


Navigating health care for children with disabilities: perspectives of male caregivers in rural Kenya

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Abstract

Introduction: UN Sustainable Development Goal 3 and the nurturing care framework highlight the importance of healthcare services and preventive measures to ensure optimal health outcomes for children, including those with disabilities. However,

the contributions of male caregivers in the general care of children with disabilities in Sub-Saharan African contexts are often overlooked. This article therefore aims to understand how male caregivers navigate and negotiate healthcare options for their

children with disabilities in rural Kenya.

Methods: A qualitative approach was adopted, following the phenomenological tradition, to collect data from 22 male caregivers of children with neurodevelopmental disabilities in rural Kenya using four focus group discussions. The data were analyzed using inductive thematic analysis. The interpretation of the findings was guided by the theoretical approach of critical disability studies.

Results: The article contributes new knowledge to the understanding of the roles and experiences of male caregivers in the healthcare of children with disabilities in rural Sub-Saharan

Keywords

children, disabilities, health, Kenya, nurturing care.

Introduction

Children with disabilities include those with 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'¹. Among the challenges faced by these children in accessing health care in rural settings in Sub-Saharan Africa are stigma and negative attitudes as well as poverty and insufficient resources, including shortage of facilities, trained personnel and equipment²⁻⁴. Physical inaccessibility of infrastructure and lack of transportation compound these challenges^{5,6}.

Caregivers play a crucial role in navigating healthcare options for their children. However, the contributions of male caregivers in the general care of children with disabilities in Sub-Saharan African contexts are sometimes overlooked and underrecognized⁷. The dominant notion of male caregivers in these contexts is often that of the absent father, abusive father, or uncaring father⁸⁻¹⁰. Empirical evidence supports this perception, with high rates of father absence observed in some countries, such as South Africa, where studies show that 63% of children do not live with their fathers¹¹. Additionally, studies document widespread domestic violence and abuse perpetrated by men, with a systematic review revealing that more than 44% of women aged 15–49 years in Sub-Saharan African countries experience some form of intimate partner violence¹².

However, this dominant narrative obscures the importance of male caregivers' roles. Societal expectations prioritizing male providership over caregiving perpetuate gendered norms, undermining male involvement in childcare⁹. Consequently, research on caregiver involvement in caring for children with disabilities in Sub-Saharan African contexts has primarily focused on female caregivers, leaving male caregivers understudied^{13,14}. A focus on male caregivers is particularly important because these caregivers are traditionally the heads of the family, income earners and primary decision-makers, including in resource allocation and matters such as access to health care, in Sub-Saharan African contexts¹⁵⁻¹⁷. These roles become more significant when there are vulnerable family members such as children with disabilities because such members often need greater access to resources than do other family members, and male caregivers are in charge of making resource-sharing decisions⁷.

African contexts. Four emergent themes are presented: '... hospitals around cannot offer a solution to their problems ...'; '... regarding finances, I have to struggle alone ...'; '... the only place one can pity you is the traditional herbalist ...' and 'I pray to God to heal him'.

Conclusion: Faced with significant challenges in accessing conventional healthcare services, male caregivers employ the local cultural resources available to them to address the healthcare needs of their children with disabilities. This emphasizes the need to complement their efforts by mobilizing the healthcare system to offer quality, equitable, culturally sensitive and inclusive healthcare solutions.

This article reports on a study exploring the journeys of male caregivers in rural Kenya as they navigate the complex landscape of health care for their children with disabilities. The aim is to uncover valuable lessons that can inform the development of better support services tailored to the needs of their children with disabilities. Ultimately, the goal is to make a positive impact on the lives of children with disabilities in rural settings by improving access to quality healthcare and enhancing their wellbeing, as envisioned in Sustainable Development Goal 3 on achieving universal health coverage¹⁸ and in the nurturing care framework component of ensuring good health¹⁹.

Theoretical underpinning

This article adopts a humble, exploratory stance, in the phenomenological tradition, to understand the journeys of male caregivers navigating health care for their children with disabilities in rural Kenya^{20,21}. We draw on critical disability studies as a guiding framework, while acknowledging this field's limitations and potential biases. This field emphasizes power dynamics, social structures, and societal norms impacting experiences of individuals with disabilities²²⁻²⁴. However, we recognize that our participants may hold diverse views on disability, potentially diverging from the assumptions of critical disability studies.

We recognize that disability can be understood through different lenses, including the medical model, which views disability as an individual's impairment or defect to be diminished or corrected through biomedical interventions²⁵. In contrast, the social model of disability, championed by scholars such as Oliver²⁶, stresses that disability is not exclusively an individual's impairment, but rather a result of sociocultural constructs and barriers.

Our study sought to explore how male caregivers navigate healthcare systems and make sense of their child's disability, acknowledging the intersections of biomedical and sociocultural factors^{20,25}. While the field of critical disability studies encourages a critical examination of systemic barriers and inequalities, we also acknowledged the importance of medicalized understandings of disability and the need for holistic care. In these regards, the ethics of care was an important theorization of the needs of children with disabilities and their caregivers, encouraging us to consider the perspectives and experiences of families and individuals with disabilities in decision-making processes and to act in ways that promote their overall welfare and quality of life²⁷.

Through these approaches, we hoped to provide a richer understanding of male caregivers' journeys, challenging prevailing assumptions and embracing the complexity of their experiences. Our goal was to contribute to a more comprehensive and empathetic understanding of the challenges faced by male caregivers and their children with disabilities, seeking solutions that extend beyond the medical and social boundaries of disability.

