"As time passes, her disability becomes severe." The struggles and challenges of caring for children living with spina bifida and hydrocephalus in Uganda: perspectives from caregivers.

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Caring for children with spina bifida in Uganda

Abstract

Purpose: Spina bifida and hydrocephalus are common neural tube defects that cause brain and spinal cord damage leading to loss of sensation, paralysis, deformities and bladder/bowel dysfunction. Children with these conditions require substantial caregiving support. However, the specific challenges caregivers face remains poorly understood. This study explored the experiences of parents and siblings caring for a child or young adult with spina bifida and hydrocephalus.

Methods: Semi-structured interviews were conducted with 18 parents and 12 siblings in Central Uganda to understand their caregiving experiences. Thematic analysis was used to identify key challenges.

Findings: Caregivers reported significant challenges, including lack of knowledge about the condition, stigma and negative attitudes, inadequate healthcare services, lack of social support, financial strain, and difficulties managing health and hygiene. These challenges also disrupted their employment, schooling, and overall well-being.

Conclusions: Caregivers face challenges such as limited resources, stigma, and financial strain, affecting both their well-being and the quality of care provided. Addressing these barriers requires improved healthcare services, greater community awareness, and enhanced social and financial support. Strengthening support systems for parents and siblings is essential to improving care and health outcomes for children. Targeted interventions are needed to better support caregivers and mitigate the burden of caregiving.

Keywords: Spina bifida, Hydrocephalus, adolescents, disability, caregivers, siblings, Uganda

Background

Globally, 150 million children aged 0-18 are estimated to be living with a disability, the majority of whom live in low and middle-income countries (LMICs) (Bickenbach, 2011; World Health Organization & World Bank, 2011). Spina bifida and hydrocephalus are life-threatening conditions that often result in severe disabilities separately or in combination. These neural tube defects are severe congenital malformations resulting into nerve damage, permanent disability and other neurological disorders (Copp et al., 2015). The pooled birth prevalence of Spina bifida ranges between 0.12% and 0.14% among new-borns in Africa (Oumer, Taye, Aragie, & Tazebew, 2020). Although major advances in medicine and long-term care have significantly improved survival rates and health outcomes for children with SBH, these improvements have also revealed new challenges. As more children with SBH grow into adolescence and adulthood, families and healthcare systems face increasing demands related to long-term caregiving, while young people themselves encounter profound health and social inequities during the transition to adulthood (Liptak, Garver, & Dosa, 2013; Patel et al., 2019).

As children with Spina bifida and hydrocephalus grow and develop, they often face various complications, including recurrent urinary tract infections, pressure sores, anaemia, heightened risks of physical and sexual abuse, and developmental disabilities (Ganshanga & Asasira, 2020). Their health needs receive inadequate attention and often over shadowed by the negative knowledge, beliefs, attitudes, and practices associated with children with Spina bifida and hydrocephalus and their parents in Uganda (Bannink, Stroeken, Idro, & van Hove, 2015; O'Sullivan et al., 2021; Sims-Williams, Sims-Williams, Mbabazi Kabachelor, & Warf, 2017). These perceptions can contribute to social exclusion, and delayed access to specialized healthcare services, impacting both the well-being of the children and their caregivers.

The psychological consequences of a disability are often devastating for the development of the child. They include a sense of guilt, loss of self-esteem, phobias and fear, sleep disorders, inability to speak and left unmanaged can result in long-term mental disorders and poor health related quality of life (Bannink, Idro, & Van Hove, 2018). Studies have shown that children with spina bifida in low and middle income countries experience significant challenges related to their health related quality of life, including social exclusion, educational barriers, and limited access to healthcare and specialized healthcare services, which further exacerbates their psychosocial distress (Sims-Williams et al., 2017; Tafesse et al., 2024).

In Uganda, socio-economic and cultural factors significantly exacerbate the challenges faced by children with disabilities and their families. Limited financial resources often prevent families from accessing necessary medical care and support services (Dowhaniuk, 2021; Ssemata et al., 2024). Additionally, deep-rooted cultural beliefs that associate disability with misfortune or punishment further contribute to stigma, social exclusion, and discrimination, leading to children being hidden away, denied, abandoned or neglected, making them extremely vulnerable (Mfoafo-M'Carthy, Grischow, & Moasun, 2024; O'Sullivan et al., 2021; Stone-MacDonald & Butera, 2012).
Social stigma and environmental pressures not only affect children with disabilities but also extend to their siblings and caregivers, often resulting in emotional strain, social isolation, and reduced overall well-being (Lestari et al., 2020). Caregivers, particularly mothers, often face significant emotional, physical and financial burden. This may lead to mental health problems and poor quality of life, especially in developing countries, where there is little available support (Jansen-van Vuuren et al., 2022; Thuy & Berry, 2013).

Caregivers and family members of children with disabilities also experience profound emotional and psychological impacts. Studies show that families raising children with disabilities report high levels of stress, anxiety, and depression, often worrying about their child's future prospects and inclusion in society (Bannink, Idro, & Van Hove, 2016; Emerson & Llewellyn, 2008). Parents and siblings of children with disabilities often experience a range of complex emotions such as protectiveness, frustration, grief, guilt, embarrassment and feelings of inadequacy regarding their caregiving and reproductive roles (Mugno, Ruta, D'Arrigo, & Mazzone, 2007).

