ORIGINAL RESEARCH

Hydrocephalus, healing, and disrupted daily living: exploring maternal experiences at Queen Elizabeth Central Hospital in Blantyre, Malawi

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Abstract

Background

Each year, nearly 400,000 new cases of paediatric hydrocephalus are estimated to occur worldwide, and almost half of these cases are expected to affect children in Africa. At Queen Elizabeth Central Hospital (QECH), an urban tertiary hospital in Blantyre, Malawi, located in south-east Africa, around 200 children received neurosurgical treatment for hydrocephalus in 2023. These children require lifelong follow-up and care, which places significant demands on their caregivers.

Objectives

The following research objectives guided the study: 1) To explore how mothers of children with hydrocephalus perceive the condition. 2) To examine the care pathways that mothers and their children with hydrocephalus engage in. 3) To identify the implications of having a child with hydrocephalus.

Methods

We applied a qualitative method with an explorative design. We conducted 15 in-depth interviews and two focus group discussions among 16 mothers (aged 20-35 years) of inpatient or outpatient children with hydrocephalus at QECH. Convenience sampling was used to recruit the 16 participants. We conducted a thematic analysis.

Results

1) Mothers referred to various disease explanations, often switching between attributing the condition to God, supernatural causes such as bewitchment, and biomedical factors. 2) The care pathways for mothers and their children with hydrocephalus at QECH are fraught with challenges, creating strenuous trajectories that hinder access to care and present significant challenges. 3) Having a child with hydrocephalus has extensive social implications, including stigma and disruption of daily living.

Conclusions

Our findings highlight the need for intersectoral action to optimise treatment and reduce stigma. This involves educational programs and awareness-raising campaigns to improve maternal health literacy. Additionally, targeted initiatives are urgently needed to improve healthcare infrastructure, transportation, and pathways to care. Since hydrocephalus management is a lifelong process, the possibility of conducting follow-up through outreach clinics or telemedicine and community-based rehabilitation should be further explored. Finally, to improve management for children with hydrocephalus in Blantyre and across Malawi includes efforts to bolster the educational, economic, social, and legal position of women.

Introduction

Paediatric hydrocephalus is a neurosurgical condition that heavily impacts the quality of life for patients[1] and caregivers[2] and is associated with stigma in many parts of the world[3-7]. While some are born with hydrocephalus, children with hydrocephalus in Africa frequently suffer from an acquired postinfectious aetiology[8]. This is also the case at Queen Elizabeth Central Hospital (QECH) in Blantyre, Malawi[9,10], which is the setting for this study.

The epidemiology of paediatric hydrocephalus in Africa contrasts with high-income regions, where there is a lower incidence[11] and a different paediatric hydrocephalus aetiological profile[12,13]. In high-income settings, intracranial haemorrhage related to prematurity is among the most common causes of paediatric hydrocephalus[14,15], while across Africa, postinfectious hydrocephalus has been identified as a common aetiology[8].

The surgical methods for treating hydrocephalus, shunting and endoscopic approaches, save lives and reduce morbidity but often lead to complications, including the need for revision surgeries[13,16]. Children with hydrocephalus are, therefore, dependent on multi-disciplinary lifelong follow-

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up care[17]. This demands considerable resources from the health system[18] and places a heavy burden on caregivers and their capacity to navigate the health system, understand and evaluate health information, and respond to signs of deterioration in the child; qualifications often referred to as health literacy skills[19].

Illustrative of the severity that hydrocephalus represents for Malawian children, studies from QECH show that a substantial proportion has developmental delay[20,21] and that the one-year postoperative morbidity and mortality rate is 33% and 15%, respectively (shunts and endoscopic procedures)[22]. A study from Kamuzu Central Hospital in Malawi's capital, Lilongwe, reported an alarmingly high three-month mortality rate of 32% for shunt-treated children. In the latter study, younger maternal age was the only factor significantly associated with mortality, indicating the essential role of social determinants[7].

In 2015, the Lancet Commission on Global Surgery modified the influential three-delays model to describe factors contributing to delays in seeking, reaching, and receiving surgical care[23], which may include cultural, educational, financial, and structural barriers[24]. These challenges are prevalent in Malawi, where, for example, cost and access to transportation act as obstacles to timely surgical management[25]. In addition, cultural beliefs, sociocultural and historical background, and religious affiliation frame disease explanatory models[26]. This has been exemplified and elucidated through ethnographic research which has depicted how the concept of "healing" is rooted in medicine (to cure) and religion (to save)[27].

Research from Africa[28,29] and Malawi[30-34] has shown that cultural and religious beliefs and stigma[29,35] impact illness interpretation and health-seeking behaviour. Similar reports are in the regional hydrocephalus literature[28,36-38], hydrocephalus studies in Malawi[7,39], and the Malawian media[40-43]. These complex and multidirectional factors may delay caregivers of children with hydrocephalus initial and follow-up visits to formal healthcare services. In addition, health system factors, including informal care providers, huge patient loads and unavailability of ambulances and fuel at the primary healthcare level, affect referral networks[44], and a limited neurosurgical workforce and scarce availability of diagnostic tools at QECH[45] may further exacerbate delays.

At QECH, where the median age at the time of surgical intervention for paediatric hydrocephalus is five months[22], mothers are the caregivers who almost exclusively accompany their children to the hospital, which is similar to descriptions in other areas of Africa[36,38,46]. In 2022, the World Health Organization identified investments in neurology and neurosurgery as a worldwide priority by launching the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders, 2022-2031 (IGAP)[47]. Explicitly focusing on low-resource contexts, IGAP aims to "reduce the stigma, impact and burden of neurological disorders, including their associated mortality, morbidity and disability, and to improve the quality of life of people with neurological disorders, their carers and families"[47]. IGAP, therefore, represents a game-changing opportunity to reconceptualise care delivery for children with hydrocephalus because it emphasises child health, caregivers, care pathways, intersectoral action, and optimised brain health across the life course, and is based on guiding principles which include "gender, equity and human rights"[47].

In response to the political resolution from the World Health Organization and to meet the need for increased investments in patients with hydrocephalus and their caregivers, it is critical to acquire more knowledge to identify gaps in resource allocation and support mechanisms which can direct future studies and guide clinical practice and policy development. Acknowledging the essential role that caregivers of children with hydrocephalus have, we conducted a qualitative study at QECH, specifically exploring mothers' experiences. We employ a broad global health focus emphasising structural and sociocultural factors. The following research objectives guided the study: 1) To explore how mothers of children with hydrocephalus perceive the condition. 2) To examine the care pathways that mothers and their children with hydrocephalus engage in. 3) To identify the implications of having a child with hydrocephalus.

Methods

Study design

Qualitative methods with an explorative design provide opportunities to discover participants experiences and their "sociocultural worlds"[48] in areas where little preexisting knowledge exists. We, therefore, considered this methodology most suitable to meet the research objectives.

Study setting

Data collection was conducted for three weeks during February 2023, at QECH, the largest tertiary hospital in Malawi. QECH serves as a tertiary referral hospital for the southern region and a national referral hospital for patients needing advanced care nationwide[49]. In addition, it serves as a district-level hospital for the population of Blantyre[44] (as there is no public secondary-level district hospital in Blantyre district) and as the Kamuzu University of Health Sciences teaching and research hospital. The official bed capacity is 1350[50], but in busy wards such as the male and female medical wards and the paediatric wards, it is not uncommon to find adult patients occupying the floors or two to three paediatric patients sharing a single bed.

The surgical department at QECH was established in 1991. Although shunting procedures for children with hydrocephalus have been performed at QECH for decades, other neurosurgical services were not available until 2011 when the second author, PDK, returned from neurosurgical training in South Africa[45]. In 2013, a bilateral exchange partnership between QECH and Oslo University Hospital in Norway was established, and the neurosurgical services have since increased and advanced[45,51]. The non-governmental organisation Child Help SBH (Spina Bifida and Hydrocephalus) Malawi provides multidisciplinary care for children with hydrocephalus at QECH.

Currently there is no operating MRI machine at QECH, but in 2020 a CT scanner became available[45]. In 2023, 849 neurosurgical procedures were performed at QECH, of which 212 were related to paediatric hydrocephalus (Martin Kampeni Ngoma, June 2024, personal communication).

Data collection

We conducted 15 in-depth interviews and two focus group discussions among mothers of inpatient or outpatient children with hydrocephalus at QECH. We developed a semi-structured interview guide (Appendix 1) and questions related to the period before seeking healthcare in general and at QECH, experiences during the stay at QECH, and thoughts about the future.

We specifically asked about traditional healing methods and beliefs in witchcraft. In addition, we carried out two focus group discussions with mothers who had participated in the in-depth interviews. We used the focus group discussions to dive deeper into the most interesting themes from the in-depth interviews (Appendix 2). We received permission to do follow-up interviews, and two participants were contacted after the initial interview for clarifications and validation of what they had expressed. We made field notes during and after the in-depth interviews and focus group discussions.

The first author, CGA, initially planned to conduct all interviews in English with the third author and research assistant, ET, as Chichewa translator because none of the mothers were fluent in English. However, after two pilots- and one interview, it became evident that a better strategy would be for ET to conduct the in-depth interviews and the focus groups in Chichewa while CGA was situated in the back of the room. There were two reasons for this. First, ET had a more culturally familiar way of communicating with the mothers which made the participants more comfortable during the interview. Second, while ET applied the guide to structuring the interviews, she managed to get the flow of the narrative more comprehensively and naturally than what seemed possible during the translation between English and Chichewa. Minor changes were made to the interview guide following the pilot interviews to capture the essence of what appeared to be important topics. The in-depth interviews and the focus group discussions were conducted in separate rooms at QECH, away from the clinical wards.

Study population, sampling strategy and sample size

An important dimension of qualitative research is to gain access to a range of diverse perspectives[48]. We endeavoured to achieve maximum variation among maternal caregivers of children with hydrocephalus and to include representation of mothers who were at QECH with their children with hydrocephalus some time ago and more recently. Therefore, we received permission to recruit participants from three inpatient wards: the paediatric nursery ward (children below six months), the paediatric orthopaedic ward (children above six months), the neurosurgical high dependency unit (critically sick children of all ages), and the outpatient department (follow-up of children treated for hydrocephalus).