Methods

This article reports on a study that was part of a broader research project aimed at establishing the status of care for young children with disabilities in rural Kenya. The objective of the segment of the study presented here was to explore the experiences of male caregivers in navigating and negotiating healthcare options for their children with disabilities in rural Kenya. To address this objective, the study adopted a qualitative approach, specifically following the phenomenological tradition to understand the essence of the phenomenon of interest^{20,21}: how male caregivers navigate and negotiate healthcare options for their children with disabilities in rural Kenya. Phenomenology operates on the premise that individuals possess distinct and subjective perceptions of the world. It prioritizes comprehending the world through the lens of participants, recognizing that personal experiences shape one's understanding of reality²⁰. Specifically, this study employed hermeneutic phenomenology, integrating descriptive and interpretive approaches to explore participants' experiences. This methodology acknowledges the researcher's subjective role in interpreting and understanding participants' narratives, while uncovering underlying structures, relationships, and contextual meanings²⁸.

The study was conducted in Siaya County, a rural region in Kenya, about 400 km north-west of Nairobi, the capital city. Figure 1 illustrates the geographical location of Siaya County within Kenya.

The majority of the residents of Siaya County are from the Luo ethnic group. Siaya County is characterized by low socioeconomic status, with 34.2% of the population living below the poverty line. Limited access to healthcare services is a significant challenge, with only one doctor per 25 000 residents and one nurse per 2000 residents. Agriculture is the primary livelihood, with maize, sugarcane, and fishing driving the local economy^{29,30}.

Guided by phenomenology²¹, data were gathered in a relatively unstructured manner from purposively selected participants, who were believed to offer rich insights into the topic. The participants were 22 male caregivers (19 fathers and three grandfathers) of children with neurodevelopmental disabilities, which affect the development of the nervous system, including the brain, spinal cord, and nerves^{31,32}. We used community health promoters within the Siaya County health system's structure to reach participants. The community health promoters supported the identification of targeted male caregivers and inviting them to the data collection exercise. To be included, a caregiver had to identify as male, have at least one child with a neurodevelopmental disability, and be available for the data collection exercise. The research team explained the details of the research and allowed the participants to decide whether or not they wanted to participate. Data were

obtained only from the caregivers who consented to participate in the data collection exercise. Table 1 presents a summary description of the participants' characteristics. Letters and numbers (eg R1 F2002, R2 F3002) have been used as anonymized code names for the participants.

The data collection was conducted in October 2023 through in-person focus group discussions (FGDs). Four FGDs were conducted, with two FGDs consisting of six members each and the remaining groups comprising five members each. The FGDs were conducted within the health facility where the caregivers of children with neurodevelopmental disabilities sought health services. Each FGD began with introductions and consent, followed by group discussions moderated by an experienced, trained facilitator, and concluded with a wrap-up. An FGD guide, developed for this study, was used to facilitate the data collection. Table 2 presents a sample of the questions used in the FGDs. The duration of the focus group discussion ranged from 1.5 to 2.5 hours. The language used for the data collection was Dholuo (the native language used in these communities), and FGDs were recorded with the permission of the research participants. The recordings were initially transcribed in Dholuo and later translated into English and subsequently back-translated into Dholuo to ensure the accuracy of the translations. This process was carried out by experienced transcribers/translators under the supervision of the second author, whose first language is Dholuo.

The data were subjected to inductive thematic analysis by AK and SO, facilitated by NVivo v20 (Lumivero; <https://lumivero.com/products/nvivo> [<https://lumivero.com/products/nvivo>]). The two authors conducted the analysis separately. The four stages of theme development proposed by Vaismoradi et al³³ were adopted: initiation, construction, adjustment, and finalization. AK held discussions with SO to explore alternative interpretations of the findings and to confirm the emergent themes.

Table 1: Description of male caregivers' characteristics

Characteristic	Value
Relationship to child, <i>n</i>	
Father	19
Grandfather	3
Caregiver age, mean (years)	44.7
Caregiver education, <i>n</i>	
Primary education or less	10
Secondary	8
College	4
Caregiver employed, <i>n</i>	
Informal employment (farming, casual laborer)	18
Formal employment	4
Marital status, <i>n</i>	
Married	20
Not married (separated, widowed, etc.)	2
Caregiver's number of children, mean	5
Child gender, <i>n</i>	
Female	12
Male	10

Table 2: FGD guide for male caregivers of children with disabilities

Topic	Questions	Probe
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Introductory questions	Please tell me briefly about yourself. <i>Lerna matin kuom ngimani?</i> What do you do to earn a living? <i>Tiji maduong' makelo chiemo en mane?</i>	
Health	Please tell us about your experience with the pregnancy of your child with NDD. <i>Lerna kaka ne chal ka ne jaodi nigi ich mar nyathini?</i>	Antenatal care attendance, any complications/danger signs and care received
	How was your experience of the birth of your child with NDD? <i>Lerna kaka nyuol mar nyathinini ne chal?</i>	Birth complications, prolonged labor, postnatal care
	Please tell us about your experience with caring for your child with NDD in relation to seeking health services. <i>Lerna kuom arita mar nyathinini e yore mag dwaro thieth?</i>	Use of local herbs, traditional healers, health facility seeking, and challenges experienced in seeking the care
	How did you know that your child with NDD was experiencing a challenge? <i>Ere kaka ne ifwenyoni nyathinini nigi chandrugni?</i>	Information from the hospital
	What is the most important information that you have been given as a father of a child with NDD about caring for your child? <i>En wach mane kata puonj mane ma iseyudo kaka wuoro man kod nyathi man kod ng'ol mar obuongo?</i>	
	What challenges or difficulties have you encountered in seeking health services for your child with NDD? <i>Gin pek mage ma iseneno kaluwore gi wech mag thieth kod gima ne nyathini ni?</i>	Cost of health services, availability, accessibility



Figure 1: Geographical location of Siaya County (shaded red) within Kenya.