In contexts marked by pervasive stigma, caregivers may also internalize societal attitudes, experiencing distress when confronted with the child's physical or developmental differences. These psychological burdens can significantly affect caregivers' ability to effectively support rehabilitation and long-term management of their child's condition (Raina et al., 2004). Parental emotional distress, such as depression, not only limits the caregiver's capacity to manage the child's illness but can also contribute to poorer emotional and psychiatric outcomes for the child, compounding the family's overall vulnerability (Brehaut et al., 2004). Emotional distress in a parent may contribute to emotional and psychiatric distress in the child and may affect the family's ability to cope with the illness; thus, the illness may have a greater impact on the family.

Despite their central role in providing care, the experiences and needs of caregivers—particularly in low- and middle-income countries remain underexplored. With a growing number of children with spina bifida and hydrocephalus (SBH) surviving into adolescence and adulthood in Uganda, caregivers of children with spina bifida and hydrocephalus (SBH) face profound challenges, as young people with SBH encounter persistent health and social inequities, including poor access to specialized care, difficulties transitioning to adult services, and limited educational and employment opportunities due to stigma and the lack of inclusive policies (Adugna, Nabbouh, Shehata, & Ghahari, 2020; Bannink et al., 2018; Fischer, Church, Lyons, & McPherson, 2015).

These systemic barriers not only undermine the well-being of children but also place significant emotional, financial, and social strain on their caregivers, contributing to poor family health outcomes and deepening economic vulnerability (O'Sullivan et al., 2021; Sims-Williams et al., 2017). Addressing this gap requires a better understanding of caregivers' lived experiences to inform the development of disability-inclusive health and social interventions. Therefore, this study aimed to explore the caregiving experiences of parents and siblings of children with spina bifida and hydrocephalus in Uganda and to highlight specific challenges they face in order to inform policy and programmatic responses.

Methods

Study design and setting.

This was an exploratory community based cross-sectional qualitative study among caregivers (parents and siblings) of children and adolescents with spina bifida and hydrocephalus. This study took place in the central region urban (Kampala & Wakiso) and Peri-urban and Rural (Mukono & Mityana) areas of Uganda.

Sampling and research participants

Working with Spina bifida and Hydrocephalus Association of Uganda (SHAU), a national coordinating body, we purposively identified and selected caregivers (Parent/ caregiver or a sibling - those involved in the care and management of children with spina bifida and hydrocephalus from the association registers who belong to the Central region. The association supported the first contact with potential participants, and these participants were contacted and information about the study shared with them. Participants were informed about the study procedures and made to understand that participation is voluntary and refusal to participate would not attract any penalty or adversely impact their relationship with the Association. One participant declined to participate but all the other participants contacted accepted the invitation and were scheduled for consenting and interviews according to their date, time and location preference.

Inclusion criteria for caregivers included:

1. Caring for a child with spina bifida and hydrocephalus as a parent and or sibling fully involved in the care and management of children with spina bifida and hydrocephalus. This was aimed to provide a comprehensive understanding of the caregiving experiences and dynamics within families of children with spina bifida and hydrocephalus.
2. Attending the Spina bifida and Hydrocephalus Association of Uganda (SHAU) clinic
3. Willingness to participate in the study
4. Residing in areas covered by the SHAU clinic in Central region of Uganda

The study obtained ethical approval from the Mildmay Uganda Research Ethics Committee (REC Ref# 0710-2020) and the Uganda National Council for Science and Technology (SS703ES). Participants provided written informed consent before the interview and specifically authorized audio recording prior to any data collection.

Data collection

Qualitative data was collected using in-depth interviews from 30 caregivers (22 parents and 8 siblings) of children with spina bifida and hydrocephalus. We included both parents and siblings as caregivers because, in the Ugandan context, as in many low- and middle-income settings, the caregiving responsibilities often extend beyond parents to include siblings. This is due to socio-economic factors, cultural norms, and the limited availability of formal support systems. Siblings frequently play a significant role in providing day-to-day care, emotional support, and assistance with tasks such as mobility, feeding, and managing continence care. Exploring the perspectives of the parents and siblings allowed us to gain a more comprehensive understanding of the caregiving experience within the family unit.

On the scheduled visit date, the researchers introduced themselves and built rapport with study participants before commencing each interview, conducted in English and/or Luganda (a commonly used dialect in Central Uganda).

A semi-structured guide with a pre-determined list of open-ended questions such as: participants' experiences caring for someone with a disability; (b) current disease management demands; (c) main concerns regarding care for a child with spina bifida and hydrocephalus, arranged in a logical sequence, was used for all the interviews.

All the interviews, conducted by the first two authors (AS and DN) were audio-recorded using a digital recorder and averagely lasted 60 minutes. The recordings were transcribed verbatim and those in Luganda were translated to English and reviewed by the third author (RN) to ensure accurate translation and transcription to avoid losing original stories.
We employed a saturation-based approach to determine the sample size of 30 caregivers for the interviews. We initially aimed to purposively interview at least 30 participants and continued data collection until no new themes emerged. Ultimately, 24 participants (18 parents, 6 siblings) were interviewed, and thematic saturation was achieved. Six additional interviews (4 parents and 2 siblings) were conducted to confirm the themes and insights obtained from the initial interviews.

