Conteh *et al.*
International Journal for Equity in Health (2025) 24:67
https://doi.org/10.1186/s12939-025-02428-z

International Journal for Equity in Health

COMMENT

Open Access

Health seeking by people living with non-communicable diseases in a pluralistic health system: the role of informal healthcare providers

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Abstract

Background There is a growing global burden of non-communicable diseases (NCDs), including diabetes, hypertension and cardiovascular diseases. NCDs constitute a growing public health concern in the Low and Middle Income Countries (LMICs), amplified by rapid urbanisation and urban inequality. Urbanisation and associated inequalities, have profound impacts on healthcare provision and health seeking decision making by marginalised populations living in urban informal settlements. The thriving nature of informality, shown through the spread of urbanisation, health pluralism and informal healthcare provision is seen as a mechanism for coping with urban inequalities. Limited understanding of the drivers of health seeking both within policy and practice remain a huge gap in designing a people centred healthcare delivery that meets the needs of people affected by NCD health problems in marginalised urban settings.

Methods We employed qualitative methods including 18 key informant interviews (KIIs), 3 focus group discussions (FGDs) and 15 narrative interviews, with purposively sampled people living with NCDs, as well as formal and informal healthcare providers, and community chiefs. We analysed our data using the qualitative framework approach, applying the adapted health belief model to understand how health seeking decisions are made by people impacted by NCD lived experiences in informal settlements.

Findings Syncretic beliefs were evident among people living with NCDs in urban informal settlements, showing that people interact with diverse healthcare providers at different times, based on the type and severity of ill health. Health seeking was also influenced by healthcare access barriers, and participants' biomedical, cultural and religious beliefs about disease causation. Despite the ongoing medical pluralism and syncretic belief systems, the Sierra Leonean health system is yet to understand and adapt to these contextual factors in its response to the NCD epidemic. Moreover, the rigid operational boundaries between formal and informal healthcare service providers continue to impact on the unmet healthcare needs of people living with NCD conditions in marginalised urban settlements in Freetown, Sierra Leone.

Conclusion Informal healthcare providers play a critical role in the provision of healthcare services for people living in low resource settings, building a trusted relationship between formal and informal health providers can help to optimise healthcare service delivery that meets the needs of people affected by NCD conditions in marginalised urban settlements.

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Keywords Informal health, Formal health, Syncretism, Health beliefs, Health seeking, Sierra Leone

Introduction

There is a growing global burden of non-communicable diseases (NCDs) with a resulting 41 million deaths annually [46]. The World Health Organisation (WHO) reports that 77% of all NCD deaths occur in low- and middle-income countries (LMICs). In many LMICs, the rise in NCDs as a public health problem intersects with rapid rates of urbanisation, poverty and precarious living conditions, such as exposures to smoke emission, unhealthy diets and poor housing conditions [35]. Current patterns of urbanisation reinforce socio-economic inequalities, with increased numbers of people living in informal settlements [37]. These processes have been shown to worsen health inequalities and have been identified as a driver of NCD burden [13, 23]. Socio-economic inequities have also been shown to increase NCD burden among women in Africa [47]. Thus, within LMICs, rapid urbanisation, poverty and worsening socio-economic inequalities increase vulnerabilities to NCDs (e.g. cardiovascular diseases, type 2 diabetes, lung and gastric cancers and chronic respiratory diseases) [7, 23, 31, 42].

Health seeking for NCDs

Despite the underlying social inequalities driving the growing vulnerability to the burden of NCDs in LMICs, little is known about how these vulnerabilities intersect to shape health seeking practices [21]. Despite a wealth of literature related to health seeking and acute illness, knowledge gaps related to health seeking for NCDs are evident. Specifically, there are few studies focused on understanding provider preferences, and the role of formal and informal providers in the continuum of care for different NCD conditions [4]. Moreover, less is known about the interplay between social identities such as gender, income and educational status and health seeking choices. Emerging evidence suggests that syncretic beliefs (seeking care simultaneously from biomedical, traditional and religious providers), underpinned by the experiences of managing comorbidities, including the transition to chronic stages, and the lack of proper diagnosis play a critical role in informing patient's decisions about where to seek care [3]. Financial burden, mediated by high out of pocket payments are also thought to influence early or delayed care seeking [38]. Weaknesses in healthcare delivery system also shape health seeking decisions. Weak health infrastructure (e.g. poor road networks, transportation, diagnostic facilities) frequently limit access to healthcare [11], and further amplify financial burden [25].

Consequently, in many African settings, health systems are becoming more pluralistic [15], with patients seeking care from traditional, religious and biomedical providers simultaneously [41]. However, this trend is less recognised within health policy and programming. While informal healthcare providers offer a huge part of healthcare services, particularly to people who are excluded from services [26], these services are not well documented [32, 33], and evidence on the types of services provided are less well understood [10].

The Sierra Leone health system in context

Sierra Leone's health system is described as one of the most fragile in the world [43]. The intersections of conflict and health shocks such as Ebola, have severely impacted the health system and healthcare service delivery [30]. Currently, the Sierra Leonean health system is organised into public and private healthcare facilities [28], which are further divided into three layers: primary, secondary and tertiary levels. The primary healthcare system is the largest in terms of geographic spread and include community health, maternal and child health facilities [17]. Secondary health facilities, include district hospitals, while tertiary hospitals include regional and teaching hospitals providing specialised services. Despite ongoing strengthening efforts, weak health infrastructure mediated by limited investment in public health [16], coupled with limited and less motivated workforce, make health care access a challenge for many people in Sierra Leone [40], including those living in informal settlements.