We applied convenience sampling often used in qualitative studies with exploratory designs[52]. The nurse in-charge of the respective wards identified potential study participants. The inclusion criteria were being a mother, 18 years of age or older, of a child with hydrocephalus and having the ability to communicate verbally in Chichewa or English. Having a child that had received surgery was not an inclusion criterion as we intentionally also wanted to hear the experiences of mothers awaiting operation for their child. Informed consent was obtained from all participants in the form of a signature or an ink thumbprint. Four mothers were excluded for the following reasons: age below 18 years, uncertainty about their age and looking very young, Mozambique origin and inability to speak Chichewa or English, and conditions related to poor mental health. In addition, one mother wanted to refrain from participating (no apparent reason was provided). A few mothers had children who were too sick to be taken out of the wards and into a room appropriate for an interview. With insufficient nursing staff to observe these children in their mother's absence, this was an unforeseen exclusion criterion.

No children with hydrocephalus were admitted to the high-dependency unit during the study period, and therefore, no mothers were recruited from this unit. However, following the two pilot interviews, we recruited four participants from the paediatric nursery ward, four from the paediatric orthopaedic ward, and seven from the outpatient department. After the 15 in-depth interviews, the same themes and topics seemed to emerge, often called saturation. For pragmatic reasons, the focus group discussions involved mothers of inpatients only, including one mother we piloted the interview guide on. Two of the participants interviewed at the outpatient department had children who were admitted, and these two mothers were included in the focus groups. The total sample size, therefore, consists of 16 mothers.

Data management and data analysis

We audio-recorded the interviews using a Dictaphone App from the University of Oslo, which immediately transferred encrypted audio recordings to a secure server in Oslo. About two-thirds of the interviews were transcribed in the following way: CGA and ET listened to the interviews together, ET translated from Chichewa to English verbally, and CGA transcribed in English. Subsequently, about one-third of the interviews were translated and transcribed by ET. All interviews were listened to at least twice during transcription to check for accuracy, and preliminary findings were discussed between CGA and ET. The transcripts were transferred to NVivo (version 12 Pro). We did a thematic analysis with an inductive approach[53], and through a cyclical process where we read the material closely and from a more meta-analytical perspective, we identified 90 codes, which we condensed to broader themes (see Table 1 for an example of codes). This flexible process of interacting with the data material and continuously refining the inherent meaning of what participants were talking about is an essential characteristic of explorative research[54]. CGA was responsible for the coding in NVivo.

Trustworthiness

We took several measures to ensure the trustworthiness and rigour of the study. First, we encouraged the participants to speak freely, emphasising that neither CGA nor ET were employed at QECH. We repeated the information provided in the information sheet and consent form regarding confidentiality.

Moreover, triangulation by collecting data from in-depth interviews and focus group discussions contributed to gaining information from two sources, providing a richer and more holistic dataset. In addition, we had permission to follow-up with mothers of inpatient children with hydrocephalus for validation of what they had expressed during the in-depth interview, and we did so on two occasions. Being present and conducting the interviews at QECH provided a more comprehensive contextual understanding of the various phenomena and experiences the mothers talked about than what would have been possible otherwise. Furthermore, except for CGA and her Norwegian supervisor HEF, all other co-authors are Malawians, and combined as a research team, we cover expertise in qualitative methods, neurosurgery and hydrocephalus, paediatrics, and the QECH healthcare system. Last, we have included quotes from the participants to support our findings.

The researchers' consideration of reflexivity is essential to ensure validity in qualitative studies. Reflexivity can be understood as "a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes"[55]. Reflection on the potential influence of the researchers on the scientific process, from formulation of the research question to data analysis, is an integral part of the research process[55]. Discussions about reflexivity in our study include but are not limited to, CGA's positionality as a European female neurosurgical nurse pursuing a PhD degree and the uneven power dynamics between CGA and the participants. However, we believe that the presence and active involvement of ET, a female Malawian journalist with experience conducting qualitative study interviews, positively contributed to the participants speaking freely about their experiences. The strong presence of Malawian researchers enabled analyses with a sensitivity to and competence in the local setting in Blantyre. Appendix 3 includes a COREQ (COnsolidated criteria for REporting Qualitative research) checklist.

Ethical considerations

The College of Medicine and Research Ethics Committee (COMREC) in Malawi approved the study (P.09/22/3772) on December 06, 2022. The Regional Committee for Medical and Health Research Ethics (REK) in Norway exempted the study from review (reference number 36312).

We notified and received approval from the Norwegian Agency for Shared Services in Education and Research (SIKT) (reference number 691276). In addition, the study proposal was presented, discussed, and approved by the Paediatric Department at QECH. We also received letters of support from the Head of the Neurosurgical Department and the hospital director at QECH. All participants received a small compensation of 1500 Malawian Kwacha (approximately 1.5 USD) for participating in the study.

Results

The mean time for the in-depth interviews was 37 minutes (26-52 minutes). The first focus group discussion lasted 75 minutes, and the second lasted 49 minutes. The participants came from nine districts, representing all three regions in Malawi (Table 2). The characteristics of the mothers are described in Table 3, and the characteristics of the children are described in Table 4.

Theme 1 A range of pluralistic disease explanations

When asked about hydrocephalus, many mothers provided a range of pluralistic explanations, which alternated between references to God, supernatural causes such as bewitchment, and biomedical factors (Table 5, quote 1). Almost all mothers referred to hydrocephalus at some point during the in-depth interview or focus group discussion through statements such as "I think it's something that God himself allows to happen" or "Only God heals" (Table 5, quote 2). The majority denied believing in witchcraft when asked directly about this in the in-depth interview. Yet, this belief would sometimes be expressed at another point in the in-depth interview and the focus group discussion. Some mothers thought that an argument or a disagreement with a family member, especially when there was a biological relationship, could cause diseases through a curse, often referred to as relatives "having a hand in" the child's disease (Table 5, quote 3). Furthermore, other mothers made references to the "devil" or "evil people" as contributing to disease development, and a few mentioned that their children were spirit mediums. Some participants changed their perceptions about a possible supernatural cause after admission to QECH, as they recognised that others were also affected by hydrocephalus (Table 5, quote 4). Interestingly, none of the participants mentioned that neonatal infections could cause hydrocephalus, but poor maternal nutritional status was sometimes cited as a causative mechanism (Table 5, quote 5). For more quotes, see Appendix 4.

Theme 2 Strenuous care pathways

The care pathways for mothers and their children with hydrocephalus at QECH are fraught with challenges, creating strenuous trajectories that impede access to care. Lack of available transportation, financial constraints for transportation and fuel, and the arduous journey from home to QECH and back exacerbate the challenges these mothers face (Table 6, quote 6). Most participants recounted their struggles seeking initial and follow-up care, highlighting the significant barriers posed by transportation costs and the time lost in income-generating activities. Despite QECH being a public hospital providing free care, the direct and indirect costs associated with transportation were significant concerns for all participants, except one from the proximity of Blantyre city who mentioned that she would walk to the outpatient department at QECH (for about one hour). For some mothers, multiple transport stages, including motorbikes, bicycles, ambulances, walking, and minibuses, were involved in their care trajectories (Table 6, quote 7).

Before reaching QECH, most mothers had sought care at local healthcare facilities or traditional healers and informal care services closer to their homes. A few had received advice from the elders in their families or communities, including suggestions to massage the baby's head to reduce fontanelle bulging, a common sign of hydrocephalus in infants with unclosed cranial sutures (Table 6, quote 8). When their child's symptoms persisted and no healing was accomplished, they went to the formal care services (Table 6, quote 9).

Despite varying degrees of destitution, all participants shared precarious life conditions, amplifying their challenges. The lack of steady income and social security support mechanisms forced some mothers to sell their assets for transportation costs (Table 6, quote 10). For many, the decision to prioritise food for their families over expenses related to hospital stays was a constant struggle (Table 6, quote 11). The expectation of returning for follow-up visits was contingent upon having money for transportation, highlighting the ongoing challenges these mothers face in accessing essential healthcare services. Some mothers waited in the hospital area to ease follow-up visits or stayed with relatives in Blantyre after discharge. For more quotes, see Appendix 5.

Theme 3 Social implications

The process of seeking care for children with hydrocephalus in Malawi carries significant social implications, influencing not only the mothers and their affected children but also their entire families, households, and communities. The challenges encountered during hospitalisation at QECH and the subsequent impact on family dynamics and social interactions underscore the profound social consequences of managing hydrocephalus.

Table 1 Example of codes

Example of codes	Example of themes
"Belief that actions are related to each other"	A range of pluralistic disease explanations
"Biomedical disease explanatory model"	
"Comparison to other children in the ward"	
"In God's hands"	
"Healing through prayers"	
"Traditional amulet"	
"Advice from community before visiting QECH"	Strenuous care pathways
"Birth trajectories"	
"Hardship of life"	
"Trouble getting back home"	
"Selecting level of care delivery"	
"Transportation route with several stops"	
"Caretaking of the other children"	Social implications
"Consequences of health seeking behaviour"	
"Disrupted marriage"	
"Feelings about return to community"	
"Stigma"	
"Mocking"	

Table 2 Geographical distribution of participants included in the in-depth interviews and focus group discussions

Region	District	N=16	Kilometres (km) from district to QECH*	Transport to QECH**
Northern	Mzimba	1	605	Ambulance
Central	Ntcheu	1	153	Ambulance
Southern	Mangochi	3	187	Ambulance
Southern	Nsanje	3	176	Ambulance (2). Own transport***(1)
Southern	Balaka	2	126	Own transport***
Southern	Mulanje	1	84	Unassigned
Southern	Chikwawa	1	47	Own transport***
Southern	Thyolo	2	40	Ambulance
Southern	Blantyre	2	Proximity	Unassigned

*Distance from the district to QECH applying Google Maps. Km does not indicate the time it takes to reach QECH, as this depends on transport mode, number of transport modalities, road quality, and weather conditions. The mothers often referred to distance by saying how much Malawian kwacha they paid for the transport (if they had not used an ambulance). **Refers to transport to QECH on first admission. ***Own transport means a public minibus or rental of a driver and a vehicle.