Ethics approval

Ethics approval and permission to conduct the study were obtained from the Amref Health Africa Ethical and Scientific Review Committee (P1445-2023) and the National Commission for Science, Technology and Innovation (NACOSTI/P/23/30392), respectively. All the research participants provided informed consent before taking part in the study.

Results

Four emergent themes are presented: '... hospitals around cannot offer a solution to their problems ...', '... regarding finances, I have to struggle alone ...', '... the only place one can pity you is the traditional herbalist ...' and 'I pray to God to heal him'.

'... hospitals around cannot offer a solution to their problems ...'

Hospitals were often a key stop for families when addressing their children's disabilities. However, the male caregivers reported disillusionment in the ability of the hospitals to address their children's needs. R5 F4001 stated, 'I have a list of people with serious disability issues seeking help in vain. Even hospitals around cannot offer a solution to their problems'. This caregiver added that the local hospital staff were ill prepared to address their children's disabilities, a factor that necessitated referrals to other

adequately prepared medical personnel: 'Therefore, I suggest that if we could be linked to specialists and experts, then it can truly help'. The disillusionment with the local hospital was exacerbated by the insensitive questions the hospital staff asked the male caregivers. R3 F4002 observed:

... there is a particular question that the doctor used to ask, and it irritated us. For instance, when she [wife of caregiver] was asked if there is someone in the family who has any form of disability or even extended family members who maybe you are not close to. They try to make us dig deeper into anyone from the extended family who has it, but we tell them there is none. However, they make us think the condition is genetic since it is already with us, and we see it as a challenge.

I have not researched if there is someone from my wife's family or extended family who has a disability, though I think she has tried to dig on my side if there is any. Generally, if they [medical personnel] discover that that is the cause of the condition, what action will they take next?

The medical personnel appeared to emphasize attributing the child's disability to genetic causes, a focus that the caregivers found offensive and lacking in priority. The caregivers observed that some of the questions posed by the medical personnel were no different from those asked by lay members of the community. R2 F3002 said:

Sometimes, we wonder why they ask us the same question, which people in the community also ask us. Therefore, we ask ourselves why they ask us such questions, yet we have not suspected that or seen any of the incidents in our family.

Cases of arrogant, dismissive medical personnel who lacked empathy were also reported. R2 F4001 said, 'When you have a disabled child of this kind, the medics become arrogant, and they do not want to handle such patients'. The same caregiver added:

They only refer you to a specialist and avoid you as well. For example, my child [with a disability] once had a toothache, and I went to Siaya, and whenever the child would be directed, the child would do the opposite. At the last minute, the doctor wrote in the booklet that the child was very rude since they did not understand the situation [disability] of the child.

According to R2 F4001, this medical officer lacked the knowledge to appreciate the disability of the child, leading them to wrongly dismiss the child as rude and uncooperative.

'... in regard to finances, I have to struggle alone ...

In addition to the foregoing negative experiences at the hospital, male caregivers also faced serious financial challenges in accessing health services and meeting the other needs of children with disabilities. R4 F2002 said:

... the therapy section [for the child with a disability] is also paid ... [the] equipment that is special for teaching him how to walk is only in the facilities, and they are not affordable ... I am the only sole provider of the family who has to ensure that the other children attend school and the sick one also gets treatment.

This excerpt introduces a masculine stereotype, where the male caregivers in this rural African community were expected to be the providers of the family. R5 F3002 reiterated that the financial provider role was mostly the responsibility of the male caregiver: 'The support from the family can be there, but in regard to finances, I have to struggle alone'. The economic hardships that male caregivers had to contend with while addressing the healthcare needs of their children with disabilities stood out. R3 F3002 observed:

... finances sometimes break me to the extent of borrowing money, begging people for help, and even taking loans to help my child [with a disability] survive. The salary is not enough, as I also have other children in school and pay for them school fees. I have to pay rent and provide food for the family, so it is not enough, making life a little bit complicated.

According to R3 F3002, he had been spending almost 25,000 Kenyan shillings (KSh) (approximately A\$310) on the child with a disability every month, which was a significantly high amount considering that the majority of the population in rural Kenya lives below the poverty line of less than A\$3.20 per day. The only financial support he had received was in the form of a contribution from friends who lived far away and from the church. He added that the family and relatives had not helped him in any way.

R1 F2002 further noted, 'We undergo a lot of challenges, and even our lives change because most of the income is directed to the child's treatment. Second, it is expensive to take our children who have disorders to the hospital'. Thus, financial challenges were brought about not only by the high cost of services offered at the hospital but also by the cost of travel to the institution. The hospitals were mostly located far from the families of the children with disabilities, and many of the caregivers could not afford the transport cost.

