and how this in turn shapes deservingness of care in clinical settings (Lopez, 2010). These assumptions of when race matters or does not matter for health contaminates medical knowledge and shapes staff-patient interactions in clinical settings; I sought to explore how this related to humanitarian healthcare in Lebanon (Saperstein, Penner and Light, 2013).I evidenced in Chapter Two how these racialized categories are created, inherited, inhabited, transformed, and destroyed. I am using and troubling categories in this study (Derrida, 1978; Jackson and Mazzei, 2011). I use socially constructed categories to capture the plurality of experiences in the clinic as a way to explore how they are produced and reproduced, experienced, and what the consequences are (Said, 1985, p. 14). In this research, I try to find a common ground of assembly between these grounds of activity to enquire into the categorization process of ‘deserving’ and to move towards better equity in spaces of aid (Omi and Winant, 1993; Saperstein, Penner and Light, 2013).

The participants in this study are typical of actors in an international humanitarian healthcare setting. They are both national and international staff, and many of the patients reside in informal settlements, all of which is typical for an MSF operation and is transferrable to similar cases (Gerring and Cojocaru, 2016, p. 394). What is divergent from the norm is the interaction and experience of MSF staff working in the public hospital, which offers insight into how established international non-governmental organisations adapt and adhere to working with formalised state structures.



Share your Experiences with
Médecins Sans Frontières

A study about
medical aid

Looking for adults 18 years or holder who have experiences as a ***patient, or are caring for someone who is a patient*** or ***Staff***

Participants will receive:
1. Transport Reimbursement

You will be asked to participate in
- One Workshop
- 60-90 minutes
- Discussing how medical aid can be improved

**Patients**
Where: [Location]
When: Monday 10am

**All Staff**
Where: [Location]
When: Saturday 12:30

If you're unsure whether you meet the eligibility, or want to learn more, contact the PhD study team at:
- Belal [Arabic] +961 [nr]
- Molly [English]: [email].gla.ac.uk

This research is part of a PhD project at the University of Glasgow

Date Approved: 13/10/2021
Experation Date: 30/09/2023
IRB: 400190080

**Figure 3-3 Recruitment poster for research participants that was shared by MSF staff via WhatsApp and Email**

شاركنا خبراتك مع جمعية
اطباء بلا حدود

دراسة عن الاغاثة
الطبية

نبحث عن بالغين 18 عام وما فوق او حامل للخبرة مثل مريض او شخص يعتني بمريض او عامل في المجال الطبي

المشاركين سوف يتلقون:
- بدل مواصلات ونقل

سيطلب منك المشاركة في:
- ورشة واحدة
- مدتها ساعة الى الساعة والنصف

سيتم النقاش عن موضوع الاغاثة الطبية وكيف يمكن تطويره

**متلقين الرعاية الصحية**
المكان:
الزمان: الاثنين 10 صباحاً

**العاملين في مجال الرعاية الصحية**
المكان:
الزمان: السبت 12:30 ضهراً

اذا كنت غير متأكد من قدرتك على المشاركة او اردت معرفة المزيد عن هذه الدراسة يمكنك التواصل مع فريق الدراسة مباشرة
- بلال (العربية) : عن طريق الواتساب
- مولي (الانكليزية):

هذا البحث هو جزء من رسالة دكتوراه في جامعة غالاسكو

Date Approved: 13/10/2021
Experation Date: 30/09/2023
IRB: 400190080

**Figure 3-4 Recruitment poster for research participants that was shared by MSF staff via WhatsApp and Email**

The participants for the co-development group in this study were staff and parents (or carers) of the children being treated by Médecins Sans Frontières for thalassemia. To recruit participants, I designed two recruitment posters (Figure 3-3 and Figure 3-4) using Canva software. Belal translated these from English into Arabic. These posters were circulated with a participant information sheet and consent form via WhatsApp by MSF's External Activities Manager and Project Coordinator to the 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. Parent recruitment was straightforward; their children's blood transfusions to treat thalassemia took approximately six hours, meaning they had time to spare at the hospital. For ease of reference, I will use the term 'service user' in this research, as I was not always able to establish whether the participant was a carer or parent (although most, if not all, introduced themselves as mothers and fathers of children with thalassemia who were treated by Médecins Sans Frontières). Staff recruitment did not pose difficulty, but staff were often distracted by work-related tasks and arrived late or left the room if they were called to support hospital-related activities. You can find a tabulation of the co-development group staff and service user participant in Table 1 and Table 2.

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. A total of 11 staff and 18 service users participated in the co-development groups, with a median of six per group. 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.

Table 1 Overview of Staff Co-Development Group Demographics

| Session | 1 | Session | 2 |
|---|---|---|---|
| Number of People | 5 | Number of People | 6 |
| Male | 3 | Male | 2 |
| Occupation Disclosed | IT; Doctor | Occupation Disclosed | 2 Drs |
| Age | 30-40 | Age | |
| Female | 2 | Female | 4 |
| Occupation | Nurse | Occupation | Nurse, Cleaning Technician, External Activities Manager |
| Age | 30-40 | Age | |
| New Participants | 4 | New Participants | 4 |
| Session | 3 | Session | 4 |
| Number of People | 6 | Number of People | 6 |
| Male | 4 | Male | 2 |
| Occupation Disclosed | 1 International Staff (Medco) | Occupation Disclosed | Dr |

| | | | |
|---|---|---|---|
| Age | | Age | |
| Female | 2 | Female | 4 |
| Occupation | | Occupation | HR, External Activities Manager, Nurse x2 |
| Age | | Age | |
| New Participants | 1 | New Participants | 1 |

Table 2 Overview of Service User Co-development Group Demographics

| Session | 1 | Session | 2 |
|---|---|---|---|
| Number of People | 6 | Number of People | 5 |
| Female | 6 | Male | 1 |
| Age | One person 20s five 30-40 | Age | One person 20s three 30-40 |
| | | Female | 4 |
| | | New Participants | 3 |
| Session | 3 | Session | 4 |
| Number of People | 6 | Number of People | 6 |
| Male | 2 | Male | 4 |
| Age | One early 50s; Five 30-40. Note: One married couple | Age | |
| Female | 4 | Female | 2 |
| New Participants | 4 | New Participants | 5 |

As I detailed in Chapter One, the research design changed many times. Table **3** presents the original design and how this pivoted to the implemented design. Originally, I sought to mix the staff and service user groups as a way to facilitate intersectional dialogue. However, this proposal was rejected in a preparation meeting by management staff, who suggested that a collaboration of staff and service users could increase tensions and lead to 'finger-pointing' and blame. They advised me to divide the populations into service users and staff. While this limited the cross-group dialogue, it perhaps resulted in a more comfortable and encouraging space for service users and staff to speak openly about the challenges they faced.

Table 3 Research Methodology and Design

| Method & Design | Original 2019 Research Design | Revised 2021 Research Design |
|---|---|---|
| Research Questions | RQ1: How are humanitarian medical operations mobilised to serve refugees living in Lebanon?<br>RQ2: What operational changes in humanitarian healthcare are needed to establish more effective and culturally appropriate aid provision?<br>RQ3: Can a co-development group be used to meaningfully engage staff and service users to collectively improve humanitarian healthcare service provision in Lebanon? | RQ1: Can a co-development group be used to meaningfully engage staff and service users to collectively improve humanitarian healthcare service provision in Lebanon<br>RQ2: How were the MSF project and its service users affected by the multiple crises in Lebanon?<br>RQ3: What challenges did the MSF project and its service users experience due to the multiple crises? |
| Case Design | Cross Case<br>1. National Humanitarian healthcare NGO<br>2. International humanitarian healthcare NGO | Single Case<br>1. International humanitarian healthcare NGO |
| Participants | National NGO:<br>• National Staff<br>• Lebanese Service Users<br>• Syrian Service Users<br>International NGO<br>• National Staff<br>• International Staff<br>• Syrian Service Users | International NGO<br>• National Staff<br>• International Staff<br>• Syrian Service Users |
| Location | 1. National NGO: City, town and rural setting | Service within a state hospital |

| | | |
|---|---|---|
| | 2. Service within a state hospital | |
| Method & Methodology | 1. Participant Observation<br>2. Semi Structured Interviews<br>3. Co-development group Participatory | 1. Audio diary<br>2. Semi Structured and Unstructured Interviews<br>3. Co-development group Participatory<br>4. MSF Internal Documents |

## Process of Enquiry

The research methods developed for this project are informed by Berryman, SooHoo and Nevin (2013, p. 4), who envisage the research context as being where the ‘researcher and research participants work in a space where resistance, critique and empowerment can occur’. The methodological approach was designed to be adaptive to people and preferences in the moment. The research methods are grounded in a pluralistic approach to knowledge creation (Denzin and Lincoln, 2011). Although not conducting an ethnography, I drew on insights from ethnographer’s research diaries, engagement and reflexivity where possible given covid constraints. The visual representation in Figure 3-5 lists the five sources of data in this study, generated by Belal and me.

Figure 3-5 Visual overview of the process of enquiry in this study

## Belal's Positionality Statement and Audio diary

The positionality of a researcher influences why they generate the data they do, depending on whether they see like a humanitarian, or a sociologist, or an aid recipient. How we see affects how we interpret data and the conclusions we draw. This research embraces a relational, reciprocal approach to research facilitation: I am not a neutral observer, and I did not hope for Belal to be one either. For this reason, prior to facilitating the co-development groups, Belal completed a positionality statement in which he explicitly discussed his positionality and how this could impact his assumptions, his perspectives, and his decisions about when to probe and when to move on during data generation. After each co-development group, he completed a reflective audio diary, as a way to capture rich data for the project, inspired by ethnography-by-proxy tools (Wallman *et al.*, 1980). To guide him in this process I compiled a list of prompts which can be found in appendix six. The audio diary enabled this study to incorporate the spatial dynamics in the hospital; he described behaviour patterns and activities and what he interpreted these to mean.

Bhambra (2014) details how localised, decolonial epistemologies must engage with the geographical context and its history. This audio-diary captured a rich description of the meaning-making process that took place in the co-development group, and the practicalities of applying the method in the space. I chose an audio-diary as this allowed Belal to express himself with ease, English not being his first language, and it also enabled me to learn more by following the 'trace' – what was not said, pauses, intonation, etc. (Derrida, 1978). I conclude the significance of these methods in Chapter Four. This reflexive approach enabled critical self-reflection by Belal and me in this process, which supported more equitable research partnerships (Kia-Keating and Juang, 2022).

Madden (2017) describes reflective methodologies as 'a way to get close, but not so close one can't step back again'. This statement provided me with an insight into how Belal's worldview and thinking affected how he steered participant dialogue. Moreover, this positionality statement supported me to comprehend how he navigated through the different ethical playing fields: his own ethics, my ethical principles (which shaped the research project), those of the participants in the room, MSF's, the University of Glasgow's, and Université Saint-Joseph de

Beyrouth (Kingori, 2013). I aimed to create a trusting relationship, a reciprocal space where Belal could feel comfortable sharing his positionality in the project and speak openly about inconsistencies and dilemmas amidst research facilitation so I could support him through the process.

## Research Diary

I spent a total of six weeks in Lebanon in the Spring of 2020, which initiated the process of developing rapport with staff. In 2021, while working remotely from Glasgow, I held a weekly meeting with staff for a check-in, alongside multiple calls with Belal to share progress updates. Throughout the PhD I had virtual Arabic classes twice weekly with my Syrian teacher in Lebanon; she shared candid insights into the daily realities of living in Lebanon. There were multiple information flows which kept me informed of the daily realities for Lebanese and Syrians living in Lebanon, all of which shaped my understanding of the research data. Although not conducting an ethnography, I was mindful of Nadai and Maeder's work (2005) which distinguishes ethnographers as having a vast implicit and explicit background knowledge of any field they are studying. I believe this to be important for my research too. I may have lacked the contextual knowledge of specific situations, but as an aid worker who had worked in - and remotely from - Lebanon over five years, I typically knew of the situations that the research participants referred to (Knoblauch, 2005). In some settings I had limited contextual knowledge, yet I utilised my understanding of the social, cultural and political structures governing these settings to access, navigate, and quickly develop the contextual knowledge I needed. I had an understanding of what to ask and who to ask it to facilitate this process. I do not think this rapport and navigating the power structures would have been as successful as they were if I had not had this experience. As you will read in the findings chapters, when I was in Lebanon, I kept a research diary. I first wrote with pen and paper, borrowing the templates advised by Spradley (2016), which you can find in appendix four. I adapted to an audio diary approach in 2022 and 2023. The research diary was transcribed electronically for organizing consolidated notes that capture the nuances and impressions and to support data protection (Madden, 2017).

## Semi-Structured and Unstructured Interview

After my initial familiarization with the data generated in the co-development groups, Belal's audio diary, and MSF's archival data, I wrote a topic guide which you can find in appendix three to explore the emerging themes in a semi-structured interview with Belal in Lebanon. This interview focused on: a) the data generated during the co-development group; b) the process of conducting the co-development group; and c) the nature of the remote international partnership design. This interview provided insights into the strengths and weaknesses of the participatory method in the contexts, as well as acting as a form of consultation of data in the co-development group anlaysis. Finally, this interview also helped me reflect on experiences of a virtual international research partnership and its research management. When I returned to Lebanon in 2022, a few weeks before the thalassemia unit closed, I conducted an unstructured interview with a member of the senior management staff. We sat in her office and I asked her an open-ended question: 'What do you think I should know about the thalassemia service?' This interview consolidated the internal and external MSF communications which informed this study.

## Internal Documents: MSF 'SitReps'

Throughout the duration of this PhD study, MSF staff emailed me internal documents called 'sitrep reports' written by project staff. These reports detail meetings with local authorities, daily operational overviews and related concerns, and map ethical dilemmas. I received security reports which provided insight into concerns for security escalations and limitations to movement. This information was crucial, because of the physical distance caused by COVID-19. These documents served as a daily record written by busy project staff conveying information to headquarters. These documents were a subject to engage with. They narrated an institutional memory, as I noted what project staff recorded, remembered but also forgotten. When I include specific details in these reports in this thesis, I removed location and project staff identifiers.

## The Possibilities of Participatory Research in Spaces of Aid

> 'the researchers are growing in numbers, the camps problems are growing too'
> (Sukarieh and Tannock, 2013, p. 499)

One of the primary research objectives of this doctoral study is to explore the possibilities of participatory research in spaces of aid. As Chapter Two detailed, there are few studies which use participatory methods in an ongoing conflict setting with aid recipients and/or refugee populations outside of North America or Europe (Jirmanus, Ziadee and Usta, 2021a). The importance of participatory research and community engagement for designing appropriate and relevant healthcare service provision is well demonstrated throughout the literature (Ormel *et al.*, 2020a). Moreover, most studies of humanitarian aid systems focus on the experience of international staff or service users. By exploring how service design can be improved for service users and staff through applying a culturally responsive methodological approach, this research contributes to the sector's understanding of whether this may prove to be a useful method in developing a crucial, yet fragmented healthcare system in what has been described as a failing state.

### Co-developing Solutions to Identified Problems

'The master's tools will never dismantle the master's house'
(Lorde, 1979)

I am building on the valuable work by scholars before me (Singh *et al.*, 2021; Robinson, Halford and Gaura, 2022; Arnstein, 1969). Co-development group processes embrace a critical approach led by community priorities and knowledge (Kia-Keating and Juang, 2022). The methodological design borrows principles from participatory learning and action (PLA) a practical, adaptive research strategy that enables diverse groups and individuals to learn, work and act 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 (Lionis *et al.*, 2016, p. 3; de Brún *et al.*, 2017; MacFarlane *et al.*, 2012). The strength of PLA is its collaborative approach, which strives to create a level playing field for participants to collectively identify a key concern - for instance in their healthcare treatment - and co-create a response that is both meaningful and relevant for them. I was, however, proceeding with caution. In their study of informal settlements in Lebanon, Sukarieh and Tannock (2013) illustrate that moving away from extractive interviews towards research labelled as 'participatory', 'action', and' community' was not inherently better for residents of the camps. One resident identified that researchers are ignorant of everyday issues, and can have missionary attitudes, arriving to teach people in the camp how to solve the problems of the Palestinian people in Lebanon. Sukarieh and Tannock (2013) highlight the particular issue of public health researchers, as participants feel that academics believe they are filthy as they are teaching camp residents hygiene. For this reason, I proceeded with an awareness that while being ‘participatory’ is an approach lauded as having increased ethical principles, it can be just as harmful.

This specific ‘co-development group’ format is drawn from the methodology that MacFarlane *et al.* (2012) deployed in the RESTORE project, which ran from 2011–2015 in Austria, Greece, Ireland, The Netherlands, and the UK to investigate how communication between primary health care workers and their migrant patients could be improved. This method was created in response to the recognition of the significance of the patient feeling understood and accepted by staff during treatment, and that socio-cultural differences can impede this relationship-building (van den Muijsenbergh *et al.*, 2014). This context and its challenges shared similarities with the research context of this doctoral study.

Having identified that participatory, co-development approaches (solutions to identified problems with affected populations) had achieved success in Europe and seeing calls for further exploration in conflict effected settings, I set out to deploy this ‘co-development group’ approach in Lebanon. However, since this form of ‘design thinking’ and the utilisation of such methods stem from Europe, I knew I would have to adapt it to be flexible for low resource settings. I will discuss how I did this in the proceeding section. As Tuhiwai Smith (2021) details, decolonisation of research does not mean a total rejection of research and theory; rather it is about centring non-Western worldviews and concerns, and coming to know and understand research with non-Western perspectives and purposes (Tuhiwai Smith, 2021, p. 43). When creating this design, I strived to enable a space for a politics of self-determination, of greater participation in aid, to consider how research could enable a space for staff and service users to discuss control, to discuss what happens in their lives (Tuhiwai Smith, 2021, p. 44).

Aligning with my decolonial and feminist research principles, it was important to me that the research in this project be useful to Belal and the research participants. However, I also acknowledge the limited scope of this project to create meaningful social change. As demonstrated in Chapter Two, the 'actions' suggested in final co-development group may have been suggested by participants who were *over researched*, and whose trust in research institutions is slight. Reid, Tom and Frisby (2006) propose that small scale participatory research is better suited to having 'modest' goals for individual or collective action. I deployed a methodological approach that '[v]alidates individual actions, instigates collective actions, and connects a multitude of actions with the broad goal of social change' (Reid, Tom and Frisby, 2016, p. 328). I hoped that the co-development group would work to build a foundation of understanding to address health inequalities (Kia-Keating and Juang, 2022). The process of working towards actionable solutions forefronts a commitment to combatting the structural racism embedded in the international refugee response and work towards global health justice. Unlike the processes of a focus group or survey that explores and documents pain and suffering, a participatory co-design approach recognises the potential to collaboratively learn, create, organise, and act (Kia-Keating and Juang, 2022, p. 304).

The objective of the co-development group was to examine the contextual social and cultural constructs of health in the space, discover how participants perceive humanitarian healthcare services, and propose solutions to collaboratively identified issues relating to healthcare. I took inspiration from Cheraghi-Sohi *et al.* (2006) to build a 'conceptual map' of preferences in the form of 'comment charts', an A1 piece of paper populated with participant responses. I designed this to question the applicability of Western understandings of the concepts of health and healthcare in non-European spaces by including questions like 'What affects your health', 'What does the phrase "the health of society" mean', 'What would you change to create a safer space for care', and 'What role does MSF play in the healthcare system'. I followed Lorde (1979), who insightfully declared that the master's tools will never dismantle the master's house. I strived to provide a flexible strategy for enquiry that Belal could work from, but I resisted providing a prescriptive recipe-style method and design based on Western ways of knowing and doing for Belal to implement. Instead, I provided a broad starting point of open-ended questions from which he could work with participants to fashion new tools to revitalise local knowledge to restructure what is termed ‘aidland’ for the over-researched populations it works to serve (Tuhiwai Smith, 2021).

The co-development groups ran for one-hour sessions weekly over four weeks through November 2021. They were conducted in parallel - staff one day and service users the following day - within the bounded case of the thalassemia service (Creswell, 2007, p. 74). This within-case analysis allowed for a rich thematic analysis of the entirety of the thalassemia unit case study, and then an analysis of the sub-units (staff experience and service user experience). This within-case design is more suitable than a multiple-case study or cross-case study as the context of the thalassemia unit is similar in each of these subunits. This enabled me to understand the shared and diverging experiences and perspectives that transcended across the space which I detail throughout this thesis.

**Figure 3-6 Scan to download a visual representation of the methodology**

There were three forms of data that derived from this co-development group process: i) the within-group dynamics, for instance the relational power between staff; ii) the process of enquiry into whether participatory methods were useful; and iii) the challenges and solutions identified alongside the process of prioritisation amongst and across staff and service users. This data was co-created, as Belal reciprocated storytelling with the participants to deconstruct his position in the room, putting him in relation to other participants, co-constructing knowledge (Kovach, 2010). Everyone was welcome, including people who are underrepresented in spaces of aid such as cleaners or human resources officers, to attend and speak for and represent themselves politically, socially, culturally, spiritually, and intellectually (Said, 1985). Participants wrote answers on post-It notes and visually presented these on 'comment charts' (A1 flipchart paper). The first session focused on topic creation (first co-development group). The participants then organised these topics into categories (second co-development group), then ranked these categories in order of importance (third co-development group). The final co-development group placed an emphasis on actions that could be co-created and undertaken to create a positive change (McNiff and Whitehead, 2009; Bradbury, 2015). For images of the room, see Figure 3-7 and Figure 3-8.

The first issue I wanted to mitigate in the process of enquiry was the resistance of slow methods in a fast-paced environment. This was due to the rapid response required in humanitarian aid settings. Moreover it responds to concerns raised by Palestinians in Lebanon who argued that for them, research is less useful and more time-consuming (Sukarieh and Tannock, 2013). For this reason, each session took less than an hour. The second issue faced by camp residents in Lebanon is the necessity to attend every session, as community-based participatory research 'is more torturous because you feel responsible for the researchers who come to teach you and you can't leave them in the middle' (Sukarieh and Tannock, 2013, p. 203). For this reason, the sessions were short, and while the design was sequential, every session allowed for participant turnover.

In 2019, while designing the co-development group, I collaborated with Amel Association and MSF to ensure its suitability. Based on our discussions, three adaptations were made. First, the sessions were limited to a maximum of one hour. Second, as aforementioned, due to social tensions between staff and service users, it was decided not to bring them together in the sessions to avoid conflicts. Lastly, participant turnover was taken into account, as it was not feasible for the same individuals to attend every session due to the chaotic lives caused by structural violence. As a result, the initial session dedicated to cocreating participation rules and ethical frameworks was replaced with a sharing circle. In this circle, five minutes were allocated for a boundary-setting exercise, enabling the establishment of group interaction rules that participants could choose to sign up to (Beauchamp and Childress, 2001; Manzo and Brightbill, 2007). For instance, participants were asked what 'ethics' means to them and were encouraged to share an ethical principle that was important to them and that they would like to be followed today (the questions that were asked included *'What are your ethics?', 'What do you understand by 'ethics'?'* and '*What are your expectations of me at present, during and after this research?*'). This allowed consent to be shaped in a common-sense, verbal, locally meaningful way. Then, at the end of session, the participants reflected on their experiences of the co-development group process, affirming positives and suggesting ways that the method could be improved. Participants had the option to share their contact details on a password-protected Excel sheet to stay informed about project updates.

**Figure 3-7 The space of co-development group data generation**

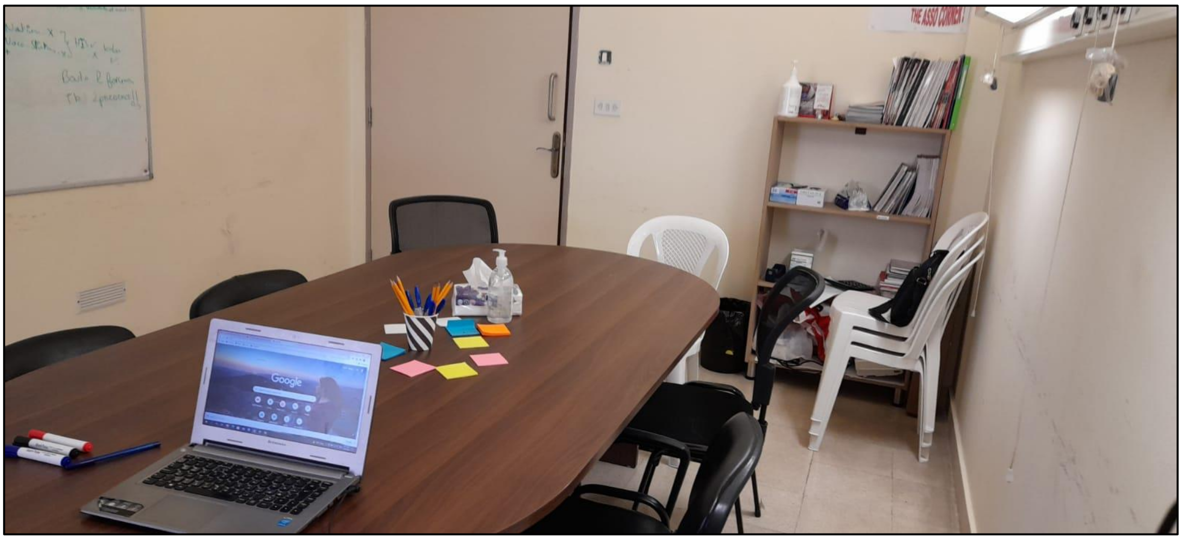


Figure 3-8  The space of co-development group data generation

### Co-development group Session One

The first session focused on ‘data generation’, running on Monday morning with staff and Tuesday afternoon with parents while their children were being treated for thalassemia. For a brief overview of the breakdown of the times and activities, see Table **4** Co-development group Session One. Belal began by asking open-ended questions (see appendix five), and the answers were written or drawn onto Post-Its and added to the ‘commentary chart’, a flipchart piece of paper that was used to record comments (see Figure 3-9). Staff had one commentary chart and service users had another. Similarly to the RESTORE project, the commentary charts served two primary purposes (Lionis *et al.*, 2016, p. 4). First, they facilitated discussion and collaborative learning around commonalities and differences in perspectives and experience. Second, after participants ‘signed up’ to the commentary charts they created, the charts travelled to different sessions and served as: i) a memory aid for previous attendees; ii) a starting point for explanation for new attendees; and iii) a crystallisation of the data. This increased multivocality at the beginning of the next session, particularly as Belal often asked, ‘Does this make sense?’ and ‘Do you think anything should be added or removed?’ at the beginning and end of each session (Tracy, 2010). Belal adapted the mode of delivery depending on the participants in the space and their preferences and needs. This responsiveness and flexibility will be detailed in the forthcoming chapter.

Finally, at the end of every session, he explained that if people would like to, they could attend the following session as well as opting into project updates. Project updates included being informed about a participant consultation session that ran in Spring of 2022 and hearing about outputs from the research. This was also a means of communication for further dialogue, for instance if participants wanted to add anything else to their answers, or perhaps remove an answer.

Table 4 Co-development group Session One

| Timing | Objective and Key Questions: Session One |
|---|---|
| Intro: 15 mins | Commentary Charts Creation: Ideas on Post its |
| First Session: 30 minutes | Topics include |
| Conclusion: 15mins | • How do staff and service users make sense of the current aid organisation’s operations, effectiveness and cultural competency<br>• What issues do participants identify as limiting effective operations<br>• Prioritisation during COVID-19 |

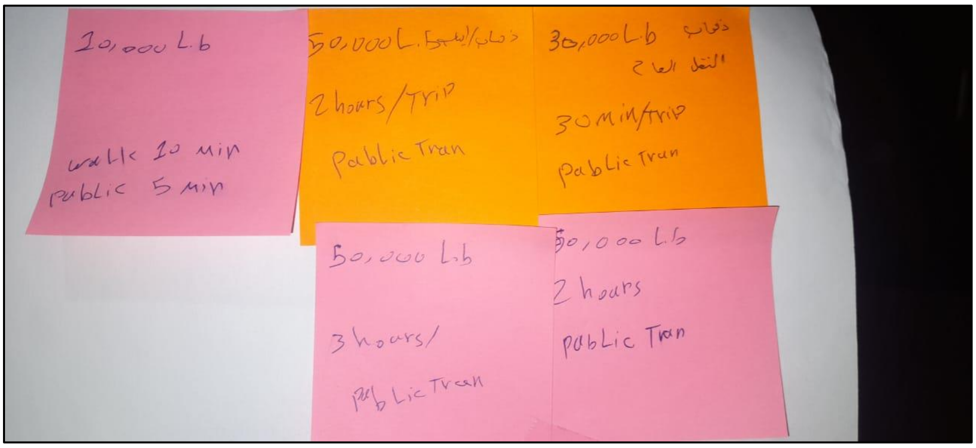


**Figure 3-9 Photo from first service user co-development group**
Time and cost to reach the hospital

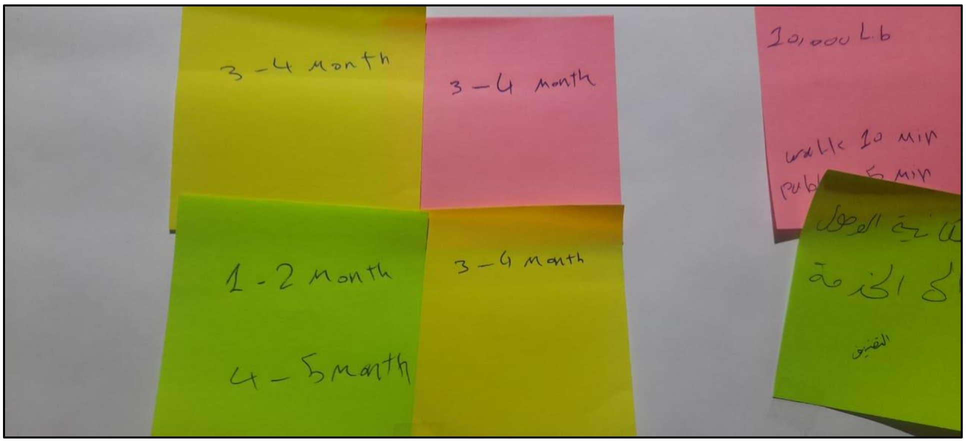


**Figure 3-10 Photo from first service user co-development group**
How often parents need to bring their children to the service

## Co-development group Session Two

Table 5 Co-development group Session Two

| Timing | Objective and Key Questions: Session Two |
|---|---|
| Intro: 15 mins | Commentary Charts: Categorise identified topics into categories. [ideas into themes]<br>This will begin the data analysis process |
| Second Round: 30 minutes | Consider approaches like ‘positive’/‘negative’; or thematically: ‘journeys’; ‘experiences’; ‘pressures’; ‘support’; ‘services that have stopped’; ‘interactions’ |
| Conclusion: 15mins | |

The second co-development group was completed one week later; see Table **5** Co-development group Session Two for an overview. Belal began the session by collaboratively discussing consent and setting boundaries, participation rules that everyone signed up to. He then reviewed what was discussed in the former session. Then he began the facilitation process for the second co-development group. This required Belal to work with participants to see if they would like anything to be added to or removed from the initial generated data. Next, Belal facilitated participants in generating categories working from the commentary chart (see Figure 3-11 and Figure 3-12). To do this, he asked participants to think about how they could make sense from the data. For instance, they could categorise the key topics that had arisen the week prior into binaries like ‘positive’ and ‘negative’; or perhaps thematically: ‘journeys’; ‘experiences’; ‘pressures’; ‘support’; ‘services that have stopped’; ‘interactions’. After proposing a few ideas, Belal handed over the categorising to the participants and facilitated the dialogue. This aligns with a participatory research approach, as it began the data analysis process. Belal ended each session by asking all the participants if they agreed with how the commentary chart was now organised into categories, asking if they felt all views were accurately represented and if there was anyone who might disagree with the proposed chart.

**Figure 3-11 Photo from second staff co-development group**
Categorisation

**Figure 3-12 Photo from second service user co-development group**
Categorisation

## Co-development group Session Three

Table 6 Co-development group Session Three

| Timing | Objective and Key Questions: Session Three |
|---|---|
| Intro: 15 mins | Commentary Charts \| Prioritisation |
| Second Round: 30 minutes | Categories are ranked in order of importance<br>• Deciding on criteria for prioritisation<br>• Voting and Ranking |
| Conclusion: 15mins | |

In the third co-development group, Belal opened the session by explaining the project and its approach and objectives, similar to the previous session (see Table **6** Co-development group Session Three). He presented the co-created categories on a flipchart (see Figure 3-13 and Figure 3-14), inviting participant input for potential additions or removals. Belal then facilitated the voting process, a democratic prioritization approach where participants voted for the category most relevant to their experiences in humanitarian healthcare. This approach required participants to collaboratively listen, learn and ask questions of each other and the data, which continued the data generation and analysis process (O'Reilly-de Brún *et al.*, 2018). Participants discussed the category meanings and voting criteria, each casting a single vote by marking their chosen post-It with a pen. Collaboratively, the participants tallied the votes and ranked the categories by importance. Belal prompted participants to reflect on their perceptions of the process, if anything surprised them, and if they were content with the result. Categories and results were shared across the participant groups for discussion and reflection. At the end of the session, Belal asked questions such as ‘Let me know your experience of today in one word’ and ‘What would you like to do differently next time?’. Asking these questions provided insight into the participants’ preferences, further shifting the methodological approach to suit low-resource settings.

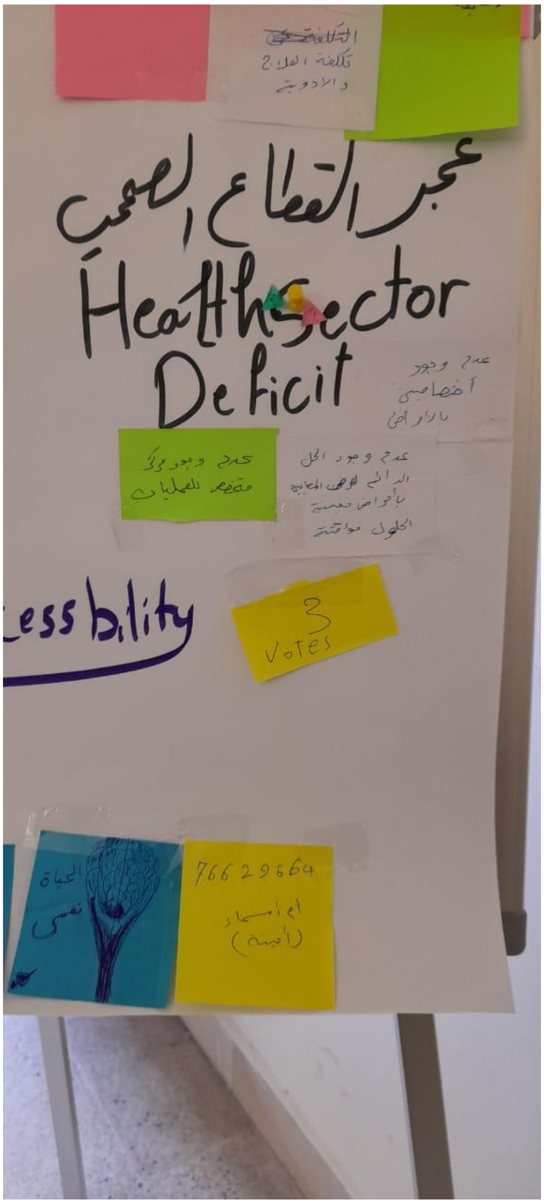


**Figure 3-13 Photo from third staff co-development group**
Image showing number of votes received

**Figure 3-14 Photo from third staff co-development group**
Image showing number of votes received

## Co-development group Session Four

Table 7 Co-development group Session Four

| Timing | Objective and Key Questions: Session Four |
|---|---|
| Intro: 15 mins | Focus on ‘Next Steps’<br>What would be a solution to the identified issues moving forward?<br>What do you think should/can be done? |

| | |
|---|---|
| | Objective: Developing actionable solutions to identified problems |
| Fourth Round: 30 minutes | |
| Conclusion: 15 mins | |

The final co-development group placed an emphasis on actions that could be co-created for positive change (McNiff and Whitehead, 2009; Bradbury, 2015). Belal began by welcoming the participants, offering refreshments, providing an overview of the research progress, and facilitating the co-construction of the ethical framework. He asked participants if there was anything they would like to add to the commentary chart, i.e., did they think that all perspectives were represented and was there anything they disagreed with. Then, to begin the final Co-development group session, Belal led the discussion on ‘next steps’. Taking the chart as a starting point, he asked what tangible steps, if any, could be taken by the participants in the room today, given the resources at hand. What could more equitable healthcare look like in this service, and what actions would need to be taken to get there? (See Figure 3-15 and Figure 3-16.) The participants worked in the final co-development group to discuss shared experiences through the dialogue process. Belal concluded this session, like every other, by suggesting that participants could leave their contact numbers with him so he could inform them about project developments or consult them on the analysis in Spring 2021. Actions in the co-development groups and the consequences of these were reflected on in Belal’s audio diary.

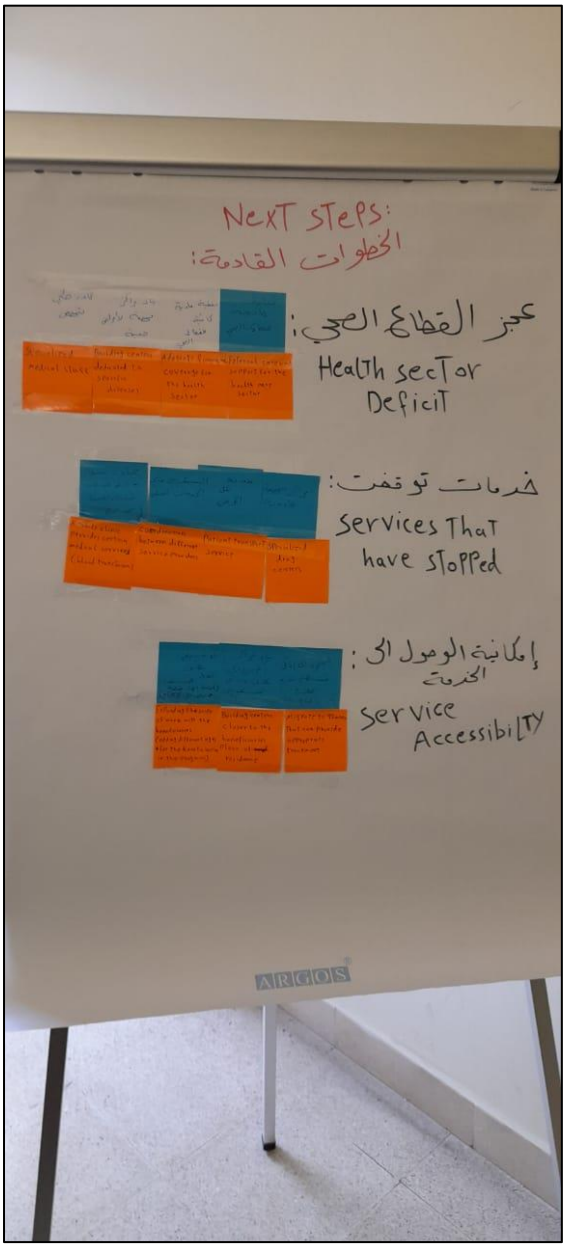


**Figure 3-15 Photo from fourth staff service user co-development group**
Actionable solutions proposed

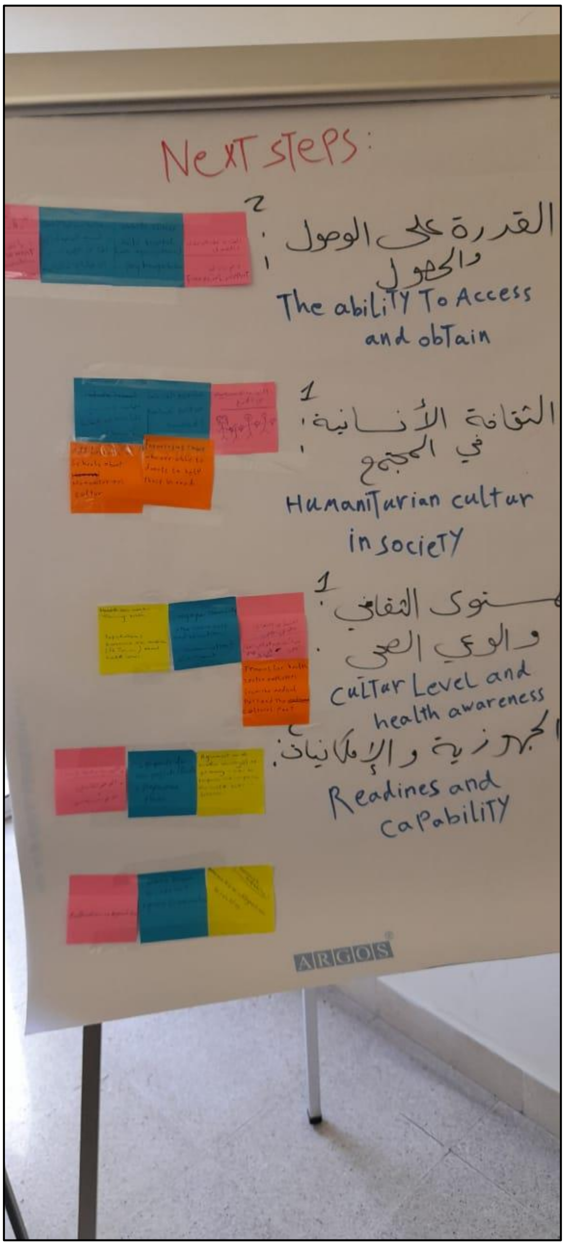


**Figure 3-16 Photo from fourth staff co-development group**
Actionable solutions proposed

## Analysing Aid Assemblages

> Analysis that centres the voices and knowledges of communities, embedding a decolonial lens and ethics of care that value people more than we value data
> (Singh *et al.*, 2021)

The theoretical basis for my analysis reflects the concepts I unpacked in the theoretical framework in this study. Specifically, I take a critical perspective to the international structures that govern the biopolitical and biosocial forces shaping the lives of people who are subject to the asylum system (Fassin, 2007;

Farmer, 2001). I interpret these structures of aid as an assemblage. Key to this is relationality and power - how people are inherently connected, caught in a power struggle. I considered how this was co-created through everyday interactions (Deleuze and Guattari, 1988).

The theoretical approach that influences my analytical approach to this work primarily stems from a social constructivist and critical theoretical paradigm, but I also think with post-structural and post-modern theories. I think with theories from multiple paradigms, across disciplines, as a way to borrow and reconfigure concepts, invent approaches, and create new assemblages that demonstrate a range of analytic practices of thought, creativity and intervention (Jackson and Mazzei, 2011, p. 717). I understand that what we ask will inevitably guide what we find, and given the theoretical framework which guided my choice of research approach - participatory dialogic methods - the analytical approach will stem from a shared paradigm.

I thought critically across disciplines from sociology, public health and education to enable the generation and application of knowledge to new situations. I evaluated multiple options, perceiving issues from different viewpoints, it was this breath of tools that enabled this interdisciplinary research analytical approach (Thonney and Montgomery, 2019). I took the ontological orientations that limit this research seriously, and considered the epistemological orientations that grounded and limited me. I did this to think past research solely as a method. I tried to consider ‘what else’ shaped the space. I questioned what counts as reality, what counts as knowledge, and how these are both produced in the process of enquiry (St. Pierre and Jackson, 2014, p. 720).

This thesis details power structures in what is known as ‘aid land’. Castells (2016) had a significant influence on how I interpreted the data during the analytical process, specifically in Chapter Five, as his work enabled me to evidence how power is the key to understanding social structure (Castells, 2016). I conducted an analysis of the relationality of power, the assemblages of aid, and how this shaped social life, norms, and institutions in one Médecins Sans Frontières-run thalassemia clinic, in the name of humanitarianism, promoting the rhetoric of modernity and development. Bhambra (2014) argues that structures governing Western interventions are constructed with inequalities, what they term the colonial matrix of power.

Castells (2016) provides a guide to researching on power, which I followed in this analytical process. He calls for a specific configuration of players who outline their interests and values (staff, service users and headquarters) to engage in power-making and counter-power strategies to connect the power in their practice. For Castells (2016), communication is pivotal in the power-making process as it constructs meaning to further interests and values. The process of decision-making through the multiple crises in Lebanon, and how this was communicated, serves as a key finding throughout this thesis' findings chapters. Through investigating who does what and how, when and why they do it enabled me to offer theoretical findings relating to power in international humanitarian healthcare, or 'aid land'. Perhaps this small contribution to the possibility of the geopolitics of knowledge production in aid, which reveals power structures, can enable a transformation from domination to liberation (Castells, 2016, p. 15).

In Chapter Six, thinking with (Butler, 2004) facilitated my conceptualisation of aid land as a space where all lives are precarious. Her critical work supported the thematic development of precarity. Moreover, I turned to Manuel Castells, who unpacks the role of communication and temporality (2016), and other scholars I encountered towards the end of the analytical process whose work I believe could inform great insights into the power dynamics and cultural collisions of aid, as I argue in the concluding chapter of this thesis (Zerubavel, 1985).

## Thinking with Critical Perspectives

In this research I framed and saw spaces of aid through a postcolonial lens and I considered how the social dynamics of power relations formed knowledge production. I strived to incorporate a pluriversal perspective in this thesis, heeding guidance from Said (1985), who demonstrated that producing a universality removes the other from the production and analysis of the 'world'. Through working with Belal, national staff, and service users and international staff in data generation and analysis consultations, I strived to follow locally relevant epistemologies. Through embracing theories of de- and postcolonialism, this research challenges the Orientalist harm of depicting people as passive, a harm which is perpetuated by the aid sector, as organisations can depict ‘beneficiaries’ as passive aid recipients (Bhambra, 2014). I discussed the intricacies of this in Chapter Two. The effects of colonialism are ubiquitous; they fade in and out in our everyday realities and practice. In this research I considered postcolonial encounters in both aid and the academy as a way to understand colonial legacies and how it shapes the hegemonic power in spaces of aid (Steinmetz, 2014).

Said (1985) argues that our contemporary systems are understood by a singular complex coherent unity, summarised as one human history observed from a Western vantage point (Said, 1985, p. 10). He urges the reader to consider who is written out of these spaces, who the people without history are. Following this argument, I strived to resist a reductive and functionalist analytical approach in the analysis. During analysis consultations, which I will discuss shortly, I considered the counter-knowledge that was offered to me - different ways of seeing. My approach to analysis stemmed from my understanding, my 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. I thought with political, methodological, cultural, material and social forces that shaped the spaces in my commitment to collectively dismantle the unintended harms within the humanitarian systems (Said, 1985, p. 15).

One of the first questions a fellow PhD researcher asked me was what the effect of the data was. This immediately aided me in making sense of it; why did I feel guilt reading one set of transcripts and validation when reading another? I incorporated feelings evoked during the process of enquiry into my analysis, for instance if I felt a sense of surprise, sadness, hope or disappointment as I read through transcripts and archival documents I trusted this intuition as a starting point for making sense of the data (Hess *et al.*, 2022). I align with Jessica Ringrose & Emma Renfold, who illustrate that analysis is ‘always already entangled with complex affective, ethical and political relationalities that circulate in, through, and outside empirical research’ (Ringrose and Renold, 2014).

I foreground relationships in this research as it was crucial for me to humanise my research findings. This process aligns with decolonial and feminist methodologies, seeing the faces of the people who led the dialogue I was analysing. I worked with Belal and research participants to collectively unpack the implied assumptions about dominant discourses that were embedded in the co-development groups. I collectively drafted research questions with Amel Association in 2019, generated data with Belal, interpreted results with the families of children being treated for thalassemia, and disseminated findings with civil society groups in Arabic (Kia-Keating and Juang, 2022). We thought with theories of postcolonialism as Belal and I enquired into how they made sense of the world, the 'aidland' they inhabited (Bhambra, 2014). Moreover, I worked with a local artist to create a video which advocates for sustainable thalassemia care. This was suggested by the families being treated at the thalassemia clinic. I did this to conduct research action towards social change, inspired in my analysis by theorists such as Freire (2005), as I sought to create benefit to improve the lives of people living with thalassemia in Lebanon.

**Figure 3-17 Illustration from the short video advocating for better thalassemia care**

## Thinking with Deconstruction

Derrida posits deconstruction as an event that is always already happening. I thought with what was deconstructed, and why, in the context of the deconstruction of a healthcare service; Lebanese politics; the healthcare system; and the deconstruction of categories. This allowed me to use and trouble categories. Thinking with and finding deconstruction was not necessarily the deconstruction of a whole institution or system, but the deconstruction of structures that were too rigid or others that were situated or perceived as an obstacle to progress (Jackson and Mazzei, 2011, p. 25). I read with the concept of deconstruction as a way to open meaning, rather than to close off other meanings and filter to succinct findings. Lebanon was advancing through a time of rapid reform caused by multiple shocks; institutions and societies as a whole were simultaneously creating and deconstructing, and these tools for thinking allowed me to capture this process and create new concepts.

A central concept to thinking with deconstruction as a theory is looking for 'the trace', a strategy that can be used to follow the deconstructive process (Jackson and Mazzei, 2011; Jackson, p. 21). Jackson and Mazzei (2011) unpack Derrida (1978) concept of the trace. Traces were accepted and troubled. Traces were found when there was an imprinted meaning, when a signifier was disrupted, when people's interpretations were destabilised. I searched for signs of this in the form of deferred meanings and explanations, seeing how they were disrupting understanding and creating deconstruction in the narratives they were creating. This approach embraced the understanding that knowledge is partial and contingent; while interpreting transcripts I sought the understanding, answers and information behind what was being said and searched for the trace: what is missing (Jackson and Mazzei, 2011, p. 23). The events contributing to deconstruction in the Lebanese humanitarian system needed to be acknowledged as purposeful in destabilising, as they produced irruptions and allowed for what was formerly impossible.

I followed the trace to explore what was produced after these deconstructions, considering both the intended and unintended consequences. Thinking with deconstruction required me to question the data that surprised me or exceeded expectations. I searched for instances of tension between memory, faithfulness, preservation, and breaks, where something new emerged and diversification occurred. These were moments when narratives and understandings became unsettled, destabilized, and redefined. Reading with these thoughts allowed the event of deconstruction to become visible. I read for the absence of responses and contemplated the implications of this absence and how it could disrupt rigid structures that perpetuate sameness. The production of difference, which resists fixed and stable categories, disrupts and deconstructs hegemony. Identifying and exposing these traces is necessary to unsettle the structural violence experienced by displaced populations.

I searched for snags to illustrate the limitations of our knowledge, identifying imperfections and loose ends in the data. These snags, where researchers and participants stumble and encounter uncertainties, reveal the complexity of understanding (Jackson and Mazzei, 2011, p. 31). Instead of seeking easy meaning, I considered the loose ends and deviations, refraining from processes like triangulation and validation. By attending to the inconsistencies and uncertainties found in the generated data, I acknowledged the non-uniformity of individuals. This approach allowed me to incorporate deviance. According to (Jackson and Mazzei, 2011), researchers can become so focused on participants' statements and predetermined topics (such as race and gender) that they overlook other voices and loose ends, failing to acknowledge what is unsaid or misaligned. This approach reshaped what was considered as data, enabling me to see what was unasked and overlooked, destabilizing norms. These aspects of dialogue, what remains after the data has been analysed, are essential.

