# The role of trust in health-seeking for non-communicable disease services in fragile contexts: A cross-country comparative study

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ABSTRACT

Non-communicable diseases (NCDs) disproportionately affect people living in fragile contexts marked by poor governance and health systems struggling to deliver quality services for the benefit of all. This combination can lead to the erosion of trust in the health system, affecting health-seeking behaviours and the ability of individuals to sustain their health. In this cross-country multiple-case study, we analyse the role of trust in health-seeking for NCD services in fragile contexts. Our analysis triangulates multiple data sources, including semi-structured interviews (n = 102) and Group Model Building workshops (n = 8) with individuals affected by NCDs and health providers delivering NCD services. Data were collected in Freetown and Makeni (Sierra Leone), Beirut and Beqaa (Lebanon), and Morazán, Chalatenango and Bajo Lempa (El Salvador) between April 2018 and April 2019. We present a conceptual model depicting key dynamics and feedback loops between contextual factors, institutional, interpersonal and social trust and health-seeking pathways. Our findings signal that firstly, the way health services are delivered and experienced shapes institutional trust in health systems, interpersonal trust in health providers and future health-seeking pathways. Secondly, historical narratives about public institutions and state authorities' responses to contextual fragility drivers impact institutional trust and utilisation of services from public health institutions. Thirdly, social trust mediates health-seeking behaviour through social bonds and links between health systems and individuals affected by NCDs. Given the repeated and sustained utilisation of health services required with these chronic diseases, (re)building and maintaining trust in public health institutions and providers is a crucial task in fragile contexts. This requires interventions at community, district and national levels, with a key focus on promoting links and mutual accountability between health systems and communities affected by NCDs.

## 1. Introduction

Non-communicable diseases (NCDs) are the leading cause of global deaths and ill health, contributing to over 73% of all-cause global mortality annually (WHO, 2018). Each year, 15 million people between the ages of 30 and 69 die prematurely from NCDs, with over 85% of these deaths occurring in low- and middle-income countries (LMICs) (WHO, 2018). As part of the 2030 Agenda for Sustainable Development (UN, 2015), governments have committed to developing national responses to reduce premature mortality from NCDs by a third by 2030 through better NCD management (SDG target 3.4). The progress towards meeting these objectives has been slow, especially in contexts affected by fragility (Atun et al., 2013).

Fragility is a multidimensional concept encompassing political, economic, security, environmental and societal risks and insufficient coping capacity by the state, system or communities to manage, absorb or mitigate these risks (OECD, 2020). In fragile contexts, public institutions often lack the capability, willingness and/or resources to address fragility drivers (e.g., economic crisis, civil unrest, armed conflict, disease outbreaks), which tend to manifest dynamically over time destabilising settings and communities (OECD, 2018). Fragility, therefore, leaves populations vulnerable to a range of threats, e.g., poverty, insecurity, health and economic inequalities (OECD, 2020). Experiences of these threats often lead to a decline in legitimising interactions and

the erosion of trust between populations and public institutions, including health systems, with critical implications for health-seeking and individuals' ability to sustain health and wellbeing (Diaconu et al., 2020).

To better understand the dynamics of the relationship between health systems and communities in fragile contexts, researchers have in recent years increasingly turned towards the construct of trust − a key locus of fragility (Blödt et al., 2021; Diaconu et al., 2020; Kittelsen and Keating, 2019). Trust is commonly defined as an individual's expectation for the other party to act in their best interest (Gilson, 2003). Trust in health systems matters as systems are inherently relational (Gilson, 2005). Institutional rationalist trust models, dominating health systems literature, postulate that trust in the health system is contingent upon the system *"perfor[ming] its expected delivery functions"* (Russell, 2005, p.1397). Trust, therefore, is built and sustained through consistent, positive exposure to, and encounters with, health systems (Gilson, 2003; Russell, 2005). Yet, such conceptual underpinnings of trust have not been without their critiques. Kittelsen and Keating (2019) argue that institutional rationalist models of trust assume that (1) health systems remain constant and unaffected by contextual circumstances; and (2) the perception of trustworthiness in health systems is generalisable to all possible interactions: *"X simply trusts Y to deliver Z at level t"* which might not hold true in fragile contexts experiencing crises. Further, mounting evidence suggests that higher levels of trust in health systems are associated with increased healthcare access, improved health-seeking behaviour, treatment adherence, continuity of care and self-reported health status (Anand and Kutty, 2015; Law et al., 2019; Ward, 2017). While trust is an important driver of individuals' health-seeking behaviour, it has increasingly been argued that the dynamics underlying how trust is developed, maintained, and lost over time, and its links to outcomes are poorly understood, requiring further theoretical engagement (Gille et al., 2015; Kittelsen and Keating, 2019).

Across the literature (Lynn-McHale and Deatrick, 2000), there is broad agreement that trust is a dynamic, intangible process based on mutual intention, reciprocity and expectations. Lewis and Weigert (2012) distinguish the cognitive, emotional and behavioural aspects of trust. The interplay of these dimensions results in the level of trust individuals' place in their social connections, known as social trust, and organisations, described as institutional trust (Mohseni and Lindstrom, 2007). To initiate health-seeking from public health institutions, there should be trust in the health system – institutional trust (Luhmann, 2000). Accessibility (geographical and financial), care quality and performance indicators, licencing of primary care centres and health providers (nurses, doctors) are all pre-requisites for ensuring and maintaining institutional trust (Mechanic and Meyer, 2000). Lyon et al. (2015), for instance, compare the ways in which individuals access public, private or alternative care as a measure of how much individuals trust public health institutions. Choosing to access private healthcare at a greater cost might reflect a degree of *mis*trust in public health institutions (Lyon et al., 2015). Others focus on individuals' perceptions of healthcare providers' communication style, reliability and technical competencies as indicators of trust in public health providers – interpersonal trust (Anand and Kutty, 2015; Topp and Chipukuma, 2016). Healthcare relationships between patients, their family members and health providers, and experiences of care can affect interpersonal trust, which can either strengthen or weaken institutional trust (Luhmann, 2000). Ozawa and Sripad (2013), however, argue that an exploration of trust in health systems should go beyond the health provider-patient relationship and consider the health system more holistically, including beliefs in policies and processes regulating systems. Further, socio-cultural contexts, including the historical and political narratives, should not be excluded from exploring health systems but considered as constitutive elements thereof (Sheikh et al., 2014).