Consequently, informal healthcare providers in Sierra Leone play a critical role in the functioning of the health system. These providers include traditional healers, religious healers and drug peddlers who operate outside the formal health system. The services provided by informal providers are mostly not recognised, as many are believed to have no formal biomedical training and are not registered to operate. Traditional healers in Sierra Leone include providers using herbs, plant based solutions and spiritual powers, while religious healers (e.g. pastors) conduct faith healing through intercessory prayers, with Islamic healers combining powers of the Quranic verses and herbs to provide healing [29]. Drug peddlers in Sierra Leone are referred to people selling western medicines, many of whom lack proper licensing and authorisation. Despite the pluralism of the health system in

Sierra Leone, there is still gap in terms of charting ways to integrate the formal and informal healthcare systems to improve healthcare access to marginalised urban residents, particularly those living with NCD conditions.

Health systems solutions

In response to the challenges of accessing NCD services, the WHO, through the Package of Essential Non-communicable (PEN) Disease Interventions, recommends an integrated approach to NCD care, particularly in low resource settings where NCD screening and treatment facilities are inadequate [46]. The PEN toolkit identifies NCD care at the primary healthcare level as vital to early detection, diagnosis and treatment. Despite this positive step, a critical knowledge gap remains regarding the response of the health system to syncretic health seeking practices in improving healthcare delivery for people living with NCDs. Understanding the role of informal health providers in NCD care provision can help to understand their capacities and strengthen the identification, treatment and/or referral of NCD cases such as diabetes and hypertension. This will help to provide NCD services within their skill sets to people living in informal settlements in Freetown, Sierra Leone, where many people are getting more exposed to NCD health problems [24]. This study therefore explores the role of informal healthcare providers and health beliefs in the seeking practices of people living with NCDs in a pluralistic health system in informal settlements in Freetown, Sierra Leone. The study applies an adapted health belief model to understand how social, cultural and personal identifiers shape health seeking decision making [39]

Methods

Study setting and link within broader ARISE research programme

This study was completed in three informal settlements in Freetown, Sierra Leone. Each settlement faces challenges with service delivery, including access to water, sanitation and healthcare [9]. Our research sites included Cockle Bay, a seaside settlement in the west of Freetown, Dwarzark and Moyiba which are hillside settlements in the central and far east of the city. The settlements were purposively selected to account for the diverse voices and experiences of informal settlement residents across differing geographies in Freetown. The study was undertaken as part of the Accountability, Responsiveness and Equity Hub (ARISE), a Global Challenge Research Fund (GCRF) initiative that applied a Community Based Participatory Research (CBPR) approach which prioritised the inclusion and active participation of community residents such as co-researchers in all phases of the research to address health and wellbeing priorities [34].

Study design, participants, & data collection

This study used a qualitative approach including 18 key informant interviews (KIIs), 3 focus group discussions (FGDs) with formal providers (in primary healthcare settings), informal healthcare providers (including traditional healers, religious healers and drug peddlers/unlicenced western medicine sellers) and community chiefs. We also conducted 15 narrative interviews with people living with NCD conditions including diabetes, hypertension and disability as a result of stroke to understand their health seeking decisions [27]. Participants for the narrative interviews were engaged through three household visits over a six-month period. The FGDs and KIIs explored healthcare provision in a pluralistic system, with respect to the role of informal healthcare providers in the provision of NCD care. During the FGDs, formal healthcare providers, community chiefs and informal health providers were divided into three groups. The group division was to ensure that power differences particularly among informal and formal healthcare providers and community chiefs did not limit participation of the informal health providers. Data collection was led by the first author (AC) alongside co-researchers and a research assistant (see details in Acknowledgements). We held training and reflexivity sessions with the team members mentioned above to discuss potential ethical and safeguarding issues to protect participants and the team from harm. Co-researchers who worked on this study were selected from the three research sites due to their imbedded knowledge about the socio-cultural and health dynamics within their communities, and their previous experience in data collection with the ARISE project.

Recruitment of participants

All participants were recruited purposively from the three study communities, with a pragmatic sample size based on available resources and the fulfilment of inclusion criteria to ensure diversity of views [20]. The following procedures were followed for the recruitment of participants for the three research methods:

KIIs

Participants for the KIIs were informed about the study using an information sheet and given five working days (one week) to decide regarding their participation. Co-researchers identified and recruited all the participants based on agreed criteria: the role of participants in healthcare provision; being in a community leadership position; and living or working in the community. Once

participants agreed to be included, a date and place for the interviews was agreed with them. Participants were informed about consent procedures to be completed before the interviews which required them to individually sign a written consent form.

FGDs

Similar recruitment procedures, including the selection criteria for the KIIs were followed. Co-researchers identified and informed participants about the research and asked them to participate. Follow ups were made after five days to enquire about their willingness to participate, particularly because the FGDs were held outside the communities. The decision to hold the FGD sessions outside the community was to enhance participation by having the sessions facilitated in a spacious and relaxed atmosphere. Participants were also informed about consent procedures as prerequisite for all sessions to be conducted.

Narrative interviews

The selection of participants was informed by pre-determined criteria which included women and men living with NCDs conditions, including diabetes, hypertension, and disability related to stroke. Recruitment was based on gender, social status and the type of NCD condition. The choice of NCD conditions was informed by reported high cases of NCD conditions in Freetown by the Sierra Leone Ministry of Health quarterly dashboard. Co-researchers worked with different stakeholders including formal health workers and household members to identify people living with diabetes, hypertension and disability related to stroke. The information sheets were read and explained to participants and were asked to participate. For this category of participants, co-researchers kept a regular contact with them as they were meant to be interviewed repeatedly over six months. This was to prepare their minds for the follow up interviews to prevent drop out from the interview sessions. Table 1 below shows a disaggregation of participants for the different study methods.