Nevertheless, the challenge of paying for healthcare services was not a universal experience. Some caregivers reported cases of hospitals that offered free treatment. R2 F2002 said, 'my child used to receive treatment for free as an inpatient [at a hospital], but here [in another hospital], I pay for the inpatient bills and even buy the drugs for my five-month-old child'. This caregiver then blamed the local government leadership for the problems with service provision at the hospital. He added, 'There are no medicines at the hospitals, and we must purchase them outside'. The caregiver also recalled how the government medical insurance fund helped meet some of the financial costs to some extent: 'When the National Health Insurance Fund was introduced, it met some expenses, though others were from our wallets'.

The constant shortage of funds led some of the caregivers to take extreme measures to cater to the financial needs of their children. R2 F3002 recounted how he sold a valuable item at a loss to raise money for his child's medical expenses: 'I ended up selling my camera of KSh25,000 (approximately A\$310) for KSh15,000 (approximately A\$187) since the doctor required some assessments to be done on my child concerning his condition'. The caregivers had no option but to raise the funds because, 'These doctors once you do not have money, they do not bother whether your child dies or not' (R1 F4001).

'... the only place one can pity you is the traditional herbalist ...'

The financial challenges faced by male caregivers, without disregarding the potential influence of other factors, likely played a role in their decision to seek alternative healthcare options for their children with disabilities. R3 F2002 noted, 'any place you step into seeking help, money is being used, and the only place one can pity you is the traditional herbalist'. Traditional herbalists seemed to fill the void left by conventional medical practitioners. R1 F2002 noted:

After discharge from the hospital, we were instructed to bring him back for physiotherapy, which I did, but later on, I could not afford the cost and stopped. I decided to find a traditional physiotherapist who used traditional herbs to massage him, and it helped since now he could sit.

Other caregivers also reported cases where herbalists' interventions produced positive results for their children with disabilities. R2 F3002 observed:

His umbilical cord also grew so large ... a traditional herbalist gave us a secret of using a coin tied on the umbilical cord with some straps, and it reduced to the normal size. After 2 months, the umbilical cord was okay ...

These male caregivers considered traditional herbalists to play a complementary role to that of conventional medical personnel. For example, R6 F2001 said, 'I have tried all means to assist him [child] in both hospital and traditional ways ...' Another caregiver noted, 'I have tried everything: the traditional herbs, taking him to the hospital and even the physiotherapy ... the one place where I have not gone to is to a witchdoctor' (R4 F3002). This caregiver was clear about the difference between the herbalist and the witchdoctor. While he could visit the former, he seemed to have reservations about the latter.

However, other caregivers cited cases where traditional herbs did not help; in the same way, conventional medical practices failed. 'They [medical personnel] tried and did physiotherapy on him, but there was no change, so I opted for traditional herbs to massage him with, but still, there was no change' (R1 F3002). R1 F2001 added, 'I decided to get my child a traditional physiotherapist who used traditional herbs to massage him and bathed him with some, though there was still no change'. R6 F3002 even expressed suspicion that traditional herbs had played a role in the condition of his child. 'She was just born as usual, and there were no complications. However, I think ... some herbs may have affected her afterwards'. Thus, while some caregivers found help in traditional herbalists and herbs, others saw the services as unhelpful and even dangerous for their children.

'... I pray to God to heal him ...'

In addition to financial challenges and because neither the hospital nor traditional herbalists appeared to help, some male caregivers opted for spirituality, leaving the predicament of the child with a disability to God. R4 F4001 observed:

My child ... did not improve while under medication. We were spending a lot of money, and there is nothing to show for it. I gave up. I left it to God to do His will since I had financial constraints.

There were cases when such spiritual interventions were seen to help. R6 F2001 noted:

... we used to take him for prayers there [at my wife's church], which has at least helped him. Since then, he has been able to walk a little bit, but he still can't talk well.

This caregiver, while noting progress in terms of the child's ability to walk, nevertheless was aware that the child still faced another challenge: he could not talk. Thus, even with the spiritual interventions, it seemed that the caregivers were caught in a constant loop of trying to cure the child's disability.

This 'looking for a cure' or healing appeared to be a significant preoccupation of the caregivers. R5 F2002 stated, 'I pray for the Almighty to heal him so he can be as normal as other children'. R2 F2002 also observed how his social network encouraged him to pursue healing from God: 'my friend ... has always encouraged me to be positive that one day God will heal my child'. Thus, it seemed that the belief in a God who could heal disability was rooted in this community. Nevertheless, just as seeking the intervention of traditional herbalists played a complementary role to conventional medical interventions, seeking God's intervention also played a

similar role. R3 F2001 reported how he had resorted to prayers when he could not access the hospital because the doctors were on strike.

We tried ... prayers several times when the doctors were on strike, accompanying them with the massages. A friend of mine then one day told me to try a certain pastor ... who could pray for her, and I went in November. The pastor then prayed for her and directed us to take her to the hospital and be seen by a children's specialist.

In looking for a cure, it seemed important to understand the cause of the disability, and religious beliefs sometimes offered that explanation. R5 F4001 said, 'We ... took to church for prayers because we thought that ... she was demon possessed'. Some caregivers also noted that they were often accused of causing their child's disability by sinning against God. R5 F2001 stated, 'they also think that my sins are the ones causing the problem that my child is experiencing'. The caregiver additionally rationalized that he was not to blame for his child's disability because 'the disorder problem is something that dates back to the past, and it is even mentioned in the Bible'. R5 F2001 appeared to reason that disability, which he viewed as a disorder, should be appreciated as a natural occurrence recognized even by the Christian religious text.