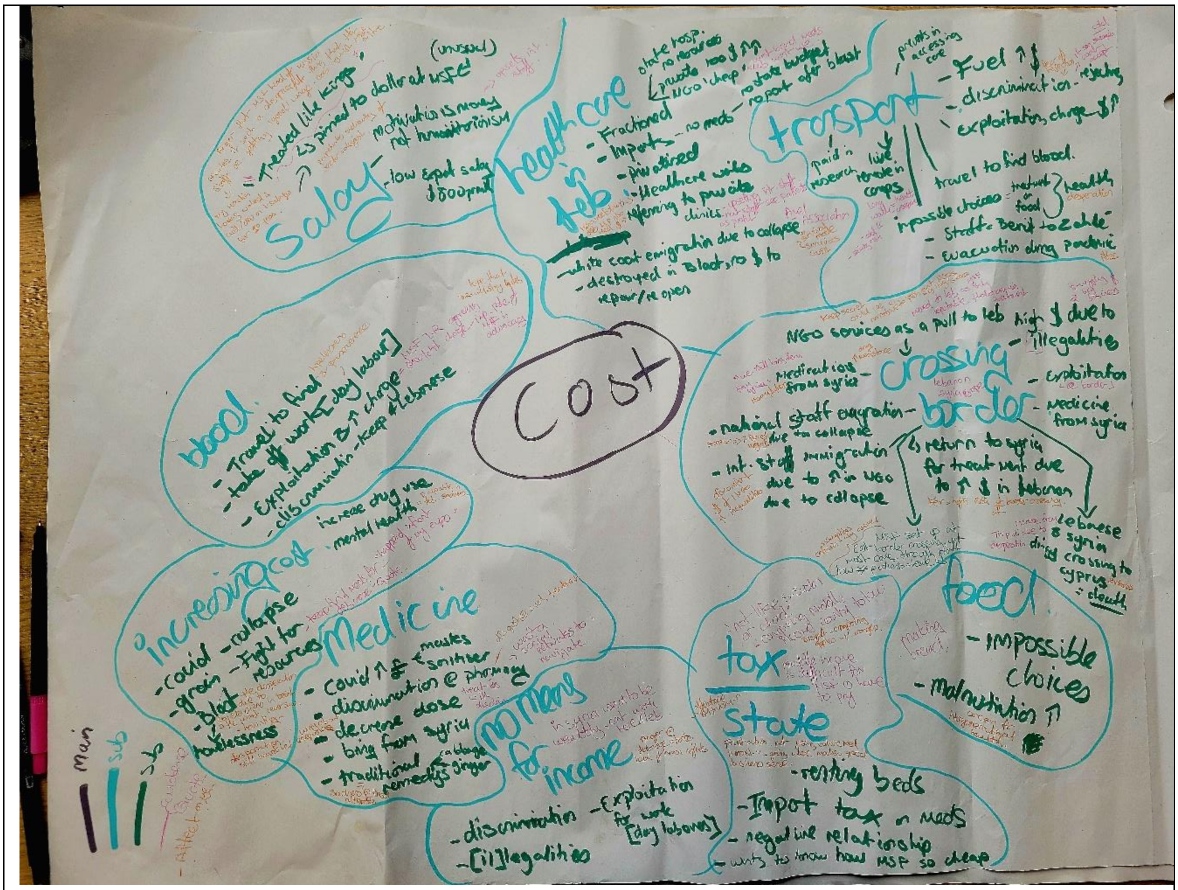


Figure 3-18 Thematic Analysis Process August 23rd 2022

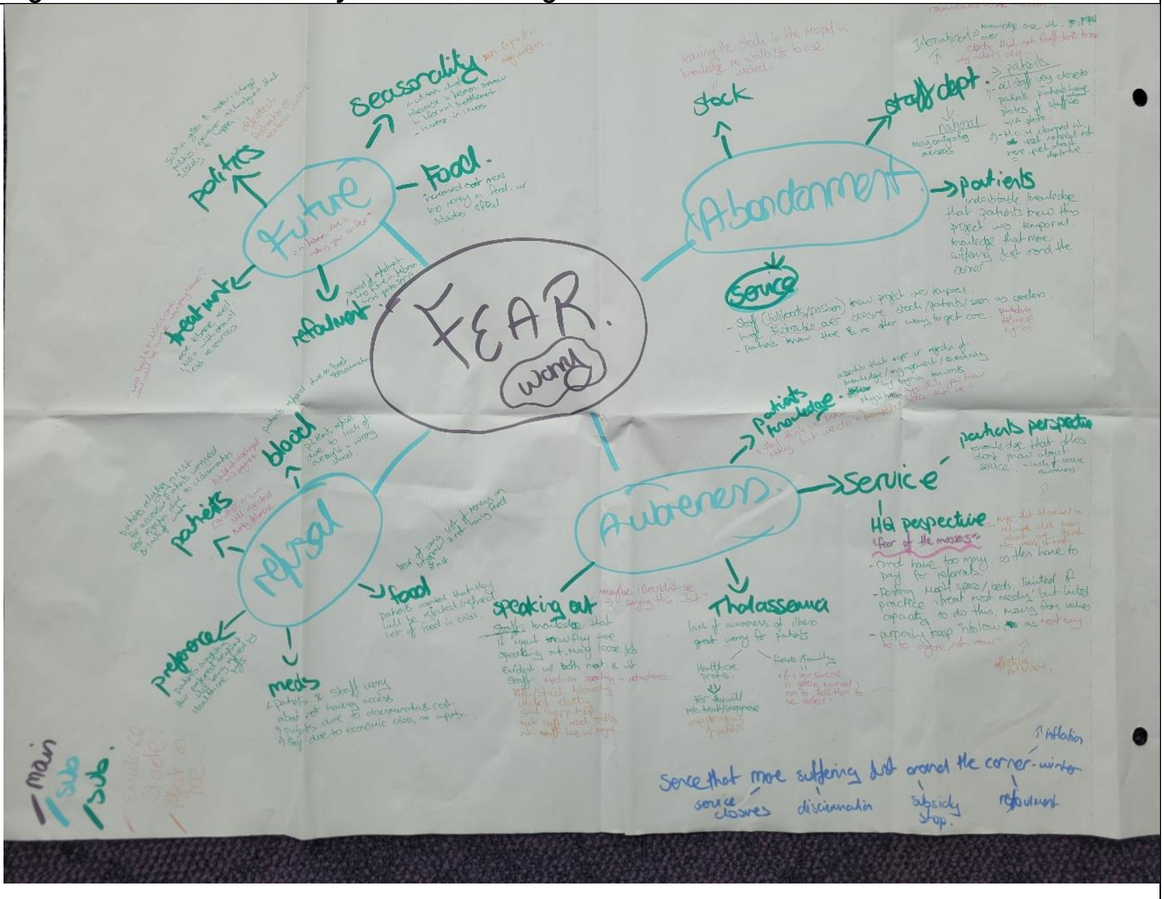


Figure 3-19 Thematic Analysis Process August 23rd 2022

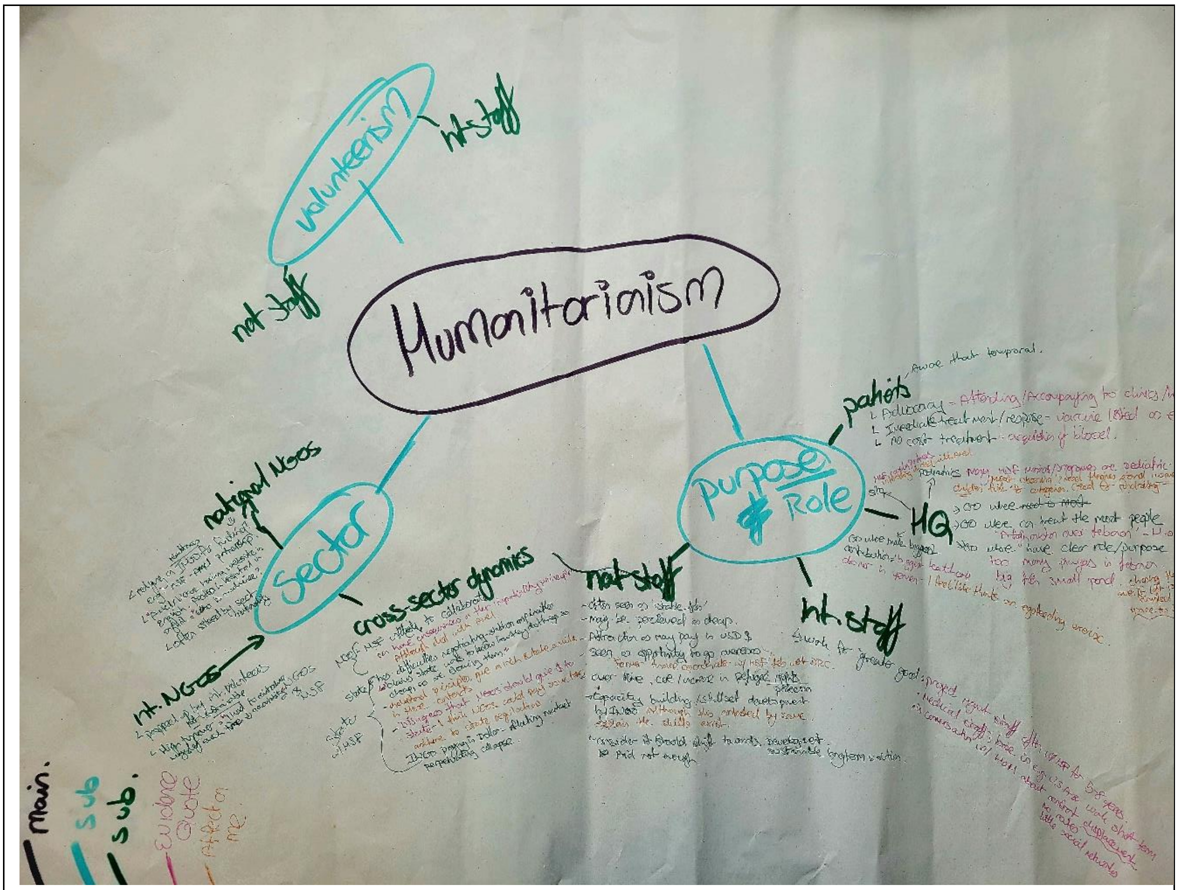


Figure 3-20 Thematic Analysis Process August 23rd 2022

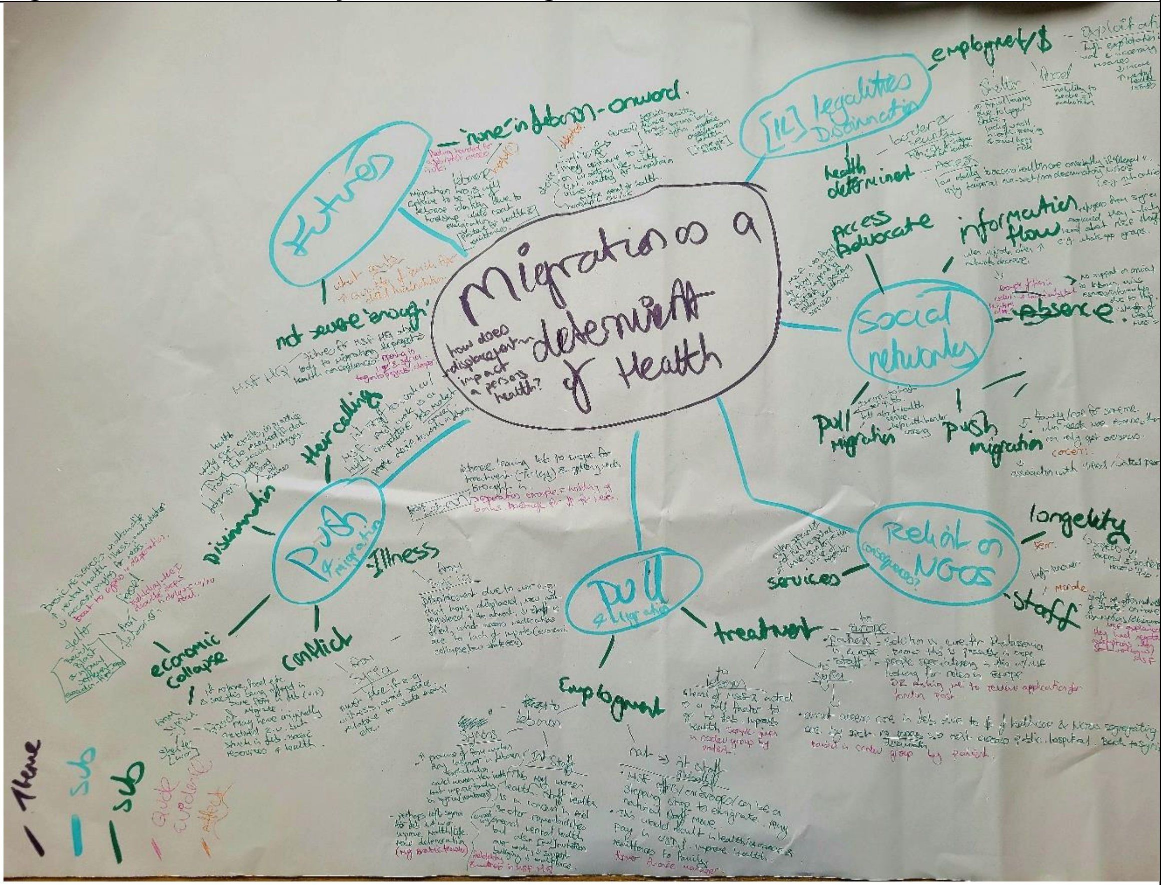


Figure 3-21 Thematic Analysis Process August 23rd 2022

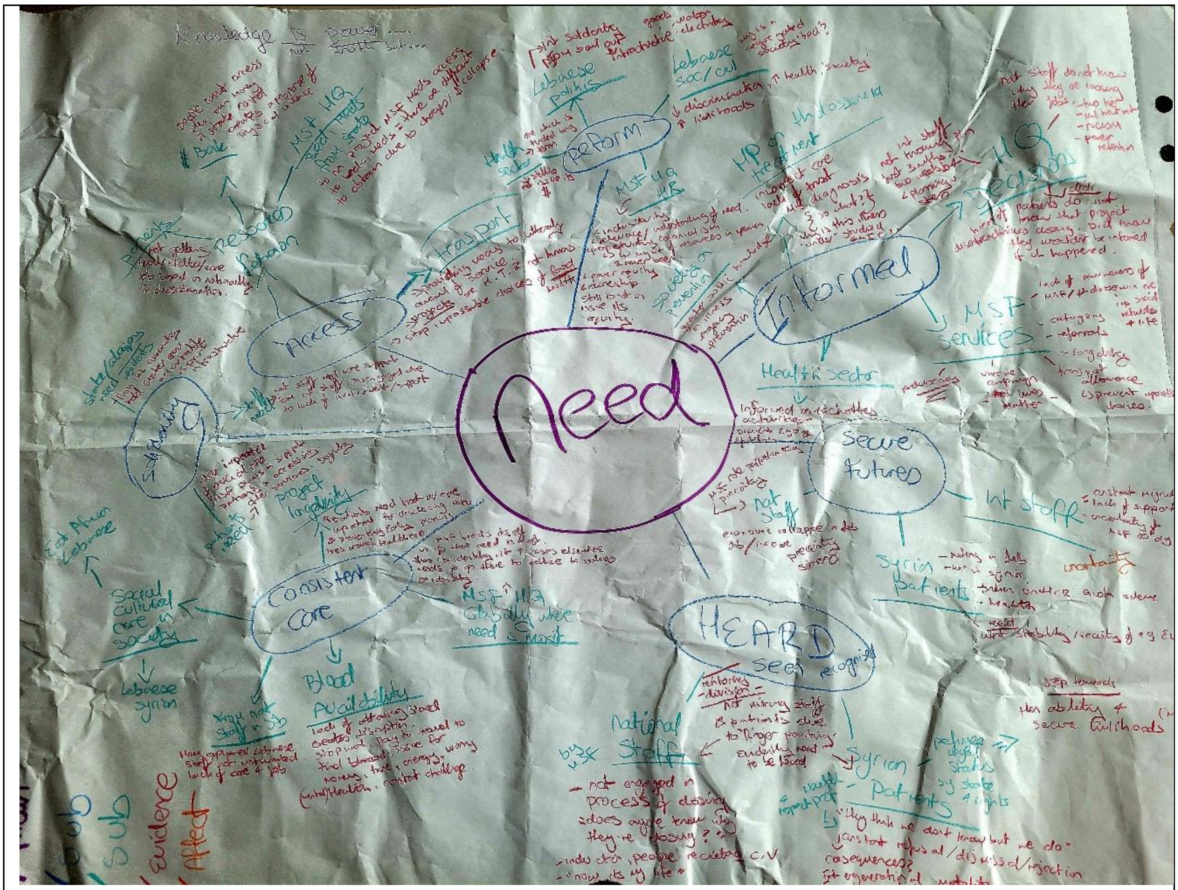


Figure 3-22 Thematic Analysis Process August 23rd 2022

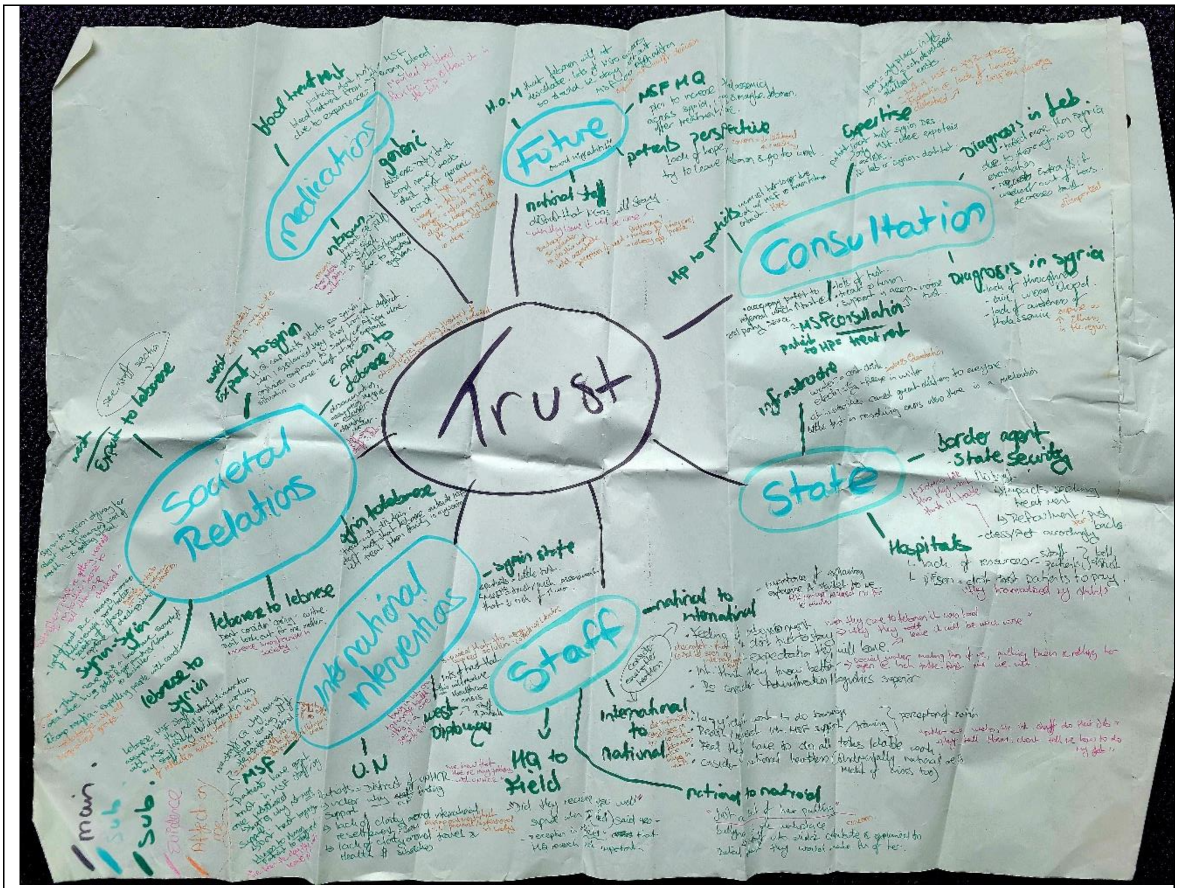
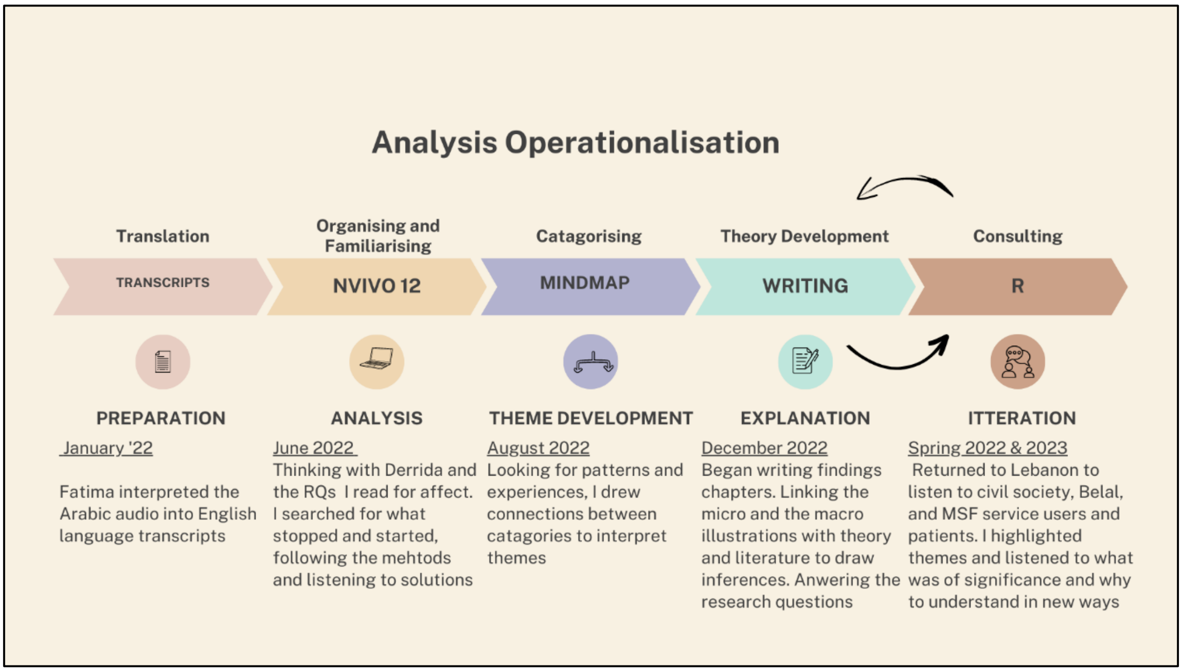


Figure 3-23 Thematic Analysis Process August 23rd 2022

## Analytical Operationalisation

> ‘It gets written down and recorded on a different paper. Where does it go? How is this research analysed? No one knows’
>
> (Sukarieh and Tannock, 2013, p. 503)



Analysis Operationalisation

Translation
TRANSCRIPTS
PREPARATION
January '22
Fatima interpreted the Arabic audio into English language transcripts

Organising and Familiarising
NVIVO 12
ANALYSIS
June 2022
Thinking with Derrida and the RQs I read for affect. I searched for what stopped and started, following the mehtods and listening to solutions

Catagorising
MINDMAP
THEME DEVELOPMENT
August 2022
Looking for patterns and experiences, I drew connections between catagories to interpret themes

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

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

**Figure 3-24 Analysis Operationalisation Chart**

In Figure 3-24 Analysis Operationalisation Chart, I detail the operationalisation of the analytical process. Belal facilitated the co-development group process through November 2021. I recruited an interpreter, Fatima, in November 2021. I conducted training with her about the project, signed a memorandum of understanding for data protection, and sent the files to her via the University of Glasgow file transfer service. When I received these files from Fatima, I uploaded these to NVIVO 12 software as a tool to organise, and I familiarised myself with the data, reading transcripts, following the methodological approach chronologically, and seeking initial descriptive responses to the research questions. Through discussions with supervisors and research colleagues at the University of Glasgow in Autumn and Winter of 2022, I began to link the data with theory and former empirical studies, interpreting patterns from the data. Illustrations of this include Figure 3-25 Mapping my Narrative, November 2022 and Figure 3-18 Thematic Analysis Process August 23rd 2022, as well as the preceding mind maps. I found St. Pierre and Jackson (2014) particularly useful, following their guidance to ask, ‘What does the data do?’ and ‘What is the effect of the data?’ rather than ‘What does the data mean?’ (St. Pierre and Jackson, 2014). I believe that analysis is about adding value to the transcripts, thinking with theory, returning to relevant theory and literature, and adding to key concepts that arise rather than storytelling chronologically.

I agree with Madden (2017) in that the data that was generated throughout this research project does not itself present hard facts, nor is it meaningless data; rather, it is material from which I must make meaning through interpreting with theory and intellect. I had to balance fact and hypothesis, separating what I saw, read and heard from what I interpreted it to mean, being aware of what effect it had on me, and why this may be – for instance, what assumptions was I making. The transcripts, audio recordings and photographs capture a snapshot of some elements and the forces they have had during the conduction of the co-development groups. These artefacts themselves have inherent meaning, yet I don't consider them to be raw data. Belal made decisions on what to ask, what to respond to and probe further, what to write, what to photograph and what artefacts to send for analysis. A level of interpretation was made at both the stage of generation and translation, but it was through consultation and transparency that the research data crystalised (Madden, 2017, p. 141).

I conducted selective coding using NVIVO 12, identifying what I interpreted to be the key themes arising from the daily observation and co-development group sessions. I coded each quote into what I interpreted as meaningful thematically, what I deemed it to be an example of, what it represents and what it indicates. My understanding of the context evolved over time. I renamed, merged, deleted, and defined codes. While NVIVo12 was helpful as a tool for organising and storing audio, video, and photos, the most significant meaning-making occurred through dialogue with aid worker colleagues and friends, the Lebanese research team, and on my visits to Lebanon for presentations and analysis consultations.

I returned to Lebanon for feedback and analysis consultations in Spring of 2022 and 2023. In Spring of 2022, I returned to Lebanon to run three separate analysis consultations with Belal, staff and service users where I presented interpreted themes and listened to feedback. Participants would point out a description or interpretation which aligned with their perspective. I returned to Lebanon four months prior to submission. I ran five feedback sessions, during which I shared the summarised drafts of each chapter with civil society organisations and activists. I did this to centre affected populations' points of view at each stage of the research. In these dialogues, people interpreted the examples of stories which were conveyed in the co-development groups, and explained what they believed to be significant. During my time in Lebanon, I encountered the same interpretations of the research project and expressions of frustration, concern, and hope, which crystalised what I found during this research process. When the research participants believed it was otherwise, I took their lead to prioritise using the participants' voices.

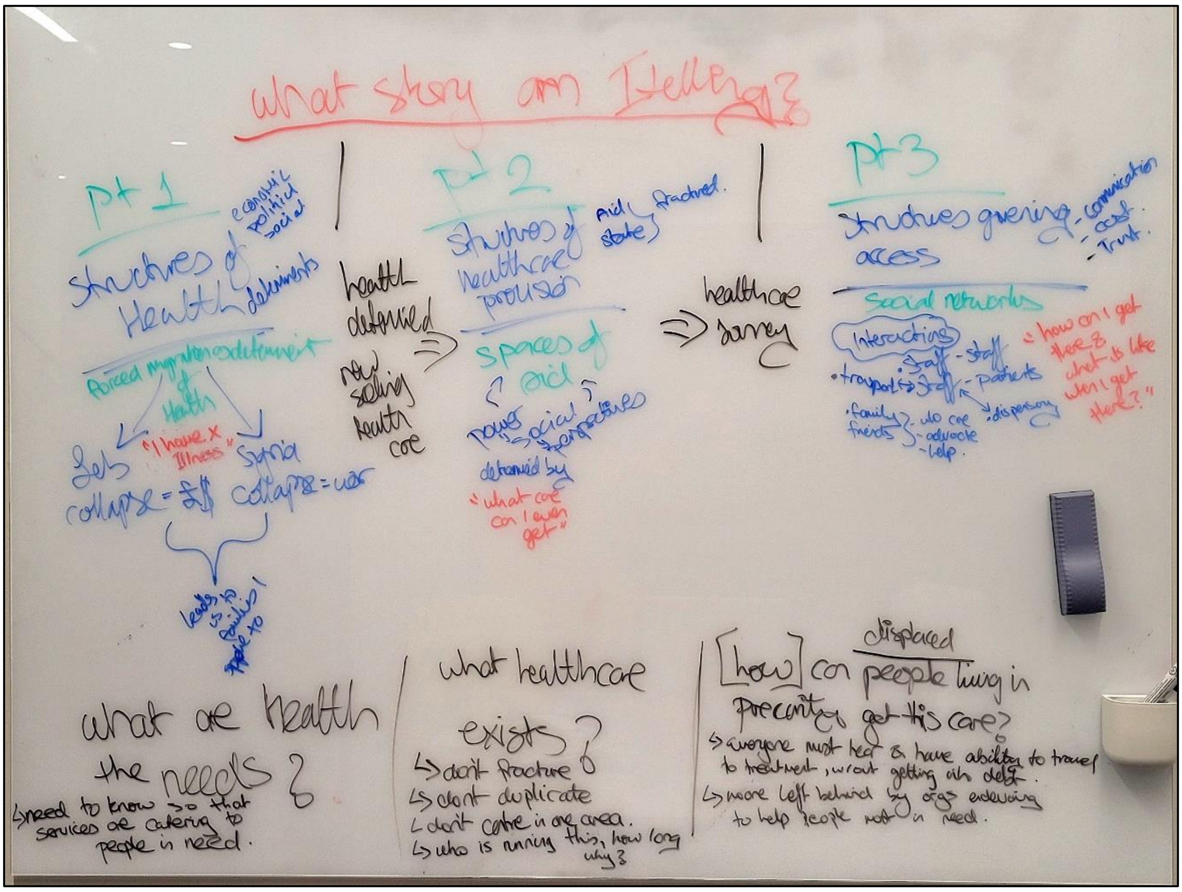


Figure 3-25 Mapping my Narrative, November 2022

In my analysis, I took guidance from Flyvbjerg (2001) in pursuing phronetic social science. When analysing the data, it was not my intention to present a predictive theory about experiences of providing and receiving thalassemia care in a humanitarian context. Rather, through this research I considered the challenges, consequences and possibilities for change in spaces of aid as a means to contribute to a social and political praxis (Flyvbjerg, 2001, p. 4).

For Chapter Five, I chose a case study design, which shaped my analytical approach. The transitions experienced by Lebanon and the changes in services resulting from multiple crises necessitated capturing the decisions made and the ensuing consequences through this research. During the redesign phase, in consultation with my PhD supervisors, it became evident that adopting a case study approach was a sensible decision. I approached the data concerning the lives of individuals utilizing the thalassemia service as a case study, tracing Lebanon's crises. This approach allowed me to present findings on the extreme hardships faced by the population and their strategies for managing daily life. In Chapter Five, I emphasise the decision-making processes, revealing whose knowledge was accessed, whose values and projects were represented, and whose were not, to uncover the relation of power in this space.

As acknowledged by (Yin, 2009), case study analysis is one of the least defined strategies in social science research due to the lack of well-defined methodologies. After coding the data, I compiled the data corresponding to each ‘in-case’ group chronologically, tracing the series of crises and their consequences. The primary focus of this study was on the staff, framed within the context of postcolonial theories in the aid sector. This provided insights into how power hierarchies shaped inequitable decision-making within the sector, and why decisions were made from European headquarters then channelled to the implementation level. Another key theoretical consideration shaping the lives of patients related to chronic illness management and how illnesses were managed during migration, as well as the creation of trust within care. This strategy enabled me to direct attention to specific data and exclude other data, organizing the case study and tracing the decisions chronologically.

This analysis strived to understand why humanitarian organisations withdraw when needs still exist and how patients and their carers manage their chronic illnesses in response to this. I explored the relational power between patients, staff and headquarters, tracing what information and materials each group has access to, and ultimately what the relational power and resistance are in the series of crises that shocked Lebanon (Castells, 2016). Following (Yin, 2009) guidance, I sought to collate all evidence available during the thalassemia project’s closure. To consider rival interpretations, I analysed data with Belal and staff and service users, proposing different interpretations of the data and working with participants to make sense of the multiple experiences of providing and experiencing care in the shifting sands, and their perceptions of decisions made.

In Chapter Six, I conduct a thematic analysis. Green and Thorogood (2018, p. 253) list five approaches a qualitative researcher can take during their analysis. This research will adopt two of these in the following ways. First, I worked on the analysis and interpretation to generate and develop ideas regarding the utilization of participatory methods in co-creating culturally and socially informed humanitarian healthcare services. You can find the process of thematic analysis in Figure 3-18 to Figure 3-23. I aimed to explore and explain the impact of the multiple shocks experienced in Lebanon from 2018 to 2022 on the provision of humanitarian healthcare and the patients under their care. This inductive analytical approach involved deriving themes and explanations from a thorough examination of the research data generated, which I deemed appropriate for the study (Green and Thorogood, 2018) as there have been very few participatory studies (eight found) completed in spaces of aid in low and middle income countries (Ormel *et al.*, 2020b). Through the exploration of the current humanitarian context in Lebanon in this exploratory study, this analysis aimed to generate new ideas relating to humanitarian healthcare provision during a pandemic in a low resource setting and test whether participatory methods can be a useful tool for identifying, prioritising and proposing solutions in a service.

My approach to thematic analysis was an interpretive approach to storytelling, an output that I actively created. I understand reflexive thematic analysis as a pattern of shared meaning, underpinned by a core concept, generated through co-development groups alongside interviews and diaries (Braun and Clarke, 2019, p. 593). While the contexts and experiences of each participant group are vastly different, I believe that participants expressed a shared meaning relating to the chronicle of crises in Lebanon (Braun and Clarke, 2019, p. 594). These themes are creative and interpretive stories I created with my Arabic teacher and Belal. We worked collaboratively and reflexively in analysis consultation sessions. We listened to the Arabic, thinking together to generate a shared understanding and to subsequently transfer this understanding from Syrian Arabic into Anglo-English.

## Linguistic Interpretation

> ‘by now, at least twenty researchers have given me voice. My voice was given in English, French, Arabic, Dutch, Swedish, and Spanish. But I haven’t heard it back and I will never do.’ (Sukarieh and Tannock, 2013, p. 500)

I used a fixed lexicon to establish the coding, developed in partnership with my research participants and translator, to ensure that each code is meaningful. These codes were in both Arabic and English, heeding advice from the co-development group and Syrian researcher, as some words cannot and do not need to be translated (Brooks, Ngwane and Runciman, 2019). I was guided by the reality that language is racialised, politicised and classified. Where possible, all efforts were made to ensure that the meanings were kept in the original source.

Listening to Arabic while reading in English was an interesting and helpful approach. It allowed me to focus on the tone and imagine the space rather than solely concentrating on the words. This separation of words from their conventional meaning offered a clearer understanding. For instance, if I perceived the tone as angry, joyful, or sad, it informed the analysis as much as the literal meaning of the spoken words. Inspired by (MacLure, 2013), I rejected the hierarchical logic of representation. Instead, I adopted an assemblage stance, as described by (Deleuze and Guattari, 2004). This meant that I did not work with only a transcript that was detached from the space and the individuals who spoke the words, as meaning is relational. I recognized the relationality between the material, physical world (the space of data collection) and the words that represented it (the transcript). I aimed to capture not only the uttered words but also the various modes of expression and the complete regimes of signs. I acknowledged that words alone cannot fully represent the entire world. Rather, I understood that the data could make themselves intelligible to us, revealing their meanings and nuances. It was not about treating the data as an indifferent mass waiting to be analysed within a coding system. Instead, I remained attentive to certain expressions or phrases that ‘jumped out’ and took the writing in unexpected directions (MacLure, 2013, p. 661).

This research was bilingual. I arranged for back translation via my Arabic teacher on sections of transcripts, meaning to translate the English into Arabic, and then cross-reference with the original source. All co-development groups and analysis consultation sessions were facilitated in both English and Levantine Arabic. All meetings were conducted in English, but I always offered a space where people could speak whatever language they were comfortable speaking in, and I could arrange an interpreter if people chose this.

## Limitations

Through my data analysis process I will acknowledge that there are further influences, both the known social and non-social, which cannot always be observed (Denzin, Lincoln and Smith, 2008). This approach supports the concept that my not having been in Lebanon for this PhD data collection does not make the data *less* valid as there are many unknowns, and that through critical reflection the process of data collection can be traced and analysed to create data in and of itself. This research approach aligns with critical realism, the belief that there is an independent reality, which exists independently of human beings and that is interpreted through perspectives shaped by culture and lived experiences (Gorski, 2013). Through working with a researcher trained for this specific research approach, who has more shared culture and lived experiences with the participants than I do, there may be less misinterpretation of meanings than if I had been working with an interpreter.

I will now present the findings that arose from this research methodology exploring the tensions of power in what is termed by critical humanitarian scholars as ‘aid land’ (Mosse, 2011). As I have argued in this thesis so far, our understanding of humanitarian needs and solutions is shaped by issue-led methodological practices that marginalise the patient-voice. The sector’s practices often focus on outcome rather than process and favour quantification due to the perceived timeliness of qualitative research. When qualitative evidence is generated, it is often with ‘key informants’, platforming the same voices of power on repeat rather than listening to alternative voices which may represent the area’s needs more accurately. In the next chapter, I will identify how this co-development group methodology offers a potential approach to uphold equity and dignity in humanitarian crises. I will discern the best practices and tools I found to be helpful as I examined how to strengthen participatory research processes in humanitarian healthcare. I will detail how participants understood, and then prioritised, what could and could not be achieved as they collectively identified solutions to improve health outcomes in humanitarian contexts (Kia-Keating and Juang, 2022).

# Chapter 4 Participatory Methodologies in Spaces of Aid

## How do we know what we know?

Beyond the designed and implemented methodology, this chapter explores the methodological findings and implications of implementing participatory research in aid land. This chapter answers Research Question One: ‘Can a co-development group be used to meaningfully engage staff and service users to collectively improve humanitarian healthcare in Lebanon?’ This chapter is dedicated to detailing what I found through implementing the methodology of this study. I begin to answer this research question by detailing the opportunities and limitations of implementing a digital design in a low-resource space of aid, and what I learned from working with Belal. I then proceed to detail the similarities and differences in the process of running the co-development groups with staff and service users, and the conclusions I reached through the process of navigating power and tensions. I conclude this chapter by reflecting on the limitations of issue-led research and reiterating the necessity for flexible research methodologies in spaces of aid.

What we know is shaped by how we come to know it. Embracing this, I took the methods of practice in knowledge generation in spaces of aid as my starting point for investigation as I asked, ‘How can humanitarian aid be otherwise?’ During my time as an assessment officer in northern Afghanistan, NGOs relied on three sources of evidence for project development: *key informant* interviews, focus group discussions with *community members*, and questionnaire data collected by enumerators from generalisable household surveys. Despite the constant influx of humanitarian aid organizations, populations remained both over-researched and under-resourced. In a bid to secure ‘external data validity’, organizations knocked on doors, asked questions, and took detailed notes to extrapolate their findings to ‘people in need’ nationwide to inform project assessment, monitoring, and evaluation purposes. I believe there is space, and equally a need, for transforming how knowledge about people’s health is understood in the humanitarian healthcare sector.

International politics and the humanitarian aid sector’s working norms sustain the demand for evaluation in humanitarian programming. Scholarly works, such as those by Forss, Lindkvist and McGillivray (2020), delve extensively into these intricacies of why and how quantified data is generated in the aid sector. Having unpacked these debates in my literature review, I concluded that perceptions of aid efficiency are ruled by the quantification of humanitarian data. Aligning with the work of (Ormel *et al.*, 2020a; Afifi *et al.*, 2020; Singh *et al.*, 2021), I aimed to develop alternative forms of practice that can be suited to low resource, conflict-affected settings. This meant re-evaluating how we understand people's health needs and embracing a collaborative, solutions-oriented approach to generating evidence. The findings presented in this chapter document the challenges and opportunities I encountered during this experimental process.

I explored questions of accountability, trust, value, and respect in humanitarian intervention, concerns shared by other scholars. In *Orientalism Reconsidered* (1985), Edward Said reflects on the lack of progress in decolonizing Orientalism and the unwillingness to address the ethical problems embedded in global structures. He argues that this reluctance is fuelled by political and epistemological forces, perpetuating repressive relations of power. The Western gaze shapes the global discourse surrounding countries affected by Orientalism, including Lebanon and Syria. This gaze influences how and why Middle Eastern countries are intervened in. I argue that in order to break the cycle of hegemonic power, the international humanitarian healthcare sector must embrace local ways of knowing (Said, 1985).

The harms associated with the West's justification of intervention in the Middle East as a way to 'alleviate suffering' are well documented (Said, 1985; Halliday, 1993; Khan, 2016). A person’s understanding of the world is inherently shaped by their localised interpretations, making health and health needs inherently relational to our society, culture, and power structures. In this study, I contemplate an alternative way of investigating health and healthcare in a humanitarian context that incorporates the social and cultural aspects.

Aid workers are recognising the importance of localised patient-centred voices in humanitarian health programming. The literature demonstrates the growing acknowledgement that previous methods can perpetuate the marginalisation of refugee communities by extracting ‘data’ without involving them in the research process. For instance, Ormel *et al.* (2020a) note that participatory research is gaining traction in humanitarian health programming. Their scoping review found a significant increase in the use of participatory research, with 50% of papers (n=3,279) published in the three years prior to the study reporting a participatory approach in humanitarian aid on an international scale. Specifically to Lebanon, applying participatory methods to service design led to increased trust between NGOs, UN bodies, and participants as without this, participants feared there was a hidden purpose behind the extraction of their data (Ormel *et al.*, 2020a, p. 5). This demonstrates the significance of working with affected populations to identify needs, to listen, and to design useful healthcare services that centre patient voices.

Motivated by the benefits demonstrated by fellow scholars, I developed the participatory methodology and design for this study. This chapter documents the lessons I learned from implementing these participatory methods and design. I outline the opportunities for meaningful engagement and discuss the challenges I encountered through this inquiry. At the end of this chapter, I summarise key learning, offering guidelines to support researchers in distinguishing the necessary elements needed when considering research methodologies and design.

# Researching in Spaces of Aid

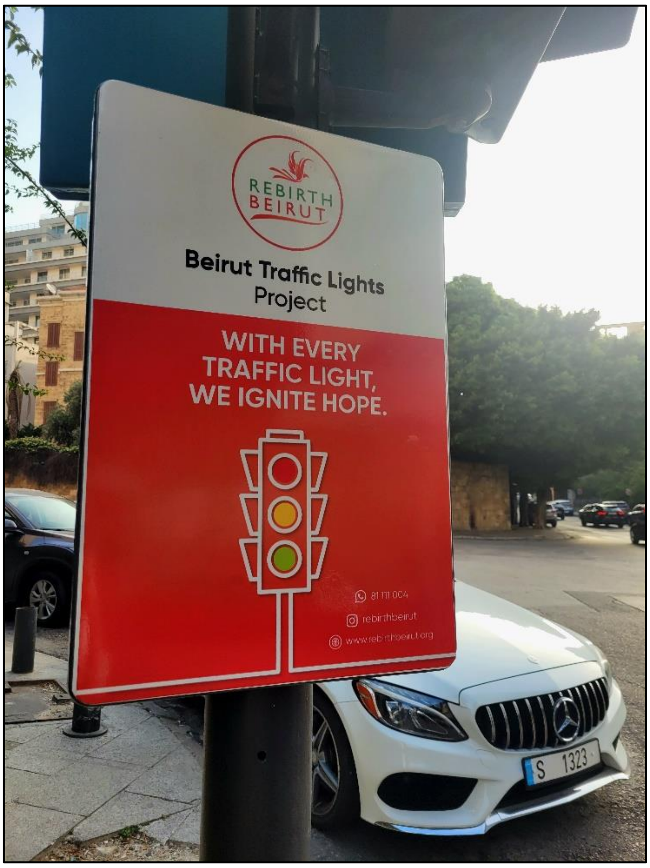


**Figure 4-1 Rebuilding of infrastructure destroyed by explosion, war and neglect. Taken May 2023**

Due to the COVID-19 pandemic, I could no longer conduct in-person research; the University considered it unsafe due to the virus transmission risk. Yet the urgency to proceed with generating data for projects remained. Amidst a transient moment of societal reflection, spurred by public health awareness and a temporary moment of international antiracist solidary (in response to the Minneapolis Police Officers who tortured and extrajudicially executed George Floyd on 25th May 2020) I took this moment to rethink research relationships and responsibilities in the pandemic. Through my research experience, I knew that a research design for fragile settings must be responsive to the political and cultural dynamics of the space. I thought, ‘Maybe I don’t have to go to Lebanon for the research to be perceived as valid.’ This section documents what I learned through striving to conduct participatory research in the digital context. These findings relate to: i) navigating priorities and participation in research partnerships; ii) researching fragile settings; and iii) implementing a digital design in low-resource settings. I will apply Robinson, Halford and Gaura (2022)

'The Spectrum of Co-Design' as a tool to illustrate the successes and challenges I encountered when creating a participatory design in this process. Figure 4-2 The Spectrum of Co-Design contrasts the perspectives of aid and academia, which I draw on to illustrate how a co-development group can support the centring of patient voices in both sectors. This chapter will specifically focus on the academic perspective and illustrate with each section of the research methodology where on the spectrum this project reached: moving from level zero, 'contextually disconnected', to level three, 'transformative exchange through decentralising power'.

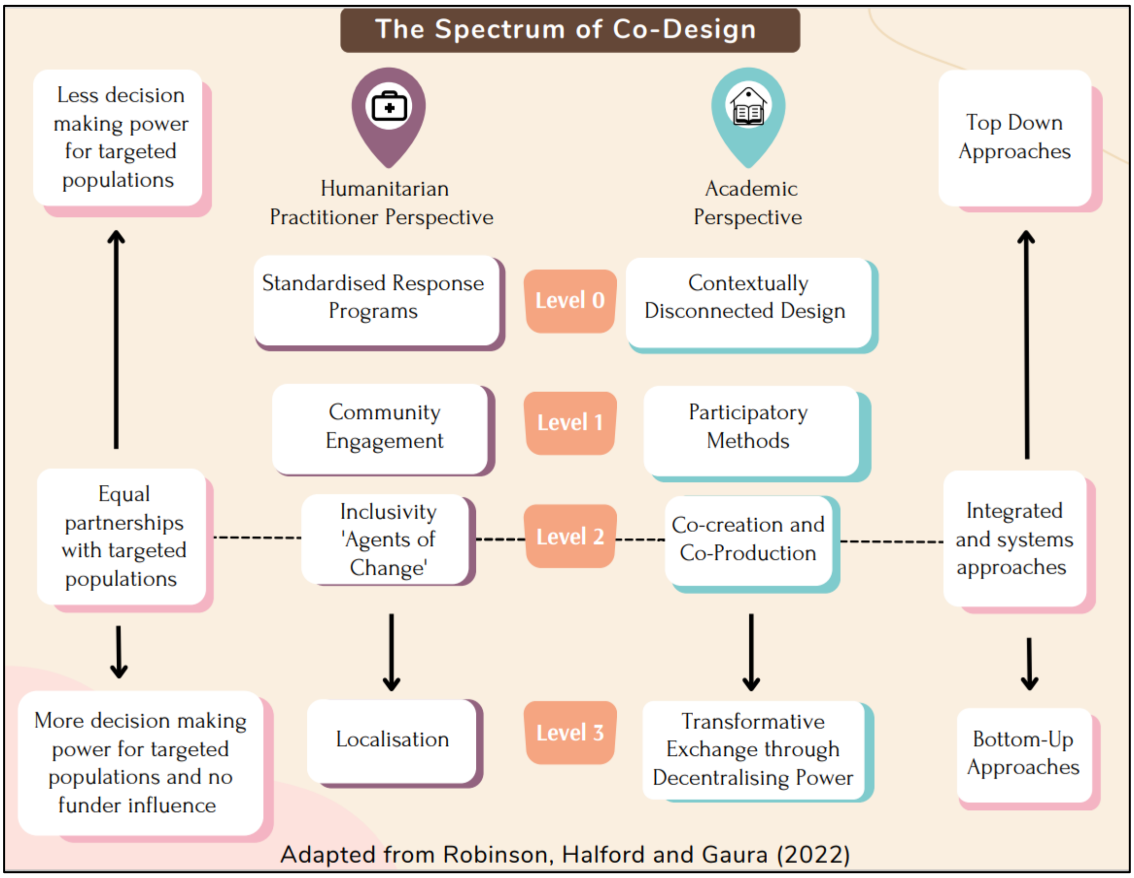


**Figure 4-2 The Spectrum of Co-Design (Robinson, Halford and Gaura, 2022)**

### *Navigating Participation and Power with Médecins Sans Frontières*

> 'Between the floor and the foot'
> (Research Diary, March 2020)

The structures I encountered in this study favoured short-term and formalised research partnerships which conflicted with the principles of community-based participatory research (CBPR), which emphasise: i) equitable relationships; ii) long-term commitment; and iii) participation throughout the research process

(Wallerstein and Duran, 2006). I will highlight the challenges I faced when implementing such research design principles with the Médecins Sans Frontières staff who worked for the Lebanon mission.

Approaching this research design with the decolonial principle of prioritising people over data (Singh *et al.*, 2021), I was committed to sharing my time, being consistent and offering reciprocal gestures of gratitude, such as gift-giving, in exchange for the resources shared by Médecins Sans Frontières. For instance, I offered to support operations in exchange for the resources shared with me through this research project. This offer was rejected by staff as I was warned that I could perpetuate the fear of job insecurity if I took over someone's workload. While I established working relationships with staff at headquarters, maintaining remote working relationships at the project level proved difficult. In part, this was due to the rotation of international coordination staff every six to twelve months, hindering our relationship-building. These structures conflicted with decolonial research principles, but also shed light on the difficulties for international staff in building relationships with local staff and patients (Loquercio, Hammersley and Emmens, 2006).

Humanitarian aid projects often operate on a six-to-twelve-month funding cycle, making long-term commitment uncertain for a multi-year research design (such as the five-year time span of my PhD). Moreover, the multiple crises in Lebanon resulted in increased demand for humanitarian healthcare, which resulted in a national NGO withdrawing from this project due to their diminished capacity to support this research, caused by Lebanon's multiple crises. This perpetuated the mis- or de-representation of minimally resourced local organisations within our global discourse, in that the experiences of national NGOs were no longer able to be heard. It was only the typical 'key informants', Médecins Sans Frontières, that had the capacity to be heard within the scope of my project. This illustrates that even as I strived to enact principles of decolonial research practice, the structures I was working in didn't enable these to be fully realised.

In the original co-development group design, I only had one group for participation; I didn't plan at that time to separate staff and service users. Although approved by headquarters, project level staff requested I separate the groups, explaining that mixing staff and service users would be 'too sensitive'

(Research Diary, March 2020). While staff worked to support this research project as much as possible, their priority remained to operations and they mitigated any risk that could jeopardise the delivery of those operations, including increased staff and service user tensions. As this chapter will detail, accusations within and across staff and service user groups were commonplace. While I think there is scope for mixing staff and service user groups, as this chapter will detail, it is vital that any research which discusses sensitive conversations on stigmatised issues is led by a researcher who can facilitate these conversations in a respectful way.

Living and working in close quarters in this stressful environment had created a sense of surveillance for all staff who worked in this space, but at times I felt this sense of surveillance too. One international staff member expressed reluctance to participate as he was ‘between the floor and the foot’, which I interpreted to mean ‘between a rock and a hard place’. He explained that he had no freedom and said he ‘doesn’t want to go home’, but that participating in my research, which may increase tensions, would result in his being sent home. Belal, the Syrian researcher in this project whose role I will detail in the next section, also articulated a sense of fear from staff in the research process. He described the typical NGO working culture as ‘I just wanna maintain my job, I’m not gonna say anything bad’ (Belal, Interview). Castells (2016) demonstrates that power is exercised by establishing communications systems that express institutional interests that shape patterns of social conduct. Systems are put in place for conduct to be rewarded and punished, and it seemed that some staff were concerned about the ramifications of participating in this study, which would require them to reflect on the structures of power in the thalassemia unit. I believe the relational power of the setting restricted people’s participation.

I invited all staff who worked in the thalassemia unit to participate in my research, with the aim of producing a balanced representation of their diverse experiences. But international staff recruitment was challenging. They explained they were too busy, suggesting I approach national staff instead. Consent was ambiguous at times, as managers rounded up their subordinates and playfully announced ‘I heard you need my staff’ on arrival to the room (Research Diary, April 2022). The hierarchies and power dynamics in this institutional setting led me to be cautious of participant research consent; for instance, in the analysis consultation, I read people's body language. I explained that participation would look different for everyone and didn't press staff for answers. While international staff occupy management positions, the vast proportion of staff are national staff in the humanitarian sector. Myfanwy James described national staff in this segmentation as 'The Other 92%' (p. 32). As a result, the ratio of national to international staff who participated in my study was reflective of the ratio in the unit and in humanitarian structures more generally.

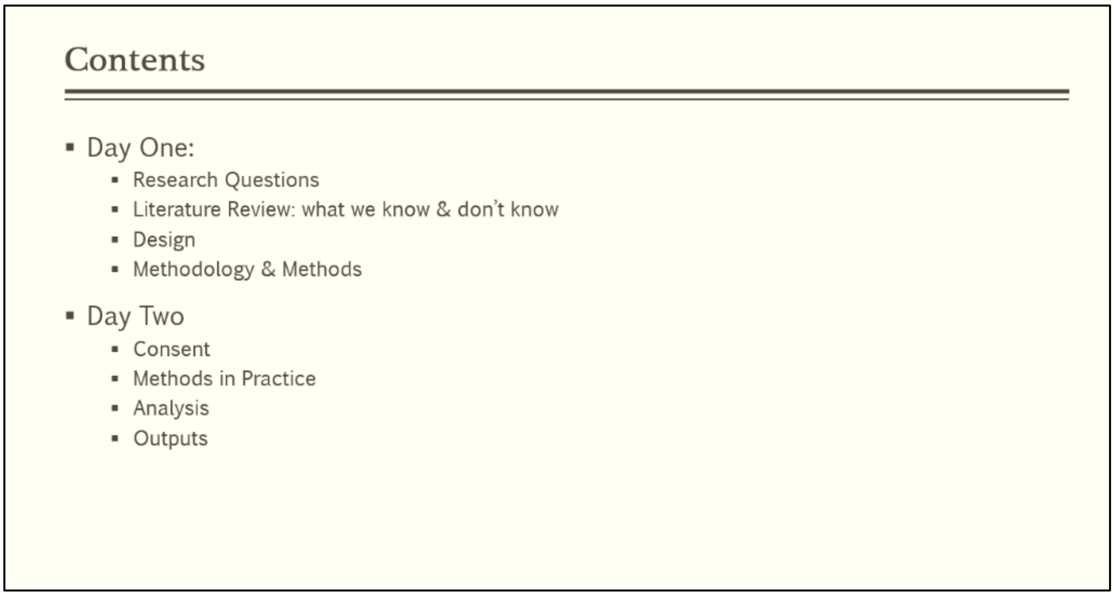
On reflection, in applying Robinson, Halford and Gaura (2022) 'The Spectrum of Co-Design' to these successes and challenges in participation, I believe I reached 'level one', 'Participatory Methods' (See Figure 4-2 The ). The design was 'contextually connected', as defined in level one, as I shaped the design with headquarters and on advice from project staff. This research project was not coproduced (level two) with the organisation; rather, participatory methods were implemented with staff (level one). While I made efforts for it to be otherwise, the organisation explained why a reciprocal and collaborative approach did not complement its operational aims; staff avoided creating and participating in situations which could cause tension, management staff changed every six months, and staff did not want to perpetuate job insecurity by providing me with a portion of their workload. Service provision remained the priority, which limited a participatory approach, and while I can understand the reasons behind this conflict avoidance, I believe it is necessary to pry open room for respectful and difficult conversations of Orientalism and power in humanitarian aid structures.

### *Researching with Belal: Shared Philosophies and Overcoming Practical Challenges.*

As states locked down and restricted travel during the pandemic, the reliance of Western institutions on moving people and things across borders was revealed. This exposed the power hierarchies between aid beneficiaries and the locations of wealth where projects were coordinated. Research could only be achieved by delegating data generation to in-country partners, heightening ethical considerations. This project was no exception. I recruited a local researcher to facilitate the co-development groups because I was restricted from travelling to

Lebanon. Working with Belal provided insights I could not have foreseen. Our research partnership and friendship were fluid, transitioning from friendly professionals to professional friends as the project demands unfolded, with each phase revealing insights into the neocolonialism embedded in the structures that shape humanitarian research.

I was conscious of the ethical considerations of delegating the risks of the COVID-19 pandemic to an in-country researcher. Singh *et al.* (2021, p. 561) encourage us to confront the power hierarchies in our knowledge production process; this might mean, for example, switching to a digital design if the risks are too high in a conflict-affected setting for me. It is also important to consider what added risks partners and participants are exposed to by their engagement with the research, how can these be mitigated, and the relative worth of the knowledge produced. It is crucial to prioritise people's wellbeing over data (Singh *et al.*, 2021).



Contents

- Day One:
  - Research Questions
  - Literature Review: what we know & don't know
  - Design
  - Methodology & Methods
- Day Two
  - Consent
  - Methods in Practice
  - Analysis
  - Outputs

**Figure 4-3 List of topics for two-part, five-hour, paid training I delivered to Belal via Zoom**

> Knowledge is never created in a vacuum but rather responds to diverse cultural, social and material needs of interest groups (Habermas, 1978; Wallerstein and Duran, 2006)

As I detailed in Chapter Three, before facilitating the co-development groups, I requested that Belal construct a positionality statement (see appendix one) to understand his praxis as data generation is personal, emotional, and identity-related work (Coffey, 1999). Listening to Belal’s statement allowed me to develop deeper understandings of the fluidity of positionality, moving beyond a hollow ‘shopping list’ of characteristics (Folkes, 2022). I provided prompts for him to reflect on his ‘invisible characteristics’ (Reyes, 2020), revealing his ontological and epistemological positioning alongside his social and cultural background. This enabled me to trace his relational, contextual, and evolving positionality in the process of enquiry. You can find a list of the questions in appendix one. While I won’t share his personal stories, his positionality statement revealed his biases, which had been shaped by his life experiences. He emphasised how ‘humans validate knowledge’ and that he is ‘biased to the scientific field and the logic of these things’ (Belal, Positionality Statement). This perspective was evident in his process of enquiry, which focused on human interaction rather than ecological, spiritual, or material aspects. For me, this insight reveals the importance of positionality statements and reflexivity when working in partnership in a digital design.

Listening to Belal’s perspective, I interpreted a social constructivist approach to his understandings of society: ‘as humans, we created the whole politics thing’ (Belal, Positionality Statement). According to Belal, knowledge is affective and derived through sensory experiences such as ‘touch, smell, eating’ (Belal, Positionality Statement). He believes that everyone possesses their own truth, which is ‘stuck until we discover them’. This ‘uncovering’ of truth influenced Belal’s approach to the co-development groups, as he encouraged participants to fully participate using different forms of literacy. His perspectives and experiences, which he generously shared, provided me with an insight into what topics he might have prioritised, his motivations to prompt or move on, as how his worldview shaped these choices (Folkes, 2022). He narrated a positive world as he stated that ‘we have the key to change anything we want’ and with solidarity we can achieve this. Methodologically, our principles aligned and I believe that this was essential to the methods’ successes. He too believed in the possibilities of the project.

I recognise that it is harmful to claim a participatory decolonial approach if I do not adhere to its principles. For this reason, I will detail reflexively how I strived to reflect on and incorporate different primary principles of practice into our research partnership. I will do this by thinking through the six considerations that Wallerstein and Duran (2006) propose for community-based participatory research on health inequalities: i) Power; ii) Privilege; iii) Participation; iv) Community Consent; v) Racial and Ethnic Constructs; vi) Research in Social Change. I will apply these to our working relationship and articulate how they shaped the study, writing with theories of postcolonialism to detail the opportunities and challenges of working with a local researcher in a protracted humanitarian setting. Moreover, as in the organisational partnership findings, I will link these principles of participation to Figure 4-2 The  to review the successes and challenges in this research partnership.

**Power:** I conducted a two-part training programme (see Figure 4-3) with Belal to support him in understanding the logic and logistics of this enquiry. These sessions also aimed to establish an equitable working relationship and to adhere to principles of decoloniality, as I sought his insight on the social and cultural suitability of the methodology. However, Belal and I were limited from the onset by the ‘continuum of control’ we were both confined to, exercised by institutions including the University of Glasgow (Arnstein, 1969). I sought to move up the ladder of participation (see Figure 4-4) by delegating power. However, according to Robinson, Halford and Gaura (2022), true localisation and decentralisation of power occur when resources are relocated from Western institutions to affected communities. As I was operating within the University’s regulations, it wasn’t possible for me to share all project resources (for instance, sharing the degree award), a requirement for localisation. Consequently, we did not reach level three, ‘Transformative Change through Decentralising Power’ on the ‘Spectrum of Co-Design’; See Figure 4-2 (Robinson, Halford and Gaura, 2022).

