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Beyond belief: understanding contexts for help-seeking for severe mental illness in urban slum communities in Dhaka, Bangladesh and Ibadan, Nigeria

Ursula M. Read [a,b,*], Bulbul Siddiqi [c], Kafayat Aminu [d], Adeola Afolayan [e], Md Tahsinul Haque [c], Ashrafuzzaman Khan [f], Nadia Alam [b,g], Srividya N. Iyer [h,i], Obafemi Jegede [j], Akinyinka Omigbodun [e], Olayinka Omigbodun [e], Tanjir Rashid Soron [k], Sagar Jilka [b,g], Swaran P. Singh [b]

[a] School of Health and Social Care, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ United Kingdom
[b] Warwick Medical School, University of Warwick, Coventry, CV4 7AL, United Kingdom
[c] North South University, Bashundhara, Dhaka, 1229, Bangladesh
[d] Department of Research, University of Puthisastra, #55, Street 180-184 Sangkat Boeung Raing, Khan Daun Penh, Phnom Penh, Cambodia
[e] College of Medicine, University of Ibadan, Nigeria
[f] American International University - Bangladesh, 408/1, Kuratoli, Khilkhet, Dhaka, 1229, Bangladesh
[g] Warwick Centre for Global Health, University of Warwick, Coventry, CV4 7AL, United Kingdom
[h] McGill University, 1033 Av des Pins O, Montréal, QC, H3A 1A1, Canada
[i] Douglas Research Centre, 6875 Boulevard la Salle, Montreal, QC, H4H 1R3, Canada
[j] Institute of African Studies University of Ibadan, Ibadan, Nigeria
[k] Telepsychiatry Research and Innovation Network (TRIN), Dhaka, Bangladesh

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ABSTRACT

Research on help-seeking for serious mental illness (SMI) has often focused on the influence of cultural beliefs and explanatory models however a number of factors also influence decisions around treatment including availability, cost and quality of care. This study utilises an ecological framework to explore influences on help-seeking for serious mental illness in deprived urban slum communities in Ibadan, Nigeria and Dhaka, Bangladesh. Interviews and observation were conducted with family caregivers and people with lived experience of SMI. Although in both settings some participants speculated on the role of spiritual agents they also expressed uncertainty around the causes of SMI. Families commonly sought help from both biomedical practitioners and traditional and faith healers Help-seeking was embedded within complex ecologies of care, informed by considerations of quality, efficacy and cost, as much as beliefs. The complexity of influences on help-seeking and dissatisfaction with health services as well as healers suggests that a contextually informed, multi-component approach is needed which addresses health system weaknesses and affordability as well as accessibility.

1. Introduction

It is well known that globally help-seeking for severe mental illness (SMI) is pluralistic with common use of traditional and faith healers (TFH) (Gureje et al., 2015; Lilford et al., 2020; Nortje et al., 2016). There are concerns that this can lead to delays in accessing biomedical treatment (Farooq et al., 2009), harmful and coercive practices (Asher et al., 2017; Sharma, 2020) and poorer outcomes (Farooq et al., 2009). Research on help-seeking for SMI has been framed within the logic of 'explanatory models' (Dein, 2007) and the influence of spiritual or cultural beliefs. A recent review of help-seeking in low- and middle-income countries (LMIC), for example, highlighted that 'cultural

* Corresponding author.
E-mail addresses: ursula.read@essex.ac.uk (U.M. Read), mohammad.siddiqi@northsouth.edu (B. Siddiqi), aminukafayat@gmail.com (K. Aminu), adeola.oduguwa@warwick.ac.uk (A. Afolayan), tahsinul.haque@northsouth.edu (M.T. Haque), ashraf@aiub.edu (A. Khan), nadia.alam@warwick.ac.uk (N. Alam), Srividya.iyer@mcgill.ca (S.N. Iyer), ogbeate@yahoo.com (O. Jegede), omigbodun@yahoo.com (A. Omigbodun), olayinka.omigbodun@gmail.com (O. Omigbodun), tanjirsoron@gmail.com (T.R. Soron), sagar.jilka@warwick.ac.uk (S. Jilka), s.p.singh@warwick.ac.uk (S.P. Singh).

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beliefs' and stigma were the most cited barriers to biomedical treatment for schizophrenia (von Gaudecker et al., 2022).

However, a focus on cultural beliefs can overshadow consideration of the complex ecologies within which help-seeking takes place, including household relationships, access to resources and costs and quality of medical services (Das, 2015). Furthermore, TFH and biomedical care are seldom viewed by users as mutually exclusive (Ayinde et al., 2023; Thirthalli et al., 2016). Research in several contexts shows that rather than linear trajectories following systematized explanatory beliefs, healing pathways are eclectic, dynamic and pragmatic, informed by circulations of knowledge and experience from varied sources (Ayinde et al., 2023; Callan, 2012; Das and Das, 2007; Read, 2012). Many studies lack specificity regarding the numerous dynamic and diverse concepts and practices subsumed under the terms "traditional", "spiritual" or "faith" healing (Lilford et al., 2020; Pigg, 1995). Failure to account for this rich diversity within and between countries risks erasing their meaning and value for those who use them (Pigg, 1995).

Besides this conceptual ambiguity, there is a need to consider the cultures, contexts and constraints of the health systems alongside which healers operate. In many settings, mental health services are unavailable or require out-of-pocket expenditure (Nyame et al., 2021). Funding for mental healthcare in LMIC is concentrated on psychiatric hospitals and efforts to integrate mental health provision into primary healthcare, as recommended by WHO, can be challenging. Health systems are over-stretched and under-resourced and focused on tackling infectious diseases which have high mortality (Esponda et al., 2020). In addition, in many settings mental healthcare services are provided through a mix of government and private providers (Chisholm et al., 2019; Iemmi, 2019). Even where psychiatric services are available and free of charge or low cost, many people discontinue treatment, particularly in the long term (Adeponle et al., 2009; Read, 2012). Though international attention has focused primarily on abuses in traditional and faith-based healing facilities, the quality of care in public and private psychiatric institutions is often poor and coercion and abuse are widespread (Sashidharan et al., 2019).

1.1. Help-seeking for serious mental illness in slums

Given this complexity, there is a need for an approach which considers help-seeking, family care and decision-making as embedded within and emerging from social, political and economic 'ecologies' (Das, 2015). This approach is particularly important when seeking to understand care pathways within marginalised and precarious communities, such as people living in slums. Globally there are growing numbers of informal and unplanned urban settlements marked by poverty, marginalisation and insecurity (Ezeh et al., 2017; UN-Habitat, 2018). Slums are defined by UN Habitat as lacking durable housing structures, sufficient living space and access to clean water and sanitation and consisting of housing with primarily insecure tenure (UN-Habitat, 2018). People living in slums are at increased risk of poor physical and mental health due to poverty, absent or inadequate services, poor quality housing, crime and environmental hazards such as flooding (Ezeh et al., 2017). Research on mental health in slums has predominantly focused on depression and anxiety and the impact of the slum environment on mental health (Greif & Nii-Amoo Dodoo, 2015; Gruebner et al., 2012; K. N. Koly et al., 2021; Subbaraman et al., 2014; Wahid et al., 2021; Williams et al., 2018). There is limited research on the lives of people with SMI in slums and little is known about the services available and how people seek help. A scoping review of help-seeking in slums for all health conditions found the most pertinent factors included health care costs, lack of time, adverse physical environments, insecurity, distrust of authorities and distance from health services (Park et al., 2022). Slum residents also considered health service organisation, availability of supplies and healthcare workers, the attitude of health care providers, the type of health facilities and waiting time (Park et al., 2022). This reveals the delicate balance between various demand and supply-side factors influencing help-seeking and a need to understand the interests and priorities of slum-dwellers (Park et al., 2022; van den Broek et al., 2023). Importantly, most interventions addressing help-seeking for mental illness in LMIC have focused on demand-side factors, for example increasing awareness of services. A recent review points to the need to develop a better understanding of how help-seeking works within particular contexts and the role of caregivers and people with lived experience in the decision-making process (van den Broek et al., 2023).