Analysis

The analysis followed a framework approach, which is applied widely in qualitative studies to enhance immersion into the data and to analytically develop themes [6]. These procedures helped us to understand how people describe health beliefs and seeking practices. This involved reviewing the data iteratively to understand the interaction of health beliefs and healthcare decision making at different times. Identified codes from the data were applied analytically to generate themes and sub-themes. We then adapted the Health Belief Model [39] in Fig. 1 below, to link our findings to the conceptual underpinnings of health seeking. Through a critical examination, we found that the Saleh model presents health beliefs from two perspectives: i) the biomedical beliefs and ii) the traditional and religious health beliefs. Our findings contributed another layer to this model by presenting the traditional and religious beliefs in separate but complementary ways. Our key argument is that traditional and religious beliefs interact in different ways, which makes it untenable to treat them as the same. We also explored structural barriers to healthcare access such as cost of care, distance and quality of care and how they shape health care decision making by people impacted by NCDs. Lastly, we explored disease understanding based on typology and severity, and how this informs pluralistic health seeking. Our findings are presented based on the adaptation of the health belief model.

Table 1 Participant categories

Method	Type & number of participants	Total participants
Key Informant Interviews	• 3 community chiefs (1 from each research site) • 9 informal healthcare providers (3 from each community, comprising drug peddlers, traditional healers and religious healers) • 3 representatives of traditional healers' association[a] (1 from each community) • 3 formal healthcare providers (1 from each community)	18
Focus Group Discussions	• 6 community chiefs (1 FGD) • 6 formal healthcare workers (1 FGD) • 9 informal healthcare providers (1 FGD)	21
Narrative Interviews	• 4 People living with diabetes (3 females; 1 male) • 5 people living with hypertension (4 females; 1 male) • 6 people living stroke/disability resulting from stroke (3 females; 3 males)	15
Total participants for all methods		**54**

[a] Traditional healers' association representatives provide leadership roles for their members at community level. At the national level, there is a traditional healers' association that is recognised by health system policy makers. While they exercise some control over traditional healers, through penalties to those who fail to comply with membership regulations, it is not known how this happens across communities in Freetown

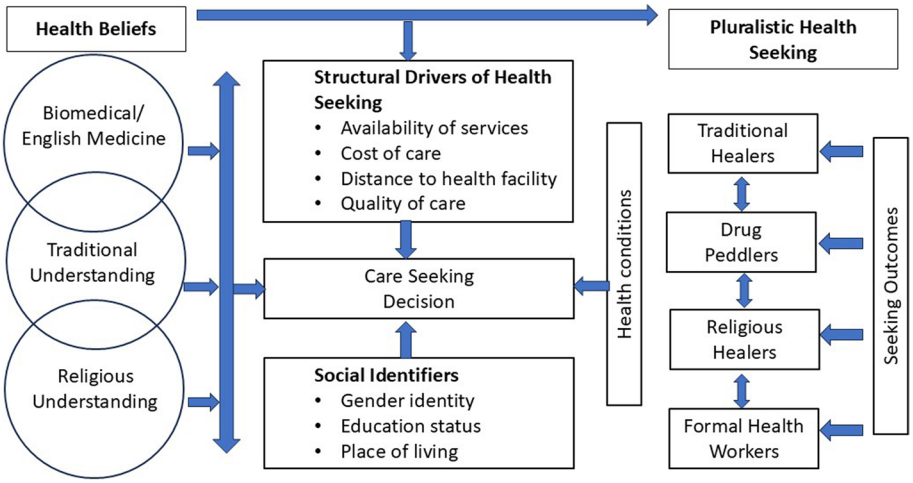

Fig. 1 An adapted model of health seeking: [39]

Ethics and safeguarding

Ethical approvals were sought and granted by the Sierra Leone Ethics and Scientific Review Committee on 4th August 2021 (Version 2.0 of 28 July 2022) with an amendment on 11th March 2022 (Version 3.0 of 11 March 2022). Approval was also granted by the Research and Ethics Committee of the Liverpool School of Tropical Medicine on 5th August 2021 (Reference 21–043). During the reflexivity sessions, the research team discussed adherence to ethical procedures by ensuring that research participants and vulnerable adults living with NCD conditions were protected from harm alongside the research team. The research team and participants were informed about referral procedures in the event of safeguarding concerns such as sexual exploitation and abuse of women and children or research participants. The phone number of the Safeguarding Lead for this study was made available to all participants through the information sheets provided. Participants were also advised to inform the safeguarding lead if they faced distressing situations during the interviews for referral to service providers within Freetown.

Results

We present findings from this study based on the adapted Health Belief Model [39] in Fig. 1. The findings highlight connections between co-occurring health beliefs (biomedical, traditional and religious) as drivers of health seeking for NCD conditions in the informal settlements of Freetown, Sierra Leone. Health beliefs are also mediated by structural barriers, interacting with social identities such as gender, education and place of living. A table has also been provided at the end of the paper to aid the interpretation of the codes within the text.

Health beliefs and health seeking practices for NCDs: biomedical, traditional and religious understandings

Syncretic belief systems were evident in health seeking decisions for people living with NCDs in informal settlements in Freetown, Sierra Leone. This shaped health seeking in different ways and meant that people engaged with different providers at different times for different reasons in their care seeking journeys. Disease understandings from different perspectives were particularly important in shaping how syncretic beliefs influenced care seeking. Self-regulatory behaviours to heal from disease were informed by participants' experiences of recurring disease episodes, associated with previous health seeking experiences and treatment outcomes. Participants narrated that unmet healthcare needs from a provider meant that they would shift to another provider until they were satisfied with the outcome. This was the case for one man living with hypertension and other symptoms such as breathlessness and mobility challenges in the Moyiba community. He said that after a long period of interaction with traditional medicine, he shifted toward formal providers because of unclear diagnosis and unsuccessful treatment:

> *"At first, I thought it was witchcraft and that my people were trying to bewitch me, so I first tried the traditional medicines. After an intensive medication, my condition did not improve, so, I decided to try the 'English medication'. That was when the health workers told me that I had hypertension." (NI_MYB_HPT_M).*

Biomedical understanding: "English medicine works better for me—my body has adapted to it."