Discussion

The findings of this article provide insights into how male caregivers in rural Kenya navigate and negotiate health care for their children with disabilities. While females are often assumed to be the primary caregivers for young children, it is essential to recognize the significant role that male caregivers play⁹. Therefore, the article considers the perspectives and contributions of male caregivers. It might have been assumed that male caregivers, being 'men', would be stronger in navigating the care of children with disabilities. However, similar levels of despair are observed, as implied in studies that include the voices of women³⁴.

According to the male caregivers, conventional medical facilities in this context often fall short in meeting the healthcare needs of their children with disabilities due to factors such as cost, distance, and personnel who seemingly do not prioritize the needs of families and their children with disabilities. A further complication is that caregivers often have high expectations regarding 'curing' the disability.

The findings echo and contribute to the growing body of global literature on the challenges faced by caregivers of children with disabilities in accessing healthcare. For instance, a meta-synthesis based in the US observed systemic challenges faced by caregivers seeking health care for children with autism, such as a lack of provider knowledge and inadequate support, further complicating access to appropriate care³⁵.

The male caregivers' abilities to seek community-based support and navigate complex healthcare systems appear to be a crucial aspect of their meaning making and maintaining hope, enabling them to cope with the challenges of caring for a child with a disability. Nevertheless, male caregivers need support to appreciate that disability may not be completely 'cured'. However, medical procedures and early interventions, as demonstrated in

studies conducted in Uganda^{36,37}, can improve functionality, care, and quality of life to some extent. Clear, honest and sensitive counseling should be provided to caregivers of children with disabilities to manage their expectations effectively.

Medical professionals could be key in providing honest counseling to caregivers. However, a key yet unsurprising finding is the dominance of the medical model of disability within healthcare systems in this setting. Similarly, Chabeda-Barthe et al suggested that the medical model of disability is widely used in Kenya³⁸. The professional training of medical personnel likely influences their views towards this model of conceptualizing disability. Indeed, Bunning et al, in a study conducted in a rural part of Kenya, noted that rehabilitation approaches for children with disabilities appeared to be informed by the professional background of the practitioner rather than the needs of the child³⁹.

It has been observed that, when applied uncritically, the medical model of disability can be disempowering and stigmatizing²². This is exemplified in the present study, in which medical personnel focused excessively on attributing disability to genetic causality, a tendency that male caregivers found unhelpful and offensive. Medical personnel need to be supported to understand that interventions for disabilities should also encompass social and cultural considerations, not biomedical approaches alone. Deliberate efforts, such as through in-service trainings, to acquaint them with the social model of disability, the ethics of care, and contextual cultural competence, for instance, could lead them to better support caregivers and their families. This aligns with international standards emphasizing cultural competence and humility as essential for effective healthcare provision⁴⁰⁻⁴². Similarly, Douglas et al³⁵, in a study from the US, have called for increased training of medical professionals and the promotion of an interdisciplinary approach to care, which they argue is more beneficial for caregivers of children with autism.

Financial constraints add another layer of difficulty for male caregivers, who are expected to provide for both their children with disabilities and the entire family. The trend of male caregivers receiving limited support from extended family members echoes findings in the literature concerning the declining role of family relationships as an economic safety net in Sub-Saharan African contexts^{43,44}. As Mulenga suggested in the Tanzanian context, communities are increasingly turning toward capitalistic ideals that favor individualism and competition⁴⁵. Nonetheless, the current study provides evidence of community resilience, wherein friends and the church take up the support role that the extended family is relinquishing.

Given the significant financial challenges faced by male caregivers of children with disabilities, it is necessary to create room for alternative worldviews beyond ableist, capitalist assumptions that often place the responsibility for economic independence on the individual. The alternative worldviews include those that favor offering financial and other support to families raising children with disabilities^{22,46}. There is a need to challenge societal norms regarding masculinity that disproportionately burden male caregivers with the responsibility for economic independence. The societal pressures of poverty and lack of job opportunities, coupled with the high demands for resources by children with disabilities, should allow redefinition of the role of male caregivers.

This means that policy initiatives aimed at providing financial support to families raising children with disabilities need to be strengthened. This imperative is echoed by WHO, which stresses that financial assistance plays a critical role in alleviating the economic costs of caregiving related to disability. WHO recommends that governments provide financial support through cash benefits, tax credits, or vouchers to individuals with disabilities and their families⁴⁷.

Another significant point concerns the role of traditional healers in the journey of male caregivers negotiating healthcare options for their children with disabilities. This study echoes the findings of research conducted in Ethiopia⁴⁸, Uganda³⁴ and South Africa⁴⁹ showing that a significant portion of the population in Sub-Saharan African communities still seek medical services from traditional healers. These healers embody cultural responses to disability, offering not only emotional support but also, at times, alternative real-life solutions where biomedical approaches to health care seem to be limited. By supplementing conventional medical care with the services of these healers, male caregivers demonstrate their commitment to meeting the healthcare needs of their children with disabilities. For instance, while caregivers might face challenges accessing conventional healthcare services due to long distances to hospitals and the high cost of services, traditional healers are often located closer to families and may offer more affordable services.