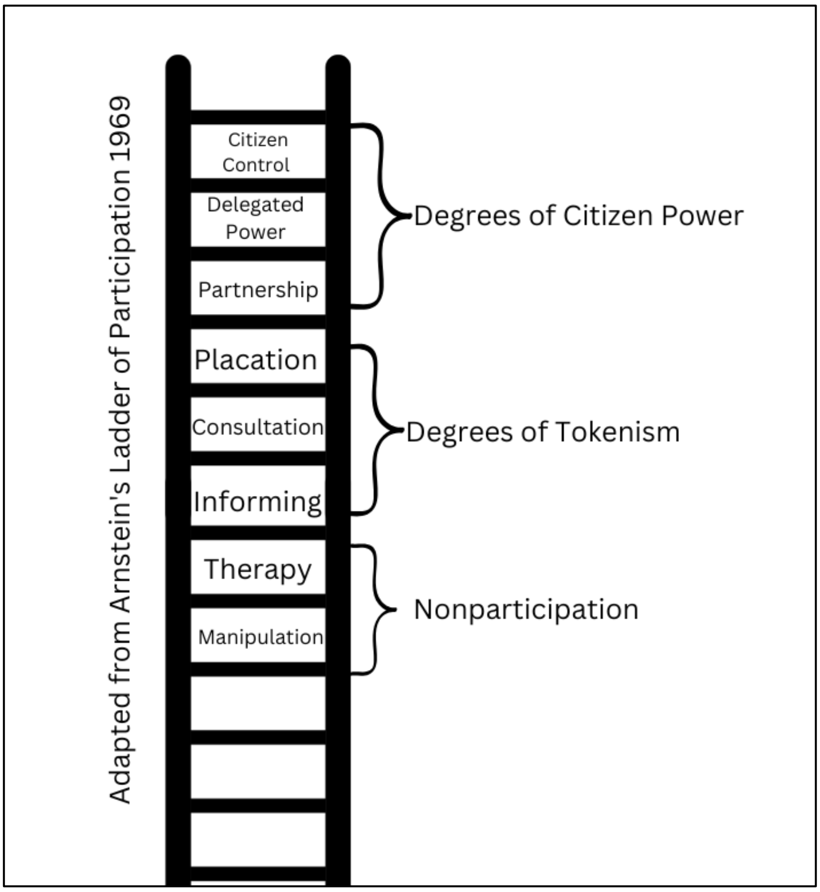


**Figure 4-4 Arnstein's Ladder of Participation 1969**

To redistribute what I could, with Belal's consent, I included him as a co-author in four conference submissions. However, he was unable to participate for several reasons, including high workloads and security risks when travelling through Lebanese checkpoints. In November 2022, for the Irish Global Health Conference, Belal wrote the following opening script, which I presented, and I write the closing statement:

> Belal's Statement for me to read: I was hoping to present today with Belal, an independent Syrian researcher based in Lebanon, but due to the chaos of the international humanitarian systems (which he is employed by and subject to), he is unavailable to join. If you are interested in connecting and learning about his work, you can contact at him at (email address).
>
> The closing statement I wrote: The last point I'd like to make is that it should not be my voice alone that you are hearing from today. Whose voices are we listening to? I believe that the humanitarian medical sector can redesign and redistribute power equitably in service design and centre patient voices in spaces of aid.

I also worked in partnership with the interpreter, Fatima, and an artist I recruited to create outputs from this study, Nader. I invited them to conference presentations and output production also, yet they too withdrew their participation due to the overwhelming realities of economic collapse, fear of deportation, extreme poverty, and preventable illness from the inability to access prescribed medications.

These challenges I faced in sharing resources gave me a sense of failing to implement decolonial practice, and highlights the reciprocal expectations and disappointment in my research partnerships. Despite my best efforts at resource sharing to redistribute power, leading with trust, transferring responsibility, and creating the space for agency, this resulted in a situation where I experienced disappointment. This outcome, I believe, arose from an attempt to level the playing field; however, structural power was not shared. I worked within a prestigious University where output production is a priority, and colleagues in Lebanon struggled to meet basic needs in a failing state. The stress from the humanitarian crises prevented their full engagement in a collaborative partnership (Afifi *et al.*, 2020). Academic systems limited resource sharing, and the challenging contexts faced by Belal and colleagues restricted their acceptance of the space and power I tried to share. For me, this demonstrates the importance of equity, as I was the only person with the resources to accept the opportunities.

I want to avoid over-emphasizing the friendship between Belal and me. On one hand, we shared meals, I spent a weekend at his home, we shared a camping trip, we exchanged gifts, and we sent each other photos of big things, like the villages we grew up in and his wedding, and small things, like our pets. Still, it is essential to acknowledge that I paid Belal for his work. I have encountered instances where researchers convey a ‘family-like’ research partnership with Global South scholars. I find this misrepresentative of this working relationship. Our power dynamics were unequal; I paid him to complete a research service. The working relationship was meaningful, but there was geographical and metaphorical distance in our lives. We had diverging priorities: mine being to finish the PhD, and his being to leave Lebanon. Once this project ended, our ways parted.

**Privilege:** Participating in this research was viewed as a privilege by Belal. In the methodology chapter, I detailed how I recruited Belal via an ad in a WhatsApp group. When he saw the project advertisement he thought, ‘It’s Glasgow at the end of it’ and ‘It’s a name where any student could dream of studying’. He expressed trust because of the ‘experts’ at the University, stating that he would have ‘99% trust’ in any project with the University of Glasgow’s name on it (Belal, Interview). He took pride in his involvement, explaining that if he ever sees the logo, he will think, ‘Hey, that’s the place where I did something.’ He felt a connection with the University and this research project: ‘I dunno, for anyone who asks, “How did you do this?”, you will refer to me in a way, you will say like, “I did it with this person, I collaborated with them”’ (Belal, Interview).

This opportunity was important for Belal. He explained that he ‘runs behind education’, he loves learning, but ‘without like being stuck as a student or whatever’ as he needs to earn an income amidst the economic collapse (Interview, Belal). Hearing this, I included as much training as I could into this project for him (for example, see Figure 4-3). The importance of education in research projects aligns with other findings, such as the Lebanese Qaderoon project (Afifi *et al.*, 2020), which concluded that ‘authentic co-learning is linked to genuine equitable partnerships’ and can support the creation of balance between research and action in protracted humanitarian settings (Afifi *et al.*, 2020, p. 385). I reciprocated the immediate trust that Belal had in the project, in the University of Glasgow, and consequently in me. From my perspective, working at the University of Glasgow and earning trust through this affiliation with people of refugee backgrounds is a privilege.

Reflecting on Belal’s positionality statement and his relative privilege, I acknowledge how it influenced the inquiry process. There were hidden voices, people I could have worked with who were hidden to me due to my limited fluency in colloquial Arabic and social networks (Wallerstein and Duran, 2006). In the process of enquiry Belal represented the University of Glasgow and was university-educated and researched with minority Bedouin and low-literacy Syrian women. Between Belal and me, I hold additional privileges as a white individual with a European passport, English fluency, a university education, and access to abundant resources at the University of Glasgow. Upon arrival at Lebanon’s border, I secured a visa free of charge. While I cannot resolve the consequences of Orientalism embedded within the institution I represented, I tried to share my privilege by gifting digital devices, paying a rate of $10 an hour, and co-authoring. By prioritizing participant voices and striving to level the metaphorical playing field, I aimed to address the imbalances caused by privilege. I delegated power to try to create a true ethical research partnership, following guidance from Figure 4-4 Arnstein's Ladder of Participation 1969. Belal felt part of the project and we worked in a trusting collaboration, but we did not change the structures we worked within. For this reason, I believe we reached 'level one', 'Participatory Methods', on the Spectrum of Co-Design in Figure 4-2 The Spectrum of Co-Design (Robinson, Halford and Gaura, 2022).

**Participation**: Belal and I had open discussions to manage our expectations and ensure feasible workloads considering the security context, and also to see that he had the necessary financial, emotional, and logistical support for the project. Collaborative planning was crucial. We used shared folders, agreed timelines, and multiple platforms to find a suitable way of working. Although complete co-design was not achieved due to the academic funding and reward systems, we achieved participatory successes. In an interview, Belal expressed equitable participation in the research project, stating: 'I was participating as much as you, this is what I felt. Like I had a chance to shift the whole thing if I wanted' (Belal, Interview). Hence, I believe we reached level two, 'Co-creation and co-production', on the Spectrum of Co-Design for Participation (Robinson, Halford and Gaura, 2022).

**Community Consent** was managed responsively. When Belal ran the first co-development group, he started the session by sharing the participant information sheets and consent forms with participants. This led to confusion and discomfort as the women explained they could not read or write. To address this, Belal adapted the approach of obtaining verbal consent through recorded sessions instead of accepting fingerprints, as suggested by one participant. Similar adaptations were made in the staff co-development group, considering potential literacy challenges. Due to participants often entering late, Belal provided quick explanations, introducing himself, the research project, its goals, and ensuring privacy protection. Belal de-identified participants by not recording names but created a password protected spreadsheet with phone numbers for those interested in project updates. In preparation for Belal's interview, we discussed the questions in advance, ensuring his familiarity with the topics. Ethical clearance was obtained from the University of Saint Joseph Beirut, and a responsive approach to research consent was implemented, considering local norms. This research embraced community-driven ethics, providing Belal with various consent approaches to choose from, including written forms and verbal methods. However, the ethical process was decided prior to Belal's recruitment, and while he engaged with participants to implement the approach that they believed was most suitable, I believe that community consent as a principle only reached level one of three on Figure 4-2 The .

**Racial and Ethnic Constructs:** In this section, I will reflect on race, ethnicity, and cultural influences in the process of enquiry broadly, considering heritage, social identity, beliefs, and practices. Belal and I navigated our relationship, acknowledging our lack of mutual knowledge due to differences in language, cultural and ethnic backgrounds, and experiences. However, we discovered that we had more in common than initially assumed. In his positionality statement, Belal described his generation of Syrians as being 'like this generation who was trying to open to the world' by creating a 'cultural uprising'. He had learned English when he 'bumped into language barriers', and he tried to 'reach across the borders that people drew on maps' (Belal, Positionality Statement). Belal reflected on assumptions we both made, but how we worked through these 'Assumptions, eventually *yanni* [colloquial Arabic, translates to 'meaning'], we're talking, it happened. We did work on this, we were on the same page, in a way, I feel like you're open to hearing me in my personal level without judging me, so I was feeling free to talk about all of these things.' (Belal, Interview). We fostered trust and created a brave space for open dialogue. Through this process, I gradually embraced cultural humility.

Working with Belal enabled the exploration of culturally bound knowledge. For instance, participants used colloquial terms and spoke in metaphors which he responded to in the moment and contextualised for me afterwards (Wallerstein and Duran, 2006, p. 315). When Belal invited parents to share their 'experiences of the health situation facing people in Lebanon', a mother explained, 'We start from the homes. As "Honsi Al-Borazan" said, "If you want to know what is in Brazil, you have to know what is in Italy." First, we need to know what's going inside the homes' (Fatima, Service User Co-development Group One). My Arabic teacher, who is from Syria, explained this quote to me: ‘to understand the situation you should understand, first, what’s behind the situation. You should go to the history, only then can you understand the situation of the current day’ (WhatsApp, June 2023). The Brazilian-Lebanese interpreter I worked with, Fatima, explained to me that this is ‘a famous phrase from a Syrian TV series *Sah Al-Noom* from the 1970s, very well known in Syria and Lebanon and imprinted in the collective memory of several generations’. I believe that on Figure 4-2, we reached level two as we included cultural responsivity into the integrated methodological approach during data generation through a cross-cultural approach to research practice.

**Research In Social Change**: While implementation for participatory methods in humanitarian contexts is called for by scholars including (Afifi *et al.*, 2020; Ormel *et al.*, 2020a), it remains rare due to contextual challenges. Service provision remains the priority in these contexts and limits participation. Participation can be demanding for people in low-resource settings, and I did not want to laud that I could *change* anything; I was wary of making false promises that could lead to disappointment. I achieved collaborative learning and meaningful dialogue throughout this research project, but it is not possible to trace the ripple effects of social change emanating from this PhD study. Most likely, I don’t know the greatest change I made. The systems of power governing humanitarian action remain for the most part unchanged. For this reason, I believe I reached level two with Belal on the Spectrum of Co-Design (Robinson, Halford and Gaura, 2022); we were collectively engaged in identifying challenges and solutions, and he identified the partnership as being equal and the methodology as co-created (a necessity for level two), but we did not secure transformative exchange through decentralising power. Nevertheless, I believe there is great potential in this methodological approach. As I will detail later in this chapter, participants found the co-development group to be a helpful process in identifying challenges and solutions in their lives.

To conclude, in regard to the organisational collaboration with Médecins Sans Frontières, our partnership achieved a minimal presence of co-design, referred to as level one by Robinson, Halford and Gaura (2022). The organisation’s priorities remained focused on medical provision, resulting in a lack of capacity for them to lead on design elements. Rather, thinking with Figure 4-4 Arnstein’s

Ladder of Participation 1969, we reached ‘consultation’ as they advised on a design I created and using their guidance I implemented the methodologies with staff. Concerning the co-design implementation with Belal, I will recap the six considerations for participatory research as defined by Wallerstein and Duran (2006) and conclude where we reached on the Spectrum of Co-Design. The first is ‘Power’, where possible delegated power within the project is considered. Here we reached level two of three as we did not secure transformative structural change in the systems we work in. The second principal is ‘Privilege’. Similarly, we did not change the structures we worked in. I tried to share the privileges I had by virtue of my positionality, but due to unequitable structures, Belal could engage with and participate in what I shared, but it was not equal. Third, for the category of ‘Participation’, I concluded that through collaborative planning and considering Belal’s perspective, he participated as much as me in the data generation process, so we reached level two in this consideration. Community Consent was the fourth consideration I reviewed, and I concluded that this partnership reached level one. I completed all ethical processes prior to recruiting Belal, resulting in him having limited decision making powers. The fifth consideration that Wallerstein and Duran (2006) propose is ‘race and ethnic constructs’, which I interpreted to include race, ethnicity, and cultural considerations more broadly. From Belal’s perspective, there was no hierarchy of knowledge, values, languages and customs in this project. He considered that every perspective was welcome without judgement, and engagement with media and culture was evidenced in the transcripts. I conclude that we reached level two in the Spectrum of Co-Design (Robinson, Halford and Gaura, 2022). Due to my inability to speak fluent colloquial Arabic, there was an inherent language inequality in this project. Moreover, as I researched with Social Science and Public Health disciplines, I focused more closely on narratives that were relevant to the research objective. Finally, when considering the level of participation for Research in Social Change, based on Figure 4-2, I conclude that Belal and I reached level two. We secured an equal system and approach to the methodological implementation, yet we did not wholly decentralise power in our research partnership.

## *Interlude*

As part of my agenda to ‘research for social change’, I worked with an artist to create an illustrated video in Levantine Arabic and English advocating for better thalassemia care. Unfortunately, due to the reasons listed above, the video was not completed at the time of thesis submission. However, there are some illustrations and a script to share.

**Figure 4-5 Scan to access the digital recording**

بِسَبَب الحَرب، كتير من السّوريين إنتَقَلوا على لبنان يلّي عم يمرُق بإنهيار إقتصادي. إرتفاع أسعار المواد الغِذائيّة سَبَّب بزيادة نِسبة الجُوع بكلّ البَلَد. مِن بَعد إنفجار بيروت و أزمة كورونا، صار الوَضع أسوأ.

بِهيدي الدِّراسة حَبّينا نِفهَم واقِع الرّعاية الصّحيّة للمُقيمين بلبنان، و شو يلّي بيقدَر يتحَسَّن بهالمَجال.

حَكينا مَع عائِلات سوريّة كان فيها أولاد عَم يتلَقّوا العِلاج لمَرَض التَّلاسيميا مِن خِلال مُنَظَّمة "أطبّاء بِلا حُدود".

التَّلاسيميا هُوَ إضطِراب وراثي بِتمّ عِلاجُه عَن طَريق نَقل الدّم . إذا إنتَرَك المُصاب مِن دون عِلاج مُمكِن هالشّي يوَدّي للمَوت.

*"مَا كِنت إفهَم إبني شو مِشكِلتُه. كان يوقَّع كلّ ما يجَرّب يمشي. أَخَذتُه عَالمِستَشفى، بَسّ الحِكَمَا مَا عِرفوا شُو بوه"*

*"أوّل مَا جينا على لبنان ما كِنت أعرف بِمُنَظَّمة أطبّاء بِلا حُدود. تعَذّبت كتير لإدفع تكاليف العِلاج وشِفت المَوت بعيوني"*

*" قَبل مَا أعرف عن أطبّاء بِلا حُدود، كِنت اضطَرّ إتدَيَّن مَصاري للعِلاج. ما كانو يقبلوا يعالجوا إبني قَبل ما إدفَعلُن. عَذّبوه كتير. كانِت إيّام صعبة كَرَّهِتني حَيَاتي "*

كانِت مُنَظَّمة أطبّاء بِلا حُدود تأمِّن علاج مَجّاني للأطفال المُصابين بالتَّلاسيميا.

*"مِن وَقت ما عِرفت عن المُنَظَّمة تسَهَّلِت الأمور كتير. أمّنولي العلاج والأدوية وساعَدوني لاقي دمّ. كِلّ ما يِلزَم كان مَوجود. عامَلُونا بإحتِرام وتَفَهُّم"*

**Figure 4-6 Electricity pole with a sign reading 'Lebanon of Tomorrow' attached**

In this section, I will document and analyse my experiences of researching in Lebanon, considering both the logistics of conducting research in the context and how I was received in everyday society.

> Imagine the research context as a space where the 'researcher and research participants work in a space where resistance, critique and empowerment can occur' (Berryman, SooHoo and Nevin, 2013).

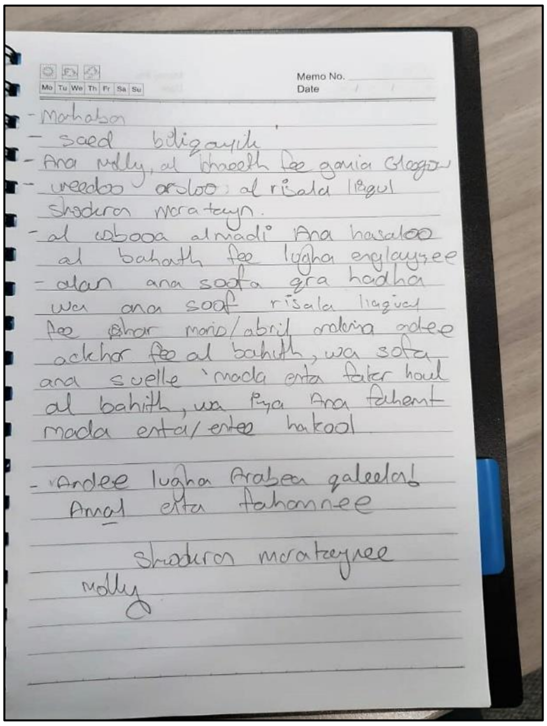
Before I started research generation, the book *Knowledge production in the Arab world* by Hanafi and Arvanitis (2015) provided valuable insights. I noticed a significant disparity in research conducted with displaced communities in Europe and Sub-Saharan Africa compared to the Middle East, especially in the field of health research. Hanafi and Arvanitis (2015) explain that research in the Middle East often revolves around international collaborations, perpetuating abstract concepts like 'Arabic' or 'Islam', rather than focusing on the localized everyday social world of Lebanon. Moreover, research centres are inhospitable due to political repression and censorship. For this reason, the authors conclude that social scientists pontificate rather than offer concrete actionable solutions for fear of visibility in hostile states (Hanafi and Arvanitis, 2015, p. 216). This echoes Belal's perspective; he explained this project would never take place in a university in Syria or Lebanon because there is 'no space and room for people to think, to try' (Belal, Interview).

During my research, I encountered participant scepticism and uncertainty about my objectives, and was often questioned about the source of funding and my affiliations. Logistical structures often pose obstacles to achieving equity in humanitarian contexts. Roadblocks, street protests, and security checkpoints hindered access to the hospital and posed a risk of deportation for Belal, leading to the rescheduling of research activities. The economic collapse further complicated matters, making it challenging to pay Belal, the interpreter, and the artist in US dollars. Project planning and support from research partners and universities helped overcome these challenges. They played an invaluable role in facilitating equitable and safe research in this fragile setting. While the impact of state politics on societal fragility presented contextual challenges, it was possible to overcome them with determination and creative thinking.

### *Research, Interrupted: Findings from a Digital Design*

As was detailed in Chapter Three, due to the COVID-19 pandemic, it was no longer possible for me to travel to Lebanon. For this reason, I used email, Instagram, Zoom and WhatsApp to advertise, recruit, train, and manage data generation from Glasgow. Three primary findings emerged from my 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 PhD thesis: 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.

It was difficult to create trust. Prior to meeting me, Belal explained he was ‘short’; he would share job updates and that would be it. Only by meeting in-person, ‘by being in the same room, giving your energy and taking their energy, talking together and thinking together’, did we truly create a meaningful connection (Belal, Interview). He explained that this digital design caused distance with the research participants: ‘I feel they wanted like, you, in a way. They wanted to meet you, so they were thinking the WhatsApp group would give them the opportunity’ (Belal, Audio diary, Service User Co-development Group Three). I wrestled with ethics and language when he told me this; creating and managing a WhatsApp group would have been extra work for Belal, and I didn’t have consent to expose people’s participation by creating one – and it was the final week of data generation. Instead, I shared voice messages for him to send directly to participants in Arabic.



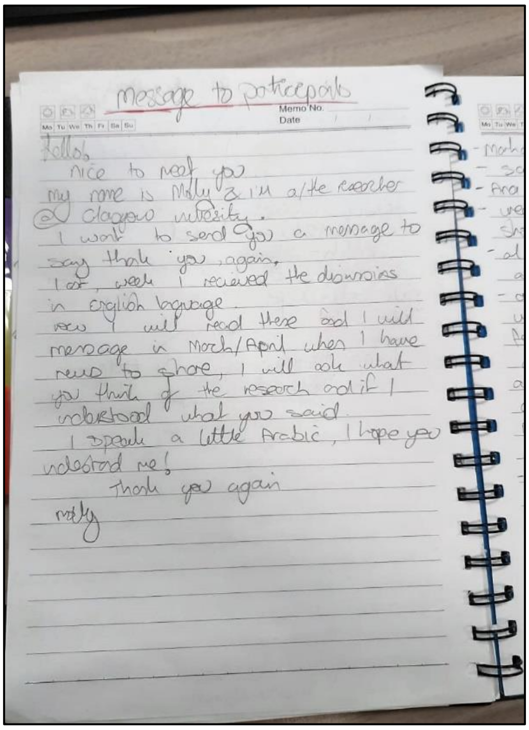
Memo No.
Date

- Marhaban
- saed biligayik
- Ana Molly, al bhaeth fee gamia Glasgow
- weedoo arsloo al risala ligul
shokran marateyn.
- al usbooa almadi Ana hasaloo
al bahath fee lugha englayzee
- alan ana soofa gra hadha
wa ana soof risala ligical
fee shar mario/abril andma andee
ackhar fee al bahith, wa sofa
ana suelle 'mada enta fakr houl
al bahith, wa Iza Ana fahemt
mada enta/entee hakool

- Andee lugha Arabee galeela!
Amal enta fahomnee

Shokran marateynee
Molly

**Figure 4-7 My Voice Message to Participants via WhatsApp June 2022 - Arabic**



Message to participants

Memo No.
Date

Hello,
Nice to meet you
my name is Molly & I'm a/the reseacher
@ Glasgow university.
I want to send you a message to
say thank you, again.
last week I recieved the discussions
in english language.
now I will read these and I will
message in March/April when I have
news to share, I will ask what
you think of the research and if I
understood what you said.
I speak a little Arabic, I hope you
understand me!
Thank you again
molly

**Figure 4-8 My Voice Message to Participants via WhatsApp June 2022 - English**

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).

Digital research presents opportunities for tracing the reach of humanitarian medicine and understanding how displaced populations shape humanitarian response mobilization in real time, centring the voices of affected communities in humanitarian contexts. Utilising this has the potential to be powerful and creative. By thinking creatively, as COVID-19 forced many of us to do, logistical challenges can be overcome and cultural values of privacy and expression can be met. The logistics of access to devices, alongside cultural values of privacy and freedom of expression, could be feasible through cocreating ethical practices and leveraging local partners for devices. Many scholars agree that the principals underpinning the ethics required for digital research are the same as they are for in-person research (Eynon, 2017). These include, for instance, managing expectations that participation would not lead to any immediate benefits, and upholding data protection practices.

I argue in favour of using the digital tools we have available to support the inclusivity of structurally marginalized populations. I achieved this with the relative resources I had. For instance, I shared a tablet with Belal and left some project cash for him to have in Lebanon to ensure the devices were always charged and topped up with phone credit so he could stay connected for the project. Moreover, I adapted my digital approach, using WhatsApp voice notes instead of calls. This allowed participants to listen to the message when they had Wi-Fi, rather than requiring them to spend their phone credit. Finally, I found these tools enabled me to build trust with participants, facilitating immediate and consistent communication. In my experience, online platforms (whether a personal website or social media platform) humanizes researchers and participants, mitigating the distance between us. During analysis, Skype and WhatsApp remained invaluable tools for me to discuss the meanings and interpretations of humanitarian healthcare in Lebanon with people from Syria, enabling me to centre voices and reduce harm (Beaton, 2017; Rajaram, 2002).

## Can a Co-development Group Improve Humanitarian Healthcare?

> *"I don't understand the university PhD students any more, they don't do their job […] they do the same interviews with the same people all the time. Why don't they use the interviews that were done by researchers before?'*
> *(Sukarieh and Tannock, 2013, p. 501)*

This section will outline what I learned methodologically by exploring the tensions of power in what is termed by critical humanitarian scholars as 'aid land' (Mosse, 2011). As I have argued so far, our understanding of aid, of humanitarian needs and solutions, is shaped by questionnaires and interviews. This approach marginalises community voice. These tensions between qualitative and quantitative approaches to knowledge generation in aid have been evidenced by Nouvet *et al.* (2016), who theorise how we know what we know about aid. They trace the formation of the aid sector's dominant approach to evidence, its expectations of 'what counts' for project monitoring and evaluation. The sector's practices often focus on outcome rather than process and favour quantification due to the perceived timeliness of qualitative research. When it is conducted, qualitative evidence is generated with 'key informants', platforming the same voices of power on repeat rather than listening to alternative voices which may represent the area's needs more accurately. Belal worked with staff in this data generation process to challenge the unidirectional assumption that only people perceived as vulnerable need intervention (Bananuka, Perry and Kadoma, 2023). This study was open to everyone in the thalassemia unit, and the people who attended were carers, fathers, mothers and siblings of patients, nurses, cleaners, drivers, doctors, finance officers, IT technicians – anyone could participate.

As was demonstrated in Chapter Two, implementing community-based participatory research in the Middle East is a relatively novel approach to working in these settings due to the multiple challenges that often prevent its implementation (Afifi *et al.*, 2020). Afifi *et al.* (2020) list five challenges to participatory research in the Middle East: i) security; ii) political complexities; iii) ethics; iv) the need to address health concerns rather than implement academic research, alongside what they term as v) the dearth of preintervention data and the challenges this can cause to perceptions of data validity. This study wrestled with these challenges, alongside the pandemic and the Beirut Blast, but with the resources available to me as a PhD student, I managed to overcome these, which illustrates the possibilities of these methodologies for fragile settings.

This section details how this co-development group methodology offers a potential approach to upholding equity and dignity in humanitarian crises. I discern the best practices and tools I found to be helpful as I examined how to strengthen participatory research processes in humanitarian healthcare. I detail how participants understood, and then prioritised, what could and could not be achieved as they collectively identified solutions to improve health outcomes in humanitarian contexts (Kia-Keating and Juang, 2022). I identify the tensions, discomforts, surprises, joys and disappointments in working to achieve a participatory design. Moreover, I explain how the processes of methodological enquiry attended to positions of power in the two participant groups, with staff and service users, and aided participants in collaboratively identifying challenges and solutions, differing between staff and service users.

**Figure 4-9 The Lebanese ICRC headquarters in Beirut. Photo taken April 2023**

### *Co-developing Solutions with Staff*

> ‘I want solutions, but not as the world in rose [tinted glasses], [like] “tomorrow we will wake up and we will have a better healthcare sector”’
>
> (Belal, Staff, Co-development Group Four)[1]

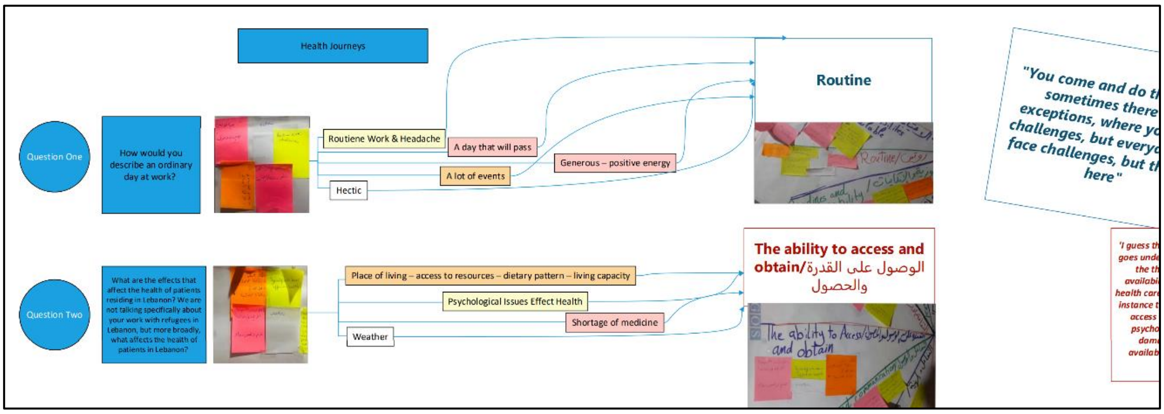


Figure 4-10 Snapshot of the visual representation of the first three co-development groups

**Table 8 Staff Co-development Group Four: Solutions to problems identified**

| Session Two: Category | Session Four: Solutions |
|---|---|
| **READINESS AND CAPABILITY** | • Money and training<br>• Strategic Planning; strong administration<br>• A third party, to administrate the healthcare sector.<br>• Funding for Lebanese Government |
| **HEALTH AWARENESS AND CULTURE** | Training and awareness |
| **HUMANITARIAN CULTURE IN SOCIETY** | • Separation of religion from state<br>• Encourage the rich to donate<br>• Health Professional Training<br>• Lebanese Community Cohesion<br>• Training in Lebanese Schools |

---

[1] Quote Guide (Belal or Participant Pseudonym, Participant Category (either staff or service user group), Codevelopment group #

- Belal, Service User, Codevelopment Group Four: Belal said this in the fourth codevelopment group with service users (who are parents of paediatric patients)
- Belal, AudioDiary, Service User, Codevelopment Group Four: Data derives from Belal’s audio diary, reflecting on the process of this codevelopment group

| | |
|---|---|
| **ABILITY TO ACCESS AND OBTAIN** | • Patient Awareness Sessions<br>• Patient Livelihood Activities<br>• Patient Transport<br>• Reform Politics<br>• Financial Support for healthcare systems<br>• Improving access for people with disabilities |

This section will reflect on the process and prioritisation of challenges and solutions in Lebanon's healthcare as identified by staff. Above, I have provided an extract of what this looks like in Figure 4-10 Snapshot of the visual representation of the first three co-development groups. Table 8 (above) offers an overview of the final session, the categories of challenges that staff created in session two, and the solutions they proposed. This process of enquiry produced different responses for staff and service user participant groups. Three key findings emerged from this methodological approach with staff and service users. First, it unravels the cultural pluralism in this setting; second, it uncovers the hidden voices that assert power in the unit; third, it facilitates a strength-based research process as it focused on solutions. These findings contribute to the limited understanding of CBPR in humanitarian contexts in the Middle East, and can provide a guide for future researchers to build on as they develop this methodological approach in the future.

### *Navigating tensions when facilitating a supportive participatory space for dialogue with staff*

One primary objective of this research is to explore the strength of harnessing pluralism, valuing diverse knowledges, and accommodating conflicting views in decision-making. We strived to achieve this through the application of a culturally and socially responsive research method in a humanitarian context. Belal worked with a guide of possible questions and activities and remained ready to shift and evolve as more participants collaborated. For example, Belal explained that in the second co-development group there were four new participants, so he 'needed to adapt the situation, because the new ones were not fully understanding the questions and the answers that had been answered before' (Belal, Audio diary, Staff, Co-development Group Two). Belal and I concluded that while it is difficult in unpredictable contexts like hospitals, stable participant attendance is important when research activities are sequential and cumulative.

A second illustration of the necessity for embracing pluralism and responsivity in humanitarian contexts was noted by a staff participant who I will call Amir. Amir explained how, in his experiences working with Médecins Sans Frontières, international staff transfer their knowledge and practices from one country to another and lack reflexive consideration of how they must adapt their working practices in a new country. This is important as rotating from one country to another, securing a promotion through accrued experience at each location, is standard practice in INGOs. This can embed a dichotomy of Western international staff and the 'local Other'(James, 2020b). Amir concluded that Lebanese NGOs must partner with INGOs for funding reasons and in turn diminish their relational power.

> *They [NGOs] need support maybe from other NGOs internationally, just for funding. Because funding is a bit like, challenging yanni (Arabic interjection for 'meaning') for everyone, but for international NGOs it's like, coming already with the power; they have the funds, they have the systems that they have been working on in other fields, they have the experience as well. They work on certain processes they tried somewhere else, so they come with this and start building. This is good, yet bad if they don't adapt. So this is the idea, if they come just blindly saying that I need to do this in Lebanon because we did this in Africa - it's completely different. And we actually experienced this here, with some expats. (Amir, Analysis Consultation, Staff)*

This co-development group process supported staff in concluding that thalassemia care can be provided in multiple ways. One way, which they termed 'routine', included 'material, equipment capacity and health', 'the ways of diagnosing the disease', and the biomedical approach to 'helping the patient get better', which is determined by their financial capacity. For Muhammad, another participant, this has no great importance to developing trust. He provided an illustration of thalassemia diagnoses given by two hospitals, one private and one public, but in the end both patients were diagnosed with thalassemia; 'both reached the same biomedical "satisfactory result", this doesn't have much importance'. He explained that what matters for quality care is 'interaction and professionalism'. For Rimsha, quality care means the way 'to deliver the message' about thalassemia and how to care for the patient; when the communication with the thalassemia team is strong, that is when patients and staff are ‘satisfied’. They illustrate how their patients need psychological care because their thalassemia is a ‘permanent’ health issue, and it takes children a while to recover after their diagnosis. This highlights the importance for staff to adapt their approach with patients to find the ‘channel of communication’. Muhammad explained that ‘you work on it until you achieve the result’, concluding that the diagnosis and treatment of thalassemia do not equate to thalassemia care alone (Staff, Co-development Group Two). This demonstrates the importance of facilitating interdisciplinary dialogue, and listening and working with the different perspectives to arrive at an inclusive consensus (Mouffe, 1999).

A participant who I will call Rashid summarised the results of a staff vote on what solutions they believe can resolve the identified healthcare systems challenges in Lebanon. Rashid cautioned that ‘in Lebanon, you got 1) the *existence* of the service, 2) readiness and *capability* of the service, and 3) possibility to *access* the service [emphasis my own]’. He explained that these are the most pertinent challenges for Lebanon today, as when these are ‘weak’, Lebanese go to ‘a difference place in the world’, referring to the emigration that is draining the country (Rashid, Staff, Co-development Group Three). Rashid dismissed the proposed solution to improve humanitarian culture, calling it too ‘advanced’ for Lebanon today. Rather than asking people to volunteer, he suggested focusing on access to basic state hospitals. For me, this demonstrates that people must have their own basic needs secured before they can voluntarily support others in securing theirs, reflecting the importance of international solidary through aid at a macro-level.

This co-development group process facilitated a meaningful dialogue which recognised the necessity for a plurality of perceptions in healthcare. When Belal asked participants what they considered the objective of Médecins Sans Frontières to be, a staff member whom I call Muhammad responded that it was ‘obvious’ - namely, to provide healthcare for the most vulnerable. Yet as Belal probed further about what this looks like in practice, Muhammad remarked on the multiple proposals offered by participants: ‘the goal is one, but the ways are different’ (Muhammad, Staff, Co-development Group Two). This difference in the challenges identified surfaced in the process of category creation. When identifying what they believe is the priority in patient care, Muhammad explained to his colleague Rimsha, ‘You are talking from your point of view as a social worker, I am talking from my point of view as a medical doctor.’ Later he reminded his colleagues that everyone sees the world differently, highlighting their ontological differences with the following analogy: ‘each one sees it from his/her own perspective. If one works with tiles, once you mention a medical sphere in front of him, he will remember the white tiles’ (Muhammad, Staff, Co-development Group Two). This methodological approach led to an elicitation of the multiple ontological positionings within the space. Staff identified how this difference of positioning relates to professions and led participants to recognise their shared objectives, challenges, and equally the many ways that they can resolve these. This evidences the opportunities of this approach in international humanitarian aid, as the method’s ability to create cross-cultural and interdisciplinary dialogues to co-construct healthcare services is evident.

Creating a method that upholds a culturally and socially responsive approach to knowledge production enabled Belal to enquire across disciplines and cultural contexts (Bananuka, Perry and Kadoma, 2023, p. 2). Belal made notes of comments on post-Its and displayed them for people to see on the A1 ‘comment charts’, and this travelled across the four co-development groups to the final analysis session. Staff participants remarked that in their perspective this design included all points of view, namely national and international staff alongside service users. Staff were curious to see the shared starting point but utterly different ending points between their group and the service users’ group.

Belal was not a neutral facilitator. He too was subject to and suffered from the shortfalls of the humanitarian aid sector. It was clear from his dialogue that he was invested in resolving the collapsing health system. He provided an analogy from this perspective which illustrates the lack of accountability and deep inequality dividing Lebanon. Belal drew on the similarities between him and staff in the room. He explained that ‘every time the son of the Health Minister gets sick, his father will put him on the plane and takes him to a foreign country to treat him without giving a thought for what is happening the healthcare sector in Lebanon. He wouldn't face the problems that *people like us* face (own emphasis). We need readiness and capabilities, because I need a medical centre that is specialized in this disease. I cannot take my son to a foreign country’

(Belal, Staff, Co-development Group Four). He gave primacy to relationships within the dialogue, sharing his own position to allow participants to share theirs in return. This moves away from Western intervention towards localisation of researchers, from extractive practices to reciprocity, and from harming trust to creating meaningful research relationships with people of refugee backgrounds - all processes towards deconstructing the colonial traditions of research (Berryman, SooHoo and Nevin, 2013).

### *Staff members' hidden and dominant voices*

There were voices that were hidden by dominant actors in the data generation process. Voices were overshadowed, and people felt that they could not contribute. Others, consciously or unconsciously, exerted control in the collaborative process (Wallerstein and Duran, 2006). This section will unravel the power dynamics, participant interactions, and associated tensions that were evident to Belal.

One particular illustration of this sits at the forefront of my mind when I think about how these interactions shaped participation. Belal's audio diary was a key tool in understanding how this humanitarian context responded to - and in part constructed its own - inequalities. In his audio diary at the end of the fourth Co-development group, Belal seemed confused. One of my favourite questions was to ask Belal, 'What surprised you the most about the session?' He reflected on how 'there was this lady who didn't talk at all', and said he tried 'to make her talk'. This reveals the power formation in practice amongst staff members, mirroring decision-making in the workplace. He confided that as he was packing up, a staff participant came back into the room. She closed the door and confided in him: 'Can I tell you something? […] I can answer all of these things, and do more, bs [interjection, translates to 'but'] I feel the staff members who were here are always together. I feel alone, so I didn't want to give any opinion because they're trying to mock me' (Belal, Audio diary, Staff, Co-development Group Four). These hidden voices, as Wallerstein and Duran (2006) remind us, reveal a world that is otherwise concealed from the researcher, hierarchies of power that play out through exclusion, intimidation and oppression (Wallerstein and Duran, 2006, p. 316).

As the co-development groups proceeded, it became clearer that Belal was struggling to encourage all participants to contribute equally. From his perspective, their ability to participate stemmed from their role in the organisation. Belal sought to maximise the data generated through this process of enquiry, he did so by ‘find[ing] doctors to participate because they’re sharing a lot’ compared to staff who work in ‘finance or IT […] because they’re not talking about the health sector in the same perspective’. He was seeking equality of contributions. He hoped to find a ‘more balanced way’ to get all participants to contribute equally (Belal, Audio diary, Staff, Co-development Group Two).

Group dynamics were in part shaped by a person’s role in the organisation, age and gender. Below are two illustrations of incidents of male-male and male-female interactions.

> Male: I am still thinking of the words I will choose, because we are talking about examples, but to choose a title...
> Male: I think it's "meeting the needs". (Staff, Co-development Group Two)
>
> Female: ‘The questions are very broad, I can tell that the health fears are being taken seriously because sometimes the patient cannot access the needed information.’
> Male: ‘It stays in the category, it's either they get the information or they don't’. (Staff, Co-development Group Two)

Belal reflected on the relational power amongst staff in his audio diary. He explained that staff wouldn’t reply to a question until the older male doctor had spoken (Belal, Audio diary, Staff, Co-development Group Three). As participants considered a category title, or how to frame a challenge, this doctor’s perception swayed the group, influencing the opinion of others due to the respect and relative power he had in the room. When the other staff did speak, Belal detailed how they asked him for help with their answers as they trusted his opinion. This co-development group process generated an insight into decision-making processes in this thalassemia unit as these social interactions mirrored the workplace dynamics (Kitzinger, 1994, p. 105). These dynamics provided an understanding into what forms of knowledge and whose voices are valued. Similarly to the thalassemia unit, the power in the co-development group was not equitably shared. As Belal tried to encourage all staff to participate, sometimes staff interjected to function as a fact checker:

> Female: ‘In all hospitals where COVID sections were opened, many nurses and doctors were recruited’
> Male (interrupting): ‘Not all hospitals, many of them fired health workers’
> […]
> Belal: Do you see that certain health services were stopped due to the COVID-19 crisis?
> Male: Many surgeries were stopped, only the most urgent and important.
> Female: The surgeries weren't stopped, but clinic hours got shorter, the numbers were reduced, as the numbers of health workers were reduced in certain centres and hospital sectors.
> (Staff, Co-development Group One)

This collective group decision-making process and the interactions amongst staff of all positions at Médecins Sans Frontières shed a critical insight onto the tensions of power in the workplace (Kitzinger, 1994). This was exposed when staff narrated their interpretation of the context, leading their colleagues to interject, build on or reject perspectives, as they related to each other’s comments as a collective remembering of the chronicle of crises which unfolded (Kitzinger, 1994, p. 105). The power dimensions, and how these facilitated or prevented research participation, may have also been revealed through other methods of inquiry.

### *Participatory Practices: Navigating ‘Finger-Pointing' among Staff*

In the fourth co-development group, Belal rallied the participants with positive solutions-focused facilitation, using prompts such as ‘You are saying they removed the subsidies, so now getting to the location is very hard. How am I going to make sure these people are still coming to the centre?’ (Belal, Staff, Co-development Group Four).

Applying a strengths-based participatory research approach to problem solving highlighted the existing capital, specifically human capital, that staff feel is not being utilised to overcome the challenges they face. Humanitarian aid organisations often rely on what Afifi *et al.* (2020) term ‘deficient problem-orientated models’ rather than leveraging existing abilities and assets in the communities. This perhaps outdated and imbalanced approach to project development caused staff to express frustration. Belal shared a solution that service users proposed: to hand over healthcare entirely to international organisations. This was immediately contested by a staff member, whom I will call Ibrahim. He affirmed that ‘we are capable, we just don’t have the money’. Ibrahim identified strengths within their existing resources to overcome the challenges that existed. However, another participant, Zainab, agreed with the service users. She believed international organisations should lead, to empower Lebanese hospitals, ‘train them, teach them to work in the same way, but not to stay dependent’ (Staff, Co-development Group Four). While identifying deficits in health systems is crucial, it is equally important to identify and leverage existing capabilities, supporting sustainable solutions (Khan *et al.*, 2021).

Staff rarely agreed on the meanings of categories and how best to implement actionable solutions. Divisions emerged regarding whether staff believed it was their responsibility to reform the structures to improve patient care. Staff participants questioned, misunderstood, and disagreed on perceptions, challenges, and solutions. This reflects the greater discourse around challenges to humanitarian action and sustainability. Zainab expressed her unease with the cycle of dependency created and sustained by aid organizations, advocating for structural reforms aimed at achieving sustainable solutions: ‘I prefer to do a [economic development] project instead of letting this person be dependent on me and I give him transport [funds]’ (Staff, Co-development Group Four). This statement sparked a debate on whether humanitarian action should prioritise providing immediate care or ‘sustainable solutions’ (Staff, Co-development Group Four). These divisions provide insight into what management deemed possible ‘finger pointing’.

This ‘finger pointing’ - divided perspectives on challenges, their causes and solutions - has the potential power to capture ‘the political’ in this diverse social space, what Mouffe (1999) terms ‘agonistic pluralism’ amongst adversaries. Belal steered these divergent, loud and quiet voices to arrive at a rational consensus, without exclusion (Mouffe, 1999, p. 755). Belal described the setting as comfortable. He never described it as hostile ‘because they all know each other so in the beginning they were, like, talking to each other. Like I felt comfortable in this atmosphere, and they were, like, super happy to attend also’ (Belal, Audio diary, Staff, Co-development Group One). While staff rarely agreed on the meanings of categories or the best solutions, it was feasible that they could leverage their collegiality to reach a shared goal.

As people were getting ready to leave the room, Belal overheard staff identifying why they enjoyed the method: because it ‘started from scratch’, that the purpose wasn’t to ‘solve everything’ but rather that ‘we start from the small things and carry it into the work until we reach a place to give solutions’. Belal narrated that the emphasis on the ‘small things’, was important for staff who cited examples like ‘living capability’, ‘dietary pattern’, ‘travel’, ‘their address’, ‘mental health’ (Staff Co-development Group Four). Belal spurred them on during his facilitation by asking, ‘How can we see the next steps so the ability to access gets better?’ Staff praised the ‘small things’ - the tangible, actionable health effects they could co-create and the solutions for use in their work. A staff member explained that this approach ‘opened our eyes to see things we didn't notice before. It's refreshing. It helps in embodying the medical healthcare sector in Lebanon’, while other staff chimed in to applaud the categorisation process, as they didn’t immediately focus on changes that the organisation needed, but rather were able to ‘start from the small details, building a greater idea’ (Ibrahim, Staff, Co-development Group Four).

The co-development group processes involved risk and open experimentation. Staff discussed how one challenge in their work was the racism and prejudice staff had towards their patients. Staff explained they saw this most acutely with new Lebanese staff and their interactions with Syrian patients. The atmosphere was uncomfortable, leading staff member Zainab to apologise to Belal, who is from Syria, an illustration of self-censorship as she summarised the concern, ‘Yes, for example, sorry for saying that, but sometimes you find: “Oh these are Syrians? They are refugees.” I think it is related to the psyche of the people. How to reduce racism’ (Staff, Co-development Group Four). Staff detailed that the space of the thalassemia clinic facilitated the deconstruction of the racial formation process (Saperstein, Penner and Light, 2013; Omi and Winant, 1993). Staff detailed how they witnessed ongoing and dynamic interactions between staff and patients within the structures of Médecins Sans Frontières, which demonstrated how race was socially deconstructed through interactions over the length of time working in the space of aid. This was evident, participants explained, when new staff members joined the team and communicated racialised ideologies. By asking for solutions to workplace challenges that Belal was able to uncover, the extent of cultural stereotyping (Napier *et al.*, 2014) was revealed and, most importantly, how staff believe this can be resolved was discussed.

The proximity and place were identified as significant in the racial deconstruction process. Zainab explained that the closer a staff member works with Syrians, the faster racial formation deconstructs: ‘Maybe they saw their suffering. Also the people who work in the field, they change faster’ (Zainab, Co-development Group Four, Staff). There were similar instances of prejudice described towards people from Ethiopia, a country with a high number of domestic workers in Lebanon. Aiza admitted that if she saw an Ethiopian at Médecins Sans Frontières, she would make an assumption that they had ‘come here to clean’, and that she wasn’t the only person who holds this assumption. Collectively staff acknowledged the harmful stereotyping they had previously held, and some they still held, but that ultimately its deconstruction would not have been possible without working in the thalassemia unit:

> Let me tell you something, as MSF staff, if you put us in comparison with another hospital that didn't work with refugees, you find a lot of discrimination. You now treat the Syrian child like the Lebanese child, but if you were in a different hospital, you would be discriminating (Zainab, Staff, Co-development Group Four).

What is significant is the juxtaposition of racial construction and deconstruction occurring in this space. The structures of aid created a workplace norm of inequality based on Hegelian constructs of Orient and Occident. Yet, though employing this methodological process, staff identified how by working with Médecins Sans Frontières, their constructs of what it means to be ‘Syrian’ or ‘Ethiopian’ were challenged, and they deconstructed their discriminatory racialised perspective (Kitzinger, 1994, p. 113). Through participant interaction in the co-development group, it was demonstrated that medical staff perspectives were highly respected. Yet the emphasis illustrated above on knowledge accrued through personal experience, personal evidence, and anecdotes seemed to be of equal importance in making sense of the challenges facing Médecins Sans Frontières patients, their families and staff. Through the co-development group process, staff identified that racial stereotyping was a challenge that the organisation must overcome, which echoes calls by humanitarian staff who have witnessed and experienced racism in the aid sector (The New Humanitarian, 2020).

### *Co-developing Solutions with Service Users*

As was detailed in the third chapter, the same methodology was implemented with both participant groups. Belal asked similar questions to service users as he did staff, yet the perspectives on challenges, prioritisation, categorisation, and interpretations of solutions differed. I believe this is due to the relational power in the space, which restricted participation. These aspects will be explored methodologically, considering how they revealed cultural pluralism, hidden voices, and the process of prioritisation in the co-development group processes. Table 9 Service User Co-development Group Four: Participant solutions to identified (below) provides an overview of the interpretation and prioritisation of the second, third and fourth co-development groups. I devised this table as a way to illustrate the similarities and differences between it and Table 8 Staff Co-development Group Four: Solutions to problems identified. Moreover, it centres service user voice and evidences the harm of the categories of access for service users, illustrated by the age limitation for care in paediatric unit (‘Accessibility’ received one vote). For two participants, 'Services that Stopped’ was their greatest concern, showing the harms of temporary NGO healthcare, which results in a regression between paying for food and medicine. Finally, the most popular category was ‘Health Sector Deficit’. According to service users, the solution to this issue was to permanently hand over healthcare to a foreign party. Syrian participants strongly asserted that Lebanese institutions were incapable of solving anything in their lives in Lebanon, leading to an ultimate distrust of these institutions.

Table 9 Service User Co-development Group Four: Participant solutions to identified problems

| **Session Two: Category** | Session Three: Vote and Reasoning | Session Four: Solutions |
|---|---|---|

| | | |
|---|---|---|
| **SERVICE ACCESSIBILITY** | 1<br>‘For me it's service accessibility’ | • ‘To have a guide’<br>• **Belal**: ‘What do you think of a mobile clinic?’ **Male**: ‘That would be a great solution.’<br>• ‘Expanding the age of patients’ |
| **DEALING WITH BENEFICIARIES** | 0 | • ‘By coordination between MSF and other medical centres or doctors at least by making a phone call’ |
| **SERVICES THAT HAVE STOPPED** | 2<br>‘Because for me it's the main issue here in Lebanon, like medications, foodstuffs, and without proper food how are they supposed to get well with the treatment? Also diesel, due to the high prices, we are not able to afford diesel for the heating’ | • ‘To establish a centre specializing in distributing medications and drugs for Syrians. You go to a pharmacy asking for Panadol, they tell you we don't have, another one who happens to be Lebanese enters asking for the same drug, they give it to him.’ |
| **HEALTH SECTOR DEFICIT** | 3<br>‘If the health sector deficit got solved, everything else would be solved’ | • ‘Some foreign party, a foreign organization, should handle the matter.’ |
| **EXTERNAL EFFECTS** | 0 | • ‘In foreign countries, they take care of the patients, the medical services are better, many people went there, did operations and got |

| | | |
|---|---|---|
| | ‘Emigration’ | better and cured of their diseases.’<br>• ‘In foreign countries, even if no operation was done, the general status of the patient would be better.’ |

*Facilitating Dialogue with Service Users*

Belal facilitated safe spaces for service user participants to share their stories during the co-development groups. Service users were the mothers and fathers of the Syrian paediatric patients. Belal learned that most of the participants were unable to read and write in Arabic. In response, he encouraged multiple forms of expression, moving past standard reading and writing literacies. Some participants expressed themselves through drawing; others used drama to act out interactions:

> She was like telling us that one of the doctors, he didn't, like, examine their child in an appropriate way. So she, like, performed the situation yanni, how he used the materials and what he told her and the expression of the face also (Belal, Audio diary, Service Users Co-development Group One).

The application of these participatory methods led to collaborative learning and action. Belal summarised the mutual co-learning process like this: ‘We learned that there's a danger to reaching the centre, as some people might be arrested at checkpoints, or be robbed. The question was what can we change in order to create a space that is safer’ (Belal, Service User Co-development Group Three). Belal displayed the answers on the A1 ‘comment charts’ and shared this across groups allowing for the participants to learn from convergent and divergent perspectives. This enabled the transfer of solutions proposed by staff and service users, generating meaningful dialogue, for instance staff’s proposal of a mobile medical unit as a resolution to the aforementioned access challenges. When participants are affected by a shared problem, they can collaboratively generate creative solutions for implementation (de Brún *et al.*, 2017). This illustrates the strength of this method as it facilitates knowledge exchange between and amongst participant groups. This approach to responding to participant literacies and preferences in participation demonstrates the responsiveness needed for an adaptable method that is suited for fragile, low-resource contexts. I argue in favour of moving beyond traditional ways of communicating in research, favouring openness and flexibility and responding to participant preference where possible (Boydell *et al.*, 2016).

In Belal's audio diary, he also narrated the many challenges he encountered when facilitating the group discussion. One illustration of this was the cultural differences and subsequent stereotyping participants detailed, conversations which Belal skilfully navigated to retain the feeling of a safe and encouraging space during research facilitation. Our research participants were from diverse backgrounds, and some participants held stereotypes about other participants, which made communication more challenging. As Belal led the second co-development group, in which participants sorted their identified issues into categories, he detailed how one woman asserted that some Syrians 'have a lot of money but want to live in bad conditions', and that the consequence of this is that Lebanese people condemn all Syrians for 'getting aid from the UNHCR [United Nations High Commissioner for Refugees] by the dollar' (Belal, Audio diary, Service Users Co-development Group Two). This cultural scapegoating created tension in the room, as one participant was from the area of Syria that the woman had specified. This again evidences the importance of working with a facilitator who has a deep understanding of the social constructions of power, and who can navigate these in a respectful way. Another illustration of in-group collisions was that one participant insinuated that another was 'undeserving' of care. There were deep-seeded divisions which unfolded in this data generation, caused by the scarcity of resources in Lebanon. Through open communication, Belal facilitated the group to overcome the collisions that emerged in the co-development group.

Aid beneficiaries are often portrayed as a homogenous group, but the contention among participants and the diversity of their cultural backgrounds as service users counteracts this concept (Fallon and Brown, 2002). Such interactions resist the Western homogenous representation of the Orient and captures the social dynamics of participant intra-group power relations. As I will demonstrate in Chapter Five, many service users previously had private healthcare, but the economic collapse had caused them to seek no-cost healthcare for the first time, which shaped their perceptions of Médecins Sans Frontières services. People used to private healthcare were seeking help from the same places as the most marginalised. This demonstrates the diversity of people and backgrounds accessing humanitarian assistance in Lebanon at that time. To conclude, the service user group members were not homogenous, meaning their expectations of healthcare, experiences of using the thalassemia service, and perceptions of issues and solutions varied greatly. This emphasises the importance of hearing and considering patient voices in decision-making processes related to treatment options and experiences of care, as it evidences the challenges which arise when service user experiences and perspectives are not heard and considered, for example the harms of stereotyping (Napier *et al.*, 2014).

### *Service User's Hidden Voices: 'It's okay, my husband spoke'*

Belal asked the same questions to staff and service user groups. What was similar across groups was how their interactions revealed the relational aspect of power. Power was negotiated, contested and exerted by service user participants in relation to one another. Participants' socioeconomic status and gender shaped intra-group perceptions and stereotyping as some were perceived as having more influence and were subsequently treated differently by fellow service users, with varying levels of regard or esteem.

de Brún *et al.* (2017) implemented a similar co-development group model across Europe with service users and staff to collectively create, categorise, and vote on identified solutions to healthcare service problems. The researchers described a 'positive, trusting atmosphere whereby all stakeholders could express their views' (de Brún et al., 2017, p. 1). The co-development group method in this study generated a different result. With service users, Belal believed that only some participants - often two of six attendees - expressed their opinions. I suspect there are many reasons behind this. For example, one participant was hard of hearing, but did not have a hearing aid, an indication of the intersecting failure of health systems. Another issue could have been the lack of trust among participants, which resulted in them refraining from sharing their perspective. This could have been caused by a fear of judgement. Belal narrated explicit examples of participants feeling self-conscious about their handwriting, or unspoken fears. Where he could, Belal supported participation by creating space for quieter participants to speak, or by reciprocating stories, which was sometimes successful. He said, 'Eventually yanni ['yanni' is an Arabic interjection that translates to ‘meaning’], like, we broke ice in a way so he started talking’, but for others the barriers to participation were too high to overcome (Belal, Audio diary, Service Users Co-development Group Four).

Sharing and reciprocity are central principles to decolonial research, and this is an approach that Belal tried to implement throughout his facilitation. He created a space for reciprocal storytelling with the Syrian families. Belal opened each session by reminding participants of how they have, in part, shared migration journeys: ‘Although all of us here are Syrians, Lebanese now began to go to these places [NGOs] as they’re cheaper. Some people said the interaction didn't change, but if you have another answer, we can add it here' (Belal, Service User Co-development Group Three).

