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Caregiving experiences, challenges, and coping strategies among caregivers of children with epilepsy and/or cerebral palsy in southwestern Uganda

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Abstract

Background Caregivers of children with epilepsy, cerebral palsy (CP), or co-occurring epilepsy and CP in low-resource settings face substantial psychological, social, and economic challenges. Despite high caregiver burden in sub-Saharan Africa, limited qualitative research has explored how caregivers perceive their experiences, their children's care needs, and the contextual factors shaping coping. This study examined caregivers' lived experiences and coping strategies to inform interventions that strengthen caregiver well-being and capacity.

Methods A descriptive qualitative study was conducted at the paediatric neurology clinic of Mbarara Regional Referral Hospital in southwestern Uganda. Twenty in-depth interviews were held with primary caregivers of children with epilepsy, CP, or both. Purposive sampling ensured variation in caregiving duration, child diagnosis, and coping patterns. Interviews were conducted in English or Runyankore, audio-recorded, transcribed, translated, and analyzed thematically using Braun and Clarke's six-step approach. Data collection and analysis occurred iteratively until saturation.

Results Caregivers described caregiving as intensive and continuous, with children requiring substantial assistance in daily activities, consistent medication adherence, physiotherapy, and coordinated school support. Access to hospitals, schools, and community resources was inconsistent, often leaving caregivers to bridge gaps in care. Financial strain, stigma, social isolation, and disruption of income-generating activities were pervasive challenges that compounded emotional distress. Despite these pressures, caregivers demonstrated adaptive coping strategies, drawing on hope, acceptance, faith, and social connectedness to sustain their roles. They reported emotional exhaustion and limited family or professional support, with minimal engagement in formal mental health services. At the same time, caregivers developed structured routines, environmental adjustments, and personalized problem-solving strategies to maintain stability and ensure continuity of care.



Conclusion This study demonstrates that caregiving for children with chronic neurological conditions, including epilepsy and CP, in low-resource settings is highly demanding, marked by substantial medical, emotional, social, and financial challenges. Despite these burdens, caregivers show notable resilience through faith, optimism, and adaptive coping strategies. The findings underscore the urgent need for comprehensive support, including reliable medication access, psychosocial services, assistive devices, and stigma-reduction efforts, to strengthen caregiver well-being and improve care for affected children.

1 Introduction

Children with chronic neurological conditions such as epilepsy and cerebral palsy (CP) often require complex, continuous, and multifaceted care, including long-term medication adherence, frequent medical follow-up, supervision to prevent injury, assistance with mobility, feeding and communication, support with activities of daily living, and access to rehabilitation and educational services [1, 2]. These care needs are typically lifelong and may fluctuate in intensity, particularly in epilepsy, where seizure unpredictability necessitates constant vigilance. Caregiving for children with these conditions is therefore a demanding and often lifelong responsibility, associated with significant psychological, social, and economic challenges for caregivers [3–5]. Although epilepsy and CP are distinct conditions, they often coexist and involve similar functional and social care demands, especially in low-resource settings [6]. In southwestern Uganda, limited specialist services and weak social support systems mean that caregiving extends beyond medical care to include home-based rehabilitation, advocacy, and protection against stigma [7–9]. In low-resource settings, these challenges are compounded by structural barriers such as limited access to healthcare, medication shortages, and pervasive stigma, all of which intensify caregiver burden and psychological distress [6, 10–12].

Existing research on caregiver mental health in sub-Saharan Africa has largely focused on quantifying the prevalence of depression and other mental health outcomes [13–16]. While these prevalence estimates establish the magnitude of psychological distress, they offer limited insight into how caregivers interpret their roles, negotiate daily care demands, and construct coping responses within specific sociocultural and health-system contexts [13–19]. Quantitative studies in Ethiopia, Nigeria, and Kenya indicate that between 35% and 68% of caregivers of children with epilepsy experience depressive symptoms related to seizure frequency, caregiving strain, social stigma, and limited healthcare access [16–19]. Similar findings in Pakistan, Poland and the United States of America (USA) among caregivers of children with CP link high physical care demands and child dependency with caregivers' emotional exhaustion and depression [20–22]. However, much of this literature examines epilepsy and CP separately, often within higher-resource systems where rehabilitation pathways and caregiver support structures differ substantially from those available in rural East Africa [20–22]. Qualitative research in Pakistan, though limited, reveals that caregivers of children with CP often view their role as both a moral and familial obligation and a source of suffering and isolation, shaped by cultural expectations, poverty, and weak health and social support systems [22]. Many caregivers describe feeling stigmatized and overburdened, particularly when their child's condition is misunderstood by the community or attributed to supernatural causes. A study from Uganda, for instance, highlighted caregivers' perceptions of

hopelessness and abandonment by family and healthcare providers, alongside persistent anxiety about their child's future [23]. Yet, few studies have examined caregiving experiences across chronic neurological conditions within a single service context, despite the shared structural and social determinants shaping these experiences.

