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Lived Experiences of Mothers of Children with Mental Illnesses: A Case Study of Mukuru Kwa Ruben Centre in Nairobi, Kenya

Esther Magara Omwamba *, Anne Wanjiru Mbwayo * and Daniel M. Kitonga

Institute of Youth Studies, School of Arts and Social Sciences, Tangaza University, Kenya.

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Abstract

This study analyzed the experiences of mothers with children diagnosed with mental illnesses at the Mukuru Kwa Ruben Centre in Nairobi, Kenya. The study aimed to understand mothers' views on the causes of mental health disorders, their preferred treatment methods, and the coping strategies they employ. The study employs the social constructivism theoretical framework, utilizing the Health Belief Model (HBM) to examine health perceptions and beliefs, alongside the Family Systems Theory (FST) to explore the impact of family dynamics on caregiving. A qualitative phenomenological methodology was employed, involving semi-structured interviews with eight mothers of children experiencing mental health challenges, such as autism spectrum disorder (ASD), Attention Deficit /Hyperactivity Disorder (ADHD), foetal alcohol spectrum disorder (FAS), and cerebral palsy (CP). The mothers were deliberately selected from those in attendance at the Centre. The data were collected in English and Kiswahili and then analyzed thematically. The findings indicate that mothers possess varying perspectives on mental illness, significantly influenced by their cultural and spiritual beliefs. Some individuals believe that mental health issues stem from supernatural influences, ancestral curses, or moral shortcomings. This notion influences their caregiving approach and the treatment options they select. Many mothers acknowledge the importance of professional mental health services, even though accessibility remains a challenge. These findings emphasize the need for culturally sensitive mental health interventions that integrate traditional beliefs with evidence-based practices, improve access to affordable professional care, and promote community education to address stigma and misconceptions. The research offers helpful suggestions for policymakers, mental health professionals, and support organizations to improve support systems for families affected by mental illnesses.

Keywords: Mothers lived experiences; Children mental illnesses; caregivers' Health Belief Model; Family Systems Theory

1. Introduction

Child mental illnesses pose a substantial public-health and social-care challenge worldwide. The World Health Organization estimates that around one in seven adolescents (14%) experience mental health conditions, which impair functioning and affect families and communities (WHO, 2024). Mothers commonly occupy primary caregiving roles; their perceptions of, and responses to, a child's mental illness therefore profoundly shape recognition, help-seeking, treatment adherence, and the child's social and developmental trajectory.

Research across settings identifies recurrent themes in how mothers perceive causes, consequences, and appropriate responses to child mental illness. Cultural and local explanatory models often foreground supernatural, familial, or moral attributions. For example, in Endebes sub-county, Trans-Nzoia, Kenyan parents and guardians cited witchcraft, curses, family inheritance, accidents, drug use, illness, and traumatic episodes as causes of mental illness (Imbwaga,

* Corresponding author: Esther Magara Omwamba and Anne Wanjiru Mbwayo

2015). Such causal beliefs influence both stigma and care choices: when communities view mental distress as spiritual or moral failing, families frequently experience blame and social exclusion (Amuyunzu-Nyamongo, 2013).

Stigma emerges as a central and pervasive force in maternal experience. Public stigma—negative community attitudes toward the child—and courtesy or affiliate stigma directed at caregivers erode mothers' social standing and emotional resources (Tekola et al., 2020). Masuda et al. (2012) link widespread public stigma to negative help-seeking attitudes, while Oz et al. (2019) document that mothers of children with autism commonly internalize stigma; this internalization correlates with elevated anxiety and depression and lower life satisfaction. Where stigma is strong, mothers report shame, concealment, and reduced engagement with formal services, compounding isolation and delaying intervention.

Mothers also report complex emotional responses that go beyond the practical burdens of caregiving. Studies from high- and low-resource contexts show grief, guilt, fear, and chronic stress as recurring experiences. Lautenbach et al. (2012) found that mothers regarded serious mental illness as uniquely disruptive compared with chronic physical conditions: they grieved the loss of the child's premorbid personality and mourned dashed hopes for the child's future. Scharer et al. (2009) identified "emotional strain" as a dominant theme among mothers of hospitalized children with serious mental illness, together with the role of the mother as advocate and the critical facilitation role played by mental health nurses. These emotional strains interact with caregiving demands to undermine maternal wellbeing and, in some cases, physical health (Manyara, 2020).