The description of biomedicine or "English medicine" by people living with diabetes, hypertension and disability related to stroke often underlined participants' syncretic beliefs, reflecting the desire to complement formal biomedical treatment with religious or traditional care to expedite healing. Women with diabetes, hypertension and disability related to stroke were constantly negotiating how and when to seek care, with severity of illness often being identified as the critical factor in these decisions.

> *"I believe in the Almighty God for anything that happens to me..... When I had a sudden heart attack, my children were advised to take me to a traditional healer, but they believed that I will be well if they took me to the hospital." (NI_CBY_DBT_F).*

Biomedical beliefs about disease symptom and origin were also important in the way participants made health seeking decisions. For example, participants living with disability resulting from stroke or co-morbidities of hypertension and diabetes often reflected on the different social and biological processes underlying their disease conditions shaping response mechanisms to treatment and the need to seek multiple types of care from providers simultaneously. The ability to understand and interpret illness from a biological standpoint often meant that people opted to seek care from formal or biomedical care providers as explained by a participant living with hypertension and disability related to stroke:

> *".....I am not saying the garlic and honey do not help to reduce my blood pressure; they do but the English medicine works better for me. English medicine works better for me than the traditional medicines, because my body has adapted to it. I often see much improvement with the English medicines..... Some people will also say that traditional medicine is the best for them because their body has accepted it." (NI_2_DZK_STK_M2).*

Such understandings about biomedicine were often based on participants' interaction with formal healthcare providers and experiences with care. Across settings, participants who had close interaction with formal healthcare providers, particularly women, reported that they receive information on NCDs and care seeking from formal healthcare providers, which enhanced their understanding of their condition, as explained by a woman with diabetes:

> *"The food I have been eating is more of white rice and "foo-foo" [food processed from cassava], and these contain high amounts of starch. According to the doctor, this might have caused the diabetes which I am living with now." (NI_CBY_DBT_F).*

Another dimension of biological understanding was based on the framing of NCDs as a genetic disease, construed by some participants as disease inherited from their parents. Although this belief was not widespread, its framing was critical to people's construction of disease causation and treatment pathways in informal settlements, making it common for some to say that *"I inherited this condition from my mother"* (NI_2_DZK_STK_F). Similar beliefs were held by men who thought that disability related to stroke can be inherited from their father:

> *"My condition was inherited from my father who suffered and died of stroke when I was very young. He was admitted at the government hospital for nearly three months. When the "English medicine" yielded no result, we decided to take him to the village for traditional treatment." (NI_MYB_STK_M).*

While biomedical beliefs and seeking were also spoken about in terms the treatment effectiveness, availability and cost of care were also relevant to health seeking (as discussed later).

Traditional beliefs: "My condition is connected to witchcraft."

Traditional beliefs about disease causation were influenced by social and cultural norms. Men and women living with NCDs expressed belief in alternative medicines such as herbal or plant-based solutions for the treatment of conditions including disability from stroke, hypertension and diabetes. For example, bitter roots such as "gbangba", and other remedies including garlic and moringa were listed as useful in reducing blood pressure and blood sugar. Participants with hypertension expressed a strong belief in mango and guava leaves for the treatment of hypertensive conditions. This was the same for participants living with diabetes:

> *"My daughter-in-law brought a bitter herb tasting like "gbangba", which has helped to reduce my blood sugar level..... I also drink gbangba, moringa and garlic to reduce my blood pressure. My brother also advised me to boil mango leaves and drink every day." (NI_MYB_DBT_F).*

Traditional beliefs about disease causation were also linked to spirituality, linking health problem to spiritual spells influenced by "evil doers". For example, hypertension was considered by some men and women as having a spiritual cause and, therefore, not a "hospital sickness". This was the same for men and women who had co-morbidities of hypertension and diabetes. Where a condition was believed to be non-biomedical, this meant that people may have experiences of failed treatment outcomes from formal healthcare providers or a strong belief that their conditions were only meant to be cured through traditional or spiritual means. People in such situations were more inclined to seek care from a traditional healer or religious healer:

> *"My condition is connected to witchcraft. I saw the long witch rope removed from my body, which looked like a charm with many cowries. It also looked like the shell of an oyster. According to the traditional healer, the 'witch cloth' was tied to my body and the 'witch rope' on my stomach. These witch items were used by a witch for over ten years to induce sickness." (NI_2_MYB_HPT_F).*

Finally, traditional understandings about disease were often associated with sexual behaviours, particularly for men. Men with disability as a result of stroke were widely believed to have engaged in incessant sexual behaviours, a view that often became internalised by affected persons:

> *"I was such a womaniser, and I was so lucky with women. I hardly got a no for an answer. A lot of women used to come around me……. It was after I retired that I started experiencing signs of stroke. So, I believe when people say that men who suffer from stroke are womanisers." (NI_2_DZK_STK_M1).*

Religious beliefs: "I devoted myself to prayers and God answered."

Faith, hope and prayers were pivotal in the description of the health seeking journeys by NCD participants. Some participants, including women living with disability related to stroke spoke about visiting places of worship such as churches, with faith in "God's healing". Across gender and NCD conditions, faith was held highly, not only for physical healing, but for coping with the physical and financial burden of NCDs. For some participants living with disability as a result of stroke, illness causation was believed to be beyond human control, as people were inclined to represent illness as "inevitable" or the "will of God".

Perceptions of inevitability and fate framed participants' decisions about health seeking. As explained by one elderly woman living with disability due to stroke, the expectedness of illness meant believing in God for healing, and the church was seen as a spiritual route to healing:

> *"I have seen many people getting healed through prayers offered by the churches. I have heard people giving testimonies after being healed from stroke and many other health problems. So, I devoted myself to prayers and God answered my prayers" (NI_2-DZK_STK_F).*

Structural barriers and the care seeking decision

The influence of health beliefs on healthcare decision making was mediated by structural barriers to healthcare access, and gendered power dynamics. Among these barriers, healthcare costs, distance to health centre and quality of care stood out prominently.

