


## RESEARCH ARTICLE

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# ‘I bring her up with love:’ Perspectives of caregivers of children with neurodevelopmental delays in western Kenya

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## Abstract

**Objective:** This study aims to understand the challenges and perspectives of caregivers with neurodevelopmental delays (NDD) in rural Kenya.

**Methods:** Semi-structured interviews and the Affiliate Stigma Scale were administered to the primary caregivers of children with NDDs recruited from the communities near Eldoret, Kenya. Constant comparison and triangulation methods were used to inductively develop relevant themes and concepts.

**Results:** Sixteen caregivers participated. Challenges, which included hardships related to safety and supervision, challenging emotions and financial difficulties, were compounded by a lack of social support and community stigma towards these children. However, caregivers still felt deep love for their children, desired acceptance from the community and found sources of strength from faith and religious institutions.

**Conclusion:** The study uncovered crucial insights into the perspectives of caregivers within this population and revealed a paucity of disability awareness and understanding within the community, possibly informing future programmes and intervention policies.

## KEYWORDS

caregivers, challenges, child development, Kenya, low- and middle-income country, low-resourced settings, stigma, support

## 1 | INTRODUCTION

Globally, tremendous progress has been made in reducing child mortality, and yet the number of children with neurodevelopmental delays (NDDs) has been steadily increasing in low- and middle-income countries (LMICs) over the past 30 years (Global Research on Developmental Disabilities Collaborators, 2018). NDDs include delays in motor skills, cognition and language and are often synonymous with conditions such as epilepsy, cerebral palsy, autism

spectrum disorder, intellectual disability and other learning disorders (Villagomez et al., 2019). Children living in LMICs are disproportionately affected by NDDs. Approximately 80% of all children with NDDs live in LMICs (World Health Organization & World Bank, 2011), making the prevalence of paediatric NDDs over 10% in many countries (Bitta et al., 2018). This is likely due to the myriad of adverse risk factors experienced within these settings, such as recurrent disease, poverty, violence and malnutrition (Global Research on Developmental Disabilities Collaborators, 2018).

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Children with NDDs become particularly vulnerable to poor outcomes, such as lack of education and community support (Sossou & Yogtiba, 2009), and they are more likely to experience abuse, inaccessibility to healthcare and premature death compared with children without disabilities (Bayat, 2015; Olusanya & Nair, 2019).

An estimated 11.4% of children in the Republic of Kenya experience at least one type of NDD (Chabeda-Barthe et al., 2019). To better support individuals with NDDs, the Kenyan government passed the Persons with Disabilities Act in 2003. This law prohibits discrimination to persons with disabilities and improves accessibility to cultural and social services, healthcare, education and employment (The National Council for Persons with Disabilities, 2003). Despite governmental efforts, significant challenges exist when caring for children with NDDs. Caregivers play a particularly influential role in their children's neurodevelopment, and their insights are critical when developing holistic and effective intervention programmes for children with NDDs (Chabeda-Barthe et al., 2019). Existing literature has found that caregivers of children with NDDs face a range of negative experiences, such as stress, sadness, stigma and lack of social support (Adugna et al., 2020). Within Kenya, this can be connected to factors such as poverty and community perception of the aetiology of NDDs (Bunning et al., 2017; Bunning et al., 2020; Gona et al., 2011; Gona et al., 2016). However, the lived experiences of these caregivers and a focused evaluation of the stigma they may face have not been well-described.

Understanding caregivers' diverse and unique experiences is a crucial first step towards developing effective intervention programmes for children with NDDs and their families. Therefore, the objective of this study is to understand the lived experience of raising a child with NDDs in Kenya, with additional focus on the stigma caregivers experience and the support systems sustaining the care they provide their children. The findings of this study will help identify current barriers and facilitators of care to inform future programmatic initiatives focused on optimizing care for children living with NDDs and reducing the stigma of NDDs within western Kenya.