These experiences contrast sharply with findings from higher-income contexts, where caregivers, though burdened, often report a sense of empowerment through structured psychosocial support, respite care, and formal rehabilitation services that foster adaptive coping and positive meaning-making [23]. Such contrasts underscore the importance of situating caregiving experiences within local health-system realities rather than assuming transferability of findings across settings.

In contrast, caregivers in low-resource settings rely more on religious and communal coping (e.g., prayer, acceptance, faith in divine healing), which may buffer distress for some but serve as avoidant mechanisms for others, limiting engagement with medical and psychosocial care [24, 25]. This variability highlights that coping responses are not inherently adaptive or maladaptive but are deeply shaped by the social, cultural, and structural contexts in which caregiving occurs. Understanding coping, therefore, requires attention not only to individual psychology but also to how caregivers perceive their children's care needs within constrained systems of care [26].

Collectively, this evidence suggests that caregivers' perceptions and coping responses are deeply contextual, influenced by culture, available resources, and societal attitudes toward disability. Yet, there remains a critical gap in understanding how caregivers themselves perceive their children's care needs and how these perceptions shape their emotional experiences and coping responses over time, particularly in low-resource settings. The study included caregivers of children with epilepsy, CP, or both conditions, reflecting shared service contexts and overlapping care demands. This approach enabled exploration of both common and condition-specific experiences within the same structural setting. Building on this gap, the present study aimed to examine caregivers' perceptions of their children's care needs and the contextual and psychosocial factors influencing their coping strategies. Guided by a contextual caregiving framework, the study asked how caregivers of children with epilepsy, CP, or both in southwestern Uganda perceive their caregiving experiences and how these perceptions shape their coping strategies. This qualitative inquiry offers a deeper understanding of the emotional and practical aspects of caregiving, highlighting potential targets for interventions that support caregiver well-being and capacity.

2 Methods

2.1 Study design and setting

We conducted a descriptive qualitative study at the paediatric neurology clinic of Mbarara Regional Referral Hospital (MRRH) in southwestern Uganda. This design was selected to allow for an in-depth exploration of caregivers' lived experiences, perceptions, and coping behaviours within their routine caregiving environment. This study is reported in accordance with the COnsolidated criteria for REporting Qualitative research (COREQ) checklist [27].

The choice of MRRH as a study site was also informed by its dual role as both a major referral centre and a university-affiliated teaching hospital, which ensures a structured clinical environment but also reflects many of the systemic constraints typical of

low-resource settings in Uganda. MRRH is the largest tertiary referral hospital in western Uganda, serving a catchment area of over five million people across several districts and functioning as a teaching site for Mbarara University of Science and Technology [28]. Its paediatric neurology clinic, staffed by a multidisciplinary team including a paediatric neurologist, residents, nurses, and rehabilitation specialists, runs weekly clinics for children with epilepsy and/or CP [28]. The clinic handles about 98 paediatric visits per month (24 new and 74 follow-up), with review intervals ranging from one to six months depending on clinical needs. This variation allowed inclusion of caregivers at different stages of the caregiving journey, making the site well-suited to explore the emotional, social, and coping aspects of caregiving.

2.2 Ethical considerations

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki and all applicable local regulations. Ethical approval was obtained from the MUST Research Ethics Committee (Approval No. MUST-2025-248), and administrative clearance was granted by MRRH. All participants provided written informed consent, and confidentiality and anonymity were assured throughout the study.

2.3 Participants and sampling

Participants were primary caregivers aged 18 years or older who were directly responsible for the daily care of a child diagnosed with epilepsy, cerebral palsy, or both, and who attended the neurology clinic during the study period (April to June 2025). A primary caregiver was defined as the individual most involved in the child's day-to-day care and decision-making.