Availability of care: "Healthcare access is poor for every sick member of this community."

Across the communities, most participants were concerned about the availability of timely and quality formal healthcare services. Concerns about quality included the limited supply of drugs, diagnosis and treatment. These healthcare barriers were reported as worse in communities with no health centre, such as Cockle Bay. Participants stated that healthcare access barriers within the formal health system made them to switch to other providers such as drug peddlers. As expressed by a participant with hypertension, experiences of poor quality of healthcare and access is widespread, and is more concerning for people living with NCD conditions:

> *"Healthcare access is extremely poor for every sick member of this community and even worse, for people with NCDs." (NI_CBY_HPT_F)*

For many participants living with diabetes and hypertension, experiences about healthcare access were related to the lack of testing facilities to check their blood pressure and blood sugar. People with hypertensive conditions were viewed as better off than those with diabetes and disability related to stroke because of the relative ease of access to blood pressure machines than testing strips for diabetes within the community. These experiences were cross checked with health workers who commented on what these health seeking experiences meant for people with different NCD conditions:

> *"People suffering from diabetes and stroke do not have any healthcare option [s] within this community because these are serious and complicated health problems—healthcare options exist only outside of the community. Hypertensive patients are a bit bet-*

ter because some have blood pressure machines and others can ask qualified nurses in the community to check their pressure." (KII_HW_CBY_F).

High cost of formal care: "Pay before service is the common practice."

High out of pocket payment for healthcare services were described by people living with NCDs and key informants as a challenge that imposes financial burden on people living in informal settlements and a barrier to healthcare. There was a general sense that high costs discouraged care seeking from formal providers, particularly when they were reported to be demanding for money before responding to patients' needs.

"Nowadays, pay before service is a common practice by healthcare providers. Healthcare is not provided to patients unless they have money to pay for the services." (KII_CC_DZK_M)

Experiences of financial barriers to healthcare were felt by people affected by NCDs from different socio-economic backgrounds, but more evidently by women who were widowed and with high financial uncertainty. One woman who was widowed with hypertension recounted being turned away at different hospitals for not having the required amount of money requested by healthcare workers:

"……..Nothing is free at the hospital; when I had a heart attack, my children changed three hospitals because of the high financial demands. The doctors called for SLN1,000,000 [about USD 45] for me to be admitted. My children pleaded for SLN600,000 [roughly USD27] but they refused." (NI_CBY_HPT_1_F).

To navigate healthcare access barriers, people living with NCD conditions said that they applied self-management strategies, which included buying low-cost medicines from drug peddlers such as pain killers to deal with pain and headache, and then later visiting the hospital when they had money for further care. A drug peddler at Dwarzark community describes how he treats patients with low budget:

"Some people access services from us, and we give them first aid treatment and then they later go to the hospital. Most times, they come to us because they do not have enough money to pay the hospital bills." (KII_MYB_DP_F).

While most formal health workers across our study settings agreed that formal healthcare costs were higher than those charged by informal providers, they suggested that the benefits of formal care far outweigh the costs. Costs, they stated were higher in formal healthcare settings because of standard treatment protocols, including diagnosis:

"Services by formal health workers are expensive because of the protocols. At the hospital, patients are asked to pay bed fees, consultation fees, plus testing and drugs. However, the fees charged by informal health service providers are lower, which is why their services are attractive." (KII_DZK_HW).

Distance and road infrastructure

Across urban informal settlements, physical constraints such as distance and poor road infrastructure were cited as barriers limiting access to formal healthcare. People living with NCDs, particularly elderly men and women felt more deprived, due to the extra challenges added to the layers of existing healthcare barriers. At intra-settlement level, spatial barriers such as hills were reported to present different healthcare access outcomes for people living with NCDs. In the hillside settlements including Dwarzark and Moyiba, it was noted that people living on the hillside slopes had more challenges in accessing healthcare than those living on flat lands, making it a necessity to seek help from informal providers:

"Those living closer to the health centres or hospitals can easily access health services, unlike people living in areas far away on the hilltops. As a result of the distance, most of those with access challenges often shift their attention to informal healthcare providers." (FGD_HW_MYB_1).

Infrastructure challenges to healthcare access such as motorable roads were cited as critical particularly when it came to life changing health crisis. Health workers themselves were not spared from these challenges when they were on the other spectrum of healthcare, needing critical intervention during crisis such as heart attack:

"I had a heart attack that made me lose consciousness; there was no means of transportation because the place where I live is not motorable. I was told later that some young men took me to the hospital, which took over an hour. I would have lost my life" (KII_CBY-HW-F).

Social identifiers and care seeking decision

Social identifiers comprising gender, educational, income and tenure status interlinked to shape individuals' experiences and health seeking choices. Gendered experiences of financial hardships and barriers of healthcare costs were significant. Barriers to education, mediated by patriarchal disadvantage was described by women

as limitation to their financial mobility and the ability to respond to healthcare needs. Consequently, when women got sick, they described facing extreme financial burden interacting with high healthcare costs:

> *"I feel extremely bad that I did not continue schooling because life would have been much easier than the way it is now, if I had formal education." (NI_CBY_DBT_F)*

Men also explained that financial limitations to respond to their healthcare needs were tied to low formal education and livelihood options, and not tied specifically to patriarchal disadvantage. Place of living also reflected women's prospects for sustainable livelihoods and financial mobility which impacted their capacity to seek healthcare when they faced health crisis.