Table 3 Maternal characteristics

Study participants' demographics	IDI (N=15)	FGD PN (N=4)	FGD PO (N=5)
Age in years-mean (range)	28,6 (20-35)	29,5 (25-35)	27,0 (20-35)
Parity-mean (range) (n)	3,3 (1-7)	4,5 (3-7)	2,6 (1-7)
Educational level (n)			
Standard 4-8 (primary school)	7	4	-
Form 2-4 (secondary school)	4	-	3
Unassigned	4	-	2
Ability to read and write (n)			
Yes	10	2	3
No	3	1	2
Unassigned	2	1	-
Way of income (n)			
Piecework/Farming/Farming and Piecework	6	1	2
Buying and reselling farm products (vegetables, bamboo etc.)	3	2	-
Small-scale business	2	-	-
None	3	1	2
Unassigned	1	-	1
Civil status (n)			
Married	12	4	4
Separated	2	-	-
Divorced	1	-	1
Place of delivery (n)			
Healthcare facility	14	4	5
On the way to a healthcare facility	1	-	-
Mode of delivery (n)			
Vaginal delivery	13	2	5
Caesarean delivery	2	2	-

Abbreviations: IDI: In-depth interviews. FGD: Focus group discussion. PN: the paediatric nursery ward. PO: the paediatric orthopaedic ward.

Table 4 Characteristics of the children with hydrocephalus whose mothers participated in the study

Children's characteristics	IDI (N=15)	FGD PN (N=4)	FGD PO (N=5)
Age in months-mean (range)	18,5 (1-72)	3,3 (2-4)	13,6 (6-24)
Sex (n)			
Male	8	1	4
Female	7	3	1
Surgery for hydrocephalus received (n)			
Yes	13	3	4
No	2	1	1
Type of surgery (n)			
Endoscopic procedure	7	1	4
Shunt	5	1	-
Not applicable (awaiting surgery)	2	1	1
ETV, then shunt	1	1	-
More than one hydrocephalus surgery received (n)			
Yes	2	1	-
No	7	-	2
No, but it is awaiting revision or readmitted from OPD	3	2	2
Not applicable (not operated yet)	2	1	1
Unclear	1	-	-
Spina Bifida (n)			
Yes	2	1	1
No	13	3	4
Hydrocephalus diagnosed at birth or within the first week (n)			
Yes*	6	2	2
No	9	2	3

Abbreviations: IDI: In-depth interviews. FGD: Focus group discussion. PN: the paediatric nursery ward. PO: the paediatric orthopaedic ward. OPD: outpatient department. *This included one child who was diagnosed after two days, one child who was diagnosed after one week, two children with spina bifida, one child born prematurely, and one child detected at prenatal scanning.

Table 5 Theme 1: A range of pluralistic disease explanations

Quote 1	"[…] when I was told that we needed to do some traditional medicine for the child, I did not accept any, and luckily it was because I was already in this hospital, so when I was discharged to go home, they suggested we use traditional medicine to stop it (referring to the head) from growing, but I said the child is too young for such and it is not the right time. I said if we accept and start giving the child traditional medicine, it is easy for witches to come and get it". FGD-PN-ID 7.
Quote 2	"This disease came from God. I wouldn't say that it was bewitchment, then I lie if I say so". IDI-PN-ID 14.
Quote 3	"At home, I argued with my aunt while I was pregnant. When I went to the hospital, I got help, and I was discharged, then I went home. When she saw that, she did not like it. She said my baby would not live long, and then after that, I noted that after a week, the baby kept on crying. When I went to the hospital with her, they told me that the head was swelling. That is when they sent me here to Queens (referring to QECH). I have never seen this kind of disease in my family. There is no such disease. I wondered why my baby had it. Then I noted that this same person I argued with is the person that has caused this disease to my child". FGD-PN-ID 1.
Quote 4	"Ahh, when I came here, I saw many people with the same sickness. And I don't think that all these people can be bewitched. No, it is just a disease that God has given, something like a plague. There are a lot of people coming here with this condition". IDI-PN-ID 15.
Quote 5	"I was very disappointed, considering I have had six of my children normal, and the seventh child has this disease. I wanted to know what was going on. So, I asked what it was, and they told me it was caused by a lack of nutrients in the pregnant mother's body. If a pregnant mother has fewer nutrients, the baby in the womb will be affected". IDI-OPD-ID 4.

Mothers who accompany their children to QECH often face prolonged stays before and after receiving surgical care, with uncertainty surrounding the timing and nature of necessary medical interventions. This extended hospitalisation disrupts the rhythm of everyday life. The burden of care falls heavily on mothers, who may struggle to meet the needs of their children with hydrocephalus while managing household responsibilities.

Mothers expressed that their absence from home caused difficulties for their other children. Some missed school and necessary healthcare appointments, such as vaccinations. A mother of twins also brought her teenage son to QECH to help her care for the twin babies. She had been in the hospital for a month with her three children, and her teenager was missing out on school (Table 7, quote 12). Others had sold all their possessions and still faced uncertainty about the future due to financial constraints (Table 7, quote 13). Stigma and discrimination further compound the social implications faced by affected families and exacerbate their challenges. A few mothers reported being abandoned by their husbands due to the stigma associated with the condition or because of extended hospital stays (Table 7, quote 14). Others experienced discrimination from their communities, including comments that it was not worthwhile bothering to care for these children (Table 7, quote 15). The need to navigate societal attitudes and perceptions adds another layer of stress and isolation in caring for children with hydrocephalus. Practical challenges, such as the inability to find caregivers, led one mother to leave her child alone at home, highlighting families' complex decisions and compromises in response to social pressures. Despite these difficulties, many mothers also told us about husbands, families, and community members who visited them and brought food to the hospital, providing a source of resilience and encouragement in the face of adversity (Table 7, quote 16). For more quotes, see Appendix 6.

Discussion

In exploring maternal experiences related to hydrocephalus, we found that 1) perceptions of hydrocephalus are based on a range of pluralistic disease explanations, 2) mothers

Table 6 Theme 2: Strenuous care pathways

Quote 6	"They said I was required to go to Queens (referring to QECH) with this disease because there was water in his head. I asked them how I was going to get to Queens because I had no transport, so they said I needed to find 30,000 Kwacha (equals around 17,5 USD) for fuel because their ambulance had no fuel, for the ambulance to get me there. I asked where I was going to get 30,000 Kwacha, and I had nothing at all. I am all empty. Even my children have no food to eat. So, they said go home and prepare yourself. You will find us when you are ready, so I left and went home. After two days, his twin was short of breath and had pneumonia. I went to the hospital, and he died. (Name of baby) was still waiting to get help at (name of hospital), but I decided to go to the district hospital with him to explain the baby's condition". IDI-OPD-ID 4.
Quote 7	"I used a sherpa (referring to a motorbike driver she hired) to get me to the bus station. From there, I got a minibus and dropped off in (name of town). From (name of town), I got on to another minibus that got me here. So, I have used like two minibuses and a sherpa". IDI-OPD-ID 12.
Quote 8	"When a baby has a big fontanelle, our parents, the elderly, would recognize it and say, let's put something on it so the fontanelle doesn't continue growing. People who do not know about this condition are always the ones to say, it's just the fontanelle; this head growing like this, it's a fontanelle. There is a need for medicine, so they take some and apply". FGD-PO-ID 9.
Quote 9	"They gave me some medicine for him to drink. After his seventh month, I noted that his head was a bit swollen one morning, so I wondered if I dropped him, but I did not. I told my husband about it at home if he knew anything. He said maybe it was normal to be like that. He had no idea, as well. So, I asked my friends if they knew anything about it, and they said maybe his head was growing because his brain had to mature as he grows. They told me to go to the witch doctor to get some medicine, and I went there because I had no idea what was happening, and my friends suggested that I get help. After the witch doctor did what he knew, there was no change at all. So, after I noted no change, I went to the hospital and explained. The doctor said I should see a specialist in Queens (referring to QECH). When I came here, they said he has water in his head". IDI-OPD-ID 3.
Quote 10	"Yes, when I went the other day, they told me the ambulance was scheduled for (mentions a specific date), but there was no other ambulance. Then I went home to sell my bicycle so that I could use the money for transport to come here". IDI-PN-ID 15.
Quote 11	"I have also left some children at home. They (referring to the children at home) do not have soap, and yet when I was home, I used to give them some. Sometimes, we do not have to depend on the father for everything because he also must wait for the monthly salary he gets once, and that money sometimes is not enough to get us throughout the month. So, they don't have food and may go to bed without it. As a mother, I try as much as possible to ensure that the children do not go to bed without food. For me, that's the problem I have with my children". FGD-PN-ID 7.

Table 7 Theme 3: Social implications

Quote 12	"I worried when I came here with my elder son and had to force him out of school. He is not going to school now. On top of that, I have left other children at home. There are three children with their father. I know he is also a parent, but a woman is the only one that organises a home. We need to care for our children, like bathing them, washing their clothes, and doing things like that. It hurts me a lot, but because what has happened, had happened. So, I accept it because I want my baby to be well. I want him to go to school so I can depend on him". IDI-PN-ID 15.
Quote 13	"We do not have anything at all. There is nothing that we depend on as a source of money. There is nothing we can sell to get money. We had property before, and we sold it all. We had fridges like those (pointing at a refrigerator), and we sold it. We also had a bicycle and sold it because of problems. Right now, all we have are utensils, chairs, clothes, mattresses, beds, and the baby's clothes and bedding. That is all. We lost everything that we could depend on to sell, and there is nothing we can show you that we did after selling everything because it's always problem after problem. My husband is looking for a job but can't find one". IDI-PO-ID 2.
Quote 14	"No, my husband left me because I stayed in the hospital; he went to marry another woman. My children are being taken care of by my parents, my mother, and my uncle". IDI-OPD-ID 13.
Quote 15	"While I am here, there are people at home clapping hands and saying many things. They say I am stuck in the hospital and expect me to return home with a dead body. So, I just want to ask the doctors to help my child so that I return with him in good health so that I do not end up being ashamed. Many enemies have surrounded me; nobody wishes me well. Now that I have this baby with such a condition, they just want him dead. God will see what he will do". FGD-PO ID 2.
Quote 16	[…] they love her. Like the people I am surrounded by, they have come to accept the baby's condition. Sometimes, they feel sorry for me. They even offer to help me with her. Now she seems ok, but the only problem is her neck. The neck is unable to carry the weight of the head". OPD-ID 11.

and their children engage in strenuous care pathways, and 3) having a child with hydrocephalus has far-reaching social implications, including stigma and disrupted everyday life. While these themes are presented consecutively in the results section, they appeared closely interconnected, and the participants frequently talked about the topics overlappingly.