Recognition and interpretation of symptoms shape whether and how mothers seek help. Large-sample surveys demonstrate that visible, externalizing behaviors—stealing, aggression, and temper outbursts—tend to be more readily identified by parents as problematic that are associated with internalizing symptoms such as persistent worry or social withdrawal (Abera et al., 2015). This differential recognition has practical consequences: children with internalizing disorders may go unrecognized and untreated, while those with externalizing behaviors may be labelled as morally troublesome, attracting punitive social responses rather than therapeutic support.

Economic and informational constraints further constrain maternal responses. In low-resource settings caregiving imposes real financial and time burdens that reduce families' capacity to secure education, healthcare, and social participation for the child. Gona et al. (2011) describe how carers in Kilifi experience the collapse of hopes for economic returns from the child, social isolation, and insufficient medical information. Poverty amplifies the practical toll of caregiving—scarcity of funds for medication, transport and schooling increases stress and limits options for care.

At the same time, studies identify protective factors that mitigate stigma and its negative effects. Family support, community acceptance, and increased awareness about developmental disorders reduce the likelihood that parents will internalize stigma and facilitate constructive responses to the child's needs (Tekola et al., 2020). Byrne (2020) emphasizes that well-informed, supported caregivers contribute positively to treatment outcomes, underscoring the importance of targeted caregiver education and community-based supports.

Across diagnostic groups, mothers of children with developmental disorders and autism report particularly high levels of caregiving strain, with elevated stress, anxiety, depression and physical exhaustion reported in Kenyan and international samples (Manyara, 2020; Oz et al., 2019). These difficulties underscore the need for interventions that attend to both child symptomatology and caregiver wellbeing if outcomes are to improve.

Taken together, the literature highlights five consistent insights relevant to urban, low-resource contexts. First, mothers frequently perceive mental illness as uniquely severe and disruptive compared to physical health conditions, and this perception shapes caregiving priorities (Lautenbach et al., 2012). Second, stigma—public, courtesy, and internalized—remains a major barrier to help-seeking and social inclusion (Masuda et al., 2012; Tekola et al., 2020). Third, symptom visibility influences recognition and response: externalizing problems attract attention more readily than internalizing problems (Abera et al., 2015). Fourth, socio-economic constraints and cultural beliefs (including supernatural explanations) compound caregiver stress and limit access to care (Imbwaga, 2015; Gona et al., 2011). Fifth, social support, family acceptance, and caregiver education can buffer adverse outcomes and promote engagement with services (Tekola et al., 2020; Byrne, 2020).

Despite this robust evidence base, important gaps persist. Much research derives from clinical samples, rural populations, or diagnostic-specific studies; comparatively few studies examine mothers' perceptions within densely populated urban informal settlements where precarious livelihoods, informal social structures, high population density, and limited-service availability intersect. Nairobi's informal settlements combine constrained material resources with complex social networks and distinct cultural dynamics that likely modulate explanatory models, stigma experiences, coping strategies, and help-seeking pathways.

This study addresses that gap by exploring the perceptions of mothers of children with mental illness in Nairobi's informal settlements. It foregrounds mothers' interpretations of their children's symptoms, the emotional and practical consequences of caregiving, the forms and sources of stigma they encounter, and the social and systemic supports they access or lack.

2. Methodology

This study adopted a social constructivist epistemology, which privileges participants' subjective meanings and lived experience and recognizes that knowledge is co-constructed between researcher and participant. This stance was appropriate for exploring how mothers interpret, cope with, and make sense of their children's mental health challenges. A qualitative phenomenological design was employed to elicit in-depth descriptions of mothers' beliefs about causes, preferred treatments, and coping strategies.

The research was conducted at the Mukuru Kwa Ruben Centre, located within the Mukuru informal settlement in Nairobi, Kenya. The Ruben Centre is a faith-based community organization managed by the Christian Brothers African Province, and it provides education, health, social services, and community development programs and served as the study's recruitment and data-collection hub.

The target population comprised mothers who were primary caregivers of children diagnosed with mental illnesses and / or developmental conditions (including autism spectrum disorder, attention-deficit/hyperactivity disorder, fetal alcohol spectrum disorder, and cerebral palsy) and who were receiving support at the Ruben Centre. The center's register identified 39 such caregivers. Following an information session and informed-consent process, 28 mothers agreed to participate. From these consenting mothers, the researcher used purposive selection criteria by capturing variation across key characteristics: From the pool of 28 consenting mothers, the researcher purposively selected 10 participants who collectively represented and met the criteria of the study. The researcher reviewed demographic information collected during the consent process and systematically selected participants to ensure representation across age ranges, educational levels, marital statuses, and children's diagnostic categories. Although ten participants were initially selected in line with the study's sample size projection, data collection ceased after eight interviews when thematic saturation was reached.