Data analysis

Data was analysed independently by two researchers (ASS and DN) using the content-thematic analysis approach (Neuendorf, 2019) a systematic and rigorous method for identifying, coding, and categorizing patterns and themes within qualitative data. This approach allowed researchers to explore the rich and detailed responses from participants, gaining a deeper understanding of their experiences and perspectives. Both manual coding and NVivo software were used to support the analysis. Transcripts were read several times to gain a deeper understanding of the information, map out similar patterns to generate codes and themes. Upon initial coding of the transcripts, a comprehensive codebook was developed and refined during data collection through an iterative process involving the co-authors and research team. Initially, researchers independently coded a subset of transcripts to identify initial themes and patterns, which were then compared and reconciled to develop a unified coding framework. The research team reviewed and refined the codes, ensuring clarity, consistency, and relevance to the research objectives. Each code was defined, and examples from the data were provided to illustrate its application, facilitating a shared understanding among the research team. The finalized codebook was then used by the first two authors, who conjointly analysed the data, discussing and agreeing on any discrepancies with the research team, and reaching a consensus on the overall analysis, thereby ensuring the reliability and validity of the findings

Findings

A total of 30 interviews were conducted for the selected participants (caregivers (n=22 (mothers n=16, grandmother n=1 and fathers =5), siblings (n=8). Table 1 below summarises the demographic characteristics of the study participants. The results indicated that the majority of caregivers were mothers (n=17), with five fathers represented. The mean age of caregivers was 39 years, with a standard deviation of 12.31. In terms of occupation, most mothers (n=7) were unemployed, while others were engaged in informal employment such as market vending (n=4) or crafting (n=1). Fathers were represented in formal employment (n=3). The siblings were primarily students (n=4), with some engaged in casual work (n=1) or farming (n=1).

Table1: showing the participant demographic characteristics

Participant ID	Caregiver-Category	Age in years	Education level	Occupation	Gender of child with SBH	Age of child with SBH	Education level of the child with SBH
01	Mother	54	Primary	Unemployed	Male	14	Lower Primary
02	Mother	36	University	Unemployed	Male	16	Lower Primary
03	Grandmother	61	University	Retired	Male	23	Upper Secondary
04	Mother	53	Primary	Hand Crafts vendor	Female	15	Lower Primary
05	Father	30	University	Skills Trainer	Female	11	Lower Primary
06	Mother	57	No education	Market Vendor	Male	23	Lower Primary
07	Mother	42	Lower Secondary	Casual worker	Female	16	Lower Primary
08	Mother	43	Primary	Unemployed	Female	14	Lower Primary
09	Father	27	University	Farmer	Male	20	Lower Primary

10	Sibling	15	Primary	Home Caretaker	Male	13	No education
11	Sibling	16	Lower Secondary	Casual worker	Male	14	Lower Primary
12	Mother	40	Lower Secondary	Farmer	Male	16	Lower Secondary
13	Sibling	15	Lower Secondary	Student	Male	21	Lower Primary
14	Sibling	33	University	Social worker	Female	18	Lower Primary
15	Sibling	15	Lower Secondary	Student	Female	13	No education
16	Mother	28	University	Teacher	Female	11	Lower Primary
17	Mother	54	No education	Market Vendor	Male	23	Lower Primary
18	Mother	37	Lower Secondary	Casual worker	Female	16	Lower Primary
19	Father	36	Lower Secondary	Unemployed	Female	12	Lower Primary
20	Mother	30	Primary	Food vendor	Female	14	Lower Primary
21	Mother	43	Lower Secondary	Unemployed	Female	15	No education
22	Father	38	University	Physical Planner	Male	13	Lower Primary
23	Mother	30	Primary	Unemployed	Male	12	No education
24	Mother	27	University	Salon attendant	Female	14	Lower Primary
25	Sibling	18	Upper Secondary	Student	Male	15	Lower Secondary
26	Sibling	23	University	Student	Male	17	Upper Secondary
27	Sibling	16	Lower Secondary	Student	Male	18	Lower Secondary

28	Sibling	15	Lower Secondary	Student	Female	13	No education
29	Mother	28	University	Salon attendant	Female	11	Lower primary
30	Father	54	No education	Market Vendor	Male	23	Upper Secondary

From the data, we were able to explore caregivers' experiences that we organised into six themes namely: 1.) Understanding the disability 2.) Negative attitudes and stigma 3.) Inadequate healthcare service provision 4.) Absence of social support 5.) impact on employment, earnings and schooling and 6.) Managing health and hygiene challenges.

1. **Understanding the disability**

The caregivers' narratives revealed a widespread lack of information and knowledge about spina bifida and hydrocephalus and disability, which significantly shaped their caregiving experiences. Most parents reported that when their child was diagnosed, they received little to no explanation or adequate medical information about the condition, its causes, or how to manage it. Additionally, caregivers highlighted a lack of awareness about the specific services their children require and the absence of information on available support services for their children.

> *"They did not tell me what the child was suffering from. I was just given a tube [catheter] to use and many parents like me don't know how to take care of children with a disability. You will find there are many other parents without any knowledge of the condition and what to do." (Participant 05)*

The lack of adequate explanations from healthcare workers contributed to widespread uncertainty and misconceptions among caregivers. Many only recognized physical symptoms such as a swollen head or a lump on the back, without a deeper understanding of how these conditions affected their child's body or development.

> *"I have seen another child with a swelling on the back and a big head, but I do not have much information. Mostly they have big heads - that is as much as I know." (Participant 15)*

Majority of the caregivers were less aware of the disability and the implications that come with it. Even among caregivers who were aware of the diagnosis, many struggled to grasp the full implications of spina bifida and hydrocephalus, especially the impact on mobility, continence, and neurological function. As a result, some caregivers expressed confusion and helplessness.