1.2. The TRANSFORM study

Transforming Access to Care for Serious Mental Disorders in Slums (TRANSFORM) aims to improve access to mental health care in deprived urban communities in Ibadan, Nigeria and Dhaka, Bangladesh by increasing the capacity of TFH and community health workers (CHWs) to identify and refer people with SMI to biomedical services (Singh et al., 2022).

Bangladesh and Nigeria have initiated policy commitments to improve access to mental health care, including integration of mental health into primary care, mental health promotion and protection of human rights (Abdulmalik et al., 2016; Chu et al., 2022; J. Eaton et al., 2021; Saied, 2023; WHO, 2023). However, these policies face challenges in implementation, primarily due to limited resources and pressures on health systems. In both countries, TFH are widely used though existing research suggests differences. For example, two studies of patients diagnosed with schizophrenia attending psychiatric hospitals in Nigeria reported that between 60 and 70 % had previously used TFH (Adeosun et al., 2013). Studies in Bangladesh suggest greater use of private and public medical practitioners for the treatment of mental illness than traditional or religious healers (Giasuddin et al., 2012; K. N. Koly et al., 2022; Nuri et al., 2018).

To inform the development of the TRANSFORM intervention, an ethnographic study was conducted to gain an in-depth understanding of the complex ecologies of help-seeking for SMI in urban slums of Dhaka and Ibadan. The study combined observation and interviews with people with lived experience of SMI (i.e., symptoms or behaviours consistent with psychotic and severe mood disorders such as schizophrenia and bi-polar disorder), family caregivers, health workers and TFHs. In this paper we focus on interviews and observations with people living with SMI and family members to explore their understandings and lived experiences, and influences on help-seeking for SMI.

2. Methods

2.1. Setting

In Dhaka, the study was conducted in Korail *basti* (slum). Korail is located in the city centre with an area of around 0.8 km^2. The population is estimated to be around 200,000–250,000 (Choudhoury et al., 2016; Zaman et al., 2022) and primarily Muslim with small Hindu and Christian minorities. In Nigeria, the study was conducted in five local government areas (LGAs) in Ibadan, the administrative capital of Oyo State in Southwest Nigeria. The study LGAs extend over about 128 km^2 with a combined population of around 1.5 million. The population are primarily Yoruba with a mixture of Christians and Muslims, as well as followers of traditional religion (Jegede, 2002).

In both settings, specialist inpatient and outpatient mental health services for SMI are provided through tertiary and secondary hospitals and some privately owned facilities. In Ibadan this includes the federal government funded University College Hospital (UCH) and Adeoyo State Hospital operated by Oyo state government. In Dhaka, the National Institute for Mental Health (NIMH) is the country's leading public mental health institution. It is located around 7 km from Korail. Other government hospitals in the city such as Bangabhundu Sheikh Mujib Medical University also provide psychiatric services.

There are notable differences in access to primary healthcare between the study settings. In Ibadan, there are 119 Primary Healthcare Centres (PHCs) across the five LGAs. Primary healthcare workers are expected to identify and refer patients with SMI and provide follow-up for patients referred from tertiary and secondary services. The Oyo State Primary Healthcare Board established Mental Health Desk Officers (MHDOs) in all LGAs who coordinate activities related to mental health care and provide initial diagnosis, treatment and follow-up. They also train primary healthcare workers in screening, diagnosing, treating and referring people with mental illness.

In Dhaka by contrast, there are no government-funded primary health care clinics within Korail and only two clinics run by local NGOs. There are numerous private drug stores in Korail *basti* which are the most common source of consultation for common and acute medical problems in Bangladesh, particularly in urban areas (Khan et al., 2012; Mahmud et al., 2015). There are also many private hospitals and doctors 'chambers' located outside the *basti*.

In both settings, there are long-standing challenges within mental healthcare services, including insufficient staff (Fadele et al., 2024; Hasan et al., 2021). In Dhaka around 500 people per day attend the outpatient department at NIMH leading to long queues with each psychiatrist seeing 70–100 patients per day. There is no government-run health insurance scheme with only private health insurance available for those who can afford it. NIMH and most government hospitals offer low-cost treatment, charging 10 BDT for consultation and providing a week's worth of medication free of charge. After that, families need to purchase their own supply. For all other expenses, patients pay out of pocket. Of the 200 in-patient beds at NIMH 70 % are government-funded and 30 % fee-paying. In Nigeria health insurance has minimal coverage for mental illness and most families pay out-of-pocket for consultation, inpatient admission and medication (Abdulmalik et al., 2016).

2.2. Community engagement and recruitment

Prior to data collection, community engagement activities were conducted in the two country sites. This included regular visits by the study team, meetings with stakeholders and the formation of a local steering committee. These activities were used to share information about the proposed study, seek advice and suggestions in planning research activities and request support for the research. In both settings respected community members were recruited to act as intermediaries to provide information on the study and support identification and recruitment of research participants. They conducted visits to households, community leaders and TFH. Community liaison workers were trained by the senior study team to identify possible signs and symptoms of SMI (such as hearing voices, paranoid beliefs, self-neglect). Training used culturally understandable and locally recognized examples (such as talking to oneself, extreme mood changes, chaotic or bizarre behaviour) while emphasizing the importance of non-stigmatizing language. To minimise stigma and preserve the dignity of participants liaison workers were also trained in safeguarding, inclusive and respectful communication and protecting confidentiality. These methods were used to identify participants with possible SMI living with the family (Dhaka) or receiving treatment from healers (Ibadan). Recruitment and consent procedures took place within households or in private spaces within healing sites. Participation or refusal was not disclosed to others in the community and families were advised on accessing mental health services regardless of whether or not they chose to participate.

2.3. Data collection

Interviews and observation were conducted by BS (anthropologist, Dhaka) and KA (sociologist, Ibadan) and a team of research assistants in each setting (see acknowledgements). Research assistants had masters degrees and backgrounds in social science. Semi-structured interviews were conducted with people living with SMI (Dhaka n = 7; Ibadan n = 9) and family caregivers (Dhaka n = 16; Ibadan n = 7) to explore experiences of living with SMI, family care and help-seeking (Tables 1–2). To protect the confidentiality of participants and avoid stigmatisation, interviews were conducted in private spaces either in the research field office (Dhaka), family homes or healer's facilities. Interviews lasted between 30 and 120 min and were audio-recorded. Interviews were conducted in Bengali in Dhaka and in Yoruba or English, or a mix of the two, in Ibadan. Naturalistic observation was also carried out in various community settings including TFH facilities, hospitals, clinics and pharmacies, places of worship, workplaces, households and public settings. Observations were documented in fieldnotes which were written in English.