The relationships between trust in health systems and health-seeking in fragile contexts are complex and remain poorly explored (Ager et al., 2019). In this respect, there is a notable scarcity of evidence particularly in relation to NCDs, which require continuity of care for better management and control (Ager et al., 2019). Building on Kittelsen and Keating (2019) critique and considerations put forward by Ozawa and Sripad (2013) and Sheikh et al. (2014), we conducted this study to analyse the role of trust in health-seeking behaviour for NCD services drawing on work completed in three fragile contexts. The study sought to contribute to the understanding of (a) how trust in health systems can be lost, or indeed built and maintained in fragile contexts; and (b) the role of contextual factors (e.g., social structures, cultural values and norms) and the resources embedded within them that can be drawn upon to promote health-seeking behaviour for NCD services in these contexts.

## 2. Methods

Our analysis stems from broader research focusing on the strengthening of primary healthcare provision for NCDs, predominantly cardiovascular diseases and diabetes, in three fragile contexts: Sierra Leone, Lebanon and El Salvador. During qualitative work in each context, trust inductively emerged as an important theme to consider – often with diverse presentations across the contexts. Thus, we conducted a multiple-case study analysis to more deeply consider the role of trust in the health-seeking behaviour of individuals and communities affected by NCDs. The multiple-case study approach is well-fitted for this purpose as it is often used to explore and gain a deep understanding of complex constructs by drawing on multiple data sources to ensure rigour and credibility of the themes emerging from the analysis (Yin, 2002).

### 2.1. Data sources

Qualitative data were collected in Freetown and Makeni (Sierra Leone), Beirut and Beqaa (Lebanon), and Morazán, Chalatenango and Bajo Lempa (El Salvador) between April 2018 and April 2019. In each context, semi-structured interviews were conducted with (a) health providers (health managers, specialist physicians, general practitioners, nurses) to explore the delivery of NCD services and capacities of the health system to tackle NCDs, and (b) individuals affected by NCDs to elicit help and health-seeking pathways for NCDs (Table 1). Group Model Building (GMB) workshops were held in Sierra Leone and Lebanon with community members affected by NCDs and health providers to create causal loop diagrams (CLDs) on health-seeking for NCDs and contextual factors impacting health-seeking patterns. GMB workshops were structured to allow consideration of variation by gender, setting (urban vs. rural) and participant characteristics (community members vs. health workers), and facilitated triangulation of evidence from thematic interview analysis. Participants were engaged in producing 'rich pictures' and developing incipient models on their perceptions of NCD causes, symptoms and health-seeking behaviours. Incipient models were analysed by the wider research teams, inductively identifying themes related to health-seeking in each context and its relations with social and structural contextual factors. This was followed by the abstraction of key themes and mechanisms explaining health-seeking pathways for NCDs (Idriss et al., 2020; Witter et al., 2020; Zablith et al., 2021).

### 2.2. Participant eligibility and recruitment

In Lebanon and Sierra Leone, participants of interviews and GMB workshops included (i) diverse gender- and age-balanced groups of community members, including Syrian refugees in Lebanon, and (ii) health providers recruited through purposive, convenience and snowball sampling techniques. Community members affected by NCDs (aged >18) and/or their carers as well as health providers involved in NCD care delivery were eligible to participate in both interviews and GMB workshops. We set no formal eligibility criteria based on the type of NCD experienced. Healthcare staff and local leaders were contacted for

**Table 1**
Methods of data collection and participant characteristics.

| Data collection | Fragile contexts | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Sierra Leone | | | | Lebanon | | | | El Salvador | | | |
| **Site** | | | | | | | | | | | | |
| Urban | Freetown | | | | Beirut | | | | Morazán, Chalatenango | | | |
| Rural | Makeni | | | | Beqaa | | | | Bajo Lempa | | | |
| **Period** | April–September 2018 | | | | February–April 2019 | | | | June 2018 | | | |
| | Total | M | F | Age (range) | Total | M | F | Age (range) | Total | M | F | Age (range) |
| **Method** | | | | | | | | | | | | |
| **Semi-structured interviews** | | | | | | | | | | | | |
| Community members with NCD/carers | | | | | 21 | 9 | 12 | 23–60 | 14 | 4 | 10 | 44–64 |
| Syrian Refugees with NCD/carers | | | | | 20 | 7 | 13 | 30–60 | | | | |
| Health providers | 12 | 7 | 5 | | 23 | 10 | 13 | | 12 | 7 | 5 | |
| Total | 12 | | | | 64 | | | | 26 | | | |
| **Group Model Building workshops** | | | | | | | | | | | | |
| Community members with NCD/carers | 71 | 35 | 36 | 24–60 | 12 | 5 | 7 | 20–50 | | | | |
| Syrian Refugees with NCD/carers | | | | | 15 | 2 | 13 | 24–55 | | | | |
| Health providers | 59 | 26 | 33 | | 10 | 5 | 5 | | | | | |
| Total | 5 | | | | 3 | | | | | | | |

Note. M-male; F-female.

recommendations and mobilisation of community members. In El Salvador, individuals with NCDs (aged >35) receiving care from primary health care centres (PHCCs) as well as health providers involved in NCD care delivery were eligible for interviews. Health coordinators at the PHCCs were asked to recommend potential staff members and individuals with an NCD who would be interested in participating. Methods of data collection and participant characteristics are summarised in Table 1.