Data were collected through semi-structured, face-to-face interviews using an interview guide informed by the literature and the study's objectives. Semi-structured interviews allowed open-ended inquiry and flexible probing to elicit rich, contextualized accounts of mothers' perceptions, causal beliefs, treatment preferences, and coping strategies. Interviews were conducted in a private, quiet room at the Ruben Centre to protect privacy and encourage candid disclosure. Two interviews were scheduled per day to accommodate participants' responsibilities; each mother chose a convenient time. With permission, interviews were audio-recorded to ensure accurate capture of participants' accounts. Interviews were conducted in English or Swahili according to participants' preferences.

The researcher analyzed the data using reflexive thematic analysis, an iterative process of close reading, coding, and theme development that is well suited to phenomenological inquiry. Analysis steps included familiarization with transcripts, generation of initial codes, collation of codes into candidate themes, and refinement of themes through recursive review of the dataset. The researcher documented analytic decisions in a reflexive journal and used constant comparison to ensure themes reflected participants' meanings rather than preconceived assumptions.

Ethical approval for the study was obtained from Tangaza University Research Ethics Committee, and a research license was secured from the National Commission for Science, Technology and Innovation (NACOSTI). Permissions were granted by the Ruben Centre administration. Participants received full information about the study and provided written informed consent; they were informed of their right to withdraw at any time without consequence. Confidentiality was assured through pseudo-nomination and secure storage of data. Participants were offered information about local support services should interview discussions elicit need for further psychosocial assistance.

3. Results

This section highlights the finding from the interviews conducted involving 8 mothers of children with mental illness at the Mukuru Kwa Ruben Centre in Nairobi. The data collected from the 8 participants was organized through thematic analysis.

3.1. Demographic Characteristics of Participants

Table 1 presents the demographic characteristics of the mothers who participated in this study. It includes information on each participant's age, educational background, marital status, and religious background. These details provide essential context for interpreting the participants' responses, highlighting the diversity of experiences, responsibilities, and perception represented in the sample.

Table 1 Demographic Details

Respondent	Age	Marital Status	Level of Education	Religious Background
Respondent 1	36	Married	Form 4	Christian
Respondent 2	38	Married	Form 4	Christian
Respondent 3	44	Widowed/Single	Form 4	Christian
Respondent 4	28	Single	Class 8	Christian
Respondent 5	30	Married	Form 4	Christian
Respondent 6	47	Single	Class 6	Christian
Respondent 7	42	Separated	Form 4	Christian
Respondent 8	35	Married	Form 4	Christian

Table 1 .presents the demographic characteristics of the eight respondents who took part in this study. The participants exhibited diversity in age and marital status, which in turn reflected a variety of caregiving experiences. The participants' ages ranged from 28 to 47 years, with a mean age of approximately 38 years. Four participants (Respondents 1, 2, 5, and 8) were married, one was widowed (Respondent 3), two were single (Respondents 4 and 6), and one was separated (Respondent 7). Regarding educational attainment, six participants (Respondents 1, 2, 3, 5, 7, and 8) had completed secondary education up to Form 4 and obtained the Kenya Certificate of Secondary Education (KCSE), while two participants had primary education—Respondent 6 completing up to Class 6 and Respondent 4 completing up to Class 8 with the Kenya Certificate of Primary Education (KCPE). All eight participants identified as Christian, reflecting a shared religious background. Each individual involved in the research described themselves as Christian, pointing to a common religious context that could impact their perspectives and methods for dealing with mental health challenges.

3.2. Lived experiences of Mothers' of children's with mental illnesses

Eight mothers attending the Mukuru Kwa Ruben Center were interviewed (R1–R8). Three principal themes emerged regarding perceived causes of their children's mental illnesses: (1) biomedical and medical explanations, (2) cultural and supernatural attributions, and (3) psychosocial and environmental causes. Each theme is summarized below with illustrative quotations.

3.2.1. Biomedical and medical explanations

Several mothers described their children's conditions using biomedical language, locating causes in neurological impairment, birth complications, infectious illness, or heredity. For these participants, medical explanations often reduced blame and oriented them toward treatment or rehabilitation.