2.4. Analysis

Interview recordings were transcribed verbatim into the language in which the interview was conducted (Bengali, Yoruba or English). Transcripts in Bengali and Yoruba were translated into English for comparison and checked and corrected by researchers fluent in English and Yoruba/Bengali. Analysis followed an interpretivist reflexive thematic approach (Braun and Clarke, 2022). Coding, interpretation and theme development was led by BS and AK in Bangladesh and KA in Nigeria in discussion with UR, a White British researcher with training in anthropology. Analysis was iterative with interpretation of the data refined through in-country and cross-country discussions and comparison of concepts and experiences expressed in English, Bengali and Yoruba. During these discussions the research team actively reflected on their privilege, personal values and experience, including religious beliefs and professional training, and how this might influence their relationship with participants, data collection and interpretation.

Data analysis broadly followed stages of data familiarisation, coding, interpretation and theme development as described by Braun and Clarke (2022). The first stage involved data familiarisation through repeated reading of interview transcripts to manually identify initial codes. These included codes derived inductively from the research questions (e.g. varied treatment modalities employed) as well as codes derived from situated experience (e.g. subjective appraisals of treatment). Coding was conducted using NVivo 20. A codebook was developed from the initial

Table 1
Interview participants: People with lived experience.

	Dhaka (n = 7)	Ibadan (n = 9)
Gender		
Female	4	6
Male	3	3
Age		
18–30	3	2
31–45	2	4
46–60	1	3
61 and over	1	0
Religion		
Christian	0	8
Muslim	7	1
Education		
Primary	3	3
Secondary	2	3
Tertiary	1	3
No education	1	0
Marital status		
Married	3	5
Divorced/separated	2	0
Single	2	4
Occupation		
Civil servant	0	2
Artisan	0	3
Trader	0	2
Self-employed	4	0
Housewife	1	0
Unemployed	2	2

Table 2
Interview participants: Caregivers.

	Dhaka (n = 16)	Ibadan (n = 7)
Gender		
Female	14	4
Male	2	3
Age		
18–30	2	0
31–45	6	2
46–60	6	3
61 and over	2	2
Religion		
Christian	0	4
Muslim	16	3
Education		
Primary	4	1
Secondary	1	4
Tertiary	0	2
No education	11	0
Marital status		
Married	12	4
Divorced/separated	0	1
Widowed	4	2
Occupation		
Civil servant	0	1
Artisan	0	2
Trader	0	1
Religious leader	0	1
Retired	0	1
Self-employed	7	1
Housewife	3	0
Unemployed	6	0

codes and refined through discussion between the country research teams and further close reading of the interview transcripts. Most codes were shared across the two settings, but codes were also developed specific to each context. For example, in Dhaka the code 'tension' was used to reflect this contextually situated idiom of distress. In Ibadan we coded 'spiritual attack', an English term widely used to refererence malign forces deployed by humans such as witchcraft, sorcery or curses. Field observations aided contextual interpretation of the interview content. Emergent themes from the interview coding were developed through discussion across the research teams. These were then reviewed and refined through further discussion and engagement with published research findings and application of social science theory to guide interpretation.

2.5. Ethics

Ethical approval was obtained from the University of Warwick Biomedical and Scientific Research Ethics Committee (BSREC), Joint University of Ibadan/University College Hospital Research Ethics Committee (UI/EC/21/0409), Oyo State Ministry of Health Research Ethics Review Committee (AD13/479/44102[A]) and Bangladesh Medical Research Council National Research Ethics Committee. Permission to conduct observation was sought from relevant authorities and community gatekeepers, such as community leaders and heads of traditional and faith-based healing facilities. All interview participants gave written and/or oral informed consent. People with SMI who were unable to provide informed consent were not interviewed though they were included in observations, for example in healing facilities.

3. Results

3.1. Slum environments: insecurity, violence and precarity

Both study locations shared characteristics typical of slums including intermittent electricity supply, poor sanitation and low quality housing. However, there were important differences which impacted on help-seeking. In Dhaka the slum consists of densely packed two-storey buildings separated by narrow alleyways, mostly only passable on foot, by bicycle or rickshaw. Residents have to negotiate these narrow alleys to reach public transport and access services beyond the slum. They often pay high rents for extremely small living spaces (many measure less than 1.5 × 2m), without private sanitation or secure tenure. Families have very limited privacy and mental distress can be highly visible in the community. There is little land available to establish health clinics and healing facilities. Complex land use and tenure issues can create disputes and sustain a general feeling of insecurity.

In the Ibadan study sites, by contrast, housing is constructed on 'customary land' owned by local families. Extended families typically lived in shared housing around a central compound. In most parts, building construction has expanded to accommodate family members without formal planning. Roads and paths are poorly maintained and suffer from erosion and flooding. Many are unsuitable for vehicular access. Transport to other parts of the city is mainly by motorbike and tricycle taxis and minibus.

Economic hardship and uncertainty are central to the lived experience of families in the study areas. Most people are in insecure employment and household income is precarious. Most of Korail's population subsist below the poverty line and rely on variable daily cash income. Men work in insecure low-paid jobs such as labourers in construction sites, rickshaw drivers and security guards. Others operate small businesses as shopkeepers and street vendors. Women commonly work as housemaids and in the garment industry. In the Ibadan study area, women play an important role in income generation for the household through trading and home industries, such as selling food or sewing. Most men work as taxi drivers, artisans, traders, carpenters and tailors. In both settings people live under threat of violence arising from criminal activity, including robbery, domestic violence, political conflict and the street drug economy. In Ibadan, 'area boys' provide informal security services in return for a fee and clashes among rival groups can turn violent. In Korail syndicates operate control of illegal access to utility services and cramped housing and space constraints create a crowded living environment that raises stress levels, restricts privacy and can provoke disputes.

3.2. Healing landscape: pluralism and diversity

At both study sites, we found a rich diversity of healing practitioners (see Table 3). In Korail religious scholars (*hujur)* and ritual healers (*kabiraj)* who combine aspects of Hinduism and Islam were commonly used, particularly for long-term or recurring conditions. In Ibadan, there was a mix of healers from Yoruba religion and various forms of Christianity and Islam. The main Christian groups in the Ibadan study area include Pentecostal and *Aláàdúrà* churches. The English term 'traditional healer' is used to refer to ritual practitioners such as *Babalawo* who also make use of plant-based medicines.

In Ibadan, religious healing sites and shrines commonly occupy spacious compounds where people with mental illness can stay for periods of time. In Dhaka, by contrast, healers operating in Korail do not provide places to stay. Rather than consulting *kabiraj* locally, most Korail residents travel to their hometown or village.

3.3. Perceived causes of mental illness: speculation and uncertainty

Signs of mental illness precipitated speculation around the nature of the condition and the possible cause. Participants in both settings commonly associated mental illness with a problem in the head or brain (Bengali: *mathay somossa*; Yoruba: *arun opolo* or *odẹ-orí*). However, many expressed uncertainty around the cause. A woman in Ibadan said:

> *'My first episode happened way before I met my husband. But since they brought me here, I must have had relapse like three times. This problem brings shame to a person, I don't know where I contracted it'* (N23, woman living with SMI)

Table 3
Traditional and faith healers in Dhaka and Ibadan.