*2.3. Data analysis*

Our analysis drew on contextual data extracted from national and international reports, interview transcripts, field notes, and assessment of CLDs from urban and rural sites of Sierra Leone and Lebanon. Three researchers with expertise in health and social sciences (SA, KJ, AD) used a deductive approach to code interview data and field notes. The pre-specified themes used in the coding process were the accessibility of services, the affordability of services, the perceived quality of services, quality of patient-provider interactions and informal social interactions and relationships. These themes are posited as pre-requisites for institutional, interpersonal and social trust in the previous literature looking at trust in health systems and a wider role of social capital in help-seeking behaviour (Anand and Kutty, 2015; Lewis and Weigert, 2012; Luhmann, 2000; Lyon et al., 2015; Mechanic and Meyer, 2000; Ozawa and Sripad, 2013; Topp and Chipukuma, 2016). Data were then triangulated with eight CLDs developed by a wider research team (KD, SW, AA, IBO) during GMB workshops in Sierra Leone and Lebanon (Idriss et al., 2020; Witter et al., 2020; Zablith et al., 2021)). Complemented by contextual data extracted from official reports, the findings for each context are presented in case summaries. Each case summary reports on: (1) institutional and social fragility features; (2) the study setting; (3) pathways of health-seeking for NCD services, including the evidence on informal social connections and embedded resources individuals accessed and placed trust in when seeking for help.

Based on consolidated findings from case summaries, three researchers (SA, KJ, AD) first created an incipient conceptual model. The model depicted how contextual manifestations of fragility and state capacities and responses to these impacted service delivery and utilisation experiences, in turn shaping institutional, interpersonal and social trust and future health-seeking pathways. Following group discussions with researchers involved in primary data collection and CLDs development, SA, KJ, AD and KD further abstracted key dynamics and feedback loops between focal themes and three forms of trust. The conceptual models were developed and refined using Vensim software (Ventana, 2020).

*2.4. Ethical considerations*

Ethics approval for studies was granted by the Ethics and Scientific Review Committee of the College of Medicine and Allied Health Sciences, University of Sierra Leone and the Sierra Leone Ethics and Scientific Review Committee at the Ministry of Health and Sanitation of Sierra Leone; American University Beirut Ethical Review Committee; the National Health Ethics Committee of El Salvador and Queen Margaret University Ethical Review Committee.

**3. Case summaries**

*3.1. Sierra Leone*

*3.1.1. Contextual features*

As a low-income country in West Africa with a population of over seven million (Statistics Sierra Leone, 2017), Sierra Leone is officially classified as a fragile state (Fragile States Index, 2017), ranking 180 out of 187 countries in Human Development Index (UNDP, 2020). After a long-lasting civil war (1991–2002), the country has been facing multiple development challenges, including poor governance, high unemployment rates, and a lack of human and material resources (Trosclair, 2017). Sierra Leone remains among the world's poorest nations, where 60% of the population lives below the national poverty line (World Bank, 2019a).

NCDs present an increasing burden to the health system, accounting for 33% of all deaths, with cardiovascular disease (CVD), cancer and diabetes representing 14%, 3% and 2% respectively (WHO, 2018). The fragile health system is still recovering from the 2014 deadly Ebola epidemic, which quickly overwhelmed the system already struggling to cater for the healthcare needs of the population (Wurie et al., 2016). Due to historical underfunding of NCD services at the primary care level, NCDs are largely managed at secondary or tertiary levels (Samba et al., 2017). Further, no dedicated funding and national guidelines are in place to effectively manage NCDs (Idriss et al., 2020). Although the Package of Essential NCD interventions (WHO, 2015) was integrated into the care packages offered at the national level, this has not been implemented consistently (Idriss et al., 2020)). A small proportion of vulnerable communities periodically benefit from receiving NCD care and medication supplied by humanitarian organisations; however, this is not commonplace (WHO, 2014).

*3.1.2. Study setting*

The chosen settings differed in fragility levels, particularly in the domains of delivery of services and community dynamics. Freetown is

S. Arakelyan et al.

Social Science & Medicine 291 (2021) 114473

the capital of Sierra Leone located in the Western Area district with a population of over a million (Statistics Sierra Leone, 2017). It is a major urban, economic, financial, cultural and educational centre of Sierra Leone. Communities living in Freetown have relatively better access to public services, including health, education and employment. Makeni is a provincial town in Bombali District in the northern province of Sierra Leone. Makeni has high poverty rates and is highly influenced by traditional practices (Idriss et al., 2020).

### 3.1.3. Health-seeking pathways for individuals affected by NCDs

Across both urban and rural settings, participants, who had predominantly hypertension and type 2 diabetes, discussed triggers for health-seeking in relation to episodes of exacerbation of symptoms or severe complications that could no longer be ignored. When displaying acute worsening of NCD symptoms, participants sought advice and support from trusted family members, friends, local community and religious leaders. These social networks helped participants navigate the uncertainties of health-seeking for NCD services, offering emotional support and assistance in deciding on pathways of NCD care:

"Counselling [as in receiving advice] by family and community members can help, even without drugs". (NCD patient, GMB)

During GMB sessions, when probed to identify influences on health-seeking for NCDs, participants identified trust in providers and socio-culturally constructed beliefs as important influences.

"Trust and beliefs drive you where to seek help from". (NCD patient, GMB)

Participants described health-seeking practices which could alleviate symptoms and/or prevent further exacerbations of these influenced by personal trust and beliefs about the nature and causation of chronic conditions. Descriptions of coping strategies with NCDs involved ritualistic, spiritual or religious practices, e.g., seeking help from the water goddess, reading Bible or Quran, praying at specific trees or rocks.