Belal was not a ‘neutral observer’ in the research process, as evidenced by his reciprocal storytelling in the process of enquiry. It is important to consider how participation is a spectrum for both participant and facilitator. As Belal steered conversations, leading dialogue in an effort to facilitate active participation, his enthusiasm for reciprocity was received by participants in different ways, as they often shared aspects of their own experiences in relation to Belal’s. For example, during a discussion with parents about their COVID-19 vaccine hesitancy, one participant directly asked him, ‘Did you receive the vaccine?’ In response, he shared his healthcare journey with them, practicing reciprocal story exchanges: ‘I talked about, like, a personal experience with them just to let them like feel, you know, I'm sharing also with you’ (Belal, Audio diary, Service User Co-development Group One). In another discussion, he related to experiences of dismissal, narrating to the Syrian parents how he was ‘told to treat myself by myself […] I was very sick’, to which Ayesha responded, ‘With all due respect, Mister Belal, this happens a lot here with us’ (Service User Co-development Group One). This conveys that perhaps his effort in creating a shared sense of understanding fell short. He detailed the invisible characteristics of his illness and an extreme case where he was rejected from care, yet for these participants, this experience of rejection is typical in their everyday lives. However, due to his effort to give primacy to relationships within this space and generously share his personal account without flaunting his knowledge, Belal said that he felt a sense of trust developing with the women, aligning with his decolonial and feminist approach to research facilitation (Berryman, SooHoo and Nevin, 2013).

Gender played a significant role in shaping participation in the space, revealing social norms and expectations about women's involvement in discussing politicised matters. There were six participants in each co-development group, which adhered to the hospital's COVID-19 restrictions at the time. The first co-development group had no males, while the final three had one, two and four, respectively. The gendered relational power was evident from Belal's reflection on the pattern of how women deferred to their husbands when asked for their perspectives on a matter. Belal prompted women during the co-development group process - 'Let's hear your opinion. Please, do you have an answer on this?' - to which Belal recalled female participants responding, 'No, I don't have an opinion on this. My husband, like, used to do these things so, like, no, I don't. I don't need to have opinions on it' (Belal, Audio diary, Service User Co-development Group One'). Belal reflected that he was surprised by how some of the women seemed afraid to speak. He reflected in his audio diary that they knew each other well because 'they even refer to each other not by the name, bs [Arabic interjection, translates to but], with the nickname like "imam hamed", you know, so that means that they knew each other' (Belal, Audio diary, Service User Co-development Group One). The apprehension and perceived threat of being reprimanded for sharing their perspectives, or that their perspective holds no value, seemed to lead some women to avoid participating in discussions. Their behaviour indicates a sense of powerlessness or fear to speak out in their lives. Research by Singh *et al.* (2021) evidences the reasons why it is imperative to conduct an intersectional analysis when researching with refugee women and girls, due to the sexism and racism embedded in the lives of forcibly displaced women and girls, social constructs that are intrinsically linked to colonial legacies. This data evidences the social construction of gender and the ways in which this construct shaped how women responded to questions, either by deferring to their husbands, which hindered their participation, or as they participated in groups together the familiar friendships between the women seemed to create a sense of ease and comfort as they shared stories from their lives.

### *Questioning Participatory Practices: 'Even if I vote, would it work?'*

I will now detail the outcome of the methodological process with regards to its potential for improving humanitarian healthcare with service users. I will detail the challenges and opportunities this process of enquiry can offer for researchers and practitioners who seek to decentre power in spaces of aid.

Facilitating voice, agency and empowerment is a crucial step in participatory methods. However, the context of Lebanon, the meeting room at Médecins Sans Frontières, and the British university-led research led by an unfamiliar facilitator, alongside many other likely forces at times created a setting of constraint (Holland *et al.*, 2010, p. 362). For agency in participation, participants must feel motivated. The absence of motivation reveals the oppressive harms caused by powerful institutions in their lives. It was not clear to me how participants felt about taking part in the research process or whether they felt like they had the opportunity to participate at all. There was a lack of trust articulated by participants. For instance, Yasmin voiced concern: 'Even if I vote, would it work?' (Service User Co-development Group Three). The structural violence of illegality, *i.e.*, the increasing threat of deportation, led to some participants presenting an absence of motivation, agency, and interest in contributing skills, ideas, and perspectives to make a positive impact for thalassemia treatment and humanitarian aid in Lebanon.

There seemed to be a misalignment between the research objective in the group and the motivation of the service users to participate in the research. This became apparent when Belal tried to lead group discussions using category generation. He focused on encouraging participants to collectively categorise challenges in thalassemia care: 'What might be the best way to communicate with each other, since we are facing the same problem?' He offered resolutions, 'a [advertisement] board saying "MSF is treating children with thalassemia". If madame saw this board three years ago she wouldn't have gone through such a struggle" (Belal, Service User Co-development Group Three). However, during these discussions, participants wanted to discuss the dwindling resources, including food, medications, and fuel. This participatory prioritisation was reflected in their voting outcome, with 'services that stopped' receiving two votes and ‘health sector deficit’ receiving three votes (Service User, Co-development Group Three).

Afifi *et al.* (2020) demonstrated the possibility of identifying solutions to community experienced determinants of ill-health when running a participatory research project in a humanitarian crisis. However, Belal found it difficult to keep participants focused on the micro (interpersonal) and meso (organisational) structures. A principal component of participants’ stories was their ‘need to be understood’, that in order for their hardships to feel seen, society must become more aware of thalassemia. This is one actionable solution resulting from this research. In the final session, Belal asked participants to contribute solutions. He expressed a sense of disappointment as he confided that from his perspective, the participants did not comprehend how to propose what he called ‘reasonable solutions’. He deliberated as to whether he had the ‘right’ participants as they were not able to give ‘good solutions’. Luborsky and Rubinstein (1995) identify three primary considerations when ‘sampling’ for appropriate ‘analytic units’ in qualitative research. Our participants fit the criteria if: i) they understood the context and represented the targeted sample: humanitarian aid beneficiary accessing a thalassemia service; ii) they interpreted their experiences of the process of the Médecins Sans Frontières service over a prolonged period of time; iii) they expressed what this meant for them within the broader social setting. I believe we had the ‘right’ participants, but I believe the specific issue-led research objective was unsuitable.

Ultimately, the solutions proposed by Syrian participants were of a legal and policy-oriented nature. These are hard to change, and were not the ’actionable solutions’ that this study was seeking; they were well beyond the scope of this project. While Belal emphasised this objective in the fourth co-development group, a vast proportion of the participant solutions focused on humanitarian relocation. I think for participants from Syria, who are subject to illegalisation from the Lebanese state, their primary concerns stem from this illegality. They spoke about what mattered to them. Just as this research focused on thalassemia, this missed the point at times for service users. In some ways, the ‘actionable solutions’ for the thalassemia unit also misses the point. Relocation - moving out of the informal settlements and away from the violence - underpins many of their challenges and solutions. This research found that this co-development group methodology can be used to meaningfully engage service users to collectively identify challenges and propose solutions, but it is essential for participants to identify what their primary challenges are.

### Balancing Priorities: What counts as relevant data?

Belal expressed a sense of defeat as he believed he had been unable to steer the conversation to keep participants ‘on topic’: ‘I'm not finding a way to make them, like, stop talking about irrelevant things, even, like, in a polite way, you know? So I don’t know if I'm able to do it or not. Yanni, I tried and it did not work well’ (Belal, Audio diary, Service User Co-development Group Two). The parents often discussed home remedies to manage healthcare needs and tactics to secure food, and expressed experiences of abuse, none of which Belal considered related to thalassemia treatment. This was a constant tension. Belal expressed that he felt like he was failing. Participants may have felt that he wasn’t listening to them, as he repeatedly steered the conversation back to thalassemia, or that their contribution of the challenge to secure fuel or food seemed irrelevant to him. As I have demonstrated, participants seemed apprehensive to express their perspectives, as detailed by the ‘silent voices’, and when they did share their experiences, the facilitator could perceive them as irrelevant. These insights taken together construct a narrative of dismissed patient voices. This finding demonstrates the importance of exploratory, flexible and participant-centred research with structurally marginalised populations.

The participants challenged the researcher-driven objective. We sought to explore thalassemia, a chronic illness with temporary solutions as a case study, and participants took this opportunity to bend the conversation in the direction that most mattered to them. This evidenced how issue-led research only partially (and sometimes not at all) speaks to the priorities of participants. Moving away from pre-determined methods and predefined research questions opens new opportunities for knowledge production and speaks to the decolonising of research practices. It decentres the focus of the researcher in favour of the agenda of the people (Muwanga-Zake, 2009). When reflecting on the research question, ‘Can a co-development group be used to meaningfully engage service users to collectively improve humanitarian healthcare?’, I answer that yes, it can be used to collectively improve healthcare, yet as researchers we miss the point if we rely solely on issue-led research. Participants explained why they participated in their own words. According to Noor: ‘We are talking to raise awareness, we need others to see this’, while Ayesha said, ‘We shared our experiences and opinions not to be hidden, but for all to see’ (Service User Co-development Group Two). I acknowledge the strength in issue-led research. These strengths by researchers in COVID-19 rapid response projects where specialist knowledge enabled researchers to anticipate and target a range of areas of enquiry to the benefit of the communities studied, in a timely manner. However, when pursuing an emancipatory agenda among the structurally marginalised, where possible, this research is evidence of the necessity to shape the research questions with participants at the beginning of the project. Rapid response research is necessary in humanitarian aid and would best suit issue-led research, yet this research found this approach conflicts with an emancipatory methodological approach. Ultimately, the agency that participants enacted in resisting the issue-led research was an unexpected insight.

The location of the research likely also had an effect on service user participants’ ability to discuss their concerns openly. For example, in the fourth co-development group, Belal explained how staff entered the meeting room twice as they were not aware the activity was taking place. Existing research concludes that it is advisable to use a familiar space that is already in regular use for group meetings where practical (Fallon and Brown, 2002), but I believe in this research, the surveillance of the participants’ everyday lives, as well as being in earshot of Médecins Sans Frontières staff, resulted in hesitancy in participation and some participants utilising this research as a stage for their performance of need.

Belal reflected on this performance in his audio diary. He explained how one participant shared how grateful she was to Médecins Sans Frontières. She did this, Belal speculated, as a way to demonstrate her need to the other participants. As illustrated previously, service users can conduct surveillance of who is deserving and who is not deserving of aid. Belal reflected that she acted out ‘how the Lebanese feel disgust towards the Syrians, they don’t love them, and that’s it'. He seemed annoyed as he narrated that ‘she performs the victim’, ‘that everything is messed up’, and how Médecins Sans Frontières is the saviour (Belal, Audio diary, Service Users Co-development Group Two). As staff were within constant earshot of the co-development groups, it is likely that this performance was for them to hear too, a narrative saying, ‘Don’t leave, we desperately need your service’. Evidence suggests that one of the many negative effects that people subject to the asylum system suffer from is the necessity to perform the deservingness of a patient; to present themselves as helpless (Huschke, 2014). This is necessitated by the politics of life and vast inequality that shapes the aid receiver and physician/aid provider constructs of humanitarian healthcare (Fassin, 2007). While Belal felt a sense of frustration at a performance of ‘Syrian refugee helplessness’, it is crucial to understand the relative power that led the participant to perform her deservingness as an aid recipient.

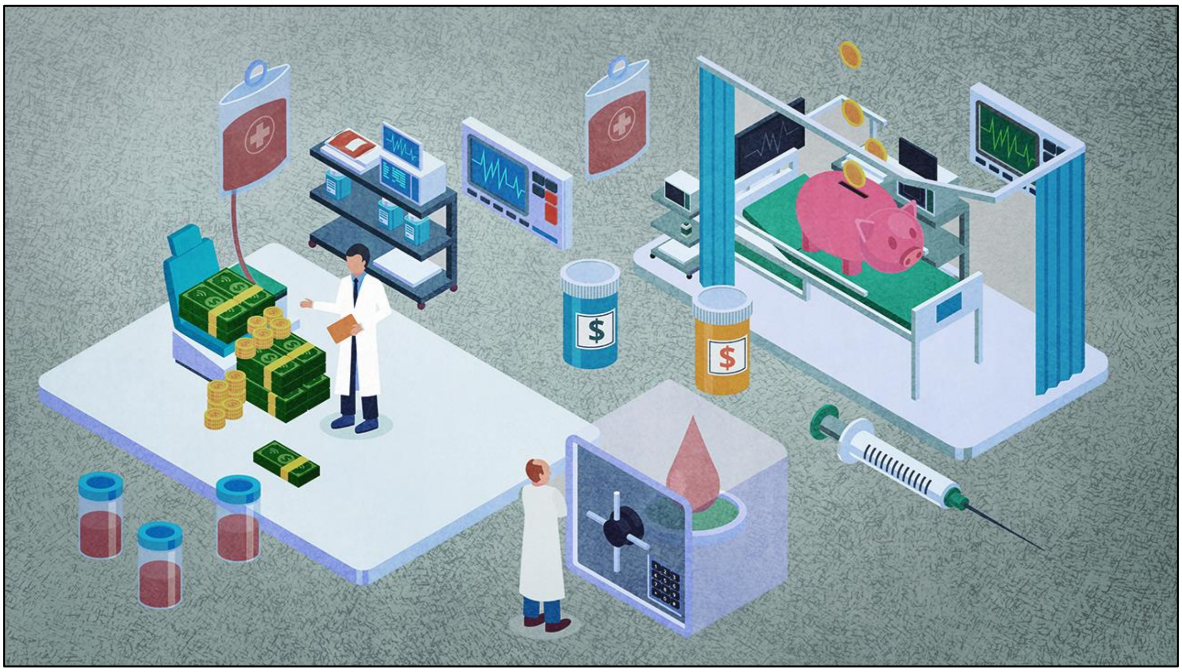


**Figure 4-11 Illustration by Nader Tabri**

### *Opportunities: ‘We say what’s inside of us and the rest is on God’*

This section will reflect on the co-development process, considering where it generated meaningful dialogue, offering improvements for thalassemia care, and where it fell short. One strength of applying this approach with aid beneficiaries is that it can improve representation of patient-voice and the integrity of evidence when justifying humanitarian intervention. This is in part what Fassin (2007) describes as the ‘politics of life’, whereby humanitarian intervention produces representations of people as suffering, rather than incorporating the geopolitical context in the narrative. While this study abstracted responses from their everyday experiences to the broader realm of the socio-political, cultural forces shaping this reality, participants reviewed the charts and, importantly, removed and redefined categories if they believed that they did not represent them. This process of consulting would not have been as feasible in more traditional forms of assessment such as focus group discussions:

> Belal: Do you think this [method] has meaning? Do you think that there's something that is not important or something that is not clear?
>
> Yasmin: No everything written is important.
>
> Belal: Do you think it expresses your experience?
>
> Yasmin: Of course, it's the life we're living.
>
> (Service User, Co-development Group Three)

The application of these participatory methods led to collaborative learning and action. As Belal summarised, ‘We learned that there's a danger to reaching the centre, as some people might be arrested at checkpoints, or be robbed. The question was, “What can we change in order to create a space that is safer?”’ (Belal, Service User, Co-development Group Three). Presenting the data on the comment charts and sharing this across groups allowed the participants to learn from convergent and divergent perspectives; the visual and tangible commentary charts were described as being colourful and aesthetically pleasing. It enabled the transfer of solutions proposed by staff and service users, generating meaningful dialogue, for instance staff’s proposal of a mobile medical unit as a resolution. When participants are affected by a shared problem, they can collaboratively generate creative solutions for implementation (de Brún *et al.*, 2017). This illustrates the strength of this method as it facilitates knowledge exchange between and amongst participant groups.

This method also facilitated collaborative action. Fatima warned that the understanding of thalassemia is not sufficient and demonstrated concern as ‘not all medications are appropriate for children’. She called on parents to get a second opinion as to what medications their children had been prescribed (Fatima, Service User Co-development Group One). These were transformative moments, a small contribution of generosity and care which strengthened group cohesion. There was a sense that participants ‘helped each other’ throughout the co-development group process (Belal, Audio diary, Service User Co-development Group Two). They helped each other through the method by collaboratively categorising and creating solutions, but also by sharing information and supporting each other to find blood donors for their children’s transfusions (Belal, Audio diary, Service User Co-development Group Three).

While the turnover required Belal to begin each session with a summary, it enabled participation in the demanding context in which the participants live and work. Belal offered accounts wherein they waited for an attendee who hoped to join, finally stating, ‘aaand she didn’t come’ (Belal, Audio diary, Service Users, Co-development group four). For those who could attend, Belal listened, reciprocated and supported involvement throughout the process. He facilitated a respectful and co-operative atmosphere where possible in an otherwise chaotic and censorious context (de Brún *et al.*, 2017).

It is possible to engage in meaningful research with structurally marginalised populations only if we, as researchers, listen and work with critique of our methodological approach, reflecting deeply on what approach would best address the contextualised problem. Over-researched populations in Lebanon have argued that they say the same answers to the same methods with no end. The solution isn’t to stop researching, but to find alternative practice (Sukarieh and Tannock, 2013). Finding alternative practice will enable sustainable knowledge production entanglements to continue to gather the evidence needed for shaping healthcare response in humanitarian contexts, wherever that may be (Bob-Milliar, 2022). This participatory methodology demonstrated the potential ability for this approach to support engagement and dialogue between stakeholders from academia, service users and staff (de Brún *et al.*, 2017). To conclude, in Belal’s words, ‘I’m not only saying this because I am taking part, but I feel like it’s the only new method that’s working with these communities. To separate this information in a different way, not just foreigners talking about the refugees – anyway – we did good’ (Interview, Belal).

## Centring the agenda of the people, not the researcher

In this chapter, I have answered Research Question One: ‘Can a co-development group be used to meaningfully engage staff and service users to collectively improve humanitarian healthcare service provision in Lebanon?’ I explored the opportunities and challenges of a digital design in a conflict-affected space. Employing a digital design, particularly through mediums like WhatsApp, allows for resource sharing and centres the voices of people affected by the international asylum system. However, there were challenges to overcome, including participant turnover, surveillance, power negotiations, and security and logistical issues. Despite these challenges, the project successfully generated the required data by maintaining a responsive design and trusting local researchers. I concluded that if a researcher is seeking to adhere to principles of decoloniality and to focus on relationship building in the research process, the infrastructure in low-resource settings does not allow for this. In-person participation for reciprocity and generosity is crucial to decolonial practices in humanitarian research.

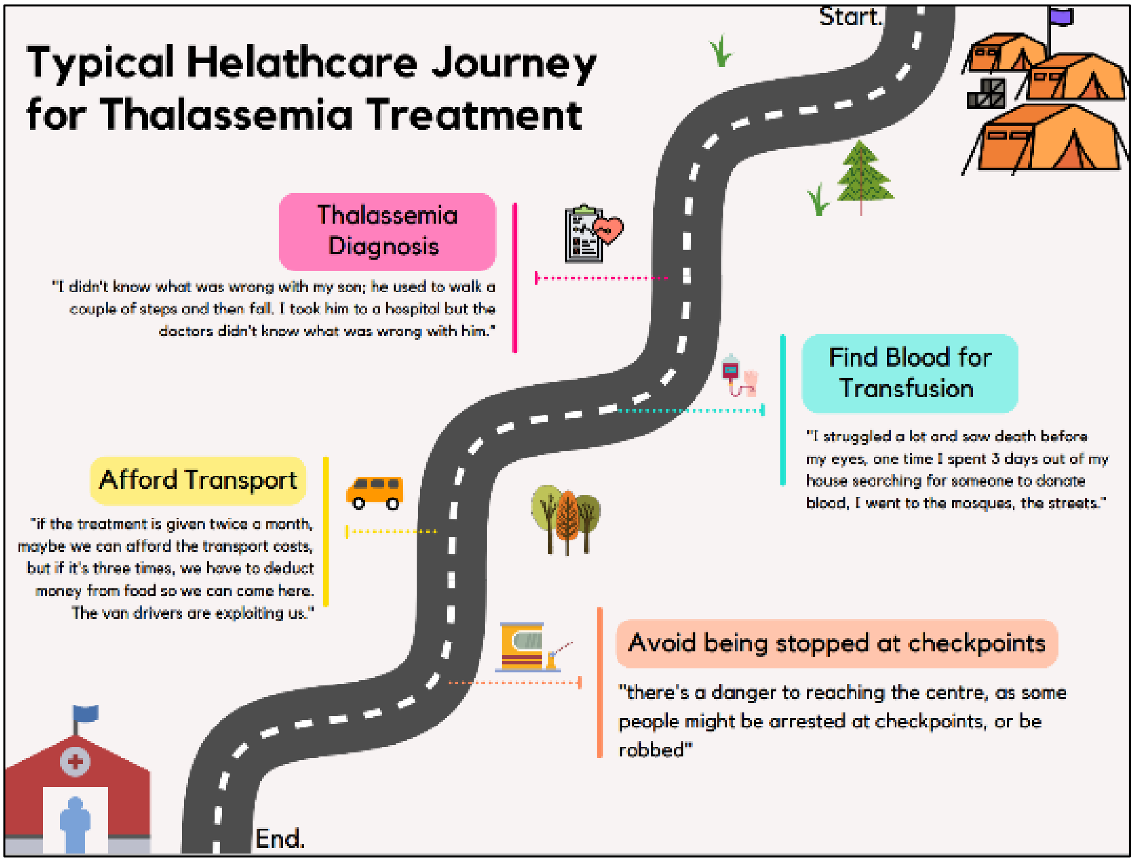
I opened this chapter reflecting on the logic of the research design and demonstrated that applying a digital design can trace humanitarian project mobilisation in real time, assessing access and service design suitability for people in need. I then applied the ‘the co-design spectrum’ for humanitarian projects devised by Robinson, Halford and Gaura (2022) (see Figure 4-2 The Spectrum of Co-Design). I concluded that this project reached level two, ‘co-creation and co-production’, of three, ‘transformative exchange through decentralising power’. From Belal’s perspective, he had just as much power in the project as I did, yet due to the academic system I work in I could not share the project’s resources entirely with people in Lebanon. This demonstrates the necessity to consider the equity needed for participation, and to adjust the research methodology to consider the relational power where necessary.

From a methodological perspective, this chapter documented the implementation of a co-development group with staff and service users in a Médecins Sans Frontières thalassemia unit. The results differed significantly. Staff followed the process, focusing on improving everyday work activities. The answer with staff was yes, they meaningfully engaged to collectively improve the thalassemia service. But the second participant group, service users, rather than discussing the thalassemia service, took the conversation in the direction that mattered most to them. There were moments when parents meaningfully engaged to collectively improve thalassemia diagnosis and treatment, yet Belal found it challenging to maintain this focus. The importance of locally identified solutions to humanitarian aid was pertinent to Belal. He believed it. He believed in the power of collective action, where people can 'choose what suits them' and remove the international intervention of a 'foreign person' who makes a selection of which lives it is possible or legitimate to save (Fassin, 2007). All the while, the service user participants were wary of the point of this process. The Syrian participants in this research faced barriers to participation in many areas of their lives; they were cautious of listing issues in the Médecins Sans Frontières office, participating in a democratic decision-making process, in a partially irrelevant issue-led research process. This highlights the limitations of issue-led research in emancipatory research and emphasizes the importance to consider the biosocial analysis of disease burdens. Researchers and practitioners need to consider all aspects of participants' lives, considering the structural violence they are subject to, and what needs to be done to enable equitable codesign and participation in spaces of aid in the Middle East.

I understand the harms of lauding participatory decolonial approaches when I do not uphold its procedures. If I could not be in Lebanon, does this mean it was less participatory? I have argued that no, this research was 'codesigned and co-created'; it was participatory with staff and with Belal. The co-development group process can be used to meaningfully create a dialogue to improve humanitarian healthcare. However, to adhere to decolonial research principles, it is crucial to be flexible and centre the agenda of the people, and not the researcher.

Figure 4-12 INGO Logo painted to the wall of state hospital. Taken May 2022

Figure 4-13 Scan to listen to a soundscape of the hospital's surroundings



**Typical Helathcare Journey for Thalassemia Treatment**

**Thalassemia Diagnosis**

"I didn't know what was wrong with my son; he used to walk a couple of steps and then fall. I took him to a hospital but the doctors didn't know what was wrong with him."

**Find Blood for Transfusion**

"I struggled a lot and saw death before my eyes, one time I spent 3 days out of my house searching for someone to donate blood, I went to the mosques, the streets."

**Afford Transport**

"if the treatment is given twice a month, maybe we can afford the transport costs, but if it's three times, we have to deduct money from food so we can come here. The van drivers are exploiting us."

**Avoid being stopped at checkpoints**

"there's a danger to reaching the centre, as some people might be arrested at checkpoints, or be robbed"

**Figure 4-14 Roadmap for thalassemia care using participant quotes. June 2023**

# Chapter 5 Shifting Sands

## Unscrambling the realities of humanitarian aid

This chapter provides insight into the decision-making processes in humanitarian healthcare service design and how staff and service users, the parents and carers of the paediatric children. experience these impacts. As was detailed in the methodology chapter, the objective of this study is to pursue phronetic social science (Flyvbjerg, 2001). This means I consider the challenges, consequences, and possibilities for change in spaces of aid as a means to contribute to a social and political praxis (Flyvbjerg, 2001, p. 4). This chapter presents a case study of humanitarian healthcare that illustrates the multiple crises in Lebanon from the perspectives of the three primary groups in spaces of aid: service users, national staff, and international staff. Discussing experiences across boundaries demonstrates how one incident can be experienced in multiple ways, revealing the construct of the inequitable formation of racialised structures (Omi and Winant, 1993). This chapter details the multiple powers at play rather than attempting to uncover deep meanings behind the actions and power governing the sector.

This chapter answers Research Question Two - ‘How were the MSF project and its service users affected by the multiple crises in Lebanon?’ - by exploring decisions, consequences, and the powers under negotiation in humanitarian healthcare settings. Specifically, this chapter will address three crises, proceeding chronologically with the first crisis, the economic collapse, and how it impacted the lives of staff and service users at Médecins Sans Frontières’s thalassemia unit. Second, I will explore how COVID-19 was experienced by the three participant groups, and third I will present how participants experienced the Beirut Blast.

Lebanon has witnessed many changes since my PhD research began in 2018, intensifying the demand for its already fractured and strained public services. The chronological chart below illustrates the multiple crises in Lebanon that have shaken the economic, social, cultural, and political structures of its society. Each of the crises listed in Figure 5-1 (below) perpetuated food insecurity, economic poverty, homelessness, and health inequalities as homes, hospitals, and livelihoods were closed or destroyed across the state. People living in Lebanon have become increasingly reliant on international humanitarian aid to meet their needs. This thesis cannot address all the consequences of the crises in Lebanon, but I hope its focus on one segment of the social realities will be useful to considering the societal consequences more generally and, most importantly, how it impacts families who are supporting children with thalassemia.

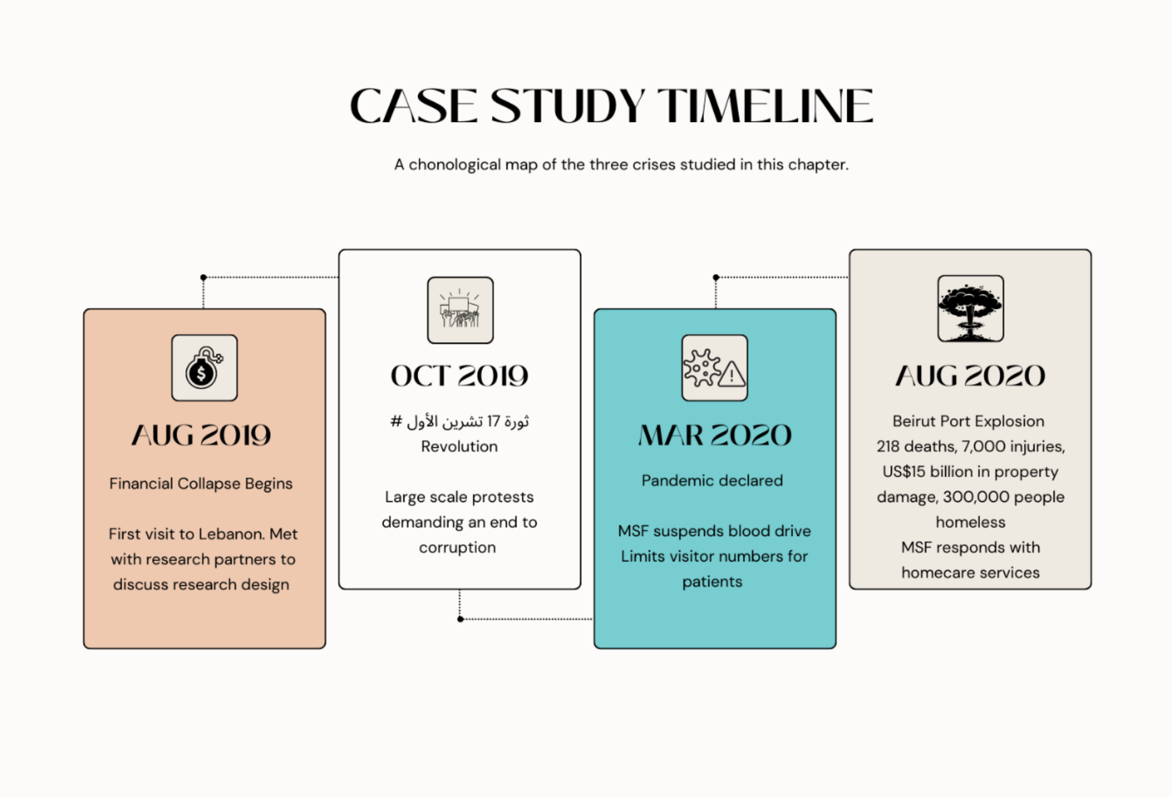


**Figure 5-1 A chronological timeline of the three crises studied in this chapter**

Figure 5-2 Image taken in Tripoli, May 2022

Figure 5-3 Scan to download a soundscape of Tripoli

## One of the worst economic collapses in recorded history.

> ‘Yesterday they removed the subsidies on everything, so getting [food] is becoming hard because the living capability of the people is low, and the prices are very high, so the solution... I don't think there is a solution’
> (Ibrahim, Staff, Co-development Group Four)

The Lebanese lira has been in freefall in recent years, with the currency being devalued by 80-90%, fluctuating daily. In March 2021, *The Financial Times* documented that the minimum monthly wage of LL675,000 per month was worth just US$67.50 (Jalabi, 2022). The UNHCR has estimated that nearly 90% of refugee populations live in poverty in Lebanon (Bosqui, 2020, p. 2). Taleb (2020) documents that the reason people believe the protests against corruption leading to the economic collapse stopped is that people faced extreme brutality from security forces when taking to the streets, and given the economic collapse, people’s concerns turned to securing food rather than political reform.

Figure 5-4 Beirut Graffiti, Taken August 2019

Figure 5-5 Beirut Graffiti; taken May 2022

The geopolitical power shaping Lebanon was revealed as Western powers intervened in response to the financial collapse. In an effort led by France, the

International Monetary Fund and the United Nations Secretary General asserted that Lebanon could only receive financial relief from the international community if it reformed its state politics (specifically the central bank system which Macron demanded) in line with their guidance (Jalabi, Lowe and Nader, 2020). No hard policies, such as state sanctions, were implemented. Furthermore, the interests of France in the region, particularly its relationship with Iran, have an impact on Lebanon's ability to achieve its state-building objectives, such as establishing a unified and robust national army. This demonstration of geopolitical network power unpacks the rules of inclusion for attaining such power. In an illustration of neo-colonial practices, France declared to its former colony that it is incapable of financial development without their economic support, and to receive this they must adhere to their conditions (Castells, 2016).

As was detailed in the literature review of this thesis, Lebanon was part of France’s colonial empire. This history is crucial for comprehending the ways in which colonial legacies continue to shape former colonies today. It is multifaceted, and there are many intermediate factors which stem from and perpetuate this; for instance, confessional power-sharing arrangements, the system of Governance requiring politics to be represented by religious groups according to their demographic weight. These arrangements were originally created for peace, but have perpetuated clientelism, sectarian tension, disproportionate representation, and inequalities. The focus on social identity in confessional power-sharing arrangements has been found to result in unequal treatment and the misuse of public funds due to political corruption (Nagle, 2019; Hughes, 2016). However, I argue that such Orientalist intervention by France in Lebanon in response to the economic collapse contributes to how citizens make sense of the absence of state healthcare systems and how this absence is met by French INGOs such as Médecins Sans Frontières and Médecins du Monde. Notably, this power is contested as other actors are also at play in Lebanon, including Eastern states such as Iran. Iran’s support for Hezbollah in Lebanon is complex; due to the limited scope of this PhD, I will refer to Salem (2006) and Wiegand (2009), who evidence how Lebanon has been used as a battleground for proxy conflicts between Iran and regional rivals via Hezbollah. This perpetuates political, security, and sectarian tensions, all of which impede

Lebanon’s development towards a more equal and stable society. Borrowing from Tuhiwai Smith (2021, p. 21), the persistence of colonising practices still hurts, still destroys, and reforms itself constantly.

**Figure 5-6 Graffiti in Beirut criticizing lebanese governance**

Humanitarian project delivery can be seen to mirror the wider geopolitical dynamics in the structural unequal power hierarchies between patients, national staff, and international staff, which mirrors the neo-colonial structures discussed so far; this has been evidenced by scholars such as Smirl (2015) and, more recently, James (2020b). Income disparity and inequitable access to resources amongst staff illustrate these hegemonic powers. This first subsection will document how the economic collapse shaped the everyday lives of service users, national staff and international staff in the thalassemia unit. It will reveal how staff and patients’ carers worked within the constraints of an economic collapse to secure thalassemia care for children suffering from the disease. Moreover, it will document the causes and consequences of social inequality at MSF Lebanon’s thalassemia unit.

## Service User Health Needs: I have a problem that is more important than food and drink

The economic collapse in Lebanon intensified hardship for the Syrian families who participated in this research. Belal opened the first co-development group by asking participants to share an insight into their everyday lives. The participants, whose children were treated by MSF for thalassemia, explained how necessities like medication and food had become increasingly scarce:

> Zara: Fruits, we haven't brought fruits to our home for a year now, the kid needs the vitamins in fruits.
> Fatima: Fruits are cheaper than potatoes. We are bringing more apples than potatoes to our homes.
> Layla: My son is 19 years old and needs a blood transfusion. I cannot afford the transfusion, medications are very expensive, also the hospital where we used to go is very expensive. I have a problem that is more important than food and drink.
> (Service User Co-development Group One)

de Certeau (1988) posits that ‘tactics’ are everyday actions of resistance - time pressured ways in which people without access to institutional power circumvent its violence. Parents detailed the ‘tactics’ they adopted to continue to provide the care their children needed for their thalassemia disease within the constraints of state violence, and how they pivoted everyday practices to survive in an economic collapse more broadly (de Certeau, 1988).

A woman whom I will call Zara explained how she began to bake bread rather than buy it in the shop as it is cheaper: ‘A kilo of flour is enough to bake several bundles of bread. We thought of a solution instead of asking someone for help’ (Zara, Service User Co-development Group One). Zara’s rejection of aid handouts provides an illustration of the ways service users resist the constructed narrative of ‘helpless’ ‘refugee’ created and reinforced by aid agencies.

Healthcare costs were another issue for most of the participants. The exploitation that participants detailed when purchasing medication illustrates the intersecting nature of the crises. The collapse of the economy intensified conflict between providers and patients, as providers sought to maximise income during uncertain times at the expense of the health of the structurally vulnerable. Participants argued that the healthcare professionals they had encountered before MSF had prioritised money over patient health: ‘What they care about is a material benefit; they offer expensive medicines’ (Fatima, Service User Co-development Group One). The service users often perceived healthcare providers as determining their healthcare needs based on their financial self-interest, and this hindered trust. One parent explained that when their child was born, it was ‘the beginning of their nightmare’, and that he had to pay £145 on hospital fees for every blood transfusion on a salary of £220 a month (Médecins Sans Frontières, 2020a). He described the humiliation he felt searching for blood for transfusions. When he could not pay for a transfusion and iron tablets, his daughter would be hospitalised due to organ failure, raising the hospital costs to as high as £1,460 for a hospital stay. While some healthcare for Syrian refugees is integrated within the national health system, service users detailed how they experienced multiple hurdles in accessing thalassemia care, increasing pressure on either the parents and NGOs to purchase expensive noncommunicable disease drugs. Before the crises, the MoPH in Lebanon used to subsidize these drugs, but this is no longer the case.

Participants swapped stories of accrued debt and struggles to care for their children without having access to the information they believed could support them in securing their children’s thalassemia treatment. For instance, one mother explained that it was only when she told the public hospital that she could no longer afford the thalassemia treatment for her child due to their increased price that they informed her about a free service in the locality (Nadia, Service User, Participant Consultation).

In the absence of knowing about MSF’s no cost thalassemia services, or perhaps when they could not afford the bus or the fuel needed for their motorbikes to reach the service, participants detailed stories of foregoing healthcare treatment, they detailed the tactics they adopted to navigate these constraints in the economic collapse. For instance, Zara told Belal how she cared for her children when they were unwell: ‘When we're not financially capable of visiting the hospital, I use flower tea, rosemary and chamomile, [they] are always in stock at home’ (Zara, Service User Co-development Group One). The neoliberal healthcare system in Lebanon resulted in an inequitable and inefficient system, which was revealed by the economic collapse. There were programmes and buffer systems implemented by the Ministry of Health, as detailed in the literature review, but the service users in this study did not perceive this as being an adequate support for their families’ healthcare needs. Participants depicted the challenges they faced in the worsening economy, illustrating the ways in which the resources they rely on to care for their children’s thalassemia are often outside their grasp due to the confines of power. Families are illegalised by the state, and they experience this illegalisation in forms of discrimination when purchasing medicine at a pharmacy, being rejected from state health and social care in thalassemia support services, and devastating poverty which results in increasing malnutrition, all of which has disastrous health consequences for the whole family.

### International Staff: Standing in the Emergency Room thinking, ‘Where is everyone?’

> ‘People could now die from totally avoidable, and otherwise easily treatable causes, just because hospitals don’t have electricity, the right supplies, or staff’
> (Médecins Sans Frontières, 2021b)

The economic collapse in Lebanon reshaped governance structures of aid at the national and international levels. This section will illustrate how international staff made sense of the economic collapse, discussing why and how they adapted the services in response, and reflect on humanitarian principles in practice to explore how power is formed, resisted, and experienced. I will detail the effects of the economic collapse through analysis of documents from MSF’s digital archive and by drawing from an unstructured interview with a senior staff member in Beirut May 2022, whom I will call Charlotte.

In 2020, due to the freefall of the Lebanese Lira, MSF headquarters made the transition to pay all staff employed at MSF Lebanon in USD, rather than the typical arrangement of only international staff having access to USD. This decision to pay in USD was taken by many international aid organisations operating in Lebanon. The negative consequences of the economic collapse became increasingly visible to me during my visit to Lebanon in May 2022. I documented the everyday project costs, including salaries, import costs for iron chelation medications, and fuel for the blood bank generators and the blood drive. Costs were spiralling due to 90% currency inflation and the port explosion had caused import complications. As an illustration, Figure 5-7 shows a sign which lists the daily rate of the fluctuating lira. The financial constraints unfolded with difficulty amongst international staff who managed the thalassemia unit budget.

**Figure 5-7 Sign which listed the daily rate of LL to USD at the entrance to a store in Beirut The exchange rate was 1,500 LL before October 2019.**

Hospitals in Lebanon began prioritising Lebanese patients in an effort to ration medications, a process which excluded Syrians further from health and social support. In response to this, in 2020, MSF asserted that the need to continue their thalassemia programme was greater than ever due to the economic collapse (Médecins Sans Frontières, 2020c). MSF was not immune to the effects of the collapse; the high cost of necessary drugs like the oral iron chelator 'deferasirox' limited the number of patients who could be treated (Médecins Sans Frontières, 2019).

After what Charlotte described as difficult negotiations, MSF headquarters decided to close the operations in Lebanon due to what was deemed unsustainably high costs and allocate the funding elsewhere, where more lives could be saved. She explained that Lebanese staff were ‘being paid and living like kings’ compared to the median Lebanese salary (Research Diary, May 2022). I encountered a similar sense of discomfort over high costs with headquarters staff as they relayed the decision to close the project in research meetings. Afghanistan was pointed to as a cost-effective alternative project. Staff applied a utilitarian rationale, where actions are evaluated based on their ability to produce the greatest amount of overall well-being. They compared Lebanon, where the thalassemia unit treated ten children a day, to Afghanistan. Charlotte pointed to malnutrition in Afghanistan as an illustration of how MSF can maximise the benefit for the greatest number of patients using the resources available; the low-cost treatment of plumpy’nut (a peanut-based paste to treat severe acute malnutrition) can be offered to a high number of children, compared to the high-cost thalassemia unit, which treats a comparatively low number of children. In alignment with Leaning, Spiegel and Crisp (2011), I believe that value should be determined by both the cost of the treatment and operations and the relative value of the healthcare both at a population health level and for what it means - the value - for the individuals and their families (Leaning, Spiegel and Crisp, 2011).

In 2020, MSF highlighted that the demand for their services had reached an all-time high due to increasing poverty. People who had previously relied on Lebanon's private healthcare system could no longer afford it. MSF staff were also taken aback by a second unforeseen effect of the economic collapse — the realization that Lebanese patients had a lack of acceptance towards MSF. Charlotte, the former head of mission, admitted staff often asked, ‘Where is everyone?’, referring to the absence of Lebanese patients presenting at the newly opened emergency room (opening had been delayed due to the COVID-19 pandemic). When speculating on why this might be, 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 this lack of acceptance was because Lebanese patients perceived MSF as cheap.

As many Lebanese citizens had previously had private healthcare, this shaped their perception of MSF services; they would have to seek healthcare where Syrian refugees were treated. For instance, to keep costs low, aid organisations use generic drugs, such as a generic iron chelation oral medication. Charlotte detailed how Lebanese patients sought brands of drug they were familiar with and trusted. She suggested that the use of generic drugs was not acceptable to Lebanese patients and that there is a stigma associated with consuming what are seen as cheap products. This stigma limited Lebanese uptake of MSF services, despite the increased need as a consequence of economic collapse. This unmet expectation shaped headquarters' decision to close the thalassemia unit and operations more broadly.

Charlotte seemed frustrated and perplexed over what she interpreted as a rejection of Médecins Sans Frontières' services. This rejection of reciprocal exchange, whereby MSF staff offer a free service and patients reciprocate with gratitude, seemed to be unfamiliar for the organisation. Charlotte made sense of it by comparing her experiences with low-income countries and the welcome reception the MSF operations received. Fassin (2020) highlights the frustration that can arise when a gift, such as humanitarian care, is rejected on the grounds of the asymmetrical nature of the exchange.

Alongside MSF-patient relationship challenges, the comparative difficulties in institutional-state relationship in middle-income countries also pose hurdles. Charlotte, drawing from her decade of experience, detailed how MSF faces challenges in Lebanon as they do not have the same level of recognition or status as in low-income countries. For instance, the Lebanese state requires MSF to pay rent and import tax on medications, resulting in higher costs coupled with lower patient trust (Research Diary, May 2022). This research echoes Fassin's (2020) depiction of frustration, or perhaps bewilderment or discontentment when the gift of humanitarian healthcare is not met with gratitude.

To summarise, there were three primary experiences reported by international staff caused by the economic collapse. These were soaring project costs due to the decision to pay staff in dollars, compounded by the state's requirement that MSF pay rent on clinic and office space and import tax on medications. The economic collapse also led to an expected increase in patients, but this never came to fruition in part due to a stigma associated with MSF being cheap. These compounding financial factors contributed to the unit's eventual closure.

## Exploring national staff's perspective on the economic collapse

'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)

As discussed so far, the economic collapse had a profound effect on the lives of all participants in this study. This section will detail how national staff experienced this change. These insights will reveal the nature of power shifts during an economic collapse in spaces of aid.

The economic collapse escalated in 2020. During my visit to MSF projects in March 2020, I witnessed national staff asking senior management on numerous occasions if they could be paid in USD. Below is an excerpt from my research diary at that time:

> In small side conversations and in meetings, Lebanese staff continue to ask if they can be paid in dollars. The Lebanese economy has plummeted in the last few years, and Lebanese staff no longer have enough money to pay rent, bills, and buy food. Other NGOs have switched to paying their staff in dollars, yet MSF refused to do this as they say that if they pay Lebanese staff in dollars then they'll have to make exemptions for other countries as well when their economies deteriorate (Research Diary, March 2020).

As was argued in the literature review of this thesis, the tiered salary system in the humanitarian aid sector is a prime example postcoloniality, categories and hierarchies at play, and the importance of challenging relational power. The above excerpt demonstrates how national staff, the subordinate group, challenged the dichotomised, racialised division of staff structures, resources, and rewards within the social hierarchy (Saperstein, Penner and Light, 2013, p. 364). This trace of troubling and deconstructing norms of categories is a display of resistance, a step towards deconstructing postcolonial logics of inequality (Jackson and Mazzei, 2011). In the two years during which national staff received payment in USD, the playing field was levelled between those who did and did not have access to a stable currency. This renegotiation of norms is significant as it demonstrates the relationality of power (Castells, 2016).

However, as has been outlined, the consequences of this change contributed to higher salaries and increased overhead costs, and led to the closure of the thalassemia unit.

While national staff could secure their own livelihoods in the collapse, witnessing the degradation in the quality of the patients' lives greatly affected their mental health. They reflected on the extreme poverty that the patients of the clinic faced and deliberated on what they could do to resolve this hardship. One concern was the absence of iron medications for thalassemia patients. Defective procurement processes were frequently pointed to as the root cause of this absence, with international trade slowed as a result (International Trade Adminstration, 2023), alongside the explosion of the country's only working port. The official website of the US International Trade Administration lists the following barriers to effective markets in Lebanon: institutionalized corruption, bureaucratic over-regulation, arbitrary licensing, complex customs procedures, outdated legislation, an ineffectual judicial system, poor telecommunication services, slow internet speeds, poor electricity provision, inconsistent interpretation of laws, and fragmented and opaque procurement processes (International Trade Adminstration, 2023).

Staff understood that they alone could not resolve these import challenges. Instead, they proposed extensive health promotion campaigns for thalassemia patients, a way to support patients as an illness prevention measure. This idea was proposed by a staff member I will call Hamza, who reasoned: 'in refugees' culture […] all the refugees came to our ER, they miss the health awareness (coughs) yanni ... even if MSF is providing healthcare, I think they should provide more cultural level and health awareness' (Hamza, Staff, Analysis Consultation). Other examples were proposed, including infection prevention control campaigns, antimicrobial resistance campaigns and the importance of presenting early at the healthcare service at the onset of illness.

Not all staff embraced the proposal for health awareness campaigns. For instance, a staff member explained that even with exemplary infection prevention control, their patients will still have thalassemia and will still need iron chelation medications and blood transfusions. They reasoned this by pointing to the structures of poverty and abuse that the families they care for are subject to in the economic collapse. For example, many patients cannot afford medications, and if they do borrow money to purchase medications, these can be tampered with. The stories staff detailed of harm to their patients were conveyed with sorrow. The tampering of medications illustrates the intersecting nature of the crises. Miriam explained the harm caused to cancer patients: ‘they were obtaining those, but it ended up it was diluted with water. Yanni ... there is no one who’s, like, the focal point later on to accuse or to ... no one was accused. Patients were dead at the end’ (Miriam, Analysis Consultation, Staff). To understand these tampered medications more clearly, I spoke with the Barbara Nassar Association, an NGO for cancer patient support. In discussions over WhatsApp, a staff member explained that most of the tampered medications were imported from Turkey and Syria, and these were most likely *Keytruda*, pembrolizumab, an antibody used in cancer immunotherapy (WhatsApp Message, July 2023).

Another solution to the accessibility challenges observed by staff was addressing the prohibitive cost of traveling to thalassemia appointments for patients. They proposed that this could be solved by a mobile medical clinic: ‘It's either they come or you go, you ease their trip to your centre, or you visit them at their homes and provide the service’ (Ibrahim, Staff, Co-development Group Four). Staff witnessed how travel hindered the ability for patients to secure the care they needed, exposing the reality that MSF services, rather than their patients, are ‘hard to reach’.

## Discussion

One primary transition that the thalassemia unit underwent in the economic crisis was the deterioration of the conditions in which the patients live. Through adopting tactics to secure alternative means to feed and to obtain money to travel for their children’s blood transfusions, parents demonstrated how they made efforts to resist the state’s forces of control. I evidence that through ‘tactics’ there are assertions of power and resistance in the everyday, demonstrated by people’s ability to adapt and respond (de Certeau, 1988). I do not align with a romanticised view of resilience; I recognise the structural violence and its consequences, which are evident throughout this thesis. I believe it is also important to share the power and agency used in resistance to these harms, and to work from these spaces of energy to redesign healthcare.

National staff, despite having worked to secure their livelihoods, also witnessed the relentless deterioration in the lives of the thalassemia patients they cared for. They demonstrated a sense of duty to work to dismantle the hardship the thalassemia patients were subject to, considering actions they could do such as mobile medical units or an increase in education campaigns. They worked collaboratively in the co-development groups to consider what needs to change in the healthcare systems for thalassemia patients to have permanent access to care.

The unintended consequence of transitioning national staff payment to USD was that headquarters closed the project as they considered the costs to be unsustainable. International staff expressed difficulty when making the decision as they waited for the increase in patients that would make their budget worthy of renewal, and while there was a notable increase in Lebanese patients, patient numbers were not deemed sufficient. International staff proposed that perhaps it was the stigma associated with using their services. Moreover, due to state constructed illegality, many Syrian families were confined to remote informal settlements, which created security and economic barriers to access. These findings highlight the importance of qualitative approaches, such as the ‘perception studies’ detailed in the third chapter of this thesis. Such studies capture an understanding of challenges like stigma and security when accessing healthcare services. Understanding and resolving these challenges can facilitate clinic access and develop trust with patients who suffer from thalassemia, providing better patient-centred care (Nouvet *et al.*, 2016).

## COVID-19: From Playground to Graveyard: the hospital seems emptier these days

**Figure 5-8 Image illustrating infection prevention control measures taken 13th March 2020 on the walls of the MSF Hospital, Lebanon**

Being present at the beginning of the COVID-19 pandemic enabled my PhD research to capture how the thalassemia unit shifted procedures throughout the pandemic. Prior to the pandemic, the MSF service: i) ran a Paediatric Intensive Care Unit (PICU); ii) provided thalassemia care; and iii) was preparing to open an Emergency Room. The following excerpt is from the research diary I kept in Lebanon in March 2020, noting the rapid and constant decisions made in response to the pandemic.

> The entrance to the hospital changed. When I enter the large front door of the public hospital, the doors are now monitored due to the Corona virus. I have to get heat checked as I walk in and then I am given hand sanitizer by two people who man the door, who sit all day at a wooden table and two plastic chairs. And then walk through a second set of doors to the left where I take the lift to the second floor, you can never get lost as there is MSF branding everywhere. Finally, you go through the coded door into the clinic. The hospital

> seems emptier and emptier these days. I hardly see any patients in the clinic anymore, maybe one or two. I recall the atmospheric transition, from a playground to a graveyard, and the increased sense of surveillance.
>
> At the beginning of my stay, there was a small table where children who were getting their bloods checked would draw with crayons and they would play with the small plastic rocking horses, which now sit unused in the corner. Full families would be there. Yet now they're emptying the inpatient beds, expecting a rise in Coronavirus patients. *(*Research Diary, March 2020)

This section of the findings chapter will provide a chronology of the responses to the COVID-19 pandemic and how they shaped the MSF-run thalassemia clinic. I will detail this with insights from parents who supported their children with thalassemia, MSF staff who assumed a leading role in pandemic responses, and MoH and headquarters' perceptions of how resources were prioritised during the many shifts to healthcare service design throughout the four-year period of this PhD. As the co-development groups were conducted in November 2021, please note that the data reporting on experiences of the pandemic are retrospective.

## Service Users: 'After they put this (points to facemask), things changed a lot'

In the co-development groups, as Belal enquired into perceptions of humanitarian healthcare, he often used the pandemic as a point of reference, as a pivot point in discussions about services and policies. When Belal asked directly about perceptions of the COVID-19 response, the participants often responded positively. They specifically described MSF's COVID-19 vaccination campaign in positive terms because it was implemented in the camps, meaning they did not have to pay for transportation costs. When Belal asked service users what they considered the purpose of humanitarian aid to be, they responded by pointing to the COVID-19 vaccine campaign and identified this as exemplary humanitarian healthcare. This reveals an important insight into how the location of a service reveals how patients can feel more valued. This can be encountered in multiple ways in humanitarian action, as organisations categorise some patients as 'hard to reach' rather than their services' locations as being 'hard to reach'.

Both service users and staff suggested that operations should take place in the camps throughout this study on numerous occasions. This could mean, for instance, going to the camps to administer thalassemia care, just as they do for the blood drive. Moreover, the hardship of paying for transport and experiencing discrimination on the journey, alongside possible deportation at security checkpoints, would be eliminated, supporting patient safety. However, even when the COVID-19 vaccination programme was mobilised in the camp by MSF, it was not accessible for every participant. One parent explained that they could not receive a vaccine because they had to care for their child:

> Belal: What is the role that the medical charity organisation, like MSF, plays in the health care sector in Lebanon?
> Zara: They will provide free coronavirus tests and vaccines; previously, we had to pay at the hospitals. I registered at the platform but couldn't go to the appointment because I was taking care of my child.
> (Service User Co-development Group One)

Research participants reflected on the COVID-19 measures implemented at the hospital, which restricted their ability to provide for their children’s thalassemia care. Parents detailed three unintended consequences of the infection prevention control measures, and the tactics they used to navigate what they depicted as the conflicting regulations they were subject to in the pandemic. These were: i) challenges in compliance with MSF’s IPC measures; ii) restricted visiting hours at the thalassemia clinic and the subsequent harm on family relationships; and iii) the hardship caused due to the suspension of blood drives.

The first consequence that this research uncovered was the inability for families to adhere to MSF’s COVID-19 protocols and the distress parents felt in evading the conflicting rules imposed on their lives. Parents explained that if they were residing in an informal settlement and confided to camp leaders that they were experiencing COVID-19 symptoms, camp leaders would expel them from the camp. The consequence of this could be dire, and parents explained that it would be safer for them and their families to not disclose their concerns about having the virus or being seen going for a COVID-19 test. Parents described similar fears of disclosing symptoms of COVID-19 at the thalassemia clinic, which they feared would prevent their children receiving treatment, and in turn, that camp leaders would find out. They understood that MSF staff perceived this as noncompliance, yet the fear of being evicted from the informal settlement took precedence over their children not receiving blood transfusions that week. For these reasons, many parents disclosed that they continued to bring their child for thalassemia treatment, and did not disclose COVID symptoms if they had them.

The second unintended consequence of the IPC restrictions was the limited visiting hours for parents, which reduced their ability to support their children staying at the hospital. This diminished the capacity for family-centred care and may have caused unwarranted distress for children and their families. MSF had staff previously described the thalassemia clinic as a ‘safe space, a playground’; I saw this too – crayons, colouring paper, toys everywhere - but all of this was stripped back during COVID-19 (Médecins Sans Frontières, 2020c). Studies such as McBride (2021) show that recovery times increased alongside experiences of pain and malnutrition when children could not see their parents during pandemic hospital stays. This study evidenced increased worry, anxiety and loneliness for both parents and children. Furthermore, for infants in a PICU, the inability to bond with their parents can have lifelong implications on their ability to form healthy relationships (McBride, 2021). This separation in conjunction with the increased burden of healthcare management, including the difficulties in securing blood donors (which will be detailed in the next paragraph), impacted those with the least resources.

Finally, at the onset of the COVID-19 pandemic, Lebanon implemented strict protocols that impacted the thalassemia unit. Examples included the inability for people or materials, such as blood, to travel due to border checks, and the banning of public gatherings. This resulted in MSF pausing blood drives for a period, meaning parents had to resort to finding blood donors for their children’s transfusions. The parents in this study detailed the difficulties this created in their lives, as they had to pay for travel and forfeit daily income. This was described as a humiliating experience, with parents wandering the streets during lockdown, approaching people to ask what their blood type was, and if they would donate as their children were in urgent need of a transfusion. The experiences families endured during the COVID-19 lockdown were another illustration of how parents used their best judgement with the little healthcare information they had access to, sometimes tactically evading rules, to care for their children (de Certeau, 1988).