Purposive sampling was employed to ensure diversity in caregiving experiences. Selection considered variation in the child's diagnosis (epilepsy only, CP only, or co-occurring epilepsy and CP), duration of caregiving, caregiver gender, and observable coping patterns. Observable coping patterns were identified during initial clinic interactions and brief screening conversations prior to recruitment, where research assistants noted differences in caregivers' expressed emotional tone (e.g., visible distress versus calm acceptance), and reliance on faith-based or community support. These preliminary observations were used only to ensure inclusion of caregivers demonstrating varied approaches, rather than to categorize or label coping styles. This strategy enabled inclusion of caregivers at different stages of the caregiving trajectory and across varied social and clinical circumstances, thereby enhancing the breadth and depth of perspectives captured.

2.4 Data collection

The study was conducted in a private consultation room within the clinic to ensure confidentiality and minimal disruption to clinical services, enabling participants to share their experiences openly and in depth. Data were collected through semi-structured in-depth interviews lasting 45–60 min, all conducted in Runyankore, the predominant local language, by trained research assistants. Interviews were audio-recorded with participants' consent and transcribed verbatim.

The interview guide was developed using Lazarus and Folkman's (1984) Transactional Model of Stress and Coping, alongside insights from prior studies on caregivers

of children with chronic neurological conditions [29]. The guide explored caregivers' perceptions of their children's medical, therapeutic, educational, and social needs; their emotional and psychological responses; coping strategies; and the barriers and supports encountered in the caregiving process. Example questions included: "Can you describe a typical day caring for your child?" and "How do you manage the emotional stress and depression associated with caregiving?" (see Supplementary Table 1 for the full interview guide). It was reviewed by two senior qualitative researchers within the study team (A.N. and J.A.), both psychiatrists with experience in caregiver research and qualitative methods, to ensure conceptual alignment and contextual appropriateness. No external reviewers were involved.

Interviews were conducted sequentially, with emerging insights informing subsequent probing and clarification. Data collection continued until saturation was reached, defined as the point at which no new themes or substantive insights emerged. Saturation was achieved after 20 in-depth interviews, consistent with recommended qualitative sample sizes [30, 31].

2.5 Data analysis

Data were analyzed thematically using Braun and Clarke's six-step approach [32], following an iterative process that occurred concurrently with data collection. Recordings were transcribed verbatim and translated into English by a bilingual research assistant. Translation accuracy was verified by a second bilingual team member (G.Z.R.) and cross-checked against selected audio recordings by the principal investigator (A.N.) to ensure semantic consistency. Transcripts were imported into NVivo 12 Plus for coding. Coding was primarily inductive: both G.Z.A. and A.N. independently coded an initial subset of transcripts, compared codes, and reached consensus before developing a codebook, later refined by J.A., that was applied to all data (Supplementary Table 2). Themes were generated through iterative comparison, constant reflection, and team discussions. The final analysis was conducted over six weeks following the last interview.

2.5.1 Reflexivity and researcher positionality

The research team comprised professionals with clinical and academic backgrounds in psychiatry (A.N., J.A.), general practice (M.M.), and psychiatric nursing (G.W.), all with prior experience in qualitative research. Some team members were familiar with the paediatric neurology clinic in a professional capacity but were not directly involved in routine clinical decision-making for participants during the study period. To minimize potential power imbalances and social desirability bias, interviews were conducted by trained research assistants who were not part of the clinical care team. Reflexive discussions were held during weekly meetings to examine how researchers' clinical training, prior assumptions about caregiver burden, and familiarity with the health system might shape data interpretation. Analytic memos were maintained throughout to document evolving interpretations and potential biases.

2.5.2 Methodological rigor

Several strategies were employed to enhance methodological rigor. Credibility was strengthened through investigator triangulation, involving independent coding and consensus discussions among a multidisciplinary team. Member checking was not

Table 1 Summary of major themes and subthemes identified from caregiver interviews

Superordinate theme	Theme	Subthemes
Caregivers' perceptions of childcare needs	1. Care needs of children with cerebral palsy and epilepsy	1.1 Daily care routines 1.2 Medical and therapy needs 1.3 Educational and social needs
Challenges and barriers to caregiving	2. Support and resource availability	2.1 Hospital-based support 2.2 School-based support 2.3 Limited community support
	3. Challenges and barriers to caregiving	3.1 Financial strain 3.2 Stigma and social isolation 3.3 Time burden and disrupted livelihoods
Coping strategies and resilience	4. Emotional and psychological coping	4.1 Hope and acceptance 4.2 Social connectedness 4.3 Maintaining routines and a sense of control
	5. Social and professional support	5.1 Lack of family support 5.2 Emotional exhaustion and burnout 5.3 Minimal engagement with mental health services
	6. Practical coping strategies and resilience	6.1 Personalized care routines 6.2 Environmental or lifestyle adjustments 6.3 Inner strengths, faith, and optimism

formally conducted; however, iterative probing during interviews ensured clarification and validation of participants' responses. Dependability was supported through systematic documentation of coding decisions and maintenance of an audit trail within NVivo. Confirmability was enhanced through reflexive memo-writing and team discussions that critically examined interpretive assumptions. Transferability was addressed by providing detailed descriptions of the study context, clinic setting, and participant characteristics to allow readers to assess applicability to similar settings.