Perceptions of hydrocephalus among mothers at QECH are fluid and diverse and often blend religious, supernatural, and biomedical explanations. This finding echoes a Lancet review concerned with caregivers' experiences related to mental health and neurodevelopmental conditions in low- and middle-income countries (the majority from Africa), which found that caregivers endorsed a mixture of beliefs[29]. It also echoes a previous qualitative study from QECH[39] and aligns with hydrocephalus studies from Nigeria[56] and Uganda[38].

Some mothers mentioned nutritional deficiencies as causes of hydrocephalus. While adequate levels of folic acid before and in the early phases of pregnancy are known to reduce the risk of spina bifida, which is often associated with hydrocephalus[57], the direct link between nutrition and isolated hydrocephalus is not widely acknowledged in the neurosurgical community. However, inadequate maternal and child nutritional status may indirectly contribute by increasing susceptibility to infections and subsequent postinfectious hydrocephalus[58]. Moreover, we found that many participants rejected the belief in witchcraft when asked directly about this, suggesting that it is a somewhat sensitive topic. Nonetheless, supernatural forces as explanatory factors were sometimes expressed at another point during the in-depth interviews or in the focus group discussions, which aligns with hydrocephalus studies from QECH[39] and Nigeria[56]. The belief in witchcraft transcends disease categorisation and hydrocephalus, and a cross-sectional survey on attitudes towards mental illness at QECH demonstrated that approximately 80% replied that the possession of evil spirits caused mental illness[59].

Conversely, a questionnaire study from Tanzania found that most mothers reported not knowing the causes of hydrocephalus, but that among those who did, a majority stated nutritional deficiencies and very few reported witchcraft or religious causes[36], which is both in line and in contrast to our findings. While we also found that some mothers mentioned nutritional deficiencies as causing hydrocephalus, our participants seemed more prone to refer to supernatural causes being involved. However, one may speculate whether a questionnaire-designed study is less prone to comprehensively pick up complexities such as beliefs about how diseases arise.

Some of our participants also mentioned advice from the elders on the treatment of the fontanelle, which aligns with earlier observations from the region[28], including Malawi[60].

A Nigerian study on paediatric hydrocephalus found that maternal socioeconomic status was significantly associated with seeking, reaching, and receiving care. Maternal health literacy was significantly associated with seeking and receiving, but not reaching, care[61]. The authors describe that only 34% of mothers sought care within two weeks after their child showed symptoms, 15% of children reached a neurosurgical facility within two weeks after the mother decided to seek care, while only 1% of children received treatment within two weeks of presentation to a neurosurgical facility.

We did not quantitatively assess delays in seeking, reaching, and receiving care. Still, our findings suggest that decisions to seek care depend on multiple factors, including beliefs in how sickness is thought to arise, its perceived severity, and theories of healing. However, seeking and reaching care also involves several pragmatic considerations beyond cultural beliefs, such as the availability and accessibility of transportation to care facilities[62] and concerns of social implications, including leaving behind children at home. This is similar to a broader surgical literature review[24]. In line with a hydrocephalus study from Uganda[38], we found that there appears to be a transition in the perception of hydrocephalus after presentation to tertiary care settings. We also found that mothers reported having stayed in the hospital for extended periods, which echoes findings from Nigeria[61] and Tanzania[63]. There may be diverse reasons for this, but because definite surgical management of hydrocephalus requires cerebrospinal fluid clarity, there is often a need for children with postinfectious hydrocephalus to undergo lengthy intravenous antibiotic treatment before surgery[64], which is also the case at QECH (Patrick D. Kamalo, August 2024, personal communication). One may speculate if this contributes to prolonged stays in African settings where postinfectious hydrocephalus is very common[8].

Although QECH is a public hospital that offers free neurosurgical care, direct and indirect costs related to health-seeking were reported as significant barriers by almost all our participants (except one who lived within a one-hour walking distance from QECH). The expectation of returning for follow-up in the outpatient department is an additional barrier due to the lack of private vehicles, shortage of ambulances, and a limited or inaccessible public transport system. These factors are commonly found in low- and middle-income countries[23]. Nonetheless, research from Uganda has shown that the five-year post-operative survival status for children with spina bifida and hydrocephalus was significantly higher in the neighbouring districts, further away from the treatment facility, compared to within the treatment facility's district. The authors attribute home support and community-based rehabilitation programs after discharge as the cause[65]. Community-based rehabilitation is offered to some extent in the southern region of Malawi. For example, Tiyende Pamodzi, a community-based organisation at Namwela in Zomba, offers community-based rehabilitation where persons with hydrocephalus are seen. In addition, the non-governmental organisation Child Help SBH Malawi initiated a mobile community-based rehabilitation program in the southern region in 2024. However, community-based rehabilitation is currently only provided in isolated areas, not covering hydrocephalus specifically but several disabilities, including hydrocephalus. Unfortunately, this does not benefit most children with hydrocephalus (Blessings A. Chapweteka, August 2024, personal communication).

In Nigeria, they found that the overall median time to receive surgical treatment for a child with hydrocephalus was 14 weeks, and children from families with a lower socioeconomic status faced a 20 times increased likelihood of experiencing delays than children from families with a higher socioeconomic status[61]. The Nigerian study attributes the delays to poverty, traditional healing methods, interfacility delays, social stigma, inadequate access to healthcare and transportation, poor health literacy, and limited education. Our third finding on the social implications of seeking care for children with hydrocephalus at QECH illuminates the interconnectedness of healthcare access, family dynamics, and societal attitudes. Addressing the social dimensions of hydrocephalus requires a multifaceted approach that includes community education, stigma reduction efforts, and support services for affected families to promote inclusivity, understanding, and social cohesion. Unintended consequences of healthcare, such as siblings falling out of school or being left at home without their primary caregiver for extended periods, children missing vaccinations, husbands leaving, and mothers losing the ability to earn money, were among the social implications reported in our study. Efforts to reduce these consequences need to be further explored. Like findings from Tanzania[36], our participants had little education; only two had completed secondary school, and very few had formal work and steady income.

Limitations and strengths

The main limitation of our study is that it only comprises mothers who sought medical attention at QECH. It is assumed that some children never present to the hospital, and our study may include a biased selection of mothers. One might also envision that our participants' responses were influenced by the fact that the interviews were conducted in a hospital setting and that, potentially, other themes would have emerged if the interviews had been carried out in the communities. Some mothers had never been to QECH before. Regardless of previous admission or not, the hospital context is probably more alienating to the participants than their local home community, which could lead to what is sometimes referred to as response bias, where participants are reluctant to convey information, or they adjust information, according to what they perceive as socially acceptable or assumptions about what the researchers want to hear[66]. In a hospital context, mothers of admitted children may, for example, be hesitant to convey experiences about traditional healing methods or witchcraft. However, the participants spoke about various healing methods, as illustrated in the quotes. In addition, information provided by our participants is based on their experiences, which may be influenced by recall bias. Moreover, because all interviews (except the first one which CGA conducted with ET as translator) were carried out by ET in Chichewa, CGA, who has more in-depth knowledge about paediatric hydrocephalus, could not ask relevant follow-up questions. Moreover, our study does not include paternal perspectives. Furthermore, our study does not include paternal perspectives. This should be considered for future research. Last, because child marriage is a substantial problem in Malawi[67], future research should also allow for the inclusion of mothers below the age of 18.

The strengths of our study include that ET, as a Malawian, is familiar with the sociocultural context and can communicate with the participants comfortably and in their language. Another strength is that we recruited mothers from different departments, which provided us with time variation since the commencement of hydrocephalus management. In addition, we collected data using two tools: in-depth interviews and focus group discussions. Although we did not include observation as a systematic data collection tool, the presence of CGA and ET in the study setting during data collection provided a thick and contextualised background of the lived experiences that the mothers were talking about.

Conclusions

Understanding the diverse beliefs surrounding hydrocephalus is crucial for designing effective health interventions, communication and clinical strategies, and improved access to care facilities for affected children and their families. Our findings underline the need for intersectoral action to optimise treatment and reduce stigma, including emphasising educational programs and awareness-raising campaigns to strengthen maternal health literacy. In addition, targeted initiatives to improve healthcare infrastructure, transportation, and pathways to care are urgently needed. This includes exploring the possibility of conducting follow-up through outreach clinics or telemedicine, and community-based rehabilitation. Lastly, improving management for children with hydrocephalus in Blantyre and Malawi includes efforts to strengthen the position of women educationally, economically, socially, and legally. This aligns with IGAP's focus on gender, carers, and human rights because, ultimately, the prevention and management of hydrocephalus in Blantyre and Malawi include the prevention and fight against poverty.

Author contributions

CGA: Conceptualisation, methodology-data preparation, data collection, data analysis, writing of original draft, project administration. PDK: Writing-review and editing, supervision. ET: Methodology-data collection, translation, and transcription, preliminary data analysis. CM: Writing-review and editing, supervision. HEF: Writing-review and editing, supervision. BAC: Writing-reviewing and editing. RB: Methodology: facilitating data collection. Writing- reviewing and editing. LMT: Writing-review and editing, supervision.

Data availability statement

The data sets used and analysed are available from the corresponding author upon reasonable request.