While the pandemic was not described by parents as a central feature in their lives, it featured as a backdrop in the chronology of crises in three ways. It hindered familial relationships, as parents were separated from their children during treatment, and for many, it accelerated the poverty they were subjected to. It also created fears and conflicting concerns of compliance between camp and MSF protocols, and increased hardship in securing blood donors. What is also important to note is that while most participants described the vaccine efforts in positive terms, social desirability may influence these findings. Considering that one of the five participants explained that they could not access the vaccine and that the participants detailed being dishonest with the authorities to prevent exclusion, it is important not to overestimate positive experiences with MSF's vaccine campaign (Bergen and Labonté, 2020).

## International Staff Perspectives on the COVID-19 Pandemic

On 13 March 2020, MSF International requested that senior management arrange a staff meeting to implement service redesign in response to the pandemic. This subsection of the COVID-19 findings will draw on fieldnotes to reflect on the power structures of this meeting in March 2020. I will trace COVID-19 measures and experiences of these through document analysis of MSF archives and interview reflections.

I attended the MSF management meeting on the 13th March 2020, when I was in Lebanon for my second research visit. It lasted about three hours and 30 staff attended. The room was set up as a classroom, with rows of plastic chairs facing a whiteboard. The senior management team started the meeting by explaining that MSF headquarters had decided to implement pandemic policies in MSF projects, and that the team had been gathered that day to adapt that decision to the two projects: the Paediatric Intensive Care Unit (PICU) and the Thalassemia project. MSF International explains that they have three implementation steps (Médecins Sans Frontières, 2020b). The first step was community awareness, such as the information posters on infection prevention control (IPC) (see Figure 5-8). The second step was implementing new standard operating procedures (SOPs) setting out the use of N95 masks, quarantine procedures and the allocation of space, triaging, and visiting hours. The third area of implementation was supporting government hospitals, for instance by creating outdoor triaging areas in the car park, to check for COVID-19 symptoms. We were informed that today was step two; we were there to adapt SOPs. I will detail how power was employed in this space at a time of emergency, turning to de Certeau (1988) to illustrate strategy, tactics, planning, and power in everyday life. Castells (2016) explains that power is expressed through interactions shaped by culture, and that power can be evidenced through interactive processes, such as the production of services. This meeting revealed the relational power at play and the ways this can be resisted and reformed in spaces of aid, as illustrated by the implementation of COVID-19 pandemic protocols.

This section will demonstrate the ways in which MSF's senior management crafted and implemented their COVID-19 mitigation strategy in the first week of the pandemic. de Certeau (1988) argues that the struggle for power is deeply connected to the control and use of space. Steinmetz (2014) outlines the four approaches to empire, of which a contemporary form of empire is informal, nonterritorial imperialism, which includes manipulative market exchanges. This findings section will consider how MSF pursued strategic tactics with other institutions, such as the Ministry of Health (MoH), to maintain power and control whilst mitigating risk at the onset of the pandemic.

### International Staff Perspectives Towards Healthcare Systems

> 'If more space is needed to respond to the Corona virus, then negotiations will take place; we will convince the hospital director, it will be done in one hour.'
> (Research Diary, March 2020)

International staff adapted MSF International's guidance for the COVID-19 pandemic operations by referring to Lebanese law. The directive was to implement infection prevention control (IPC) measures as they understood that the medical needs of the communities, including thalassemia, could not be put on hold (Médecins Sans Frontières, 2020b). Starting from existing epidemic knowledges and incorporating the understanding that their patients were living in crowded informal settlements and had weaker health status and the inability to access state healthcare, staff began to create and implement IPC measures (Médecins Sans Frontières, 2020b). As senior management staff made decisions, they asked, ‘What is the law on this? Can we stop people visiting their children?’ in addition to trying to understand the severity of diseases: ‘What happens if people aren’t treated for thalassemia? Do they die?’ (Research Diary, March 2020). One transition was that the thalassemia unit was moved to a separate area to protect patients from exposure to COVID-19 (Médecins Sans Frontières, 2020b). Turning to de Certeau (1988), this enables us to consider how MSF drew from their access to Lebanese law and prior experiences with epidemics to create a strategic plan to control the risk of COVID-19 infection outbreak in the clinic, all of which aided the thalassemia unit in continuing its operations.

MSF leveraged strategic tactics through their institutional partnerships when creating their COVID-19 response (de Certeau, 1988). For example, the thalassemia blood drive was in partnership with the Lebanese Red Cross, the COVID-19 vaccine campaign was with local NGO Amel Association, and they rented the space for their clinic from the public hospital. It is unusual for an MSF project to rent the space in a public hospital for a project as typically they work from an isolated building. This created extra negotiating dynamics in the pursuit of control and risk mitigation in creating a pandemic strategy. As an illustration, during this pandemic meeting, staff were concerned about the need for quarantine space. As a demonstration of relational power, a staff member I will call Maria affirmed MSF’s position by declaring, ‘If more space is needed to respond to the coronavirus, then negotiations will take place. We will convince the hospital director, it will be done in one hour’ (Research Diary, March 2020). As a consequence of sharing a hospital with the MoH, MSF’s spatial control was restricted. This spatial sharing was significant, insofar as many international staff explained it was not ‘a real MSF mission’ as they did not have their typically high level of spatial control and power in decision-making.

A ‘real’ MSF mission, turning to Smirl (2015), is an enclosed compound just for the organisation, a protected space removed from wider society justified by reasons of security. A ‘real’ MSF mission has a headquarters in the capital and the project in field. The close proximity of coordination staff to the project level staff, as well as the project being located in an MoH hospital, resulted in a sense of disorientation for international staff. A ‘real’ MSF mission in a warzone adheres to a distance from wider society; with that distance removed, a sense of exposure and close proximity to new actors appeared, which had to be navigated. While Lebanon was not a warzone, the chronic state neglect left its health systems in disarray that was comparable to a conflict setting (Médecins Sans Frontières, 2021c). This dynamic of a dire health system in need of support during the pandemic in conjunction with relative societal tranquillity underpins the logic of why MSF withdrew operations. The crises, whether COVID-19 or otherwise, were not perceived as severe enough to warrant sustained healthcare intervention.

To support response, there were increased opportunities for INGO funding and power as a result of the pandemic. In March 2020, staff members voiced concerns about how INGOs could leverage this as a funding opportunity that would have ramifications for social tensions. An INGO-led pandemic response in Lebanon had the potential to further segment patients based on nationality, furthering the illegalisation of Syrians and the geographical confinement of Palestinians (Research Diary, March 2020). Unfortunately, these concerns transpired. In conversation with an international staff member in May 2022, Charlotte reflected on MSF’s role in responding to the pandemic. She described how different populations received different brands of vaccine based on their (lack of) residency status. This created the perception that some vaccines were more effective than others, and that these were allocated by levels of perceived societal deservingness. She explained how that dynamic resulted in the perpetuation of vaccine hesitancy and a distrust of powerful institutional actors for many refugee populations in Lebanon (International Staff, Interview, March 2022).

As I sought to understand who received which brand of vaccine, the narrative of who was offered what and why became less clear. As another former Médecins Sans Frontières staff member explained, ‘the vaccines were distributed according to availability, and not nationality. For example, my thalassemia patients who were referred for vaccination, they all received the Pfizer Vaccine with no complications’ (Email, July 2023). A review of the academic literature showed that Pfizer was administered via the COVAX scheme, which ran in partnership with humanitarian healthcare organisations, and the MoH secured Oxford AstraZeneca for use in its state-run vaccine centres (Zeitoun *et al.*, 2022). The Lebanese MoH vaccination plan guidance stated that health facilities were mapped by population size (Republic of Lebanon Ministry of Public Health, 2021). An inference based on this information is that populations who resided in informal settlements were geographically delineated and in turn may have received a different vaccine based on grounds of geography rather than nationality, and/or they were offered the COVID-19 vaccine through the COVAX scheme via humanitarian healthcare services as they were already linked with these organisations. After a review of the literature in response to this discrepancy, the formal distinction published is a geographical one; however, discussions with interlocuters and my interview with the senior staff member at Médecins Sans Frontières narrated how people experienced the state offering the vaccine based on residency status, facilitated by the INGO sector. The pandemic created a need for a rapid healthcare response, a void of care that could only be filled by international humanitarian healthcare actors with the resources to mobilise so quickly. It was an opportune moment for INGOs to secure funding and position themselves as prominent actors in the Lebanese health system, but the consequences were further segmentation and distrust of the people they mobilised to care for.

### Management Perspectives Toward Project Staff

> ‘Tell your team that people are clapping all around the world for them’
> (Research Diary, March 2020)

As the pandemic planning meeting unfolded on 13 March, Maria, an international staff member, explained that the purpose of the meeting was to plan how to shift from a normal to an emergency project. The management team leading the meeting outlined that this would be the only time decisions were made and that it was the responsibility of all staff managers in the room to disseminate information among their respective teams. Decisions were made in hierarchical order. The power structure between the senior manager and the coordination teams was reflected in the room layout, with Maria standing at the front, her senior management colleagues in the front row and all other staff seated behind them. Admission was strict; an international staff member was removed from the room by a senior management colleague who explained, ‘You are not allowed to be in this meeting because you are not a manager’ (Research Diary, March 2020). The international staff was taken aback by this, and I overheard them reiterating their surprise later that evening. The typical hierarchical order of staff categorisation, which has been termed the ‘unbearable whiteness of expats’ (Redfield, 2012b), led this person to assume they would have access to the information in the room by virtue of being international (Saperstein, Penner and Light, 2013). This micro level of understanding who has access to spaces, information, and subsequently power is key to understanding how spaces of aid operate. This troubling inclusion and exclusion criteria to the establishment of power can lead us to follow what Derrida (1978) terms as a ‘trace’, what is left unsaid, the incompleteness of language that illustrates how systems are never fixed. The trace is what is left behind after we try to capture meaning in a conceptual system. What was significant about this moment was that this was a second instance in which racialised categories are subject to resistance and reform rather than reproduction, the first being the reform to pay national staff in US dollars (Saperstein, Penner and Light, 2013, p. 360).

There was a sense of urgency in the room. The atmosphere was pressured; international staff were under pressure from headquarters and people worried for their families’ safety. What was significant was the pivot and tension between the strict authoritarian decision-making and the yearning for collegiality into which it fleetingly transitioned. I noted in my research diary that I admired how the senior manager strived for a dialogical approach to this meeting. The ability for an actor to exercise power is based on cooperation, rallying staff around the shared institutional goal (Castells, 2016). She routinely reinforced the importance of communication throughout the meeting. For instance, once standard operating procedures (SOPs) had been redesigned regarding how the remaining facemasks would be distributed amongst the units, she asked, ‘Do we agree with this?’ in a demanding tone (Research Diary, March 2020). Castells (2016) details that power is exercised by means of coercion, as evidenced so far, and by shaping people’s meaning-making processes. But coercion is a weak form of power, and it is not sustainable, and this form of communication did not shape staff’s commitment to collegiality. This attempt at coercion was evidenced by management’s dialogue with staff. Senior management declared that staff running the blood drive would ask blood donors in the camps if they had symptoms of COVID-19 as an IPC measure. Subordinate staff were anxious and distrusted this approach, asking, ‘What if they have no symptoms?’ and ‘What are the symptoms?’, to which the response was, ‘The symptoms are obvious’. The manager of the blood drive asked, ‘Is this contagious through blood?’ ‘No, it’s not AIDS,’ a colleague interjected (Research Diary, March 2020). People were uncertain for many reasons, including the newness of the pandemic, which meant there were questions around how to act, contagion, and the illness’ severity. They were reassured that with disinfectant and masks they would not die, in an endeavour to lessen their worries and keep projects running at the onset of the pandemic.

This uncertainty led to confusion about operating procedures. I found it difficult to follow the conversation that morning. Staff jumped from one topic to another, interjecting their concerns about their respective healthcare services, asserting their needs for IPC resources. I couldn’t decipher what was important. I realised that I was the only one with a pen and paper noting what was being opened, closed, and rearranged. There was a sense of distrust that ran throughout the meeting. National staff distrusted the COVID-19 information they were given by international staff, who in turn did not trust that national staff would continue working.

Maria’s rallying cry was for management to keep their staff working. This was the primary objective from management and they reiterated it throughout their communications. Castells (2016) demonstrates that power is exercised by establishing communications systems that express institutional interests to shape patterns of social conduct. Systems are put in place for what is rewarded and what is punished. Maria explained that project staff would take advantage of the working-from-home directive. In that event, management would lose their ability to monitor colleague’s actions due to the loss of spatialised control (de Certeau, 1988). She expressed fear that staff may try to use the confusion around COVID-19 to their own advantage. Maria explained in her characteristically blunt manner that ‘people will get infected, but it does not mean that you will die. People will be burnt out, but how do we keep staff and subsequently beds open? By keeping staff morale high’ (Research Diary, March 2020). This was the mantra of the management team, supporting staff to keep projects running because unlike COVID-19 contagion, burnout could be avoidable.

Maria's enthusiastic cheerleading to encourage agency when creating the pandemic strategy did not resonate. The staff showed concern. They knew they were under-resourced, and she acknowledged that 'soon there will not be enough machines, there will not be enough beds, and staff will burn out' (Research Diary, March 2020). She recognised the challenge of leading a hospital team through a pandemic, with little access to resources. She stood in front of subordinates and pleaded for them to provide their teams with support and clear information: 'There will be a sense of confusion, they will feel lost, they will feel frustrated and threatened. They must want to come to work, they must want to protect and inform patients' (Research Diary, March 2020). Ideas reach people often based on their level of exposure, and Maria yearned for the staff to deliver information to their teams (Castells, 2016). For the remaining hour, management weighed the risks of stretching resources as far as they could. Any confusion and fear from the staff caused by the unknowns of COVID-19 were met with clarity and direction by senior management, who communicated that teams should keep going to work.

To conclude, when shifting to an emergency project in this setting, decisions were made hierarchically. Senior managers led the meeting and sought consensus with their judgements. Moreover, there was a strict entry criterion to the meeting room based on level of seniority, reiterating the inclusion and exclusion of the space. While the senior manager attempted a dialogical approach, a sense of distrust and uncertainty among staff prevailed, leading to confusion about pandemic operating procedures. This lack of trust was reciprocated as Maria emphasised the need to keep working, keep morale high, and keep communicating with teams, despite the challenges posed by the pandemic.

## National Staff Perspective on the COVID-19 Pandemic

'you will only get one ventilator, do you choose to save your mother or
your father' (Research Diary, March 2020)

Below is an excerpt from the Monday morning of the 16th of March 2020. This was the morning I was told by Maria, the Head of Mission, that I would have three hours to leave Lebanon. It was the morning of implementation of all IPC measures. This day the reality of pandemic began to feel even more real. The following excerpt details my interpretation of the national staff's sense of confusion, distress, and hopelessness that morning, as they processed the significance of the pandemic.

> I set up my desk and expected my colleagues to join me. The human resource officer didn't seem to be working at all. They sat in the kitchen, like a ghost. They seemed to be staring at the wall aimlessly, as someone who was processing traumatic news would be, it was very unsettling. Most of the staff seemed to be this way, dazed. The head of the social work team was also working from the office that morning. I'd gotten to know her quite well as I had sat with her during lunch once or twice. I made conversation with the head of the social work team and they relayed stories to me from the media saying, 'you will only get one ventilator, do you choose to save your mother or your father?'. The finance and human resource manager told me that the head of the social work team had been relaying this story over and over. [That] They seemed incredibly distressed by it.
>
> I heard that she had been crying, and was very upset, about catching the coronavirus and transmitting it to her parents. She told me she lived with her parents and had four children who lived with them also. She was also very concerned about how they were going to run the blood drives in the refugee settlements, she continued to say that the thalassemia patients will die if they don't receive blood. Although, I remembered at the meeting on Friday, that the head of the thalassemia unit said that the patients would not die if they didn't receive blood.
>
> The human resources coordinator continued staring at the wall, glazed eyes, for about an hour now. I asked them how they were, he glared at me and told me he was fine. Didn't engage in conversation whatsoever.

*(*Research Diary, March 2020)

MSF evacuated me to Glasgow in March 2020. Following this, I had intermittent Zoom calls with the headquarters, and I followed the project management's decisions through the Situational Reports emailed to me. The onset of the pandemic was a stressful and distressing time for all staff in this project. The next opportunity I had to enquire about national staff's pandemic experience was 20 months later, in the co-development groups in November 2021 led by Belal.

I will begin by detailing the three positive insights national staff reported about the pandemic. First, staff identified the significance of the increased employment opportunities in the healthcare sector due to COVID-19. In a state that is enduring economic collapse, the intersecting crises led to a rare opportunity for income due to the influx of international funding from the World Health Organisation alongside INGOs. Second, national staff relayed the successes of the COVID-19 vaccination campaign in refugee camps and the Lebanese MoH in primary healthcare centres. They explained that people no longer feared COVID-19, which they attributed to high vaccination rates and successful information campaigns. Moreover, national staff explained the significance that every resident in Lebanon, regardless of nationality, were eligible to receive a COVID-19 vaccine. The participants saw this as a crucial step towards health justice in Lebanon.

Third, staff expressed appreciation and approval of what they described as a successful working partnerships between (I)NGOs, including MSF, and the MoH through the pandemic. Staff explained that the MoH demonstrated great leadership as they guided and supported state hospitals in mobilising COVID-19 operations. Moreover, the strategic tactics employed by the MoH enabled state hospitals to absorb patient overflow from the INGO hospitals.

While national staff perceived positive outcomes as a result of pandemic service decisions, they critiqued Lebanon’s pandemic response on two grounds, namely healthcare campaigns and resources for emergency preparedness. These critiques came to the fore when national staff compared their experiences of working in healthcare internationally. This was a similar approach to international staff, who often made sense of the MSF Lebanon effectiveness through comparing Lebanon with other countries.

One national staff member, whom I call Muhammad, was working in Canada at the beginning of the COVID-19 pandemic. This international work experience for him was significant in how he made sense of Lebanon. While he was not in the ‘international staff’ category with Médecins Sans Frontières, he drew on experiences of working in North America to make sense of Lebanon’s health systems. This blurring of boundaries demonstrates the formation of what Omi and Winant (1993) call the racial formation process in societal categorisation. Categorisation processes are unstable, historically embedded, gendered, and politically fraught (Saperstein, Penner and Light, 2013; Omi and Winant, 2014).

Muhammad understood the pandemic successes and failures by comparing responses. 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 there was a failure in the Lebanese response due to the high levels of transmission. He stressed that these failures were due to a lack of information campaigns, which shaped how people in Lebanon perceived the pandemic. Specifically, for Muhammad, people did not take guidance on physical distancing seriously enough. In a failing state where an estimated half of the population are of refugee backgrounds and illegalised, the perceived cultural differences can be used as a scapegoat for the failures of the healthcare systems. Thinking with Napier *et al.* (2017), the reductive structural stereotyping vocalised by this staff member hinders practical understandings of suffering and illness in a clinical setting. The assumptions of cultural differences seen here between Lebanese and Canadians mask the intersecting factors, such as poverty, age, gender, and legal status, which put a person at risk of health inequalities. In order to significantly improve the care at MSF's thalassemia clinic moving forward, it is important for staff to remain sensitive to their patients' living conditions and day to day experiences rather than critique patient noncompliance to COVID-19 legislation.

In the third co-development group, Rashid explained that Lebanon had never had the capacity to be prepared and that it remains unprepared for public health crises. He pointed to the materials that Lebanon lacked that are necessary for an emergency response, such as pop-up beds and tents, which the state could purchase in preparation. Rashid explained that 'there's a problem here, you cannot prepare an army of nurses and doctors that perhaps a pandemic might occur' (Rashid, Staff, Co-development Group Three). Collectively, staff concluded that while materials can be purchased in advance of an emergency, ensuring appropriate human resources is comparatively difficult, especially in a state enduring mass emigration. Muhammad concluded that in contrast to Lebanon, materials in Canada were available, but healthcare professionals were not. The staff summarised that perhaps no country had access to both human and medical resources. High-income countries lacked human resources, while middle-income countries like Lebanon, which had a pool of competent professionals, lacked the materials they needed to provide care.

Specific to thalassemia care, the COVID-19 restrictions made collecting blood donations increasingly difficult. While this was not raised by staff in the co-development groups, it was highlighted by service users, and it was reported on the MSF website. The staff member responsible for managing the blood donations drive explained that the restrictions for travel and prohibition of gathering people in a group resulted in extreme hurdles in collecting blood for the blood bank. The societal fear of COVID-19 resulted in people not trusting MSF staff who entered the camp seeking blood donations for the thalassemia unit (Médecins Sans Frontières, 2020c). MSF staff have encountered concerns of distrust, contagion and misunderstanding of their services and interventions amidst epidemics on many occasions, such as in Sierra Leone and DRC during Ebola, and these challenges evidently remain (Farrar, 2019). The national staff member who managed the blood drive explained that people living in the informal settlements perceived the staff, who worked in the hospital, as a transmission risk. Moreover, he explained that every day he had to convince the communities in the informal settlements surrounding the hospital that it was okay to donate blood. He explained that he had started to travel further searching for blood donations, saying that ‘we will keep fighting, it is the only way’ (Médecins Sans Frontières, 2020a).

To conclude, the COVID-19 pandemic provided national staff with a basis for international comparison, an insight into how Lebanon’s health systems could be. This provided a sense of hope for healthcare justice and comfort in the knowledge that no country had a perfect COVID-19 response. Staff had positive experiences, including elements of the vaccine campaign, and they unpacked the MoH’s successes and failures of leadership, yet it is clear that COVID-19 transmission prevailed in part due to distrust. Finally, the intersecting health and economic crises provided a unique livelihood opportunity for many healthcare professionals as they were thankful for the job opportunities and security the pandemic provided them.

## Discussion

The COVID-19 crisis provided insight into convergent and divergent experiences between the groups of participants. The most striking example of this was the MSF vaccine campaign, which illuminated issues of health justice on a global and local scale. National staff and service users illustrated the vaccine campaign's successes, pointing to: i) high vaccination rates; ii) no-cost provision; and iii) the fact that it was mobilised inside the camps. All participants deemed the vaccine campaign significant because everyone, regardless of legal status, creed, and age could receive the vaccine at no cost. However, my conversation with Charlotte of the MSF management staff provided me with an alternative insight, which I had encountered with Syrian interlocuters in Lebanon. Charlotte explained that the vaccine campaign perpetuated the normalisation of segmentation on the grounds of residency status in Lebanon and the distrust of institutions. While this was not raised in the co-development groups, desk-based research provided insight into the distrust this campaign created.

Vaccine hesitancy was evidenced by the INGO International Rescue Committee, who conducted a survey on vaccine acceptance among Lebanese and Syrians in their healthcare centres. Their reported vaccination rates were 57.6% for Lebanese and 32.9% for Syrians (Ali *et al.*, 2022). This finding conflicts with the high uptake described by national staff and service users. Depictions of the COVID-19 vaccine campaign were at once convergent and conflicting, depicting a complex, multifaceted divergence of experiences. This reveals a potential social desirability bias in these research findings, shedding light on the power dynamics in the thalassemia unit amongst Belal, the parents, and the staff who work to care for their children. Based on this divergent information, a likely inference is that being within earshot of thalassemia staff and being within the confines of the hospital led to patients not feeling comfortable to share their experiences and perceptions with complete honesty.

This research contributes to an understanding of how staff experience humanitarian healthcare mobilisation in response to a global pandemic. The dissemination of information and morale encouraged by the Head of Mission did not resonate with the staff. They prioritized their concerns outside of work, specifically how this pandemic would impact their family's wellbeing. Improving staff support is crucial to responding to the increasing threat of pandemics in a globalised world and is one recommendation I conclude from this study. The excerpt below is my reflection on staff response after the pandemic process management meeting:

> After this meeting, I overheard both the medical staff and the management staff agree and explaining to each other that there was no clear procedure. There was sense of fear and confusion amongst staff. They didn't share this in the meeting, I only heard this consensus afterwards in offices, hallways and over meals, that people explained how they were frustrated, that they were completely unclear as to what they expected to do? "We have to look after ourselves". A staff member had already taken the week off over concerns about catching and spreading coronavirus, exactly what the HoM was trying to prevent. After the morning meeting, I was working from the three-person office with the Thalassemia Unit team.
>
> Staff from the Unit came in to talk with the manager to share concerns. One senior staff member concluded, "we will get coronavirus". After this was stated there was silence amongst the three of them. A colleague responded, "we've been put into this situation, and we've received no support".

Research Diary, 13th March 2020

The final shared finding across the responses to the pandemic related to concerns arising from COVID-19 compliance. Staff struggled to retain workplace morale and adhere to guidance while patients living in informal settlements experienced tensions in a different way. Many patients and their families did not have the ability to comply with the MSF pandemic protocols. MSF stipulated that if patients had COVID-19 symptoms, they could not go to the hospital for treatment. Self-isolation is not an option for people living in overcrowded conditions. If an organisation is to implement these measures, it is crucial that they support patients in being able to adhere to them by implementing a biosocial approach to healthcare which integrates 'power into the understanding of disease dynamics' (Farmer, 2004).

# Beirut Blast

**Figure 5-92 Image of Beirut Port; taken April 2021**

**The cranes were put there for artistic and political reasons; each crane has a noose hanging from it and represents a politician whom the artists believe should be killed due to the neglect which caused the Beirut Blast.**

**Figure 5-10 Scan to download to a soundscape of Beirut Port**

The Beirut explosion in August 2020 caused great damage to Lebanon's health systems. As a result, NGOs and civil society were among the first healthcare responders. This surge in humanitarian healthcare mobilisation further fragmented health systems. Many NGOs have since withdrawn services, yet the state healthcare system has not recovered, leaving residents of Lebanon with deteriorating healthcare and increased unemployment for healthcare professionals. This section will detail the research participants' experiences of the Beirut Blast and its consequences for healthcare services.

Conversations with interlocuters during a research dissemination visit in Lebanon in May 2023 revealed the politicised outcome of this explosion through the healthcare response mechanisms. MoH and NGO staff explained to me that state-wide healthcare funding was reallocated to organisations that had headquarters in Beirut. The consequence of this was that healthcare organisations who operated in already resource scarce contexts, such as North Lebanon, moved operations to Beirut. This perpetuated the allocation of already stretched resources to the country's capital, where much of the wealth is concentrated. Thalassemia patients travel from all over Lebanon to the MSF unit for treatment, from remote locations such as Akkar in the north or smaller informal settlements in the south. As a result, local NGOs running primary healthcare centres moved from these remote regions to Beirut to pursue temporary funding opportunities. This migration of NGO healthcare projects in response to temporary international funding was explained to me on multiple occasions with frustration, anger, sorrow, despair, and almost with a sense of indifference on multiple occasions.

Figure 5-9 above depicts the cultural material created by an artist who expressed the political resistance held across Lebanese society at that time. It stood as a resistance of power in search of political accountability (Castells, 2016). As with the findings section above related to COVID-19, please note that this research into the port explosion took place one year after the event.

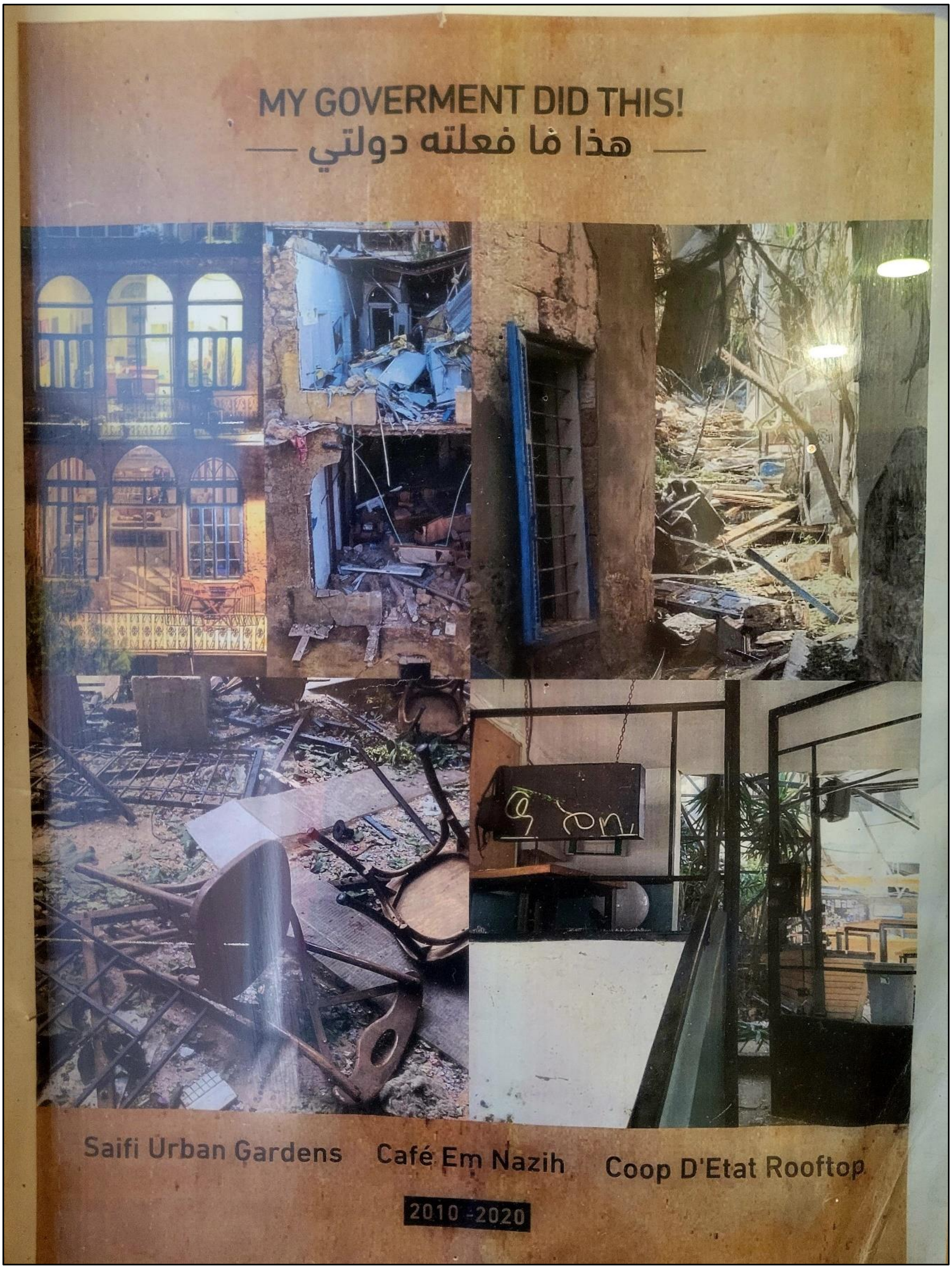


**Figure 5-11 Poster evidencing damage caused to a hotel by the Beirut Blast. Photo taken May 2023**

## Service User Perspective on the Beirut Blast

As Belal worked through questions about how parents supported their children with their thalassemia treatment and healthcare journeys broadly, service users never mentioned the consequences of the Beirut Blast. The absence of reference to one of the worst global explosions on record illustrates the severity of everyday crises in their lives. The World Bank estimates that since the Civil War, manufacturing has comprised 1% of the state GDP, meaning that food, medications, and other everyday items necessary for survival must be imported (Abouzeid *et al.*, 2020a). Participants only discussed the effects indirectly; for example, they described the extremities of the food insecurity they faced and how their worry for their children's malnutrition had worsened over time. Moreover, one participant raised how MSF used to procure medications for thalassemia patients, yet the organisation could no longer guarantee these due to the destruction of the port, where imported medications arrive, alongside the bureaucratic and infrastructural impediments which slow and could prevent imports entirely. The destruction of the state's only port thus directly impacted on the lives of people who lived in Lebanon in myriad ways, forcing Lebanon's most marginalised further into extreme poverty.

## International Staff Perspective on the Beirut Blast

Strikingly, international staff also did not refer to the catastrophic explosion during data generation. The absence of any mention of such a devastating incident when reflecting on the humanitarian project's timeline is evidence of the everyday, more pressing, state crises that staff are subject to.

An MSF article published in August 2021 on the MSF UK website entitled 'Beirut Blast: One year on, the situation in Lebanon has only got worse' details the consequences of the explosion on patient lives. The author, a coordination staff member based in Lebanon, outlined how medication and food are out of reach for many people in Lebanon, resulting in chronic illnesses worsening due to a lack of nutrients (Médecins Sans Frontières, 2021a). An international staff member explained that for the first time, patients had begun asking for food (Médecins Sans Frontières, 2021b).

The article affirmed that due to the destruction of Lebanon's only port, MSF had to commission private planes to import medication, which substantially increased operational costs for the MSF mission in Lebanon. Basic drugs and medications had to be imported as there was no infrastructure to make them locally. Front line medications such as Deferasirox are necessary for children with thalassemia to reduce their iron overload (Médecins Sans Frontières, 2019). According to a survey conducted by MSF, which involved 253 patients suffering from non-communicable diseases (NCDs) like thalassemia, 29% of patients were practicing drug rationing prior to the explosion. Within this 29%, 11% attributed the rationing to a lack of available drugs, while nearly half attributed it to financial constraints (Médecins Sans Frontières, 2021c). The consequences of this for children with thalassemia is that it will become more difficult for them to properly follow their treatment and increased malnutrition will perpetuate their sickness.

Hospitals were experiencing power shortages that last for hours due to shortages of fuel for their generators. One MSF hospital had a 44-hour power cut, meaning they had to ration fuel so they could only respond to emergencies, resulting in a suspension of secondary care (Médecins Sans Frontières, 2021b). The organisation communicated a bleak future for Lebanon due to hospitals and pharmacies not having lifesaving items such as fuel for a blood bank or iron medications in stock. MSF often refers families to other healthcare services, but this became more difficult due to the scarcity of resources caused by the explosion. Many organisations were prioritising certain patients and no longer accepted Syrians, or NGO projects closed as a means to save fuel. Due to import restrictions and increasing patient numbers, management staff explained that ‘we are painfully aware that we cannot help everyone’ (Médecins Sans Frontières, 2021b).

Two months later, the November 2021 Situational Report detailed the social and political implications of the blast. The report detailed the political deadlock amongst political parties caused by the refusal to take responsibility for the explosion. The neglect of accountability for the explosion resulted in street demonstrations organised by Amal and Hezbollah. The associated violence led to seven people being killed in October 2021. The Beirut Blast and its political consequences got international attention. The November 2021 Situational Report highlighted societal tensions in advance of the 2022 parliamentary election, including strenuous diplomatic negotiations between Lebanon and the International Monetary Fund. A cornerstone for neo-colonialism is intervention in former colonies through humanitarian aid and development, this power relation is indispensable in geopolitics. The lack of political accountability, diplomatic failures, and health system deterioration were direct results of the blast. These fuelled poverty and adverse health effects for the people in Lebanon, creating a context which diminished chances of political reform, escalated by the increased regional tensions due to the temporarily increased wealth that (I)NGOs in Beirut had access to.

## National Staff Perspective on the Beirut Blast

Interestingly, national staff did not mention the Beirut Blast when Belal asked about their experiences of working in the thalassemia unit during Lebanon's period of multiple crises. Similarly, to patients, rather than mentioning the event, national staff reflected on the decreased access to food and medications and the consequences of these issues for patient health. I will outline how the Beirut Blast affected the lives of staff working in the thalassemia unit, namely: i) the decreased availability of stock; ii) the deteriorating health of the patients who presented at the clinic; and iii) the socio-political consequences and how these shaped everyday life in the thalassemia clinic.

There was a notable decrease in the availability of materials for patients conveyed by staff, as they explained how families presented to the unit with fewer resources to care for their children than before. The staff listed everyday materials that parents could no longer afford such as baby formula, diapers, wet wipes, healthy food, and prescription medications for their children. Moreover, the community health worker who ran the blood drive explained that it was hard to secure blood donations after the Beirut Blast for the thalassemia unit because people had already donated to people injured in the explosion (Médecins Sans Frontières, 2020c). One tactic that MSF used was to pay for transport for donors to the Lebanese Red Cross centres that MSF worked with, leveraging their strategic tactics by working in partnership with a national organisation in order to secure blood for the patients they treat (de Certeau, 1988).

MSF imported medications by plane. Due to supply chain shortages, they also started to import and provide materials such as diapers and milk, so parents could access the items they needed to care for their children with dignity(Médecins Sans Frontières, 2021a). When Belal directly asked staff whether there had been increased patient numbers after the blast, they explained that while patient numbers had not increased, patient hardship had, coupled with MSF’s inability to meet patient needs due to supply chain issues.

What is striking here is the translation work - the invisible labour that national staff were required to perform. They translated the difficult circumstances that the organisation was experiencing, and how they were navigating to overcome the hurdles to care for the patients. For instance, they would explain whether the organisation had blood or medications in stock that week for paediatric patients, and operational MSF rules, policies, and approaches that were decided by headquarters back to service users, and also translated the hardship service users were experiencing back to senior management as a result (Crain, Poster and Cherry, 2016). Castells (2016) terms this role as ‘switchers’, and details the complex subtle systems of power that these switchers hold in shaping the power-making systems. This echoes the findings of James (2020b), who documented the significance national staff have in the success of humanitarian action due to their central role of what she calls the politics of humanitarian fixing and brokerage.

Staff identified the deterioration in patient mental health after the Beirut Blast and discussed the consequences that this has had for their mental health. When asked to describe a typical day at the thalassemia clinic, one staff member wrote ‘Routine Work & Headache’ on a comment card (Staff, Co-development Group One). These depictions convey a similar tone to what staff described in relation to the COVID-19 pandemic: a feeling of not being supported. Muhammad explained a typical workday like this: ‘You come and do the work, sometimes there are exceptions, where you face challenges, but every day you face challenges, this is it here.’ He reflected on the toll that living in Lebanon had on his patients and the difficulty in accessing psychological care:

> I guess the main influences on human health go under "Access and Availability" […] it's either you can't access the health care services or it isn't available. If we take all the answers [given so far]: housing accessibility, […] dietary pattern, […], unavailability of medicines, all these go under "availability", for instance the psychological affects go under access because there's no chance to get psychological help even if one is totally damaged psychologically, so I think availability and access to medical care is the dominant theme (Muhammad, Staff, Co-development Group Two)

The third change staff identified as a consequence of the Beirut Blast was their decrease in trust in the ability of Lebanese politicians to provide public healthcare. This sense of heightened distrust was similarly found in experiences of the COVID-19 pandemic, as staff described the wavering trust perceived by Syrian patients. In response to Belal asking what the solution was to the multiple crises in Lebanon, staff collectively wrote ‘Reform Politics’. Zainab explained, ‘Let’s say if I'm trying to come to work, this is something related to the economic and political: roadblocks, fuels crisis and so, so the solution? It's political’. There is agreement in Lebanon that the Beirut Blast was not an accident; rather, it was caused by six years of political neglect that epitomised the structural violence imposed by politicians on the people of Lebanon (Abouzeid *et al.*, 2020a). This explosion exemplified Lebanon’s political determinants of health. This crisis demonstrated politicians’ disregard for Lebanese health and safety. Staff agreed unanimously that for the thalassemia clinic to function, staff had to have the necessary medications to treat patients, and for this to be achieved, politics had to be reformed.

**Figure 5-12 Graffiti outside the Beirut central bank. Taken April 2023**

**العلمانية هي الحلّ : ‘Secularism is the solution’; to solve issues in Lebanon, separate religion from the political.**

## Discussion

What I found most surprising was how staff and service users did not reflect on this catastrophic event. It is important to consider what is termed as selection biases in the participant group, many participants did not live in Beirut for instance, however this can also provide an insight into the scale of the everyday crises in the lives of the service users and staff. The blast killed 190 people, injured 6,500 people, damaged 40% of Beirut’s buildings, left 300,000 people homeless, destroyed three hospitals and left another three severely damaged. Not one participant raised this catastrophe. The blast and the devastation it caused constituted a humanitarian emergency. It destroyed the remaining trust many residents had in the governance of Lebanese healthcare systems as the Beirut Blast response, steered by international funding, evidenced its precarity. What was unmistakable through this enquiry was the nature of the intersecting crises. While their experiences of the explosion were not directly referred to, they were still causing devastating hardship, like the structural violence in the everyday lives of Syrians in Lebanon.

Parents relayed the increasing difficulty they faced in being able to clothe, feed, and provide medications for their children. Parents depicted the MSF thalassemia unit as the one space that provided them with items that allowed them to live with dignity, yet the port explosion removed this lifeline of having access to blood banks and medications and pushed systems to the edge of collapse. To prevent people in Lebanon from dying from preventable illnesses in the absence of medications, MSF teams began importing medications themselves. Importing medications not only increased costs but also transitioned operations away from emergency humanitarian aid, blurring the line between temporary aid and replacing state medical supply chains.

I witnessed through the national staff’s descriptions of their experiences that there was a sense of feeling unsupported in their roles at the thalassemia unit. The Beirut Blast created a notable deterioration in patient mental health. Staff described increasingly difficult patient interactions, unpaid emotional labour, and the toll this took on their own wellbeing as they did not have the materials to provide the care they previously had or hoped to provide. There may be lifelong consequences for all participants, including the children being treated for thalassemia, who are still living through a state-wide protracted mental health crisis.

It is difficult to fully appreciate and comprehend silence. Rather than hesitation, lull, or lapse in communication, what manifested through this data generation process was an almost total absence of a topic, a significant form of communication about this explosion (Nakane, 2012). Communication is not solely a verbal activity and there are rich cultural groundings in silence (Kawabata and Gastaldo, 2015). Silence holds profound significance, especially in collectivist non-Western contexts, as demonstrated by Kawabata and Gastaldo (2015). If I failed to recognise the absence of discussion on the Beirut blast, this would have been an oversight in research findings, as silence should not be equated with a lack of evidence. Rather than perceiving this as an absence, I have critically considered what the silence surrounding the catastrophic event might mean.

How people communicate varies across culture, meaning that silence can pose a significant challenge in interpreting cross-cultural communication, insofar as Kawabata and Gastaldo (2015) explain that silence is one of the most complex forms of communication to understand. As an illustration of the myriad meanings of silence, it can be a tool for the negotiation of power, a form of social deviance, social control, politeness, a distancing tactic to avoid conflict in Italy, a way of managing intense emotional states for Western Apache (Nakane, 2012, p. 162; Bengtsson and Fynbo, 2018; Kawabata and Gastaldo, 2015). For some societies, the less said, the better; falling silent and avoiding the topic is preferred, rather than showing what might be signs of weakness through expressing personal feelings in a formal conversation (Kawabata and Gastaldo, 2015, p. 3).

For this reason, the absence of the Beirut blast does not necessarily convey a message of disinterest or irrelevance to the topic. It was a traumatic event for the country reinforcing regional divides. Silence in this instance can be political, a form of resistance, a rejection of research participation. Looking for what Derrida (1978) terms ‘the trace’, there is an imprinted meaning in the silence surrounding the Beirut blast, yet it is difficult to interpret. Rather than reinforce cultural bias and seek participants verbal accounts, voice-as-data, to validate research findings, I conclude that this nonverbal communication is also evidence of the significance of the Beirut blast, and that by including its absence I am opening up its many meanings rather than concluding its irrelevance (Mazzei and Jackson, 2012). This silence is significant in the record of this messy and constrained research project (Mazzei, 2007; Mazzei and Jackson, 2012).

To conclude, service users, national staff, and international staff all reflected on the challenges of not being able to obtain the medications needed as a consequence of the Beirut Blast. National and international staff reflected on the political turmoil and the necessity for accountability as a result of the blast. Finally, the sheer absence of any participant raising the catastrophic explosion is a significant finding, its absence highlights the comparable violence of other crises they are subject to.

## Conclusion

This findings chapter has detailed three catastrophic crises in Lebanon and how they affected the lives of service users and staff in an MSF-run thalassemia service. The finding of this study evidence how the collisions of crises in Lebanon made the power dynamics and inequalities all the more visible. I described decision-making processes and related power struggles as MSF’s thalassemia service was redesigned in response to the crises. I explored these dynamics through the tactics and strategies employed by parents to care for their children and by staff (de Certeau, 1988). I discussed the process of racial formation, as well as the resistance and reforms aimed at addressing the resulting inequality. For example, I examined how measures related to COVID-19 and equitable funding impact access to medical resources. Additionally, I explored how international geopolitics and humanitarian principles influence patients' access to medical services and the subsequent impact on trust in interactions between staff and service users. There is a nodding consensus about the harms of the racialised structures in aid and the need for structural reform to support staff equity. This research responds to Saperstein, Penner and Light (2013) calls for further documentation of the microprocesses that evidence the everyday discrimination, mechanisms and assumptions about who occupies the hierarchies of power.

The three participant groups experienced the crises differently. As I have demonstrated, the timing of the COVID-19 pandemic during the economic collapse provided financial stability for national staff while deteriorating the lives of the families MSF cared for. I encountered illustrations of how the multiple crises intersected throughout this process of enquiry. One consequence that the Beirut Blast, economic collapse, and COVID-19 pandemic shared was that they perpetuated societal tensions and distrust across Lebanon. Finally, what was most surprising was the absence of the Beirut Blast and COVID-19 crises in participants' reflections. The absence of such devastating incidents is significant and may illustrate evidence of the everyday, more pressing, crises that the participants in this study were subject to.

One important observation for humanitarian practice is for organisations to support national staff by providing them with clearer, more transparent, communication on service changes. They are ‘the other 92%’ of staff and are the ‘switchers’ in communication between policy and patients (James, 2020b; Castells, 2016). There was a constant sense of uncertainty from national staff throughout this research. National staff repeatedly heard the concerns of parents, stemming from poverty and the absence of sustainable thalassemia care for their children, which caused them distress. Moreover, parents’ worries, caused by poverty and the lack of sustainable thalassemia care for their children, transferred to national staff. For all people in Lebanon, whether they are Lebanese or otherwise, the economic crises and deteriorating living conditions came on top of already traumatic events they have had to experience (Médecins Sans Frontières, 2021c). These compounding crises are deteriorating people’s wellbeing. MSF staff tried to help where they could, but as people’s vulnerability increased, it became more difficult for the organisation to support their patients’ living decently given what they termed ‘their limited capacity to respond’ (Médecins Sans Frontières, 2021c).

In conclusion, I propose that implementing a strategic transition of humanitarian healthcare services to national services, under the oversight of NGO umbrella groups like such as humanitarian working clusters, would lead to individuals with thalassemia gaining access to sustainable treatment for their illnesses. By choosing to hand over to a national organisation, the postcolonial effects of international intervention, illustrated by the inequity of resources in the systems of aid and the unpaid emotional labour placed on staff, could be mitigated. Steinmetz (2014) details how postcolonialism incorporates varying degrees of indirect rule, the lingering structural colonial powers, with undefined end points, much of which can be found in INGO partnerships. These partnerships are framed through a neo-colonial gaze sees the subordinate population is perceived as legally, culturally, biologically, socially, and administratively inferior. This perception of inferiority is central to many INGOs, who understand their purpose as supporting states in their development, and perceived inferiority prolongs international interventions. Staff explained that they do have the knowledge needed for response; it is just the materials they lack. Sustainable thalassemia care is needed. This can be achieved by advancements in the aid, development and peace nexus to support sustainable healthcare delivery alongside supporting a localised delivery of care through the handover of resources from INGOs to national organisations.

There are limitations to these findings. It is important to reiterate that while service users described the vaccine campaign positively, ‘social desirability’ - the pressure to say the ‘right’ thing - may influence these findings. Moreover, Situational Reports do not represent the views of all international MSF staff. For national staff, the vast proportion of data inquiry occurred after COVID-19 and the Beirut Blast response, so they are a reflection of their experiences.

To conclude, this chapter has mapped how the thalassemia services were mobilised, redesigned and eventually closed amidst multiple crises in Lebanon. These crises provided a provocative and insightful lens through which to examine the complexities of pursuing humanitarian health justice amidst turmoil. The collapse of the economy, compounded with COVID-19 and the Beirut Blast, made overstretched public health services even more difficult for Syrian families to access (Médecins Sans Frontières, 2020c). Understanding how people experience restrictions, navigating their harms, is crucial to understanding how power operates and shifts and the consequences of this for how people experience working in and receiving humanitarian healthcare.

# Chapter 6 The Collapsing Tent

As was detailed in Chapter Five, the chronicle of crises in Lebanon affected the three participant groups in this study differently. This chapter, by contrast, highlights similarities in their experiences. I do this to offer a potential starting point for actors in spaces of aid to come together, to decentre the structures of governance from European headquarters, to move towards localised ways of knowing in spaces of project implementation. This aligns with the objective of humanitarian governance declared during the ‘Grand Bargain’ commitment, to be ‘as local as possible, as international as necessary’ (Kelly, Pardy and McGlasson, 2022, p. 6). The objective of this chapter is to harness the power of finding similarities in spaces where many of the actors seem to have so many differences - differences of opinion, differences of languages, and differences of legal status. I analysed the staff and service user co-development groups and generated three themes that the participants conveyed as they articulated their experiences of humanitarian aid. This chapter details my participants’ shared values of concern to reveal the viewpoint I constructed of ‘communality’, as all participants in this study have been affected by war and crises. Seeking to find meaning across space and cultural and social norms and moving towards justice in the structures of aid is a ‘difficult task’, but one that I believe can act as a catalyst for change (Galtung, 1969, p. 169).

This chapter works with three themes: loss, cost, and precarity, translated to التكلفة, الخسارة and دقة in Arabic. I chose to write with colloquial Arabic in this chapter to centre participants’ voices. I did this to uncover the iterative, interpretative analytical and linguistic process in this thematic analysis. I wanted to take a step back to recentre participant voices, to illustrate how I interpreted these themes by aligning to their words and their meaning. Below, you can find a selection of Arabic expressions spoken by my participants, some of the building blocks I used in the interpretive thematic process:

- Loss; ‘ضغط’ ‘Incapable’ ‘استهتار’ ‘Expel’
- Cost; ‘Breaking our Back’ ‘كاسر ضهرنا’; ‘Economic Burden'; 'الانهيار الاقتصادي صار في عبء; ‘Lebanese are between my arms’ ‘لبنان وهو بين ايدي’

- Precarity; ‘مرضت’ ‘Sick’ ‘استغلال’ ‘Exploitation’.'

All of the Arabic quotes in this chapter have English translations above or below them in the text aside from Carol’s (an interpreter in this project) explanations for her Arabic terms. Carol’s definitions of the three Arabic language themes are all similar to my English language definition, although her definition retains Arabic cultural nuances. The interpretive process and how I worked collaboratively across language to create this thematic storytelling is detailed in Chapter Three. In English, all three terms are often used in economic senses; for instance ‘profit and loss’, ‘cost’ (i.e., the price of an item), and the ‘precarity’ of a market or employment. These terms are used slightly differently in Syrian and Lebanese Arabic and English, but my Arabic teacher and I worked to retain the meaning as much as possible through the translation from the source language into spoken English and then into sociological academic English for thematic generation.

Most of the participants’ depictions of their lives related to the economic collapse. Taking this as a starting point, I delved into deeper meanings of how participants made sense of their situations through concepts, typologies, and metaphors, with the objective of finding common ground. The themes convey the hardship participants experienced in the thalassemia unit, both working in and being treated by the humanitarian aid sector against the backdrop of an economic collapse. The first theme, loss, was conveyed by all participants as they reflected on their experiences of loss, through stories of belonging, family home, and the support this provided them. This theme also provides an insight into how my participants propose to reconstruct and recover from this sense of loss. Cost - the second theme in this findings chapter - depicts the dedication participants demonstrated in caring for the children whose lives are detailed through this study and the consequences my participants endured in providing and securing this treatment. Finally, I illustrate the shared importance of time and movement for all participants and the shared sense of feeling trapped and uncertain.

This chapter draws on the theme of the collapsing tent to illustrate the effects of the humanitarian aid sector on my participants. I use this theme as an analogy for the inherent precarity in the sector, and the consequences of this on people’s lives. The collapsing tent was an experience narrated by families and foreseen by staff. An MSF situational report detailed how in informal settlements, the collapsing tent, which fails under the weight of the snow, ‘can trap, suffocate and result in death’, ‘trap’ illustrating the precarity of living in a tent, and ‘death’ relating to ‘loss’, the first theme. The themes in this chapter also incorporates the threat of the climate crisis, which will inevitably shape and likely overwhelm the humanitarian aid sector in the future. Drawing on these themes of loss, cost and precarity to illustrate shared meaning, this chapter answers Research Question Three: ‘What challenges did the MSF project and its service users experience due to the multiple crises?’

Similarly to Chapters Four and Five, this chapter incorporates the perspectives of headquarters, staff, and service users at the thalassemia unit. It does so to consider a broad range of perspectives, noting concerns and concluding suggestions to document the ways in which the service could transition to create equity. As I detailed in Chapter Three of this thesis, I embrace democratic pluralism to illustrate shared and divergent perspectives amongst and across participant groups as a way to reduce the persistence of colonising practices in the humanitarian aid system and improve staff and service user support (Mouffe, 1999; Said, 1985).

Listening and working with differences can improve humanitarian healthcare acceptance by mitigating risk and increasing trust, as was documented in Chapter Two. This chapter, however, identifies shared values, meanings and experiences in these differences, in the context of an unequal setting shaped by social, cultural and political collisions amongst national staff, international staff, and service users. This can support staff to care for their patients by increasing empathy and shared understanding, and improve wellbeing for staff and service users. As in the two former findings chapters, I will divide this chapter into three parts: three themes from three perspectives, beginning with service users.

Figure 6-1 Illustration by Nader Tabri

## Loss: What Does it Mean to Lose a Patient

Loss is a process. It is defined as the inability to maintain, and in this study participants detailed their inability to maintain their health on arrival to Lebanon from Syria. Loss: The deterioration or absence of a function. This can illustrate the deterioration of the Lebanese healthcare system, or the eventual absence of thalassemia care for people from Syria. Loss: The harm of separation, the separation of a family during the migration process, or due to COVID-19 hospital protocols (Merriam-Webster, 2023b). Loss was conveyed through storytelling, from Syria to Lebanon - loss of self, loss of the Lebanese state, and the narrative of the thalassemia project told by headquarters. After familiarisation with the data, Carol Bittar, the Syrian Arabic interpreter on this project, interpreted this sense of loss as:

الخسارة هي معالجة، يتم تعريفها إنها عدم القدرة علي الحفاظ على شيء مَا.

وفي هذا البحث الخسارة تتجلى بخسارة الحياة، المستقبل، الكرامة، الانسانية والوطن.

### Service User Loss: They were expelling us as if we were animals

> ‘No matter how much they [MSF] will pay, we won't get cured. In foreign countries, even if no operation was done, the general status of the patient would be better’
> (Aleena, Service User Co-development Group Four)

I identified three forms of loss in the service users’ stories: biographical loss (what it means to be a child from Syria), the loss of a home, and the 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.

Belal, the Syrian researcher I worked with, asked during the participant analysis consultation, ‘You are all from Syria, right?’ Jamal clarified on behalf of the group: ‘Yes, we are all refugees here’ (Service User, Analysis Consultation). During everyday conversations shared over meals during my time in Lebanon, it became apparent that in Lebanon, being Syrian is synonymous with being a refugee. My participants shared how they had lost their dignity and identity since arriving there.

> Maryam: 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. (Service User Co-development Group Three)

‘عدم المواخذة كل انسان بيحبّ نفسو، كان في تحيز كتير وكان في استهتار فينا مش !
طبيعي’

Throughout the co-development groups, parents listed examples of how health professionals dismissed their concerns and symptoms, and treated them with disdain. This is consistent with other studies, including Janmyr (2016). ‘If the aunt, for example, [gives] the cabbage solution for asthma [to] the wise, he might make fun of her, they disregard the solutions we offer, and treat us with arrogance as if we are ignorant of a matter, most doctors treat us in this way’ (Fatima, Service User Co-development Group One). 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 institutions. Families did not trust that they would be taken seriously if they presented their symptoms, resulting in deteriorating health conditions and avoidable death.

’ستهزئوا فينا و بيقرفوا مننا و بيعتبرونا غشم لاننا سوريين و بيقولوا نحن بهايم وما منعرف شيءا‘

(Fatima, Service User, Co-development Group One)

Participants shared stories of their children being bullied in the camp for having thalassemia: ‘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’ (Zara, Service User Co-development Group One). Living with thalassemia is difficult for any child; they must learn to manage their chronic illness and its complications, go to the hospital multiple times a month to be pricked by needles, take medications for their rest of their lives, and know that their lives are a little different from their peers (Médecins Sans Frontières, 2020c). Parents narrated the ways their children were losing out on their childhood due to their illnesses. ‘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’ (Jamal, Service User Consultation). Chen and Schweitzer (2019) evidence the harms of the asylum system for youth from refugee backgrounds as it creates discrimination, a feeling of disconnect from their environment, and results in a lack of a sense of identity. Chen and Schweitzer (2019) demonstrate that health is determined by a sense of belonging. 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 thalassemia staff they trust and family support is essential in mitigating further harm.

Parents detailed the implications of losing a house that provided them with safety from snow, rain, the cold and heat. Their homes in Syria were away from pollution, a quiet space with privacy. 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 (Chen and Schweitzer, 2019). Participants identified that living in informal settlements or overcrowded and squalid housing often created sickness and hindered their recovery process. Migration itself was a determinant of health. Fatima details this powerfully in the quote below, which captures the place and materials they are confined to, and how their sense of belonging is socially hindered by the discrimination they face, all of which prevents the home-making process in Lebanon. Specifically, she details the consequences of this for her children.