Similarly, male caregivers employ spirituality to negotiate the health care of their children with disabilities. It is suggested that 'turning to God' may emerge as a resort for caregivers, including when biomedical and traditional interventions appear ineffective. Indeed, some caregivers believe that these spiritual interventions can be effective. Spirituality has been argued to be an effective coping mechanism in the context of disability and illness^{50,51}. The caregivers who resort to prayer for healing demonstrate agency and autonomy. Their prayers serve as expressions of their deepest desires, hopes, and beliefs. This underscores the importance of respecting these expressions. In the same vein, Chidarikire, in the context of mental health, contends that medical personnel must acknowledge and integrate the spirituality of their patients into treatment plans, regardless of their personal beliefs or positions⁵².

Nevertheless, it is essential to acknowledge and respect the diverse cultural and spiritual resources available to male caregivers while simultaneously promoting informed decision-making. This may involve encouraging dialog between traditional and spiritual healing practices and evidence-based medicine, recognizing that both can offer valuable insights and support for caregivers and their children with disabilities. Integrating traditional/spiritual healing practices resonates with global efforts by WHO and the scientific community to incorporate traditional medicine into healthcare systems^{53,54}. The present study provides evidence of spiritual leaders referring male caregivers of children with disabilities to conventional healthcare facilities. Similarly, in South Africa, in the case of HIV, some traditional healers refer individuals to clinics for testing or counseling before administering their own treatment⁵⁵. However, it has been suggested that traditional healers demonstrate greater willingness to collaborate with medical professionals than do medical professionals⁵⁶. By

enhancing open communication and mutual respect between traditional/spiritual healers and medical professionals, a more holistic and inclusive approach to disability care can be achieved.

The Community-Based Inclusive Development approach, which leverages local resources and expertise, could enable traditional/spiritual healers and medical professionals to collaborate, bridging gaps in service delivery⁵⁷. By integrating this approach, healthcare services can become more culturally responsive, accessible, and equitable for families of children with disabilities. However, it is important to advocate for caution and discernment when considering traditional and spiritual healing approaches to ensure that they do not inadvertently reproduce marginalization and that they align with the best interests and wellbeing of children with disabilities.

A strength of this study is the emphasis on amplifying the voices of male caregivers, an often-overlooked group, who play a significant role in providing health care to their children with disabilities in this specific context in Sub-Saharan Africa. Although the perspectives of male caregivers in this context of rural Kenya provide valuable insights into the experiences of this specific group, they may not fully represent the diversity of male caregiving experiences or healthcare challenges they face in other regions of Sub-Saharan Africa. Future research could consider including the perspectives of male caregivers in urban settings or other cultural contexts for theoretical generalization or theoretical falsification. Additionally, although we attempted to explore specific challenges faced by male caregivers, including the disproportionate economic burden due to masculine expectations, we acknowledge the need to comprehensively capture their distinctive masculine perspectives. Future research should investigate masculine perspectives in caregiving, considering the influence of societal expectations, gender norms, and power dynamics on their experiences, to inform targeted support interventions.

Conclusion

References

- 1 United Nations General Assembly. *Convention on the Rights of Persons with Disabilities and Optional Protocol*. 2006. Available: [web link](#) (Accessed 10 July 2024).
- 2 Zuurmond M, Nyapera V, Mwenda V, Kisia J, Rono H, Palmer J. Childhood disability in Turkana, Kenya: Understanding how carers cope in a complex humanitarian setting. *African Journal of Disability* 2016; **5(1)**: a277. DOI link, PMID:28730061
- 3 Bunning K, Gona JK, Buell S, Newton CR, Hartley S. Investigation of practices to support the complex communication needs of children with hearing impairment and cerebral palsy in a rural district of Kenya: a case series. *International Journal of Language & Communication Disorders* 2013; **48(6)**: 689-702. DOI link, PMID:24165365
- 4 Bunning K, Gona JK, Newton CR, Hartley S. Empowering caregivers of children with learning and developmental disabilities: from situation analysis to community-based inclusive development in Kilifi, Kenya. *Tizard Learning Disability Review* 2022; **27(1)**: 1-10. DOI link

Contrary to the hegemonic perceptions towards male caregivers of children with disabilities as being absent, abusive, or uncaring, male caregivers in this specific context of Sub-Saharan Africa are actively involved in caring for their children and seeking ways to address the healthcare challenges they face. In the face of difficulties in accessing conventional healthcare services, the male caregivers mobilize local cultural resources available to them, such as traditional healers and spirituality, to address the healthcare needs of their children with disabilities. This calls for policymakers and disability rights advocates to complement the efforts of these caregivers through mobilizing the healthcare system to offer quality, equitable, culturally sensitive and inclusive healthcare services to enhance the wellbeing of children with disabilities in rural settings. To achieve a more holistic and inclusive approach to disability care in such rural settings, specific policy advocacy strategies are recommended: establishing interdisciplinary working groups, developing cultural competence training programs for medical practitioners, advocating for policy reforms that integrate traditional/spiritual healing practices, and supporting research initiatives that investigate effective integrated care models.

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Conflicts of interest

The authors declare that they have no competing interests.

Data availability

The datasets used and/or analyzed during the current study are available from <https://aphrc.org/microdata-portal> on reasonable request.