3 Results

Of the 20 in-depth interviews conducted, 16 caregivers were married, three were single, and one was widowed, with the majority being females (17/20). The participants ranged in age from 27 to 80 years. Most of the participants were also caring for children with Epilepsy only (14/20), (3/20) caring for children with CP only, and (3/20) caring for a child with both CP and Epilepsy.

3.1 Summary of themes

Analysis of the interviews generated six overarching themes that reflected caregivers' experiences and needs. See Table 1.

3.2 Detailed findings

The intensity and type of daily-care demands differed by condition.

4 Care needs of children with cerebral palsy and epilepsy

4.1 Daily care routine needs

Caregivers consistently highlighted the need for continuous, around-the-clock support for their children, emphasizing the significant demands involved in managing daily routines. They reported that their children, regardless of age, required assistance with nearly all activities of daily living such as feeding, bathing, dressing and mobility. Even older

children, who might typically be expected to manage more independently, remained heavily reliant on caregivers due to safety concerns.

"I handle all his daily needs, feeding, bathing, and general care, because he is completely dependent on me. Although he's three years old, he hasn't started walking yet. But I appreciate the progress he's made through the services we've received; he can now crawl, sit up on his own, and change positions in bed, which he couldn't do before. He is truly improving." P7, 35 years old, Female. (Child's diagnosis - CP).

"You constantly have to plan; your mind is always thinking. But the child is always the top priority. If you leave her unattended, even briefly, like when you go to do laundry and don't return in time to check on her, you may find that she has soiled herself and no one has helped her. That's because we are their hands, their legs, their minds, their eyes, we are everything to them." P12, 31 years old, Female. (Child's diagnosis - CP)

4.2 Medical and therapy needs

A noticeable pattern was the caregivers' emphasis on the vital role of medication, particularly antiepileptic drugs, in improving their children's quality of life. They expressed anxieties over potential interruptions in medication supply, viewing consistent access as essential for their children's stability. Beyond medication, caregivers identified important therapy needs. Counselling was especially valued for older children, who often struggled with questions about their health, treatment duration, the possibility of a cure, and feeling different from peers. Caregivers of children with CP described physiotherapy as essential for maintaining mobility and preventing complications. Nonetheless, they reported challenges in continuing therapy at home due to the lack of supportive equipment, such as standing frames and specialized chairs, which were often unavailable but regarded as indispensable.

"What I need most for my child is her medication. The Lamotrigine she takes is expensive, and sometimes when I come to the hospital, it's out of stock and I may not have the money to buy it elsewhere. When she misses even a single dose, she ends up having convulsions. That's the medication that works best for her. Even if she's on Carbamazepine, without Lamotrigine, she still gets affected..." P19, 46 years old, Female. (Child's diagnosis - epilepsy)

"My child mainly needs physiotherapy, along with the medication prescribed for her condition. I've seen that when she takes the medicine, she behaves normally, but when it was stopped, her condition worsened. So she really needs consistent medication, physiotherapy, counseling, and love." P11, 27 years old, Female. (Child's diagnosis - CP)

"Of course, the medicine every night is essential. Without it, there are serious problems. There was a time I couldn't get it for a week, and I noticed a significant deterioration he became much worse than before. So I always make sure he takes his medicine every night. Even he knows its importance; as an older child, he gets concerned and tells me, 'Mummy, my medicine is running out.'" P16, 42 years old, Female. (Child's diagnosis - CP)

4.3 Educational and social needs

A frequently highlighted issue was the critical role of school engagement in supporting caregiving. Caregivers described the need to inform school authorities about their child's medical condition to promote safety and facilitate appropriate care during school hours. Disclosure was viewed as a crucial step in fostering collaboration with teachers and school health personnel, particularly in ensuring medication adherence and timely response to seizures or other health-related emergencies. Caregivers also emphasized prioritizing school fees and requirements, often above other household expenses, to minimize their children's emotional or social distress and help them feel well-prepared for school.