## 2 | METHODS

### 2.1 | Study setting

This cross-sectional, qualitative study was conducted in western Kenya within the Academic Model Providing Access to Healthcare (AMPATH) programme, a long-standing collaboration between Moi University School of Medicine, Moi Teaching and Referral Hospital (MTRH) and a consortium of North American academic medical centres led by Indiana University School of Medicine (Einterz et al., 2007). Utilizing AMPATH's research infrastructure and prior engagement in community-based research, study participants were identified and recruited with the aid of community leadership.

#### Key messages

- Caregivers of children with neurodevelopmental delays in Kenya continue to face a myriad of challenges, which predominantly centres around the children's lack of independence, paucity of emotional support, financial challenges and negative community perceptions.
- Many caregivers experience affiliate stigma, which can lead to poorer caregiver mental health outcomes.
- Despite the significant challenges that caregivers faced, they felt deep love for their children and desired help, understanding and acceptance from their surrounding community. In particular, faith and places of worship were a source of strength for caregivers.

### 2.2 | Recruitment and sampling

Convenience sampling was used for families living in and around the town of Eldoret, Kenya. To adequately connect with this vulnerable population, recruitment was performed through word of mouth according to cultural norms, with the aid of local chiefs, assistant chiefs and village elders. These community leaders are well-known by families in the region and often serve as liaisons for study activities or other external programming. The participating liaisons visited the homes of children with NDDs to inform them of the study and to assess interest in participating. If families were interested, they provided contact information to the liaison, who then provided it to the study staff. According to one chief's request, a research assistant accompanied him to the homes of families when discussing the study in-person. Potential participants were asked to come to our private research offices, located within the MTRH medical campus, for review and completion of the informed consent and study activities.

### 2.3 | Participants

We performed private, semi-structured interviews with caregivers of children with NDDs, which allowed them to address topics specific to their lived experiences while providing room for further pursuit of an idea or response (Gill et al., 2008). Inclusion criteria included the following: (1) must be 18 years in age or older; (2) must speak English or Kiswahili; (3) must live within the MTRH catchment area and (4) must be the primary caregiver of a child with a severe disability. Our definition of severe disability was described in common terms, such as being unable to talk, walk or complete age-appropriate developmental activities. After being referred for enrolment, all participants ( $n = 16$ ) were noted to have met the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) criteria for intellectual disability, neurocognitive disorder or neurodevelopmental disorder. One participant initially expressed interest in participating and was referred for enrolment but later was unable to be contacted by the research team.

## 2.4 | Discussion guides

We created interview guides based on literature on childhood disability in LMIC settings (Adugna et al., 2020; Chabeda-Barthe et al., 2019; Mbale et al., 2017; Muñoz et al., 2017; Nota et al., 2015; Paget et al., 2016; Tilahun et al., 2016) and input from the research team, which comprised of a US-based paediatrician, a Kenyan paediatrician with neurology training and research assistants working in the field of child development in Kenya. Qualitative interviews were chosen because they are particularly suitable to provide more in-depth understanding of complex topics such as NDDs in cross-cultural settings.

To better understand the stigma that caregivers experience, a self-rated 22-item questionnaire was verbally administered as part of the interview (Mak & Cheung, 2008). The Affiliate Stigma Scale was developed by Mak and Cheung in 2008 to quantitatively measure affiliate stigma: the way stigmatized individuals perceive themselves. This instrument uses a 4-point Likert scale to evaluate the affective (seven items), cognitive (seven items) and behaviour (eight items) domains of affiliate stigma. The separate domains reflected caregivers' individual emotions towards having a child with a disability; how they viewed other people's perceptions of them and their children and how these caregivers changed their daily behaviours due to the presence of their children. Higher scores for items on the questionnaire indicate higher levels of affiliate stigma.

## 2.5 | Data collection and management

Sixteen semi-structured interviews took place between 9 July 2020 and 6 November 2020. Prior to data collection, one female interview facilitator, who was well-connected to the local community and familiar with themes of childhood disability, was trained to administer the interview guides with the study PI to ensure high-quality data collection. Data collection for the semi-structured interviews lasted between 30 and 90 min and was audio-recorded. In accordance with COVID-19 pandemic precautions, all interviews were performed with a distance of 2 m between individuals, both of whom were wearing masks. Interviews were performed outside the home if privacy was ensured and study participants agreed. Participants received 500KSh (\$5USD) reimbursement for their time and travel for the study. The interviews were then transcribed verbatim and translated into English. The translated text was verified by a separate bilingual (English- and Kiswahili-speaking) research assistant and de-identified.