Dhaka	
Drug sellers	A primary source of medical advice and consultation. They sell a wide variety of medicines, including psychotropic medicines, without prescription. Most do not have formal training and certification. There are at least 76 private drug stores in Korail slum located approximately every 50 m.
Fakir	Islamic saint/holy man who acts as a religious teacher, healer and spiritual guide. *Fakirs* are commonly seen at *dargah* or *majar* (Sufi shrines).
Hujur	Religious scholar or imam who provides advice, guidance and treatment for health issues associated with spiritual causes, including *jinn* possession and *najar laga* (evil eye). These activities usually form part of their role as religious teachers, rather than being a distinct occupation. *Hujur* use readings from the Qur'an and Hadith in healing often accompanied by *pani pora* (holy water). The *hujur* recites Qur'anic verses and performs rituals over water which is given to patients to drink. Other substances used include *Zamzam* (spring water from Mecca), black seed oil, soaps, candles, perfumes, and incense. These are used during *ruqyah* (exorcism) and sometimes applied directly on the patient. Inscriptions from the Qur'an are also written on slates and diluted in water which is ingested or used to bathe. Some Islamic healers combine these practices with plant-based medicines.
Kabiraj	*Kabiraj* combine aspects of Hindu and Islamic practices, including Ayurveda, a Hindu system of plant-based medicines and rituals including *ban marse* (blowing on affected areas) and *jhar-fuk* (lit. 'holy blows' i.e. blowing on the person after reading the Qur'an). Some *kabiraj* invoke Hindu deities or incorporate rituals and symbols associated with Hinduism.
Ojha	A shamanic healer in South Asian (especially Indian and Bangladeshi) rural communities. *Ojha* are believed to possess spiritual powers for treating illnesses and driving away spirits. They use mantras and amulets (*tabeez*) and perform rituals including *jhar-fuk*, *totka* (lit. 'tricks'/folk remedies) and exorcism (*bhoot badha*).
Tantrik	Tantric healer who performs healing rituals using spirits.
Ibadan	
Babalawo	Priests of the *Òrìṣà* (deities) of Yoruba traditional religion. They use *Ifa* divination to identify the cause and the remedy and offer interventions for diverse health and life problems, including mental illness. *Babalawo* use plant- and food-based medicines, cloth, ashes, animals and other items for healing purposes. They also use ritual bathing to cleanse the patient of evil spirits, skin incisions, *iwure* (prayers) and incantations. Sometimes *babalawo* counsel help-seekers to observe taboos to complete the healing process and prevent relapse.
Onísègùn ìbílẹ ('herbalists')	Knowledgeable in plant-based medicines prepared from herbs, plants, roots, and bark which may be boiled, dried, blended to powder or burnt and may be administered orally or inhaled as steam or snuff. Some are administered through bathing in water mixed with these medicines or medicines are rubbed on the skin or into incisions made on the scalp or other parts of the body.
Aláàdúrà	'White garment' churches combine elements of Christian and traditional religion, such as animal sacrifice. Symbolic practices include dressing in white robes (*soutanna*), anointing with holy water and using candles and incense for purification. Many *Aláàdúrà* churches are situated along riverbanks. Supplicants may be taken to the river for ritual baths and touched with palm fronds for deliverance from evil spirits. Prayers and prophetic revelations are sought to diagnose the cause and cleanse the individual of spiritual causes of mental distress.
Indigenous churches	These churches combine elements of indigenous and Pentecostal practices. They primarily attribute mental illness to spiritual afflictions like demonic oppression or ancestral curses. Treatment is centred on intense prayer, fasting, and deliverance sessions.
Pentecostal churches	Pentecostal/Charismatic Christian churches offer a variety of interventions for mental illness including intense prayers, Bible recitation, fasting, "laying on of hands", deliverance from evil spirits and 'breaking' of curses. 'Holy water' and 'anointing oil' are also used by some churches. These are prayed over and used on the patient topically or ingested. Many Christian healers hold all-night prayers, miracle healing services and multi-day crusades to engage in 'spiritual warfare' against evil spirits. Some combine rituals and plant-based medicines. Some Pentecostal churches may encourage supplicants to seek medical help while simultaneously seeking divine intervention.
Islamic healer/*Alfa*	Similar practices to *hujur* in Dhaka

Disruptive and unusual behaviours were widely referred to using highly stigmatizing terms synonymous with the English 'madness' or 'craziness' (Bengali: *paglami;* Yoruba: *wèrè* or *igbona*). Madness was widely perceived to run in families. This could be considered a consequence of a curse on the household or evil committed by a family member. People's thoughts turned to such spiritual matters when there was no obvious reason for the onset of mental illness. Healers they consulted might also suggest a spiritual cause. In Ibadan this was often framed as a 'spiritual attack' by witches, spirits or demons:

> *'when I saw how he was behaving I thought that it must be a spiritual attack because there is no one that has it in my lineage and in the lineage of his father and it was not in history that maybe there was someone who had such problem'* (N16, caregiver, female)

Muslim participants in both Dhaka and Ibadan commonly suspected possession by *jinn*, consistent with Islamic teaching. A father in Korail described how a *kabiraj* had suggested that *jinn* had been living in a well under his son's bed which had been broken up when they repaired the floor. He saw his son's unusual strength as evidence of *jinn* possession:

> *'He's got something inside him, that I know. He's got strength. No one can beat him, even my younger son cannot.'* (B13, caregiver, male)

Notably participants in both settings did not discuss spiritual causes in isolation. A combination of social, psychological and biological factors were also seen as important influences on mental health. This included physical illness, drug use, poverty, food insecurity, unemployment, domestic violence, marital breakdown and bereavement. As described by this caregiver in Ibadan, poverty, hunger and isolation could have devastating consequences:

> *'Societal issues is poverty. When, okay, there is a person who is a bit ill, he could not get any care, the thing will continue. Oh, this place I am, lack of food has caused up to two or three [cases of mental illness]. I see it in my community that no food to eat has turned people to something else.'* (N13, caregiver, male)

In Dhaka, participants described 'tension' resulting from poverty, family conflict and other social factors. For example, a participant in Dhaka described how her aunt's 'tension', arising from her husband's drug use and violence and subsequent family breakdown, had 'turned into a mental problem':

> *'I think the problem originated from my grandfather. He used to have the same kind of problems. He also used to talk too much. I don't know, God knows. If it's hereditary, then she's got it from there. Another reason can be the breaking up of her family. The child is away. For the carelessness of the brothers. Combining all these, her tension turned into a mental problem.'* (B12, caregiver, female)

3.4. Help-seeking: experimentation, hope and desperation

In both settings, help-seeking was initiated by family members who were responsible for day-to-day care. Experiences perceived as disruptive, harmful or dangerous generally prompted help-seeking. These included talking 'non-stop', responding to voices, sleeplessness, agitation, roaming around, and refusing to bathe or eat. Such unusual behaviours set in train a search for solutions.