> Belal: So do you think the migration journey we did from Syria to Lebanon actually affected the health situation of patient children and their parents?
>
> Fatima: Of course it did, we were living in a vast country house, where the girls, the boys, and the parents had separate rooms. Today we are seven persons living in one room, and we are incapable of moving to a bigger apartment. Also, with the discrimination and hatred we are facing from the Lebanese neighbours, children can't go out and play, we don't have any freedom here at all.

’الانتقال كان له تأثير علينا كلنا ع الاولاد والبالغين

يوجد ضغط كبير من الجيران ومن الشعب اللبناني عامة وكره مش طبيعي للشعب السوري‘

> (Service User Co-development Group One)

Zara added that ‘if the society you're living in is good, then you are good, if it's not, then you're not’ (Zara, Service User Co-development Group One). For some participants, such as Jamal, the thalassemia illness acted as a determinant of return migration to Syria. Jamal explained that he returned to Homs, Syria for his 11-month-old daughter’s diagnosis and treatment as he could not afford it in Lebanon. There were many stories of parents returning to Syria for their children’s thalassemia care. This illustrates the significance of the Médecins Sans Frontières unit, and how opening and closing the thalassemia unit can act as a push and pull factor on migration. The role that the humanitarian sector plays in push-pull migration has been debated, weaponised, politicised, and theorised in critical migration studies and societal discourse more broadly. I align with Garelli and Tazzioli (2021), who argue in favour of the transformative role of critical knowledge, generating the evidence needed to depoliticise and decriminalise organisations that mobilise to support life-seekers.

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’ (Service Users Co-development Group Three). Families share the burden of one member's ill-health. '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' (Yasmin, Service User Co-development Group Three). 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' (Service User, Analysis Consultation). Many parents suffered from the deaths of their children caused by thalassemia, including Amira, who lost her elder daughter to thalassemia. Following her daughter's death, her younger son was diagnosed with the same disease and was subsequently referred to the Médecins Sans Frontières thalassemia unit (Médecins Sans Frontières, 2020a). The suffering and loss experienced by service users were narrated in the past, present, and future illustrating the necessity for long term care for people subject to the global asylum system.

## International Staff Loss: Forecasting a future in humanitarianism

International staff made sense of the multiple transitions the thalassemia unit underwent by conveying a sense of loss. While patient loss related to material, spatial, and family loss, international staff detailed their loss of operational funding, which led to service closure and the perceived loss of patients due to onward or return migration. Similar to service users, spatial loss emerged as a prominent theme for international staff. Médecins Sans Frontières acquired both space and human resources from public hospitals to run their operations, an attractive transition for staff as they received payment in USD. These dynamics caused tensions between the two institutions. Negotiations over access, space, and resources were constant, with MSF often asserting superiority (Research Diary, March 2020).

A staff member wrote the term 'loss of patients' in the November 2021 Situation Report, referring to fluctuating patient numbers caused by migration (for an illustration of how the project staff kept track of patient numbers, see Figure 6-2 Thalassemia Unit reception with '10-5-2022 10 Patients Thalassemia' written on the ). These dynamics underpinning patient tracking management are a departure from the traditional system of confining displaced populations to refugee camps (Pallister-Wilkins, 2018). Charlotte, a senior manager, detailed the difficulty she faced in predicting patient numbers. There was a sense of uncertainty, one which reflected the uncertainty of the aid system itself. She reflected on how the organisation got it wrong; they incorrectly predicted where and when ‘would-be’ patients migrated and they incorrectly forecasted the region’s instability (Charlotte, Interview). These ‘lost patients’ - the failed forecasting of patient numbers - contributed to the thalassemia unit’s closure. The Lebanon project lost funding from headquarters as a result of this. This decision to close is evidence of the utilitarian philosophy underpinning humanitarian aid and the conceptual failure in forecasting a project’s future. Resources must be utilised to serve the highest number of patients globally. As a result, people with chronic illnesses that are expensive to treat who are in need of humanitarian healthcare may not receive the long-term care they need.

Headquarters understood that there would be many consequences to closing the thalassemia service and made efforts to mitigate these harms. The human resources department tried to mitigate unemployment by offering training and support for staff to transition to international positions. However, national staff showed little interest in dedicating extra time to an organisation where they saw no future. I believe that is due to a loss of trust, which I will demonstrate in the proceeding section. Finally, the Head of Mission explained that the Ministry of Public Health (MoH) would receive the purchased medical equipment to prevent a loss of investment and service provision. The organisation invested in expensive equipment in the unrealised expectation of an increase in patients. However, Charlotte considered that it is unlikely that the MoH could secure the expertise and funding to run this treatment. These challenges highlight the conceptual failures in forecasting a future in humanitarian aid.

Figure 6-2 Thalassemia Unit reception with '10-5-2022 10 Patients Thalassemia' written on the whiteboard

## National Staff Loss: The Need for Staff support

National staff spoke about the consequences that caring for paediatric patients and their families had had on their mental health. The loss of a patient's life and the support they 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 (Leila, Staff, Co-development Group Three). Belal was taken aback by the clarity, weight, and candour staff spoke with when detailing the toll that the loss of patient life takes on their health (Belal, Staff, Audio diary, Co-development Group Three). Staff spoke about the 'psychological impact' of their work. Rashid, an IT technician, narrated how he could hear families crying when he was working in his office and the toll that this had taken on his wellbeing over time (Staff, Co-development Group Three). A second challenge that staff spoke of was the 'white coat emigration' - the loss of colleagues to emigration caused by the deterioration of state functions. Emigration has shaped Lebanon's history over generations, and numbers have increased in recent years due to the economic collapse (see Figure 6-3 Political poster attempting to appeal to voters by evoking sadness due to the mass emigration). This created increased staff workload and an overall sense of system failure.

**Figure 6-3 Political poster attempting to appeal to voters by evoking sadness due to the mass emigration**
**Translates to ‘they [politicians] deserted your children’. Taken March 2022**

## Discussion

The three participant groups expressed the meaning that the multiple crises had had on their lives in Lebanon. The concept of loss revealed the ways that these experiences were shared, and at times diverged, for service users and staff at the thalassemia unit. All perspectives contribute a component of what unfolded. Some perceptions were shared across participant groups; for instance, participants speculated about what was likely to be lost after the service closed, including employment, materials, relationships, and health. The most notable of these is the concept of ‘loss of patients’ through return or onward migration, or through preventable death due to the absence of treatment.

National staff discussed the loss of a patient through the frame of the detrimental impact it had on their mental health. Service users articulated death through malpractice, causing a loss of trust in the healthcare systems, ultimately leading them to the Médecins Sans Frontières service. Finally, for international staff, the loss of patients exposed the limitations of humanitarian forecasting in fragile settings. The predicted patient numbers which led to initial mobilisation were never realised, resulting in the service’s closure. As international staff left for their next country and national staff left the thalassemia unit to secure future employment, parents continued to search for sustainable thalassemia treatment for their children. While the multiple crises, including the Syrian war, COVID-19, the economic collapse, and the Beirut Blast created challenges for all of my participants, for international staff these experiences were likely to only last as long as their temporary contracts. National staff, on the other hand, may suffer long-lasting impacts on their health from the stress of these experiences while working in this thalassemia unit. As for patients, they need life-long thalassemia treatment, and the loss of this service is a matter of life and death. Those at the lower end of the welfare continuum - women, children, Bedouins, refugees, illegal, sick - suffered the most. I align with Leaning, Spiegel and Crisp (2011), who argue in favour of dialogue to determine the limits of humanitarian health responsibility in providing secondary and tertiary care. They argue that by determining what is outside of this realm of the humanitarian sector’s responsibility, actors can work out how necessary care can be allocated and promoted to move towards intersectional health justice.

## Cost

The term ‘cost’ encompasses multiple meanings, including the price paid for something, a penalty incurred, and the sacrifices or efforts made to achieve something (Merriam-Webster, 2023a). After familiarisation with the transcripts and listening to participant voices, Carol Bittar, the Syrian Arabic interpreter on this project, interpreted this sense of cost thematically as التكلفة, meaning:

يشمل مصطلح “التكلفة” معانٍ متعددة، بما في ذلك الثمن المدفوع لشيء ما، والعقوبة المتكبدة، والتضحيات أو الجهود المبذولة لتحقيق شيء ما

في هذا البحث يمكننا أن نقول أن الناس تكلفوا الكثير، فالثمن الذي دفعوه ليس مادي فقط بل معنوي أيضاً، هم دفعوا من حياتهم من أجل الحفاظ على حياتهم

I have chosen this term to capture the sustained efforts of the participant groups in the thalassemia unit. It represents the labour and dedication that contributed to the unit's functioning and its success in saving children's lives over a five-year period. By highlighting the shared understanding of what it has cost the participants, a collective sense of dedication to healthcare in humanitarian settings emerges. Starting from this shared dedication to thalassemia care, it becomes possible to achieve collective action and resolve differences in spaces where socio-cultural and political collisions occur.

The economic collapse in Lebanon reshaped the lives of everyone residing in the state. My introduction to this was when I first arrived in Lebanon in March 2020 for data generation. I was taken to an unofficial currency exchange shop by MSF staff, my first lesson in how to secure a reasonable exchange rate in a collapsing economy. As we started to exchange money at the counter, the cashier looked to the staff member who brought me and quipped in Arabic, ‘She's lucky she's here as a tourist, our economy is fucked’ (Research Diary, March 2020). As has been detailed throughout this thesis, Lebanon is undergoing one of the worst economic collapses in recorded history. This has resulted in malnutrition and the further deterioration of public health and related services, leading to the re-emergence of epidemics such as cholera (World Health Organization, 2022).

## Service Users: ‘The heavy medical expenses are breaking our backs’

> ‘The UNHCR must not expel families,
> The financial situation is hard, we can’t afford transportations to bring the children to the centre, we can’t afford proper food for them. They are depriving the children of their rights’
> (Fatima, Service User Co-development Group One)

The rising cost of necessities and the withdrawal of refugee support were central topics in discussions with participants. Parents faced difficult choices between buying medicine or food, leading to increased malnutrition rates. A report by the Lebanon Nutrition Sector revealed that nine out of ten children under two years old are not receiving adequate food for healthy growth (Lebanon Nutrition Sector, 2022). Samir, a father whose child was being treated for thalassemia with MSF, explained that the UNHCR had stopped the financial support provided to his family. He described how the road fares to get to the MSF thalassemia unit metaphorically break his back. He explained that his family used to receive 1,500,000LL: ‘We're a family of 5 people, we pay 800,000LL for transportations only, how are we going to eat? That's what's paralyzing us’ (Samir, Service User Co-development Group Three).

بكل البلد ما في أمان، يلي كاسر ضهرنا هو المصاريف التقيلة، فمثلاً نحن خمس أشخاص بالبيت ومعنا مليون ونص وإذا دفعنا
800000 أجرة طريق شو بيبقى للأكل والشرب؟ هيدا يلي عم يعجزنا
مصروف الطريق والأدوية

The food shortages and aid withdrawal were exacerbated by the Russian invasion of Ukraine, which escalated malnutrition levels. Research conducted by the American University of Beirut found that in order to continue to feed themselves, households were giving up on the quality of what they eat, on education or health care, and are even skipping some meals, as approximately 85% can no longer afford to buy basic foodstuffs. Dr Fakih concluded that there is a looming famine in Lebanon (Fakih, 2022). The scarcity of resources fuelled tensions between Lebanese and Syrians, which resulted in conflict, negative stereotyping, and a decline in the quality of care (Napier *et al.*, 2017). Participants detailed how limited food and medication supplies were prioritized for Lebanese individuals, creating fear, a distrust of medical services, and societal tensions, which negatively impact well-being. Studies have evidenced that emergencies and their aftermaths give rise to discrimination towards refugees due to increased fear, which leads to stigma (Spiritus-Beerden *et al.*, 2021). The findings in this PhD are no different; the economic collapse in Lebanon increased the hardship of participants’ already difficult lives. This leads to a pressure cooker effect. Participants in this study relied on their informal networks, on one another, for support, exacerbating their distress and leading to a higher risk of negative health outcomes.

The impact of poverty, lack of education, malnutrition, and untreated medical conditions are likely to impact these families for generations to come. Evidence from the Dutch Hunger Winter (1944–45) and the Chinese Famine (1959–1961), evidences the association between early life malnutrition and adult body size, schizophrenia and type 2 diabetes (Lumey and van Poppel, 2013; Zimmet *et al.*, 2018; Srichaikul, Hegele and Jenkins, 2022). There is an increasing likelihood of an intergenerational transmission of illness and chronic poverty for these families, rather than the transmission of positive assets and capital such as land, livestock, status, education, and kin group (Harper, Marcus and Moore, 2003).

Participants shared their experiences of financial hardship prior to receiving treatment from MSF. Yasmin, whose child has thalassemia, described the increased poverty her family had faced since her husband's death. They were left with no income. Before accessing MSF services, she would spend days searching for someone to donate blood for her child: ‘I struggled a lot and saw death before my eyes’ (Yasmin, Service User Co-development Group Three). While MSF aims to provide blood for treatment, there have been challenges, such as during the COVID-19 pandemic when physical distancing measures affected blood donations. Participants highlighted that the biggest obstacle in finding a blood donor was not the blood match, but rather the difficulty in finding someone willing to take time off work and bear the travel costs to donate blood. Without donations for transfusions, children’s diseases often need care at an intensive care unit to monitor their disease progression. Fatima provided a moving account of her child’s hospital stay, drawing on the intersecting emotional, physical, and financial harms they experienced and the important role that Médecins Sans Frontières plays in mitigating these harms:

> The hospital there reminded me of the prison, as in life incarceration prison. I had a document that confirms that they will, but at [name] hospital, they told me I am not allowed to leave the hospital without paying 1,500,000 LL, although the document said that the UNHCR and MSF will pay the fees. I had no money and had to borrow some for the transportation cost. They kept the serum although it was empty, they refused to remove it until I paid. I went to bring some food for my child, two followed me to make sure I wouldn't run away. I couldn't secure the money until the second day in the morning, they kept the serum injected until the second day when my husband came with the money and they released us. Those couple of days were horrible, I hated my life because of them. They traumatized my child, he was crying and asking them to remove the empty serum because it was causing him pain. Here at [name] hospital, especially with MSF, I and my child were met with respect and understanding.
>
> (Fatima, Service User Co-development Group One)

MSF played a crucial role for the parents in this research by providing documentation stating the need for frequent hospital visits. This documentation helped them navigate security checkpoints, avoiding risks such as violence, intimidation, detainment, and illegal deportation to Syria. Without this, many people self-detain in the informal settlement. They cannot afford the cost of a work visa, a process that often results in extortion and forced labour. The simple act of safe passage that MSF created through providing a document to those who are categorised as ‘undocumented’ conveyed a sense of legitimacy to their healthcare journeys for Lebanese security services. Participants explained this was important in mitigating the harms they faced. Médecins Sans Frontières provided more than thalassemia care; they treated families with respect, supporting them to feel a sense of dignity, and worked to dismantle the harms of illegalisation, although this offered only a temporary respite in their lives.

I have demonstrated that the participants became increasingly dependent on the aid sector due to the heightened stigma caused by the economic collapse. This aid-beneficiary relationship is inherently interdependent, as aid organisations need patients, but at numbers they deem suitable. The harmful system of dependency on the humanitarian aid sector can in different ways both remove and provide a sense of dignity for service users. To conclude, in this section, I evidenced how the economic collapse increased the stigma experienced by families in this study. I outlined how the services at the thalassemia unit provided them with an invaluable, albeit temporary respite which restored a sense of respect and legality in their lives. Yet the temporal nature of aid can leave victims of conflict feeling trapped in the knowledge that once aid is withdrawn, families must again shift tactics to develop new precarious ways of securing thalassemia treatment for their families (Yi-Neumann *et al.*, 2022, p. 27).

## International Staff: How Can They Run Things So Cheaply?

> ‘*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’
> *(Doctors Without Borders, 2021)*

In the news section published on the MSF website in September 2021, the Head of Mission for Lebanon explained the increasingly dire drug scarcity in Lebanon, resulting in previously stable patients’ health deteriorating. This was coupled with electricity shortages, resulting in hospitals cutting services as they could not afford the fuel for the generators.

As costs increased and funding decreased, staff resorted to more direct tactics of generating income. Treating thalassemia is expensive as it entails running a blood bank, which requires consistent generator power. The cost of treating each patient per month reached up to £450 (Médecins Sans Frontières, 2020a). Upon arriving in Lebanon in March 2020, my first task was to assist the Hospital Director and Social Worker as they went from room to room on a task to fundraise for the MSF project. We did this by going from hospital bed to hospital bed, room to room asking parents if we could take photos of the children being treated for thalassemia; my research diary detailed, 'The photos are needed for a blog that will raise money to keep this service running. The staff explained that "funds have dropped by 10% and would they like to be in a photo? It can either be a photo of their child alone or the parent and the child"' (Research Diary, March 2020). This coercive, Orientalist representation of the refugee child led me to feel uneasy, I understood the difficulty for parents to refuse such a request that involved their child's image being used to secure funding to keep the unit open. This sense of discomforts speaks to how the system of humanitarian healthcare can remove dignity through the creation of the refugee category to decipher who deserves care, framing the Orientalist, humanitarian gaze for fundraising, and requiring them to perform their deservingness on receipt of care (Zetter, 2007; Huschke, 2014; Said, 1978).

In March 2022, Charlotte informed me that state hospitals had stopped receiving MSF referrals due to cost of treatment, and that they would only receive a referral if MSF provided the medications for the treatment of the patient (for example, magnesium for post-partum illnesses). Throughout this research, staff expressed frustration with the costs and complexities of working with the Ministry of Health (MoH); they tried to work with the state for sustainability but incurred costs at every turn. The medical procurement systems were described as rigid, complicated, and costly. There was a sense that the state structures were working against them. Charlotte mentioned that the state-imposed taxes on medications and charged fees for MSF's operations at the hospital. These expensive and intricate operational costs imposed by the Lebanese state ultimately influenced MSF's decision to withdraw (Charlotte, Interview). By employing utilitarian ethics, the costs were deemed too high to justify the low number of children they were treating. An MSF Head of Mission explained that the Lebanese state was not taking responsibility for providing essential medications; they cited that former patients who had stable health conditions returned to MSF seeking medications, explaining that they could no longer receive their prescriptions from government healthcare centres (Médecins Sans Frontières, 2021b). Médecins Sans Frontières deemed these tasks and associated costs to fall outside their remit.

The Head of Mission at the time detailed their reasoning for closing the project on the MSF website:

> We remain committed 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.
>
> (Doctors Without Borders, 2021)

Funds are committed for programmes on a temporary basis. This enables headquarters to relocate resources if they believe there is a greater demonstrated need. This low cost and flexible operations style was noted by the Lebanese Ministry of Public Health, who approached MSF to ask them how they could 'run things so cheaply' (Charlotte, Interview). One tactic MSF used was to not advertise their services. All service users learned about the thalassemia service by word of mouth. This resulted in lower patient numbers coming to their emergency room, and subsequently lower referral, a cost-saving strategy. As I explained, referrals are expensive as the total cost, including medications, would have been paid for by MSF. This was a rationing strategy of resources put in place to avoid increased operational costs. Médecins Sans Frontières were not able to provide the highest attainable quality of care and services, as from their perspective, the state ignored its responsibilities and prohibited them from achieving this. This could in turn destabilise established in-country healthcare that Syrians could previously have accessed and create an even bigger support gap on their departure (Broussard *et al.*, 2019). It is nearly impossible to reach those most in need amidst resource shortages, but notwithstanding, it is not wise to try to treat everyone in society as equal. To adhere to the principle of humanity, it is pertinent for aid organisations to approach health as a relative need. Not all populations are in the same need. By considering what resources and needs exist within refugee populations, healthcare services can target those who have the least.

While working with the MoH created tensions, it also enabled a concealment, warding off undue attention, a subsequent surge in cost, or inability to offer care. Working from within a Ministry of Health hospital shaped this humanitarian space; as (Smirl, 2015) reminds us, humanitarian infrastructure shapes the environment. MSF Lebanon services are built on shifting social, cultural, political, and economic grounds and the future is uncertain. Merton (1936) identifies unintended consequences of social action, and argues that announcing intentions can alter the shifting ground further. Hanna and Kleinman (2013) consider that announcing the creation of a healthcare service prior to construction in a low resource setting can lead to a surge in patients for care for which no hospital is ready. This rationale was offered to me by staff on many occasions: there was only a handful of beds in the PICU, so they could not advertise the service or healthcare workers would be faced with ill patients and nowhere to treat them. For international staff, turning patients away who are in need was more immoral than not advertising their services. However, I believe these patients were still in need; they were just out of sight. I argue in favour of moving away from an egalitarian approach in refugee response as this will only exacerbate inequalities. Instead it is important to consider what it means to individuals who receive the care, alongside considering what it accomplishes at a greater level (Leaning, Spiegel and Crisp, 2011). There are intra-group differences that are crucial to consider in order to move towards a health justice approach to humanitarian healthcare.

Purpose, accountability, funding, and legitimacy are increasingly prominent issues in the sector. As was demonstrated in Chapter Two, the sector's knowledge has crystallised and aid workers conduct tasks governed by an increasingly formalised, institutionalised system of governance (Kleinman, 2010). Charlotte admitted that MSF is 'turning into the UN' and, consequently, is 'past its critical phase'; the organisation is resistant to change, and staff feel alternative voices aren't considered. This observation was made to me frequently by interlocutors. At the sectors inception, prominent aid actors asserted they were not meant to provide a structural solution but instead they adopted a temporary approach. It is the bedrock of the MSF Nobel Peace Prize Speech: ‘Humanitarianism occurs where the political has failed or is in crisis. We act not to assume political responsibility, but firstly to relieve the inhuman suffering of that failure’ (Orbinski, 1999). This has subsequently shaped employees' understanding of their purpose (Brun, 2016). It is what Pallister-Wilkins (2022) calls ‘pop up humanitarianism’ - aid in response to informal settlements, state withdrawal of access, or service closure. Taken together, this creates uncertainty and insecurity, as all actors are prevented from planning for the future and pursuing long-term goals.

Aid provides respite and a sense of dignity for those living with uncertainty, as is evident in the stories shared by families in this research. However, there comes a point when aid institutions deem it no longer proportionate to allocate funds for a medical project (Fassin, 2007). As was outlined in Chapter Five, the International Monetary Fund requested Lebanese politicians to make reformations. This never took place. The cost of inaction was that the lira went into freefall. MSF’s decision to withdraw was based on a careful deliberation between the project’s financial cost, and the cost to the institution’s values, and perhaps the aid sector as whole. For staff, the project could not continue to operate in a context void of possible yet unwilling political reform. The humanitarian sector relies on grants and donations; funds are secured in response to specific mandates as to where they commit their operations. For instance, Médecins Sans Frontiers ‘go where they are needed most’(Médecins Sans Frontières, 2015). Moreover, organisations strive for transparency in their spending. In following their principles, they could not justify continuing to fund operations if they identified a humanitarian crisis elsewhere, ‘where they are needed most’.

## National Staff Perspective: The Cost of Humanitarian Culture

> ‘If I receive a Lebanese, no one is doing the [financial] coverage, he's between my arms and I have to offer him healthcare, I will have to cover the fees. The UNHCR doesn't cover it, so financially, it's a burden on me as an NGO’ (Muhammad, Staff, Co-development Group Two)

National staff observed one primary change in their daily experience of providing thalassemia care: an increase in Lebanese patients. Previously, Lebanese people often sought treatment at private hospitals, but due to the economic collapse they started turning to organizations like MSF. Unlike Syrians of refugee backgrounds, Lebanese people are not eligible for UNHCR financial reimbursement, and as a result, humanitarian healthcare organizations must bear the full cost of their treatment. Despite the financial burden on NGOs, staff members maintained that they do not allow this to affect their treatment of patients, stating that Lebanese will receive the same care as any other patient. This is important as they are adhering to the humanitarian principle of impartiality.

> التغييرات الصحية حدثت مع زيادة المرضى اللبنانيين طبعا من الناحية المالية وليس من ناحية الخدمات الصحية، اذا والمنظمة بتدفع 25% بس لما USAid %عم اتعامل لاجئ النظام هو هو وسهل انا ببعتو على المستشفى و 75'انا في لبناني وهو بين ايدي أنا ما فيني اعمل شي و هو عبء عليي ك منظمة، إلا إذا في منظمة خيرية بتقول انا بدفع وبهتم بلبناني بس حالياً في الانهيار الاقتصادي صار في عبء على المنظمة

That being said, implicitly staff expressed frustration to Belal about the challenge they face with patients not adhering to medical guidance. Ibrahim cautioned that ‘not everything needs antibiotics’; patients request antibiotics, but by saying no to this request, you’re doing your job (Staff, Co-development Group Four). Staff also shared their lack of trust in patients regarding their medical history, honesty about COVID-19 symptoms, and completion of antibiotic courses, which can cost them in terms of the effectiveness of treatment. To address this issue, staff suggested improving their communication skills and emphasized the need for better health awareness among patients. Ibrahim summarised that for families in the thalassemia ward, ‘it's zero health awareness’, illustrating how parents often purchase drugs directly from the pharmacy without seeking medical consultation. While staff articulated the importance of humanitarian ethics, they indirectly expressed frustration and prejudice through painting narratives of ignorant, sick Syrian families who live in informal settlements.

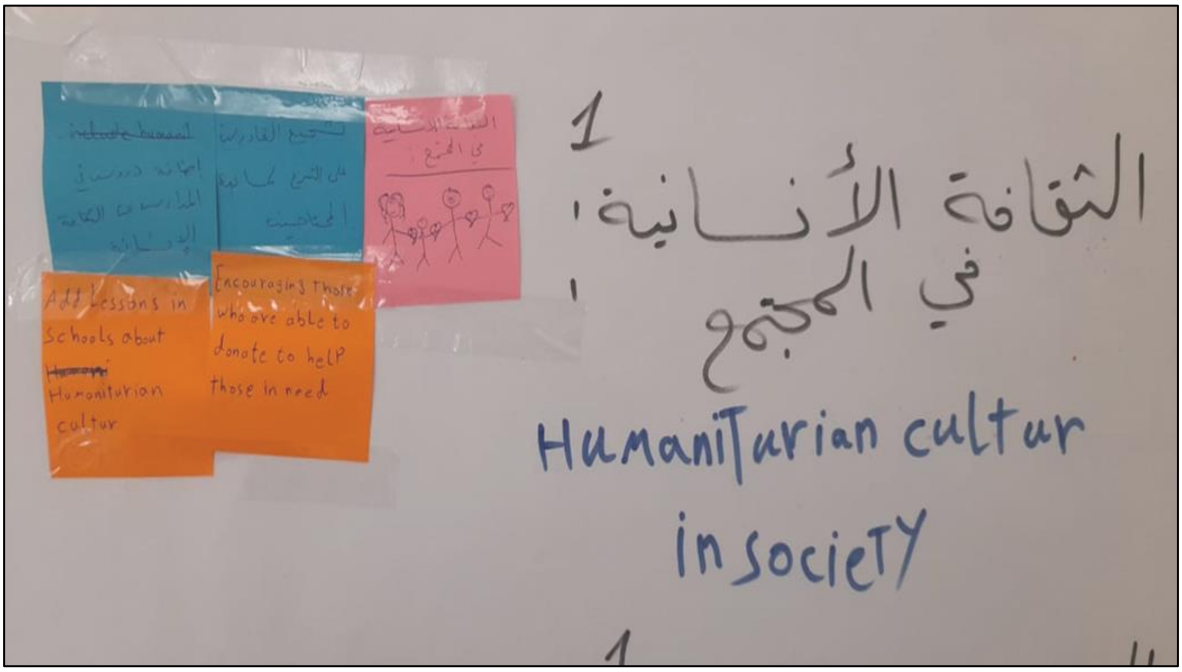
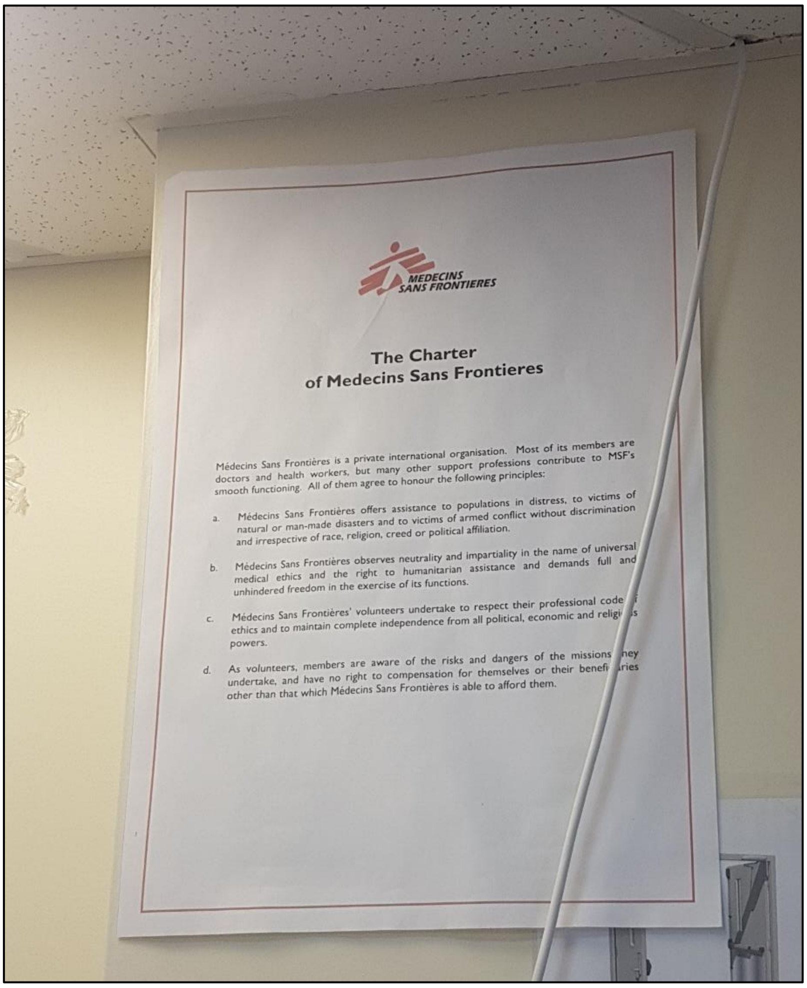


**Figure 6-4 Staff's proposal to improve humanitarian culture in society, as listed on the comment chart**

In the final co-development group, staff discussed solutions to improve health outcomes for the families using the service. While it was accepted that the cause of the public health decline is multifaceted, staff deliberated on whether the economic collapse or the perceived lack of a ‘humanitarian culture’ was more responsible for this deterioration of public health. Ultimately, they concluded that the absence of a humanitarian culture, which includes donating money or materials to share resources, volunteering with an NGO, and caring for others in communities, perpetuated inequalities between Lebanese and Syrians (see Figure 6-4). Staff explained that the cost of not having this culture resulted in hostilities. Lebanese individuals struggled to afford medications while witnessing the dedicated organisations distributing aid for Syrians, exacerbating tensions. Participants explained that these tensions even led to an informal settlement being set on fire. However, staff also acknowledged that in a resource-deprived context, it was understandable for individuals to prioritize their children's well-being by stockpiling resources where they could. Staff concluded that it was not immoral to do what you can to feed your child. To address Lebanese-Syrian opposition caused by insufficient access resources, Zainab proposed introducing "humanitarian education" in schools as a means to overcome divisions based on nationality and sect, moving beyond existing societal constructs (Staff, Co-development Group Four). This section demonstrates the difficulties of enacting humanitarian principles in practice. Through working at the thalassemia unit, staff were required to navigate the organisation's charter (see Figure 6-5 ), which stipulates the organisation's principles staff must follow, their own personal morals, and the influence of societal tensions over resource constraints and cultural sensitivities. Ethical challenges and humanitarian principles were in tension, such as 'not taking sides in a conflict' and 'providing the highest quality of care to all patients'. Scholars have previously made calls for international actors to create frameworks to support staff in navigating their way to fulfilling ethical and humanitarian commitments in practice (Broussard *et al.*, 2019). This section has evidenced that staff seek to enact humanitarian principals in practice, despite the many societal pressures against them doing so.



MEDECINS
SANS FRONTIERES

The Charter
of Medecins Sans Frontieres

Médecins Sans Frontières is a private international organisation. Most of its members are doctors and health workers, but many other support professions contribute to MSF's smooth functioning. All of them agree to honour the following principles:

a. Médecins Sans Frontières offers assistance to populations in distress, to victims of natural or man-made disasters and to victims of armed conflict without discrimination and irrespective of race, religion, creed or political affiliation.

b. Médecins Sans Frontières observes neutrality and impartiality in the name of universal medical ethics and the right to humanitarian assistance and demands full and unhindered freedom in the exercise of its functions.

c. Médecins Sans Frontières' volunteers undertake to respect their professional code ethics and to maintain complete independence from all political, economic and religi s powers.

d. As volunteers, members are aware of the risks and dangers of the missions hey undertake, and have no right to compensation for themselves or their benefi ries other than that which Médecins Sans Frontières is able to afford them.

Figure 6-5 MSF Charter at the hospital reception. Taken March 2020

## Discussion

The perspectives of the intersecting crises in Lebanon led to convergence and divergence between international staff, national staff, and service users as to what the primary challenges were in the thalassemia unit. I argue that the concept of cost (financial, emotional and opportunity cost) revealed the intersecting nature of the crises and the adversities participants faced in the unit. The cost of accessing medication was a central concern for all participants, but their experiences of the cost associated with this varied. Parents often had to forego food to afford medication and faced increased discrimination at pharmacies. Headquarters and international staff encountered lengthy and challenging procurement processes, which influenced the decision to withdraw operations. National staff had to care for more Lebanese patients, leading to increased workloads in the knowledge that the thalassemia treatment they offered was being rationed amongst people in need even further. For me, these challenges and consequences of humanitarian action demonstrate the complexities of humanitarian principles in practice. If Médecins Sans Frontières had stayed in Lebanon and met the need of importing and providing medications, they may have perpetuated Syrian exclusion from the health systems even further. Instead, they closed operations, to which the consequence is unknown, but it is likely dire for families with ill children.

Another aspect of cost was associated with the process of sharing, and restrictions in receiving, information. Parents faced hardships due to a lack of information about the thalassemia treatment centre, resulting in them spending days traveling the country in search of blood donations. International staff limited the thalassemia unit’s advertising to save on costs of treatment. Fuel expenses had forced healthcare services to close, and people could no longer afford private treatment, meaning NGOs were absorbing these patients. In turn, MSF fundraised for donations. They created information campaigns about thalassemia in English for international independent donations. Finally, national staff participants expressed concerns about patients' understanding of medication dosages and their reluctance to share information about COVID-19 symptoms. Having access to important information is a crucial step in health equity for structurally marginalised communities; without this, diseases like thalassemia will not be detected and people’s overall health will deteriorate.

A shared understanding among participants was the consequence of inaction and non-reform in Lebanese governance amid the economic collapse. In the absence of this, Syrian families faced increased hostilities and mounting debt, while

Lebanese national staff expressed concerns about the absence of a humanitarian culture in society. International staff worried that continuing the thalassemia service might compromise humanitarian principles and integrity, as aid services are temporary and cannot replace state-run services. The principles of humanitarianism were significant to all participants. It led to the creation of the space, where national staff described treating all patients with kindness and dignity, but ultimately to the project's closure as well. The thalassemia service provided a space for reimagining everyday experiences and practicing humanitarian culture beyond the confines of the service.

## Precarity: The Future is Contingent

Precarity: Dangerous, likely to cause harm, dependent on unknown developments (Merriam-Webster) - or دقة in Arabic, interpreted by Carol Bittar thematically to mean:

> احتمالية انهيار الاشياء وخاصة البيت (الخيمة) التي يعتبرونها غير ثابتة وممكن خسارتها او ازالتها في أي لحظة
> وهذا يولد عدم الاستقرار الدائم

Precarity is defined in many different ways (Millar, 2017). I will briefly contextualise how the term 'precarious' has been conceptualised in academic discourse to date. I do not see precarity solely as a labour condition, as proposed by Bourdieu's meaning of 'précarité', relating to poverty and job insecurity (Bourdieu, 1998), or thinking with Guy Standing's 'precariat' (precarious and proletariat), people who lack a work-based identity (Standing, 2011). I nod to the labour tensions in this study, as for two of the three participant groups, the thalassemia unit was where they worked, and it was indeed precarious. But for me, it is more than this. Moving towards my application, a final and third contribution comes from Judith Butler, who offers the concept of a 'precarious life' (Butler, 2004). This is closer to how I apply this term because it captures more than the labour relations. Vulnerability is intersectional; it is relational and therefore some lives are more 'grievable' than others. For Butler, precariousness is our societal, unavoidable vulnerability, and precarity is the inequality of life caused by socio-economic and political institutions. Ultimately, we are interdependent. She argues that by staying with the precariousness, we can recognise the precariousness of others. Precarity is a resource that gives us the potential to move towards the other (Millar, 2017). This is more aligned with how I employ the term 'precarity'. I generated this theme from the data as a way to illustrate the power of similarities, how participants illustrated shared meanings from the challenges of working in, or being treated by, the thalassemia unit.

I will detail how my participants understood their lives as being precarious. This incorporates the material and the social. In this study, I employ precarity as meaning 'the likelihood of collapse'. This is because, when I hear this, I recall an image narrated by a participant who detailed the collapse of their tent under the weight of the snow. Freezing cold temperatures. Frostbite. Their family huddled together, sleeping in the elements. This image is familiar to me. I had encountered it before. Tents collapsing from landslides, which resulted in families sleeping in snow, when I researched with the Shelter Cluster in Afghanistan (Shelter Cluster, 2020). In Greece, 2016, as I evaded security at military camps to sneak in tents and sleeping bags for families whose tents had fallen apart. What is striking for me is the hidden forces that created this exposure. The snow may have caused the tent to collapse, but it is the structural violence which forces the families to sleep on the streets. Moreover, this word is often related to economic conditions in common parlance. It depicts the everyday realities of Lebanon's financial collapse. I believe it portrays the tangible and intangible instability of the material and social components of everyday lives in spaces of aid.

## Service User Precarity: Sometimes we imagine a scenario where the project finishes

'I wasn't sick back in Syria, I got sick here.'

(Umm Mohammad, Service User Co-development Group Three)

أنا ما مرضت بسوريا، مرضت هون

'My blood type is hard and every time I get sick, I need blood. In Syria I went to hospital and they gave me the blood directly. But here, in Lebanon, I could die. I need a donator and money, and I don't have this'

(Ali, Service User Co-development Group Three)

أنا فئة دمي صعبة ولهيك كل ما مرضت انا بحاجة لدم بس بسوريا كنت روح ع
المستشفى ويعطوني الدم دغري اما هون بلبنان فممكن موت لانو بدون متبرع و
مصاري وانا ما مع

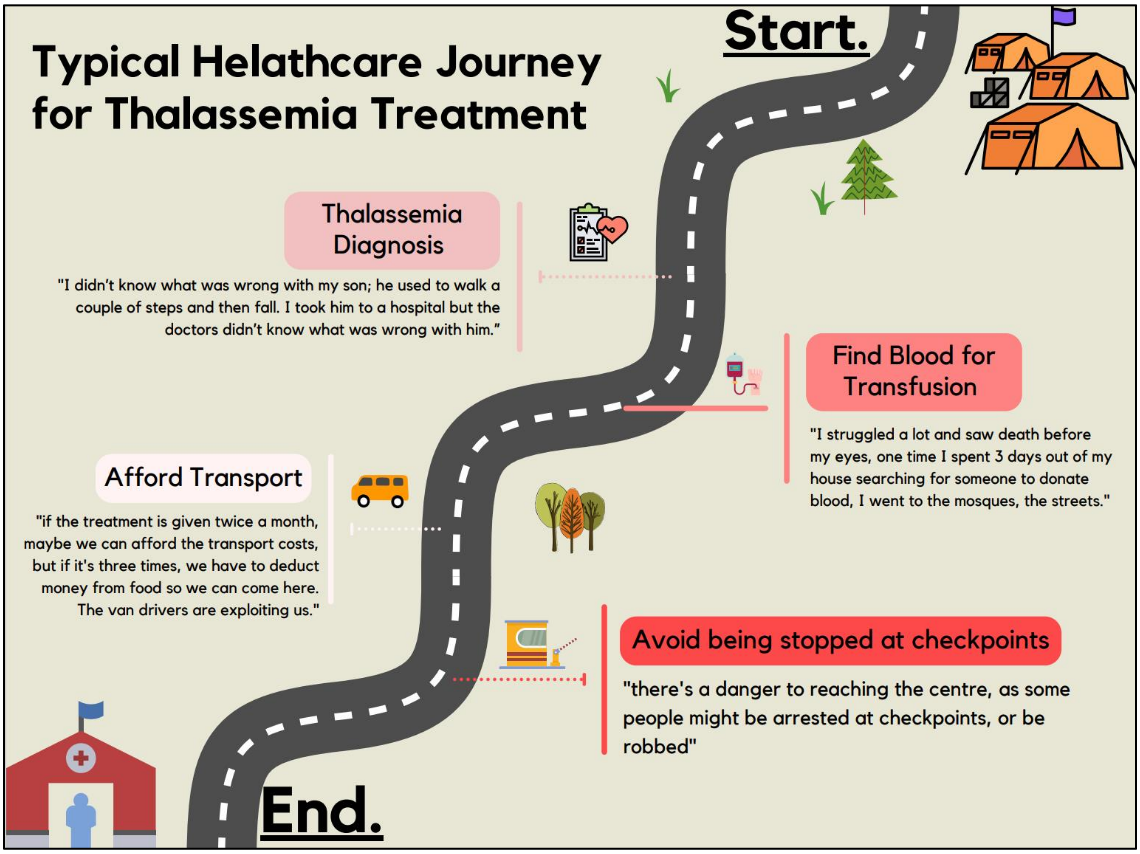
As is illustrated in the quotes above and in Figure 6-6 below, the parents in this research detailed the risks and harms in their typical healthcare journeys for them and their children’s thalassemia. Participants often conveyed a sense of being stuck, unable to move. In Syria during the war, if their town was under siege, families were trapped, and could not leave to purchase iron chelation medications for their children (Médecins Sans Frontières, 2020c). Parents resorted to informally collecting blood donations and arranging home blood transfusions (Médecins Sans Frontières, 2020c). This sense of entrapment continued in Lebanon.

As I have demonstrated so far, transportation to the thalassemia unit became uncertain due to the economic collapse and high fuel costs. Families faced the dilemma of whether they could afford the journey. Sometimes they did not have to pay for their child to take the bus, but other times they did. They often had to walk back for hours if they couldn't afford the price: ‘If the treatment is given two times per month, maybe we can afford the transportation costs, but if it's three times, we will have to deduct the money from the cost of food so we can come here, and also the van drivers are unimaginably exploiting us’ (Yusuf, Service User Co-development Group Four). The sense of being trapped in Syria, needing to get out, being stuck in Lebanon, needing to travel to the thalassemia unit was ubiquitous; being forced on a dangerous journey they could not afford.

‘In Lebanon there is nothing you can fix!’

(Nadia, Service User, Analysis Consultation)

’بالنسبة للبنان ما في شيء فينا يتصلّح‘



Typical Helathcare Journey for Thalassemia Treatment

Thalassemia Diagnosis

"I didn't know what was wrong with my son; he used to walk a couple of steps and then fall. I took him to a hospital but the doctors didn't know what was wrong with him."

Find Blood for Transfusion

"I struggled a lot and saw death before my eyes, one time I spent 3 days out of my house searching for someone to donate blood, I went to the mosques, the streets."

Afford Transport

"if the treatment is given twice a month, maybe we can afford the transport costs, but if it's three times, we have to deduct money from food so we can come here. The van drivers are exploiting us."

Avoid being stopped at checkpoints

"there's a danger to reaching the centre, as some people might be arrested at checkpoints, or be robbed"

**Figure 6-6 Thalassemia healthcare roadmap depicting typical healthcare journeys and risks using participant quotes**

As illustrated in Figure 6-6, the journeys were risky, with the potential for robbery, arrest at checkpoints, and forced return to Syria, which came with life-threatening risks including torture and execution. Noor, a mother in the second co-development group, explained that 'the hospital here used to help us by giving us a report, facilitating passage, so they wouldn't stop us at the checkpoints'. The act of solidarity by MSF in healthcare is crucial, a transformative act changing the journeys of people subject to the asylum system, because it changes how they are responded to in their societies, even if only in a short interaction, such as by enabling them to buy medication at a pharmacy or pass through a checkpoint. Solidarity, a humanitarian principle, implies togetherness, a consultation with community members to hear their needs (Broussard *et al.*, 2019). Transportation, or 'passage facilitation', is an illustration of principles in practice.

كانت المستشفى هون تساعدنا انو تعطينا تقرير وبس تمرق عَ حاجز تقلو انو عندك موعد بالمستشفى وخلنا نسمي تسهيل مرور

> ‘we are finding help here, but sometimes one might imagine a scenario where the hospital will close, or the project finishes’

The closure of the thalassemia service by Médecins Sans Frontières (MSF) left participants with limited options. In the absence of Médecins Sans Frontières, participants explained that they turned to informal dispensaries to purchase medications without prescriptions, even though they considered them untrustworthy. The nature of these informal networks was uncertain, with participants unsure about the contents of the medications, illustrating the nature of the intersecting crises: ‘you tell the one you're having a headache, he'll give you a pain killer, you tell him your arm aches, he'll give you a pain killer, they give you the pills in an envelope, you don't know what you're taking; if you get better, it works, if you get worse, it doesn't’ (Yusuf, Service User Co-development Group Four). Another parent resorted to bringing medications from Syria, a dangerous border crossing. The absence of formal healthcare provision increases danger and perpetuates the lack of accountability and health justice for these families. The rapidly shifting parameters for access and service design, alongside precarious living conditions and migration journeys, create great difficulties in healthcare management due to disruptions in care, complications in treatment, and oversights in referrals.

The climate collapse further exacerbated the challenges faced by participants. The consequence of seasonality was stipulated in the December 2021 MSF Situational Report. It documented how roads were closed for several days at a time due to snow, preventing movement, and resulting in patients being unable to attend the service for treatment. It identified how seasonality particularly impacted refugees in informal tented settlements, as their tents often collapsed from the weight of snow, which can ‘trap, suffocate, and result in death’. Parents would light fires near the tent to prevent their families freezing. This would often set the tent on fire, leaving families without shelter, endangering lives, and leaving families exposed. Year on year, the climate collapse is causing intense drought in the summer, floods in spring and heavy snowfall in the winter, perpetuating the hardship of providing a life for one’s family - staying safe while living in a tent.

To conclude, participants detailed the dangerous healthcare journeys they endured to care for their child's thalassemia. From Syria to Lebanon, from the informal settlements to the MSF unit, they portrayed a narrative of being trapped on a journey with many risks. Looking forward, alongside climate collapse, in the absence of Médecins Sans Frontières services, Yusuf provided a glimpse into tampered medication and its possible side effects. Participants expressed a desire for a future outside of Lebanon, where they could secure permanent treatment for thalassemia and contribute meaningfully to society. They longed for stability and the ability to focus on other aspects of life, such as supporting their children's education, which had been hindered by the absence of long-term care for their children's sickness.

## International Staff: The Precarious Short-Term Memory of Humanitarian Aid

I traced the uncertainties caused by the shifting economic, political and social grounds in Lebanon, and the challenges that this created for the thalassemia service in MSF monthly situational reports. This hindered everyday operations; for instance, the precarities of running the 'blood drives' for the thalassemia blood bank were detailed prior to the unit's closure: 'Places to do blood drives started to be a challenge; we are struggling sometimes to find a host for organizing campaigns in different places' (MSF Situational Report; October 2021). In part, this was caused by societal unrest. Below, MSF illustrates how the socio-cultural and political context of Lebanon has created 'worsening life conditions', a precarious life, for their patients:

> In Tripoli, the city still witnesses scattered demonstrations and road blocks, these protests are for varied reasons, mostly related to worsening life conditions. Also violence and armed clashes increased in the city on the 6 November 2021, armed clashes erupted due to old family feud where 2 civilians were injured. Illegal migration by the sea attempts has increases. Couple of demonstrations late November by the family of *illegal immigrant* (own emphasis) have blocked El Mina road in protest for detained their sons, after report of Turkish coast guard detained 6 Lebanese migrations.

(MSF Situational Report, November 2021)

The unrest in this excerpt details the fragility of the Lebanese civil society and the forms of violence on people in Lebanon. Across all participant groups, demonstrations, roadblocks, and an increase in armed clashes were noted by residents over the duration of this study. While international staff experienced operational challenges, for some families living in Lebanon, whether Lebanese, Palestinian, or Syrian, the safest option, or perhaps what might be the only option for these life-seekers, is to make the treacherous journey from Lebanon to Cyprus by sea in a precarious boat when faced with this degree of direct, ‘cultural and structural violence’ (Galtung, 1990).

A second uncertainty for humanitarian healthcare management related to international staff’s future imaginaries. Mobility, the practice of working across borders, is at the heart of much international humanitarian practice. It’s about moving past supporting your kinship to developing a connection and supporting affected populations whom you have no obligation to other than a moral sense of duty (Pallister-Wilkins, 2018). Indeed, practitioners define their work as being practiced without borders. For many international aid staff, and reflecting on my own experience, there are challenges with this perpetual temporary relocation. Employment contracts run for six to 12 months and create challenges, if not impossibilities, for a homemaking process. Poor pay (a starting ‘volunteer stipend’ with MSF is £800 per month) results in staff being unable to financially retain a home, meaning many staff don’t have anywhere to go back to. Charlotte and colleagues I have worked with over the years expressed feeling trapped in a cycle of redeployment. Conversations around dinner tables, including with an MSF Lebanon Head of Mission, reflected on the absence of home, family, and relationships. The confinements of a compound do not allow for making connections and prohibit any work-life balance (Visser *et al.*, 2016). International staff expressed a desire to partake in a homemaking process, a finding shared, as evidenced earlier in this chapter, with Syrian families.

My conversation with Charlotte underpinned the reality that constant redeployment for job retention and separation from one’s family is unsustainable. She narrated experiencing a forced, perpetual migration for income and career progression, alongside retaining a sense of belonging and purpose. Many international aid workers live out of a backpack and lack material welfare. International aid workers live in the knowledge that the emotional support networks surrounding them, with colleagues turned flatmates, will be lost to the permanent transience of the sector. Contextual project knowledge is also lost in this migration, perpetuating the short-term memory of the sector (Hayden, 2023). Moreover, this impedes the principle of solidarity with patients and national staff, and aid workers are at a distance because of culture, language, or being geographically removed in a compound, staying only temporarily, never having the chance to form meaningful connections (Broussard *et al.*, 2019). This perpetuates harmful perceptions of 'otherness', an Orientalist gaze which perpetuates neo-colonial styles of thought. This short-term memory puts the Westerner in the upper hand (Said, 1978), as it normalises the superiority of forms of knowledge accrued through the series of short term contracts rather than localised ways of knowing, as identified in Chapter Four of this thesis by national staff.

Yet working in fragile settings is also a passion project for many colleagues I have met over the years. The fast pace and dedication to 'humanitarianism' and their principles shapes people's sense of identity. When speaking with Charlotte, she reflected on the two-sided coin: i) unpredictability that the lifestyle brings, a sense of excitement and the privilege of asking 'where next', and equally ii) an absence of belonging to a place, aside from perhaps spaces of aid, due to constant onward migration (Smirl, 2015). I believe being separated 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. I argue that 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 (Butler, 2004).

## National Staff: The Power of Rumours and Suspicion

Castells (2016) explains how power is exercised within institutions through communication systems that reflect interests and shape social conduct. Tensions among staff were immediately noticeable upon my arrival in Lebanon in 2019. When attending a staff meeting, we overheard shouting in the corridor. When the Head of Mission peered out the meeting room door, she dismissed it as 'just a bit of hair-pulling' by the nurses (Research Diary, 2019). In the everyday workplace, collegial surveillance and the fear of being implicated in any collusion led to a national staff colleague telling me it would be best if I ‘didn’t mention that they gave me a lift home’, as it could create an atmosphere of suspicion. People would talk. This sense of surveillance in the project was everywhere, like pollution; I didn’t notice it at first but over time I saw the harm it created. I will detail below how the workplace context increased stress and anxiety, reduced trust and morale, and impeded staff’s ability to express innovative ideas and demonstrate problem-solving due to the fear of repercussions – a perception similarly expressed by international staff in the former section.

As I discussed in Chapter Four, when revising the research design with MSF, I was told not to mix staff and service users in an effort to keep the peace, to prevent finger-pointing and blame. Moreover, in 2022, prior to conducting the participatory analysis session with staff, international staff forewarned me that there might be tension, a bad atmosphere, amongst and from national staff as they had been informed that the project would be closing. The examples of group tensions were many. The difficulty of retaining a livelihood due to the failing state and a high-pressured job seemed to create a sense of stress in every aspect of working life for the national staff at MSF.

The consequence of the temporariness of humanitarian aid projects for national staff who live in a failing state like Lebanon is that their livelihoods are inherently precarious. Academics acknowledge that the data relating to job insecurity on employee wellbeing is inconclusive (Witte, 1999), but De Cuyper and De Witte (2006) posit that job insecurity may damage one’s physical and mental health and may harm employees’ attitudes and behaviours towards their employers in the workplace. This echoes the work of Standing (2011) on the social consequences of precarity, demonstrating the anger and alienation that derives from not being able to access a stable income and job security. National staff are dependent on, and made vulnerable by, their employer. Future uncertainties shape the permanently temporary nature of NGO projects. This was discussed by Leila in the third co-development group. Similar to international staff, she acknowledged that in Lebanon, futures are uncertain. However, this in itself should not result in project closure when patient numbers are not realised. Patients are in need of care, and those who are more structurally vulnerable need reasonable adjustments to attend the clinic. Prioritisation and triaging to focus on people with urgent needs and increased vulnerability is necessary when there is a high demand that exceeds the resources available. From the national staff’s perspective, rather than proceeding with a health justice approach to service provision, MSF relied on service information not being shared amongst weak social networks:

> There was something strange. When we came, the floors used to be full, and our hospitals empty, we used to talk and 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)

’كان في شي غريب انو لما اجينا نحكي عن التلسميا كانو خايفين ينشروا الاخبار ويقولوا انو مشروع هو للبنانين والسوريين
كمان، ضلوا قديش الطابق فاضي وما في معلومات، خايفين يجي ناس بزيادة ، كان في شي مش مظبوط.
ما كان في منهجية، كان في كتير فردية وبيجي واحد بيقول بدنا نعمل هيك و نشتغل هيك بس ع أرض الواقع ما في شغل‘

Staff deliberated on tentative solutions to resolve the precarity of the health sector. Belal illustrated the solutions proposed by care providers the day prior, describing how they suggested bringing in foreign external administrators to manage the operations. As Belal argued, the issue isn’t economic it’s political:

> Belal: ‘Bring someone who’s got money, like the UN can take care of the healthcare sector, they are funding a lot of NGOs working in the sector. Come and put your hands on the medical care sector, entirely in Lebanon.’
>
> Zainab: ‘Nice answer’
>
> Ibrahim: ‘But this is not a solution’
>
> (Staff, Co-development Group Four).

Despite differing opinions, there was a consensus that any alternative future that establishes a functional healthcare sector, whether through international intervention or other means, is preferable to the current situation. The main priority is to ensure that patients receive necessary treatment for their illnesses. Ultimately, a foreign entity with greater transparency compared to the collapsing and what participants defined as a corrupt Lebanese state was seen as a solution.

## Discussion

The illustration of collapsing tents and state systems was poignantly conveyed by participants in this study. The process of this collapse was central to how participants made sense of their experiences of precarity. The significance of temporality in humanitarian structures was demonstrated by Brun (2016) as she expressed that people often feel ‘stuck’ in humanitarian systems, but in reality people undergo geographical and social movement to a better or worse condition (Brun, 2016, p. 393).

The emergency imaginary is an important component of humanitarian reason (Brun, 2016, p. 401). resulted in geographical mobility for international staff. This was often accompanied by an absence of knowledge retention at the project level. For national staff and service users, it resulted in a mobility towards worse conditions with a shared sense of fear, of impeding unemployment and seeking to work elsewhere for staff, as well as deteriorating health for service users.