"It is through the scientific knowledge that I have gained in and out of this center that I can clearly explain how brain chemistry or neurological imbalance can be a cause of mental illness." (R1)

"If the brain structure is tampered with, it stops being okay. My child had normal development of milestones till she had convulsions at nine months as a result of high temperatures due to severe malaria. The outcome is what caused my child's mental illness." (R3)

"After I gave birth to my child, the doctor told me to my face that my child will not have a 'normal' life, he was diagnosed with cerebral palsy as a result of prolonged labor and its effects." (R5)

“After being educated on mental health... my attitude changed. I now know it is an illness just like any other sickness that needs attention with medication and care. Similarly, I have learnt to be loving and caring to my child unlike before when I wished him death (God forgive me).” (R8)

These accounts indicated that exposure to health education and prior medical events shaped some mothers’ causal attributions, shifting beliefs from moralizing explanations toward treatable biological models.

3.2.2. Cultural and supernatural attributions

A number of mothers grounded their explanations in local cultural frameworks, attributing illness to witchcraft, curses, or spiritual hostility. Such attributions often generated fear, anger, and social withdrawal, and in some cases delayed engagement with biomedical services.

“I have never heard of mental illness that is not brought about by witchcraft and/or superstition... What I hear and know about mentally ill people, since I was a child, is that mental illness is caused by different types of witches tied to superstitions or black magic, period.” (R4)

“Before I joined this great group here at Mukuru Kwa Ruben Centre, nobody would convince me that my child’s cause of mental illness was not witchcraft. I strongly believed my child was bewitched. But now the knowledge I have has driven me to believe otherwise.” (R8)

“I was married where my mother-in-law hated me. To date I view the rejection as a curse... Though I managed to run away from that home the curses caught up with me and here I am with this mentally ill child who has their flesh and blood.” (R7)

“Many people in the community say if someone is mentally ill it is because someone put a spell on them; you are blamed, and people stay away.” (R2)

(Respondent R2’s comment reflected wider community narratives and the social consequences of supernatural attributions.)

These quotations show how cultural narratives about witchcraft and curses framed some mothers’ understanding and compounded social isolation and blame.

3.2.3. Psychosocial and environmental causes

Several mothers linked their child’s difficulties to prenatal factors, maternal behaviors, substance use, or childhood injuries. These accounts often blended lay epidemiology with personal experience and directed mothers toward prevention, supervision, or medical help-seeking.

“The fetus feeds from what the mother feeds on while in the womb; for instance, abusing alcohol and poor diet can be a contributing factor to malformation of the fetus.” (R6)

“When a child falls the brain’s damage can lead to mental illness... I found myself as a mother of a mentally ill child. My house help did not explain how it happened though we had her slide and fall while being carried.” (R3)

“Physical causes like head injury and falling can damage the brain. That is what affected my child. Our brain is fragile, more so that of a child, hence should be handled with a lot of care.” (R5)

“Children can accidentally hurt their heads when playing. Never take it lightly as it can be a cause of mental illness... Maybe if I had taken what the siblings reported seriously and sought medical attention, maybe I would not be here. However, I cannot keep blaming myself; it was due to ignorance.” (R7)

These narratives highlighted that these mothers recognized modifiable risks (nutrition, alcohol, supervision) and acute events (head injuries) as plausible contributors to later developmental or behavioral changes. Mothers’ explanatory models were frequently mixed rather than mutually exclusive: several participants shifted from supernatural to biomedical explanations after exposure to health education at the center (e.g., R8). Explanatory beliefs shaped emotional responses (guilt, grief, anger), initial help-seeking trajectories, and the kinds of supports mothers pursued, a pattern explored further in the Discussion section.

4. Discussion

This study found that mothers attending the Mukuru Kwa Ruben Center held complex, have mixed, explanatory models for their children's mental illnesses. Three interrelated themes emerged; biomedical and medical explanations, cultural and supernatural attributions, and psychosocial/environmental causes, and many mothers shifted between or combined these models, frequently after exposure to health education at the Centre Explanatory beliefs shaped mothers' emotional responses (guilt, grief, and anger), their caregiving strategies, and the timing and type of help sought for their children.

These findings resonate with earlier work showing the heavy emotional and practical toll of child mental illnesses on families. Lautenbach et al. (2012) documented parental grief, guilt, and the perception that mental illness produces uniquely disruptive family consequences; similar sentiments were evident here as mothers described loss of expectations, social stigma, and altered household roles. Where Lautenbach and colleagues contrasted mental and physical illnesses in perceived impact, this study adds nuance by showing how exposure to information can move some caregivers from supernatural to biomedical frameworks, changing both meaning and action.

The study's accounts of internalized and public stigma mirror the patterns described by Oz et al. (2019) and Tekola et al. (2020): mothers reported shame, social exclusion, and anxiety that undermined wellbeing and delayed engagement with formal services. Unlike studies focused on specific diagnostic groups (e.g., autism) or rural parents, this research extended those insights into an urban informal settlement and across a range of mental and developmental conditions, underscoring the pervasiveness of stigma irrespective of diagnosis or setting.