## 2.6 | Data analysis

The interview transcripts were analysed for themes relating to the caregiver experience, the stigma that they faced and their perceived needs (transcripts are available on request). To better understand the lived experiences of our study participants, an adapted phenomenological approach was taken to qualitative analysis. First, a priori

codes were created from the interview guide and interview transcripts as a starting point. Then constant comparison and triangulation were used to identify central concepts (Glaser & Strauss, 1967; Strauss & Corbin, 1990). The investigators individually performed line-by-line coding using the qualitative analysis software Dedoose (Dedoose, 2014). From these data, relevant themes and concepts were developed inductively and then shared with the interview facilitator to ensure these data were aligned with the live interview experience and notes. Some of the quotes were edited minimally for clarity.

## 2.7 | Ethics

All caregivers provided written informed consent for the enrolment of this study. This study was approved by the Institutional Review Board of Indiana University School of Medicine in Indianapolis, Indiana, and by the Institutional Research and Ethics Committee of Moi University School of Medicine and MTRH in Eldoret, Kenya.

Additionally, families who were unaware of or not well-connected to services for their children were referred to the public MTRH paediatric neurology clinic for evaluation and therapy recommendations. Families who were uninsured were also given detailed instructions on how to apply to a government programme that provides free basic health insurance and the potential to receive a small government-sponsored stipend for the child with NDDs.

## 3 | RESULTS

### 3.1 | Caregiver demographics

Sixteen caregivers of children with NDDs participated in this study. Fifteen were female and the mother of the child with NDD. One was male and the father of the child with NDDs. Approximately 50% of caregivers did not work outside the home, and fewer than half received education beyond primary school. Additional details about the study participants can be found in Table 1.

### 3.2 | Overall challenges faced by caregivers

Throughout our interviews, we identified several themes that emerged from the data. The most prominent theme that arose from the discussions was the vast nature of challenges involved when caring for a child with NDDs. Table 2 summarizes the categories of challenges indicated by caregivers, with illustrative quotes found in Table 3. Four themes of challenges arose: supervision/safety, emotional, financial and community perceptions. Despite these challenges, caregivers felt deep love for their children and desired help, understanding and acceptance from their surrounding community. In particular, faith and places of worship provided sources of strength for caregivers within their community.

**TABLE 1** Participant demographics

Variable	Total
Age (in years), mean (range)	36 (24–52)
Gender of caregiver interviewed, <i>n</i> (%)	
Male	1 (6.25)
Female	15 (93.75)
Number of children at home, mean (range)	3.5 (1–8)
Occupation of caregiver, <i>n</i> (%)	
Housewife	8 (50)
Casual labour	7 (43.75)
Other	1 (6.25)
Amount of education caregiver completed, <i>n</i> (%)	
None	2 (12.5)
Some primary school	1 (6.25)
Completed primary school	3 (18.75)
Some secondary school	2 (12.5)
Completed secondary school	6 (37.5)
University or additional training	2 (12.5)
Caregiver is able to visit family members living in the village, <i>n</i> (%)	
Yes	7 (43.75)
Caregiver is able to take child to place of worship, <i>n</i> (%)	
Yes	13 (81.25)
Age of child, mean (range)	8.685 (1–17)
Gender of child, <i>n</i> (%)	
Male	11 (68.75%)
Whether child was able to attend school, <i>n</i> (%)	
Yes	6 (37.5%)

**TABLE 2** Categorization of challenges faced by caregivers of children with neurodevelopmental disabilities

Supervision/extended dependency/safety	Safety of the child Lack of independence of the child Inability of the child to attend school
Financial	Inability to afford medication Lack of transportation to clinic and other places within the community Difficulty providing for a child's basic needs such as food or diapers
Emotional	Lack of substantial social support Sadness/stress/worry Stigma
Community perceptions	Aetiology of witchcraft/sin Inconvenience/discomfort of engaging with child