- 5 Grut L, Braathen SH, Mji G, Ingstad B. Accessing community health services: challenges faced by poor people with disabilities in a rural community in South Africa. *African Journal of Disability* 2012; **1(1)**: 1-7. DOI link, PMID:28729977
- 6 Adugna MB, Nabbouh F, Shehata S, Ghahari S. Barriers and facilitators to healthcare access for children with disabilities in low and middle income sub-Saharan African countries: a scoping review. *BMC Health Services Research* 2020; **20**: 15. DOI link, PMID:31906927
- 7 Karisa A, McKenzie J, De Villiers T. 'Their status will be affected by that child': How masculinity influences father involvement in the education of learners with intellectual disabilities. *Child: Care, Health and Development* 2021; **47(4)**: 517-524. DOI link, PMID:33675047
- 8 Eddy MM, Thomson-de Boor H, Mphaka K. *So we are ATM fathers. A study of absent fathers in Johannesburg, South Africa*. Johannesburg: Centre for Social Development in Africa, University of Johannesburg, 2013.

- 9** Karisa A, McKenzie J. I be Africa man original: Towards a contextual conceptualization of father involvement in the education of children with disabilities in Kenya. *Disabilities* 2022; **2(1)**: 28-40. DOI link
- 10** Morrell R. Fathers, fatherhood and masculinity in South Africa. In: L Richter, R Morrell (Eds). *Baba: Men and fatherhood in South Africa*. Pretoria: HSRC Press, 2006; 13-25.
- 11** Statistics South Africa. *General Household Survey data set*. Pretoria: Statistics South Africa, 2018.
- 12** Muluneh MD, Stulz V, Francis L, Agho K. Gender based violence against women in sub-Saharan Africa: a systematic review and meta-analysis of cross-sectional studies. *International Journal of Environmental Research and Public Health* 2020; **17(3)**: 903. DOI link, PMID:32024080
- 13** Lynch A, Raziano V, Feehan K, Thompson E, Massey P, Turchi R. Unmet needs of male caregivers of children and youth with special health care needs. *Maternal and Child Health Journal* 2021; **25**: 1992-2001. DOI link, PMID:34652597
- 14** Karisa A, McKenzie J, De Villiers T. 'It's a school but it's not a school': understanding father involvement in the schooling of children with intellectual disabilities in Kenya. *International Journal of Inclusive Education* 2021; **28(7)**: 1150-1165. DOI link
- 15** Mayekiso A. 'Ukuba yindoda kwelixesha' ('To be a man in these times'): Fatherhood, marginality and forms of life among young men in Gugulethu, Cape Town. Cape Town: University of Cape Town, 2017.
- 16** Richter L, Morrell R. *Baba: Men and fatherhood in South Africa*. Pretoria: HSRC Press, 2006.
- 17** Mwoma T. Fathering in Kenya. In: JL Roopnarine (Ed.). *Fathers across cultures: The importance, roles, and diverse practices of dads*. Santa Barbara: Praeger, 2015; 10-28. DOI link
- 18** United Nations. *Transforming our world: The 2030 agenda for sustainable development*. New York: United Nations, 2015.
- 19** UNICEF. *Nurturing care for early childhood development: a framework for helping children survive and thrive to transform health and human potential*. Geneva: World Health Organization, 2018.
- 20** Frechette J, Bitzas V, Aubry M, Kilpatrick K, Lavoie-Tremblay M. Capturing lived experience: Methodological considerations for interpretive phenomenological inquiry. *International Journal of Qualitative Methods* 2020; **19**: 1609406920907254. DOI link
- 21** Husserl E, Moran D. *Ideas: General introduction to pure phenomenology*. London: Routledge, 2012.
- 22** Meekosha H, Shuttleworth R. What's so 'critical' about critical disability studies? *Australian Journal of Human Rights* 2009; **15(1)**: 47-75. DOI link
- 23** Goodley D. Disentangling critical disability studies. *Disability & Society* 2013; **28(5)**: 631-644. DOI link
- 24** Flynn S. Critical disability studies. In: G Bennett, E Goodall (Eds). *The Palgrave Encyclopedia of Disability*. Cham: Springer Nature, 2024; 1-6. DOI link
- 25** Fisher P, Goodley D. The linear medical model of disability: Mothers of disabled babies resist with counter-narratives. *Sociology of Health & Illness* 2007; **29(1)**: 66-81. DOI link, PMID:17286706
- 26** Oliver M. *The politics of disablement*. Basingstoke: Macmillan Education, 1990. DOI link
- 27** Kittay EF. The ethics of care, dependence, and disability. *Ratio Juris* 2011; **24(1)**: 49-58. DOI link
- 28** Godden L, Kutsyuruba B. Hermeneutic phenomenology. In: JM Okoko, S Tunison, KD Walker (Eds). *Varieties of qualitative research methods: selected contextual perspectives*. Cham: Springer International Publishing, 2023; 225-230. DOI link
- 29** Kenya National Bureau of Statistics. *Siaya County Socio-Economic Profile*. 2019. Nairobi: Kenya National Bureau of Statistics.
- 30** Stats Kenya. *Siaya County*. Available: web link (Accessed 10 July 2024).
- 31** Harris JC. New classification for neurodevelopmental disorders in DSM-5. *Current Opinion in Psychiatry* 2014; **27(2)**: 95-97. DOI link, PMID:24441422
- 32** Wills CD. DSM-5 and neurodevelopmental and other disorders of childhood and adolescence. *Journal of the American Academy of Psychiatry and the Law Online* 2014; **42(2)**: 165-172.
- 33** Vaismoradi M, Jones J, Turunen H, Snelgrove S. Theme development in qualitative content analysis and thematic analysis. *Journal of Nursing Education and Practice* 2016; **6(5)**. DOI link
- 34** Namazzi G, Hanson C, Nalwadda C, Tetui M, Nampijja M, Waiswa P, et al. Caring for children with neurodevelopmental disability: Experiences from caretakers and health workers in rural eastern Uganda. *PLoS ONE* 2020; **15(7)**: e0236488. DOI link, PMID:32716925
- 35** Douglas SN, Jensen EJ, West P. Barriers and benefits experienced by caregivers seeking medical care for their children with autism spectrum disorders: a qualitative meta-synthesis. *Review Journal of Autism and Developmental Disorders* 2023; **10(3)**: 492-504. DOI link
- 36** Tann CJ, Kohli-Lynch M, Nalugya R, Sadoo S, Martin K, Lassman R, et al. Surviving and thriving: early intervention for neonatal survivors with developmental disability in Uganda. *Infants & Young Children* 2021; **34(1)**: 17-32. DOI link, PMID:33790497
- 37** Nanyunja C, Sadoo S, Kohli-Lynch M, Nalugya R, Nyonyintono J, Muhumuza A, et al. Early care and support for young children with developmental disabilities and their caregivers in Uganda: The Baby Ubuntu feasibility trial. *Frontiers in Pediatrics* 2022; **10**: 981976. DOI link, PMID:36177453
- 38** Chabeda-Barthe J, Wambua T, Chege WL, Hwaga D, Gakuo T, Rotich GC. Child developmental disabilities, caregivers' role in Kenya and its implications on global migration. *International Journal of Environmental Research and Public Health* 2019; **16(6)**: 1010. DOI link, PMID:30897762
- 39** Bunning K, Gona JK, Odera-Mung'ala V, Newton CR, Geere J-A, Hong CS, et al. Survey of rehabilitation support for children 0-15 years in a rural part of Kenya. *Disability and Rehabilitation* 2014; **36(12)**: 1033-1041. DOI link, PMID:23991677
- 40** World Health Organization. *Cultural Contexts of Health and Well-being*. Geneva: World Health Organization, 2017.