Rural communities in particular shared beliefs that hypertension, diabetes and cancer could be caused by evil spirits or witchcraft; therefore, "… visiting shrines, oracles, idols …" or "… seeing magicians who use the abracadabra …", as some of the GMB participants described them, can help bewitch the spell caster and alleviate NCD symptoms. Additionally, families, neighbours and community leaders often advised and supported individuals to seek affordable "quick fixes" for acute NCD symptoms from trusted informal traditional or religious providers, e.g., herbalists, Moray men and/or Alpha men, Yabai women. Affected individuals noted they accessed public health institutions only if no improvements in symptoms were observed.

When prompted to reflect on the barriers to health-seeking from public institutions, participants agreed that service access, affordability, staff and medication shortages were key. GMB discussions (Supplementary Material A) highlighted how poor provider-community relationships, time-consuming travel to PHCCs where staff may be absent and diagnostic tests and medicines could be unavailable undermined trust in this pathway.

Health-seeking from traditional healers and informal drug peddlers, who prescribe medicine and other pharmaceuticals despite not being officially recognised and regulated by the health system, was often the health-seeking pathway of choice for participants (Supplementary Material B). This choice reflected both uncertainties in the likely availability of services at public health institutions and community sources of social trust in informal providers. GMBs confirmed that seeking access to care from informal providers was not motivated principally by cost (with vivid accounts of costly treatments) but by accessibility and strong social convention in having faith in such local resources.

Health providers agreed that quality of care at PHCCs was often poor, also citing issues of affordability, a poorly distributed health workforce and limited medication and diagnostic supplies:

"Many people cannot afford NCD care, and affordability of medication affects adherence". (Health provider, interview)

"Not all facilities have a glucometer. Supply of medicines is not consistent all year, it stops sometimes. So, we give the patient a prescription, and he needs to go and buy the medicines himself". (Health provider, interview)

Despite these shortcomings, during GMB discussions both health providers and NCD affected community members agreed that public institutions potentially offered better quality NCD care than informal and traditional providers, though accessibility and availability of services eroded confidence in this provision.

### 3.2. Lebanon

#### 3.2.1. Contextual features

Lebanon is a middle-income country in the Middle East with approximately six million people (EU, 2018). Over decades, Lebanon has experienced chronic political instability, sectarian division and recurring civil unrest, affecting the country's ability to maintain order and security, and develop equitable policies (Ammar et al., 2016; EU, 2018). These have been compounded by ongoing instability in the region, an influx of displaced populations, a decrease in foreign investment and an increase in public deficit (UN, 2019). The World Bank characterises Lebanon as a setting exhibiting high institutional and social fragility (World Bank, 2020).

NCDs are a leading cause of mortality and disability in Lebanon, with 91% of all-cause deaths attributed to NCDs (WHO, 2018). CVDs and cancer make the largest contributions to NCD-associated mortality, with 47% and 16% each. Despite the introduction of the National NCD Prevention and Control Plan (2014–2020) in 2016, many contextual fragility risks have impeded its endorsement and implementation. These include economic and humanitarian crises and the absence of a dedicated governance structure empowered to coordinate various activities and stakeholders involved in national NCD response (Adib et al., 2014). More, the health system in Lebanon is highly fragmented, characterised by a dominant private sector and a strong civil society sector. Half of the population has health insurance covered by six social insurance funds under different governmental bodies (Ammar et al., 2016), providing health insurance coverage with patient co-payments for accessing services mainly in the private sector. The remaining half is entitled to the health coverage of the Ministry of Public Health (MoPH), but only for secondary care. Civil society organisations (religious, charitable or community groups), meanwhile, own and operate approximately 68% of PHCCs (UN, 2019). These organisations provide NCD services of varied quality to the vulnerable and socially disadvantaged (Ammar et al., 2016). Refugee populations registered with the UNHCR are given free access to health services at PHCCs and urgent secondary care through support from humanitarian organisations, the MoPH and the Ministry of Social Affairs (UN, 2019).

#### 3.2.2. Study setting

The two settings were purposively selected to reflect sites with contrasting fragility profiles. Beirut is the capital and main urban centre of Lebanon with a population of over 2 million, including 206,628 Syrians and 17,486 Palestinians (UN, 2019). Poverty rates are the lowest in Beirut, attracting relatively wealthier Syrian refugees. The capital benefits from the highest concentration of health services, including specialised secondary and tertiary care services. Beqaa is predominantly a rural region, hosting a high proportion of the Syrian refugees (36%) living in tented settlements (UN, 2019). The refugee influx has resulted in an unprecedented increase in demand for under-resourced health and social services in Beqaa, putting considerable strain on the provision of services for both Lebanese and refugee populations.

### 3.2.3. Health-seeking pathways for individuals affected by NCDs

Across GMB workshops and interviews, participants, primarily suffering from hypertension and type 2 diabetes, discussed health-seeking initiation in relation to managing the effects of disease-associated complications. Although health-seeking from formal health institutions was common, the cost of care was a central barrier, especially for Lebanese community members without health insurance coverage. Gaps in health coverage for Syrian refugees were also noted, specifically for cancer care, with patients being compelled to seek care at the secondary level with higher out-of-pocket expenditures.