> *"I know my girl has Spina bifida, she got paralyzed downwards, her legs are no longer functioning - but I have never understood why she can't help herself to urinate or can't even notice faeces passing out. Many times I don't know how to help." (Participant 19)*

A few participants highlighted how attending hospital-based training sessions or receiving instructions from healthcare workers had a significant positive impact on their ability to care for their child. One caregiver emphasized the importance of seizing any opportunity to attend trainings viewed as empowering, offering caregivers both knowledge and a sense of agency.

> *"Also attending pieces of training enhances confidence and knowledge on how to care for these children. In case someone has an opportunity to attend, I strongly encourage them. (Participant 24)*

2. Negative attitudes and stigma

Participants experienced negative attitudes and pervasive stigma from the community, often rooted in cultural misconceptions and harmful stereotypes about disability. The caregivers described their emotional pain arising from the way members of the society spoke about their children. Some caregivers noted that community members frequently attributed the child's condition to witchcraft, curses, or promiscuity, intensifying the caregiver's isolation and pain.

> *"People always stare at him, and you feel bad. Some people speak dreadful things about him, saying he was sacrificed to the gods by the parents. We became enemies with the neighbours insulting my child to be the one that defecates everywhere, even when it is another child who has done it because they knew he does not have bowel control." (Participant 27)*

> *"My former landlord told me he does not like people who have problems to stay in his house. He went ahead to say - I have no money yet I have a child with a very big head, and I do not care whether the child goes to school or not.. All he wanted was his money, something that made me feel sad and ashamed." (Participant 30)*

Such experiences not only shaped how caregivers were treated by others but also affected how they viewed themselves and their children. Some caregivers acknowledged that this had an effect on their wellbeing.

> *"When you hear all these stigmatising conversations, you sometimes develop a bad feeling towards your child. Because of the frustration, you lock the child in the house or hide them." (Participant 21)*

Caregivers with children in school noted that stigma in school was common and difficult to control as they were not with the children during school time. Children were often ridiculed by peers for their physical appearance, incontinence, or use of assistive products like diapers. Children in the end become reluctant to return to school.

> *"Stigma is real because our children are mocked by their colleagues at school and there is no way you can stop that. These children are discriminated for example when they are given something to eat, another child cannot accept to share with them." (Participant 04)*

Caregivers noted that stigma extended directly to the children affecting their self-esteem leading to a negative self-concept. As a result, the children often withdraw from spending time with others and resort to self-isolation, locking themselves up in the room and sometimes decline to eat.

> *"At one time my child told me that while at school, one of the children told him "Why don't you die" something that made him feel bad. When he started using pampers [a brand of diapers] in primary five, he was stigmatized at school by others who nicknamed him 'Pamper.' He never wanted to spend time with others and did not want to talk to us completely." (Participant 11)*

Despite the pervasive stigma, participants reported that accessing medical care and building trust with healthcare professionals marked a crucial turning point in their caregiving journey. For many, this trust helped them resist harmful societal narratives and cultural misconceptions surrounding disability. One caregiver reflected on the importance of focusing on medical guidance despite widespread community stigma.

> *"What I first learnt was to keep going to the hospital... I ignored listening to what people said, such as those who claimed I was bewitched during pregnancy, but I kept in touch with the doctors." (Participant 7)*

This theme highlights the dual burden that caregivers carry - caring for a child with complex needs while simultaneously confronting harmful societal perceptions.

3. Inadequate healthcare service provision

Most caregivers expressed concerns about the inadequacy and fragmentation of healthcare services available to meet the complex needs of children with spina bifida and hydrocephalus. They described specialized care services where they were referred as ‘virtually non-existent and inaccessible’.

> *“I remember, when she made 7 years, I went back to Bogere [a referral hospital]. When I reached, the health workers said they cannot manage her since they had no experience with the condition. They told me to go back to Mandev hospital [specialist hospital] something that I did, but all of them could not understand my child’s problem. They gave me some drugs which could not help her.” (Participant 29)*

Additionally, some caregivers reported that their children required specific medical supplies, equipment, and medications. Daily-use medications and essential items like catheters were often out-of-stock, pushing parents to search across multiple health facilities or incur high private sector costs.

> *“The child needs special drugs which are scarce and not easy to get on the market, yet they to use them daily and that’s when the suffering started. Sometimes you even go to Kananansi [specialised service provider], and they tell you the drugs are out-of-stock.” (Participant 09)*

Some caregivers described situations where healthcare providers were unable to conduct appropriate assessments and diagnose other conditions when their children developed additional symptoms. In some cases, healthcare providers would issue referrals without proper explanation, further examination or diagnostic support. Some parents noted that some healthcare providers would observe that the child has a disability and immediately refer them.

> *“Another challenging period was when he had made eight months, he was infected with tuberculosis. I just noticed him losing weight and having a swollen stomach, so I took him to a nearby hospital, but they seemingly feared do any investigations to find the sickness.” (Participant 17)*

Additionally, caregivers noted that their children’s health deteriorated with age often requiring often requiring additional surgeries or prolonged hospitalization for management. Some caregivers indicated that as their child’s condition deteriorated, their hope faded, and this deepened caregivers’ emotional and psychological strain.