Another emerging theme related to schooling preferences, with some caregivers expressing a desire to enroll their children in special schools where they could interact with peers facing similar challenges, perceiving such environments as more understanding, inclusive, and emotionally supportive than mainstream settings.

"...You see our children should be placed in special schools where they can be with peers who have similar conditions. When a child sees others like themselves, it helps them feel calmer and understood. In regular schools as parents, we often hesitate to tell teachers about our child's condition because many don't keep such information confidential. If the child misbehaves, some teachers respond harshly slapping them or humiliating them by talking about their condition openly." P20, 39 years old, Female. (Child's diagnosis - epilepsy)

"I worked hard to raise the money and enrolled her in a boarding school. I handed her medication to the school nurse and always follow up with calls to remind her not to forget. The nurse understands since my daughter is still a child, she can easily get distracted by play and forget to take her medicine. The nurse ensures she takes it on time, sometimes even sending other students to call her when it's time for her dose." P10, 40 years old, Female. (Child's diagnosis - epilepsy)

5 Support and resources

A thematically significant issue was the varied experiences of support across settings. Caregivers described receiving valuable assistance in hospitals, including welcoming attitudes, counselling, specialist reviews, and prescriptions. At the same time, they voiced strong frustration over frequent shortages of essential medicines, which hindered consistent treatment. A commonly reported experience was related to school-based support, where caregivers generally felt that teachers and staff provided care and attention to their children. In contrast, limited support from the broader community emerged as a concern. Caregivers spoke about their children being treated differently because of their medical condition, with some noting a complete absence of help or understanding from neighbors and friends.

"...the support I receive from the school has been helpful. When I explained my child's condition, the school nurse took it seriously. If she spends days trying to find him to take his medication without success, she calls me. She'll say, 'You need to come and talk to him about taking his medicine.' When I go and speak to him, he listens and gets back on track." P1, 45 years old, Female. (Child's diagnosis - epilepsy)

“When it comes to neighbors and the community, there are things you’d rather keep private (laughs), because people can use them to mock or insult you—saying things like, ‘So this problem has reached you too.’ People talk. But on the positive side, when my child started improving, it really helped. We’d often find him playing with other children, and that made a big difference. When he’s engaged with peers, he’s less restless and demands less attention, which eases on the burden...” P15, 45 years old, Male. (Child’s diagnosis - epilepsy)

“What I’ve personally noticed is that the main gap in hospital services is the lack of essential medication. Most times, only the cheaper drugs are available, while the more effective and expensive ones are missing. Unfortunately, the medications we truly need are often the ones that aren’t stocked leaving us with the ones that cost as little as 100 shillings. So yes, the hospital really lacks the necessary medicines.”P9, 29 years old, Female. (Child’s diagnosis – CP & epilepsy)

6 Challenges and barriers

A central theme related to the substantial barriers caregivers encountered, most prominently financial strain. The cost of medications, transport to health facilities, with more frequent hospital reviews, and meeting daily needs placed a heavy burden on the families. Stigma was another major barrier, with many caregivers especially mothers reporting rejection or lack of support from their immediate families, particularly their husbands. Community level stigma further contributed to feelings of isolation and distress. Caregiving was also described as extremely time-consuming, often requiring near constant attention and as a result, many caregivers struggled to balance their responsibilities with income generating activities.

“...of course, everything involved in caring for a sick child is stressful. If you don’t have money, the stress is even worse. For example, you may have bought medicine for three months, but as that supply runs out and you know the school will soon call to say it’s finished and you have no money to buy more that becomes a major source of anxiety...” P1, 45 years old, Female. (Child’s diagnosis - epilepsy)

“I can’t pretend that life is easy as I mentioned, I’m a single mother, and my days are really tough. I became a single mother because of my child’s illness. The child’s father and his family rejected us. His mother even told him to consider the child as good as dead. But I said to myself, ‘If I don’t care for this child, no one else will and she’ll die.’ So I decided to take responsibility. I had to find any kind of work. Now I fry chips along the streets at night, and I go with my child. We spend the night there together.” P7, 35 years old, Female. (Child’s diagnosis - CP)

“Yes, this situation has really affected my daily life. Even when I work, I can’t manage to save anything and without savings, there’s no progress. If you’re renting, you just keep renting, with no chance to improve your situation. I also struggle to take care of myself. Sometimes I want to go somewhere, but I end up not going. For example, if there’s a party in the village, I avoid attending because people keep asking questions like, ‘What happened to the child?’ or ‘Was he bewitched?’ or they suggest maybe the father was unfaithful. To avoid all that judgment and gossip, I just stay away.” P7, 35 years old, Female. (Child’s diagnosis - CP)