This caregiver in Ibadan described what happened to her son:

'Maybe, it was voices he heard or maybe he sees things. He said "They are here, they are here o!" They want to tear his cloth and then he tore his cloth. He was eating. He did not sleep o. If he sleeps a little, he will wake up and sometimes he would be saying different things. He would just be talking. The things he used to say were like preaching – "Pray, do this". You know he was not shouting for everyone to hear but as we are seated now, he would be talking and walking around in the house.' (N16, caregiver, female)

A participant in Dhaka explained how her unusual behaviour prompted her family to consult a *kabiraj*:

'when I was reading at three o'clock in the night, I threw away the books and started reciting […]. Then my mother came and told me, she had a small broomstick with her, "Why do you study all night and do this? Why are you being crazy?" She just tortured me a little bit, then I slept. When I got up the next morning, I would mess up my clothes, flip through books, read a lot. Seeing that I was doing this, they said that she has a problem, so take her to kabiraj.*'* (B05, woman living with SMI)

Agitated or aggressive behaviour was particularly disruptive within the densely inhabited slum environment in Korail and caused distress and alarm. Family caregivers described complaints from people living in the neighbourhood. For example, this father described how his daughter had been ill for around 15 years. He reported that she used to beat and bite people and strip naked. As a consequence, he moved several times and resorted to restraining her:

'I changed house three times. People object. She screams. I tie her up, she screams more. What will I do? I tied her up for six months […] She searches from shop to shop. People complain to me, "Your daughter, your crazy daughter, tie her up" […] She took something costing 20 taka but wants to pay 10 taka. People don't understand the situation. They say, "Keep your crazy daughter chained up."' (B15, caregiver, male)

As these quotes illustrate, such behaviours could lead to harsh responses and prompted some families to remove the person to a healer or hospital where they would be sedated, confined or restrained. Participants in both settings reported consecutive or concurrent use of a wide variety of treatment options, including various TFH, as well as public and private medical facilities. Key influences on help-seeking included cost and accessibility, the quality of treatment, perceptions of efficacy and the search for a cure. Rather than a clear course of action driven by spiritual or medical convictions, caregivers expressed confusion and uncertainty. In making decisions around treatment, participants therefore sought advice from family, friends, neighbours and, sometimes, religious leaders or health care providers. As one caregiver in Dhaka put it: '*Wherever people tell me to go, I will go*'. In this uncertainty and, often, desperation, stories of powerful healers and miraculous cures could offer hope. This was particularly notable in Ibadan. For example, a woman living with mental illness stated:

'*I heard the good testimony about this place that God answers prayers here. No one leaves with the problem he brought*'. (N23, woman living with SMI).

On the other hand, the search for miracles could also open families up to exploitation and potentially harmful treatment. A man in Ibadan described how a healer gave him Largactil (chlorpromazine) mixed with herbal medicine, for which his father paid a 'huge amount of money':

'*They took me to a traditional healer's place … One thing I saw there was that I knew the taste of Largactil because I used to buy it. They would take that Largactil, put it in herbs, and tell me to drink it so I would sleep. That was all the treatment I got, yet my father paid a huge amount of money for it at that time*'. (N04, man living with SMI)

'Healer shopping', the consecutive trying out of multiple forms of healing (de-Graft Aikins, 2005), was common in Ibadan as illustrated by this caregiver, who described how her family drove her sister around to various healers:

'*Then we went to xx hospital, when we left the facility of that Islamic cleric then the children of my mother' s younger sibling were taking us around […] Then they suggested that we try the place also. Even in that place, like her condition may be better, then after some days it would become critical.*' (N01, caregiver, female)

While rumours about spiritual causes such as 'witchcraft' and 'jinn' influenced recommendations for healers, many people also recommended 'mental hospitals' and medical treatment. This mother in Dhaka, for example, was advised by an acquaintance to take her son to Pabna mental hospital, outside the capital. When her son reacted badly to the medicines, other people in the community advised her to use a private doctor:

'*Those medicines made my son mad, everyone advised to stop those medicines, which had a bad reaction, his eyes protruded. Too much medicine was not suiting my son's brain. Then people of this area asked me not to take these medicines. Then what should we do? One person gave the news of a good doctor who had a chamber at x. We heard that patients were getting well from him. From there on we have been taking medicine from there for 2–3 years.*' (B03, caregiver, female)

Chronic symptoms, frequent relapses and prolonged treatment with medication could lead people to continue searching for an effective and lasting cure. This was often driven by pragmatism and experimentation rather than systematized 'belief'. Indeed, this Christian caregiver in Ibadan explained that she consulted a healer more out of desperation than conviction:

'I do see them but I do not believe in what they do. That is not my way of belief […] but when I did not know what to do again, I remembered the place as soon as I woke up.' (N03, caregiver, female)

In addition, use of healers did not necessarily align with specific religious or cultural affiliations. For example, Muslims in Dhaka visited healers whose practices are informed by Hindu traditions and Muslims in Ibadan sometimes visited Christian healers. This reflects the ways in which healers in both settings creatively combine elements of different religious and spiritual traditions (see Table 3). A caregiver in Ibadan emphasized that whatever the religion of the healer, the primary goal was that their family member was healed:

'Religion - it is different. It stands separately. Hmm, treatment is different. If it is Muslim, if it's from babalawo *that he'll get healing, we will take him there. If it's a church that he'll get healing, we will take him there, and if it's at an* alfa*'s* [Islamic healer] *place, and even if it's with doctors, where they care for sick people, as long as he gets healed is our goal. It has nothing to do with religion.*' (N013, caregiver, male)

Although caregivers in both settings had made use of biomedical treatment at some point, most were convinced that this alone would not provide a total cure. Caregivers commonly combined medical and spiritual treatment as described by this woman in Ibadan: '*they said it is not medical alone, that we should add spiritual aspect too*.' (NG16, caregiver, female).

3.5. Experiences of using traditional and faith healers: help and harm

Consistent with this view, all participants experiencing SMI had received treatment from healers, interspersed with use of various public and private medical facilities (see Tables 4 and 5). In Dhaka, four out of seven participants treated for SMI had been taken to a *kabiraj* or *hujur* as the first port of call (see Table 4). All the *kabiraj* visited by participants in Dhaka were located outside Korail, although a couple reported that healers had come to visit them at home. Families travelled distances ranging from 150 to 400 km to seek treatment from *kabiraj*, incurring significant time and expense. In Ibadan, healers were more easily

Table 4
Help-seeking pathways in Dhaka.

ID	Gender	Caregiver	Source of treatment in chronological order (+ indicates simultaneous use of treatment sources)	Sources used (total)	TFH	Biomedical
B01	Male	Mother	*Kabiraj* (Korail) → *Fakir* (2 different *fakir*), *Hujur*, (Sylhet district), *Kabiraj* (Dhaka) → *Kabiraj* (2 *kabiraj*, different districts) → private medical doctor → private hospital (Dhaka) → private neuroscientist (Dhaka) → *Hujur* (Dhaka)	11	8	3
B02	Male	Wife	*Dargah*/shrine (Dhaka) → 2 famous shrines, (Sylhet district) → shrine (Chittagong district) → shrine (Dhaka) → private hospital → private medical doctor	7	5	2
B03	Female	Parents and neighbours	*Kabiraj* (Dhaka) → private medical doctor → *Kabiraj* (Tangail district) → *Kabiraj* (Barisal district) → private hospital → private doctor → NIMH	7	3	4
B04	Female	Son and daughter-in-law	General government hospital + *Kabiraj* (Korail) → Pharmacy/private doctor (Korail)	3	1	2
B05	Female	Mother and maternal uncle	*Kabiraj* → private laboratory/medical centre → private doctor → *Kabiraj* (Dhaka) → private laboratory/medical centre → private doctor (telemedicine)	4	2	2
B06	Female	Mother and sister	Kabiraj (Narayanganj) → government psychiatric hospital (Dhaka) → Kabiraj (Haraspur, Comilla) → NIMH (Ist admission) → NIMH (2nd admission) → NIMH (out-patient)	4	2	2
B07	Male	Wife	Various drugstores + private doctor (Korail) + *Hujur* → private clinic (Dhaka)→ government psychiatric hospital (Dhaka)→ private doctor (Dhaka)	6	2	4

Table 5
Help-seeking pathways in Ibadan.