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References

1.Kulkarni AV, Shams I. Quality of life in children with hydrocephalus :results from the Hospital for Sick Children, Toronto. J Neurosurg. 2007;107(5):358-64. https://doi.org/10.3171/PED-07/11/358

2.Kulkarni AV. Assessment of Mother and Father Concern in Childhood Hydrocephalus. Qual Life Res. 2007;16(9):1501-9. https://doi.org/10.1007/s11136-007-9258-5

3.Shattnawi KK, Qananbeh FS, Khater W. The experiences of mothers of children with hydrocephalus in Jordan: A phenomenological study. J Pediatr Nurs. 2023;69:e127-e35. https://doi.org/10.1016/j.pedn.2022.12.026

4.Yusuf AS, Omokanye HK, Adeleke NA, Akanbi RO, Ajiboye SO, Ibrahim HG. Management and Outcome of Infantile Hydrocephalus in a Tertiary Health Institution in Nigeria. J Neurosci Rural Pract. 2017;8(2):249-53. https://doi.org/https://dx.doi.org/10.4103/jnrp.jnrp_321_16

5.Mathebula RC, Lerotholi M, Ajumobi OO, Makhupane T, Maile L, Kuonza LR. A cluster of paediatric hydrocephalus in Mohale's Hoek district of Lesotho, 2013-2016. JIEPH. 2018;1(3).

6.Muir RT, Wang S, Warf BC. Global surgery for pediatric hydrocephalus in the developing world: a review of the history, challenges, and future directions. Neurosurg Focus. 2016;41(5):E11.

7.Reid T, Grudziak J, Rodriguez-Ormaza N, Maine RG, Msiska N, Quinsey C, Charles A. Complications and 3-month outcomes of children with hydrocephalus treated with ventriculoperitoneal shunts in Malawi. J Neurosurg. 2019;Pediatrics..1-8. https://doi.org/https://dx.doi.org/10.3171/2019.2.PEDS18325

8.Aukrust CG, Paulsen AH, Uche EO, Kamalo PD, Sandven I, Fjeld HE, et al. Aetiology and diagnostics of paediatric hydrocephalus across Africa: a systematic review and meta-analysis. Lancet Glob Health. 2022;10(12):e1793-e806.

9.Adeloye A, Khare R. Ultrasonographic study of children suspected of hydrocephalus at the Queen Elizabeth Central Hospital in Blantyre, Malawi. East Afr Med J. 1997;74(4):267-70.

10.Waluza J, Borgstein ES. Management of hydrocephalus using the Chabbra shunt. Malawi Med J. 2005;17(1):7-8. https://doi.org/10.4314/mmj.v17i1.10861

11.Dewan MC, Rattani A, Mekary R, Glancz LJ, Yunusa I, Baticulon RE, et al. Global hydrocephalus epidemiology and incidence: Systematic review and meta-analysis. J Neurosurg. 2019;130(4):1065-79. https://doi.org/10.3171/2017.10.JNS17439

12.Warf BC. Hydrocephalus in Uganda: the predominance of infectious origin and primary management with endoscopic third ventriculostomy. J Neurosurg. 2005;102(1 Suppl):1-15. https://doi.org/10.3171/ped.2005.102.1.0001

13.Karimy JK, Reeves BC, Damisah E, Duy PQ, Antwi P, David W, et al. Inflammation in acquired hydrocephalus: pathogenic mechanisms and therapeutic targets. Nat Rev Neurol. 2020;16(5):285-96. https://doi.org/10.1038/s41582-020-0321-y

14.Kahle KTMD, Kulkarni AVMD, Limbrick DDMD, Warf BCD. Hydrocephalus in children. Lancet. 2016;387(10020):788-99. https://doi.org/10.1016/S0140-6736(15)60694-8

15.Whitehead WE, Weiner HL. Infantile and childhood hydrocephalus. N Engl J Med. 2022;387(22):2067-73. https://doi.org/10.1056/NEJMra2116504.

16.Drake JM, Kestle JRW, Milner R, Cinalli G, Boop F, Piatt J, et al. Randomized trial of cerebrospinal fluid shunt valve design in pediatric hydrocephalus. Neurosurgery. 1998;43(2):294-305. https://doi.org/10.1097/00006123-199808000-00068

17.Paulsen AH, Due-Tønnessen BJ, Lundar T, Lindegaard K-F. Cerebrospinal fluid (CSF) shunting and ventriculocisternostomy (ETV) in 400 pediatric patients. Shifts in understanding, diagnostics, case-mix, and surgical management during half a century. Childs Nerv Syst. 2016;33(2):259-68. https://doi.org/10.1007/s00381-016-3281-1

18.Simon TD, Riva-Cambrin J, Srivastava R, Bratton SL, Dean JM, Kestle JRW. Hospital care for children with hydrocephalus in the United States: Utilization, charges, comorbidities, and deaths. J Neurosurg Pediatr. 2008;1(2):131-7. https://doi.org/10.3171/PED/2008/1/2/131

19.Kickbusch IS. Health literacy: addressing the health and education divide. Health Promot Int. 2001;16(3):289-97. https://doi.org/10.1093/heapro/16.3.289

20.Manda M, Nambuzi E, Kaphesi F, Likalowa C, Mwambyale T, Kaunda J, Kamalo P. Comparing motor development in children with hydrocephalus after treatment with ventriculoperitoneal shunt and endoscopic third ventriculostomy: a cross-sectional study. Malawi Med J. 2024;36(1):7-12. https://doi.org/10.4314/mmj.v36i1.2

21.Rush J, Paľa A, Kapapa T, Wirtz CR, Mayer B, Micah-Bonongwe A, et al. Assessing neurodevelopmental outcome in children with hydrocephalus in Malawi. A pilot study. Clin Neurol Neurosurg. 2022;212:107091-. https://doi.org/10.1016/j.clineuro.2021.107091

22.Chimaliro S, Hara C, Kamalo P. Mortality and complications 1 year after treatment of hydrocephalus with endoscopic third ventriculostomy and ventriculoperitoneal shunt in children at Queen Elizabeth Central Hospital, Malawi. Acta Neurochir. 2022. https://doi.org/10.1007/s00701-022-05392-7

23.Meara JG, Leather AJM, Hagander L, Alkire BC, Alonso N, Ameh EA, et al. Global Surgery 2030: evidence and solutions for achieving health, welfare, and economic development. Lancet. 2015;386(9993):569-624. https://doi.org/10.1016/S0140-6736(15)60160-X

24.Grimes CE, Bowman KG, Dodgion CM, Lavy CB. Systematic review of barriers to surgical care in low-income and middle-income countries. World J Surg. 2011;35(5):941-50. https://doi.org/10.1007/s00268-011-1010-1.

25.Varela C, Young S, Mkandawire N, Groen RS, Banza L, Viste A. Transportation barriers to access health care for surgical conditions in Malawi: a cross sectional nationwide household survey. BMC Public Health. 2019;19(1):264-. https://doi.org/10.1186/s12889-019-6577-8

26.Kleinman A, Eisenberg L, Good B. Culture, illness, and care. Clinical lessons from anthropologic and cross-cultural research. Ann Intern Med. 1978;88(2):251-8. https://doi.org/10.7326/0003-4819-88-2-251

27.Hannig A. Beyond surgery: injury, healing, and religion at an Ethiopian hospital: University of Chicago Press; 2017.

28.Miles M. Children with hydrocephalus and spina bifida in East Africa: Can family and community resources improve the odds? Disabil Soc. 2002;17(6):643-58. https://doi.org/10.1080/0968759022000010425

29.Ademosu T, Ebuenyi I, Hoekstra RA, Prince M, Salisbury T. Burden, impact, and needs of caregivers of children living with mental health or neurodevelopmental conditions in low-income and middle-income countries: a scoping review. Lancet Psychiatry. 2021;8(10):919-28. https://doi.org/10.1016/S2215-0366(21)00207-8

30.Manglos ND, Trinitapoli J. The Third Therapeutic System: Faith Healing Strategies in the Context of a Generalized AIDS Epidemic. J Health Soc Behav. 2011;52(1):107-22. https://doi.org/10.1177/0022146510395025

31.Morris B. Medical herbalism in Malawi. Anthropol Med. 2011;18(2):245-55. https://doi.org/10.1080/13648470.2011.591200.

32.Ware SG. Perceptions and experiences of caregivers of severely malnourished children receiving inpatient care in Malawi: An exploratory study. Malawi Med J. 2018;30(3):167-73. https://doi.org/10.4314/mmj.v30i3.7

33. Paget A, Mallewa M, Chinguo D, Mahebere-Chirambo C, Gladstone M. “It means you are grounded” - caregivers’ perspectives on the rehabilitation of children with neurodisability in Malawi. Disabil Rehabil. 2016;38(3):223-34. https://doi.org/10.3109/09638288.2015.1035458

34.Adolfsson JS, Moss SM. “Even the NGOs Never Talk About Ufiti [Witchcraft]”: a Decolonial and Feminist Cultural Psychological Analysis of Individualized Development Clashing with Communal Ways of Being. Human arenas: an Interdisciplinary journal of psychology, culture, and meaning. 2023;6(3):423-43. https://doi.org/10.1007/s42087-021-00230-1

35.Owolabi MO, Leonardi M, Bassetti C, Jaarsma J, Hawrot T, Makanjuola AI, et al. Global synergistic actions to improve brain health for human development. Nature Reviews Neurology. 2023:1-13. https://doi.org/https://doi.org/10.1038/s41582-023-00808-z

36.Henderson D, Ndossi M, Majige R, Sued M, Shabani H. Understanding the Mothers of Children with Spina Bifida and Hydrocephalus in Tanzania. World Neurosurg. 2020;142:e331-e6. https://doi.org/10.1016/j.wneu.2020.06.224

37.Eriksen AA, Johnsen JS, Tennoe AH, Tirsit A, Laeke T, Amare EB, Wester K. Implementing Routine Head Circumference Measurements in Addis Ababa, Ethiopia: Means and Challenges. World Neurosurg. 2016;91:592-6.e. https://doi.org/https://dx.doi.org/10.1016/j.wneu.2016.04.132