Consistent with Scharer et al. (2009) and Gona et al. (2011), mothers here enacted dual roles as caregivers and advocates under significant emotional and economic strain. Participants described intensified caregiving responsibilities, altered sibling roles, and financial pressure that limited opportunities for education and work—echoing Gona et al.'s account of the socio-economic disruptions experienced by carers of disabled children. These intersecting burdens contribute to diminished maternal wellbeing and constrain the family's capacity to mobilize sustained care.

Interpreting these findings through the Health Belief Model (Rosenstock, 1988) clarifies how perceptions translate into health behavior. Mothers' perceived causes (biological vs. supernatural), perceived severity (loss of future, functional impairment), perceived benefits (medical treatment, support groups), and perceived barriers (stigma, cost, cultural expectations) together shaped help-seeking decisions. For example, mothers who came to endorse biomedical explanations after Centre-based education were more likely to describe treatment-oriented responses, whereas those who maintained supernatural attributions were more prone to secrecy or seeking spiritual remedies.

Family Systems Theory (Titelman, 2012) further illuminates how individual beliefs operate within broader relational patterns. Explanatory models were embedded in family narratives, intergenerational beliefs, and marital dynamics; in several accounts, in-law hostility and family conflict were interpreted as causal or contributory to the child's condition, reinforcing shame and fracture within households. The family context therefore functioned both as a potential resource (supportive relatives, acceptance) and a risk factor (blame, ostracism), mediating access to care and the emotional climate surrounding the child.

Practical and policy implications follow directly from these patterns. First, the transformative effect of mental health education reported by several mothers (e.g., R8) suggests that targeted, culturally sensitive psychoeducation delivered in trusted community hubs can shift explanatory models and encourage treatment-oriented behaviors. Second, stigma-reduction interventions must be community-wide, combining awareness-raising with practical supports (peer groups, family counselling) to mitigate courtesy and affiliate stigma. Third, given mothers' concern about prenatal health, injuries, and supervision, prevention messaging that addresses maternal nutrition, substance use, and child safety could form part of integrated community programs. Fourth, strengthening referral pathways between community centers (like the Ruben Centre), primary health facilities, and specialist services will help translate changed beliefs into timely access to care. Finally, family-focused interventions that engage extended kin and leverage familial resources may be more acceptable and effective than individual-only approaches in this context.

Methodologically, this study's qualitative design yielded rich, contextualized insights but also entails limitations. The sample was small (eight interviewed mothers) and drawn from a single Centre within one informal settlement, which limits generalizability. Social desirability may have influenced some accounts, particularly where participants described changed attitudes after interacting with the Centre. At the same time, strengths include in-depth interviews conducted in participants' preferred languages, and purposive engagement with a community Centre trusted by residents.

5. Conclusion

There are varied ways in which mothers at the Mukuru Kwa Ruben Centre perceive mental illnesses, revealing that cultural beliefs and personal experiences significantly influence their comprehension and reactions. This diversity in perspectives impacts not only their approach to caring for their children but also their choices regarding seeking professional mental health support.

Recommendation

Mothers should be encouraged to participate in peer support groups and structured programs that integrate both traditional and medical approaches. Engaging with community education initiatives can help them gain a deeper understanding of mental health while respecting their cultural values. Secondly, Future research should test the transferability of these findings across other informal settlements and examine the effectiveness of community-based psychoeducation and family-inclusive interventions in shifting help-seeking and improving child and caregiver outcomes. Mixed-methods studies could link mothers' explanatory models to measurable care-seeking behavior and child functioning, while intervention research could evaluate stigma-reduction strategies tailored to urban informal settings.

Compliance with ethical standards

Disclosure of conflict of interest

The researcher affirms that there are no conflict of interest related to the conduct or publication of this study. No personal, financial, or professional ties existed that might have affected the research process or its findings.

Statement of ethical approval

Ethical approval for this study was granted by the Tangaza University Research Ethics Committee and formally authorized by the National Commission for Science, Technology and Innovation (NACOSTI). All study procedures complied with the ethical standards of these bodies to protect participant confidentiality and welfare.

Data Availability

Data for this study were generated through semi-structured, face-to-face interviews, audio-recorded with participants' consent and transcribed verbatim. Analysis was conducted using reflexive thematic methods, and the transcripts and coding framework that underpin the findings can be made available by the corresponding researcher on reasonable request. Access will be granted only in accordance with ethical approvals and data-protection requirements to safeguard participant confidentiality.

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