ID	Gender	Source of treatment in chronological order (+ indicates simultaneous use of treatment sources)	Sources used (total)	TFH	Biomedical
NG04	Male	Hospital (private) → Indigenous church A → Mosque → *babalawo* → Hospital (private) → UCH	6	3	3
NG05	Female	Indigenous church A → *babalawo*	2	2	0
NG06	Female	Indigenous church A → Indigenous church A → Pentecostal church A + UCH	4	3	1
NG07	Female	*Aláàdúrà* church A → UCH	2	1	1
NG08	Male	Mosque → Indigenous church A → Adeoyo State Hospital → UCH	4	2	2
NG09	Female	*Aláàdúrà* church B → Pentecostal church B → UCH → Pentecostal church B → UCH	5	3	2
NG10	Male	Adeoyo State Hospital → UCH	2	0	2
NG15	Male	Faith healer → Hospital (Catholic) → UCH → Pentecostal church C	4	2	2
NG23	Female	Prayer house → Adeoyo State Hospital → Indigenous church A → Indigenous church B → Indigenous church C	5	4	1

accessible as there were many healing facilities spread across the LGAs. However it was also common for people to visit healers away from their neighbourhood, whether to visit a reputed healer or to avoid stigma. Seven out out of nine participants had visited a healer as the first option. All except two had utilized both biomedical services and TFH. One had only used TFH and one had only used biomedical services (see Table 5).

In both contexts, use of TFH was often on a 'trial and error' basis. Some people sought help from healers when symptoms did not improve with medical treatment, especially when *jinn* or other spiritual influences were suspected. A caregiver in Dhaka explained how when his mother showed signs of mental illness the medical doctor for whom his sister worked as a housemaid advised that they take her to a private hospital and paid for the treatment. However, after five months taking medication, his mother's condition did not improve. He then tried a private mental hospital but again there was little change. Finally, he visited a *kabiraj* who advised that his mother was afflicted by a spirit. He therefore decided to try his treatment:

> '*I said, "Okay. Whatever you want to give, hand it over, I will try by the grace of Allah". He gave* pani pora *and holy oil. He said, "Massage the oil and drink the water. Everything will be fine* inshalla".' (B14, caregiver, male)

Spiritual practitioners could also be used to *rule out* spiritual causes, as well as to confirm them. Despite the improvement in her son's condition after hospital treatment, a mother in Dhaka also approached a couple of *kabiraj*. They assured her that there was no involvement of *jinn* or ghosts and since her son had a 'brain problem' she should seek better medical treatment, rather than spiritual treatment:

> "*I told him [the* kabiraj*] to carry on the treatment, I have been to several places but they couldn't cure him. Please have a look at him and tell us what happened to him. I was told that he was suffering from a brain problem. He said that as his brain is in trouble I should visit a better doctor.*' (B03, caregiver, female)

For some people living with SMI spiritual rituals could be perceived as providing calm and comfort. This man from Korail described the 'mental peace' he experienced at an Islamic shrine:

> '*I used to visit the shrines because I found it personally enjoyable. It gave me a sense of solace and tranquillity as I engaged in* Zikir, *the remembrance of Allah. By invoking the name of Allah and His Prophet, I found a source of mental peace during times of stress. It was a place that many individuals frequented for similar reasons, seeking spiritual comfort and relief.*'
> (B02, man living with SMI).

On the other hand, several participants found healers to be ineffective and harmful. The majority of people in Ibadan who had used TFH reported inhumane treatment. This included beatings, chaining, prolonged periods of involuntary 'fasting', and sexual abuse. The common use of restraints was also observed during field visits to healers, whether Christian, Islamic or traditional. A woman from Ibadan explained how she asked her father to take her away from the church where she was mistreated:

> '*I was always asking my dad to come and pick me up, taking me from one church to the other until we knew about UCH. Before I started getting treatment, I prayed. I was being chained everywhere they took me to. I had marathon fast, I did everything*' (N06, woman living with SMI)

A caregiver in Ibadan similarly reported how her son was beaten and deprived of food:

> '*they used to beat him whenever he did not cooperate. The only thing I observed was that he was underfed there because if he was well fed, he wouldn't be as lean as he was. […] What I used to detect that they were*

not giving food was that whenever he sees us come inside the church for a programme if he sees somebody's food he would carry it, if he sees a child with a biscuit, he would forcefully collect [take] it.' (N16, caregiver, female)

3.6. Experiences of biomedical treatment: conflict, coercion and distrust

Almost all families in both settings had also used biomedical treatment. Participants in Dhaka were generally unaware of the availability of specialist psychiatric hospitals such as NIMH and instead visited a variety of private doctors, clinics and hospitals (see Table 4) as well as drug sellers. Most could not recall a diagnosis other than a 'brain problem' and reported being prescribed various injections, medicines and pills:

'*I went to see about four* kabiraj *and saw five to six doctors. Lastly, I went to the doctor and he gave me antibiotics, I went twice to him. He gave me medicine, then just said to continue with those medicines.*' (B03, woman living with SMI)

In Ibadan all except two participants had made use of UCH, even when also having used TFH, suggesting more familiarity with this tertiary facility (see Table 5). Some participants reported successful treatment from psychiatric facilities. For example, this man in Ibadan found the medication from the psychiatric hospital to be more effective than interventions he had received from various healers:

'Later, my dad requested that they take me away from there and they took me back to x hospital. I started taking my medication again properly and my life was balanced. None of those interventions had significant relief for me. They all couldn't pinpoint the exact cause of my condition.' (N04, man living with SMI)

However, while some caregivers in both settings perceived medication to be helpful, particularly in calming disruptive behaviours, their relative with SMI could refuse to take it. This could lead to conflict and coercion. A woman in Dhaka living with her husband with SMI described how although he seemed to get calmer and 'cool' when taking medication, he often refused it:

'We give him medicine, but he does not want to take it so we mix the medicine with rice. Whenever we talk about taking medicine, he scolds me. He doesn't want to take medicine at all. Whenever I ask him to take medicine, he talks nonsense and says "What is wrong with me? Why are you giving me medicine? You go and treat yourself, you are sick"' (B11, caregiver, female)

A health worker in Ibadan who was caring for her sister described how she threatened to kill their mother because her sister believed she was coming to inject her:

'She said, "I will kill you, this is where they are going to bury you", where they buried my daddy. She said, "You will be beside your husband". As soon as she saw me in uniform, she said "You have brought injections again". She started shouting. So she was aggressive and can kill my mother.' (N03, caregiver, female)

Several participants living with SMI described harmful or unpleasant effects of medication, as described by this woman in Dhaka:

'I sought medical assistance from a female medical doctor, but unfortunately, she administered an incorrect treatment. For example, after receiving an injection from the doctor in my arms, I experienced discomfort. Subsequently, I experienced symptoms such as excessive salivation and a temporary paralysis in my hands and feet. Despite seeking medical attention, I did not notice any improvement.' (B05, woman living with SMI)

A woman in Ibadan described how she felt that the drug her family bought for her did not 'suit' her and so she refused to use it:

'You see that drug, it doesn't align with my destiny, because each time I use it like this, it's always like I will be dull, with my eyes dimmed. […] When I get the drug like this, me, I trash the drugs. They have bought this drug about three times. I did not use it. My family members pleaded with me several times but each time I use it, I feel dizzy. They told me it happens to other people as well. It doesn't suit me.' (N23, woman living with SMI)

A caregiver in Dhaka similarly described how she took her daughter to a private hospital but stopped the medication because of the harmful effects she observed:

'She was in a very bad condition. After stopping the hospital medicines, she could walk properly. When we brought her back from hospital, she was acting as if she was dead. Her whole body was stiff and cold.' (B12, caregiver, female)

These experiences could lead to distrust and fear of medical treatment. Some suspected that private doctors were only motivated by money, as this caregiver complained:

'The doctor didn't say anything. All they care about is money, don't you understand? It's the greed of money.' (B13, caregiver, female)

Other negative experiences reported included the attitude of some health workers and long waiting times.

3.7. Treatment costs: affordability and sustainability

Poverty and financial insecurity were major impediments to accessing treatment of any kind, particularly in the long-term. Families reported struggling to pay treatment costs, whether from healers or medical facilities, both government and private. The latter was particularly noted in Dhaka where caregivers reported significant expenditure on private doctors. Biomedical treatment included payments for consultation and medication, as well as transportation. This placed a high burden on households, particularly over the long term. At the time of data collection, the cost of consultation at mental health clinics in Ibadan was 2000–2500 NGN per visit and inpatient admission around 150,000 NGN per month. A caregiver stated that for each visit to the hospital she spent over 30,000 NGN, including the cost of transportation (15,000 NGN) and medication (18,500 NGN). At the time of data collection the legally mandated minimum wage in Nigeria was 30,000 NGN per month (around 40USD) however many participants earned considerably less than this. For example, a woman living with SMI in Ibadan stated she made about 8000 NGN per month from petty trading. She complained of the 'huge' amount of money she had to pay for medication:

'I see that drug as though it wants to make one foolish because of the huge amount of money that was spent in purchasing the drug. The receipt [consultation] alone costs 2000 [NGN], and we would also be in a long queue. The cost of the drug too is too much' (N23, woman living with SMI)

Cost was also calculated in terms of the time needed to visit health facilities, particularly specialist facilities outside the slum areas. In both settings, insecure work and long working hours meant that time spent seeking treatment could lead to loss of earnings. As described above, most people were self-employed or in casual labour and therefore dependent on variable day-to-day earnings. As witnessed during field observations and described by the participant above, in both settings travel times on public transport and long queues within government hospitals could mean that seeking medical treatment could take the best part of a day.

Participants in both settings also described spending substantial sums of money for treatment by healers. This included buying animals and other objects to complete rituals. Participants expressed frustration that despite this outlay, they did not see any change.

'*One* kabiraj *told me he needed a big goat, a chicken, and red clothes. I gave all of these to him. But the* kabiraj *only got the money from us, but we did not find any benefit […] I took her to another* kabiraj. *He took 5000 BDT for blowing after reciting something.*' (B15, caregiver, female)

'*The second day we did not see any changes, the third day there were no changes. They now added that we should buy an animal. Right there we told them that we did not have money to buy any goats o, that we have not seen any changes*' (N01, caregiver, female)

Costs for healers in Ibadan varied widely. Some caregivers reported that treatment from healers was more expensive than biomedical care, others claimed the contrary. Some reported that healers had provided care despite their inability to pay. Compared to the hospital, healers could also offer flexibility as they permitted payment in installments. However, cost was balanced with judgements of perceived efficacy. If treatment was effective then the outlay may be considered justified, as described by this caregiver in Ibadan:

'When I got there [healing church]*, they said they are going to collect 300,000 naira. They collected a huge amount of money. Three hundred thousand, yes, we have paid up to one sixty [160,000 NGN]. The first day we went there, we went with a hundred [100,000 NGN]. I had cash with me. It can build a house, a good amount of money. They admitted her at xx, xx and xx (hospitals) [….] We contributed 60,000 [NGN] for her treatment. We can't really calculate the amount we spent on her but we didn't mind, we only wanted her to get better.'*
(N03, caregiver, female)

Whether from hospitals or healers, treatment costs could deplete precious family capital, as described by a caregiver in Dhaka:

'My husband reserved some money for buying a house at Korail. He brought some money from his grandfather's house. That time it was possible to buy land and make a home with 10-12,000 taka, with the fence. Then my daughter had such a situation and we spent all the money for her treatment. Now we can't build our own home.' (B02, caregiver, female)

Changes in household circumstances could have a direct impact on this precarious ability to meet treatment costs. A caregiver in Ibadan indicated that the family had stopped seeking specialist treatment for his brother's mental illness due to the death of their father who was paying his hospital bills:

'Since his father passed away no one is taking care of him. He only takes paracetamol anytime he is not feeling too well. He buys over the counter drugs and uses it' (N02, caregiver, male)

Faced with these unsustainable costs, caregivers commonly discontinued treatment over time as this mother in Dhaka explained:

'Because I am a poor person, I could not afford to seek medical treatment. I am spending all the money that I am earning. I don't have the money to treat her right now. To take her to a good doctor, is it not a matter of money? If there is no money, the doctor will not give treatment.' (B01, caregiver, female)

4. Discussion

For families living in poor urban communities in Dhaka and Ibadan mental illness deepens existing precarity and marginalisation. Within these communities harm not only emanates from individual-level stigma and discrimination towards people with mental illness, such as mockery, neglect, or violence from families and community members, and vulnerability to coercion and exploitation within health services and healers, but is compounded by structural violence, that is systemic exclusion from resources, services and infrastructure (Gyamfi et al., 2025). The result is that those most in need face the greatest obstacles to care and support. In the face of these exclusions at both individual and structural levels, our findings suggest that family responses are grounded less in the abstractions of belief, than in the necessity to mobilise the resources at hand to seek solutions.

Veena Das highlights how 'ecologies of care' emerge within the social and material conditions of poor urban communities (Das, 2015). In these contexts, possibilities for care are constrained by the precarity of lives and livelihoods. As Das describes in India, faced with SMI, families in slum communities of Dhaka and Ibadan strategized treatment 'within the institutions of their local ecology' (Das and Das, 2007, 87), including faith-based, 'traditional', public and private medical practitioners. In this pluralistic landscape, explanations of illness present as 'possibilities' or 'propositions', engaging with structural contexts of health systems and the political economy as much as individual cultural and religious orientations (Das and Das, 2007; Susan Reynolds Whyte, 2002). Thus, while spiritual causes were sometimes suspected, for slum dwellers in Dhaka and Ibadan help-seeking for SMI was also shaped by contexts of poverty, violence, marginalisation and insecurity.