> *"I have a freezer which I used to sell cold drinks and water, and I used the profits for my treatment. But the electricity voltage has been low for a while and could not power the freezer. I stopped the business, so I could not make money. This has been the main reason why I have not been able to go to the hospital in the last six months." (NI_CBY_HPT_02).*

Finally, health seeking decisions were influenced by relationships though friendships and family. People within these networks shared their experiences of local remedies for the treatment of NCD conditions and encouraged others to replicate them. For example, some women affected by diabetes were often concerned about rapidly losing weight which they described as stigmatising, as women were expected to look rounded. Given this experience and the fear of stigma, some women said that they were encouraged by others to try bitter roots such as "gbangba" to reduce their blood sugar levels.

Health pluralism, seeking and treatment outcomes

Health pluralism was evident in our analysis which shows that different providers were present and functional in informal settlements. Healthcare providers, according to key informants, typically included the formal health providers within government and private healthcare facilities, and informal health providers including traditional healers, religious healers and drug peddlers or "Pepe doctors". Perspectives about formal and informal healthcare providers were based on the experiences of service users, healthcare workers and informal providers themselves. While these providers operate in the same geographical settings, it was clear from our analysis that they do not always understand the operations of each other, partly because of operational boundaries, making it difficult for them to work together. We describe these providers and their relationships, and the services they offer to patients.

Traditional healers

The classification of traditional healers was based on the services they provide and the experiences of people receiving care from them. There were strong indications that services provided by traditional healers were drawn from knowledge systems on the use of herbs and spiritual powers. However, the use of traditional knowledge and their outcomes for NCD treatment was often a driver of mistrust between biomedical providers and traditional healers. While many NCD participants expressed a strong belief in traditional medicine, biomedical providers were often critical of the services provided by these providers due to concerns about drug reaction due to the lack of precision in the application of their treatment:

> *"Informal health service providers, especially traditional healers and herb sellers give blind treatment to people without measurement, exposing patients to the risk of overdose which can lead to other complications." (KII_DZK_HW_F).*

However, traditional healers had a common thread in their statements about the kinds and efficacy of the care they provide. Many expressed that the skills and experiences of their craft were uniquely rooted in traditional knowledge, which was utterly different from biomedicine. As explained by a traditional healer, traditional knowledge on the use of herbs had been tried in the treatment of disability as a result of stroke and related conditions:

> *"I don't understand "English medicine", but I treat stroke patients with herbs. I give my stroke patients herbs to chew. I mix the leaves with honey and give them to drink or chew until they feel better." (FGD_TH_DZK_F).*

Participants' descriptions of disease conditions also reflected the dichotomy of medical knowledge systems such as biomedicine and traditional medicine. For example, participants' classification of certain diseases as "non-hospital sickness" was linked to their socio-cultural construction of illness and treatment pathways. When participants had prior negative experiences with diagnosis and care, leading to slow recovery from certain disease conditions within the formal healthcare system, this was construed as not having a cure within the formal setting. Such individuals were more prone to turning to traditional health providers:

> *"There are certain diseases that cannot be cured in the hospital, so most people come to us for treatment.... I have helped save someone with stroke and*

other severe sicknesses. In fact, most people come to me when the formal healthcare yields no positive results, and they have never been disappointed with my service." (KII_MYB_TH_M).

Regarding treatment outcomes, NCD participants had different experiences depending on the type and severity of illness, and time of intervention. For those who associated their conditions to spirituality, there was a general feeling of satisfaction with treatment outcomes. Such individuals believed that their conditions could not be explained biomedically, and therefore needed spiritual intervention:

"I trust country medicines……. If I went to the hospital, they might run a series of tests, but would find nothing, because what is inside me is spiritual. From what I hear from other people, certain sicknesses cannot be detected or treated by a machine or English medicines." (NI_2MYB_HPT_F).

However, trust in traditional providers was not always certain. A woman living with disability related to stroke said she had experienced extortion and poor treatment outcomes from two traditional healers in the past, which worsened her physical mobility:

"He started applying the herbs to my body, but I noticed that the treatment caused severe cold, so I decided to discontinue it. I bathed with the solution prepared with boiled leaves and tied the pounded ones around my waist. I used it for one and half months, but it only worsened my situation; my feet started to cramp, and my body was always cold……" (NI-2_CBY_STK_F).

Participants with such experiences preferred to prepare herbs for themselves, based often on the experiences of others who have tried them before. There was a general sense of satisfaction by participants preparing their own herbs to treat hypertension and diabetes as they described them as much cheaper and safer.

Drug peddlers (Medicine sellers)

Descriptions of the services of drug peddlers known locally as "Pepe doctors" pointed to a broad spectrum of care for conditions including malaria, diarrhoea, generalised body pain, sexual and reproductive healthcare services and NCD conditions. Peddlers/Pepe doctors were considered as illegal by many formal health workers because they were believed to have no licenses or qualifications to administer western medicines to patients. Two classifications of peddlers emerged from participants: the first category being identified as those offering "basic drugs" such as paracetamol and painkillers for the treatment of symptoms they associated to NCDs such as body pain, headaches and fever:

"As for us the drug peddlers, we sell basic drugs such as paracetamol and pain killers to people in need within and outside the community." (MYB-DP-F)

The second category related to providers offering "comprehensive patient care" including consultation, screening and treatment of conditions including malaria and NCD-related conditions such as hypertension:

"I treat many people including the young and the aged. I have a lot of customers because I do tests for illnesses like malaria, high blood pressure, etc. I treat them even if they don't have money at the time of care, and they pay later." (FGD_DP_CBY_F).

Regarding their contribution, the services of drug peddlers were surprisingly viewed by some formal healthcare providers as helpful by making essential drugs available to people who are not reachable within the communities, including those affected by NCD health conditions:

"Not all their activities are harmful. They supply basic drugs like paracetamol, flagyl, ciprofloxacin tablets, malfan and others which are prescribed for patients even in the hospital." (KII_CBY_HW_F).