### 3.3 | Supervision/extended dependency/safety

One main challenge was predominantly due to the lack of independence of the child, as most children were unable to care for themselves. Many caregivers feared for the safety of their children due to

their cognitive impairment, for example, worrying that they would accidentally light fires or run out on the street. On the rare occasions that caregivers would receive help and be able to leave their homes, they would ceaselessly worry about the well-being of their child. These worries were compounded by the feeling that they were the only ones who were truly capable of caring for their child. As a result, most caregivers spent the majority of their time with their child, isolated and rarely able to leave them alone.

Caregivers with children who attended school had a daytime respite that enabled them to perform income-generating activities to provide for their families. However, several noted that the schools and teachers were not prepared or able to adequately care for their child, and the other children often treated them poorly:

There are children who cannot understand him. Another child may slap him and the sound that he makes, the other children enjoy it. Even when he is pinched, he makes some noise that it will make you run to him. That makes me worried, but there is no option; he has to stay in school. Age 40; female

### 3.4 | Financial

Despite the uneasy benefits of school, over 60% of children were unable to attend due to factors such as age or severity of disability. Therefore, some caregivers were required to quit their day jobs to care for their child. The presence of a child with NDDs contributed to significant financial difficulties for many families. The lack of additional income and added expenses resulted in sources of stress regarding the inability to provide necessities, including food, diapers or medication. In many cases, caregivers stopped seeking professional help for their children because they lacked the money or transportation to do so. Although there is some government assistance for children with NDDs, many caregivers were unaware of their existence and thus did not receive additional help.

### 3.5 | Emotional

These hardships are compounded by the limited support network that these caregivers appeared to have, with most having only one to two individuals to help them with their child and some lacking any support.

It pulls me down every time because like this moment when my mother has died, I do not have anywhere to start from. I have to start from scratch. So I am wondering who I will leave my child with. Age 26; female

For most Kenyans, being able to see extended family in their villages provides a critical support network. However, more than half of the families interviewed are unable to do this, due to factors such as a

**TABLE 3** Representative quotations of the challenges caregivers faced

Challenges	Example quotations
Supervision/extended dependency/safety	<p>'When he is at home, you must get concerned about where he is. Either fire, electricity, anything that is sharp. He can beat his sibling'. – Age 48; female</p> <p>'Yeah, because he can fall down. When you leave him alone on the bed and then he starts to convulse, it can throw him from the bed. So someone must have to be there' – Age 44; female</p> <p>'He cannot see where he is going to. You cannot leave him alone. He just goes without knowing where he is going to. He cannot speak; he hears but cannot do what is wanted of him to do. He defecates on himself, he does not understand himself'. – Age 28; female</p> <p>'It is very difficult for someone to take care of a child for you. It is very difficult. People have different hearts'. – Age 33; female</p> <p>'My concern is that he depends on me for everything. He cannot do anything for himself' – Age 40; female</p>
Emotional	<p>'Because I have that child who is sick, at one time I was much stressed and got very sick. Even up to now I have pressure because sometimes she bothers me, and I don't have money to buy those drugs for her. So I get stressed in my mind.' – Age 52; female</p> <p>'You will find yourself very sad. I mean you try to imagine like, "why me?" So someone should try to comfort you by talking to you so that you can know such things are there and it is not only on your child alone'. – Age 28; female</p> <p>'I think at the initial stages I experienced a lot of frustrations but when I came to terms, I am just coping with it. You know as the child keeps on growing and developing, he is now becoming a bit supportive but under the supervision of the sibling. If those happens, if he happens to learn those skills that he can express himself, then the less anxiety, the less sadness' – Age 48; male</p> <p>'Sometimes I have to carry her covered. Someone tells you, you are carrying a big child on your back, why don't you put her down to walk? So I don't answer them. What will I tell them? Sometimes she cries. She is grown and wants to look at things yet I have covered her. You feel embarrassed because some people cannot understand you' – Age 27; female</p> <p>'I am sad sometimes when I see how he is like that. When you tell him to do this, he does not do it'. – Age 40; female</p>
Financial	<p>'The first challenge is the money paid for therapy, [transport] fare and lunch. Sometimes I have to come on foot carrying him'. – Age 40; female</p> <p>'The support that is needed is financial, for bringing her for therapy. That is the big thing that I would wish someone to help me with. You know if I have to bring her for therapy continuously without stopping that will help her. When I don't go for therapy, her progress stalls'. – Age 27; female</p> <p>'The problem that we have that is a real problem is buying diapers especially for a grown child. Her urine is acidic and she is almost getting to adolescence' – Age 33; female</p> <p>'I used to sell chips just outside our gate. I saw he was suffering and I had to stop [the business]. His sister is nine and this boy is six years. So I have had to stop [working] and take care of him'. – Age 28; female</p>
Community perceptions	<p>'People fear such children. Not all people have the courage to face someone with disability'. – Age 44; female</p> <p>'He urinates on himself. When he is in someone's place like for example your home, you will get angry and say, your child has urinated in my house and if he is with other children, they will laugh at him' – Age 26; female</p> <p>'When he goes outside and someone beats him up or is offended by other children and then he explains it out, he is not understood. So they blame him for the mistakes. He cannot explain himself. That is my only worry'. – Age 40; female</p> <p>'The boys did this and that to [my son]. They are happy with [my son]'s illness. I even think they will be happy if he dies'. – Age 30; female</p>