When prompted to reflect on trust levels in health providers and public institutions, participants talked about profit-driven attitudes of providers as a contributor:

"People do not trust all doctors. As for the healthcare system, they do not trust it at all. Lebanon however is known to have the best doctors in the world. Most doctors specialised in the US or France. The problem is that they [health providers] view patients as sources of money, so there is no humanity in dealing with patients. (Lebanese community member, interview)

While community members who did not experience financial constraints sought care from private clinics, the majority grappled with exceedingly high costs:

"I think there is first a financial obstacle. Every doctor you might go to asks for a $50 consultation fee. Not everyone can afford that. The Ministry of Health does not cover everything, and some hospitals do not admit you unless you have insurance. Some people wait until they get paid by the beginning of the month". (Lebanese NCD patient, interview; Zablith et al., 2021, p.7)

The cumulative cost of repeated utilisation of private services was high, at times resulting in patients dropping out of care entirely. Lebanese community members who had compromised trust in public health institutions or could not afford care from private hospitals looked for alternative health-seeking pathways. The most commonly noted sources of health-seeking for both Lebanese and Syrians were local pharmacists, perceived as both affordable and trusted:

"I do not believe in medical centres here. You need to be almost a beggar to go there. We do not go there." (Lebanese community member, interview)

"They usually go to the pharmacy first … It's because they would save on doctor's fees. So, they go straight to the pharmacist and get diagnosed and tested there". (Lebanese community member, interview; Zablith et al., 2021, p.7)

"What I hear is that refugees only go to the pharmacist. They don't go to the doctor's. They take antibiotics and hypertension medication without prescriptions. Because they don't have money; it is easier that way". (Health provider, interview)

The lack of comprehensive health insurance coverage, along with the financial hardship experienced by Lebanese when accessing services, were linked by all study participants to issues in political governance including corruption within governmental structures. These ultimately led to economic stagnation and the persistent underfunding of public health and social welfare systems. Participants perceived that the state authority and the health system were not geared towards protecting citizens' best interests. In this way, wider issues around affordability and social protection appeared to contribute to the compromised trust in public authority:

"The most important thing is work through social security and ministries. For example, I was recently fired. I used to work for [a private company] for 28 years. I had both social security and insurance but now, I can afford neither social security, nor insurance.

Work is really slow now, and I have instalments to pay to the bank. If anything happens to me, I would have to rely on my siblings, but they all have their own issues to handle. After working for 28 years, you end up with no social security or even a pension. There is nothing! I just hope that I do not get sick." (Lebanese community member, interview)

"You are discussing things that need good governance. There is no government, everyone steals from people. I am not going to tell you that the minister has been doing a good job. His work is not good …. The system in Lebanon is so corrupt, and if anyone from civil society tries to do something, they fight them". (Health provider, interview; Zablith et al., 2021, p.5)

When prompted to reflect on the quality of NCD care, community members discussed sub-optimal experiences in relation to the availability of essential medication, diagnostic equipment, routine testing and provider attitude and impartiality, which compromised their trust in public institutions:

"Here in the Beqaa, not everyone trusts the hospitals, so they go to Beirut directly". (Lebanese community member, interview; Zablith et al., 2021, p.8)

"We cannot say that the services are not available. They are just not up to people's expectations". (Lebanese community member, interview)

Quality of care was perceived to be better in hospitals or private clinics in Beirut as those were equipped with a better trained health workforce, essential medication, diagnostic equipment and technology.

"Well, most people who are of the rich class here go to Beirut because they trust the big [university or research] hospitals …. Doctors who graduate and work in the Beqaa do not update their information much". (Health provider, interview; Zablith et al., 2021, p.8)

Expanding on the health providers' reflections, Syrian refugees cited criteria such as patient load, consultation times and friendliness of health provider communication as influencing their perception of the quality of NCD services and, therefore, future health-seeking:

"Not all doctors give their patients advice. There is a lack of care for the patient. There is negligence … Sometimes, they only want to get rid of the patient. So, they don't give them enough time, talk to them, give them the right medication, and they don't explain things". (Syrian refugee, interview)

"The problem is about the doctors' upbringing and ethics. Sometimes you see very ethical doctors. Other times doctors ask you for upfront fees even if you have social security. This becomes very materialistic". (Lebanese community member, interview)

Social connections' experiences of the quality of care when accessing PHCCs additionally influenced participants' trust levels and future health-seeking pathways. Participants, however, acknowledged that drastic health improvements were not commonplace due to the dysfunctional referral system and compromised continuity of care essential for the effective management of NCDs.

### 3.3. El Salvador

#### 3.3.1. Contextual features

A middle-income country in Central America with a population of over six million people (World Bank, 2019b), El Salvador has for decades been witnessing civil unrest, violence and an ongoing armed conflict between local gangs ("maras"), leading to displacement and thousands of deaths every year. A country with one of the highest homicide rates in the world (Amnesty International, 2019), El Salvador is not on a list of officially recognised fragile states despite being increasingly recognised

as "the deadliest country" in the world outside a war zone (Branu, 2016).

NCDs are the main cause of premature mortality among ageing populations, accounting for 74% of all-cause deaths (WHO, 2018). Cardiovascular diseases and cancer are estimated to account for 23% and 16% of total deaths registered nationwide (WHO, 2018). Since 2009, when a new left-wing political party came to power, the Ministry of Health in El Salvador has been implementing the Health System Reform (HSR). The HSR is based on the Comprehensive Primary Health Care (CPHC) principles - the right to health with equity and solidarity through quality health care provision at the point of delivery (Ministry of Health of El Salvador, 2009). Health insurance coverage was expanded by increasing the number of PHCC and community family health teams, especially in rural and poor municipalities (MoH, 2009). This significantly improved access to, and utilisation of, NCD services, particularly amongst the vulnerable residing in remote and/or rural areas (PAHO, 2012). The HSR has been promoting the strengthening of community organisations and facilitating their participation in health decision-making processes through participatory mechanisms of the National Health Forum (NHF) (PAHO, 2012). The NHF, a social movement that grew out of years of social mobilisation due to prolonged war and social violence, was integrated into the HSR to collaborate and co-govern with the Salvadoran Ministry of Health. Since then, it has succeeded in developing and implementing strategies promoting equity, quality, social inclusion and the population's right to health (PAHO, 2012).