In terms of treatment outcomes, NCD participants seeking care from drug peddlers reported that they were generally satisfied, although some said that relief from these conditions was sometimes temporal:

"For the peddlers, I would say their drugs and treatments are somewhat better because they provide quick relief, but the pain quickly returns. Most of the peddlers come to my house to sell their drugs, while I come across others in the community." (NI_2_MYB_HPT_M).

Some participants were also concerned about the safety of treatment from drug peddlers including the sale of expired drugs, which were believed to be exposed to the heat from the sun, while some others believed that drug peddlers provided care beyond their scope of work.

Religious healers

Religious healers were identified as providers of care through prayers and religious worships. Christian worship was identified as the most common type of spiritual healing which participants said was done through "deliverance" from the evil spirit. Religious healers, during FGD sessions noted that their interventions respond to both physical and spiritual symptoms of disease conditions:

"Most of the problems presented to us are demonic, convulsion and other illnesses..... So, our spiritual interventions cover physical and spiritual illnesses because we believe all kinds of illnesses can be healed through the help of God...." (FGD_RH_DZK_M).

To determine whether conditions presented were physical or spiritual, religious leaders noted that they consult with their patients extensively. Consultation, they said was also vital in determining whether the conditions presented had physical biological symptoms to help them to advice patients to visit formal healthcare providers first and later address the spiritual elements. Much emphasis was placed on spiritual ties with God, which religious leaders viewed as essential in "receiving revelations" about disease causation and treatment:

"Just as the hospitals diagnose illnesses, we also diagnose spiritually. We get our insights from prayers and fasting as it is during these moments that God reveals information about patients. We also get information about the physical symptoms of patients, particularly if the man of God in question is well trained and possesses the spirit of God." (FGD_RH-CBY_F).

Formal healthcare providers

Formal healthcare providers were described differently based on the positionalities of different participants, with some describing them as "recognised by the government". Many participants identified formal providers as trained and qualified, in dealing with "English medicine". Perceptions about professional care with respect to precision in diagnosis and treatment outcomes informed participants' decision about seeking care from formal providers:

"Ever since I started going to the hospital and working with the doctor's advice, I have seen a lot of improvement because the palpitation of my heart has stopped." (NI_2_CBY_HPT_F2)

However, some patients reported that treatment outcomes following their engagement with formal healthcare providers were not always positive:

"I cannot say there is no improvement, there is, but very little. The treatment I receive from the hospital sometimes makes me feel better, but sometimes not." (NI_DZK_STK_M_1)

Discussion

To understand the dynamics of health seeking for NCD conditions including diabetes, hypertension and disability resulting from stroke in informal settlements in Freetown, Sierra Leone, we conducted a qualitative study that captured the range of experiences of people affected, formal and informal healthcare providers. Findings from this study show that health seeking is influenced by factors, including religious and cultural beliefs, reinforced by experiences of interactions with both the formal and informal system as well as structural barriers to formal healthcare access. These barriers were mediated by gender and other socio-structural circumstances such as distance and geography. We discuss these findings and their implications for healthcare delivery and access for people affected by NCDs.

We applied and adapted the health belief model [39], to understand how beliefs of disease causation shape health seeking outcomes. In recent times, the health belief model has been applied to different health topics such as: the health outcomes of dietary habits [19],vaccine hesitancy, particularly during infectious disease emergencies [44],hesitancy to childhood vaccination [12],and the management of long-term illnesses through patient and healthcare worker relationships [22]. Its widespread use emphasises its relevance to understanding the drivers of health seeking in different cultural contexts [8] and is essential in supporting policy makers and healthcare providers to understand and respond to the complexity of health seeking. Our approach has contributed to this discourse by applying the health belief model in urban informal settlements, where limited NCD services exist. Our analysis supports the assertion that health beliefs are complex and multi-layered, requiring systematic understandings in new and emerging contexts such as informal settlements [14]. Our utilisation of narrative methods to explore health seeking in informal settlements of Freetown was a particular strength of this study as it allowed us to consider how individual health seeking journeys had been influenced by and are intertwined with a complex web of individual, social and structural factors.

Our findings emphasise people's oscillation between different healthcare providers with the hope of improved outcomes. Pluralistic health seeking was observed among people with lived experiences of NCDs based on their social construction of illness or previous experiences with providers. This corresponds with other studies that have shown similar oscillations in relation to other NCDs (e.g. common mental health conditions), calling for the integration of biomedical and traditional medical care into syncretic health systems in LMIC settings to address patient preferences and ongoing treatment gaps [15, 36].

Our study has contributed to understanding the role of syncretic health beliefs in health seeking decisions amongst NCD patients. The clear reliance on medical pluralism within health seeking journeys for persons affected by NCDs in this study points to critical gaps

in current health systems responses to the NCD epidemic in Sierra Leone. These observations are crucial for policy making as they present syncretism as human agency in the response to critical healthcare access challenges. Our findings show that despite the critical importance of syncretism, there is currently very little collaboration between informal health providers and biomedical health providers. This is different to some other countries in Africa, who have been more open to the creation of syncretic systems. For example, in South Africa Traditional Health Practitioners (THP) are actively integrating traditional medicine with spiritual and biomedical practices to provide specific care based on symptoms presented by patients (Galvin et al., 2024). The creation of such systems where different healing traditions exist side-by-side offers hope for the Sierra Leonean health system if it is truly to address the NCD burden. Caregivers providing informal care within households emerged as an important layer in the syncretic health seeking journeys of people affected by NCD conditions. These household interventions included the preparation of herbal medicines combined with biomedical care to heal diabetes and hypertension. Further studies are needed to explore the role of informal family caregivers in the syncretic health seeking practices for NCD conditions and to understand how health seeking decisions are negotiated between caregivers and people living with NCDs. This can be useful if health system actors in Sierra Leone, including policy makers seek to strengthen their engagement with informal healthcare providers through knowledge exchange, the delivery of basic essential healthcare services and referrals, particularly in areas where NCD healthcare services are limited, such as in informal settlements.