38.Bannink F, Stroeken K, Idro R, van Hove G. Community Knowledge, Beliefs, Attitudes, and Practices towards Children with Spina Bifida and Hydrocephalus in Uganda. Int J Disabil Dev Educ. 2015;62(2):182-201. https://doi.org/10.1080/1034912X.2014.998174

39.Chidziwisano C, Experiences of caregivers of children with hydrocephalus at Queen Elizabeth Central Hospital [Masterthesis]. Kamuzu College of Nursing; 2018 [cited 2024 April 30th]. Available from: https://nkhokwe.kuhes.ac.mw/server/api/core/bitstreams/5b753aeb-5988-417f-8342-ada030ddb266/content

40.Phiri B. We want to challenge stigma. The Nation Online: Nation Publications Limited; 2013, November 16th [cited 2024 April 16th]. Available from: https://mwnation.com/%E2%80%98we-want-to-challenge-stigma%E2%80%99/

41.Kumbani P. Why did a surgeon weep? The Nation Online: Nation Publications Limited; 2018, November 6th [cited 2024 April 16th]. Available from: https://mwnation.com/why-did-a-surgeon-weep/

42.Nation Online. NGO sensitises communities to brain, spinal defects. The Nation Online: Nations Publications Limited; 2019, September 10th [cited 2024 April 16th]. Available from: https://mwnation.com/ngo-sensitises-communities-to-brain-spinal-defects/

43.Kumbani P. Qech has no CT scanner The Nation Online: Nation Publications Limited; 2018, October 25th [cited 2024 April 16th]. Available from: https://mwnation.com/qech-has-no-ct-scanner/

44.Aukrust CG, Kamalo PD, Finyiza G, Mula C, Chapweteka BA, Fjeld HE, Manda-Taylor L. ‘It is the child with the big head’ - Primary healthcare providers’ perceptions of paediatric hydrocephalus in Blantyre, Malawi: A qualitative study. Glob. Public Health. 2023;18(1):2276242-. https://doi.org/10.1080/17441692.2023.2276242

45.Slettebø H, Aukrust CG, Rønning P, Tisell M, Kamalo P. Establishing neurosurgery in Malawi–the story of a fruitful collaboration. Journal of Global Neurosurgery. 2022;2(1).

46.Ogunleye Olabisi O, Ismail Nasiru J, Lasseini Ali SBB. Management of childhood hydrocephalus in our centre. Parents’ knowledge, experiences and expectations. Glob J Res Anal. 2018;7(4).

47.World Health Organization. Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders, 2022-2031. 2023 [cited 2024 March 5th]. Available from: https://www.who.int/publications/i/item/9789240076624

48.Moen K, Middelthon A-L. Chapter 10 - Qualitative Research Methods. Elsevier Ltd; 2015. p. 321-78.

49.Pittalis C, Brugha R, Bijlmakers L, Mwapasa G, Borgstein E, Gajewski J. Patterns, quality and appropriateness of surgical referrals in Malawi. Trop Med Int Health. 2020;25(7):824-33. https://doi.org/10.1111/tmi.13406

50.Gadama Y, Kamtchum-Tatuene J, Benjamin L, Phiri T, Mwandumba HC. The significant gap between international standards and stroke management practices at Queen Elizabeth Central Hospital (Malawi):

An audit report. Malawi Med J. 2019;31(4):249-55. https://doi.org/10.4314/mmj.v31i4.6

51.Aukrust CG, Kamalo PD, Prince RJ, Sundby J, Mula C, Manda-Taylor L. Improving competencies and skills across clinical contexts of care: a qualitative study on Malawian nurses' experiences in an institutional health and training programme. Nurs. Open. 2021;8(6):3170-80. https://doi.org/10.1002/nop2.1030

52.Green J, Thorogood N. Qualitative methods for health research. 4th edition. Thousand Oaks, California: SAGE; 2018.

53.Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101. https://doi.org/10.1191/1478088706qp063oa

54.Maxwell JA. Qualitative research design : an interactive approach. 3rd edition. Los Angeles: Sage; 2013.

55.Olmos-Vega FM, Stalmeijer RE, Varpio L, Kahlke R. A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. Med Teach. 2023;45(3):241-51. https://doi.org/10.1080/0142159X.2022.2057287

56.Bakare M. Community perception about children with hydrocephalus in Lagos State, Nigeria. NJSA. 2020;18(1):148-64. https://doi.org/10.36108/NJSA/0202/81(0101)

57.CHYSPR. Comprehensive Policy Recommendations for the Management of Spina Bifida and Hydrocephalus in Low-and Middle-income Countries: Program in Global Surgery and Social Change, Harvard Medical School, MA, 641 Huntington Ave, Boston, MA 02115, USA; 2021 [cited 2024 April 16th]. Available from: https://www.chyspr.org/

58.Ssentongo P. Intersection of Childhood Undernutrition and Postinfectious Hydrocephalus 2021 [cited 2024 August 16th]. Available from: https://etda.libraries.psu.edu/catalog/18883pxs60

59.Crabb J, Stewart RC, Kokota D, Masson N, Chabunya S, Krishnadas R. Attitudes towards mental illness in Malawi: A cross-sectional survey. BMC Public Health. 2012;12(1):541-. https://doi.org/10.1186/1471-2458-12-541

60.Adeloye A. Management of infantile hydrocephalus in Central Africa. Trop Doct. 2001;31(2):67-70. https://doi.org/10.1177/004947550103100203.

61.Idowu OE, Idowu JO, Badmus OC. Improving access to pediatric hydrocephalus care for all: the role of maternal health literacy and socioeconomic status. J Neurosurg Pediatr. 2024:1-8. https://doi.org/10.3171/2023.11.PEDS23493

62.Thaddeus S, Maine D. Too far to walk: Maternal mortality in context. Soc Sci Med. 1994;38(8):1091-110. https://doi.org/10.1016/0277-9536(94)90226-7

63.Aukrust CG, Parikh K, Smart LR, Mdala I, Fjeld HE, Lubuulwa J, et al. Pediatric Hydrocephalus in Northwest Tanzania: A Descriptive Cross-Sectional Study of Clinical Characteristics and Early Surgical Outcomes from the Bugando Medical Centre. World Neurosurg. 2022;161:e339-e46. https://doi.org/10.1016/j.wneu.2022.02.003

64.Padayachy L, Ford L, Dlamini N, Mazwi A. Surgical treatment of post-infectious hydrocephalus in infants. Childs Nerv Syst. 2021;37(11):3397-406. https://doi.org/10.1007/s00381-021-05237-1

65.Warf BC, Wright EJ, Kulkarni AV. Factors affecting survival of infants with myelomeningocele in southeastern Uganda: Clinical article. J Neurosurg Pediatr. 2011;7(2):127-33. https://doi.org/10.3171/2010.11.PEDS10428

66.Collins M, Shattell M, Thomas SP. Problematic Interviewee Behaviors in Qualitative Research. West J Nurs Res. 2005;27(2):188-99. https://doi.org/10.1177/0193945904268068

67.Melnikas AJ, Mulauzi N, Mkandawire J, Amin S. Perceptions of minimum age at marriage laws and their enforcement: qualitative evidence from Malawi. BMC Public Health. 2021;21(1):1-1350. https://doi.org/10.1186/s12889-021-11434-z

Appendix 1: Interview guide for in-depth interviews

To begin with, I have some questions about your background:

- Can you please tell me your age? And how many months is your child? (Age in years for mother and in months for child)?
- Living area (rural/urban) (distance from the hospital)?
- How many people live in the same household (adults and children)? Are you married?
- Education/profession? Do you know how to read/write?
- Mode of birth delivery (home or at the hospital)?
- Complicated or uncomplicated birth?

The period before seeking help/seeking initial help

1. Can you please tell me about your family? How many children do you have?

   (Probe: the child you are hospitalised with now is number? Are your other children healthy? Who is taking care of your other children while you are here?)

2. Can you please tell me about the first period after birth? *(Probe: How were you doing? How was your child doing? Was he/she sick in any way, with fevers or anything else?)*

3. Can you tell me what you remember when you started to suspect something was wrong? *(Probe: how did you understand this: crying, irritability, bulging fontanelle, reduced appetite, not developing as you expected? Other things?)*

4. How was this experience for you? *(Probe: Were you worried? Did you talk to anyone about your worries? What did they advise you to do? Did you have anyone in your life to provide you with emotional support? Who, other women where you live? Your husband?)*

5. In our communities, some women think that bewitchment may be the reason for sickness. What are your views on this? (Probe: *Have you or anyone you know thought that was the case?)*

The period before seeking help at Queen Elizabeth Central Hospital

6. If you received any help for your child before you came here to Queens, please describe this to me. *(Probe: from whom/where did you get this help?)*

7. I have the understanding that it is quite normal to visit traditional healers in Malawi. Some do this, but not all. What is your experience with this? *(Probe: how was this experienced? What advice were you given? Was this helpful? Why or why not? Did the traditional healer perform examinations or provide the child with some treatment? What mode of transport did you use, and how far away from your home was this? If relevant, what about your other children, who cared for them while you were away?)*

8. What about the primary health centres? If you visited them, can you tell me a little bit about what your experiences are like? *(Probe: Maybe it is concerning vaccinations? How was this experienced? What advice were you given? Was this helpful? Why or why not? Did the people working at the primary health centres perform any examinations or provide the child with some kind of treatment? What mode of transport did you use, and how far away from your home was this? If relevant, what about your other children? Who cared for them while you were away?*

The period at Queen Elizabeth Central Hospital

9. What led to the admission to Queens? *(Probe: when were you referred, and who referred you? Is this your first time in the hospital? Mode of transport?)*

10. Can you please describe what examinations and treatments your child has received while you have been in Queens? It may be challenging to know what these examinations and treatments are called. If you want to, you can just describe them to me in your own words. *(Probe: what about head circumference measurements? Has this been done now or earlier? Do you have a SHIP passport?)*

11. Can you explain to me, in your own words, what you have been told about the condition of your child? *(Probe: Who and when were you informed? Did the person inform you about the reason your child has become sick? Can you tell me what you know about the treatment/surgery?)*

12. Please tell me what you knew about hydrocephalus before you came to Queens. *(Probe: had you heard about hydrocephalus earlier or seen other children who had it?)*

13. Can you please tell me about your stay here in Queens? *(Probe: What have they done with your child? With you? Who has provided this? What kind of information have you received? How have you and your child slept? Have you talked to any surgeon? Do you have one nurse that you speak to more than other nurses? How have you experienced the companionship with the other mothers who have stayed here in Queens with you? Have you received support from your husband? Do you know how long you are going to stay here?)*

About the future

14. Thinking ahead, can you please share some of these thoughts with me? *(Probe: For your child? For you? For your family? Do you know how much longer you will stay here? Follow-ups? How will you get back home? Have you come to accept the condition of your child?)*

15. If you could give some advice to the people that you reached out to for help before you came to Queens that you think would have been good for you to know, what would that be? (Probe: *Looking back at how you felt when you realised your child was developing differently, what would you have wanted to know then that you know now?)*

16. If you could give some advice to the people who work in Queens that you think would have been good for you to know, what would that be?