### 3.3.2. Study setting

The three sites were contrasting fragility settings selected from three different departments of El Salvador. Morazán is an urban setting located in the northeast part of El Salvador and has a population of approximately 200,000. People residing here have higher literacy and employment rates, better access to social services and lower poverty rates (Binford, 2010). Chalatenango is a small urban area in the Chalatenango department. Historically, this department has been marginalised from public health and social policies, contributing to communities' mobilisation and collective actions to tackle emergent health issues. Bajo Lemp is a rural setting located within the Usulutan department. The region is marked by high poverty rates (Mejía et al., 2014). These sites were selected considering socio-economic, historical and geographic disparities between them and potential security issues during fieldwork in El Salvador.

### 3.3.3. Health-seeking pathways for individuals affected by NCDs

Study participants with heart disease, type 2 diabetes and chronic kidney disease described health-seeking from PHCCs initiated by the early onset of NCD symptoms (e.g., fatigue, chest pain, mood swings). Participants felt high level of trust in public health institutions and health providers contributing to the increased utilisation of services from PHCCs following the 2009 HSR. Immediacy of services, i.e., local availability, accessibility and affordability of services, brought by the reform may have played a role in this.

"Well, the opening of the health unit in our community has been a great achievement really. This health unit did not exist in the past [before the reform]. It has been a blessing, right, it has helped all of us". (NCD patient, interview)

"Now [following the reform], all the medicines and consultations are free. You pay only in the private clinics. I cannot say that in health units they are charging for the treatment because it is a lie. This was achieved with the marches. I can see now that patients leave health units with lots of medicines". (NCD patient, interview)

"I trust my doctor here [health unit] and thank God, she is a good doctor. Since she has been seeing me, I cannot complain about anything. Also, here [ health unit] I do not have to buy the medicines". (NCD patient, interview)

"Look, during previous two governments, the consultations should have been paid in full – both for children and adults. That was an issue; now it is suspended, and it is mainly free". (NCD patient interview)

Socio-economically secure participants also described health-seeking from private clinics for chronic conditions requiring special diagnostic equipment. In rare cases, participants sought care from informal health providers (i.e., herbalists or naturalists) as a source of continuity of NCD care once formally diagnosed.

Health providers highlighted the central role of health promoters and community organisations in identifying patients at risk of NCDs and linking them with local public health services.

"We work in a network; this means that each Community Family Health teams are connected with the Community Health team specialised within the area as well as with community organisations in order to properly approach the real needs of the population". (Health provider, interview; Jimenez Carrillo et al., 2020, p.6)

Local community organisations created spaces where community members felt safe to share their experiences of NCDs and receive information and counselling about NCD care and clinical outcomes:

"A group for elderly chronically ill patients was established in my area. A doctor comes every month with great enthusiasm to help elderly patients. He gives a talk every month, and we make plans together. Also, in Santa María hospital, if it is maintained, meetings are held on last Thursday of each month; they [health providers] hold discussions with chronic patients there as well". (NCD patient, interview)

"For the daily support for people with a chronic disease like me, it is nice that we all get together in these groups where we learn more about our disease. It allows us to give each other advice and learn to survive in the best way with a specific chronic health problem …". (NCD patient, interview; Jimenez Carrillo et al., 2020, p.13)

In areas where local community organisations were absent, participants cited fear of gangs and street violence as undermining their willingness to trust and seek help from others outside their household, including public health institutions. Meanwhile, in areas where local organisations were active, participants felt empowered and equipped to better respond to their NCD needs:

"Thankfully, we are part of an organised community; because of this, we formed an association. And in that association, we were able to get professional support. So, we had to form our own groups in order to mutually help each other." (NCD patient, interview; Vidal et al., 2020, p.11)

Participants had a positive perception regarding the quality of offered services, waiting times, health workers' attitude and communication skills once diagnosed with NCDs:

"The care in the health unit is good; they treat us well. The waiting time depends on the order of arrival. If they had more dialysis machines it would been better". (NCD patient, interview)

"The information I received was good because they explained what my disease was and how to take the medicine. Everything is fine. They always try to assure us that we understand everything correctly". (NCD patient, interview; Jimenez Carrillo et al., 2020, p.10)

"I explain them [patients] the medications and their schedules. I indicate how they are going to take them. I also ask them to repeat what I have just told them to check that they have understood correctly." (Health provider, interview).

Health providers cited persistent issues with the referral systems that lacked a strong coordination across the different levels of care. They, however, conceded that services had been improving since the health reform, giving patients a more comprehensive response to managing NCDs. Health providers saw a value in feedback mechanism established between health units and communities.

"Since the reform, we have more health specialists, laboratories and better medicine supply in pharmacies; we have more diagnostic tests". (Health provider, interview)

"The new reform is trying to ensure that all patients have the best care in the shortest time possible. For instance, if chronically ill patient needs to see a doctor and a psychologist or a physiotherapist, we make sure that they see all specialists on the same day, especially those who come from far." (Health provider, interview).

"They [local communities] have these spaces in a health unit or community assembly to voice impending problems and difficulties they had when visiting health units. They show us things we do not do well … They show how to improve or coordinate with them a particular situation to better support them." (Health provider, interview)

## 4. Discussion

In this cross-country comparative study, we drew on multiple sources of evidence to explore the role of trust in health-seeking behaviours for NCD services in fragile contexts. We found that institutional rationalist models of trust, arguing that trust in health systems is determined by consistent, positive exposure to health services, held true across three fragile contexts. However, building on the critique of the rational approach to trust in fragile contexts by Kittelsen and Keating (2019), we also identified the important role of contextual changes, historical narratives, social bonds and links with the health system in shaping trust and health-seeking pathways for health services.