The future imaginary for service users is at the disposal of the humanitarian system. Humanitarian organisations have the ability to ‘save a life’, operating either through humanitarian medicine as biopolitics (Fassin, 2007) or refugee relocation through geopolitics (Brun, 2016). This chapter has detailed the forced immobility when living under siege in Syria, and the subsequent forced mobility to Lebanon of people and things, including lifesaving medicine, from Syria to Lebanon. For international staff, the future is inherently contingent; it is decontextualised from the present. Brun (2016) explains that humanitarian work will continue if it is short-term relief to save a stranger’s life. She writes that if the crises become protracted, as they did in Lebanon, there can be no return to what perhaps never existed (for instance, thalassemia care for Syrian refugees). The humanitarian rationale at this point is to withdraw. The movement towards worsening conditions, an increase in crisis and a decrease in the availability of medications, resulted in operational withdrawal. The importance of a framework to support national staff in navigating the multiple and sometimes conflicting humanitarian principles and social morality of the spaces they occupy was demonstrated. Moreover, the need for all staff at Médecins Sans Frontières to feel that they can express their perceptions of challenges and propose alternative solutions, without fear of repercussions, is a crucial step needed to stifle staff turnover and shift towards a long-term memory of aid, as well as improve trust, morale, and overall staff wellbeing.

## Conclusion: The Consequence of Forced (im)mobility

Participants conveyed a sense of loss, an absence of hope, of employment, of life. Indeed, Belal asked service users in the analysis consultation, 'What can fix the problem in the health sector, in your opinion?', to which Nadia, a mother whose child was being treated for thalassemia, asserted with anger, 'In Lebanon there is nothing you can fix!' (Service User, Analysis Consultation). Staff and service users expressed this sense of loss in response to shared crises they experienced; loss of the thalassemia service, loss of relationships. They responded to each other's loss in different ways, sometimes with distrust, and at other times with reassurance and solidarity. If someone loses, there is often a winner. I argue that the temporality conveyed by the word 'loss', or الخسارة in Arabic, reflects the nature of the aid industry: loss is a process, it is permanently temporary. Identifying the harms caused in the process of loss and identifying the shared meaning can help us to find a middle ground, a truce to collisions and conflict caused by the structures of aid. All participants conveyed a sense of uncertainty of the future, of vulnerability within the industry. While their experiences differed, their meanings were expressed in similar ways.

Both staff and service users conveyed a sense of despair at the cost of thalassemia treatment. For parents, the price of blood donations and transfusions led to fear for their child's health, and for international staff the cost of a blood bank and medications consumed their budget. In response to the increasing prices, staff began fundraising efforts and rationed resources amidst increasing patient numbers. In a bid to increase revenue, the MoH imposed tax and charges on MSF operations, which further strained their relationship. Ultimately, the project costs were deemed disproportionately high. One tactic

Médecins Sans Frontières implemented was to limit advertising of their services, which may have cost many would-be patients their lives due to their lack of awareness that the thalassemia service existed. In response to this resource management strategy, national staff functioned as translators between deprived families seeking blood transfusions, processing referrals and medications, to a strained management system. This cost them their wellbeing. Médecins Sans Frontières mobilised in Lebanon to support a section of the health system on a temporary basis. The state did not reform its health systems, a conditional demand for international support, and as a result, Médecins Sans Frontières discontinued their operations. They did this to adhere to humanitarian principles, but I have argued the necessity to move towards health justice, which considers health in a contextualised and relative frame, rather than taking a utilitarian approach to resource management.

The humanitarian system created an uncertain future. Through the analogy of the collapsing tent, I have argued that the system of aid created precarity due to its temporary structures, and I have shown the effects of this in the lives of my research participants. For many, there was a shared hope in a future with migration, either through redeployment with a promotion for international staff, white coat emigration for national staff, or UNHCR refugee relocation for service users. This illustration of different experiences in a shared space of aid demonstrated the multiple mobilities. Staff and service user lives are interconnected through a hope of future migration, through shared vulnerabilities and a dedication to imagining a more equitable health system. Contexts transitioned from bad to worse; people and medications experienced forced (im)mobility across borders as headquarters renewed or rejected project budgets through the financial cycle. By centring the lives of people experiencing crises, I have illustrated how different participant groups made sense of their present and future biological and biographical selves. Through thematic analysis, I answered Research Question Three, which asked, ‘What challenges did the MSF project and its service users experience due to the multiple crises?’. I narrated their different experiences through a shared sense of meaning-making by using three themes to illustrate their primary challenges: ‘loss’, ‘cost’, and ‘precarity’, or الخسارة, التكلفة , and دقة in Arabic. By finding a shared sense of experience, by centring voices that are often silenced, humanitarian aid structures can dismantle the systems that often lead to their staff and service users to feel ‘stuck’ in the present.

In the next chapter, I will pick up on these arguments and those in Chapters Four and Five to draw conclusions. I will tie together the theoretical threads throughout this thesis and present my concluding arguments, specifically regarding the nature of power and participation in aid and how these shape and create tensions of localised value systems, and the resulting absence of sustainable care for long-term illness. Moreover, drawing from the conclusions of this study, I will present recommendations for research and practice, tentative ways for the humanitarian healthcare sector to move towards greater equity.

# Chapter 7 Conclusion

This thesis set out to explore how humanitarian healthcare could be improved in Lebanon. In this thesis, I have deconstructed the heterogeneous entities (actors, discourses, practices, material elements) of aid to explore how the ‘not yet’ of project decisions, the ‘not yet’ of project closure, and the handover and its consequences for people and things (materials) affected the connected people ‘feeling stuck’ in this power struggle. Through non-hierarchical thinking in these aid assemblages, I have evidenced the relationships and connections between ideas and between the headquarters and project implementation to understand how humanitarian healthcare can be otherwise.

I did this by implementing co-development groups with staff and service users to explore the potential for participatory codesign in spaces of aid. Taking an MSF-delivered thalassemia unit as a case study, I explored the opportunities and challenges of participatory programme design in international humanitarian healthcare. Chapter Five explored the chronicle of crises in Lebanon and how the shifting sands underpinning humanitarian healthcare revealed the power dynamics and made inequalities in this space all the more visible. I evidenced what knowledge and values informed project decisions, and what the consequences were for staff and the families of patients treated at the NCD unit. Chapter Six weaved together the theoretical threads of analysis of power, postcolonialism, precarity, and participation to illustrate the consequences of the emergency imaginary for everyday lives. I used the analogy of the collapsing tent to portray the precarious structures people are subject to in the sector.

Since Belal and I generated the data for this thesis, Lebanon’s currency has continued to plummet, the Lebanese Armed Forces have increased deportations of Syrians back to Syria, putting them at risk of persecution and torture, and white-coat emigration from Lebanon has continued (Amnesty International, 2023). As for the Médecins Sans Frontières thalassemia unit, it closed operations in May 2023. Participants of this research pivoted; staff secured new positions and parents continued to find ways to treat their children’s thalassemia. Via email communication with former Médecins Sans Frontières staff, I was offered the following update on the healthcare journeys of the families seeking care for their children’s thalassemia; it illustrates the unwavering dedication of national staff to provide permanent thalassemia care in a system favouring temporary solutions:

> Regarding the thalassemia project, of course it would be great to include the situation now, and here's a summary:
>
> So when MSF France decided to close the thalassemia unit due to various reasons, they were still committed to the patients and they wanted to ensure that their treatment would not be disrupted. Stakeholder mapping and analysis was done, and almost all of the NGOs in Lebanon working in health were contacted, but none of them accepted to take over the thalassemia cohort, either because it's out of their scope, or because there was no budget, or they were not interested.
>
> A series of assessments were conducted by MSF France, and then Karma NGO was validated as the partner to take over the cohort. Karma tried hard to get funds for the project, but it was a very short notice for the possible donors, so eventually, MSF France funded this project for a period of 12 months, giving Karma the opportunity to find funds for the continuity of the project while making sure no disruption in the treatment plans of the patients.
>
> So currently Karma is delivering the same services to the thalassemia patients including: 1- iron chelation medications which were donated by MSF France, phenotype-matching blood transfusions in the Governmental Hospital, having the blood supply from the Lebanese Red Cross, MRI T2* to check for iron overload for few patients, funded by Medical Hope, and referrals for subspeciality consultations, in addition to psychosocial support including supporting with transportation fees. All these services are delivered to the patients for free.
>
> Karma had to hire some staff to run the project, which started with 89 underprivileged patients with thalassemia, of different nationalities, taking into consideration keeping the administrative costs as low as possible to make sure the biggest percentage of the money donated goes for the treatment of the patients.
>
> Currently, Karma aims at raising funds to guarantee the continuity of the treatment of patients already in our cohort, and try to include more patients in need of support, in addition to advocating for the thalassemia patients in Lebanon and raising awareness about thalassemia and the importance of donating blood to help these patients survive.

(Email Communications, July 2023)

While this thesis focused on one NGO-run NCD unit in Lebanon, its findings are applicable more broadly. First and foremost, it has revealed the limitations of humanitarian intervention - specifically, the infrastructural boundaries the sector instils, by which the state is ultimately responsible for the necessary logistical assemblages and if these do not materialise, the humanitarian NGO can withdraw. I have detailed what the consequences of this situation are for people who are living with thalassemia - the patients and their parents - when they ‘feel stuck’ in an emergency and cannot secure the long-term healthcare they need. This evidence contributes to the significance of implementing the ‘triple nexus’, the interconnectedness and integration of humanitarian assistance, development and peacebuilding, and the challenges of this. This in-depth account of life with a chronic illness, a sense of feeling trapped in temporary care, contributes not only to critical humanitarian studies, but also to studies on the sociology of medicine and processes of public health more broadly at a time when many public health systems are suffering from austerity and people are increasingly illegalised.

Each of this thesis’ findings chapters answered one of the three research questions with its own theoretical argument. In Chapter Four, I answered Research Question One: ‘Can a co-development group be used to meaningfully engage staff and service users to collectively improve humanitarian healthcare in Lebanon?’ I answered ‘yes’, evidencing the possibilities of participation with humanitarian national staff while acknowledging the limitations of participation with international staff in part due to a sense of surveillance, and with service users due to the myriad forms of structural violence they are subject to. In Chapter Five I answered Research Question Two: ‘How were the MSF project and its service users affected by the multiple crises in Lebanon?’. In this chapter I traced the three crises in Lebanon and detailed the challenges that participants had experienced due to the value system underpinning the prioritisation of care. In Chapter Six I answered Research Question Three: ‘What challenges did the MSF project and its service users experience due to the multiple crises? I thematically illustrated how participants created a shared sense of meaning evoked by a sense of loss, stemming from the dedication of all participants to care for the patients, and the temporal tensions arising from the structures of aid.

Taken together, I demonstrated the significance of situated seeing - how the social and the cultural shapes our particular ways of knowing. I demonstrated the necessity, and proposed ways, for humanitarian systems to shift, rethink, and alter practice to move towards greater equity. In this sense, the impact-driven humanitarian affairs research contained in this thesis has documented why humanitarian healthcare can be otherwise: otherwise configured, otherwise provided, otherwise designed. I specified the role that hegemonic power has in creating the need for change through the consequences of service design, and in turn how better equity can be achieved through participation and patient-centred care.

## Key Contributions

This section highlights the key analytical and methodological contributions of this research. In particular, I discuss the following contributions:

- Power and participation in spaces of aid;
- The need to incorporate localised value systems in humanitarian healthcare;
- The necessity to rethink the modus operandi and forecast a future of humanitarian healthcare.

The pages of this thesis weave the ways in which relational power creates barriers and opportunities for staff and service users to participate in humanitarian action. Through this study, I analysed the dynamics of everyday operations as a decolonial critique of the humanitarian aid sector. I argued in Chapter Two that in order to decentre neo-colonial power from the ‘West’ and move towards localisation and patient-centred care, an analysis of methods of humanitarian practice is a necessary and logical starting point. In Chapter Four, I argued that embracing local ways of knowing is essential in order to break the cycle of hegemonic power and better address the health needs of affected communities. This recognition has gained traction in the humanitarian sector, and is increasingly seen as a means of improving power relations and trust between NGOs, UN bodies, and service users (Barakat and Milton, 2020; Kelly, Pardy and McGlasson, 2022; Roepstorff, 2020). While I emphasised the transformative power of pluralist dialogical approaches in designing effective healthcare services that centre patient voices, I recognised how barriers to participation can hinder this. In Chapter Five, I illustrated this through failed dialogical efforts on the part of senior management and national staff during the transition to emergency operations as a result of the pandemic, and I considered the opportunities and limitations of dialogical research methods in Chapter Four. The reasons for these failures lie, in part, in the lack of trust between the participants and the structures they are subject to. To adhere to decolonial research principles, flexibility is essential, centring people's agendas over the researcher's. I concluded that in low-resource settings, in-person participation is crucial for reciprocity in humanitarian research with a decolonial focus. However, as a white academic at a British university, I demonstrated that I did not have to be *there*. Refugee studies' projects are often driven by an implicit, urgent, moral imperative that 'they' need to be studied, and be studied by 'us'. This is not the case. Such research practices can reinforce the hostile European border regime as this scholarship itself is part of the 'refugee regime' (Cabot, 2019). While such 'refugee studies' scholarship may appear benign or emancipatory, it often contributes to reinforcing illegalisation of migration and the politics of life though deciding who is worthy of being studied (Fassin, 2011, p. 499; Cabot, 2019, p. 262). This is crucial learning for humanitarian action, as researching with already over-researched and structurally vulnerable populations can indeed do more harm in already damaged lives.

One of the central tenets of this research relates to the ways of seeing in humanitarian aid (Cowling, 2020). The ethics and moral principles underpinning international humanitarian action stem from the value system that has been shaped by our socio-cultural ways of interpreting the world. I have argued that this can be interpreted as an Orientalist gaze. The humanitarian aid sector, propped up by precarious staff contracts and project funding, responding to healthcare needs in spaces of economic crises results in the omission of a biosocial approach to long-term care for NCDs. The call for improving NCD healthcare provision in humanitarian settings has been made by scholars including Spiegel *et al.* (2010), and more recently Aebischer Perone *et al.* (2017). Many Western value systems, and specifically - as I have evidenced in this thesis - the value system underpinning humanitarian healthcare, reflect Western ways of knowing about health and healthcare systems. Often, value is interpreted as value for money, favouring the less expensive primary care (over more expensive hospital treatment), rather than the value of improved health for a patient and their family through NCD treatment. This was evidenced in Lebanese healthcare systems, as the MoH sought to understand how Médecins Sans Frontières ran things so cheaply, and also by Médecins Sans Frontières, who cross-compared budgets between low- and middle-income countries in a cost-benefit analysis of value for money. I argue that the postcoloniality in humanitarian settings erases the complexity of health and healthcare needs through the discourse and its associated powers, shaping how people see healthcare needs, and thus how they respond to needs and design services.

This thesis has evidenced how international humanitarian healthcare is driven by utilitarian ethics, and it has illustrated the consequences of this for staff working in, and patients being treated by the sector. I argue that considering the value of what the healthcare means to individuals who receive it, alongside considering what it accomplishes at a macro epidemiological level in terms of improved health outcomes, will achieve a localised, synergetic way of understanding health, reducing cultural collisions. I conclude that one way to improve humanitarian healthcare is to redesign the value system that shapes service design to consider several factors, including the cost of treatment, the impact of the healthcare on the population's well-being, and its effects for individuals and their families. This approach moves towards incorporating multiple literacies and centring patient voices to listen to the different values the healthcare brings, and to transition from a unilateral charitable system that perpetuates the ‘beneficiary’ towards a more meaningful, localised, and sustainable health system driven by solidarity. Taking this approach would enable a move beyond the traditional humanitarian practices of meeting basic needs for survival towards enhancing lives. As it stands, in protracted humanitarian settings against a backdrop of increasing NCDs, aging populations and urbanisation, an approach to healthcare that responds to biosocial needs in a sustainable way, supporting the public health systems, is necessary in order to support health equity. A clear delineation of responsibilities between the humanitarian sector and state is necessary so the continuum of care required can be provided to patients.

## Limitations and Further Research

There are several limitations to this work, which I hope to address where feasible in my future research. These include demography, language and contextual familiarity, relationships and trust with participants, contextual limitations, and limited insights due to the singular international research partner.

The first of these - the demographic limitation – refers to the international staff in the methodologies, including the participatory element and the limited interviews. The pandemic limited my in-person engagement with the Médecins Sans Frontières project and its staff, as it was not possible for me to be in Lebanon to develop the relationships required for multiple semi-structured interviews with international staff. It is crucial to include all perspectives in a participatory dialogic approach, but the research refusal due to the pandemic rendered this unfeasible. If I had not been evacuated from Lebanon and stayed for the planned three months with MSF, I may have developed the trust and working relationships required to recruit more international staff as participants in the research project's methodologies. Future research could consider this national and international staff cross-dialogue approach to collaboratively identify challenges and solutions and think across disciplines and positions of power.

A second limitation to this work is the language barrier. As I only have basic Levantine Arabic, my ability to engage with the transcripts is limited, meaning I heavily relied on the English language transcripts during interpretation. Moreover, I am not Lebanese or Syrian. I have limited understanding of the context, and while there are strengths to being an 'outsider', and while I am an 'insider' aid worker, this situated seeing inevitably has limitations. I addressed the linguistic limitation through working closely with my Arabic teacher, and running three consultation sessions and feeding back findings sessions.

The third limitation relates to Belal's positionality as a male. Some of the co-development groups consisted solely of mothers, meaning (as I evidenced in Chapter Four) the relational power of gender both hindered and facilitated the research process. Moreover, Belal and I only met in-person after the co-development group data generation. As I concluded in Chapter Four, our trust in one another developed after meeting in-person, as there had been a metaphorical distance caused by our geographies. The co-development group participants sought to meet me too, but due to pandemic limitations it was not possible for me to be in Lebanon. I infer that this project would have aligned more closely to decolonial principles, creating greater participation and equity, had I been in Lebanon and met participants prior to the co-development group facilitation. However, the outcome of running this participatory design digitally provides important insights for facilitating research remotely at a time of climate collapse, when flying less is necessary, and the call for greater localisation is increasing.

The context of the co-development groups created inherent limitations. During data generation, staff were within earshot of senior management staff, and service users within earshot of healthcare practitioners, creating a sense of surveillance that likely impeded my participants' comfort during data generation, as I discussed in Chapter Four. However, this context also had benefits; service-users referred to the thalassemia unit as the only space where they felt they were treated with dignity in Lebanon, and for staff with busy lives responding to multiple crises in a hospital, it had the benefit of convenience. High participant turnover was a limitation in this sequential and cumulative methodology, with Belal spending 15 minutes of each one-hour session explaining the questions and what had happened in the prior sessions as participants were unsure of the objectives, causing some frustration for participants who had attended previously. However, given the inherent time constraints of researching with parents whose children needed their support and with staff on-shift at a hospital, it was important for Belal and me to be responsive to the nature of the context and its demands. While conducting the research in the unit had limitations, it did offer the benefit of familiarity for all co-development group participants.

Working with Médecins Sans Frontières for this research also created limitations. The staff turnover at Médecins Sans Frontières created limitations as I had to create new relationships every six months with the international senior management staff, but this also reflects the realities of how knowledge is valued by headquarters. Knowledge accrued through international staff redeployment is favoured over national staff's localised, contextual knowledge. Nevertheless, there were logistical impediments caused by the necessity to reintroduce the project and develop trust during project management. It is also important to note that many PhDs on humanitarian aid have been facilitated in recent years by Médecins Sans Frontières, including Caleo (2021); D'Mello-Guyett (2022); Stellmach (2016); Joxe (2019); Atterton (2021) and James (2020a) to name but a few. It is likely that Médecins Sans Frontières is one of the organisations that facilitate the most humanitarian-focused research due to the comparative resources they have to host PhD studies. While this study's original design was a cross-case, seeking to provide insight into the divergence of structural resources during the pandemic, resources prevented this from happening. For this reason, focus of this study became institutional, which is not new; however, the context of study did provide a new insight, especially as MSF's unit was embedded in a MoH hospital.

The final limitation to this study was the pandemic. The original design included an ethnographic approach to working with Médecins Sans Frontières and Amel Association. However, due to pandemic travel restrictions, it was not possible for me to continue the rich ethnographic immersion I had originally planned. Nevertheless, I retained ethnographic tools, including a research diary, participant engagement, and deep reflexivity throughout the research process. This necessity to pivot, reprioritise, and redesign reflects the nature of working in aid systems and its inherent risks. Moreover, aid organisations priority is to provide healthcare rather than facilitate academic research resulting in the necessity for project suspensions on occasion.

In this research, there are clear parallels between the consequences of the 'burn out jobs' and increasingly neo-liberal model of many global healthcare systems (Purvis, 2015). This research contributes to the literature in human geography, human resources, sociology, anthropology, and public health by evidencing the need for improved staff support in humanitarian aid. At times, national staff are subject to similar conditions as patients, and as this research has demonstrated, national staff conduct exhausting translation work between patients, their parents, and senior management. To make the necessary improvements in the working culture of international humanitarian aid, there must be greater communication from headquarters to project staff regarding service design to increase trust, accountability, and morale in humanitarian healthcare provision.

This research also illustrates the fundamental need for long-term secondary care for patients seeking humanitarian healthcare. The global epidemiological transition to noncommunicable diseases in conjunction with the climate crises have resulted in an increased population crossing borders requiring treatment for illnesses including diabetes, cancer, and thalassemia (Aebischer Perone *et al.*, 2017). Médecins Sans Frontières published a study of a thalassemia unit in Syria, detailing how they ultimately closed this service due to the logistical challenges of running an NCD unit in a conflict setting (MacVinish *et al.*, 2023). Thalassemia is an extreme case for NCD management as it requires secondary care, however, lessons can be applied to more typical cases, such as type two diabetes, hypertension and mental health conditions, such as depression. It is crucial at a time of increased NCDs that, when a context experiences a crisis, permanent continuity-focused secondary healthcare is provided so that the management of NCD disease is not compromised at the expense of primary care. This also adheres to The Sphere guidelines, which detail that people in humanitarian settings with NCDs should be stabilised clinically and receive maintenance therapy (The Sphere Project, 2011).

Future research exploring the NCD treatment people received prior to crossing borders could support humanitarian healthcare response in forecasting the tactics parents use to ‘make do’ in low-resource conflict settings, and the health complications that can arise from this. As an illustration, in Chapter Six I noted how parents detailed arranging blood transfusions in their homes, a fatal process if done incorrectly without the necessary oversight. It is imperative to understand how people arrange NCD treatment in conflict-affected settings in order to forecast possible complications on arrival in a safer second country. Moreover, further research can develop the understanding of the role of NCDs in creating forced *immobility* for people and their families, asking who is left behind and how this affects the family unit’s migration and health trajectory.

This thesis evidenced how the conflict arising from temporal tensions was significant. I believe delving into temporal tensions further, thinking with scholars such as Eviatar Zerubavel who writes about ‘hidden rhythms’, offers an important scope to tease out the ways these tensions can be overcome through exploring the intersecting and competing forces which shape cultures and temporality, and how these shape the biopolitics of humanitarianism (Zerubavel, 1985).

Finally, I recommend researching with national humanitarian healthcare organisations, either as a single or cross-case study with an INGO. This this was the original study design and that remains a necessary piece of work. NGOs are often subject to restrictive donor requirements on how their funding can be used, whereas INGO Médecins Sans Frontières are unique in that the vast proportion of their funding is independent, resulting in comparative financial freedom. Moreover, researching NCD treatment with a national organisation would provide a rich insight into the localised socio-cultural situated seeing of disease management, revealing convergent and divergent perspectives on the prioritisation of care in contrast to an INGO. This NGO single or cross-case study will reveal new insights into localised discourses and how this shapes how people see healthcare needs and respond to these needs through service design.

To offer straightforward solutions would not recognise the complicated context I have detailed throughout these pages. The simplification of the spaces and solutions may result in a ‘one-size-fits-all’ approach that conflicts with the shift in praxis that is needed to create socially and culturally responsive practice. Nevertheless, I offer a summary of shifts in practice that participants voices offered in this study as a starting point for further discussion.

Table 10 Table of Recommendations

Recommendation One: Stakeholders should work to safeguard sustainable thalassemia treatment in fragile health systems.

Rationale: My research findings demonstrated the harms of disrupted thalassemia treatment, including return to conflict settings for iron chelation therapy, children admitted to ICU care due to compromised health and death in extreme circumstances. This study concludes that, where feasible, healthcare providers must sustain thalassemia care in emergency contexts. If treatment at a clinic cannot be sustained due to conflict, then I recommend disseminating thalassemia survival kits, with medications, supporting materials in relevant languages, including information on disease management in low resource settings. My research findings can help inform how the necessary information for this can be best co-created and shared with families in a relevant and sensitive manner.

This recommendation is most applicable to fragile health systems responding to a high number of thalassemia cases.

Recommendation Two: Blood banks should preserve blood for thalassemia treatment amidst crises.

Rationale: Healthcare professionals often redirect blood to trauma care in conflict settings and in the event of crises, however this research traced the consequences of the absence of blood in the blood bank in response to the Beirut blast. Parents spent days on the streets searching for a blood donor, losing income needed for food and other essentials. It is therefore necessary to safeguard blood for thalassemia treatment.

This recommendation is most applicable to fragile health systems responding to a high number of thalassemia cases.

Recommendation Three: NGOs must provide no cost travel for service users to and from treatment.

Rationale: This project evidenced the need for humanitarian healthcare organisations to support patients in reaching their services, requiring financial assistance and necessary documents for risk mitigation at checkpoints. This finding is increasingly relevant due to rapid urbanisation in LMIC.

This recommendation applies to humanitarian action globally.

Recommendation Four: NGOs should raise awareness of no-cost specialist treatment to improve health outcomes for the most marginalised

Rationale: This research found that NGOs do not widely advertise services to potential users. This is a deliberate economic resource rationing strategy, and consequently people who have weak social networks cannot secure thalassemia care. Advertising health services widely to prospective patients supports the necessary shift towards equity of care.

This recommendation is most applicable to fragile health systems responding to a high number of thalassemia cases

Recommendation Five: Improve mental health support and employee engagement for National Staff at INGOs

Rationale: This study evidenced the exhaustive translation work that national healthcare staff conducted: translating insufficient service communication from coordination staff to service users, and stories of hardship from service users to coordination staff. I recommend humanitarian aid organisations improve national staff mental health support and improve internal communications, seeking meaningful national staff input into decision-making processes and subsequently providing clearer information about why decisions are made. This will improve workplace relationships, communication and morale.

This recommendation applies to humanitarian action globally

## Final Words

My main goal in this research was to understand how humanitarian healthcare could be improved in Lebanon. I concluded that implementing participatory methodologies with staff and service users offers a crucial opportunity to centre often unheard voices in research and practice.

Through this research project, I have evidenced the harms of the temporary care people in receipt of humanitarian provision are offered. This creates great concern for chronically ill patients and the loved ones trying to care for them, as they do not know how long they can access services for, and may experience disruptions or discontinuation in their treatment, compromising their health. As I evidenced earlier in this chapter, the Médecins Sans Frontières unit has closed, and the findings in thesis offer one of the last narratives of everyday life in the unit.

At a time of climate crises exacerbating vulnerability through conflict over resources, as people’s homes are lost to wildfires, landslides and floods and crops fail and water sources diminish, more people than ever will be forced to cross borders and seek safety. The international humanitarian healthcare sector will continue to respond, through geopolitical influence and people who are driven by the urge to ‘help’ mixed with a sense of adventure, just as I was. Supporting people in need, whether caused by conflict or climate, is a just cause. But the power, politics and subsequent unintended harms warrant consideration. The data in this thesis was generated in a fleeting moment of ‘decolonising’ and global public health solidarity that has since passed. This thesis has shed light on the failings of ‘decolonising’ aid and healthcare, amidst a global movement towards hope for improved public health, a racial justice awakening, and increasing pressure for the triple-nexus and localisation of aid. At the time of writing, people living in Lebanon continue to fall further into hardship, and its infrastructure remains in many ways dilapidated. I am writing this thesis from the United Kingdom, a country which is implementing an ‘illegal migration bill’, extinguishing access to asylum in the UK for anyone who arrives ‘irregularly’, furthering erosion to refugee rights and normalising the illegalisation of humans. But collective action can change unequal structures, and many scholars and practitioners remain committed to improving humanitarian healthcare, decentring Western power, and centring patient voices.

This thesis has documented the great hardships faced by people subject to the asylum system who are in need of long-term healthcare, but I hope it also offers some hope, that through a change in situated seeing, yes, humanitarian healthcare can be improved. We live in a world with many worlds, and by listening and capturing and acting on different ways of seeing, we can move towards greater solidarity and patient-centred humanitarian healthcare.

# References

Abi Saad, M., Haddad, A. G., Alam, E. S., Aoun, S., Maatouk, P., Ajami, N., Khairallah, T., Koussa, S., Musallam, K. M. and Taher, A. T. (2014) 'Preventing thalassemia in Lebanon: successes and challenges in a developing country', *Hemoglobin,* 38(5), pp. 308-311.

Abou-Rizk, J., Jeremias, T., Nasreddine, L., Jomaa, L., Hwalla, N., Tamim, H., Frank, J. and Scherbaum, V. (2021) 'Anemia and Nutritional Status of Syrian Refugee Mothers and Their Children under Five Years in Greater Beirut, Lebanon', *Int J Environ Res Public Health,* 18(13).

Abouzeid, M., Habib, R. R., Jabbour, S., Mokdad, A. H. and Nuwayhid, I. (2020a) 'Lebanon's humanitarian crisis escalates after the Beirut blast', *The Lancet (British edition),* 396(10260), pp. 1380-1382.

Abouzeid, M., Habib, R. R., Jabbour, S., Mokdad, A. H. and Nuwayhid, I. (2020b) 'Lebanon's humanitarian crisis escalates after the Beirut blast', *The Lancet,* 396(10260), pp. 1380-1382.

Aebischer Perone, S., Martinez, E., Du Mortier, S., Rossi, R., Pahud, M., Urbaniak, V., Chappuis, F., Hagon, O., Jacquérioz Bausch, F. and Beran, D. (2017) 'Non-communicable diseases in humanitarian settings: ten essential questions', *Conflict and health,* 11(1), pp. 1-11.

Afifi, R. A., Abdulrahim, S., Betancourt, T., Btedinni, D., Berent, J., Dellos, L., Farrar, J., Nakkash, R., Osman, R., Saravanan, M., Story, W. T., Zombo, M. and Parker, E. (2020) 'Implementing Community-Based Participatory Research with Communities Affected by Humanitarian Crises: The Potential to Recalibrate Equity and Power in Vulnerable Contexts', *Am J Community Psychol,* 66(3-4), pp. 381-391.

Agamben, G. (2002) *Homo sacer*. IRCISOD.

Ager, A., Pasha, E., Yu, G., Duke, T., Eriksson, C. and Cardozo, B. L. (2012) 'Stress, mental health, and burnout in national humanitarian aid workers in Gulu, northern Uganda', *J Trauma Stress,* 25(6), pp. 713-20.

Airhihenbuwa, C. O. (1995) *Health and Culture: Beyond the Western Paradigm.* SAGE Publications.

Akbarzada, S. and Mackey, T. K. (2018) 'The Syrian public health and humanitarian crisis: a ‘displacement’in global governance?', *Global Public Health,* 13(7), pp. 914-930.

Al-Hajj, S., Pawliuk, C., Smith, J., Zheng, A. and Pike, I. (2021) 'History of injury in a developing country: a scoping review of injury literature in Lebanon', *J Public Health (Oxf),* 43(1), pp. e24-e44.

Alameddine, A. and Kerbage, H. (2021) 'Could the Aid System Be Reinforcing Mental Health Symptoms Among Refugees? Clinicians' Experiences from Lebanon', *J Immigr Minor Health,* 23(3), pp. 650-652.

Alawa, J., Hamade, O., Alayleh, A., Fayad, L. and Khoshnood, K. (2020) 'Cancer Awareness and Barriers to Medical Treatment Among Syrian Refugees and Lebanese Citizens in Lebanon', *J Cancer Educ,* 35(4), pp. 709-717.

Alhaffar, M. and Janos, S. (2021) 'Public health consequences after ten years of the Syrian crisis: a literature review', *Globalization and Health,* 17(1), pp. 1-11.

Ali, Z., Perera, S. M., Garbern, S. C., Diwan, E. A., Othman, A., Ali, J. and Awada, N. (2022) 'Variations in COVID-19 Vaccine Attitudes and Acceptance among Refugees and Lebanese Nationals Pre-and Post-Vaccine Rollout in Lebanon', *Vaccines,* 10(9), pp. 1533.

Amnesty International (2014) *Agonizing Choices: Syrian Refugees in Need of Health Care in Lebanon*, London.

Amnesty International (2023) *Lebanon: Halt summary deportations of Syrian refugees*. Available at: https://www.amnesty.org/en/latest/news/2023/05/lebanon-halt-summary-deportations-of-syrian-refugees/ (Accessed: 21/07/2023.

Andersen, L. E. (2016) *The neglected: Palestinian refugees in Lebanon and the Syrian refugee crisis*. DIIS report.

Anderson, K. (2019) *Tearing down the walls Confronting the barriers to internally displaced women and girls' participation in humanitarian settings*: UNHCR.

Anholt, R. (2020) 'Resilience in Practice: Responding to the Refugee Crisis in Turkey, Jordan, and Lebanon', *Politics and Governance,* 8(4), pp. 294-305.

Apthorpe, R. (2011) 'With Alice in Aidland: A seriously satirical allegory', *Adventures in Aidland: the anthropology of professionals in international development,* 6, pp. 199-219.

Arar, R. (2017) 'The New Grand Compromise: How Syrian Refugees Changed the Stakes in the Global Refugee Assistance Regime', *Middle East Law and Governance,* 9(3), pp. 298-312.

Arendt, H. (2009) 'We Refugees', *The Jewish Writings*. New York: Schocken, pp. 264-274.

Arendt, H. (2013) *The human condition*. University of Chicago Press.

Arnstein, S. R. (1969) 'A ladder of citizen participation', *Journal of the American Institute of planners,* 35(4), pp. 216-224.

Asgary, R. and Junck, E. (2013) 'New trends of short-term humanitarian medical volunteerism: professional and ethical considerations', *J Med Ethics,* 39(10), pp. 625-31.

Atterton, C. B. (2021) *Quality Care in unequal Landscapes. The Meanings of Quality Healthcare in Humanitarian Settings*. The University of Manchester (United Kingdom).

Aubel, J. and Chibanda, D. (2022) 'The neglect of culture in global health research and practice', *BMJ Global Health,* 7(9), pp. e009914.

Aveling, E. L. and Martin, G. (2013) 'Realising the transformative potential of healthcare partnerships: insights from divergent literatures and contrasting cases in high- and low-income country contexts', *Soc Sci Med,* 92, pp. 74-82.

Baggini, J. (2018) *How the world thinks: a global history of philosophy*. Granta Books.

Bajis, D., Bajis, S., Akel, M., Bizama, A. P. and Chaar, B. (2023) 'A grounded theory approach to exploring the experiences of community pharmacists in Lebanon to a triple whammy of crises: The Lebanese financial crisis, COVID-19 pandemic, and the Beirut port explosion', *Exploratory Research in Clinical and Social Pharmacy,* pp. 13.

Bananuka, T., Perry, M. and Kadoma, A. (2023) 'Researching Without "Methods": An Experiment in Socio-Ecological Sustainability Research With Rural Communities', *International Journal of Qualitative Methods,* 22.

Barakat, S. and Milton, S. (2020) 'Localisation across the humanitarian-development-peace nexus', *Journal of Peacebuilding & Development,* 15(2), pp. 147-163.

Barnett, M. (2018) *Empire of humanity: A history of humanitarianism*. Cornell University Press.

Barnett, M. S., J (2011a) 'The Grand Strategies of Humanitarianism', in Barnett, M.W., T. G (ed.) *Humanitarianism in Question: Politics, Power, Ethics Cornell Paperbacks Ser*. 1 ed: Cornell University Press, pp. 143-171.

Barnett, M. W., T. G (2011b) 'Humanitarianism as a Scholarly Vocation', *Humanitarianism in Question Politics Power Ethics*: Cornell University Press, pp. 235-263.

Bauman, Z. (1990) 'Modernity and ambivalence', *Theory, Culture & Society,* 7(2-3), pp. 143-169.

Beaton, B. P., D; George, C; O'Donnell, S (2017) 'Engaging remote marginalized communities using appropriate online research methods', in *The SAGE Handbook of Online Research Methods* [Online]. Version. Available at: http://sk.sagepub.com/reference/the-sage-handbook-of-online-research-methods-2e (Accessed: 14/06/2023).

Beauchamp, T. L. and Childress, J. F. (2001) *Principles of biomedical ethics.* Oxford University Press, USA.

Bengtsson, T. T. and Fynbo, L. (2018) 'Analysing the significance of silence in qualitative interviewing: Questioning and shifting power relations', *Qualitative Research,* 18(1), pp. 19-35.

Bergen, N. and Labonté, R. (2020) '"Everything is perfect, and we have no problems": detecting and limiting social desirability bias in qualitative research', *Qualitative health research,* 30(5), pp. 783-792.

Berryman, M., SooHoo, S. and Nevin, A. (2013) *Culturally responsive methodologies.* Emerald Group Publishing.

Bhabha, H. (1984) 'Of mimicry and man: The ambivalence of colonial discourse', *October,* 28, pp. 125-133.

Bhambra, G. K. (2014) 'Postcolonial and decolonial dialogues', *Postcolonial Studies,* 17(2), pp. 115-121.

Bizri, A. R., Khachfe, H. H., Fares, M. Y. and Musharrafieh, U. (2021) 'COVID-19 Pandemic: An Insult Over Injury for Lebanon', *J Community Health,* 46(3), pp. 487-493.

Bob-Milliar, G. M. (2022) 'Introduction: methodologies for researching Africa', *African Affairs,* 121(484), pp. e55-e65.

Bosqui, T. (2020) 'The need to shift to a contextualized and collective mental health paradigm: learning from crisis-hit Lebanon', *Global Mental Health,* 7.

Bourdieu, P. (1998) 'Acts of Resistance Against the Tyranny of the Market, trans', *Richard Nice (New York, 1998),* 88(3).

Boydell, K. M., Hodgins, M., Gladstone, B. M., Stasiulis, E., Belliveau, G., Cheu, H., Kontos, P. and Parsons, J. (2016) 'Arts-based health research and academic legitimacy: Transcending hegemonic conventions', *Qualitative Research,* 16(6), pp. 681-700.

Bradbury, H. (2015) *The Sage handbook of action research.* Sage.

Braun, V. and Clarke, V. (2019) 'Reflecting on reflexive thematic analysis', *Qualitative Research in Sport, Exercise and Health,* 11(4), pp. 589-597.

Brooks, H., Ngwane, T. and Runciman, C. (2019) 'Decolonising and re-theorising the meaning of democracy: A South African perspective', *The Sociological Review,* pp. 0038026119878097.

Broussard, G., Rubenstein, L. S., Robinson, C., Maziak, W., Gilbert, S. Z. and DeCamp, M. (2019) 'Challenges to ethical obligations and humanitarian principles in conflict settings: a systematic review', *Journal of International Humanitarian Action,* 4(1), pp. 1-13.

Brun, C. (2016) 'There is no future in humanitarianism: Emergency, temporality and protracted displacement', *History and anthropology,* 27(4), pp. 393-410.

Butler, J. (2004) *Precarious life: The powers of mourning and violence.* verso.

Cabot, H. (2019) 'The business of anthropology and the European refugee regime', *American ethnologist,* 46(3), pp. 261-275.

Caleo, G. (2021) *Epidemiology and control of Ebola Virus Disease (EVD) in Sierra Leone: analysis of data from the Médecins Sans Frontières (MSF) response, 2014-15*. London School of Hygiene & Tropical Medicine.

Carter, P. L. (2005) *Keepin'it real: School success beyond Black and White*. Oxford University Press.

Castaneda, H. (2013) 'Structural vulnerability and access to medical care among migrant street-based male sex workers in Germany', *Soc Sci Med*, 84, pp. 94-101.

Castells, M. (2016) 'A Sociology of Power: My Intellectual Journey', *Annual Review of Sociology*, 42(1), pp. 1-19.

Castles, S. (2003) 'Towards a Sociology of Forced Migration and Social Transformation', *Sociology*, 37(1), pp. 13-34.

Center for Operational Analysis and Research (2021) *Conflict Analysis Central Bekka*, Limassol, Cyprus. Available at: https://coar-global.org/2022/02/17/lebanon-conflict-analysis-central-bekaa/ (Accessed: 17/01/2024).

Chen, S. and Schweitzer, R. D. (2019) 'The experience of belonging in youth from refugee backgrounds: A narrative perspective', *Journal of Child and Family Studies*, 28, pp. 1977-1990.

Cheraghi ‐ Sohi, S., Bower, P., Mead, N., McDonald, R., Whalley, D. and Roland, M. (2006) 'What are the key attributes of primary care for patients? Building a conceptual ‘map’ of patient preferences', *Health Expectations*, 9(3), pp. 275-284.

Chimni, B. S. (2008) 'The Birth of a 'Discipline': From Refugee to Forced Migration Studies', *Journal of Refugee Studies*, 22(1), pp. 11-29.

Choudry, A. and Kapoor, D. (2013) *NGOization: Complicity, contradictions and prospects*. Bloomsbury Publishing.

CHS Alliance, G. U., Sphere Project (2014) *Core Humanitarian Standard on Quality and Accountability* 978-2-8399-1564-9). Available at: https://corehumanitarianstandard.org/files/files/Core%20Humanitarian%20Standard%20-%20English.pdf (Accessed: 17/01/2024).

Coffey, A. (1999) 'The ethnographic self', *The Ethnographic Self*, pp. 1-192.

Cooper, F. and Stoler, A. L. (1997) *Tensions of empire: colonial cultures in a bourgeois world*. Univ of California Press.

Cornish, C. and Szalay, E. (2021) 'Lebanese currency plunges to new low fuelling nationwide protests', *Financial Times*. Available at: https://www.ft.com/content/811bc4c2-98ca-4e9a-a23e-3d3764d5e435`.

Cornwall, A. (2003) 'Whose voices? Whose choices? Reflections on gender and participatory development', *World development*, 31(8), pp. 1325-1342.

Cowling, F. (2020) *Seeing like a humanitarian: legibility in Lebanon's emergency response*. University of Oxford.

Crain, M., Poster, W. and Cherry, M. (2016) *Invisible labor: Hidden work in the contemporary world*. Univ of California Press.

Crawley, H. and Skleparis, D. (2018) 'Refugees, migrants, neither, both: categorical fetishism and the politics of bounding in Europe's ‘migration crisis'', *Journal of ethnic and migration studies*, 44(1), pp. 48-64.

Creswell, J. W. (2007) *Qualitative inquiry and research design: Choosing among five approaches, 2nd ed*. Thousand Oaks, CA, US: Sage Publications, Inc.

D'Mello-Guyett, L. (2022) *Prevention and control of cholera in complex emergencies in Sub-Saharan Africa: evaluating the effectiveness of water, sanitation and hygiene interventions used by Médecins Sans Frontières*. London School of Hygiene & Tropical Medicine.

'Data on movements of refugees and migrants are flawed', (2017) *Nature*, 543, pp. 5-6.

de Brún, T., O'Reilly-de Brún, M., van Weel-Baumgarten, E., Burns, N., Dowrick, C., Lionis, C., O'Donnell, C., Mair, F., Papadakaki, M. and Saridaki, A. (2017) 'Using Participatory Learning & Action (PLA) research techniques for inter-stakeholder dialogue in primary healthcare: an analysis of stakeholders' experiences', *Research involvement and engagement*, 3(1).

de Certeau, M. (1988) *The practice of everyday life*. Berkeley: University of California Press.

De Cuyper, N. and De Witte, H. (2006) 'The impact of job insecurity and contract type on attitudes, well – being and behavioural reports: a psychological contract perspective', *Journal of occupational and organizational psychology*, 79(3), pp. 395-409.

Deane, K. and Stevano, S. (2016) 'Towards a political economy of the use of research assistants: reflections from fieldwork in Tanzania and Mozambique', *Qualitative Research*, 16(2), pp. 213-228.

DeJong, J. (2020) *The Challenges of a Public Health Approach to COVID-19 Amid Crises in Lebanon*. Middle East Research and Information Project. Available at: https://merip.org/2020/05/the-challenges-of-a-public-health-approach-to-covid-19-amid-crises-in-lebanon/ (Accessed: 07/07/2021.

Deleuze, G. and Guattari, F. (1988) *A thousand plateaus: Capitalism and schizophrenia*. Bloomsbury Publishing.

Deleuze, G. and Guattari, F. (2004) *EPZ thousand plateaus*. A&C Black.

Denzin, N. K. and Lincoln, Y. S. (2011) *The Sage handbook of qualitative research*. Sage.

Denzin, N. K., Lincoln, Y. S. and Smith, L. T. (2008) *Handbook of critical and indigenous methodologies*. Sage.

Derrida, J. (1978) *Writing and difference*. University of Chicago press.

Dijkzeul, D. and Wakenge, C. I. (2010) 'Doing good, but looking bad? Local perceptions of two humanitarian organisations in eastern Democratic Republic of the Congo', *Disasters*, 34(4), pp. 1139-1170.

Doctors Without Borders (2021) *Lebanon Scarce supplies of fuel and medicine push health system to the brink* (Accessed: 14/10/2022).

Doná, G. (2007) 'The microphysics of participation in refugee research', *Journal of Refugee Studies*, 20(2), pp. 210-229.

Donini, A. J. F. M. R. (2007) 'Hard questions for the future of the humanitarian enterprise', 29, pp. 49-51.

Duffield, M. (2001) 'Governing the borderlands: decoding the power of aid', *Disasters*, 25(4), pp. 308-320.

Dumeden, I. (2012) 'The research assistant: Invisible and silenced, exploited and disposable', *Discourse, Power, and Resistance Down Under*: Brill, pp. 9-19.

Eastmond, M. (2007) 'Stories as Lived Experience: Narratives in Forced Migration Research', *Journal of Refugee Studies*, 20(2), pp. 248-264.

England, K. V. (1994) 'Getting personal: Reflexivity, positionality, and feminist research', *The professional geographer*, 46(1), pp. 80-89.

Eynon, R. F., J.; Schroeder, R. (2017) 'The ethics of online research', in *The SAGE Handbook of Online Research Methods*. pp. 19-37 [Online]. Version. Available at: http://sk.sagepub.com/reference/the-sage-handbook-of-online-research-methods-2e (Accessed: 14/06/2023).

Facon, C. 2021. Lebanon. A "Republic of NGOs", for the benefit of whom.

Fadiman, A. (1999) 'The spirit catches you and you fall down', *New York: Noonday*.

Fakhoury, T. (2020) 'Refugee return and fragmented governance in the host state: displaced Syrians in the face of Lebanon's divided politics', *Third World Quarterly,* 42(1), pp. 162-180.
Fakih, L. (2022) *A Looming Famine in Lebanon*: International Politics and Society. Available at: https://www.ips-journal.eu/topics/democracy-and-society/a-looming-famine-in-lebanon-6286/ (Accessed: 23/01/2023.
Fallon, G. and Brown, R. B. (2002) 'Focusing on focus groups: lessons from a research project involving a Bangladeshi community', *Qualitative Research*: SAGE, pp. 195-208.
Farah, R. (2020) 'Expat, local, and refugee:"Studying up" the global division of labor and mobility in the humanitarian industry in Jordan', *Migration and Society,* 3(1), pp. 130-144.
Fares, M. Y., Musharrafieh, U. and Bizri, A. R. (2021) 'The impact of the Beirut blast on the COVID-19 situation in Lebanon', *Z Gesundh Wiss,* pp. 1-7.
Farmer, P. (2001) *Infections and inequalities: The modern plagues.* Univ of California Press.
Farmer, P. (2004) 'An anthropology of structural violence', *Current anthropology,* 45(3), pp. 305-325.
Farrar, J. (2019) 'Responding to the Ebola virus disease outbreak in DR Congo: when will we learn from Sierra Leone', *Lancet (British Edition),* 393(10191), pp. 2647-2650.
Fassin, D. (2005) 'Compassion and Repression: The Moral Economy of Immigration Policies in France', *CULTURAL ANTHROPOLOGY,* 20(3), pp. 362-387.
Fassin, D. (2007) 'Humanitarianism as a Politics of Life', *Public Culture,* 19(3), pp. 499-520.
Fassin, D. (2011) *Humanitarian reason: a moral history of the present.* Univ of California Press.
Fassin, D. (2020) 'Are the two approaches to moral economy irreconcilable?', *Humanity: An International Journal of Human Rights, Humanitarianism, and Development,* 11(2), pp. 217-221.
Fisk, R. (2001) *Pity the nation: Lebanon at war.* Oxford University Press, USA.
FitzGerald, D. S. and Arar, R. (2018) 'The Sociology of Refugee Migration', *Annual Review of Sociology,* 44(1), pp. 387-406.
Flyvbjerg, B. (2001) *Making social science matter: Why social inquiry fails and how it can succeed again.* Cambridge university press.
Folkes, L. (2022) 'Moving beyond 'shopping list'positionality: Using kitchen table reflexivity and in/visible tools to develop reflexive qualitative research', *Qualitative Research*, pp. 1-18.
Forss, K., Lindkvist, I. and McGillivray, M. (2020) *Long term perspectives in evaluation: Increasing relevance and utility.* Routledge.
Fouad, F. M., Barkil-Oteo, A. and Diab, J. L. (2021) 'Mental health in Lebanon's Triple-Fold crisis: the case of refugees and vulnerable groups in times of COVID-19', *Frontiers in public health,* 8, pp. 1-6.
Foucault, M. (2003) *" Society Must Be Defended": Lectures at the Collège de France, 1975-1976.* Macmillan.
Freire, P. (2005) *Pedagogy of the oppressed.* 30th anniversary edition edn. USA: Bloomsbury Publishing.
Galtung, J. (1969) 'Violence, peace, and peace research', *Journal of peace research,* 6(3), pp. 167-191.
Galtung, J. (1990) 'Cultural violence', *Journal of peace research,* 27(3), pp. 291-305.
Garelli, G. and Tazzioli, M. (2021) 'Migration and 'pull factor'traps', *Migration Studies,* 9(3), pp. 383-399.

Geha, C., Kanaan, F. and Saliba, N. A. (2020) 'Breaking the Cycle: Existential Politics and the Beirut Explosion', *Middle East Law and Governance,* 12(3), pp. 357-368.

Gerring, J. and Cojocaru, L. (2016) 'Selecting Cases for Intensive Analysis', *Sociological Methods & Research,* 45(3), pp. 392-423.

Gibbons, P. and Otieku-Boadu, C. (2021) 'The question is not “if to localise?” but rather “how to localise?”: perspectives from Irish Humanitarian INGOs', *Frontiers in Political Science,* 3, pp. 1-12.

Goodman, S. and Speer, S. A. (2007) 'Category use in the construction of asylum seekers', *Critical Discourse Studies,* 4(2), pp. 165-185.

Gorski, P. S. (2013) '“What is Critical Realism? And Why Should You Care?”A Realist Theory of Science', *Contemporary Sociology: A Journal of Reviews,* 42(5), pp. 658-670.

Gould, J. (2004) 'Introducing aidnography', *Occasional Paper*, pp. 1-14.

Gramsci, A. (2011) *Prison notebooks volume 2.* Columbia University Press.

Green, J. and Thorogood, N. (2018) *Qualitative methods for health research.* sage.

Green, M. G. (2006) *Enabling design in frontier contexts: A contextual needs assessment method with humanitarian applications.* Ph.D., The University of Texas at Austin, United States -- Texas [Online] Available at: http://ezproxy.lib.gla.ac.uk/login?url=https://www.proquest.com/dissertations-theses/enabling-design-frontier-contexts-contextual/docview/304980961/se-2?accountid=14540 (Accessed: 08/06/2023).

Gupta, A. (2014) 'Authorship, research assistants and the ethnographic field', *Ethnography,* 15(3), pp. 394-400.

Habermas, J. (1978) 'Knowledge and human interests (2nd [English] ed.)', *London [etc.]: Heinemann Educational.*

Habib, R. R., Ziadee, M., Abi Younes, E., El Asmar, K. and Jawad, M. (2020) 'The association between living conditions and health among Syrian refugee children in informal tented settlements in Lebanon', *J Public Health (Oxf),* 42(3), pp. e323-e333.

Hagan, M. (2022) *Contingent camps: An ethnographic study of contested encampment in the northern French and northern Moroccan borderlands.*

Hall, S. (1996) 'Who needs identity', *Questions of cultural identity,* 16(2), pp. 1-17.

Halliday, F. (1993) '‘Orientalism’and its critics', *British Journal of Middle Eastern Studies,* 20(2), pp. 145-163.

Hamadeh, R. S., Kdouh, O., Hammoud, R., Leresche, E. and Leaning, J. (2021) 'Working short and working long: can primary healthcare be protected as a public good in Lebanon today?', *Confl Health,* 15(1), pp. 23.

Hanafi, S. and Arvanitis, R. (2015) *Knowledge production in the Arab World: The impossible promise.* Routledge.

Hanna, B. and Kleinman, A. (2013) 'Unpacking global health', *Reimagining global health: An introduction*, pp. 15-32.

Harper, C., Marcus, R. and Moore, K. (2003) 'Enduring poverty and the conditions of childhood: lifecourse and intergenerational poverty transmissions', *World development,* 31(3), pp. 535-554.

Harrell-Bond, B. E. (1986) 'Imposing aid: emergency assistance to refugees'.

Hayden, S. (2023) *My Fourth Time, We Drowned: Seeking Refuge on the World's Deadliest Migration Route.* National Geographic Books.

Hess, J. M., Vasquez Guzman, C. E., Hernandez-Vallant, A., Handal, A. J., Huyser, K., Galvis, M., Medina, D., Casas, N., Chavez, M. J. and Carreon Fuentes, A. (2022) 'Innovative participatory bilingual data analysis with Latinx/@

immigrants: Language, power, and transformation', *Cultural Diversity and Ethnic Minority Psychology,* 28(3), pp. 389-401.

Hilhorst, D., Jansen, B. J. J. D. and Change (2010) 'Humanitarian space as arena: A perspective on the everyday politics of aid', 41(6), pp. 1117-1139.

Hindle, S. (2004) 'Civility, honesty and the identification of the deserving poor in seventeenth-century England', *Identity and Agency in England, 1500–1800*: Springer, pp. 38-59.

Hoelscher, K., Miklian, J. and Nygård, H. M. (2015) *Understanding Attacks on Humanitarian Aid Workers*: The Peace Research Institute Oslo (PRIO).

Hokland, P., Daar, S., Khair, W., Sheth, S., Taher, A. T., Torti, L., Hantaweepant, C. and Rund, D. (2023) 'Thalassaemia—A global view', *British Journal of Haematology,* 201(2), pp. 199-214.

Holland, S., Renold, E., Ross, N. J. and Hillman, A. (2010) 'Power, agency and participatory agendas: A critical exploration of young people's engagement in participative qualitative research', *Childhood,* 17(3), pp. 360-375.

Holmes, S. M. and Castañeda, H. (2016) 'Representing the "European refugee crisis" in Germany and beyond: Deservingness and difference, life and death', *American Ethnologist,* 43(1), pp. 12-24.

Hughes, A. (2016) 'The Sykes Picot Agreement and the making of the modern Middle East', *The Conversation*.

Hujale, M. (2019) ''Were excluded from the table': Somali UN staff say they struggle in two tier aid sector', *The Guardian*.

Human Rights Watch (2021) *World Report 2022 Lebanon*.

Huschke, S. (2014) 'Performing deservingness. Humanitarian health care provision for migrants in Germany', *Social Science & Medicine,* 120, pp. 352-359.

Ingleby, D. (2012) 'Ethnicity, Migration and the 'Social Determinants of Health' Agenda*', *Psychosocial Intervention,* 21(3), pp. 331-341.

International Trade Adminstration (2023) *Lebanon Market Challenges*.

Jackson, A. Y. and Mazzei, L. (2011) 'Thinking with theory in qualitative research: Viewing data across multiple perspectives': Routledge.

Jackson, s. M., S 'Thinking With Theory A New Analytic for Qualitative Inquiry': SAGE Publications.

Jalabi, R. 2022. Lebanon's economic crisis is pushing families to the brink. Financial Times.

Jalabi, R., Lowe, C. and Nader, Y. A. (2020) 'Macron to Lebanese leaders: reform swiftly or face consequences', *Reuters*. Available at: https://www.reuters.com/article/us-lebanon-crisis-idCAKBN25S3XJ.

James, M. (2020a) *Instruments of Identity: Médecins Sans Frontières and humanitarian negotiations for access in the Democratic Republic of the Congo.* University of Oxford.

James, M. (2020b) ''Who Can Sing the Song of MSF?': The Politics of 'Proximity'and Performing Humanitarianism in Eastern DRC', *Journal of Humanitarian Affairs,* 2(2), pp. 31-39.

James, M. (2022) 'Humanitarian fables: morals, meanings and consequences for humanitarian practice', *Third World Quarterly,* 43(2), pp. 475-493.

James, M. V. and Lees, S. S. (2022) '"Are you sure it's not the Corona vaccine?" An Ebola vaccine trial during COVID-19 in DRC', *Medical anthropology,* 41(5), pp. 503-517.