“...many people who once had jobs lost them after having children with these conditions. Why? Because you’re forced to choose between working and caring for your

child you can't do both. If you speak to most parents in this situation, they'll tell you, 'I had to leave work.' Very few have been able to keep their jobs after having a child with such special needs..." P12, 31 years old, Female. (Child's diagnosis – CP & epilepsy)

7 Emotional and psychological coping

Another overarching theme related to caregivers' emotional and psychological coping mechanisms. They described maintaining optimism and hope for their child's improvement as a vital source of resilience. Caregivers also emphasized the importance of social support, having someone to talk to, such as fellow caregivers or trusted individuals, which helped them share their emotional burden and cope more effectively with the stresses of caregiving. They reported efforts to manage stress by intentionally focusing on the positive aspects of their situation. Maintaining a sense of organization and control, such as keeping medications and daily routines well managed, was also described as an important coping strategy that helped reduce psychological distress and foster emotional stability.

"When I got to know my child's condition and what treatment to use, I tried not to stress over things beyond my control. Of course, the worries come at times, but once I accept that some things are out of my hands, I'm able to let go and find peace..." P1, 45 years old, Female. (Child's diagnosis - epilepsy)

"You can relieve stress if, for example, you get a job, earn some money, and are able to buy your child's medicine then there the stress eases. When you're able to provide your child's necessities, you feel happier. Also, spending time with friends, sharing laughter, or receiving encouragement and counseling from others really helps to lift the burden." P2, 35 years old, Female. (Child's diagnosis - CP)

"Of course, when your child first falls ill and the condition is explained to you, fear sets in. But over time, you begin to accept the reality and find ways to encourage yourself. You know it won't be easy, but you keep pushing forward. Once you build that psychological strength, your mindset begins to shift you start thinking more positively..." P6, 39 years old, Female. (Child's diagnosis - epilepsy)

8 Social and professional support

A salient theme reflected the limited social and professional support available to caregivers.

8.1 Social support

A pattern that stood out was caregivers' experiences of inadequate social support, particularly from immediate family members. Caregivers, especially mothers, described feelings of isolation and being solely responsible for their child's care. This lack of support was often intertwined with experiences of stigma and emotional abandonment. The absence of shared caregiving responsibilities further heightened their sense of helplessness and psychological distress, emphasizing the emotional toll of unsupported caregiving.

"My child's illness feels like my burden alone because I have no support from either side of the family. Even from my own family, no one really makes time for him. On

his father's side, they no longer respond when I call. In the beginning, they used to ask how the child was doing or if there was any improvement. Sometimes they'd suggest changing hospitals, but it always felt like they were just trying to find out if he would recover. And whenever I'd mention that the child is improving but I need money for medication, they would abruptly hang up the phone." P7, 35 years old, Female. (Child's diagnosis - CP)

8.2 Professional support

Another shared experience was emotional exhaustion and burnout experienced by caregivers throughout their caregiving journey. Caregivers described feelings of depression, loss of self-worth, and episodes of emotional breakdown as part of their lived experiences. Despite these significant mental health challenges, most had not sought professional psychological support, reflecting a gap in mental health service utilization among caregivers.

"...there was a time I experienced a complete mental breakdown, I was not in my right state of mind for about nine months. But somehow, I still had to care for my child. It all began gradually after I gave birth; when she was around six months old, my mind just started slipping. I don't even understand what exactly happened to my brain I lost touch with reality. I would undress and behave irrationally. Looking back, I believe it might have been triggered by the overwhelming stress and constant worrying about my child's condition..." P12, 31 years old, Female. (Child's diagnosis - CP & epilepsy)

9 Practical coping strategies and resilience

A central aspect of caregivers' experiences involved the practical strategies they developed to manage the demands of caregiving. Caregivers described developing individualized approaches tailored to their child's specific needs to ensure consistent care. By establishing structured routines and systems, they were able to balance caregiving responsibilities with other commitments such as work. These practical adaptations were viewed as essential for maintaining stability, managing daily challenges more effectively, and sustaining their caregiving role over time.