lack of support from their extended families and transportation. Without this extended network that many families rely on, the caregiver's support network is fragile. Furthermore, even though multiple families recruited for this study were from around the same area, none seemed to be aware of the existence of others, and thus all desired a support group so that they would feel less isolated. This isolation appeared to be partially due to the lack of disability awareness within the community; more than half of caregivers were unaware of positive messages in barazas (community gatherings) and churches that have been shared regarding the need to pray for children with NDDs and understand the cause of disease.

The increased burden of caregiving, lack of financial and social support and community stigma towards children with NDDs resulted in feelings of sadness, stress and worry for the caregivers. Although they were determined to care for their child, nearly all were

concerned about making ends meet; many worried about the fate of their child once they, as parents, had passed away.

I usually ask God to give me many years in this world. That is the biggest, leave alone the issue of food and so forth. That is the only thing that I ask God for. It is something that cannot be done by anyone else, it is only God. Age 40; female

### 3.6 | Community perceptions

Participants noted that the community had many misconceptions about children with NDDs, including the belief that the aetiology of childhood NDDs was witchcraft or punishment for a sin committed by

a parent prior to or during pregnancy. Occasionally, stigma from others influenced the way caregivers perceived their relationship with their own child and affected their ability to seek help for their child, despite their own beliefs towards their child's disability. Caregivers were often ashamed to bring their child out in public in fear of being taunted.

### 3.7 | Affiliate Stigma Scale

Within the Affiliate Stigma Scale, the following statements had the highest scores: 'I feel helpless for having a family member with mental illness/intellectual disability' (affective domain), 'I feel sad because I have a family member with mental illness/intellectual disability' (affective domain) and 'I reduce going out with my child' (behavioural domain). Caregivers overall appeared to agree with the affective domain of affiliate stigma more than the behavioural or cognitive. Statements in the cognitive domain, such as 'I have cut down the contacts with my child', had the lowest scores (Table 4). These findings reflect the views of the caregivers throughout the interviews: feelings of sadness were often prevalent, but this did not impact the care they provided to their child.

### 3.8 | Sources of strength

Despite these challenges, many caregivers found strength in their faith and religious organizations. Over 80% of families were able to attend a church or mosque. Not only did their children generally enjoy being there but also religious community members would often look after them which provided a respite for caregivers. In addition, many caregivers believed that their child was given to them by God. As a response to their hardships, caregivers would provide reflections such as 'that is the work of God' or 'Alhamdulillah (translates to "praise be to God" in Arabic), God will bring'.