Janmyr, M. (2016) 'Precarity in exile: The legal status of Syrian refugees in Lebanon', *Refugee Survey Quarterly,* 35(4), pp. 58-78.

Jirmanus, L. Z., Ziadee, M. and Usta, J. (2021a) 'Confronting Structural Inequities: The Limits of Participation when Developing a Community Health

Intervention with Syrian Refugees and Host Communities in Lebanon', *Social Science & Medicine,* 272, pp. 113699.

Jirmanus, L. Z., Ziadee, M. and Usta, J. (2021b) 'Confronting Structural Inequities: The Limits of Participation when Developing a Community Health Intervention with Syrian Refugees and Host Communities in Lebanon', *Soc Sci Med,* 272, pp. 1-9.

Journal of International Affairs (2020) *Corruption, Protest and Hope in Lebanon - An Interview with Assaad Thebian*. Available at: https://jia.sipa.columbia.edu/corruption-protest-and-hope-lebanon-interview-assaad-thebian (Accessed: 30/06/2021.

Joxe, L. (2019) *Les ressorts de l'(in) satisfaction: le cas du personnel international humanitaire*. Université Sorbonne Paris Cité.

Kawabata, M. and Gastaldo, D. (2015) 'The less said, the better: Interpreting silence in qualitative research', *International Journal of Qualitative Methods,* 14(4), pp. 1609406915618123.

Kelly, M., Pardy, M. and McGlasson, M. (2022) *Listening and Localisation*, Center for Humanitarian Leadership. Available at: https://centreforhumanitarianleadership.org/wp-content/uploads/2022/06/Listening-report_v2.pdf (Accessed: 04/12/2023).

Khan, A. (2016) *100 Years of the MiddleEast: The Struggle for the Post Sykes-Picot MiddleEast*. www. maktabaislamia. com.

Khan, M., Abimbola, S., Aloudat, T., Capobianco, E., Hawkes, S. and Rahman-Shepherd, A. 2021. Decolonising global health in 2021: a roadmap to move from rhetoric to reform. BMJ Specialist Journals.

Kherallah, M., Alahfez, T., Sahloul, Z., Eddin, K. D. and Jamil, G. (2012) 'Health care in Syria before and during the crisis', *Avicenna journal of medicine,* 2(03), pp. 51-53.

Kia-Keating, M. and Juang, L. P. (2022) 'Participatory science as a decolonizing methodology: Leveraging collective knowledge from partnerships with refugee and immigrant communities', *Cultural Diversity and Ethnic Minority Psychology*.

Killian, C. and Johnson, C. (2006) '"I'm Not an Immigrant!": Resistance, Redefinition, and the Role of Resources in Identity Work', 69(1), pp. 60-80.

Kingori, P. (2013) 'Experiencing everyday ethics in context: frontline data collectors perspectives and practices of bioethics', *Soc Sci Med,* 98, pp. 361-70.

Kirkwood, S. (2017) 'The humanisation of refugees: A discourse analysis of UK parliamentary debates on the European refugee 'crisis'', *Journal of Community & Applied Social Psychology,* 27(2), pp. 115-125.

Kitzinger, J. (1994) 'The methodology of focus groups: the importance of interaction between research participants', *Sociology of health & illness,* 16(1), pp. 103-121.

Kleinman, A. (2010) 'Four social theories for global health', *The lancet,* 375(9725), pp. 1518-1519.

Knoblauch, H. 'Focused ethnography'. *Forum qualitative sozialforschung/forum: qualitative social research*.

Knudsen, A. (2005) *Precarious peacebuilding: Post-war Lebanon, 1990-2005,* Bergen, Norway: Chr. Michelsen Institute12). Available at: https://open.cmi.no/cmi-xmlui/bitstream/handle/11250/2435894/Working%20paper%20WP%202005-12.pdf?sequence=2.

Kovach, M. (2010) 'Conversation method in Indigenous research', *First peoples child & family review,* 5(1), pp. 40-48.

Labbé, J. and Daudin, P. (2015) 'Applying the humanitarian principles: Reflecting on the experience of the International Committee of the Red Cross', *International Review of the Red Cross,* 97(897-898), pp. 183-210.

Landry, M. D., Alameddine, M., Jesus, T. S., Sassine, S., Koueik, E. and Raman, S. R. (2020) 'BMC health services research title: the 2020 blast in the port of Beirut: can the Lebanese health system "build back better"?', *BMC Health Serv Res,* 20(1), pp. 1040.

Leaning, J., Spiegel, P. and Crisp, J. (2011) 'Public health equity in refugee situations', *Conflict and Health,* 5, pp. 1-7.

Lebanon Nutrition Sector (2022) *Nutrition in Times of Crisis*.

Lionis, C., Papadakaki, M., Saridaki, A., Dowrick, C., O'Donnell, C. A., Mair, F. S., Van Den Muijsenbergh, M., Burns, N., De Brún, T. and De Brún, M. O. R. (2016) 'Engaging migrants and other stakeholders to improve communication in cross-cultural consultation in primary care: a theoretically informed participatory study', *BMJ open,* 6(7), pp. e010822.

Lokot, M. (2021) 'Whose voices? Whose knowledge? A feminist analysis of the value of key informant interviews', *International Journal of Qualitative Methods,* 20, pp. 1609406920948775.

Lopes Cardozo, B., Gotway Crawford, C., Eriksson, C., Zhu, J., Sabin, M., Ager, A., Foy, D., Snider, L., Scholte, W., Kaiser, R., Olff, M., Rijnen, B. and Simon, W. (2012) 'Psychological distress, depression, anxiety, and burnout among international humanitarian aid workers: a longitudinal study', *PLoS One,* 7(9), pp. e44948.

Lopez, S. H. (2010) 'Workers, managers, and customers: Triangles of power in work communities', *Work and Occupations,* 37(3), pp. 251-271.

Loquercio, D., Hammersley, M. and Emmens, B. (2006) *Understanding and addressing staff turnover in humanitarian agencies.* Overseas Development Institute.

Lorde, A. 'The master’s tools will never dismantle the master’s house. Comments at ‘the personal and the political’panel'. *Second Sex conference, USA. Retrieved May,* 2011.

Lowndes, V. and Sullivan, H. J. L. g. s. (2004) 'Like a horse and carriage or a fish on a bicycle: how well do local partnerships and public participation go together?', 30(1), pp. 51-73.

Luborsky, M. R. and Rubinstein, R. L. (1995) 'Sampling in qualitative research: Rationale, issues, and methods', *Research on aging,* 17(1), pp. 89-113.

Lumey, L. and van Poppel, F. W. (2013) 'The Dutch famine of 1944-45 as a human laboratory: Changes in the early life environment and adult health', *Early life nutrition and adult health and development,* 3, pp. 59-70.

Lutz, C. and Collins, J. (1991) 'The Photograph as an Intersection of Gazes: The Example of National Geographic', *Visual Anthropology Review*, pp. 134-149.

MacFarlane, A., O’Donnell, C., Mair, F., O’Reilly-de Brún, M., de Brún, T., Spiegel, W., van den Muijsenbergh, M., van Weel-Baumgarten, E., Lionis, C. and Burns, N. (2012) 'REsearch into implementation STrategies to support patients of different ORigins and language background in a variety of European primary care settings (RESTORE): study protocol', *Implementation Science,* 7(1), pp. 1-10.

MacLure, M. (2013) 'Researching without representation? Language and materiality in post-qualitative methodology', *International Journal of Qualitative Studies in Education,* 26(6), pp. 658-667.

MacVinish, S., van Leeuwen, C., Hoetjes, M., Aoki, Y., Foley, D. and Roggeveen, H. (2023) 'Lessons identified from initiating a thalassaemia programme in a conflict setting: a case study from northeast Syria', *Conflict and Health,* 17(1), pp. 5.

Madden, R. (2017) *Being ethnographic: A guide to the theory and practice of ethnography*. Sage.

Madsen, M. L. (2004) 'Living for home: policing immorality among undocumented migrants in Johannesburg', *African Studies*, 63(2), pp. 173-192.

Magone, C., Neuman, M. and Weissman, F. (2012) *Humanitarian negotiations revealed: the MSF experience*. Oxford University Press.

Makdisi, S. and Sadaka, R. (2003) 'The lebanese civil war. 1975-1990', *Understanding Civil War : Evidence and Analysis, Volume 2. Europe, Central Asia, and Other Regions*: World Bank Publications.

Malkki, L. H. J. A. r. o. a. (1995) 'Refugees and exile: From" refugee studies" to the national order of things', 24(1), pp. 495-523.

Manzo, L. C. and Brightbill, N. (2007) 'Toward a participatory ethics', *Participatory Action Research Approaches and Methods_ Connecting People, Participation and Place*: Routledge.

Martin, R. (1999) 'NGO Field Security', *Forced Migration Review*, 4, pp. 4-7.

Mazur, R. E. J. C. S. (1988) 'Refugees in Africa: The role of sociological analysis and praxis', 36(2), pp. 43-60.

Mazzei, L. A. (2007) *Inhabited silence in qualitative research: Putting poststructural theory to work*. Peter Lang.

Mazzei, L. A. and Jackson, A. Y. (2012) 'Complicating voice in a refusal to "let participants speak for themselves"', *Qualitative inquiry*, 18(9), pp. 745-751.

McBride, D. L. (2021) 'The impact of visiting restrictions during the COVID-19 pandemic on pediatric patients', *Journal of Pediatric Nursing*, 61, pp. 436-438.

McNiff, J. and Whitehead, J. (2009) *Doing and writing action research*. Sage Publications.

Médecins Sans Frontières (2015) *International Activity Report*.

Médecins Sans Frontières (2019) *Treating Syrian children suffering from thalassemia*. Available at: https://www.msf.org/treating-syrian-children-suffering-thalassemia-lebanon.

Médecins Sans Frontières (2020a) *Changing young lives in Lebanon Thalassemia in the shadow of COVID-19*. Available at: https://msf.org.uk/article/changing-young-lives-lebanon-thalassemia-shadow-covid-19.

Médecins Sans Frontières (2020b) *MSF responds to coronavirus COVID-19 in Lebanon*. Available at: https://www.msf.org/msf-responds-coronavirus-covid-19-lebanon.

Médecins Sans Frontières (2020c) *Saving the lives of children with thalassaemia in Lebanon*. Available at: https://www.msf.org/saving-lives-children-thalassaemia-lebanon.

Médecins Sans Frontières (2021a) *Beirut blast One year on, the situation in Lebanon has only got worse*.

Médecins Sans Frontières (2021b) *Healthcare system in Lebanon crumbles amidst political and economic crisis*. Available at: https://www.msf.org/healthcare-system-lebanon-crumbles-amidst-political-and-economic-crisis.

Médecins Sans Frontières (2021c) *Overlapping crises increase needs and worsen access to care*. Available at: https://www.msf.org/lebanon-overlapping-crises-increase-needs-and-worsen-access-care.

Médecins Sans Frontières (2022) *MSF Charter* Médecins Sans Frontières (MSF) is a private international association. The association is made up mainly of doctors and health sector workers and is also open to all other professions which might help in achieving its aims. (Accessed: 10/10/2022.

Melrose, M. J. (2001) 'Maximizing the rigor of action research: why would you want to? How could you?', *Field Methods*, 13(2), pp. 160-180.

Merriam-Webster *Precarious*: Merriam-Webster.com Dictionary. Available at: https://www.merriam-webster.com/dictionary/precarious (Accessed: 26 06 2023) 2023).

Merriam-Webster (2023a) *Cost*. Merriam-Webster.com dictionary. Available at: https://www.merriam-webster.com/dictionary/cost (Accessed: 25 June 2023).

Merriam-Webster (2023b) *Loss*. Merriam-Webster.com Dictionary. Available at: https://www.merriam-webster.com/dictionary/loss (Accessed: Accessed 25 Jun. 2023).

Mershed, M., Busse, R. and van Ginneken, E. (2012) 'Healthcare financing in Syria: satisfaction with the current system and the role of national health insurance—a qualitative study of householders' views', *The International journal of health planning and management,* 27(2), pp. 167-179.

Merton, R. K. (1936) 'The unanticipated consequences of purposive social action', *American sociological review,* 1(6), pp. 894-904.

Metcalfe-Hough, V., Fenton, W. and Poole, L. (2019) *Grand Bargain Annual Independent Report 2019*: Humanitarian Policy Group.

Millar, K. M. (2017) 'Toward a critical politics of precarity', *Sociology compass,* 11(6), pp. e12483.

Mjaess, G., Karam, A., Chebel, R., Tayeh, G. A. and Aoun, F. (2021) 'COVID-19, the economic crisis, and the Beirut blast: what 2020 meant to the Lebanese health-care system', *Eastern Mediterranean health journal,* 27(6), pp. 535-537.

Molony, T. and Hammett, D. (2007) 'The friendly financier: Talking money with the silenced assistant', *Human Organization,* 66(3), pp. 292-300.

Mooney, E. D. (1995) 'Presence, ergo protection? UNPROFOR, UNHCR and the ICRC in Croatia and Bosnia and Herzegovina', *International Journal of Refugee Law,* 7(3), pp. 407-435.

Moran, M. H. (2017) 'Missing bodies and secret funerals: The production of" safe and dignified burials" in the Liberian Ebola crisis', *Anthropological Quarterly,* pp. 399-421.

Mosse, D. (2011) *Adventures in Aidland: The anthropology of professionals in international development*. Berghahn Books.

Mouffe, C. (1999) 'Deliberative democracy or agonistic pluralism?', *Social research,* pp. 745-758.

Muwanga-Zake, J. W. (2009) 'Building bridges across knowledge systems: Ubuntu and participative research paradigms in Bantu communities', *Discourse: Studies in the Cultural Politics of Education,* 30(4), pp. 413-426.

Nadai, E. and Maeder, C. 'Fuzzy fields. Multi-sited ethnography in sociological research'. *Forum Qualitative Research, On-line Journal*: Freie Univ. Berlin, 1-10.

Nagle, J. (2019) 'The biopolitics of victim construction, elision and contestation in Northern Ireland and Lebanon', *Peacebuilding,* 8(4), pp. 402-417.

Nakane, I. (2012) 'Silence', *The handbook of intercultural discourse and communication,* pp. 158-179.

Napier, A. D., Ancarno, C., Butler, B., Calabrese, J., Chater, A., Chatterjee, H., Guesnet, F., Horne, R., Jacyna, S. and Jadhav, S. (2014) 'Culture and health', *The Lancet,* 384(9954), pp. 1607-1639.

Napier, A. D., Depledge, M., Knipper, M., Lovell, R., Ponarin, E., Sanabria, E. and Thomas, F. (2017) *Culture matters: using a cultural contexts of health approach to enhance policy making*. World Health Organization. Regional Office for Europe.

National Center for Biotechnology Information (1998) *Thalassemia*. Genes and Disease. Available at: https://www.ncbi.nlm.nih.gov/books/NBK22200/.

Nguyen, V.-K. (2019) 'An epidemic of suspicion—Ebola and violence in the DRC', *New England journal of medicine,* 380(14), pp. 1298-1299.

Nouvet, E., Abu-Sada, C., de Laat, S., Wang, C. and Schwartz, L. (2016) 'Opportunities, limits and challenges of perceptions studies for humanitarian contexts', *Canadian Journal of Development Studies/Revue canadienne d'études du développement,* 37(3), pp. 358-377.

O'Doherty, K. and Lecouteur, A. (2007) '"Asylum seekers","boat people" and "illegal immigrants": Social categorisation in the media', *Australian journal of psychology,* 59(1), pp. 1-12.

O'Reilly – de Brún, M., de Brún, T., O'donnell, C. A., Papadakaki, M., Saridaki, A., Lionis, C., Burns, N., Dowrick, C., Gravenhorst, K. and Spiegel, W. (2018) 'Material practices for meaningful engagement: An analysis of participatory learning and action research techniques for data generation and analysis in a health research partnership', *Health Expectations,* 21(1), pp. 159-170.

OCHA (2012) *What are Humanitarian Principles?* : United Nations Office for the Coordination of Humanitarian Affairs (Accessed: 13 May 2019).

OECD (2019) *Development aid drops in 2018, especially to neediest countries.*

Omi, M. and Winant, H. (1993) 'On the theoretical status of the concept of race', *Race, identity and representation in education*, pp. 3-10.

Omi, M. and Winant, H. (2014) *Racial formation in the United States.* Routledge.

Orbinski, J. (1999) *The Nobel Peace Prize Speech*: Médecins Sans Frontières.

Ormel, I., Salsberg, J., Hunt, M., Doucet, A., Hinton, L., Macaulay, A. C. and Law, S. (2020a) 'Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review', *Glob Health Action,* 13(1), pp. 1826730.

Ormel, I., Salsberg, J., Hunt, M., Doucet, A., Hinton, L., Macaulay, A. C. and Law, S. (2020b) 'Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review', *Global Health Action,* 13(1), pp. 1826730.

Owen, E. R. J. (1976) 'Essays on the Crisis in Lebanon', *(No Title).*

Pallister-Wilkins, P. (2018) 'Médecins Avec Frontières and the making of a humanitarian borderscape', *Environment and planning D: society and space,* 36(1), pp. 114-138.

Pallister-Wilkins, P. (2021) 'Saving the souls of white folk: Humanitarianism as white supremacy', *Security Dialogue,* 52(1_suppl), pp. 98-106.

Pallister-Wilkins, P. (2022) *Humanitarian Borders : Unequal Mobility and Saving Lives.* La Vergne, UNITED STATES: Verso.

Papadopoulou, A. J. J. o. R. S. (2004) 'Smuggling into Europe: transit migrants in Greece', 17(2), pp. 167-184.

Pauletto, E. (2018) 'The Shocking Inequity In Foreign Aid Nobody Talks About', *Bright.*

Pincock, K. and Bakunzi, W. (2021) 'Power, participation, and 'peer researchers': Addressing gaps in refugee research ethics guidance', *Journal of Refugee Studies,* 34(2), pp. 2333-2348.

Pitel, L. (2017) 'Cash card scheme brings 'dignity' to Turkey's refugees', *Financial Times.*

Pottie, K., Martin, J. P., Cornish, S., Biorklund, L. M., Gayton, I., Doerner, F. and Schneider, F. (2015) 'Access to healthcare for the most vulnerable migrants: a humanitarian crisis', *Confl Health,* 9, pp. 16.

Purvis, K. (2015) 'Stigma, guilt and gaps in the system; it's time for NGOs to step up on staff mental health', *The Guardian*, p. 4.

Quesada, J. (2012) 'Special issue part II: Illegalization and embodied vulnerability in health', *Soc Sci Med,* 74(6), pp. 894-6.

Quesada, J., Hart, L. K. and Bourgois, P. (2011) 'Structural vulnerability and health: Latino migrant laborers in the United States', *Med Anthropol,* 30(4), pp. 339-62.

Rajaram, P. K. J. J. o. R. S. (2002) 'Humanitarianism and Representations of the Refugee', 15(3), pp. 247-264.

Redfield, P. (2012a) 'THE UNBEARABLE LIGHTNESS OF EX-PATS: Double Binds of Humanitarian Mobility', *Cultural Anthropology,* 27(2), pp. 358-382.

Redfield, P. (2012b) 'The unbearable lightness of ex – pats: double binds of humanitarian mobility', *Cultural Anthropology,* 27(2), pp. 358-382.

Redfield, P. J. C. a. (2005) 'Doctors, borders, and life in crisis', 20(3), pp. 328-361.

Reid, C., Tom, A. and Frisby, W. (2006) 'Finding the 'action'in feminist participatory action research', *Action Research,* 4(3), pp. 315-332.

Reid, C., Tom, A. and Frisby, W. (2016) 'Finding the 'action' in feminist participatory action research', *Action Research,* 4(3), pp. 315-332.

Republic of Lebanon Ministry of Public Health (2018) *The Collaborative Governance of Lebanon's Health Sector*, Lebanon: Policy Support Observatory.

Republic of Lebanon Ministry of Public Health (2021) *Lebanon National Deployment and Vaccination Plan for COVID-19 Vaccines*.

Reyes, V. (2020) 'Ethnographic toolkit: Strategic positionality and researchers' visible and invisible tools in field research', *Ethnography,* 21(2), pp. 220-240.

Ringrose, J. and Renold, E. (2014) '"F** k rape!" Exploring affective intensities in a feminist research assemblage', *Qualitative Inquiry,* 20(6), pp. 772-780.

Robertson, D. W., Bedell, R., Lavery, J. V. and Upshur, R. (2002) 'What kind of evidence do we need to justify humanitarian medical aid?', *The Lancet,* 360(9329), pp. 330-333.

Robinson, B. L., Halford, A. and Gaura, E. (2022) 'From Theory to Practice: A review of co-design methods for humanitarian energy ecosystems', *Energy Research & Social Science,* 89.

Roepstorff, K. (2020) 'A call for critical reflection on the localisation agenda in humanitarian action', *Third World Quarterly,* 41(2), pp. 284-301.

Rosstalnyj, N. (2022) *Deserving and undeserving refugees? An analysis of the EU's response to the 'refugee crisis' in 2015 compared to the refugee influx from Ukraine in 2022.* Central European University.

Rowe, E., & O'Brien, E (2014) ''Genuine' refugees or illegitimate 'boat people ': Political constructions of asylum seekers and refugees in the Malaysia', *Australian Journal of Social Issues,* 49(2), pp. 171-193.

Rutazibwa, O. U. (2019) 'What's There to Mourn? Decolonial Reflections on (the End of) Liberal Humanitarianism', *Journal of Humanitarian Affairs,* 1(1), pp. 65-67.

Safieddine, H. (2019) *Banking on the state: The financial foundations of Lebanon.* Stanford University Press.

Said, E. (1978) 'Introduction to orientalism', *1978,* pp. 1279-95.

Said, E. W. (1985) 'Orientalism reconsidered', *Race & class,* 27(2), pp. 1-15.

Said, E. W. (2001) *The war for Palestine: rewriting the history of 1948.* Cambridge University Press.

Salem, P. (2006) 'The future of Lebanon', *Foreign Aff.,* 85, pp. 13.

Saperstein, A., Penner, A. M. and Light, R. (2013) 'Racial Formation in Perspective: Connecting Individuals, Institutions, and Power Relations', *Annual Review of Sociology,* 39(1), pp. 359-378.

Secen, S. (2021) 'Explaining the Politics of Security: Syrian Refugees in Turkey and Lebanon', *Journal of Global Security Studies,* 6(3).

Shallal, A., Lahoud, C., Zervos, M. and Matar, M. (2021) 'Lebanon is losing its front line', *Journal of Global Health,* 11.

Shelter Cluster, U., REACH (2020) *Local Architecture Review: Key findings on vernacular shelter designs, materials and local building practices in Afghanistan.*, Kabul: REACH Available at: https://sheltercluster.org/afghanistan/documents/local-architecture-review-key-findings-vernacular-shelter-designs-materials.

Singh, N. S., Lokot, M., Undie, C. C., Onyango, M. A., Morgan, R., Harmer, A., Freedman, J. and Heidari, S. (2021) 'Research in forced displacement: guidance for a feminist and decolonial approach', *Lancet,* 397(10274), pp. 560-562.

Slim, H. (1997) 'Doing the right thing: relief agencies, moral dilemmas and moral responsibility in political emergemcies and war', *Disasters,* 21(3), pp. 244-257.

Slim, H. (2015) *Humanitarian ethics: A guide to the morality of aid in war and disaster.* Oxford University Press.

Smirl, L. (2008) 'Building the other, constructing ourselves: Spatial dimensions of international humanitarian response', *International political sociology,* 2(3), pp. 236-253.

Smirl, L. (2015) *Spaces of aid: how cars, compounds and hotels shape humanitarianism.* Zed Books Ltd.

Spearin, C. (2001) 'Private security companies and humanitarians: A corporate solution to securing humanitarian spaces?', *International Peacekeeping,* 8(1), pp. 20-43.

Spiegel, P. (2010) 'Urban refugee health meeting the challenges', *Forced Migraton Review,* pp. 22-23.

Spiegel, P. B., Checchi, F., Colombo, S. and Paik, E. (2010) 'Health-care needs of people affected by conflict: future trends and changing frameworks', *The Lancet,* 375(9711), pp. 341-345.

Spiritus-Beerden, E., Verelst, A., Devlieger, I., Langer Primdahl, N., Botelho Guedes, F., Chiarenza, A., De Maesschalck, S., Durbeej, N., Garrido, R., Gaspar de Matos, M., Ioannidi, E., Murphy, R., Oulahal, R., Osman, F., Padilla, B., Paloma, V., Shehadeh, A., Sturm, G., van den Muijsenbergh, M., Vasilikou, K., Watters, C., Willems, S., Skovdal, M. and Derluyn, I. (2021) 'Mental Health of Refugees and Migrants during the COVID-19 Pandemic: The Role of Experienced Discrimination and Daily Stressors', *International Journal of Environmental Research and Public Health,* 18(12), pp. 6354.

Sprusansky, D. (2021) 'Rami Khouri: Lebanon Has Lost its Distinctiveness', *The Washington Report on Middle East Affairs.* Available at: https://www.wrmea.org/waging-peace/rami-khouri-lebanon-has-lost-its-distinctiveness.html (Accessed: 09/08/2023).

Srichaikul, K., Hegele, R. A. and Jenkins, D. J. (2022) 'Great Chinese Famine and the Effects on Cardiometabolic Health for Future Generations', 79(3), pp. 532-535.

St. Pierre, E. A. and Jackson, A. Y. (2014) 'Qualitative Data Analysis After Coding', *Qualitative Inquiry,* 20(6), pp. 715-719.

Standing, G. (2011) *The precariat: The new dangerous class.* Bloomsbury academic.

Steinmetz, G. (2014) 'The Sociology of Empires, Colonies, and Postcolonialism', *Annual Review of Sociology,* 40(1), pp. 77-103.

Stel, N. (2020) *Hybrid political order and the politics of uncertainty: Refugee governance in Lebanon.*

Stel, N. (2021) 'Uncertainty, exhaustion, and abandonment beyond South/North divides: Governing forced migration through strategic ambiguity', *Political Geography,* 88, pp. 102391.

Stellmach, D. (2016) *Coordination in crisis: The practice of medical humanitarian emergency*. University of Oxford.

Stevano, S. and Deane, K. 2019. The role of research assistants in qualitative and cross-cultural social sciences research. *In:* Liamputtong, P. (ed.) *Handbook of Research Methods in Health Social Sciences*. Singapore: Springer.

Stierl, M. (2022) 'Do no harm? The impact of policy on migration scholarship', *Environment and Planning C: Politics and Space,* 40(5), pp. 1083-1102.

Sukarieh, M. and Tannock, S. (2013) 'On the problem of over-researched communities: The case of the Shatila Palestinian refugee camp in Lebanon', *Sociology,* 47(3), pp. 494-508.

Taleb, W. (2020) *Lebanon's PM struggles to form Cabinet amid economic crisis*: Al Monitor. Available at: https://www.al-monitor.com/originals/2020/11/lebanon-government-formation-stall-french-initiative.html (Accessed: 20/06/2021.

Thapar – Björkert, S. and Henry, M. (2004) 'Reassessing the research relationship: location, position and power in fieldwork accounts', *International Journal of Social Research Methodology,* 7(5), pp. 363-381.

The New Humanitarian (2020) 'Médecins Sans Frontières needs 'radical change' on racism: MSF president'.

The New Humanitarian (2022). Is "decolonised aid" an oxymoron? *In:* Aly, H. (ed.) *Rethinking Humanitarianism.*

Author (2011)*: The Sphere Project Handbook*: Practical Action Publishing. Available at: www.sphereproject.org.

Thebian, A. (2020) 'Corruption, Protest, And Hope In Lebanon', *Journal of International Affairs,* 73(2), pp. 239-246.

Thomas, N. (1994) *Colonialism's culture: anthropology, travel, and government.* Princeton University Press.

Thonney, T. and Montgomery, J. C. (2019) 'Defining critical thinking across disciplines: An analysis of community college faculty perspectives', *College Teaching,* 67(3), pp. 169-176.

Tracy, S. J. (2010) 'Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research', *Qualitative Inquiry,* 16(10), pp. 837-851.

Tuhiwai Smith, L. (2021) 'Imperialism, History, Writing and Theory', *Decolonizing Methodologies : Research and Indigenous Peoples.* 1 ed. London: Zed Books, pp. 21-47.

UNHCR (2021a) *Health Care Programme Lebanon Factsheet May 2021.*

UNHCR (2021b) *Syrian Refugees' Perceptions & Intentions on Return To Syria.* Available at: https://data2.unhcr.org/en/documents/details/85739.

UNHCR (2022) *Lebanon - Needs at a glance.*

UNRWA (2023) *Syria, Lebanon, Jordan Emergency Appeal.*

van den Muijsenbergh, M., van Weel-Baumgarten, E., Burns, N., O'Donnell, C., Mair, F., Spiegel, W., Lionis, C., Dowrick, C., O'Reilly-de Brún, M. and de Brun, T. (2014) 'Communication in cross-cultural consultations in primary care in Europe: the case for improvement. The rationale for the RESTORE FP 7 project', *Primary health care research & development,* 15(2), pp. 122-133.

van Voorst, R. (2019) 'Praxis and paradigms of local and expatriate workers in 'Aidland'', *Third World Quarterly,* 40(12), pp. 2111-2128.

Visser, M., Mills, M., Heyse, L., Wittek, R. and Bollettino, V. (2016) 'Work-life balance among humanitarian aid workers', *Nonprofit and Voluntary Sector Quarterly,* 45(6), pp. 1191-1213.

Vohra, A. (2021) *Syrian refugees' plight in Lebanon 10 years after the uprising*: Al Jazeera.

Wallerstein, N. B. and Duran, B. (2006) 'Using community-based participatory research to address health disparities', *Health promotion practice,* 7(3), pp. 312-323.
Wallman, S., Dhooge, Y., Goldman, A. and Kosmin, B. (1980) 'Ethnography by proxy: Strategies for research in the inner city', *Ethnos,* 45(1-2), pp. 5-38.
Warnock, R., Taylor, F. M. and Horton, A. (2022) 'Should we pay research participants? Feminist political economy for ethical practices in precarious times', *Area,* 54(2), pp. 195-202.
Waters, T. (2001) *Bureaucratizing the Good Samaritan: The limitations of humanitarian relief operations.* Routledge.
Weinberger, N. J. (1986) *Syrian intervention in Lebanon: the 1975-76 civil war.* Oxford University Press, USA.
Weissman, F. (2004) *In the shadow of'just wars': violence, politics, and humanitarian action.* Cornell University Press.
Wiegand, K. E. (2009) 'Reformation of a terrorist group: Hezbollah as a Lebanese political party', *Studies in Conflict & Terrorism,* 32(8), pp. 669-680.
Witte, H. D. (1999) 'Job insecurity and psychological well-being: Review of the literature and exploration of some unresolved issues', *European Journal of work and Organizational psychology,* 8(2), pp. 155-177.
World Food Programme (2021) *WFP Lebanon Country Brief* (Accessed: 14/07/2021).
World Health Organisation (2016) *WHO calls for immediate safe evacuation of the sick and wounded from conflict areas.*
World Health Organization (2022) *Disease Outbreak News; Cholera - Lebanon.* Available at: https://www.who.int/emergencies/disease-outbreak-news/item/2022-DON416.
World Population Review (2023) *Countries with the Highest National Debt 2023.* National Debt by Country. Available at: https://worldpopulationreview.com/country-rankings/countries-by-national-debt (Accessed: 27/07/2023).
Yacoubian, M. (2006) *Syria's Role in Lebanon*, Washington: United States Institute of Peace.
Yeoh, R. and Kim, N. (2022) 'Nameless, voiceless, and helpless: visual framing of distant outgroups in online humanitarian appeals', *Journal of Intercultural Studies*, pp. 1-23.
Yi-Neumann, F., Lauser, A., Fuhse, A. and Bräunlein, P. J. (2022) *Material Culture and (Forced) Migration: Materializing the Transient.* UCL Press.
Yin, R. K. (2009) *Case study research: Design and methods.* sage.
Yohannes, H. T. (2021) *The realities of Eritrean refugees in a carceral age.* University of Glasgow.
Zeitoun, A., Hallit, S., Helali, M., Chehade, S., Allam, C., Ibrahim, A., Dimassi, H. and Karam, R. (2022) 'Vaccination process evaluation at COVID-19 vaccination centers in Lebanon: a national study', *Journal of Pharmaceutical Policy and Practice,* 15(1), pp. 63.
Zerubavel, E. (1985) *Hidden rhythms: Schedules and calendars in social life.* Univ of California Press.
Zetter, R. (1988) 'Refugees and refugee studies-A label and an agenda', *J. Refugee Stud.,* 1, pp. 1.
Zetter, R. (1991) 'Labelling refugees: Forming and transforming a bureaucratic identity', *Journal of refugee studies,* 4(1), pp. 39-62.
Zetter, R. (2007) 'More labels, fewer refugees: Remaking the refugee label in an era of globalization', *Journal of refugee studies,* 20(2), pp. 172-192.

Zetter, R. and Deikun, G. (2010) 'Meeting humanitarian challenges in urban areas', *Forced Migration Review*, pp. 5-7.
Zimmet, P., Shi, Z., El-Osta, A. and Ji, L. (2018) 'Epidemic T2DM, early development and epigenetics: implications of the Chinese Famine', *Nature Reviews Endocrinology,* 14(12), pp. 738-746.

# Appendices

## Appendix 1: Positionality Statement Questions

Please speak about each of the below four points, and their subpoints, and how they influence how you approach this research project (e.g. *aid sector, medical care, public health, participants, university, participatory action research*).

It's your life story, and how events shape how you see/understand each of the below topic points.

You can be as reflective and open as you're comfortable with.

1. Background
    a. Social
    b. Cultural
    c. Spiritual
    d. Professional
2. My approaches/worldview
    a. Politics
    *b.* Epistemology: 'what is [valid] knowledge' – scientific v lay? 'is there an objective truth waiting to be *discovered?*'
    c. Ontology: What 'truth' exists in reality? Who decides what is 'real'?
    d. 'reality' exists independent of the researcher or does 'reality' exist subjectively or negotiated
3. Approach to practice
    a. Assumptions: what do I assume will happen?
    b. Biases

How this (above) impacts hopes, fears, objectives (personal and professional) for this project

## Appendix 2: Audio diary Prompts

- Date
- Time
- Number of people in attendance at co-development group
- Location
- Participant Group

Please use this topic guide to focus your reflection on a) the *data generated* during the co-development group b) the *method of conducting* the co-development group and *your experiences* during this time.

It is important that you **distinguish what you saw and heard from what you interpret this to mean**.

*Setting the Scene…*

- Describe arriving, the set up process and interactions you had
- People: Describe the people in the room where appropriate/relevant e.g. sex, age, nationality etc. and what impact you think that may have had on the responses in the room?
- Space: Describe the materials, colors in the room, temperature and weather, was it busy, loud, quiet, etc.
- Any notable absences, who was not in the room, from your perspective? Please explain why this may be important

*Responses…*

- Describe behaviors, body language, nonverbal communication
- Who spoke the most and least, do you think there is a reason for this?
- What responses were accepted?
- What responses were challenged?
- Was there any taken for granted assumptions? Please explain
- What surprised you about the session - tell me about this
- Do you think any perspectives or experiences were not shared i.e. was not said?

*Reflection…*

- What moment did you enjoy the most? Please explain why you think this is?(Do you think this moment was shared by everyone in the room? How did it come about?)
- Which moment did you enjoy the least? (Describe any feelings of discomfort? Tension? Frustration?) Please describe this and what you think caused this (multiple causes?)? Do you think this moment was shared by everyone in the room?
- What questions were responded to with ease, and which weren't: explain reactions and why you think this might be
- What would you do differently next time? Reimagine the session – what would be different? please explain

# Appendix 3: Semi-Structured Interview Guide

This topic guide focuses on a) the *data generated* during the co-development group b) the *process of conducting* the co-development group and c) the *nature of the remote international partnership* created in this project.

Examples of Questions:

*process of conducting* the co-development group

1. How would you describe your experience of facilitating the co-development groups?
2. Tell me about what surprised you the most during your experience to date e.g. the responses you received, the method, working procedures?
3. What would you change about the method if you ran them again?

*nature of the remote international partnership* created in this project.

4. How do you think your experience might have been different if there was no international partnership, for instance, if I was based at a University in Lebanon?

    a. What do you think are the main benefits from this international design?
    b. What do you think are the main drawbacks from this international design?

# Appendix 4: Participant Observation

**Date:**

**Location:**

**Participants:**

**Time**

Saw & Heard

---

Interpreted

# Appendix 5: Co-development group Guide

## First Co-development group

5 mins: Introduction about research

This workshop is part of a Doctoral research project at the University of Glasgow. The main purpose of this study is to explore whether people's needs are being met by the humanitarian healthcare being provided in Lebanon today, especially in relation to any changes made by organisations in response to the pandemic, economic collapse and Beirut Blast.

This research is being conducted with both service users and staff in humanitarian healthcare clinics in Lebanon to discuss how we may be able to work together to improve humanitarian medical care. I want to understand more how people define effective and relevant humanitarian medical care.

This research project will run four workshops, lasting up to 90minutes each, in the coming weeks. You will be asked different questions like 'can you describe a recent healthcare journey' 'can you think of any issues you face in accessing healthcare' 'what do you think solutions can look like'? You are invited to all sessions, but if you can only attend today – that's okay.

Are there any questions?

10 mins: Consent

Create a sharing circle and co-create consent:

I would like to co-create an ethics and consent agreement today, a system of principles and rules that help us determine boundary setting that we can all choose sign up to (Beauchamp and Childress, 2001).

*What does ethics mean to us? Can we all share ethical principle that is important to us which we would like to be followed today? For example: doing good and doing no harm* [go around the room and collect responses]

Ask if everyone in the room signs up to list on paper/wall/whiteboard etc. Ask if everyone in the room is okay for the audio recorder to be turned on.

- 30mins: ‘Commentary Charts’: Creation [Create Data]

This session will focus on asking research participants to comment on how they make sense of the current aid organisations operations, effectiveness and cultural appropriation and what issues do they identify as limiting effective operations.

The comments identified by the participants, will be written on post its and termed a ‘comment card’, and placed visually on a ‘Commentary Chart’, see template below (de Brún *et al.*, 2017). The identified comments will be then be reflected upon and questions will be asked to ensure that each participant has expressed their perspective on the matter, following the lead of O'Reilly-de Brun et al . This cyclical structure aligns with the PAR cycle of ‘‘planning, acting, observing, and reflecting’’ (Melrose, 2001, p. 162)

Prompts given to share experiences and perspectives. People go around in a circle to share their thoughts, write comments on post it and stick on paper. Ask research participants to comment on:

- how they
    - make sense of the current aid organisations operations,
    - effectiveness
    - cultural appropriation
- what issues do they identify as *limiting* effective operations
- Prioritisation during COVID-19

Commentary Charts: Creation

Questions/Topic Guide 30minutes to create words/small phrases, symbols, a quick image or symbol, scribble or even a sign/stance (whatever is the easiest and safest way for each person) with 6-8 people.

## Questions

*Health Journeys…*

Syrian and Lebanese Participants: Access care want/need

- Can you describe your healthcare journey here today? (How long did it take, how did you get here, how much did it cost?)
- Tell me about the decisions you had to make to be here; did you have to make decisions over recourses like money or time? (Doing x instead of Y?)
- Have you been here many times? More than once - what are the reasons you return here?
- What do you think is [are] the biggest factor[s] which shape your health?
- If/when you are unable to access healthcare here at this clinic, where do you get treatment? At home? [self-treatment/lay-treatment/last resort]
- Do you think there is anyone who may be unable to access this clinic today?
- Syrian: How do you think your migration journey has affected your health? How do you think your migration to Lebanon may continue to affect your health today?

[inter]national Staff – ask perspective of the patients?

- Can you describe a typical day for you?
- What are the main influences on people's health today in Lebanon?
- Has there been/tell me about a time when a patient hasn't been able to get the care/drugs they need, what happens then? [last resort?]

*Social & Cultural Responsiveness…*

Syrian and Lebanese Participants & Staff

- Explain what having 'good health' means to you, describe a 'healthy life'
    - Explain the term 'community health'?

**Communication:**

- Are the ways that health/clinic information shared appropriate? (e.g. word of mouth, digital, posters?)

**Relational and interpersonal**; Attitudes; knowledge that they have [health professional/patient as a person]

- Describe a typical consultation at this clinic and the examples of interactions that you have
    - Understand if health concerns taken seriously? Listen to your story?
    - Is there anyone who would disagree with this?

**Knowledges**

- Patient: When the health professional advises treatment, when you share your perspective how does the health professional respond?
- Staff: How do you respond when a patient has a specific treatment in mind, or prefers an alternative? Does this often happen?

**Relevance**

*[Healthcare services are often tailored to people's age, sex and the way people live; food they eat, work they do, how they interact with the environment, level of activity, relationships in their life and their religious beliefs too]*

- Tell me whether you think the healthcare services here are tailored to the lives you have, and the healthcare needs you have
- In clinics you've attended before [worked/patient], are there differences in the care offered [maybe the way symptoms are recognised?]

*Aid Systems & Spaces…*

Syrian and Lebanese Participants & Staff

**Empathy & Understanding:** *does an organisation who works specifically with structurally vulnerable populations offer an improved experience of care?*

- In your experience, how does the interactions with patients/staff at this [NGO] health service compare to others (private, state care) you may have used/worked in.
- Tell me about a time when you had a positive experience at this clinic? What about this moment made it positive for you? Would this happen often? Have others had this experience?
- What do you think it's important for patients/staff be aware of during a consultation?
- What kind of conversations do you hear between patients and staff here?

**Representation of staff & patients:** e.g. in fundraising

- Do you see/hear yourself in the organisation's e.g. advocacy and fundraising work?
- What do you think of the messaging they share to raise awareness?

**Purpose and role of humanitarian medical care**

- What <u>role</u> do you think 'humanitarian/charity' medical services, like Amel/MSF, play in the healthcare system?
- Reimagine healthcare – what would be different? please explain

**Space**

- What words, images, stances, symbols (…) come to mind when you think of spaces of medical aid today (e.g. describe tones of conversations, free, safe, [mis?]trust, confidence)
- What would you change to create a safer space for care?

*Current Context in Lebanon*

<u>Syrian and Lebanese Participants & Staff</u>

**COVID-19**

- Explain how you saw health services change during COVID-19

    - Do you think any important health service was stopped during this time?
    - Do you think anything is missing now?
    - What's been the impact of this?

Staff

**Increased patients:** due to economic collapse

- Explain the changes you have seen with patients in the past 18 months
    - Do you think there any changes in patient needs?
    - What changes has there been in consultations due to the increase in Lebanese patients (e.g. services, interactions)

Is there anything that you think is important to share today on this topic?

- 15 mins: Wrap Up

- Project M&E; all participants respond to open—ended questions, rapid/interactive.
    - Aim; we all describe experiences in our own words, affirm positives and suggest areas for improvement. Take temperature and build on positives and
    - **suggest areas for improvement for methodological development** (Is this method relevant? Is there another way that we can answer these questions that make more sense e.g. forms of expression - song, narrative story telling, or e.g. walking interviews around the clinic)

- Review confidentiality agreements/Retake consent

- Option to sign up for next session – take contact details for whose who want to stay informed about

    - Newsletter/WhatsApp group for PhD updates

    - Final session for creating actionable solutions

- Platform for engagement: would participants like to move forward [action]? If so, what kind of action do people suggest? [idea of co-created platform?]

- Express gratitude to participants, if a gift/benefit-in-kind for participation has been identified as appropriate then this will be shared

<u>Co-development group Data Collection Tools</u>

**Commentary Chart**
**Stakeholder Group**
**Date**
**Topic**

| Positive | Negative |
|---|---|
| | |

## Second Co-development group

- 5 mins: Introduction about research

This workshop is part of a Doctoral research project at the University of Glasgow. The main purpose of this study is to explore whether people's needs are being met by the humanitarian healthcare being provided in Lebanon today, especially in relation to any changes made by organisations in response to the pandemic, economic collapse and Beirut Blast.

This research is being conducted with both service users and staff in medical aid clinics in Lebanon to discuss how we may be able to work together to improve humanitarian medical care. I want to understand more how people define effective and relevant humanitarian medical care.

This research project will run four workshops, lasting up to 90minutes each, in the coming weeks. You will be asked different questions like ‘can you describe a recent healthcare journey’ ‘can you think of any issues you face in accessing healthcare’ ‘what do you think solutions can look like’? You are invited to all sessions, but if you can only attend today – that’s okay.

Are there any questions?

<u>10 mins: Consent</u>

Create a sharing circle and co-create consent:

I would like to co-create an ethics and consent agreement today, a system of principles and rules that help us determine which actions are right and which are wrong that we can all choose sign up to (Beauchamp and Childress 1998).

What does ethics mean to us? Can we all share ethical principle that is important to us which we would like to be followed today? For example: doing good *and* doing no harm [go around the room and collect responses]

Ask if everyone in the room signs up to list on paper/wall/whiteboard etc. Ask if everyone in the room is okay for the audio recorder to be turned on

- 30mins Commentary Chart: Categorise Outputs into Themes [begin analysis]

*<u>Beginning: 10 mins</u>*

The following questions will be reflected upon in the sharing circle format specified above, to facilitate the democratic identification of issues:

- *Review through four key topics and ask whether the chart makes sense*
    - *Aid system*
    - *Social and cultural competency & responsiveness*
    - *Health journeys*
    - *Lebanese context: Decisions & their effects*
- *Are diverse views sufficiently and accurately represented?*
- *Does anything need to be added as we reflect on the Chart?* [or removed & why]

*<u>Middle: 10 mins</u>*

Through using the sharing circle format described above, participants will be asked to categorise the comments by category [theme]. This will begin the data analysis process.

Possible Themes; identified across literature:

- staff support
- communication between field office and head office
- communication between patient and service staff
- service accessibility (mobile clinics, cost to access clinic)
- services that have stopped
- services that have started
- short term care
- long term care
- translators and interpreters
- service-user engagement and feedback mechanisms
- perception of service users by aid organizations

*End: 10 mins*

The following questions will be reflected upon in the sharing circle format specified above, to facilitate the democratic identification of issues:

*Does the Commentary Chart make sense?*

- *Are stakeholders comfortable with their data display?*
- *Is there anything striking/odd about the data display?*
- *Are diverse views sufficiently and accurately represented?*
- *Does anything need to be added as we reflect on the Chart?*
- *Are stakeholders willing and content to "sign off" on the Chart?*
- *Can it now be presented to another stakeholder group (as needs be) for discussion and development*

15 mins: Wrap Up

- Project M&E; all participants respond to open—ended questions, rapid/interactive. Aim; we all describe experiences in our own words, affirm positives and suggest areas for improvement. Take temperature and build on positives and suggest areas for improvement.
    - **suggest areas for improvement for methodological development** (Is this method relevant? Is there another way that we can answer these questions that make more sense e.g. forms of expression - song, narrative story telling, or e.g. walking interviews)
- Retake consent
- Option to sign up for next session – take contact details for whose who want to stay informed about

  - Newsletter/Whatsapp group for PhD updates
  - Final session for creating actionable solutions

- Platform for engagement: would participants like to move forward with this [action]? If so, what kind of action do people suggest? [idea of co-created platform?]

- Express gratitude to participants, if a gift/benefit-in-kind for participation has been identified as appropriate then this will be shared

## Third Co-development group

5 mins: Introduction about research

This workshop is part of a Doctoral research project at the University of Glasgow. The main purpose of this study is to explore whether people's needs are being met by the humanitarian healthcare being provided in Lebanon today, especially in relation to any changes made by organisations in response to the pandemic, economic collapse and Beirut Blast.

This research is being conducted with both service users and staff in medical aid clinics in Lebanon to discuss how we may be able to work together to improve humanitarian medical care. I want to understand more how people define effective and relevant humanitarian medical care.

This research project will run four workshops, lasting up to 90minutes each, in the coming weeks. You will be asked different questions like 'can you describe a recent healthcare journey' 'can you think of any issues you face in accessing healthcare' 'what do you think solutions can look like'? You are invited to all sessions, but if you can only attend today – that's okay.

Are there any questions?

10 mins: Consent

Create a sharing circle and co-create consent:

I would like to co-create an ethics and consent agreement today, a system of principles and rules that help us determine which actions are right and which are wrong that we can all choose sign up to (Beauchamp and Childress 1998).

What does ethics mean to us? Can we all share ethical principle that is important to us which we would like to be followed today? For example: doing good *and* doing no harm [go around the room and collect responses]

Ask if everyone in the room signs up to list on paper/wall/whiteboard etc. Ask if everyone in the room is okay for the audio recorder to be turned on

30mins Commentary Chart: Prioritise Themes

*Beginning: 10 mins*

The following questions will be reflected upon in the sharing circle format specified above, to facilitate the democratic identification of issues:

- *Review through four key topics and ask whether the chart makes sense*
    - *Aid system*
    - *Social and cultural competency & responsiveness*
    - *Health journeys*
    - *Lebanese context: Decisions & their effects*
- *Do the themes make sense?*
- *Are diverse views sufficiently and accurately represented?*
- *Does anything need to be added as we reflect on the Chart?* [removed & why?]

*Middle: 10 mins*

Deciding criterion for priority

1. For this session, participants will be encouraged to choose a physical object from the room to represent issues being ranked

2. Discuss priorities and importance of the identified issues that these items represent, and what will be the ranking criterion for prioritizing these

issues (all participants will be encouraged to listen, learn, question, assess, reflect)

2. Participants will place these on a sheet for visual mapping [see template below]

*End: 10 mins*

Voting and Direct Ranking

1. Everyone gets a ‘vote’ (item such as a coin, match, paper clip –object to be decided by the co-development group)

2. Count the votes per issue and write this on post-it note and attach to comment card

Continue to ask and reflect: ‘looking at the Direct Ranking chart and encouraging stakeholders to share their unique knowledge and insights, to exchange differential knowledge by asking:’ (O'Reilly-de Brún et al., 2018, p. 162)

- *Does it make sense?*
- *Do stakeholders feel comfortable with the outcome?*
- *Is there anything striking/odd about the result?*
- *Having been decided by democratic vote, is the result definitely acceptable?*
- *Are stakeholders* willing and content to “sign up” to the result?

15 mins: Wrap Up

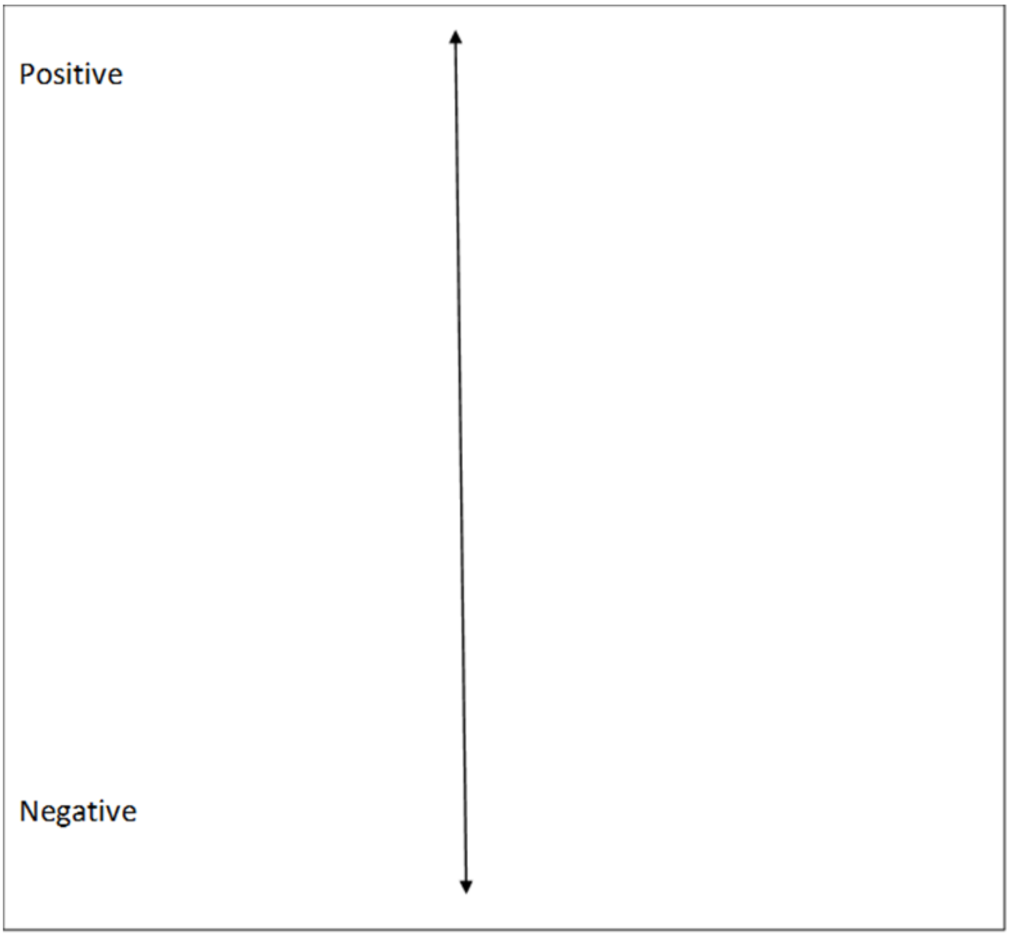
- Project M&E; all participants respond to open—ended questions, rapid/interactive. Aim; we all describe experiences in our own words, affirm positives and suggest areas for improvement. Take temperature and build on positives and suggest areas for improvement.
    - **suggest areas for improvement for methodological development** (Is this method relevant? Is there another way that we can answer

these questions that make more sense e.g. forms of expression - song, narrative storytelling, or e.g. walking interviews)

- Review confidentiality agreements/Retake consent
- Option to sign up for next session – take contact details for whose who want to stay informed about
    - Newsletter/Whatsapp group for PhD updates
    - Final session for creating actionable solutions
- Platform for engagement: would participants like to move forward with this [action]? If so, what kind of action do people suggest? [idea of co-created platform?]
- Express gratitude to participants, if a gift/benefit-in-kind for participation has been identified as appropriate then this will be shared

Co-development group Data Collection Tools

**Direct Ranking**
**Stakeholder Group**
**Date**
**Topic**



## Fourth Co-development group

<u>5 mins: Introduction about research</u>

This workshop is part of a Doctoral research project at the University of Glasgow. The main purpose of this study is to explore whether people's needs are being met by the humanitarian healthcare being provided in Lebanon today, especially in relation to any changes made by organisations in response to the pandemic, economic collapse and Beirut Blast.

This research is being conducted with both service users and staff in medical aid clinics in Lebanon to discuss how we may be able to work together to improve humanitarian medical care. I want to understand more how people define effective and relevant humanitarian medical care.

This research project will run four workshops, lasting up to 90minutes each, in the coming weeks. You will be asked different questions like ‘can you describe a recent healthcare journey’ ‘can you think of any issues you face in accessing healthcare’ ‘what do you think solutions can look like’? You are invited to all sessions, but if you can only attend today – that’s okay.

Are there any questions?

10 mins: Consent

Create a sharing circle and co-create consent:

I would like to co-create an ethics and consent agreement today, a system of principles and rules that help us determine which actions are right and which are wrong that we can all choose to sign up to (Beauchamp and Childress 1998).

What does ethics mean to us? Can we all share ethical principle that is important to us which we would like to be followed today? For example: doing good *and* doing no harm [go around the room and collect responses]

Ask if everyone in the room signs up to list on paper/wall/whiteboard etc. Ask if everyone in the room is okay for the audio recorder to be turned on

30mins: Final Session: Next Steps

This will be the closing session. The group will co-decide on what final outputs will transpire from these workshops. If tasks transpire from the co-development group, as illustrated in de Brún et al. (2017), make sure that the workload is not burdened on e.g., practice staff. I will encourage tasks to be shared and realistic to manage expectations.

- *Beginning: 10 mins*

Explain workshop and findings so far
Discuss proposed ideas of possible ‘actions’ raised to date

- *Middle: 10 mins*

Create a sharing circle and prompt perceptions and experiences with the questions:
*What would be a solution to the identified issues moving forward?*
*What do you think should/can be done*?

- *End: 10 mins*

Create actionable tasks to identified problems

Extra Activities Towards Close:

- Finalise and revise communications plan with research participants (for those who want to move forward).
- Project M&E; all participants respond to open—ended questions, rapid/interactive. Aim; we all describe experiences in our own words, affirm positives and suggest areas for improvement. Take temperature and build on positives and suggest areas for improvement.
    - **suggest areas for improvement for methodological development** (Is this method relevant? Is there another way that we can answer these questions that make more sense e.g. forms of expression - song, narrative storytelling, or e.g. walking interviews)
- Review confidentiality agreements/Retake consent
- Option to sign up for next session – take contact details for those who want to stay informed about
    - Newsletter/whatsapp group for PhD updates
- Express gratitude to participants, if a gift/benefit-in-kind for participation has been identified as appropriate then this will be shared