"...the thing I do is maintain regular communication with the teacher at school since I'm not physically there. I call every week to get updates on how my child is doing. They inform me that he's taking his medication well and let me know how many tablets are remaining. I do pill counting, since he takes supply for a month, weekly updates allow me to monitor adherence. If they report more tablets remaining than expected, I know he must have missed some doses..." P1, 45 years old, Female. (Child's diagnosis - epilepsy)

"What I did was disconnect from social media I switched to using a basic phone because I realized that's what would give me peace of mind. I felt it would help me regain mental clarity. If someone calls just to greet me and then starts a long conversation, I simply excuse myself or cut it short I'm busy..." P9, 28 years old, Female. (Child's diagnosis - CP & epilepsy)

"What I did was set up a reliable system to help me keep track of time for my child's medication. I use two phones a small one and a smartphone both with alarms set to

ring six minutes before the scheduled time. If one phone is charging, the other will still alert me. This reminder system ensures I never forget. And if I'm far from home, I call whoever is with the child to remind them that it's almost time to give the medicine..." P4, 41 years old, Male. (Child's diagnosis - epilepsy)

In addition to practical adaptations, caregivers drew heavily on personal strengths that enabled them to sustain their caregiving roles despite persistent challenges. These strengths varied among individuals, reflecting their values and coping styles. Faith and religious beliefs were frequently described as central sources of hope, comfort, and purpose. Some caregivers found motivation in small but meaningful improvements in their child's condition, while others were driven by a strong sense of duty and the belief that they had to remain strong for their child. Attributes such as optimism, patience, and determination emerged as vital internal resources that fostered resilience and emotional stability throughout their caregiving journey.

"What keeps me strong is my faith in God. I place everything in His hands and trust that since He gave me this child, He had a purpose for it. I didn't expect to have a child with this condition, but I believe He has a reason, and that belief is what gives me strength..." P2, 35 years old, Female. (Child's diagnosis - CP)

"...most of the time, as the primary caregiver, you are the child's main source of encouragement. You're the one who cares for them daily, who truly understands their needs and behaviors. That means you must stay strong and focused because if you lose track or break down, everything else falls apart. In many ways, you are the lead clinician in the child's life." P1, 45 years old, Female. (Child's diagnosis - epilepsy)

"What gives me strength is seeing my child happy especially when she hasn't had another episode. That brings me a sense of relief and hope. I've also realized that spending time with friends helps me stay emotionally strong." P3, 35 years old, Female. (Child's diagnosis - epilepsy)

"...I believe in the power of positive thinking. In my life, I avoid negativity and don't want to hear discouraging words. As they say, what you believe can save you, so even when facing difficulties, I prefer to be surrounded by encouragement and support..." P6, 39 years old, Female. (Child's diagnosis - epilepsy)

10 Discussion

The aim of this study was to explore the caregiving experiences, needs, challenges, and coping strategies of caregivers of children living with epilepsy and/or CP. The findings illustrate that caregiving in this setting is shaped by a combination of intensive daily care demands and persistent structural constraints, with caregivers navigating medical, social, and economic pressures simultaneously.

Consistent with prior studies in sub-Saharan Africa, caregivers described intensive daily care demands, financial strain, medication insecurity, stigma, and limited institutional support as central features of caregiving [33–36]. Persistent dependence in activities of daily living and high out-of-pocket expenditure for medication mirror challenges reported across resource-constrained settings [37, 38]. These findings therefore confirm that structural health-system limitations, particularly medication stock-outs and limited rehabilitation infrastructure, remain major drivers of caregiver burden.

However, this study contributes additional insight into how caregivers actively adapt within these constraints [39, 40]. Rather than portraying caregivers solely as overwhelmed or distressed, the findings reveal deliberate, structured, and highly practical coping strategies embedded in everyday routines. Participants described systematic medication monitoring through alarms and pill counting, coordinated communication with teachers, and intentional adjustments to social engagement to preserve emotional stability. These context-specific strategies, which are rarely elaborated in African caregiver research, demonstrate active agency and adaptive problem-solving under sustained pressure. Consistent with literature emphasizing the protective role of internal strengths in long-term caregiving [39, 40], caregiving in this setting emerged not only as a source of strain but also as a space of purposeful resilience.

Although epilepsy and CP involve distinct clinical challenges, caregiving experiences in this study were shaped as much by shared structural realities as by diagnosis. Caregivers of children with epilepsy emphasized medication continuity and seizure preparedness, while those caring for children with CP highlighted long-term physical dependency and rehabilitation needs. Caregivers of children with co-occurring conditions appeared to experience compounded demands. Yet across groups, financial strain, limited assistive devices, stigma, and inconsistent institutional support were common. This suggests that in low-resource settings, health-system constraints may shape caregiver experience as strongly as clinical differences [41].