My life, we just say Alhamdulillah. What can you do?  
Even if I have difficulties, what can I do? We just say  
Alhamdulillah. Age 30; female

Fuelled by their faith, most caregivers expressed a deep love for their children and a desire to increase NDD awareness in their community. Many expressed gratefulness that their child was otherwise healthy. They found joy in some personality quirks, such as the fondness one child had towards listening to music and continued to have hope that their child's condition would improve while feeling responsible for their well-being. They hoped community members would understand that children with NDDs require and deserve love and are continuously improving and that their NDDs are not caused by the sins of the caregiver. In addition, many caregivers hoped to learn about how to help children with NDDs, not just for their own sake but for the sake of others in the community.

At first I used to feel that I am suffering but I have learnt to love her and currently she is part of me. I bring her up with love. Age 33; female

## 4 | DISCUSSION

Within this qualitative study, we sought to understand the lived experiences of caregivers of children with NDDs in Kenya. These caregivers, who were recruited from western Kenya, provided crucial insight into their everyday challenges, sources of support and emotions related to raising a child with NDDs. Overall, caregivers felt an increased burden in caregiving duties and worried about the safety and welfare of their children. They also lacked financial and social support due to stigma that was prevalent around the community yet were able to find strength in their faith and religious institutions and experience deep love and acceptance for their child.

In this study, the most distinct challenges faced by caregivers were the increased burden of caregiving and lack of social and financial support. These feelings are also echoed in existing literature in sub-Saharan Africa and beyond: children with NDDs are significantly more likely to live in impoverished households due to the increased cost of treatment and the caregiver's loss of income (Fujiura & Yamaki, 2000). Fragile support networks and financial difficulties were also barriers to seeking care for South African children with NDDs (Mkabile & Swartz, 2020). Children in Malawi with musculoskeletal impairments experienced exclusion from their communities (Alavi et al., 2012), and caregivers of children with NDDs in Turkana, Kenya, experienced isolation from even their family members (Zuurmond et al., 2016). The isolation of caregivers of children with NDDs in the community can generate a cyclical product of stigma among caregivers themselves, negatively impacting their own ability to care for their child by keeping them isolated and preventing them from seeking support.

While the results from the Affiliate Stigma Scale indicated that our caregivers felt sad and helpless caring for a child with disabilities, their behaviour or interactions with their children remained independent of these feelings. This reflects the attitudes of caregivers in many parts of the world (Banga & Ghosh, 2017; Ma & Mak, 2016; Werner & Shulman, 2013). Affiliate stigma is affected by the severity of the child's illness and amount of time that the caregiver spends with the child (Shi et al., 2019), which has been correlated with poor caregiver mental health outcomes (Banga & Ghosh, 2017; Zhou et al., 2018). Therefore, it is crucial that interventions target caregivers' well-being and mental health for the benefit of both child and caregiver.

Religious organizations were identified as a critical source of support and a facilitator of care for children with NDDs. They played a crucial role in providing caregivers with hope, love and acceptance for their children. Because religious organizations are often the main support network for many sub-Saharan families (Chiu et al., 2008), they have tremendous potential to support struggling caregivers of children with NDDs. For example, caregivers of children with NDDs in Addis