To put these observations into context, in Lebanon and El Salvador, we found that important drivers of institutional trust appear to arise from contextual political changes or a shift in the existing political narratives. More specifically, persistent political and economic crises, poor political governance and a lack of essential services provision in Lebanon, and the change in governing political party followed by an immediate launch of the 2009 HSR in El Salvador shifted the landscape of perceptions of institutional trust in a substantial way. These effects, however, were conditioned and filtered through personal circumstances, socio-culturally constructed perceptions and past experiences with accessing health services. Vulnerable and socially disadvantaged communities in Lebanon lacked trust in public institutions and health providers largely due to a lack of geographic and financial accessibility to quality NCD services and sub-optimal experiences with accessing services at PHCCs. Underlying the accounts of participants from Lebanon, we identified a narrative wherein the expectations placed by individuals and their social connections on public institutions to provide accessible, affordable, effective and good quality NCD care were not met, resulting in health-seeking from alternative sources - private hospital care or local community pharmacists (if unable to afford private care).

Accounts of participants from El Salvador, by contrast, suggested improved institutional trust and interpersonal trust facilitated to some extent by improved accessibility (both geographic and financial) and quality of NCD services at community-based health units and centres in both urban and rural settlements following the HSR. Additionally, here trust was gradually regained through participatory mechanisms of local community organisations such as through the NHF, which has been facilitating communities' empowerment, engagement in health decision-making and links with community health services. Participants coming from communities with social organisation reported improved

social trust and perceived feelings of safety and security. Trust here partially developed as a product of emotional safety and security – critical to address in contexts of ongoing violence and conflict.

In the case of Sierra Leone, we found that historical resource constraints and wider systematic challenges, driven predominantly by a decade-long civil war and Ebola outbreak, contributed to communities' persistent exposure to under-resourced and under-equipped NCD services. Similar to Lebanon, health-seeking from public institutions in urban sites was shaped by trust and the perceived effectiveness of services, resting largely on past experiences and associated access costs. In rural areas, 'traditional' socio-cultural beliefs, norms and practices around NCDs influenced decisions and choices of health-seeking behaviour. Communities in Sierra Leone placed higher social trust in their informal social connections and resources available to them, which helped individuals navigate through the diversity of health-seeking pathways.

Fig. 1 presents a conceptual model depicting the interplay between contextual fragility, three forms of trust and health-seeking pathways for NCDs. Our findings signal that firstly, the way health services are delivered and experienced shapes institutional and interpersonal trust and future health-seeking pathways in fragile contexts. If institutional arrangements are not in place to deliver accessible, affordable, effective, quality NCD services that ensure positive experiences, health status improvements and financial risk protection from catastrophic health expenditures, institutional and interpersonal trust, and, therefore, utilisation of NCD services will be compromised. These findings are affirmed in a study by Rockers et al. (2012) which established a direct association between health systems performance factors (quality, responsiveness, fair treatment, financial risk protection) and trust in public health institutions in 38 LMICs.

Secondly, service delivery is just one aspect shaping institutional and interpersonal trust. Historical narratives about public institutions and state authorities' responses to contextual fragility drivers (political, economic, security, environmental and societal risks) impact broader institutional trust and utilisation of services from institutions it represents. Similar trends have been reported by Nixon and Mallett (2017) who looked at service delivery and public perceptions of state's legitimacy in low resource settings. Thirdly, social trust can facilitate health-seeking behaviours through bonds and links with health services but similarly may act to constrain the choices of individuals towards one type of provider or another.

### 4.1. Implications for practice and policy

NCDs are chronic illnesses requiring repeated and sustained utilisation of health services. This assumes repeated interactions with public health institutions where communities affected with NCDs have the opportunity to explore all necessary means to trust or distrust the system. Individuals with compromised institutional and interpersonal trust are less likely to utilise services and follow the advice or recommendations of health providers. They are more likely to look for alternative care options that are often costlier and less sustainable, eventually resulting in poor health outcomes (Mohseni and Lindstrom, 2007; Radin, 2013). Understanding, restoring and maintaining trust in public health institutions and providers is thus essential for better management and control of NCDs in fragile contexts.

Building and maintaining institutional and interpersonal trust in fragile contexts is a complex undertaking. There is also a lack of evidence of what the primary targets of trust-building interventions should be. Meyer et al. (2008), for instance, argues that institutional trust is built on and predetermined by interpersonal trust - an outcome of interpersonal interactions which influences decisions about future interactions (Luhmann, 2000). Mistrust predominantly starts from interactions with the people who represent the system (Meyer et al., 2008), in this case, health providers. The evidence further suggests that interpersonal trust in health providers can be facilitated through
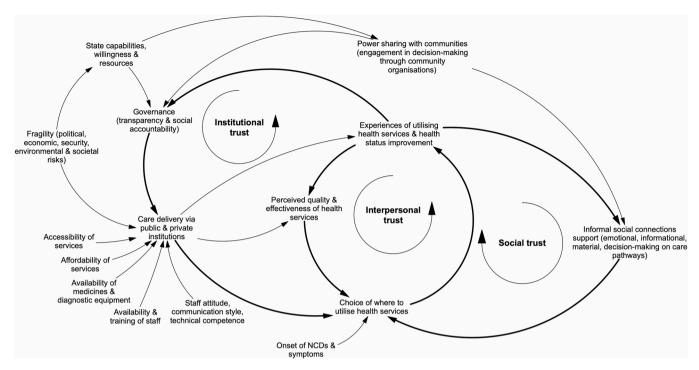
**Fig. 1.** Conceptual model depicting the interplay between contextual factors, trust and health-seeking pathways for NCDs in fragile contexts.

person-centred care – an open, equal, interactive and enabling process of dialogue between providers and patients, all of which result in positive patient experiences and health outcomes (Anand and Kutty, 2015; Gilson, 2005). Delivering care in a person-centred way implies recognising individuals' capabilities and potential to manage and improve their own health by providing the knowledge, confidence and skills to do so.