> *"I was often discouraged watching other children having a similar problem dying, and the healthcare workers would tell us that during the operation the child might survive or die. It put me on tension thinking my child may not survive, and by the time they operated her, I had already lost hope." (Participant 04)*

> *"As time passes, her disability becomes severe, and she passes out sometimes. When we went for review, the doctors discovered that the tube [shunt] had moved out of its position, so she had to undergo another operation. When she was operated, the tube [shunt] could not be fixed to enable the water [cerebrospinal fluid] to flow out of her head." (Participant 10)*

In addition to poor service delivery, many participants described unethical practices, including the demand for informal payments from the healthcare workers to receive medical services for their children. One parent noted that 'everything needs money including paying someone so they can add you to the list to see a doctor' after several attempts of waiting at the health facility. Financial constraints made it difficult for caregivers to pay such fees or to return repeatedly to facilities without guarantee of specialist care.

> *"The line was always long at the hospital, and to see a healthcare worker would require us to pay some kitu-kidogo [informal payment]. At times, you fail to see them. Remember I did not have enough money, but because of my child's condition, I had to struggle. Because of his health condition, I said cannot bear another child." (Participant 18)*

4. Absence of social support

Many caregivers reported feeling isolated and overwhelmed due to the lack of adequate social support. Some mothers reported that they were pushed to assume a new role of father as many of the fathers abandoned their responsibilities and apportioned blame to the woman for giving birth to a child with spina bifida and hydrocephalus. For these mothers, becoming the sole provider and caretaker meant assuming both maternal and paternal roles as a single parent, often without emotional, financial, or practical support.

> *"The men abandon their wives after giving birth - you find when all the responsibilities are on a woman alone. Remember that is not the only child they have; there are even other children in a family who need care." (Participant 13)*

> *"It is very hard to raise the children as a single mother, and worse if you do not have support from your family. It is better when the man is available - even if he is poor but at least you can share responsibilities. Their father gave up on them, leaving most of the things to the mother." (Participant 01)*

Beyond spousal support, caregivers expressed the need for support from other family members, such as siblings, to help care for children with spina bifida and hydrocephalus, especially during times when caregiving became difficult and overwhelming. In extreme situations, caregivers felt forced to leave the child temporarily in order to fulfil other responsibilities.

> *"The most challenging thing I have is that she does not have a sibling that can I leave her with, because I have only one child, and no extra support from anyone - something that hindered me from working because have to be around and take care of her." (Participant 06)*

> *"I abandoned him in hospital one time for some days because I was the one who was supporting home. I had to take care of the children that I had left home, and I also had to go to the hospital and look after him." (Participant 12)*

Despite these challenges, some caregivers expressed a deep sense of resilience and commitment to their children, even in the absence of external support. One caregiver reported that,

> "*It's not an easy task; we just live by the grace of God because many parents neglect children due to their disability. Many parents do not expect anything from them, but we have to hang in there, even without any support, because they remain your child."(Participant 22)*

Participants highlighted the importance of extended family support and networks in alleviating the caregiving burden. When such support was present, it significantly improved their ability to cope.

> *"...Even if the mother felt overwhelmed, there were other people to step in... at least they could relieve her." (Participant 11)*

In the absence of family support, some caregivers found solace and strength in peer relationships developed through the training and socialization opportunities during the health facility visits where parents and children would gather. These spaces offered more than clinical care—they became centres of shared experience, learning, and hope.

> *"Seeing other children's progress gave them hope. We would talk with other caregivers, exchange ideas and form valuable friendships. Some have become good friends – it helps when you are not alone."* (Participant 9)

Caregivers faced substantial challenges of limited educational support and finding the right school that can provide inclusive education and services. The caregivers noted that many schools lacked the necessary infrastructure, understanding, or resources to support children especially in managing incontinence or providing tailored learning support.

> *"I always worry about finding a suitable supportive school for her because I know I cannot take her to any school. It's difficult to find the school but I wanted her to study. She was lagging behind in terms of schooling compared to other children and a time came when she could not even walk or live on her own without anyone to give support." (Participant 09)*

5. **Impact on employment, earnings and schooling**

Caregivers described the difficulty of balancing paid work or education with the demands of full-time caregiving. For many, the absence of reliable social support systems meant having to prioritize their child's care over employment or schooling, often with long-term economic and personal consequences. Several caregivers assumed primary caregiving responsibilities that limited their ability to fulfil other roles, leading to blame, frustration and a sense of loss as expressed in the except below:

> *"I got challenges managing my work and the child. Sometimes they need me in the office, yet have to take care of her at the same time. I had to skip some time out of the office to take care of the child. Right now, I don't have a job because this one [pointing at the child with SBH] hindered me from working." (Participant 01)*

Some families made difficult trade-offs to sustain income while meeting the child's daily care needs. In some cases, siblings had to drop out of school to stay home and support childcare, allowing the parent to continue working. The demands for full-time care for children with spina bifida and hydrocephalus could not allow for completion of other tasks.

> *"My mother decided that I stop schooling so I can take care of my little brother so that she can keep working and we can have food to eat. Because she had stopped working for some time to care for him, she now could not afford school fees for me." (Participant 13)*

Being out of employment, also meant that caregivers became financially unstable and unable to provide optimal care for their child. They faced difficulties affording basic needs such as hygiene supplies, medications, paying medical care bills and transport to health facilities. This situation posed significant challenges particularly for single parents, who bore the sole responsibility of providing for their families.