**TABLE 4** Caregiver scores within the Affiliate Stigma Scale

Items of the Affiliate Stigma Scale	Mean	Median	Standard deviation
I feel inferior because one of my family members is a child with developmental delay.	1.87	1	1.3
I feel emotionally disturbed because I have a child with developmental delay.	2.07	1	1.28
The behaviour of my child makes me feel embarrassed.	1.86	1	1.19
I feel helpless for having a child with developmental delays.	2.53	3	1.25
I feel sad because I have a child with developmental delays.	2.43	3	1.22
I worry if other people would know I have a child with developmental delay.	2.08	1	1.30
I am under great pressure as I have a child with developmental delay.	2.27	2	1.33
<b>Affective domain score</b>	<b>2.16</b>	<b>2.08</b>	<b>0.26</b>
Other people would discriminate against me if I am with my child.	2.13	1	1.36
My reputation is damaged because I have a child with developmental delay at home.	1.93	1	1.33
People's attitude towards me changes when I am with my child.	2.13	1	1.36
Having a child with developmental delay imposes a negative impact on me.	2.27	1	1.44
Having a child with developmental delay makes me think that I am incompetent compared with other people.	1.71	1	1.34
Having a child with developmental delay makes me think I am lesser to others.	1.64	1	1.28
Having a child with developmental delay makes me lose face.	1.46	1	0.97
<b>Cognitive domain score</b>	<b>1.90</b>	<b>1.93</b>	<b>0.30</b>
I avoid communicating with my child.	1.15	1	0.55
I dare not tell others that I have a child with a developmental delay.	1.60	1	0.99
I reduce going out with my child.	2.33	2	1.23
Given that I have a child with developmental delay, I have cut down the contacts with my friends and relatives.	1.93	1	1.39
When I am with my child, I will keep an especially low profile.	1.86	1	1.23
I have cut down the contacts with my child.	1.29	1	0.73
I dare not participate in activities that are related to developmental delay for fear that others suspect that I have a family member with a developmental delay.	1.47	1	0.91
Given that I have a child with developmental delay, I have cut down the contacts with my neighbours.	1.67	1	1.07
<b>Behavioural domain score</b>	<b>1.66</b>	<b>1.63</b>	<b>0.38</b>
4-point Likert scale: 1 = <i>Strongly disagree</i> ; 2 = <i>Somewhat disagree</i> ; 3 = <i>Somewhat agree</i> ; 4 = <i>Strongly agree</i>			

Ababa, Ethiopia, use prayer as a coping mechanism (Tilahun et al., 2016), those in the Philippines find emotional support and acceptance from church members (Alontaga & Durban, 2012) and those in Kenya often turn to God and took their children to church for prayers. Faith-based organizations in Africa have been shown to reduce stigma towards diseases such as HIV/AIDs by providing social support, speaking publicly about illness and encouraging others to care for the ill (Campbell et al., 2011). Expanding networks of support to encompass other educational and societal domains will further strengthen the facilitators of care for these families. Given the prevalence of community stigma towards NDDs, religious organizations can provide a figurative shelter for caregivers of children with NDDs by predicating crucial support networks and areas of strength, hope and acceptance within the community.

Community support mitigates social and financial hardships and highlights a vital need to increase the infrastructure for children with NDDs through community education, caregiver support groups and

increased access to special education. Because many caregivers had never heard educational messages about NDDs in barazas or churches, these places of socialization could be the focus of intervention strategies for childhood development to increase the awareness of pre-existing resources. Support groups for caregivers themselves also have a role in creating infrastructure and mental health support resources for caregivers, as it has been shown to improve their mental health in similar situations: caregivers of those with disabilities in both Ghana and China saw increased well-being after being placed in support groups (Wei et al., 2012; Zuurmond et al., 2019). Within our study, sending children to school helped to alleviate the burden of caregiving, even if it exposed their children to negative interactions with their peers. Although the Kenyan Special Needs Education mandated equal access to education for those with NDDs (Mutuota, 2009), children with disabilities are less than half as likely to enrol in school compared with those with no disabilities (Moyi, 2017), highlighting a need for continued support within this area.

This study was limited in its recruitment, in part due to the COVID-19 pandemic. Furthermore, all caregivers interviewed live near an urban centre, were well-connected to their chiefs and likely have better access to healthcare than others. Therefore, these results may not represent the views of all caregivers of children with NDDs within this setting. However, direct accounts of the experiences raising a child with a NDD are very limited in western Kenya. Our study provides crucial insights and perspectives to understand the lived experiences of this group.

## 5 | CONCLUSION

This study highlights the lived experiences of caregivers of children with NDDs in Eldoret, Kenya. Significant challenges regarding the dependence of children with NDDs, financial difficulties, lack of emotional support and stigma were reported. Despite these obstacles, caregivers found strength in their religious organizations and faith and experienced great acceptance and love for their children. The insights gained from this study reveal a paucity of disability awareness and understanding within the community and may inform future programmes and intervention policies in LMICs.

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### CONFLICT OF INTERESTS

The authors have no conflict of interests or financial disclosures related to this study.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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