17. Is there anything you want to add that we haven't discussed?

Appendix 2: Focus group discussion thematic guide

The questions in the focus group discussions revolved around themes that emerged through the in-depth interviews that seemed interesting to gain further information relevant to the study objectives.

The questions centred on

- The period before seeking help/seeking initial help (who you saw, how this was experienced, what you remember from this time, did you get any help or advice from anyone, and did you consider this helpful).
- The stay at QECH (how has it been experienced).
- The future (how do you picture the future; how do you picture the return to your home place/village).
- What advice would you give the healthcare providers you have met on your pathway to care (from the people in your local community, the primary healthcare centres and QECH)?

Appendix 3

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	N/A
Occupation	3	What was their occupation at the time of the study?	9
Gender	4	Was the researcher male or female?	9
Experience and training	5	What experience or training did the researcher have?	9
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	N/A
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	N/A
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	7
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	7
Sample size	12	How many participants were in the study?	8
Non-participation	13	How many people refused to participate or dropped out? Reasons?	7
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	6
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	10
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	9
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	8
Field notes	20	Were field notes made during and/or after the inter view or focus group?	6
Duration	21	What was the duration of the inter views or focus group?	10
Data saturation	22	Was data saturation discussed?	8
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Appendix 4: Additional quotes theme 1: A Range of pluralistic disease explanations

"But if I was alone or just the two of us were in the ward, I would have said maybe it has something to with witchcraft. I have seen several people with this disease, so how can I say that I was bewitched? No way, it's not witchcraft. It is just a natural disease that was given on earth". *IDI-OPD-ID 4.*
"We are married into one family, so she is like a sister-in-law. They told me this person had a hand in everything happening to my child. But then, I believe that that person and I have no blood relation, so she could not bewitch my child, but this story has been there". *IDI-OPD-ID 11.*
"My baby was born in this hospital, so there was this enmity with somebody. I always thought they had a hand in the baby's illness […]. I was ready to look for traditional help, but my mum believes in God. She said we could go to a witch doctor with money, but that witch doctor would fail. Then we started attending prayers until now, but I still have that feeling that somebody has a hand in my baby's sickness. I still feel it, until now. The way that woman behaves, I still think she has a hand in everything. Then she (*referring to her mother*) said, I should not blame anyone. It is just a disease that is there". *FGD-PO-ID 2.*
"I now believe that maybe somebody has a hand in how things happen. Because there is another woman from my mother's family, I said some things to her that she did not like, but I know that I never said anything bad. She once asked me to fetch water for her, and then I said; I cannot do it because you are not sick. I told her that if you wanted to see sick people, go to the hospital. You'll see many sick people there. So, she said, you have refused to fetch water for me. We'll see. I didn't know that she still had this thing in her about the situation. You see, I came here once, and now am here again. Then she told my elder sister that your sister said there are sick people in Queens (*referring to QECH*). Between her and me, who have been in the hospital, I came to notice that what she said before is what is happening to me now. She started this thing, so she upset me. So, I don't have to ask her about anything because everything is left in God's hands. Only God will help me». *FGD-PN-ID 7.*

"They say "mmimba ndi mchipala" *(Chichewa language, meaning the womb is unpredictable*). Some babies are born dark, and others are light (*referring to skin colour*). You can give birth to four perfect children, and the fifth one can be disabled. They (*referring to the elders*) say our eyes cannot see what is inside the womb, so whatever comes out, we must receive it. These people who are always talking about other people's children should know that God is in heaven. The tongue that says bad things about other people should be very careful because tomorrow, the same things can happen to them*". FGD-PO-ID 4.*
"So, now that I am here (*referring to QECH*), it is not possible for them to involve him (*referring to one of her older children*) in their evil deed. […] Sometimes, when they come, he can see them (*referring to spirits*), but we cannot do that. They cannot even take him with them when they try to pick him up. He called to tell me the evil people came [xxx]. I even explained this to this one (*pointing at another participant in the FGD*) last week. His father said that nothing bad was going to happen; it (*referring to the evil deeds*) did not even happen on the day that I went to the theatre (*referring to the operating theatre*), so I concluded that witchcraft was real, but I let God be God". *FGD-PN-ID 15.*
"The issue of witchcraft is everywhere. I had no idea that I was pregnant when I fell pregnant with this child. I could feel that I was pregnant. It was not growing as it was supposed to be. Then, after some time, two months later, I went to the hospital to be examined to determine if I was pregnant or not. The doctors confirmed that I was a month pregnant. I accepted the fact that I was pregnant, and then they told me to go back after a month, which I did". *FGD-PN-ID 12.*
"He (*referring to the devil)* filled me. I had no idea that God is great. I have seen God through this child, and God himself works through these doctors by giving them wisdom so they can work". *IDI-OPD-ID 13.*
"[…] only God will save her. Of all the situations that I have been through to get here today. I would use traditional medicine then, but I never saw any changes, so I left everything in God's hands, and I made up my mind from that day that wherever I go, I would follow my God's way so I would not give my child any traditional medicine. I leave everything in God's hands; he is great and can heal any disease, no matter how big". *FGD-PN-ID-12.*
"My family believes in God only, that he is the only doctor with healing powers". *IDI-PO-ID 2.*
"I don't think he was bewitched. I think it was something God himself let happen. He was operated here, they took out a sample, they found out that the water in his head was yellow, a bright yellow". *IDI-PN-ID 15.*
"I have always suspected that it could be this one or that one, but no; when I went to the hospital, and they explained this condition to me and gave me a book to read (*referring to the SHIP passport),* then I realised that it is not the people that are suspected of having a hand in the baby's sickness, but it is just a disease that comes from the creator". *FGD-PO-ID 9.*
"I did not go anywhere with him (*referring to the baby*); I was just praying for him at home and church […]. Even here, when the preachers come, we attend the prayers, and they give us holy water to drink for the children. This is how we are living here. So, I let the evil people do what they do, and I do what I do. My wish is to ask God to heal my child because I cannot do anything to evil people. After all, they do evil things". *FGD-PN-ID 15.*
"At first, I thought that was the case, that someone did something. People usually behave differently in the community when you quarrel with them. They may talk bad about you or the child, or they may confess to doing something bad to the child through witchcraft. So, sometimes, you can connect the dots that someone did something. But still, I don't take it at heart because I don't know God's plan". *IDI-OPD-ID 3.*
"No, you cannot suspect somebody. It is just a disease. It's not witchcraft". *FGD-PO-ID 8.*
"The person that told me this once had a baby with a big head. So, when she saw my baby, she advised me not to waste my time visiting traditional healers but rather rush to the hospital with the baby where they will give us the proper treatment". *IDI-PN-ID 14.*
"Yes, they told me that the baby's head was swelling. When it swells it means there is water inside. Every child should have water, but this one has too much water". *IDI-PN-ID 16.*
"I was planning to go see a witch doctor once I was discharged. But because the hospital opened my eyes before I went home, I dared to accept the situation". *IDI-PO-ID 2.*

Abbreviations: IDI: In-depth interview. FGD: Focus group discussion. PN: the paediatric nursery ward. PO: the paediatric orthopaedic ward. SHIP: Spina Bifida and Hydrocephalus Interdisciplinary Program.

Appendix 5: Additional quotes theme 2: Strenuous care pathways

"When the labour started, I took the bicycle to the hospital. So, the bicycle broke down on the way to the hospital. When the bicycle was being fixed, I snuck out into the bush. I gave birth right there. After the bicycle was fixed, we proceeded to the district hospital". *IDI-OPD-ID 13*.
"They tell us to wait. They tell us not to go home, and we wait there (*referring to the healthcare level below QECH*). After they drop off the patients, the ambulance comes for a second trip to pick up other patients, and there may be a space for us to go". *FGD- PN-ID 1.*
"Sometimes it happens that we do not have transport to go to the hospital that they tell us to go to, and they also happen to tell us that there is nothing we can do about that. Then, you can just go home. Most of us do nothing for a living but have many problems. We may get a shunt or ETV, but when you go home, things may go wrong, and a baby may have a seizure. So, what can you do to help a baby who has seizures? You need to go to the hospital, but there is no transport to take you there, so they return home". *FGD-PO-ID 9.*