Health providers, however, do not act in a social vacuum; they are embedded in health systems which are public institutions reflecting national priorities and values (Gilson, 2003). Public authorities play a central role in ensuring effective and efficient functioning of health systems by setting up and regulating training and deployment of the health workforce; financing and structuring health services; legislating and enforcing national guidelines and regulations. Health systems and health providers' performance is intrinsically associated with good governance (Rockers et al., 2012), emphasising the need for consistent investment in health systems and good governance in improving trust in authority and the institutions it represents (Risse, 2012).

Guided by findings of our case studies and literature, restoring and protecting institutional and interpersonal trust in health providers will require interventions in multiple interlinked systems. At a community level, access to essential person-centred NCD services should be facilitated. Here, we view access as individuals, especially vulnerable and socially disadvantaged, being able to identify their health needs, seek health services, reach affordable person-centred care resources and obtain NCD services responsive to their needs.

Given fragility is dynamic, and at any time, countries can move from chronic into acute fragility situations where access to health services can be acutely compromised, we further stress the importance of health services being tailored to promote patient self-management approaches (Hearn et al., 2019). To be effective, self-management, education and empowerment approaches should be designed and delivered with a good understanding of the cultural beliefs of affected communities and in close collaboration with local community organisations. These might not be achievable without consistent investment in health services, strategies targeting health providers' interpersonal skills and technical competencies as well as promoting empathic connections within health systems and links between health systems and community organisations.

At community, subdistrict and district levels, we underline the

importance of community engagement based on principles of social participation in health-decision making around tackling NCDs and developing feasible mechanisms for facilitating access to essential NCD services. The effectiveness of these is evidenced in our case study from El Salvador and previous research (Marston et al., 2016, 2020). Engaging communities affected by NCDs in an open dialogue and partnership via trusted social mediators can help achieve solutions for ensuring health for all. This is because communities have the expert knowledge and insights of local needs and what mechanisms would work best for their context (Marston et al., 2020). Accountability and transparency are crucial elements in this process as communities may disengage and lose trust if they do not see any positive changes and feedback (Marston et al., 2016). Local community organisations, including village development committees (VDCs) in rural and remote sites, can provide safe spaces for sharing and learning about the real needs and challenges of people living with NCDs. Local community organisations are also uniquely placed to mobilise political awareness and advocate for better NCD prevention and control.

At a national level, consistent investments in health systems and welfare programmes are needed to ensure the provision of essential person-centred NCD services while demonstrating commitment towards promoting power-sharing, social accountability, and transparent two-way communication with affected communities. This is because equitable and well-functioning health systems providing tailored care to most in need can bring important health and state-building (i.e., strengthening public institutions and promoting state legitimacy) benefits in fragile contexts (Kruk et al., 2010). Further, public institutions acting on the basis of equal rights to health, power sharing, social accountability tend to have higher institutional trust and reduced health and social inequalities (Robbins, 2012; Sun and Wang, 2012). These are a complex set of interventions that might not be achievable without both targeted financial and capacity-building support from development actors and strong advocacy efforts from health providers, community organisations and NCD-affected individuals and communities.

Finally, we recognise the role of private health providers – formal and informal – in addressing health needs in fragile contexts where the reach and capacity of public health systems are constrained. Reflecting on the preceding analysis, while state authorities may be unable to

provide required services, they have an important responsibility to ensure the accessibility, quality and accountability of private provision. In terms of trust, the role of the state is to promote mechanisms of regulation and quality assurance such that NCD-affected communities are equipped to make sound judgments in their choices of health providers.

### 4.2. Limitations

We acknowledge the presence of limitations. First, the findings presented here are based on a secondary analysis of qualitative data. Therefore, interpretations presented here may be influenced by researchers' perspectives who had no opportunity to follow up with the study participants. To account for this, we discussed the findings with researchers involved in primary data collection in each context and a wider multidisciplinary team of researchers involved in the research write-up. Second, while the participatory nature of GMBs secured a strong engagement with communities and health providers, this method did not reliably secure verbatim quotations from the intense discussions established. The rich pictures and diagrams produced by participants were the principal source of data informing analysis. Third, while we call for measures to facilitate communities' engagement in health decision-making to rebuild trust, the most efficient ways of doing this have yet to be explored. Future research should consider drawing upon the notion of social capital and its bonding and bridging dimensions to understand how social interactions, community participation and social accountability can help rebuild trust and improve access to services in fragile contexts (Ager and Strang, 2008; Kirkby-Geddes et al., 2013).

### 5. Conclusion

In conclusion, our study maps the dynamics between contextual factors, institutional, interpersonal and social trust and health-seeking for NCD services in fragile contexts. It highlights that beyond the ways health services are delivered and experienced, trust in public health institutions, and therefore utilisation of public services, is shaped by historical narratives and state authorities' responses to the drivers of fragility. It identifies the mediating role of social trust in health-seeking behaviour through social bonds and links between affected communities and health systems. We argue the need for multiple interventions at community, district and national levels targeted towards rebuilding and maintaining trust in public health institutions and providers for better NCD management and control in fragile contexts.

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### Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2021.114473.

### Credit author statement

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Feedback loop surrounding **interpersonal trust** indicates how positive experiences of utilising health services work over time to influence perceptions of quality and effectiveness of specific health providers, in turn influencing the choice of where to seek care. This feedback loop implies that interpersonal trust can facilitate health-seeking behaviour from health services providing positive experiences and perceptions of good quality care.

Arrows surrounding **social trust** illustrate how experiences of health-seeking are communicated to informal social connections and may shape the views and advice of these connections on health-seeking pathways. Social trust therefore can facilitate health-seeking behaviour through bonds and links with health services, but similarly may act to constrain the choices of individuals towards one type of health provider or another.

Feedback loop surrounding **institutional trust** denotes how state governance mechanisms in each context affect the accessibility, affordability, effectiveness and quality of services offered at health institutions, in turn shaping trust in health systems. Institutional trust can be (re-)build by interventions promoting access to equitable, affordable quality public health services and power sharing with- and social accountability towards NCD affected communities.

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