> *"When you do not work, you don't get the money, yet everything rotates around you and money. These children are always on medication, which is expensive. It worries me every time when I don't have the money, yet I have to go and get the medicine." (Participant 05)*

> *"The care is expensive. It needs a lot of money for healthcare because we spend most of the time in the hospital. And now he is an adult - no longer putting on diapers for kids but adult ones, which are 4,000 shillings per piece. A parent with no money cannot afford." (Participant 03)*

The economic burden of caregiving extended beyond the present and into concerns for the future. Several caregivers expressed deep worry that their child's inability to access education due to financial hardship would limit their later independence and quality of life. .

> *"I face financial constraints. Sometimes I fail to buy even a match box and for them as children, they cannot understand that I have no money to pay for fees, even though I want them to have a bright future." (Participant 24)*

> *"Hospital bills are high, medicines are expensive to buy, pampers [diaper brand] are expensive to buy everyday. So, they have to go without them, yet these are needed for a lifetime. You deal with these financial challenges from childhood to adulthood." (Participant 08)*

6. Managing health and hygiene challenges

Caregivers expressed concern over managing the health and hygiene of their children. Some reported that their children's experienced recurrent health issues which they attributed to a weakened immune system. This resulted in repeated hospitalizations, which disrupted the child's development and well-being as well as the family's routines and financial stability.

> *"Children with* spina bifida and hydrocephalus *contract infections so fast compared to others, and they are too expensive to treat so you have to make sure they are fully recovered and just as they recover, another infection sets in due to their weak immunity." (Participant 21)*

Maintaining good hygiene and daily health routines was considered essential, and caregivers played an active role in promoting these habits. However, some caregivers were distressed that even with keen support, their children were prone to illnesses. Others described frustration and emotional strain when their older children resisted or neglected self-care practices, undermining efforts to foster independence.

> *"When I try telling him to clean himself, he says he got tired, yet I want him to be more responsible to keep away the recurring infections. You have to remind him all the time. Now his sister who used to help him is gone and he needs to do these things on his own - that is my problem." (Participant 23)*

In relation to hygiene, some caregivers mentioned that they had concerns and difficulties managing urine and stool related hygiene practices among their adolescent children. As the children grow, many become reserved and secretive about what was happening in their lives, making it difficult for caregivers to understand and respond to their needs.

> *"Since he is becoming an adolescent, I see him stressed and losing weight, but he doesn't share anything with me. I know it is something to do with catheterisation and am looking for someone else that can help me talk to him—someone he feels comfortable with." (Participant 26)*

Some parents reported proactively teaching their children essential self-care practices, such as independent catheterization, to promote autonomy and future independence. One caregiver shared,

> *"...so as she grew up, I started teaching her how she can remove the urine by herself... in case I have gone somewhere for a week, I know that she can take care of herself." (Participant 03)*

Other participants reported reduced stress after adopting practical solutions, such as the use of adult diapers, which provided reassurance when they had to leave their child in someone else's care. One caregiver shared,

> *"We no longer get worried even when she's left with someone else at home because right now she uses Pampers [diaper brand], which makes it so easy." (Participant 14)*

These experiences illustrate how caregivers are constantly adapting their approaches—balancing the need to foster independence while managing complex hygiene needs.

Caregivers also expressed the challenges of initiating meaningful conversations around sexuality, puberty, growth and development. As children with spina bifida and hydrocephalus grow older, caregivers noticed shifts in behaviour, particularly related to personal hygiene and bodily autonomy. Many described feeling uncertain about how to provide necessary care while respecting the child's growing sense of privacy and identity.

> *"They are growing and becoming shy. I can tell he feels uncomfortable when I bathe him, wash his clothes and undergarments, or help with catheterisation. He's older now, but still can't manage these things on his own. I have been helping him since childhood, but now am unsure how to support him. He can't shave himself, and he refuses to bathe unless reminded. You end up confused on how to help as a parent." (Participant 06)*

> *"As she grows, it's getting harder to bathe her. She has gained weight and started experiencing body changes, but she's not comfortable talking about them. As a parent, I also feel shy initiating topics like menstruation." (Participant 08)*

These reflections highlight the complexity of caregiving during adolescence, where developmental changes intersect with disability-related needs, leaving caregivers feeling emotionally conflicted and unprepared for conversations around sexual and reproductive health

Some caregivers highlighted that children with spina bifida and hydrocephalus required constant guidance, repetition, and a great deal of patience. Care routines often had to be repeated consistently, as the children could be quick-tempered and easily lose focus.

Caregivers described the need to remain calm and supportive in the midst of juggling other children and responsibilities.

> *"My son gets upset very quickly and if you are not patient enough, you might also end up acting harshly. Even when you feel so low or moody, you have to speak and act politely. Some people find it hard to be patient with such children. For example; you can teach them not to do something today, and by tomorrow they've already forgotten—they need to be guided and reminded all the time." (Participant 23)*

Considering our findings, caregivers face a number of emotional and practical challenges, ranging from a limited understanding of the condition to difficulty accessing healthcare, all of which shape both the present and future caregiving experience.