Finally, our study shows that health seeking was informed not only by religious and cultural norms, but by the structural barriers that impede access to formal healthcare. Such barriers to healthcare access could be attributed to factors beyond the facility level to broader health system challenges. For example, in Sierra Leone, the government's expenditure on health is estimated to be less than 10% of the country's gross domestic product, which increases out of pocket payments for healthcare to about 45% and limits the expansion of service infrastructure [16]. This was also reflected in the geographical impediments to healthcare access highlighted by our participants, resulting in more frequent interactions with informal healthcare providers to close the healthcare access gap, as also emphasised by Azeez et al. [2] as a challenge in accessing healthcare. Despite this potential, the contribution of informal healthcare providers is seldom valued within policy circles (See Conteh, et., al Forthcoming) and is notably absent within WHO's PEN strategy. We recommend that in addition to promoting the decentralisation of NCD services to the primary healthcare level, WHO's PEN toolkit should work to provide guidance on the critical role that informal health providers can play in NCD care provision, such as early case detection and referral. Without such modification, interventions towards collaborative care for people living with NCDs on the margins of society, such as residents of Freetown's informal settlements, will remain a challenge as they continue to face exclusion from health service provision [1, 9].

The strength of this study is its innovative use of the health belief model to understand NCD health seeking practices in urban informal settlements in Freetown, Sierra Leone. Through this approach, the study has enhanced the understanding of the relationships between religious, cultural and biomedical beliefs that need greater consideration within health policy and planning in Sierra Leone. Finally, exploring the views of diverse health system stakeholders including formal and informal healthcare providers and people impacted by NCDs has contributed to diverse and insightful perspectives about health seeking in these largely under researched geographies. However, one of the limitations of this study was the difficulty to recruit and engage some sections of informal healthcare providers, particularly drug peddlers. While we intended to enhance diversity of voices, this was difficult to attain as selection was sometimes based on availability and willingness to participate. Some informal healthcare providers were not willing to speak, fearing arrest by health system actors working with the police and community leaders. This sentiment may have impacted the depth of information we received during the KIIs. However, further engagements were made through FGDs to build on the initial data we collected from drug peddlers, traditional healers, religious healers, formal healthcare and community stakeholders to triangulate their different perspectives. We were only able to include a few formal healthcare providers in this aspect of the study, largely due to the limited number of formal healthcare providers living and working within the health facilities located within the informal settlements where this study took place. We tried to mitigate this challenge by listening to more voices within each formal healthcare settings through a focus group discussion. Additionally, perspectives of formal healthcare providers in more senior positions within the health system are captured in Conteh et al., *forthcoming*.

Conclusion

Findings from this study indicate that syncretic beliefs are evident among people living with NCDs, which are relevant to the way health seeking practices develop. These practices are situated within diverse factors, including

prior experience with the formal healthcare system, sociocultural and religious understandings about disease. Yet, the opportunities offered by health pluralism and syncretism have not been fully utilised to build trust between formal and informal healthcare providers because of the rigid boundaries between them. This is a profound limitation to improving healthcare access by people impacted by NCD conditions living in marginalised urban settings. We argue that since informal healthcare providers already contribute to addressing healthcare access gaps in low resource settings, such as informal settlements in Sierra Leone, it is imperative for the formal health system to work with them to optimise improved and timely access to healthcare. This is particularly important for people living with long term illnesses, whose health needs are frequently under prioritised within the health system. The WHO's PEN toolkit is an important start, aimed at strengthening primary healthcare to facilitate early detection and treatment of NCDs. However, as our data shows, this toolkit does not currently discuss the inclusion of informal healthcare providers in NCD care, a critical need to enhance health equity, build trust among different health and to support the attainment of universal health coverage.

Notes

Drug peddlers in Sierra Leone are informal healthcare providers known for selling medicines to clients particularly in areas healthcare services are not easily accessed like in informal settlements. Many of these providers are unlicensed and unrecognised by policy actors and formal healthcare providers.

Description of In-text Codes by Alphabetical Order

This table has been provided to ease the interpretation of the codes with the text

Code name	Meaning	Code name	Interpretation
CBY	Cocke Bay	M	Male
CC	Community chief	MYB	Moyiba
DBT	Diabetes	NI	Narrative Interviews
DP	Drug peddler	RH	Religious healers
DZK	Dwarzark	STK	Stroke
F	Female	TH	Traditional healer
HW	Health worker		
HPT	Hypertension		

Acknowledgements
We are grateful to co-researchers living in the research sites, Abu Sesay, Issa Turay, and Sinneh Turay, and Research Assistant, Christiana Priddy for helping with participant recruitment and for conducting some of the key informant interviews.

Authors' contributions
AC conceptualised the research ideas analysed data and wrote the first draft; LD, ST & AW conceptualised the research ideas, interpreted the data, and reviewed the first draft; JM & BK reviewed the final draft. All authors reviewed and approved the first draft.

Funding
This study was funded by the United Kingdom Research and Innovation (UKRI) through the Accountability and Equity Hub ARISE with grant reference number: ES/S00811X/1.

Data availability
Thank you for the request. All data necessary to support the analysis is available in the paper. However, data can be made available by the corresponding author if requested.

Declarations

Ethics approval and consent to participate
The ethics application for my PhD study was approved on 5th August 2021 after fulfilling all the requirements by the LSTM Research and Ethics Committee (21–043). The study was also approved by the Sierra Leone Ethics and Scientific Review Committee (Version 2.0 of 28th July 2021) on 4th August 2021 after fulfilling all requirements. Both approving bodies requested the submission of all research tools including interview and focus group discussion guides, information sheets, and consent forms. The ethics approvals provided adequate safeguards for the protection of research participants.

Competing interests
The authors declare no competing interests.

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Received: 1 October 2024 Accepted: 23 February 2025
Published online: 11 March 2025

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