Help-seeking in both sites reflected what Whyte (1997) terms a 'pragmatics of uncertainty', drawing on advice and recommendations from family, neighbours and religious leaders and experimentation with varied forms of treatment, sometimes aligning with spiritual beliefs, but sometimes not. TFH were valued by some, particularly for the social and spiritual support they provided and the possibility of a cure. Healers also operated as sites of containment at points of crisis, whether within healers' compounds in slum communities in Ibadan, or home villages in Bangladesh. However, this could lead to abuses such as beatings and restraint which were commonly reported within healing facilities in Ibadan. In both settings, there were also reports of financial exploitation through high charges for rituals and treatments which eventually turned out to be ineffective.

Alongside these encounters with healers, families also experimented with biomedical treatment. However, while in Ibadan people were more likely to make use of government hospitals, in Dhaka families commonly made use of various private medical services, including hospitals and 'doctor's chambers'. This is consistent with previous studies of family help-seeking for mental illness in rural and urban areas in Bangladesh (Callan, 2012; Koly et al., 2024) Whilst some participants found medical treatment helpful in controlling distressing symptoms, participants in both settings reported unpleasant and, for some, dangerous effects from medication. At times this could lead to conflict with family caregivers who could resort to coercive treatment. Both of these are a major disincentive to adherence, particularly in the long term (Adeponle et al., 2009; Teferra et al., 2013). While harmful effects of pharmaceuticals are reported globally, there are additional risks where their administration may be poorly regulated (Ayenew et al., 2021; van der Heijden et al., 2019) and coercion may be institutionalised, whether in private or government facilities. As our study shows, this can delay access to biomedical healthcare and reinforce distrust of health services, highlighting the need to improve the quality as well as the accessibility of care, including ensuring that treatment is not coerced or enforced.

While the integration of mental health into primary care is recommended to improve access and reduce stigma (Patel et al., 2023), this pathway was not available in Dhaka due to the absence of primary health clinics within Korail, a noticeable contrast to rural areas of Bangladesh (Kabir et al., 2019). In Ibadan, while primary care clinics are more widely available in the study sites and a designated mental health officer was in post, no participants reporting making use of primary care for SMI. As found in an earlier study in Nigeria (Julian Eaton et al., 2017), this points to the need to raise awareness of these community-based resources, beyond potentially more familiar institutional routes such as psychiatric hospitals.

Our findings underscore the importance of a multi-component approach to help-seeking interventions for SMI, that move beyond raising awareness to addressing both supply *and* demand side issues (van den Broek et al., 2023). In Bangladesh, a recent study which included

interviews with people with lived experience of mental health issues (though not with SMI) highlighted individual and systemic influences on the use of mental health services, including stigma, access, mental health literacy, and affordability of services, as well as care pathways, workforce, governance and finance issues (Koly et al., 2024). Promising interventions include the use of community health workers, trusted community members and peer support workers to provide advice, advocacy and support to navigate pathways to care alongside strengthening community-based services (van den Broek et al., 2023).

Our study also highlights the importance of 'context-within-context' (Fayehun et al., 2022) in developing interventions, so as not to exclude marginalised groups, such as slum communities, within comparatively well-resourced urban settings. Given the poverty and insecurity within slum communities, costs were a major consideration in help-seeking decisions. These included transport to specialist mental health facilities as well as lost earnings due to travel and long waiting times. Though costs may be higher for those travelling from rural areas (Koly et al., 2024), our findings show that affordability remains an important consideration for marginalised urban communities (Fayehun et al., 2022). Treatment costs for SMI can present heavy demands on the poorest households, particularly over the long-term (Addo et al., 2018). Families attempted to meet these through selling property, taking loans and spending savings. Health expenditure can have a catastrophic impact on poor households (Hoque et al., 2015) and changes in circumstances, such as unemployment or the death of the main breadwinner, could abruptly curtail the ability to meet treatment costs. This could ultimately exclude people with SMI from any kind of treatment, whether from hospitals or healers. As Das argues, this challenges moralising narratives of family abandonment, highlighting instead the dilemmas facing families living at 'the margin of economic survival' who must balance different claims on their care and resources (Das, 2015). Personalised, informal interactions with healers could enable greater flexibility in meeting their costs and may contribute to healers being a more accessible source of support compared to more rigid financing requirements within formal services.

As our study and others have shown (Callan, 2012; Das, 2015; Estradé et al., 2023; Verity et al., 2021), decisions about care for SMI are relational, embedded within family life with its conflicts, priorities and values. Despite the precarious conditions within the study settings, participants' accounts reveal the lengths to which families went to seek help, often at great expense over long periods of time. Yet people with lived experience of SMI and their families are seldom involved in service planning (Lempp et al., 2018; Ryan et al., 2019) and our study points to the restricted role of people with lived experience in decision-making around their care. This suggests the importance of centering people with lived experience of SMI and their families to ensure that interventions are responsive to their lived realities, as well as their preferences, values and priorities.

4.1. Limitations

This study reports on a small sample of people living with SMI and their caregivers and a larger sample would have enabled exploration of a wider diversity of experiences. Safety concerns and time constraints also limited naturalistic observation conducted within the slum communities. This constrained our ability to enrich interview accounts with observations of family interactions and healing encounters which would have provided more in-depth consideration of care in practice. Nonetheless, our findings resonate with those of other studies while providing new insights into the complex influences on help-seeking for SMI of families living in slums. In addition, our close engagement with local steering committees and community liaison workers within the research sites facilitated our understanding of the precariousness of daily life in slum communities in Dhaka and Ibadan.

5. Conclusion

With rapid urbanisation and growth in slums, there is an increasing need to consider inequalities in access to treatment and support for people living with SMI in these marginalised communities. Our findings highlight the ways in which families in slum neighbourhoods in two different contexts struggle to access effective and affordable treatment and care. While cultural beliefs certainly play a role in shaping how people make sense of mental illness, an emphasis on beliefs can distract attention from systemic issues such as accessibility and affordability of treatment options, as well as the quality of health services. It can also overlook influences on decision-making in contexts of poverty, stigma and exclusion, in which people with lived experience may have little opportunity to express their preferences for treatment and care. The complexity of influences on help-seeking and dissatisfaction with health services as well as healers suggests that a contextually informed, multicomponent approach is needed which addresses health system weaknesses and affordability as well as accessibility. Policy and interventions also need to go beyond health systems to address social, political and economic sources of discrimination and structural violence (Burgess et al., 2025) which sustain marginalisation and prevent meaningful recovery and inclusion.

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CRediT authorship contribution statement

Ursula M. Read: Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Bulbul Siddiqi:** Writing – review & editing, Writing – original draft, Supervision, Software, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Kafayat Aminu:** Writing – review & editing, Writing – original draft, Supervision, Software, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Adeola Afolayan:** Writing – review & editing, Writing – original draft, Project administration, Investigation, Formal analysis. **Md Tahsinul Haque:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Data curation. **Ashrafuzzaman Khan:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Data curation. **Nadia Alam:** Investigation, Data curation. **Srividya N. Iyer:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Obafemi Jegede:** Writing – review & editing, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Data curation. **Akinyinka Omigbodun:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization. **Olayinka Omigbodun:** Writing – review & editing, Supervision, Resources, Project administration, Methodology, Funding acquisition, Data curation, Conceptualization. **Tanjir Rashid Soron:** Supervision, Methodology, Data curation. **Sagar Jilka:** Writing – review & editing, Supervision, Project administration, Methodology. **Swaran P. Singh:** Supervision, Methodology, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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