Discussion

Our results are in line with our study objective to explore the experiences of caring for a child with spina bifida and hydrocephalus and to raise awareness of the problems faced from the perspective of the parents and siblings as caregivers in Uganda. Our results indicated that most of the caregivers' lack information and knowledge about spina bifida and hydrocephalus and less aware of the disability and the implications that come with it. Our results align with a scoping review that described mothers in low and middle income sub-Saharan African countries having poor knowledge on child developmental disorders including spina bifida and hydrocephalus (Adugna et al., 2020). Most of the mothers attributed much of the problem to a lack of awareness and understanding, including among healthcare providers at the facilities where the children are treated, who often don't provide parents with clear guidance or next steps. The lack of skills and knowledge lowered their confidence to provide care for children living with spina bifida and hydrocephalus as also reported by Tilahun et al. (2016a). Provision of education and hands-on training for caregivers in relation to the care and management of patients with spina bifida and hydrocephalus from a multidisciplinary team of health workers is necessary. Consistent and repetitive training sessions are essential to maintain knowledge and skills (Pattisapu et al., 2023).

Studies have suggested the need for greater community awareness and understanding of childhood disabilities and disorders through education and outreach (Adugna et al., 2020; Bannink et al., 2016). When caregivers possess a deeper understanding of the causes and origins of diseases or disabilities, they are better equipped to challenge prevailing misconceptions and influence community attitudes and beliefs, even in contexts where significant barriers persist. This shift in perception can lead to greater support for children with disabilities and foster a more inclusive environment (Fischer et al., 2015; Moosa-Tayob & Risenga, 2022).

Despite the persistence of barriers such as cultural beliefs, limited access to information, and stigma, empowering caregivers with accurate knowledge can be transformative. Informed caregivers are better positioned to advocate for their children's rights, promote their inclusion, and share their experiences to educate others within their communities (Patel et al., 2019; Tilahun et al., 2016b). This process not only helps dispel stigma but also encourages gradual changes in societal attitudes, fostering acceptance and social inclusion for children with spina bifida and hydrocephalus.

Our results also indicated that the community's discriminatory attitudes and stigma had a profound impact on caregivers and siblings, causing significant emotional pain, stress and anxiety (Bannink et al., 2016). Caregivers were deeply affected by the thoughtless and hurtful language used to describe their children and the community blamed their children's disabilities on family flaws, like witchcraft or promiscuous behaviours, rather than recognizing the actual causes. The weight of the circumstances and the stigma was too much for some caregivers to bear, affecting their mental health and leading to occasional negative emotions and attitudes towards their child. The experienced stigma had a devastating impact on the children's self-esteem, leading to negative self-perception and self-isolation. The children become withdrawn, refusing to interact with others, and may even neglect their basic needs like eating. Our findings align with previous studies that showed how social participation of children with spina bifida were greatly affected by the community stigma (Fischer et al., 2015). Recognizing and discussing stigma is the first step towards a more inclusive and supportive community. Healthcare providers and community leaders can foster a cultural shift by integrating inclusive training, advocacy, and community engagement into healthcare practice making healthcare environments more inclusive and supportive. This also encourages caregivers and children to gain confidence and autonomy in health seeking practices. For example, disability-inclusive training programs have been shown to improve healthcare providers' attitudes and practices, ultimately reducing stigma and enhancing disability inclusion (Azizatunnisa, Rotenberg, Shakespeare, Singh, & Smythe, 2024; Smythe, Ssemata, Slivesteri, Mbazzi, & Kuper, 2024). Similarly, community-based engagement interventions have been used to challenge stigma and create improvements in functioning, and social participation (Pathare et al., 2023).

Our study also showed that caregivers expressed frustration about the insufficient healthcare services available for children with spina bifida and hydrocephalus, noting that specialized care is virtually non-existent and access to referred services is challenging and children required specific medical materials, equipment and drugs that are frequently unavailable and out of stock (Mwangi et al., 2021). Our findings indicated that caregivers encountered demands for informal payments by healthcare workers in order to receive medical attention or to be added to the waiting list. The absence of specialist care and the corrupt practices discouraged parents from seeking hospital care, with one caregiver forced to pay a bribe to secure admission for her critically ill child. These experiences reflect broader issues of inequity and informality within the health system, where limited resources and lack of oversight can give rise to unofficial practices. For families already burdened by the cost of care and transportation, such payments further exacerbated financial strain and undermined trust in the healthcare system.

Addressing these systemic barriers requires urgent policy interventions and health system strengthening strategies such as increasing investments in specialized paediatric neurological care, ensuring a consistent supply of essential medical resources, and enforcing strict anti-corruption measures within healthcare facilities. Additionally, implementing community-based healthcare models, where trained community health workers support families at the household level, could also improve access to essential care and reduce reliance on overstretched hospital services (McCollum, Gomez, Theobald, & Taegtmeyer, 2016; Ndambo et al., 2022).

Our findings also show the need for available, accessible and reliable adequate healthcare services which is important in supporting caregivers as they provide care. This is critical especially as many children with spina bifida and hydrocephalus are prone to infections, may require regular hospital appointments and specialised medical care. Our findings align with previous studies showing that spina bifida and hydrocephalus often occurs majorly in LMICs where healthcare demands are often challenging (Pattisapu et al., 2023). Access to appropriate medical facilities and resources is beneficial in the care of children with spina bifida and hydrocephalus. Due to the shortage of healthcare workers and specialist health professionals to manage children with spina bifida and hydrocephalus in LMICs, one recommendation has been task-shifting of these responsibilities to other healthcare service providers in addition to making referrals (Pattisapu et al., 2023). This may involve training low cadre healthcare workers in remote areas to provide initial care and refer complex cases to specialists thereby reducing on the healthcare burden especially of cases that could be managed at the grassroots (Azizatunnisa et al., 2024; Ndambo et al., 2022).