- 41** Stubbe DE. Practicing cultural competence and cultural humility in the care of diverse patients. *Focus* 2020; **18(1)**: 49-51. DOI link, PMID:32047398
- 42** Handtke O, Schilgen B, Mösko M. Culturally competent healthcare – A scoping review of strategies implemented in healthcare organizations and a model of culturally competent healthcare provision. *PLoS ONE* 2019; **14(7)**: e0219971. DOI link, PMID:31361783
- 43** Gabrielli G, Paterno A, Sacco P. Living arrangements in sub-Saharan Africa between modernization and ethnicity. *African Population Studies* 2018; **32(2)**. DOI link
- 44** Ikamari L, Agwanda A. Changes in families and households in East Africa. In: CO Odimegwu (Ed.). *Family demography and post-2015 development agenda in Africa*. Cham: Springer International Publishing, 2020; 259-285. DOI link
- 45** Mulenga DC. Mwalimu Julius Nyerere: A critical review of his contributions to adult education and postcolonialism. *International Journal of Lifelong Education* 2001; **20(6)**: 446-470. DOI link
- 46** Newbury J. Inclusion and community building: Profoundly particular. In: S McNamee S, MM Gergen MM, C Camargo-Borges, EF Rasera (Eds). *The Sage handbook of social constructionist practice*. Sage Publications, 2021; 548-558. DOI link
- 47** World Health Organization. *World report on disability 2011*. Geneva: World Health Organization, 2011.
- 48** Abyot E, Zewdu B, Tefera A, Mohammedberhan A, Mulugeta F. Capacity buildings of traditional medicine practitioners' as a primary health Care Workers in Gondar Town, Northwest Ethiopia. *Homeopathy & Ayurvedic Medicine* 2014; **3(151)**: 2167-120.
- 49** Mothibe ME, Sibanda M. African traditional medicine: South African perspective. *Traditional and Complementary Medicine* 2019; **2019**: 1-27. DOI link
- 50** Kaye J, Raghavan SK. Spirituality in disability and illness. *Journal of Religion and Health* 2002; **41**: 231-242. DOI link
- 51** Sango PN, Forrester-Jones R. Intellectual and developmental disabilities, spirituality and religion: A systematic review 1990-2015. *Journal of Disability & Religion* 2017; **21(3)**: 280-295. DOI link
- 52** Chidarikire S. Spirituality: The neglected dimension of holistic mental health care. *Advances in Mental Health* 2012; **10(3)**: 298-302. DOI link
- 53** Ikhoyameh M, Okete WE, Ogboye RM, Owoyemi OK, Gbadebo OS. Integrating traditional medicine into the African healthcare system post-Traditional Medicine Global Summit: challenges and recommendations. *The Pan African Medical Journal* 2024; **47(146)**. DOI link
- 54** World Health Organization. *WHO global report on traditional and complementary medicine 2019*. Geneva: World Health Organization, 2019.
- 55** Audet CM, Clemens EM, Ngobeni S, Mkansi M, Sack DE, Wagner RG. Throwing the bones to diagnose HIV: Views of rural South African traditional healers on undertaking HIV counselling and testing. *AIDS Care* 2021; **33(10)**: 1316-1320. DOI link, PMID:32799661
- 56** Lampiao F, Chisaka J, Clements C. Communication between traditional medical practitioners and western medical professionals. *Frontiers in Sociology* 2019; **4**: 37. DOI link, PMID:33869360
- 57** World Health Organization. International Disability Development Consortium. *Community-based rehabilitation: CBR guidelines*. Geneva: World Health Organization, 2010.

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