Stigma emerged not only as social rejection but also as a complex relational negotiation. Caregivers described carefully balancing disclosure of their child's condition in school settings to ensure safety while protecting confidentiality and dignity. This nuanced decision-making extends beyond the generalized stigma narratives often reported in prior studies and underscores the importance of structured school-health collaboration [42]. The findings suggest that stigma operates within specific institutional relationships, not only within communities broadly [42].

Coping strategies reflected both cultural grounding and pragmatic adaptation. Faith, acceptance, and social connectedness were important sources of meaning and emotional endurance, consistent with regional literature [38–41]. At the same time, caregivers demonstrated strong problem-focused coping, structuring daily routines to maintain control in unpredictable circumstances. While some caregivers reported emotional exhaustion, burnout, and even prolonged psychological distress, few had accessed formal mental health services. This gap between distress and service utilization highlights an overlooked dimension of paediatric neurological care: caregiver mental health remains insufficiently integrated into routine services.

10.1 Implications for practice and policy

These findings have practical implications for supporting caregivers in similar low-resource settings. Caregiver mental health needs should not be overlooked within paediatric neurology services. Simple measures, such as routine emotional check-ins, brief counselling, or peer-support groups facilitated by nurses, could provide meaningful support without requiring major system changes [43].

Ensuring consistent access to essential medications and affordable assistive devices would also make a tangible difference. When drugs are unavailable or equipment is out

of reach financially, the emotional and economic burden on families increases significantly [44].

Closer collaboration between health facilities and schools is equally important. Training teachers to respond appropriately to seizures and handle medical information confidentially could improve both safety and dignity for affected children, while reducing stigma [45].

Finally, broader social protection measures, such as transport support or disability-linked financial assistance, could help ease the persistent economic strain that many caregivers described, enabling them to focus more fully on their children's well-being [45].

10.2 Transferability

Although grounded in southwestern Uganda, these findings are likely transferable to similar low-resource contexts characterized by centralized specialist services, medication stock variability, and limited rehabilitation infrastructure. The emphasis on structural drivers of caregiver burden suggests relevance across comparable sub-Saharan African settings.

10.3 Limitations

This study has several limitations that should be considered when interpreting the findings. First, as a qualitative study conducted in a single referral hospital in southwestern Uganda, the findings may not be fully generalizable to all caregivers of children with chronic neurological conditions in other regions or settings. The experiences described here may differ in contexts with more robust healthcare systems, stronger social support networks, or different cultural beliefs. Second, because the study relied on self-reported narratives, the data may be subject to recall bias and social desirability bias, with participants potentially underreporting sensitive experiences such as emotional distress or maladaptive coping strategies. Third, although efforts were made to capture diverse perspectives, the sample was relatively small and predominantly female, reflecting caregiving roles in this context but potentially limiting insights into male caregivers' experiences. Finally, the cross-sectional nature of the data captures a snapshot in time and does not account for how caregivers' experiences and coping strategies may evolve as their children grow or as their conditions change. Future research using longitudinal designs and including broader geographic and demographic diversity could deepen understanding and enhance transferability.

11 Conclusion

This study highlights the complex and demanding nature of caregiving for children with chronic neurological conditions in a low-resource setting. Caregivers face significant medical, emotional, social, and financial challenges but demonstrate resilience through faith, optimism, and practical coping strategies. The findings emphasize the need for comprehensive support, such as reliable medication access, psychosocial services, assistive devices, and stigma reduction, to improve caregiver well-being and enhance care for affected children.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12982-026-01703-w>.

Supplementary Material 1.

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Author contributions

A.N. and J.A. conceptualized and designed the study. Data collection was coordinated and supervised by M.M. A.N. conducted the primary data analysis and drafted the initial manuscript. M.M.K., M.M., G.Z.R., and G.W. contributed to data interpretation and critically reviewed the manuscript for important intellectual content. All authors participated in manuscript revision, approved the final version for publication, and agree to be accountable for all aspects of the work.

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Data availability

The qualitative datasets generated and analyzed during the current study are not publicly available due to the sensitive nature of the data and the need to protect participant confidentiality. De-identified data may be made available from the corresponding author upon reasonable request, subject to approval by the relevant ethics committee and in accordance with institutional and ethical guidelines.

Declarations

Ethics approval and consent to participate

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki and all applicable local regulations. Ethical approval was obtained from the MUST Research Ethics Committee (Approval No. MUST-2025-248), and administrative clearance was granted by MRRH. All participants provided written informed consent, and confidentiality and anonymity were assured throughout the study.

Competing interests

The authors declare no competing interests.

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