Mothers overwhelmingly bore the primary caregiving responsibility, often after fathers abandoned their roles, leaving them to shoulder the emotional, physical, and financial burdens of caring for their child with spina bifida and hydrocephalus. Many mothers reported experiencing blame and neglect from their husbands, who attributed the child’s condition to them, reinforcing deeply ingrained gender norms that place the responsibility of child-rearing and particularly the care of children with disabilities on women. This aligns with broader literature on gender disparities in caregiving, which highlights how women, particularly mothers and sisters, are disproportionately expected to provide care, often at the expense of their own well-being, economic opportunities, and social participation. Although some research suggests that having a child with a disability can strengthen a marriage (Rofail et al., 2012), our findings indicate that caregiving without adequate support leads to stress, frustration, abandonment and a heightened sense of isolation among mothers. Many women emphasized the need for support from extended family members, including siblings, to share caregiving responsibilities and prevent feelings of abandonment. Sisters were more likely than brothers (in our study 6 of the 9 siblings were female) to be called upon for caregiving, further perpetuating gender imbalances within families. To address these disparities, interventions should actively promote male involvement in caregiving and encourage open communication between spouses.

Additionally, targeted social and economic support systems for female caregivers, such as peer support groups, financial assistance, and flexible work opportunities, could help alleviate the disproportionate burden placed on caregivers . A gender-responsive approach to caregiving support is essential to fostering more equitable caregiving dynamics and improving the overall well-being of parents and siblings (Bannink et al., 2016; Lestari et al., 2020). Similarly, provision of social support and opportunities for social interaction for children with spina bifida and hydrocephalus fosters a positive self-concept which builds self-esteem critical in maintaining good health and well-being. Promotion of inclusive education with Special needs provisions such as spaces for conducting clean intermittent catheterisation will promote acceptance, confidence, comfort and personal hygiene among school going children with spina bifida and hydrocephalus (Fischer et al., 2015; Rofail et al., 2012).

Caregivers faced significant challenges in maintaining their child's health and hygiene, leading to concerns about the impact of frequent illnesses and hospitalizations on the child's development and wellbeing. This has cost burden implications to the caregivers in relation to lost wages and significant out-of-pocket costs for medical and non-medical costs (Patel et al., 2019; Pattisapu et al., 2023). Caregivers widely acknowledged the importance of teaching good hygiene practices and self-management skills, particularly as children grew older and the prevalence of faecal and urinary incontinence increased. However, some caregivers expressed concern that their children's compromised immune systems and executive function impairments, which affect their ability to develop independence, made them more susceptible to illnesses and heightened vulnerability. These concerns were especially pronounced as children transitioned into school-age, a period when exposure to infections and the demand for self-care skills increased similar to previous studies (Pattisapu et al., 2023; Sims-Williams et al., 2017). We recommend targeted caregiver training programmes, strategies and support systems to address hygiene management and self-care skills for children with spina bifida and hydrocephalus.

Our study also shows that caregivers of children with spina bifida and hydrocephalus face a range of challenges, from understanding the condition and its impact to accessing necessary healthcare services, which can significantly affect their daily lives and prospects. Therefore, recognizing the challenges caregivers face in supporting children with spina bifida is the first step in designing effective interventions that promote growth, development, and independence (Patel et al., 2019; Sims-Williams et al., 2017). By acknowledging these challenges, we understand the importance of involving caregivers in healthcare decision-making, giving them greater control over their care. This will consequently lead to the development of comprehensive policies that manage spina bifida from a holistic perspective, enabling caregivers to advocate for better care and supporting other providers in enhancing the quality of life for these children (Pattisapu et al., 2023).

Strengths and Limitations

This study fills important research gaps by providing insights into the perspectives of both parents and siblings caring for children with spina bifida in Uganda, a population that has been underrepresented in previous research. The study's strength lies in the diversity of its participants, who came from urban, peri-urban, and rural communities. This geographic variety adds robustness to our findings, which were consistent across different residential locations. By including both parents and siblings as caregivers, the study captures a broad spectrum of caregiving experiences, offering a comprehensive understanding of the challenges faced by these families.

Despite efforts to include all potential participants, the lower number of siblings in the study means the findings related to siblings as caregivers should be interpreted with caution. A larger sample size, particularly of siblings, would have provided a more comprehensive understanding of the caregiving dynamics. Another limitation of this study was the focus on study participants from Central Uganda which limits the generalizability of the findings. Experiences of caregivers from other regions or those with diverse cultural backgrounds may differ and are not captured in this study.

Conclusion

The findings underscore the critical need to strengthen support systems for parents and siblings, who play a central role in the care and management of children with spina bifida and hydrocephalus; by ensuring they have access to adequate resources, training, and institutional support to navigate their caregiving responsibilities effectively. Caregivers face significant challenges, including limited access to resources, stigma, and financial strain, which can impact both their well-being and the quality of care they provide. Addressing these barriers requires a multi-faceted approach, including improving access to accurate health information, enhancing healthcare services, and fostering community awareness to reduce stigma. Strengthening social support networks and providing financial assistance can further alleviate the caregiving burden. By prioritizing these efforts, healthcare providers and policymakers can create more inclusive and responsive care systems. Future research should explore targeted interventions that enhance caregiver support and assess their long-term impact on family well-being and child health outcomes.

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Declaration of Interest

The authors report there are no competing interests to declare. The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in drafting this article.

Data availability statement

The authors confirm that the data supporting the findings of this study are available within the article.

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