"Yes, they are very important. If I had relatives nearby, I would have spent some nights there waiting to come here. The problem is money. Had it been that there were lots of ambulances coming this side, it would have been easy to jump in and come along. Going back, I may get help from well-wishers. Where I come from, it is very difficult to find money. Like once a year, after selling things from the farm. Whether you get money from selling cotton or anything, but if it doesn't go as planned, you must wait for another year of rain to get your farm products". *FGD-PN-ID 12.*
"It is difficult, and I don't know how to help them because I have nothing. I don't even have money. I have completely nothing, but all I want is for my baby to get well. If I find a man willing to take me in, I'll let him take me so that he helps care for my children. Because if you hide anything, people will think you're married. It's difficult to get help. I don't have transport money, 18 000 Kwacha, to take me home". *IDI-OPD-ID 13.*
"The thing is that I don't know how I am going to get back home when they discharge me. I used my transport coming here. I did not come by the ambulance". *IDI-PN-ID 15*.
"I don't know at the moment. If I know the date I will be discharged, I will know how to get home. Sometimes, if you are lucky, you find an ambulance to drop off some patients, and you can get on that when you return. If you do not have transport and there is no ambulance, we can wait until an ambulance takes us home". *IDI-PO-ID 9.*
"I did not pay anything when coming here; they just brought me here, so I don't know how I will return because they said the vehicle does not come here often. So, I don't know what I will do". *IDI-PO-ID 8*.
"I will see when that time comes. I can't say anything now because I am waiting to get help, so I can't think about how I am returning home now. Our life is bad; everything is difficult". *IDI-PO-ID 10.*
"It will be difficult to come for check-ups because of transport. Things have changed now. Money is scarce. So, I must do piecework to feed my family, care for my children, and look for transport money to come here. It will be challenging to come on the days they tell me to come (*referring to follow-up dates*) because I cannot manage to come every time they say so. For example, if they say to come this month and next, it will be difficult because I mostly depend on borrowing from friends. Even the owner of the money will be waiting for their money on the agreed dates. Sometimes, I may not get the piecework, so I will have no money to pay back. When the check-up date is due, it may be difficult to come because there is no money for transport. So, is it impossible to borrow more money before you pay back your debt? No, I think it will be difficult to come for check-ups because of lack of transport because I live very far from this hospital". *FGD-PN-ID 12.*
"I'll have to make plans so that I come. Otherwise, I'll have to budget for two people to come here because of the twins. I cannot come alone with the twins and need help. So, it means coming here will depend on whether I get money. Life is hard now, and money is scarce. As I said before, I do what I do to get money, so I'll need to do the same work I do to get money. I may not be able to come like this week, but surely the other week I will be able to". *FGD-PN-ID 15.*
"I will have to plan way before the due dates for me to be able to come. If money is available, I come. Because if I miss the check-up xxx. For example, if I did not come for a check-up a few days ago, I would not have known that her wound was producing some puss. So, coming for check-ups will be a must. When I have money, I'll have to walk down here". *FGD-PN-ID 7*.
"They told me the child had water in the head and needed to go the theatre. So, he went to the theatre, and they put a shunt on him. Then they told me that I had to come for a check-up so that they could see how it went. Because of lack of transport, I cannot come for these." *IDI-OPD-ID 5.*
"They said I was supposed to go today. When they asked me where I lived, I said (*name of district*). Then they said that it was far. They must do the check-up before I leave, so I was told to wait until then. So, I have three days to wait so that they see how it goes with the baby". *IDI-PO-ID 8.*
"I waited too long ...then I went back to the hospital. On the 18th, I waited for five days at the deposit. Luckily, I had money, 6000 Kwacha. Then, I left at around four because I didn't want to wait more than a week. I started and spent the night at (*name of town*). In the morning, I saw an ambulance coming from (*name of town*), which stopped at (*name of town*). I spent a night at a rest house in (*name of town*). Then I asked him where he was going. He said he was going to (*name of district).* From there, I jumped into the ambulance and went to (*name of district).* I have noted that the waiting was too long, but I don't have transport money to take me home. I can't even go to my uncle's place to ask him for money". *IDI-OPD-ID 13.*
"The only problem is the one that I have already spoken about, that I am a poor woman. I depend on people to give me money for transport to the hospital. If they also fail to give me money, I do not have a choice but to fail to go to the hospital. Like last month I failed to come because of lack of transport. So, there are a lot of problems with the family I come from. I am the third wife, and there is not enough help for all of us. My husband fails to provide for all three of us, but maybe things would be different if only the two of us existed. But now he cannot attend to the children and me because he is always rotating from one home to another, and his help depends on which house he is living in at that time. I am doing everything all alone, which is difficult for me". *IDI-OPD-ID 4.*
"I made a phone call at home asking them to send me transport so I could go. Because my family did not have money to send to me, the people from the church I go to had to contribute the little they had put together and send to me. The church people have even allowed me to come for a check-up by giving me money for transport today. Now, I must call my family to send some money so I can go back after the check-up, but if they don't happen to have any, the church people will have to send me. I asked the people from my church if they could help with money so that I could come to the hospital with the child because I am very poor. Sometimes they can help me, but sometimes I must help myself by looking for piece work". *IDI-OPD-ID 4.*

Abbreviations: IDI: In-depth interview. FGD: Focus group discussion. PN: the paediatric nursery Ward. PO: the paediatric orthopaedic ward. OPD: the outpatient department.

Appendix 6: Additional quotes theme 3: Social implications

"I was doing my work at home; I do irrigation farming. I stopped because of the baby's condition. My friends were still working in their fields when I left. I only planted maise because I was coming here for my baby's treatment". *IDI-PO-ID 8.*
"This child needs a lot of things. Yes, we are managing some things, but we are mostly not. He is three years old now, and if he had not had this condition, I would have put him into nursery school so he could be with his friends. At the school, they said they could change his nappies, but they could not give him the care that I do at home, which requires a lot of money, which I do not have". *IDI-PO-ID 2.*
"I have also left some children at home. They (*referring to the children at home*) do not have soap, yet when I was home, I gave them some. Sometimes, we do not have to depend on the father for everything because he also must wait for the monthly salary he gets once, and that money sometimes is not enough to get us throughout the month. So they don't have food. They may go to bed without food, so as a mother, I try as much as possible to ensure that the children do not go to bed without food. That is the problem I have for my children". *FGD-PN-ID 7.*
"I am also worried about my children because children are happy with their parents, eating, bathing, and washing. They all depend on me. So, nothing happens at home, even at school, when I am here. They are not going daily (*to school*). They go here and there. Their father also had to go for piecework, so he couldn't cook or bathe them. Even though I am here in this hospital, my heart is at home, thinking about my other children". *IDI-PN-ID 15.*
"There are several problems. One is that my other children are not going to school. The 11- and 7-year-olds are failing to attend school because of my absence". *IDI-PN-ID 7.*
"I was not able to start visiting the postnatal because the child was sick since he was born. As I speak, I haven't attended any postnatal visits. They (*referring to twins*) haven't even gotten their BCG vaccine". *IDI-PN-ID 15.*
"Yes, he does, but now he stopped because he went to live with another woman. He doesn't care anymore. He can't care anymore" (*referring to her husband*). *OPD-ID 13.*
"The thing is, by the time I was coming here, we were together (*referring to her husband*), but now it seems like we are not". *IDI-PN-ID 14.*
"I have not, but some friends have complained to me that their marriages have come to an end because of this condition. Or perhaps they are being ill-treated and mocked because of the bay's condition". *IDI-OPD-ID 3.*
"(*Laughs*) Lots of problems. I can even marry if anyone is willing to take me in so that he takes care of me. It's like I am on sale". *IDI-OPD-ID 13.*
"No, my husband left me because I stayed in the hospital; he went to marry another woman. My children are being taken care of by my parents, my mother, and my uncle". *IDI-OPD-ID 13.*
"Nobody can take care of my child or do anything. They fail to carry him or do anything with him. I do everything for this child all by myself. When I go somewhere, like to the maise mill, I make sure that I feed him, bathe him, and leave him. I don't go with him because the maize mill is very far away from the house, so I cannot carry a child on my back and a basket of maise on my head, and I have to walk a very long distance. I leave him while sleeping because other people refuse to stay with him. I find him okay on my way back. If it goes to the farmland, I don't go there because I cannot manage it; my elder children do the farming for me. For example, they did the work for me last year, and I got one bag of maise, and that's what I am eating with the children at home". *IDI-OPD-ID 4.*
"I have this neighbour who disappointed me with her comments on the baby's sickness when she saw him. She has a tuck shop. So, I went there to buy sugar. She asked me about my child's sickness. I told her yes; my child is sick and is having a problem with his head. It's getting big. Then she comments, saying children with such a condition never get better, they are just wasting your time, and in the end, he would die. So, for me to come here to the hospital, I had to gather some courage to bring the child to the hospital. Most people disappointed me by saying that the baby will stop me from farming, but in the end, he is going to die anyway". *IDI-PN-ID 15.*
"It is very painful. I have stayed at Chatinkha (*a ward at QECH*) for three months. Sometimes, I lock myself inside the house and sob for as long as I can. So, there was a time when I left Chatinkha with swollen eyes. The doctors asked me why I was failing to take care of the child, but I couldn't. And when I went home, I heard even worse things. I ended up taking blood pressure pills. There is still nothing good until now. All I want is to leave the place that we are living. I asked my mother if she could sell the land, but she found it difficult because it was her land, which she got at a reasonable price. It will be difficult for her to sell it and buy another land. My reason for leaving is that I want peace of mind, but I can't leave my mother alone because I am her first child and her only daughter, and this is her grandson. So, these people say a lot, knowing that the land was bought cheaply, and we built our houses there. The money we may get from selling the land will not be enough to buy another house. Even if I were offered money, it would not be enough. So, she suggested that we stay and put up with it all and that only God will set us free. I still experience a lot of things that are very painful to me". *FGD-PO-ID 2.*
"There is one boy around my house who scares them (*referring to her other children*) that he will kill them. So now that I am not around, they cannot attend school. They are disappointed. They even told me that they wanted to follow me here at the hospital and be with me, and that pains me because they would come, and it would be painful if they got lost on the way. My business is not working; I don't earn money, and my husband is spending so much sending here at the hospital, plus the children's school fees. We are currently not doing well financially, and I wonder when this sickness will go away". *IDI-PN-ID 7.*
"Oh, I have a comment. I am pleading with fellow mothers that parents...Men should not mock the children's condition and blame it on us mothers as if we are the reason for the condition. We do not know how this condition is caused, so most men should not be teasing mothers with such children". *IDI-OPD-ID 3.*

Abbreviations: IDI: In-depth interview. FGD: Focus group discussion. PN: the paediatric nursery ward. PO: the paediatric orthopaedic ward. OPD: the outpatient department.